

**Facioscapulohumeral  
Muscular Dystrophy (FSHD)**

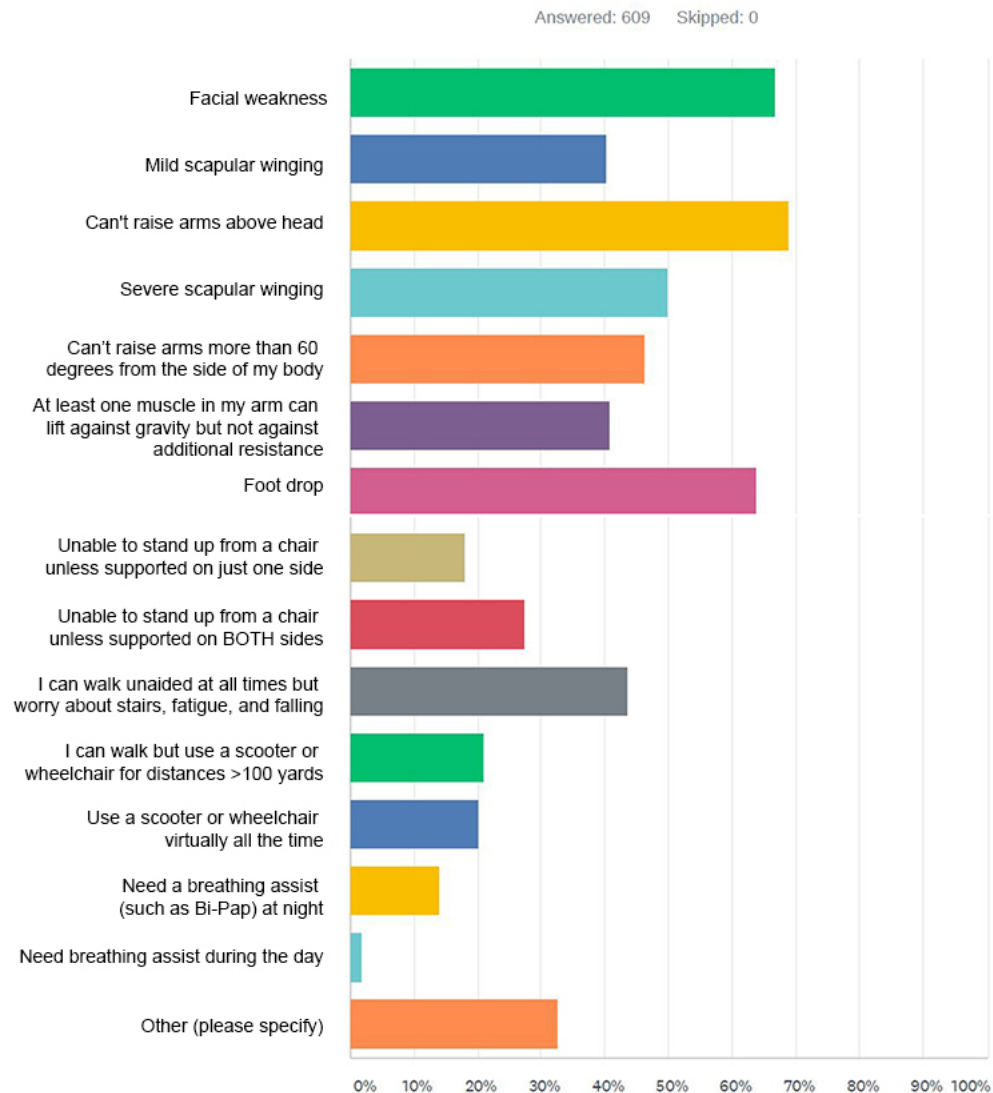
# VOICE OF THE PATIENT REPORT

**APPENDIX VI:  
Responses to  
pre-meeting survey**



*This report is dedicated to the individuals  
who courageously shared their stories.*

## Q1 How severely are you affected? Check all that apply.



ANSWER CHOICES	RESPONSES	
Facial weakness	66.83%	407
Mild scapular winging	40.07%	244
Can't raise arms above shoulder height	68.80%	419
Severe scapular winging	49.75%	303
Can't raise arms more than 60 degrees from the side of my body	46.14%	281
At least one muscle in my arm can lift against gravity but not against additional resistance	40.72%	248
Foot drop	63.88%	389
Unable to stand up from a chair unless supported on just one side	18.06%	110
Unable to stand up from a chair unless supported on BOTH sides	27.42%	167
I can walk unaided at all times but worry about stairs, fatigue, and falling	43.51%	265
I can walk but use a scooter or wheelchair for distances greater than ~100 yards.	21.02%	128
Use a scooter or wheelchair virtually all the time.	20.03%	122
Need a breathing assist (such as Bi-Pap) at night	13.96%	85
Need a breathing assist during the day.	1.97%	12
Other (please specify)	32.68%	199
Total Respondents: 609		

Facial weakness, mild scapular winging, Can't raise arms above shoulder height, can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Need a breathing assist (such as Bi-Pap) at night, Use cane or walker at all times unless in a wheelchair for distance.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling.

Facial weakness, Mild scapular winging, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging

Facial weakness, Severe scapular winging, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, lordosis, severe weakness in both arms, cannot lift them at all

Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. I use a cane when I do walk. I have a chair in the shower. I have a handle on my bed to help me turn and get up.

Severe scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling. Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Facial weakness, Mild scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time. Use a walker for short distances.

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Other (please specify): weak abdomen muscles, weak hip, severe neck pain (reduced muscles)

Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

Mild scapular winging, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time. Other (please specify): Use a walker

Facial weakness, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): have to use the handrail to go upstairs, can only get upstairs with the left leg leading

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop,

I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Lordosis

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Facial weakness, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Atrophy in fingers, sore at night

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

I have yet to have noticeable symptoms.

Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time. Other (please specify): Significant Abdominal weakness

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time. Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Other (please specify): Appetite loss, weight loss, cramps on different parts of body that come and go, muscle cramps.

Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Muscular pain

Severe scapular winging

Facial weakness, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Other (please specify): Can stand up from a chair in certain situations. Have to push off table/desk with right arm, push off chair with left arm, swing body over table and push off table/desk with both arms into standing position. Cannot do if table/desk or chair is too low; Can lift arms above head if I swing them up quickly and they can rest on something. Need better options for this question...hard to type so much...

Mild scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): My level of fitness keeps going down with further progression because I can't do the same things as before. I also have a tendency to sprain my ankles more than ever.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): In the house I use a walker to keep the amount of falls to as few as possible. In the yard/outside the scooter is used. Whenever I go to a store I have to use one of those rolling baskets.

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Use a scooter or wheelchair virtually all the time. Other (please specify): Lorisosis, bowel and urinary issues

Foot drop

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): I walk unaided most of the time but worry about crowds (being knocked down), stairs, fatigue and falling. I use a walking stick or rollator in crowds or on uneven ground.

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, Severe scapular winging

Mild scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Haven't been able to do a sit up in 30-35 years and am 50 now

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Severe scapular winging, Foot drop

Facial weakness, Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.



Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Feel Pain in my Foot all the day - can't walk for more than 10 mins - Find difficulty in my breathing but don't need assist yet, and feel fatigue in my heart Pain in Neck and Spine.

Pain and Severe Fatigue in my fingers, that I cant hold anything Left Scapula winging / shoulder condition is Mild while the Right is severe.

Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Other (please specify): It hurts to chew.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height

Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Need a breathing assist (such as Bi-Pap) at night

Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Overall fatigue!

Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Other (please specify): Use walker. ANYTHING ANYTHING U GUYS NEED FROM ME TISSUE WHAT I WILL ME UR Guinea pig. I have so much hate for this illness that if they needed me to do a Procedure, it could possible cost ur life but we might find a cure. Im ur girl. I don't think anybody wants to find a cure for this more them me! Edna M. Vega 1-224-365-9125 Ednamvega18@gmail.com

Facial weakness, Severe scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Need a breathing assist (such as Bi-Pap) at night. Other (please specify): need full AFOs to walk, unable to scale stairs or steep ramps, stomach weakness, core balance is compromised (but not severe yet)

Facial weakness, Mild scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Need a breathing assist (such as Bi-Pap) at night, Need a breathing assist during the day.

Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): bowel issues

Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Use a scooter or wheelchair virtually all the time.

Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Need a breathing assist (such as Bi-Pap) at night, Other (please specify): I'm a little confused as to what you mean by "supported" when standing up from a chair. To me, supported means you have a person helping you up. I don't usually need anyone to help me up; however, if the chair is low, I do. I do need to use both my arms to push up on the arms of the chair in order to stand up. I'm not able to stand up without using my arms to push up.

Facial weakness, Severe scapular winging, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Use a scooter or wheelchair virtually all the time.

Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night, Need a breathing assist during the day. Other (please specify): Tremors in face also in hands with weakness that causes dropping things constantly. Also use wheelchair for long distances.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Very weak core. Back pain

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height

Can't raise arms above shoulder height, Severe scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): I can only walk using a cane

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Discomfort and social anxiety.

Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Can't raise arms above shoulder height, Severe scapular winging

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, Other (please specify): Use Blue Rocker AFOs on both legs to walk outside of home at all times. Occasionally use a cane.

Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): I walk with a cane most of the time. One of my biggest issues is that I am unable to climb stairs. I use railings to pull myself up stairs.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time

Facial weakness, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time.

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Other (please specify): Need walker to walk at all times

Facial weakness, Severe scapular winging, Foot drop, Other (please specify): bilateral scapular fusions ..wear AFOs on both leg to help with foot drop...walk with stick...slowly. I cant really walk with shoes without AFOs

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time.

Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time.

Can't raise arms above shoulder height, Severe scapular winging

Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): I need a biPAP but my primary insists on a C-Pap, so I have nothing. I am seeing a Pulmonologist next week who sees FSHD patients for a second opinion. It's been six months since my sleep test.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): I walk with a cane

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time. Other (please specify): Cannot stand from chair or toilet that is only 50 cm high. This leads to very restricted outings from the house

Mild scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): failure in calf muscles causing balance/stability issues.

Can't raise arms above shoulder height, Severe scapular winging

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): difficulty putting arms behind me, cannot stand for long

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time. Other (please specify): Have had frequent falls while trying to transfer

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degree from the side of my body, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): More questions need to be asked about walking. These are too limited. I can walk inside using a walker but must stop to rest after about 15-20 steps.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

None currently

At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): Survey doesn't ask about being able to walk with device assistance: canes, walkers, AFOs, crutches. I can walk with bilateral AFOs and a cane. Also, survey questions on arm and shoulder ability/strength doesn't consider people who have had scapular-thoracic fusion surgery, as I have. Before surgery, I could not raise my arms above my head. Now I can. I have also had the supinator muscles' attachment moved from below my elbow to above it, allowing me to curl my arms.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): painful daily muscle spasms in both arms and legs.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

I can walk but not upright unless I'm leaning on something with my hands . I use a rollator or 2 canes



Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Other (please specify): I use a walker in my home and a power chair outside my house.

Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time. Other (please specify): I have heart failure.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling.

Other (please specify): At this point, I am only mildly affected - I cannot point to specific symptoms.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance

Facial weakness, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Other (please specify): Fatigue

Mild scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Can't raise arms above shoulder height, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time. Other (please specify): CPAP

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

At least one muscle in my arm can lift against gravity but not against additional resistance, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards. Use a scooter or wheelchair virtually all the time.

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Need a breathing assist during the day. Other (please specify): trunk of body collapsed by about a foot in height compressing breathing muscles, forcing abdominal organs forward, compressing bladder.

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Fatigue in everything I do resulting in diminished quality of life

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): I have much pain in the neck and shoulder area that greatly increases as the day goes on.

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): Unable to stand or walk unassisted. Use walker or power wheelchair all the time. Use power hospital bed.

Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Arms get tired very quickly

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Other (please specify): Unable to walk at 18 years of age due to spinal fusion surgery.

Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but

not against additional resistance, Foot drop, Unable to stand up from a chair unless supported

on just one side, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Can't raise arms above shoulder height, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): combined with arthritis and fibromyalgia I cannot distinguish what is caused by MD but the weakness across my neck and shoulders and up in to my head makes the pain very difficult to bear without pain killers regularly it would become unbearable.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time, Other (please specify): Hearing impairment, can't get up/out of bed without assistance, can't transfer independently from toilet.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Mild scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Really poor gait, weak gluteus quads and leg muscles in general- exhaustion relating to mobility issues

Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Extreme weakness in my left leg, I can't tippy toe and other leg functions. I need a C-Pap, not sure what a Bi-Pap is.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): I USE A CANE AND/OR ROLLATER FOR SHORT DISTANCES

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Other (please specify): Weakness in quads, calf and ankles in

both legs. Constant severe pain in both knees, back and neck. Had scapular fusion surgery in 1988 that helped me be able to lift my right arm over head but can't lift my left arm even 50 degrees.

Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Need a breathing assist (such as Bi-Pap) at night, Need a breathing assist during the day, Other (please specify): Use a walker

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Use a scooter or wheelchair virtually all the time, Other (please specify): Severe curvature of the spine - iordosis. Loss of dexterity - cannot open hands into flat position.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Severe scapular winging, Foot drop, Other (please specify): I walk with sticks and need frequent rests to catch my breath. I cannot walk far.

Facial weakness, Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Other (please specify): Extreme muscle atrophy with asymmetrical muscle development.

Can't raise arms above shoulder height, Severe scapular winging, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Can't raise arms above shoulder height, Severe scapular winging, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): I use a cane to help with balance while walking.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Use a scooter or wheelchair virtually all the time.

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Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

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Facial weakness, Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

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Facial weakness, Mild scapular winging

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Other (please specify): Beginning stages of losing hand grip strength

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Foot drop, Unable to stand up from a chair unless supported on BOTH sides

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Can't raise arms above shoulder height, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't

raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify):  
Walk with cane and AFO on both feet

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Other (please specify): i can walk with carbon fibre afo and with no assistance in my own home i use a scooter for long distances ...can still walk 1-3 miles although, 3 mile leaves me exhausted.

Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Facial weakness

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Chronic pain

Can't raise arms above shoulder height, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity

but not against additional resistance

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Scoliosis and back pain; severe dry mouth; trouble breathing at night but not on bipap yet; lordosis and protruding abdomen

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, Severe scapular winging, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): unable to stand unless I have a table or something to help pull me up severe back curvature due to lack of core muscle strength

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): Unable to get out of a chair without help.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Leg weakness; extremely difficult to walk up stairs

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height



Mild scapular winging, Can't raise arms above shoulder height, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): Fall easily, need a walker, shoulders ache after sleeping on side, upper shoulder falls across throat causing difficulty breathing when on side, can't turn over in bed

Facial weakness, Mild scapular winging

Facial weakness, Mild scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): Weakness, can't open pill jars, bottles, carry my grand baby,

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): Thoracic outlet syndrome with hand numbness, especially while sleeping. Back pain.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Muscle weakness in both legs and mid body. Pain walking, standing and sitting.

Facial weakness, Severe scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): digestion problems that I believe are in part due to my weakened abdominal muscles and pelvic floor.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Other (please specify): I use a walker at home and at school. Cannot walk unaided. Wheelchair for long outings and the bus ride. Significant lordosis. I am 10.

Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Other (please specify): NEED SARALIFT FOR TRANSFERS. CAN'T SELF BATHE/SHAVE/GET DRESSED/STAND. IN WHEELCHAIR OR LIFT CHAIR ALWAYS

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Facial weakness, Mild scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, Other (please specify): Some tongue weakness and trouble swallowing. One arm has very limited motion and the other has much fuller range of motion.

At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Don't currently use AFO's all the time, or any other assistance, but can't walk more than a couple hundred yards before needing a rest.

Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Use a scooter or wheelchair virtually all the time.

Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, I can

walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Nocturnal lagophthalmos

Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): CHRONIC PAIN AND FATIGUE

Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Other (please specify): Require AFOs to walk with shoes. Walking stick helps with longer walks.

Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Need a breathing assist (such as Bi-Pap) at night, Need a breathing assist during the day.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body

Mild scapular winging, Other (please specify): Back pain (low back and between shoulder blades)

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Need a breathing assist (such as Bi-Pap) at night

Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Unable to stand up from a chair unless supported on just one side

Mild scapular winging

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Lost bicep and tricep and rely on assistive devices to help pull my arms up against gravity

Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

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Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time, Other (please specify): I am unable to stand at all.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): My hand and finger muscles are weakening which makes it hard to use computers and other tech items which has a big impact on my enjoyment of them. I've wondered if the kids at MIT could make a simple plastic type outer skeleton to lift my fingers up allowing me to use the gripping muscles that still are strong. I could type again.

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): use forearm crutches, AFO one leg and KAFO other leg

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

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Mild scapular winging, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Need a breathing assist (such as Bi-Pap) at night

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Other (please specify): Use platform walker in house but need to be bent over to move it. Also lose balance easily if I let go

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances

greater than ~100 yards.

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): core weakness use poles to maintain balance while walking

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Use a scooter or wheelchair virtually all the time, Other (please specify): I can walk if holding onto a walker, railing or person - but not well with just a cane.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Walk with a rollator

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop,

I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Abdominal weakness, lordosis

Mild scapular winging, Can't raise arms above shoulder height, Other (please specify): I'm asymmetrical - I can't raise my right arm above shoulder level - arm straight.

Can't raise arms above shoulder height, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time, Other (please specify): Dry eye due to eye lids not closing tightly at night.

Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): need to use a cane to walk

Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance

Mild scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a

chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): I hold onto a partner or friend's hand/arm for long distance walking, uneven ground including crossing roads or walking up significant inclines.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): Having trouble lifting fork to feed myself. Must drink through straw since can't lift glass

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop

Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Leg fatigue after around 40 minutes of walking, leg buckling and falling after around 1 hour and 30 minutes of walking

Mild scapular winging, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on just one side, Other (please specify): Use a cane to ambulate



Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): can walk with a cane, but for sustained distance use scooter. can walk with a cane, but worry about stairs and falling. Do fall sometimes. Hard to get up after falling.

Facial weakness, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Other (please specify): Got scapular surgery (scapulopexy, scapulas tethered to each other) to reduce neck and shoulder pain.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): experience back pain, severe fatigue, need assistance with

activities of daily living

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging

Mild scapular winging, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Other (please specify): legs are weak, difficulty standing for long periods of time

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, At least one muscle in my arm can lift against gravity but not against additional resistance

Facial weakness, Mild scapular winging. Other (please specify): Permanent wheelchair user.

Hoisted for transfers.

Very weak arms, reduced finger dexterity.

Mild scapular winging, Can't raise arms above shoulder height, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Other (please specify): Use a wheelchair ALL the time. Why is that option missing from the list? Weakness in wrists and

hands.

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Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

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Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): I walk with a rollator at all times at home, and use a scooter away from home. I have a large, bulky wheelchair but don't use it much.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): Eyes don't shut totally at night. Muscles can't relax.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Lack of biceps muscle makes it difficult to curl arms lift groceries drunk from cups

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Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

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Facial weakness, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): dropped head due to muscle weakness

Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): ELEVATED DIAPHRAGM AND FATTY LIVER

Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): High risk of falling due to weakness in right knee

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Need a breathing assist during the day, Other (please specify): Feeding tube Tracheostomy

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): Neck and shoulder pain. Back pain. Balance issues, especially in a crowd.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on BOTH sides

Mild scapular winging, Can't raise arms above shoulder height

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at

night, Need a breathing assist during the day.

Facial weakness, Mild scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Require specific muscle strengthening physical therapy for periodic sessions throughout the year. Also declining strength in axial muscles that support my head.

Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): I need to walk with the help of a walker (rollator) at all times

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): Cannot stand or bear weight at all.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Can't lift or run after my children. Struggle to take my children in and out of a crib, lift onto high chair, put into a swing etc.

Mild scapular winging, Can't raise arms above shoulder height, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Need a breathing assist (such as Bi-Pap) at night

Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on just one side, Other (please specify): Walk with aids worry about stairs, balance, pot belly & gait

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all

times but worry about stairs, fatigue, and falling

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): Cannot take a step without the support of a cane or rollator. Difficulty typing due to loss of finger and hand strength.

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I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Other (please specify): I need a walker all of the time and a scooter for anything more than just 100 feet, I also have a rolling stool in each of four rooms in my home.

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Mild scapular winging

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): I walk with a rollator.

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Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

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At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

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Facial weakness, Severe scapular winging

Facial weakness, Can't raise arms above shoulder height, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Need a breathing assist (such as Bi-Pap) at night, Other (please specify): Don't need a walker but use a walking stick for distance walking. I have it with me in the car at all times. Don't need to use it around the house just when needed from car to and around where ever I go.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time, Other (please specify): Can't sit up in bed without assistance

Mild scapular winging

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Need a hand railing for even small steps

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): severe fatigue, mild difficulty chewing and swallowing

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): One arm can't be bent up from the elbow

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Mild scapular winging, Can't raise arms above shoulder height

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Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): Use rollator outside for most of my walking

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify):

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Pain in legs/hips especially after walking uphill or for more than 10 minutes of non-stop walking.

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Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): Use a walker inside my home 100% of the time.

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Mild scapular winging, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Need a breathing assist during the day, Other (please specify): Can't lift arms at all. Can't raise fingers to wave. 24-hr vent dependent. Have a tracheostomy for ventilation.

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Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): I use a walker as I can no longer straighten my back.

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Facial weakness, Mild scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Can't raise arms above shoulder height, Severe scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling

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The biggest impact is that I can no longer pursue my dream career so that's FSH in general. Daily effects the biggest issue is not being able to raise my arms as I cannot put my hair up or reach top shelves etc.

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): can't hold my hands straight

Facial weakness, Mild scapular winging, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Other (please specify): wheel rollator used in the house

Facial weakness, Mild scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling  
Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Inflammatory pain in knees & legs..bad. Neck pain. Hip pain. Lots of pain. Made Major Depression and Anxiety worse. Isolation.

Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards, Other (please specify): Personal care and going to the bathroom

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

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Can't raise arms above shoulder height, Severe scapular winging

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Mild scapular winging, Severe scapular winging

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Can't raise arms above shoulder height, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Other (please specify): Stomach muscles on left very week. Weak core. Sway back. All leads to back problems.

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): The weakness in my back and abdomen.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards., Other (please specify): Mentally it SUCKS and there is severe pain

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Facial weakness, Severe scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop,

Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Pain and fatigue

Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Other (please specify): My daughter has had two major shoulder operations under Dr. Romeo. She is very limited with this. Many modifications to her life even with the shoulder operations

Facial weakness, Mild scapular winging, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards., Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Fatigue

Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Use a scooter or wheelchair virtually all the time.

Facial weakness, Mild scapular winging, Can't raise arms more than 60 degrees from the side

of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance

Facial weakness, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Mild scapular winging, Can't raise arms above shoulder height, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time. Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, At least one

muscle in my arm can lift against gravity but not against additional resistance, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): I can walk aided with hiking/walking sticks and leg brace

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Can't raise arms above shoulder height, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time.

Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up

from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Other (please specify): wheelchair bound + no walking since I was 21. diagnosed at 12. now 35

Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): Cannot walk at all. Use an electric wheelchair exclusively. Cannot transfer independently; am transferred by caregivers using a ceiling lift.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards., Need a breathing assist (such as Bi-Pap) at night, Other (please specify): Very slow going up/down stairs, causes fatigue. Carrying cup of tea

Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards., Need a breathing assist (such as Bi-Pap) at night

Can't raise arms above shoulder height, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Other (please specify): Significant back pain and leg or feet numbing if I stand for more than a few minutes.

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Look pregnant due to no abdominal muscles

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Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): Moderate pain of muscles and joints

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards., Other (please specify): Have an appointment with a pulmonary Dr next month to see if Bi-Pap is needed

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Facial weakness, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on just one side, Other (please specify): I can walk but use walls or canes for support.

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Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing

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assist (such as Bi-Pap) at night, Other (please specify): Exclusive use of power wheelchair

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I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): My gastrocnemius muscles appear to be the most effected at this time. I am not able to support any weight on the balls of my feet and have no "push off" when I walk.

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Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): I use a stick to support walking

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging

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Facial weakness, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

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Facial weakness, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Can't raise arms above shoulder height

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Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards., Other (please specify): Tired all day long

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't

raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): Have issues with self care and hygiene. High amount of pain and fatigue with daily activity.

Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Other (please specify): I cannot stand at all. I don't see that as an option.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Eyes not closing completely leading to consistently dry eyes, especially when I first wake up.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time.  
Mild scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging, Can't raise arms above shoulder height, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): I suffer with debilitating, chronic pain in dealing with my confirmed FSHD Type 2 and in turn causes moodiness because of my constant pain. I have found Cymbalta helps (taken for Fibromyalgia) but I have side effects associated with that but it is better than dealing with the pain.

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the



side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Need a breathing assist (such as Bi-Pap) at night, Need a breathing assist during the day.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Need a breathing assist during the day, Other (please specify): Cannot raise my arms at all. Cannot get up from a chair at all. Cannot walk at all. Require mechanical ventilation 24/7. Have severe dysarthria.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time.

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Can't raise arms above shoulder height, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop

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Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Partially paralyzed diaphragm.

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Use a scooter or wheelchair virtually all the time.

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Facial weakness, Mild scapular winging, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Hearing loss, Coats Disease

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Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

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Severe scapular winging, At least one muscle in my arm can lift against gravity but not against

additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Need a breathing assist during the day, Other (please specify): Unable to stand even when aided due to severe lordosis

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Other (please specify): Unable to weight bear at all

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): Walk aided with walking sticks and leg braces

Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop

Foot drop

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): Use a leg brace Left leg foot drop) whenever I leave the house

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides

Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my

arm can lift against gravity but not against additional resistance

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, I can walk but use a scooter or wheelchair for distances greater than ~100 yards., Use a scooter or wheelchair virtually all the time, Other (please specify): Unable to stand up from normal chair. Can stand using chair or toilet with 30" lift

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height

Facial weakness, Mild scapular winging, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): muscle pain, especially the muscles compensating for weaker muscles - shoulder, neck, lower back pain

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Mild scapular winging

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Cannot get up from floor without assistance, and must have a hold of walker/wall/arm to walk

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Other (please specify): Lessening ability to walk distances / hard to climb stairs or walk up even gentle slopes / takes longer to do self care tasks and other activities / depend on an AFO and wear an abdominal brace / difficult to lift things at all / can no longer safely climb into or out of bathtub / harder to reach things even on level surfaces / more difficult to change positions in bed / hard to visit friends and family if stair climbing is involved

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time.

Mild scapular winging

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Can't raise arms more than 60 degrees from the side of my body, Foot drop

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards., Other (please specify): Bilateral failed intercostal muscles. Right phrenic hemi paresis

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body

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Mild scapular winging, Can't raise arms above shoulder height, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Use a scooter or wheelchair virtually all the time, Other (please specify): Hearing loss

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Mild scapular winging, Other (please specify): Hip flexors weak left side, biceps and deltoid get stuck and pain in sub scapularus. All left side

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Facial weakness, Severe scapular winging, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

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Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Other (please specify): Use wheelchair 100% time, trouble coughing, cannot write with a pen/pencil, cannot dress/bath/toilet/transfer myself, cannot cook.

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Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on just one side

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

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Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

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Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on just one side, Other (please specify): Lordosis is the most difficult aspect for me

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

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Facial weakness, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Other (please specify): -Have a CPAP but haven't used -I've had a scapular fusion surgery so I no longer have winging but still have difficulty lifting my arms -Difficulty getting up from chairs but I don't always have to use one or both sides to get up -I can walk but have a wheelchair for long distances

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Mild scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): I do have weakness in my hands and fingers; I also live with a great deal of pain on a daily basis

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Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on just one side, Other (please specify): I can walk unassisted if I know there is something close by to grab onto if I lose balance or footing. Use a cane if I go out alone to stores, restaurants, etc. The fear/anxiety of falling is debilitating. I will literally freeze up.

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Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms

more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on BOTH sides

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling

Mild scapular winging

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time, Other (please specify): Unable to stand/transfer . Hare 24 hour care and use Hoyer lift.

Can't raise arms above shoulder height, Foot drop

Mild scapular winging, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, Other (please specify): unable to stand up straight unaided, walk with 2 canes for short distances, then must rest a bit. Unable to take grandkids for a walk because I cant hold their hands and walk...need 2 canes

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Other (please specify): Leg braces

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time, Other (please specify): Dry eyes, have very specific motion to get out of bed or out of chair

Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, I can walk unaided at all times but worry about stairs, fatigue, and

falling, Other (please specify): Muscle weakness in both hips and in my hamstrings, lordosis, and protruding stomach

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): My knees tend to lock sometimes or give way

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): I use a cane to walk in the street.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Other (please specify): I can't make whistle and air blow with mouth

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Calf atrophy, asymmetrical but progressing to both

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards., Other (please specify): I walk short distances inside my home with the help of a rollator. I use a wheelchair every time I leave the inside of my home.

Facial weakness, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards., Other (please specify): Unable to walk stairs without support or aid of my family. Unaided I fall

Facial weakness, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Symptoms affect, and diminish quality of, nearly every part of life.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, Foot drop, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night, Need a breathing assist during the day.

Mild scapular winging, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Suffer from mild fatigue, unable to sleep well due to muscle pain

Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, I can walk unaided at all times but worry about stairs, fatigue, and falling, Need a breathing assist (such as Bi-Pap) at night

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my



arm can lift against gravity but not against additional resistance, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Foot drop, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Mild scapular winging, Can't raise arms above shoulder height, Can't raise arms more than 60 degrees from the side of my body, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards., Other (please specify): I use a walker, a cane interchangeably, and must wear a velcro back support

Facial weakness, Mild scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Use a scooter or wheelchair virtually all the time.

Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, Unable to stand up from a chair unless supported on just one side, I can walk but use a scooter or wheelchair for distances greater than ~100 yards.

Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on just one side, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Need a breathing assist (such as Bi-Pap) at night

Mild scapular winging, Can't raise arms above shoulder height, Foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling

Facial weakness, Can't raise arms above shoulder height, At least one muscle in my arm can lift against gravity but not against additional resistance

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Mild scapular winging, Can't raise arms above shoulder height, I can walk unaided at all times but worry about stairs, fatigue, and falling

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Facial weakness, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, Use a scooter or wheelchair virtually all the time, Other (please specify): Can stand but not ambulatory

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Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, Can't raise arms more than 60 degrees from the side of my body, At least one muscle in my arm can lift against gravity but not against additional resistance, Foot drop, Unable to stand up from a chair unless supported on BOTH sides, I can walk but use a scooter or wheelchair for distances greater than ~100 yards., Other (please specify): I cant sit up out of bed i have to roll onto my side to pull myself up with arms and walker, I can go up a few stairs but have to catch my breath. I pull myself up stairs with arm rail while pushing my legs to climb slowly, Lower legs and feet fall asleep and also hand go numb when i sleep in bed flat. I fall sometimes out of nowhere when i walk or stand up.

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## Q2 Of all the symptoms you have experienced because of FSHD, what are the top three symptoms that you consider to have the most significant impact on your daily life?

Answered: 598      Skipped: 11

Inability to move arms for ADLs Pain in shoulders. Pain in hip.

fatigue, inability to raise my arms, fatigue

Walking, running, and doing stairs. Hard for a 9 year old to keep up with peers when you don't have the strength. The impact is no team sports, have to always think through a strategist the simplest of events or parties, which can lead to isolation or withdraw from normal everyday life as a 9 year old.

- 1 foot drop-afraid to trip and fall
- 2 week abs and legs- hard to go places in fear offending and using a accessible toilet
- 3 people stare

Cannot raise from ground. Stairs I need hold somewhere to climb

weakness in the arms, weakness in the legs weakness, in my left hand, I have only scapular winging, cannot lift my arms at all, cannot stand up with or without help, breathing problem

Difficulty walking, Unable to carry items with me and overall weakness that makes it difficult to complete daily tasks

Not being able to do things requiring my hip and buttock and leg muscles. Climbing, squatting, getting on floor, running, biking, walking, jumping

1. Fatigue
2. Imbalance
3. Inability to participate in athletic activities

Pain, weakness, instability

Foot drop, Breathing issues, use of limbs

- 1) I can't punch with any force, & I worry that I can't protect myself.
- 2) Shoulder and low back pain
- 3) I have a negative body image supported by looks and comments from others. Mostly my abdomen, winged scapula, and right mouth droop.

Losing the ability to walk, the ability to stand from a low position, becoming fatigued quicker than normal, losing my smile

Walking, standing up from chair, lifting arms

Tiredness, being unable to use legs properly, pain

walking, standing from seating, rolling over during sleeping

neck pain

1. Arm weakness and mobility.
2. Leg weakness, no stamina.
3. Soreness and pain

Foot drop, muscle weakness

1. Weakness in trunk
2. Weakness in upper legs - quads and thighs
3. Foot drop

Pain, fatigue, and difficulty brushing teeth and shaving.

Foot drop scapular winging lordosis

Foot drop  
Weak lips and mouth Shoulder pain

1. Leg weakness (inability to stand from chair )
2. Abdominal weakness
3. Arm weakness

unable to walk (wheelchair)

Cannot stand or walk Significant loss of hand function constant fatigue

Always feeling sore and tired, fear of losing more muscles and mobility, atrophy in right arm and fingers  
(challenge typing, texting and writing)

get out of bed  
not being able to raise my arms climbing stairs

At this point, what impacts my life the most is waiting for those first effects to come and the stress of knowing each of my children may have this disease as well.

walking difficulty, stairs, and arm weakness

Unable to walk any real distance Significant abdominal weakness Unable to lift any real weight with arms

Muscle fatigue, muscle pain/discomfort, low energy levels.

Lifting my arms, walking, falling over

Walking and getting up and down

Being able to walk up stairs without a railing and being able to raise my arms

Winged scapula on both sides, can't raise both hands above head height, facial weakness that leads to inability to pronounce properly.

Shoulder weakness, Core weakness, fatigue

Muscular weakness, pain, depression

muscle weakness, daily pain, inability to do certain things

Mental health (from things like vulnerability, humiliation, disability discrimination, relationships, employment, housing, insurance, etc.), dropping things, falling

Weak Ankles Weak Hamstrings Foot Drop

1- Losing the ability to walk it is by far the hardest the slow progression. there are times that you feel that you won't lose the ability because you will go a year or two where there is little to no change and then you'll come out of a winter and you have lost so much it tears your heart to pieces you think you could be in a wheelchair within a couple years. I could write a few pages about how the legs have impacted my life.

2- loss of strength I just can't do things anymore I am unable to work on the car do yardwork even the simplest of chores (sweeping the floor and picking up the dirt) take their toll on me. People Do Not Understand why you can't Do or Pick up things. For the most part I look normal. Again I could go on and on about this.

3- Not having the ability to Smile. is a simple thing that no one thinks about and they take it for granted. Everyone thinks you don't like them or maybe mad etc. This little problem has effected my social life I believe all the way back to grade school.

1. Worrying about stairs, fatigue and falling.

Arm limitations (washing my hair and lowering a dish down from cabinet),  
Legs struggle going up stairs and then severe fatigue, lifting leg to the side to get out of car very difficult, slow reflexes pain in muscles at night

Foot drop, fatigue, ability to not lift

Left lower leg weak Difficulty walking distance Fatigued at end of day

Struggle walking distances, standing long periods of time, doing anything overhead.

Bicep can lift against gravity, but not resistance Fatigue  
Foot Drop

1) Loss of lower back muscles. 2) Fatigue easily. 3) Psychological effects of both physical constraints and body appearance.

raising right arm above shoulder, scapular winging, lack of strength primarily in right arm

Foot drop, fear of falling, fear of not being able to walk

Not being able to get up off a chair or toilet unassisted.  
Arm weakness that makes it hard or impossible to lift drink bottles or other heavy items. Pain in my neck and across top of my shoulders.

Walking especially stairs and long distance, it's a struggle. Breathing - use Bi-pap at night along with oxygen concentrator. Strength in upper body

Foot drop  
Facial weakness  
Loss of abdominal muscles

Abdominal weakness and severe leg & foot pain

**Respondent skipped this question**

Foot drop, muscle weakness, noticeable walking differences

Leg weakness, fatigue, foot drop

1- Arms / Shoulders Pain 2- Spin  
3- Legs Fatigue

Fatigue Pain

The CONSTANT pain

Neck and back pain. Often can't turn my head when my neck is out.

Inability to lift, push, pull, carry items over 20lbs

Fatigue

Unable to stand out of a sitting position. Unable to walk. No biceps.

Walking with out assistants, sleeping, and most of all muscle pain

Foot drop, winging and fatigue

facial weakness  
loosing the ability to walk and stand by myself hands weakness

core balance, difficulty breathing, foot drop

Arm strength, footdrop, needing help with some daily chores as making bed and taking things out of fridge and oven

Anxiety about future Speech facial weakness Fatigue

Fatigue, muscle weakness, dry eyes

Fatigue, limited walking distance, dry eyes - and the effort to manage that

breathing, bowel issues (they say not related but sure they are as my mother had the same). Walking

Mobility arm restriction, independence

Pain, shoulder luxation, weakened respiratory muscles

Leg weakness Falling  
Weak facial muscles preventing proper formation of lips

I would like to be as active as I was when I was younger. Can no longer run or walk long distances.

Foot drop  
Getting up after a fall Breathing

I cannot hold my torso vertical while sitting due to weak abdominal muscles. This is also the reason why I cannot stand up or walk.

Inability to walk Fatigue  
Not being able to do things I used to do

The inability to walk without using a walker or wheelchair. Needing a bipap at night.  
Not being able to get out of a chair without help.

Leg weakness, Facial weakness, arm/ shoulder/hand weakness.

Scoliosis, leg weakness, hip weakness (increases scoliosis)

Foot drop  
Weak core which makes bending and standing up very challenging - unloading a washing machine, unpacking a dishwasher Can't wash my own hair or brush properly due to arms not going above shoulder



Walking, facial weakness, hand/arm movement

Worry about the future  
Fatigue from doing hardly anything  
Foot drop makes me have to think about every step

Extreme pain in my shoulder and upper back, fatigue

Footdrop and arm strength

Foot drop

1- walking up stairs  
2- getting up from seated position (chairs, toilets, etc) 3- if having fallen, getting up unaided

Lack of being able to walk

Neck pain fatigue can't lift left arm to wash hair etc.

Very Weak Abdomen Shoulder and Neck Weakness Right arm and hand weakness

foot drop  
need to use both hands to get up from a chair must use a cane

Discomfort, no verbal communication skills, fatigue

Upper body weakness, foot drop & leg weakness

Weak legs Weak arms Swallowing

Pain, fatigue, decreased arm strength

Walking more than 100 meters Raising arms  
Foot drop

Pain, had to stop the sports I used to do and were part of my life , fatigue

Inability to walk/run (need of a wheelchair), loss of arm strength (inability to do any manual labor (work on my car, swing a hammer, climb a ladder, etc.), loss of core strength and effect on sex life

Inability to walk without bilateral AFOs Fatigue  
Muscle pain (shoulders, arms, legs)

Arms not being able to lift, hands curling in, very weak back

Fatigue, raising arms above my head and weight gain

Inability to climb stairs, inability to stand from a seated position without assistance. Inability to straighten from a bent position without using something to push myself upright.

**Respondent skipped this question**

Can't raise my arms  
I need a wheelchair to move about Arms muscles weakness

Arm raising poor. Arm strength poor. Walking up hill poor.

Foot drop. Facial weakness and pain

Foot drop. In growing eyelashes. Right arm raising.

Arm weakness Foot drop Back pain

- 1) Anything with my arms (weakness, winging, etc.)
- 2) leg weakness
- 3) facial weakness
- 4)

Difficulty walking, fatigue, pain

1. Weakness.
2. Exhaustion
3. Slurred speech after teaching for three hours
- 4.

Foot drop  
Leg weakness Scapula weakness

Debilitating fatigue. Inability to raise arms to properly groom myself. Lordosis.

While I do not have these symptoms yet, anything related to mobility/lower limbs would have by far the greatest impact on my daily life. Upper body weakness is something I can manage; lower body weakness is something that would be terrible.

Weakness, fatigue, depression

Weakness Reaching limitations  
Tendency toward muscle spasms and tendonitis

weakness in legs /mobility. back issues ... fatigue

Core weakness which affects balance and whole body function, mechanism and scapular weakness and pain, facial weakness with developing speech slurring

Can't raise my arms Drop foot  
Scapular winging

Lack of grip to hold things.  
Inability to transfer independently.  
Inability to walk.

Difficulty walking, loss of balance Pain in shoulders  
Greatly diminished strength

Foot drop, muscle weakness, fatigue

leg weakness which leads to worry about falling, foot drop, lack of ab muscles that cause lordosis

Weakness in Arms and Legs. Shoulder/upper body pain Depression due to disability

The chronic pain is the worst. The muscle imbalances cause unpredictable spinal/pelvic/cervical pain that can be debilitating.

Not being able to use my arms.  
Walking is starting to get worse.

Lifting my arms. Severe weakness in my right arm. Tripping.

My neck, I am told, has the most muscle loss of anyone with FSHD in the US. I could get my Ex to stop tailgating. When he hit the brakes hard, it would follow that I would have neck muscle loss.

Leg weakness, not able to raise arms, facial weakness

Lower back pain, leg pain and lack of energy

yes, but I have had corrective surgeries to help improve quality of life.

Cannot use outdoor toilets because most disabled toilets are too low. Cannot get up any steps. Cannot get up from regular chairs. All this means that I cannot visit any friends in their homes or leave the house for very long.

Foot drop and calf muscle failure

Not being able to raise my arms. I have trouble picking up my son. I'm also in a lot of pain

can't put arms above my head, limited walking ability, difficulty putting arms behind me

Unable to get out of bed or go the bathroom without assistance causes extreme stress of being alone.

- 1 - unable to get up from a any seated position.
- 2 - unable to walk more than a few steps even with a walker 3 - unable to do any stairs/steps.

1. My left leg not being able to withstand any of my weight, my right leg still can. So can get in a passenger side of a car but not the drivers side without great difficulty.
2. Being afraid to go to people's home to visit and not being able to use the bathroom. So I stay home a lot.
3. The ache in the muscles at times is hard to deal with, being able to reach things.

inability to stand up or walk; inability to raise arms above shoulder height or lift against resistance; lordosis

N/A

Generalized weakness. It limits my ability to walk, sit up, stand, straighten up after bending over, grip items, carry items, get out of bed and chairs, dress myself, balance, etc. It has caused me injuries (concussion, fracture of one scapular-thoracic fusion, cuts and bruises) through falls.

Not being able to lift my arms. Stairs and Walking fatigue Muscle pain

- unable to stand up from a chair unless supported.
- balance problems when standing
- back pain all the time

Unable to lift or use upper body properly. This is the reason why I don't have children because I'm afraid I wouldn't be able to hold them during first few years.

general upper body weakness and core weakness  
bicep weakness, fatiguing quickly, everything much slower

Having only the range in motion I have, the pain, and the stamina.

My lordosis causes a lot of back pain and stares from people. Walking up stairs is very difficult. Falling and feeling like I'm going to fall.

Weak back and abdominals making me unable to stand erect without leaning on my hands

Loss of use of leg muscles Loss of use of arm muscles  
Loss of use of use of right hand due to weak forearm muscle

- 1) unable to walk
- 2) lack of strength in muscles 3) facial weakness

Lack of use in my arms makes most daily tasks difficult. Lack of being able to stand for long.  
Lack of being able to walk vary far.

Foot drop causing me not to walk outside the house, not being able to sit up on my own, and not being able to get up on my own, especially when using a toilet, sitting in any chairs, or traveling.

Lack of mobility/range of arm

Discomfort and appearance of scapular winging Weakening of leg muscles and foot drop

Heart failure, inability to walk, constant fatigue.

The symptom that has had the most significant impact on my life would be the inability to walk up flights of stairs, for long periods of time, and the constant worry about falling especially in bad weather  
The facial weakness has also had an impact on my everyday day life and with my current profession as I work directly with clients. The third symptom is the overall weakness in my body. This makes daily tasks much harder and they often take twice the time to complete.

Climbing stairs is difficult as is getting up from the floor without grabbing hold of something.

Fatigue ,drop foot ,muscle weakness

Daily back and sacroiliac pain that disrupts my sleep and limited ability to exercise.

Lack of being able to reach up

Not being able to walk any distance

Fear of falling, and what the fall could bring on

Weakness, impeded gait, physical slowness

Weakness in walking, stair climbing. weakness i right arm. Unable to lift arms above shoulders.

inability to walk

inability to stand from sitting position occasional difficulty with speaking

reduced mobility, pain

1. inability to walk
2. deteriorating strength to perform functions like rolling over
3. breathing

Not being able walk without legs giving in, not being able to lift arms to eat, comb hair, shower, eye's wont close all the way, can't whistle

speech affected, cough ineffective, severe mitral valve prolapse, severe premature ventricular contractions of the heart, fixed by personal treatment, previously lower lobes of lungs collapsed and diaphragm elevated and non functional, both fixed with personal designed treatment, severe choking on saliva 3 times in 15 minutes, fixed by personal treatment. loss of ambulation, loss of structural muscle supporting body, loss of breathing.

Very weak arms, foot drop with leg weakness, painful spasms in mid to upper back and neck

1.) Severe weakness in my core area. 2.) Severe fatigue.  
3.) General weakness in arms and legs.

Pain, stairs and being able to walk long distances

Muscle atrophy Muscle atrophy Muscle atrophy

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The above mentioned neck and shoulder pain accompanied with being unable to hold my head up.

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Затрудненное Движение рук, ног , повышенная усталость

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Swallowing, unable to lift arms

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Inability to bathe, transfer or toilet independently.

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Inability to walk constrains what am able to do in most areas of normal living. Even with support of a walker and scooter, overall mobility is limited.

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Hip weakness Drop foot Fatigue

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UNABLE TO HOLD OR REACH THINGS, SMILE, WALK

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Lordosis, foot drop and weakness in the arms and shoulders

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Loss of mobility

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Lower back pain, reaching, sitting in a hard back chair, walking long distances

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fatigue, inability to walk, clinical depression

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Unable to stand up by myself  
Unable to walk more than 10 feet (assisted)  
Unable to stand more than a couple of minutes then having to sit down

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**Respondent skipped this question**

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#200

Pain, neck and back weakness and low mood

COMPLETE

Can't use my arms for most things, wheelchair-bound, hearing impairment

Cant do things over my head, like washing my Hair, in the kitchen i need help with heavy pans and the higher cupboards, getting dresses/undressed over the head

Unable to walk Unable to Stan erect Fatigue

Mobility- footdrop , weak leg muscle strength and weak abdominals all leading to poor mobility

weakness in legs weakness in arms  
can't run or do things overhead

Falls, not being able to climb stairs, manage steps or tie my hair up

WEAK SHOULDERS, BALANCE, GETTING UP FROM THE FLOOR

1. Constant pain
2. Not being able to walk any longer
3. Sleeping issues

Pain, unable to walk, unable to breathe

**Respondent skipped this question**

1. Facial weakness - emotional impact of being unable to smile when interacting with others.
2. Spinal curvature - produces significant, chronic pain.
3. Loss of dexterity and strength in hands.

Leg strength. I can walk up or down stairs Arm strength. Can't pick up more than a book  
Overall weakness destroying my balance can't

Fatigue, weakness, balance

Walking ,standing as balance is poor and raising my arms

Atrophy of facial muscles (inability to smile, to open or close eye completely).  
Atrophy of chest, back and arm muscles. This is both a problem with function and aesthetics.

- 1) Inability to stand without assistance
- 2) Inability to walk without assistance

Pain, tired, Unable to lift arms

#208

Respondent skipped this question

COMPLETE



#222

COMPLETE

Leg weakness  
 No strength when arms raised  
 Loss of chest and abdominal muscle

Decreased leg strength, pain, inability to carry and lift things

**Respondent skipped this question**

Legs going Spine Walking

leg weakness, foot drop, inability to go up stairs the lack of ability to get up from a chair without arms..I can not use a public toilet etc., grab bars do not work for me. not being able to walk of any distance. Not being able to open doors because of lack of strength. Just because something says it's " handicap accessible" doesn't mean that it is truly accessible.

Ability to move/walk quickly Ability to climb stairs Limited range of arm motion

1. Foot drop and associated leg weakness (quads) affects ambulation
2. Hand and wrist weakness (extensor) affects computer use (work) and activities of daily living
3. Abdominal weakness - affects standing/walking distance

- 1) Muscle Loss, Constant Fatigue, Weakness in arms, legs, stomach and back.
- 2) Pain & Numbness - overall body pain & constant discomfort
- 3) Loss of balance, strength & inability to get up from something as simple as a normal toilet

Inability to step up or down (stairs, curbs, etc), inability to bend down, and low back pain.

Unable to walk more than a few paces. Cant stand up for long without needing to sit down

Can, not walk anymore , no longer independent,, arms and legs very weak

Walking, driving, and doing things around the house

**Respondent skipped this question**

Foot drop  
Leg weakness Balance

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leg pain at night that keeps me awake not being able to walk long distances stairs are getting more challenging

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Unable to walk. Difficulty rising from a chair.

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1. Upper back weakness causes pain and exhaustion in that area especially in times when work is busy (desk job).
  2. Double vision that I believe has been caused by FSHD effects my ability to read. I often have to close one eye to be able to read.
  3. Weak abdominal muscles cause a "beer gut" type look and I have difficulty getting out of low sitting positions, like a car close to the ground, and getting out of bed.
- 

Loss of leg use  
Loss of strength in arms General pain

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Pain, fatigue, muscle weakness

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1. Upper body strength for doing daily tasks like dishes, washing my hair, household chores.
  2. dry eyes
  3. foot drop/tripping
- 

Chronic pain, fatigue and uncertainty of how I am going to feel each day

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Walking  
Arm strength Muscle pain

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tiredness, weight gain, able to do things myself

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Muscle weakness in arms and shoulders that makes it difficult for me to wash my hair, do my makeup, brush my teeth, carry a plate of food. Muscle weakness in my legs that keeps me from running and I'm starting to get unevenness in walking.

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Not being able to use my arms, not being able to walk long distance and not being able to go up or down stairs.

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1. Mobility
  2. Ability to get up from seated position.
- 

lordosis, difficulty walking, cannot lift heavy things like a baby or toddler

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Foot drop and leg weakness; not being able to lift arms and arm weakness; dry mouth due to not closing mouth enough

Leg weakness, Foot Drop, Arm Weakness

Unable to walk distances, unable to lift objects or raise arms, unable to stand on a ladder

1. Not being able to get out of a chair.
2. Not able to climb stairs / go down stairs without rail on each side.
3. Not able to walk easily without linking arms with another person. Because of lordosis a walker doesn't really work because it requires leaning forward, which is difficult.

Pain.  
Unable to walk.  
Fatigue.

1. Foot drop-must now use AFOs to stabilize gait
2. Leg weakness-difficulty standing up; walking up stairs, and getting up from sitting or kneeling

Not being able to raise my arms. Not having strength in my arms. Finding it harder to climb stairs

lack of walking over 25 feet, difficulty moving in bed and getting up from bed, tire easily because every movement is an effort

Aching muscles Body image Speech

Pain, fatigue, weakness

(1) arm weakness - impacts nearly every activity of daily living (2) facial weakness - in addition to the physical issues (dry eye, eating/drinking) there is a huge emotional/mental burden associated with always appearing to be mad/frowning (3) breathing - my father died from breathing complications due to FSHD when he was just 10 years older than I am now. Although my breathing issues are minimal at this time, it is a significant fear for the future.

Steps--Falling--Walking

Unable to lift arms, weakness in legs, pain

Difficulty walking. Loss of biceps. Back pain.

foot drop  
leg and hip weakness that impacts walking, balance and climbing stairs abdominal weakness impacting rising from lying down and lordosis

Muscle spasms due to winging. Drop foot now with both feet, lower back pain do to the way I now walk.

fatigue, pain and unsteadiness on my feet

Lordosis, inability to smile, walking upright.

CAN'T STAND/WALK/DRIVE

Tension in neck leading to headaches. Pain  
Fatigue

- muscle weakness in hands
- foot drop
- facial weakness - at work I come over as sleepy and unfriendly

Very limited mobility Pain  
Fatigue

Foot drop

Neck and upper back pain, cramps. Difficulty finding comfortable sleeping positions; waking up with neck and upper back cramps. Difficulty sitting up at office all day. Quick fatigue walking, sitting, cooking, etc.

Difficulty walking; Difficulty ascending/descending stairs; Getting up from a seated or lying position

pain, breathing and fatigue

Neck, arm and back pain due to weak shoulders Leg weakness  
Foot drop

Walking unaided. Range of arm motion. Maintaining erection.

Arm weakness Pain  
Being asked when my baby is due

Lagophthalmos resulting in exposure keratopathy Fatigue  
Arm weakness

Using arms for daily living, muscle weakness, fatigue

Foot drop  
Unable to do stairs without support Scapula winging

Cannot smile. Lack of arm lift. Cannot walk or exercise enough.

PAIN CONSTIPATION  
SHORTNESS OF BREATH

1. Foot drop and leg weakness. Legs = mobility! Once legs are affected FSHD becomes a completely different ballgame.
2. Inability to raise arms above head. Not the end of the world, but it still stinks.

Needing breathing support

Not being able to raise arms above shoulder height. Sever scapula winging.  
Weak facial muscles (particularly lips).

Back pain, muscle soreness and fatigue after activities that last up to 2 days

Pain, Loss of strength in all extremities, loss of range of motion

weakness in arms/upper legs/hips, difficulty walking too far/much, fatigue

core weakness, spinal abnormalities and leg weakness.

Arm weakness  
Inability to raise arms overhead

Weakness, no weight or power in my body (49 yr old man skin and bone!!) body dysmorphia and anger- upper body pain, tripping up when I walk

Shoulder, foot drop, fingers

Pain. Not being able to lift arms and exercise. Struggling to hold myself up.

Walking, lifting, daily routines

Weak leg muscles Full use of arms Weak torso

Balance  
Raising arms above head Walking for long distances or time

loss of bicep and tricep  
loss of core muscles leading to a protuding stomach potential loss of my ability to walk

walking with a cane; weak arms; unable to reach up

## Breathing

1. Hip and knee pain at night while trying to sleep.
2. reaching for things above shoulder height.
3. A paralyzed left lung makes it seem sometimes like I cannot get enough air. And, I seem to get pretty tired fairly quickly.

Muscles lock up unexpectedly causing me to fall or struggle to move or walk. Doing simple chores varies in quantity according to my day concerning pain. I don't sleep well because I need to roll to my other side often due to pain.

Inability to stand or walk.inability to lift objects with my hands. Inability to raise my arms up to my face and head

- 1 leg weakness
- 2 upper body weakness/bad posture 3 lungs

inability to walk much, inability to get up from most chairs on my own, loosing more strength in my arms

Fatigue  
Limited Range of Motion Future mobility constraints

Constant lower back pain, leg pain, drop foot and risk of falling

## FOOT DROP,LEG WEAKNESS AND BREATHING

Getting up from a chair.  
Not being able to walk very far with walker.  
Can't get out of bed without help

Poor mobility Unable to lift arms  
Weak face muscles make me appear sad

Weakness in legs Weakness in arms

not being able to raise arms above shoulder height; becoming quickly fatigued while exercising; growing difficulty with stairs

diminishing ability to walk or do stairs  
unable to lift objects of more than a couple lbs pain

Lack of mobility - walking.  
Standing up from a seated position requires special accommodations - usually at least another chair to lean

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Pain in neck/shoulders, fatigue, weakness

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Inability to do stairs. Fear of falling. Inability to walk far without pain

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Leg weakness contributes to falling and injury, hip weakness contributing not independently able to get up from low chairs and toilet.

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Falling, the weakness of my right arm & my prominent belly

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Foot drop weakness in my hips and starting to experience shortness of breath.

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raise arms

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1. Foot drop
  2. Unable to lift arms above shoulders/scapular winging
  3. Abdominal weakness
- 

Muscle weakness in all muscles;  
Loss of range of motion;  
Inability to do what I used to do - participate in sports, run around with kids, stay active

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Loss of power in my right arm Loss of power in my right leg Have trouble walking

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Not being able to raise my arms above shoulder height

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I can't walk or drive  
I need supplemental oxygen  
I need help dressing and showering

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pain  
muscle fatigue/weakness  
unable to get off the floor after a fall

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Not being able to use my right arm above chest height. Foot drop  
Joint weakness

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Pain, fatigue and lack of endurance

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Leg weakness making walking difficult and high risk of falling. Arm weakness. Dry eye.

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difficulty walking difficulty using my arms  
difficulty doing all of the things I need to do to live independently

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Upper body strength Working above my shoulders Walking upright

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Loss of low back muscles means I can't stand upright anymore, have to use walker and it's so tiring

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Losing the ability to walk.  
Losing the ability to get up from a seated position or the floor. The weakness in my arms is so bad that I can't lift a pan to cook.

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Losing the ability to stand unaided for more than a few (4-5) minutes without AFOs; inability to roll over unaided while sleeping causing prolonged fatigue; burning muscle pain in one quad after standing

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Poor core strength causing instability with standing and walking.  
Weak hip/quadriceps muscles impacting ability to walk especially up curbs, steps. Hyperlordosis and low back pain and weakness.

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Cannot raise hand

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Can't walk at all. Right arm and hand has almost no movement. Left arm has very limited movement.  
Extreme lordosis is painful

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1- back pain 2-hip pain 3-arm pain

---

Scapula winging on right. Foot drop. can't lift my right arm above the shoulder

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Leg weakness - difficulty with uneven surfaces & stairs Lifting arms over my head  
Abdominal weakness

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1. Arm weakness
  2. Leg fatigue
  3. Inability to raise arms above shoulder height
- 

Pain inflammation sore hips fatigue

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Tiredness, difficulty to climb stairs & walk, eyes burning and bulging especially if I am tired my right eye will have a burning sensation and also it is little bulged

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Pain, left leg weakness, fatigue

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Unable to walk up stairs, unable to get up from chair, constantly tired

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Fatigue, inability to lift arms, pain.

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Mobility due to legs weakness.

Wrist weakness affects typing and writing. Breathing problems

- 1) facial muscles - not too bad, but self conscious)
- 2) weakness in core, hips and legs with foot drop... had to modify or stop some of my favorite physical activities... intermittent numbness and tingling in fingers and toes
- 3) scapula winging and arm weakness - can't lift as much or raise left arm over shoulder height

Drop foot and not be able to raise my arms above my head.

weak core, weak leg muscles, weak shoulder muscles

Weak Facial muscles, falling, low core strength

Was neck pain before scapulopexy surgery.

Was also shoulder instability (dislocations, subluxations) before surgery, but improving since surgery. Now it is limited shoulder range of motion.

1. Difficulty walking
2. Unable to raise my arms above shoulders
3. Difficulty bending over and inability lifting over 16 lbs

Pain, losing abilities which I once had and depression

arm weakness, scoliosis, leg weakness

Pain, fatigue, depression

1. Myalgias exacerbated by pressure (e.g. sitting/lying supine affecting gluteals, lying on side affecting deltoid) - prevents adequate sleep
2. Arm paresthesias due to shoulder girdle atrophy and traction on brachial plexus.
3. Weakness and fatigue

Limited walking and standing, stairs, unable to stoop without falling or getting up from floor.

difficulty standing for long periods

legs get fatigued, particularly at nite. Have difficulty walking long distances, ie over a mile

Unable to stand up from chair unless supported from one side. Severe scapular winging.

foot drop

difficulty raising arms

Raising my arms

Muscle weakness, extreme tiredness, aching shoulder muscles when I stand too long

Breathing, circulation. Tiredness. I am almost normal when starting, but get very tired fast. Walking uphill, stairs.

Inability to walk anymore.  
Inability to stand from sitting.  
Pain in muscles and joints.

Breathing. Raising my arms and leg weakness.

Leg muscle weakness, abdominal/core weakness, and back pain.

Inability to walk.  
Weakness in wrists and hands.  
Inability to raise arms.

The inability to run or walk properly Difficulty with hills and stairs Impact on self confidence

Inability to walk, Speech problems Muscle fatigue

Unable to stand.  
Wheelchair.  
Breathing difficulty.

Pain in back, legs and hips. Loss of muscle in both arms. Inability to walk unaided.

Can't walk. Breathing probs Lack of sleep

Foot drop causing fatigue and fall/tripping  
Limited mobility above shoulder height makes all around tasks and daily living difficult at times  
Last just the loss of muscle mass in general causing strain on other parts (lower back, shoulders and arms the most) along with the lack of muscle it makes my joints lose so I have issues with dislocations by doing things as simple as gripping something to tight

Not able to lift my head up.  
Not able to stand.  
Not able to lift up my arms

- muscle weakness
- being not able to raise the arms high enough
- weak muscles in the legs and the danger of falling

dropped head, inability to walk distances, difficulty reaching high shelves

TROUBLE WALKING, TROUBLE BREATHING, AND CONSTANT PAIN

Very limited ability to walk; poor strength and reach in arms; limited ability to bend down

Can't walk

Can't transfer myself from toilette to wheelchair for example Need all day assistance

Not being able to use my arms properly for the simplest of tasks Walking for any length of time in pain  
Eating anything as very difficult to put food into my mouth

Limited speech

Breathing problems (tracheostomy, ventilation) Pain

Leg weakness, shoulder/neck pain, pelvis instability causing back/hip pain

As an interior designer I can no longer work as I cannot lift or carry. I loved cooking and baking but find the process difficult due to my weakness. Anything with stairs is impossible. Walking very slowly and in an unsteady pattern is a problem in any crowded environment. Cannot walk in NYC where I lived for over 30 years. I cannot keep pace and get in the way as others are walking. Weakness with my right hand challenges my ability to shower, brush my teeth and eat.

- 1) Loss of strength in legs making balance difficult and worry about falling.
- 2) Loss of stomach muscles making upright posture difficult
- 3) Headaches in back of neck when posture slips after working at computer or sitting/driving for long periods.

### Respondent skipped this question

legs arms shoulders

Walking

Strength in my arms/hands Fatigue

Can't walk Can't raise arm

Breathing problems

Neck support, trunk weakness, limited shoulder use and strength.

Can't raise my arms , not being able to walk without the rollator and having so much difficulty to raise from a seat.

1. Breathing issues because of the resulting fatigue
2. Bathroom related difficulties
3. Pain and/or discomfort

holding head erect, loss of lifting ability, physical posture

1. Pain-- always in pain. Difficulty sleeping and a reminder of my body dying.

2. Fatigue-- so tired and I

can't keep up with the demands of everyday life.  
moving my life forward because I feel so sorry for myself.

3. Depression-- I get paralyzed from

Can't walk more than a couple hundred feet Unable to stand for more than a minute or two Weakness in hands

Leg Weakness, Fatigue and bicep weakness

Walking, lack of energy, feeling unsafe

My difficulty walking impacts my life the most - I'm terrified of falling because I can't get up from the ground on my own and fear breaking any bones because I would be even more dependent on help from others.

Inability to raise arms, reach out normally. Facial weakness

Lower Lordosis of the spine is the worst symptom. It has caused so much pain that has exceeded the speed of other deterioration i.e. inactivity from back pain speed up muscle wasting.  
Scapula winging.  
Facial expressions being weakened.

1. hyperlordosis
2. footdrop
3. loss of finger and hand strength

fatigue, muscle weakness, balance

Not being able to walk or climb stairs unaided  
Not being able to lift anything above a pound or two.  
Not being able to straighten up from a bent over position without having something or someone to push myself up on.

Facial expression, waling and falling

Fatigue  
Weakness/Range of Motion Mobility

Inability to walk, inability to stand in one place for only a minute or so, pain.

Fear of falling.  
Lack of ability to lift arms/no strength. Severe shoulder pain from muscle loss.

Lack of mobility, fatigue, inability to stand more than about five minutes

Unable to walk muscle weakness fatigue

significant breathing issues complete muscle loss inability to smile

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Facial weakness

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Falling climbing lifting my arms

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Walking stamina, exertion stamina, strength.

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Not able to walk, only being able to type with one finger and getting tired easily

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Weakness Looks Circulation

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Walking troubles/stair troubles, unable to get up from the ground, unable to pick things up from the ground

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fatigue, muscle weakness in arms, facial weakness/swallowing

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Overall weakness, difficulty lifting arms and pain

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Can't walk for any distance.  
Severe impact on use of arms.  
Pain.

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Walking and not being able to lift my arms

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Foot drop, Bicep weakness/ total loss of bicep muscle, fear of falling

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I have issues with my neck and shoulders all the time. Holding an object for a distinct period of time. Turning my head side to side. Hand weakness.

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Wash and hair dry my hair

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Leg weakness limits mobility. Shoulder and scapula pain interferes with sleep. Bouts of fatigue.

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Scapular winging  
Facial muscle loss around mouth

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Pain, fatigue, lack of stamina

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Pain, not being able to lift ANYTHING, not being able to sleep due to pain.

---

Unable to walk without a walker - leg weakness. Falling.  
Arm weakness.

---

Can't reach above my shoulders, standing is becoming difficult due to weakness in my shoulders and tripping is becoming an every day issue

---

1. Weak lungs during pneumonia forced me to get tracheostomy, now vent - dependent with trache.
  2. Can't stand or walk: wheelchair dependent.
  3. Can't lift arms to reach for things and can't carry anything arms stretched forward.
- 

Loss of my core muscles. Loss of my facial muscles and loss of my arm muscles

---

Loss of facial muscle is number one for me. Smiling and eating in front of others are difficult and affect my social life.

---

The biggest impact is that I can no longer pursue my dream career so that's FSH in general. Daily effects the biggest issue is not being able to raise my arms as I cannot put my hair up or reach top shelves etc

---

not having enough muscle strength to do the simplest things such as standing up unassisted from a crouching position or having to drag myself to the nearest surface that's the right height to lift myself up with or asking someone for help. the lack of muscle strength has affected my life in every way, no job and having to rely on disability and living under the poverty limit. I can't smile so people think i'm pissed off all the time or have anger issues. Just feeling tired and fatigued after doing simple tasks.

---

#457

COMPLETE

Ability to stand. Balance. Tiredness.

Leg muscle wasting

Pain, fatigue and increasing difficulty walking

Pain. Weakness. Fatigue.

Walking, walking, and walking

I can't walk, therefore I need to use a wheelchair all of the time. Lack of strength in arms. Need assistance to get into wheelchair in the morning.

instability for walking  
inability to lift weights about shoulders

Not being able to stand up Not being able to lift my arms Lordose

weak neck, weak arms, weak legs

Getting up from sitting Getting up from the toilet Walking without assistance

Weak abdominal (midbody) muscles Fatigue  
Can't raise my arm

Not able to walk far Worry of falling  
Not being able to get up from the floor unassisted

The shoulders/arms because I can't lift my arms. It has an impact on many thing I have to do with arms.

Inability to raise arm above shoulder Weak shoulder  
Occasional pain

leg weakness and arm mobility and pain

Currently discomfort and weakness in arms and shoulders

Fatigue after any physical activity Muscle pain

#457

COMPLETE

Weakness of hip and low back muscles

---

Shoulder arm and core weakness.

---

My weakness in my back and abs. Unable to stand or walk for any length of time.

---

Arm weakness, shoulder subluxation and inability to raise arms above my shoulders.

---

Facial weakness. I wish I could smile. Plastic surgery could fix that. It's hard when everyone thinks you're angry.

Fatigue. I'm always tired. Always sore. Always sleepy.

The deformity from losing muscles. Do my spine my rib cage. My organs. My shoulder blades. So scapular winging. It's severe and hurts a lot

---

Unable to raise hands/arms above my head

Pain/discomfort in making certain motions with arms in particular Fatigue and hip discomfort when walking any significant distance

---

Respiratory problems. Fatigue. Pain.

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**Respondent skipped this question**

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Bad lower back, problems with my knee, leg weakness

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Ribs hurt because of shoulder operations, hips hurt, breathing to adjust ribcage

---

loss of Quadriceps. Pain. Fatigue

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Steps

---

Mobility, Pain, and Fatigue

---

Fatigue, awkward smile, inability to walk long distances.

---

The inability to lift my arms has a very significant impact on my daily life. This affects regular routine activities like washing my hair and brushing my teeth as well as work and home related actions like pointing, reaching for things, lifting things, working on/fixing things that are high up (changing a light bulb...)

---

Inability to walk far

Inability to ascend and descend stairs Loss of balance



#457

COMPLETE

---

Unable to stand Unable to walk Unable to lift arms

---

Leg weakness, loss of use of left arm, foot drop.

---

1: not being able to carry my children as we walk.

2: not being able to raise my hand high enough to shake other peoples hands

3: felling exhausted all the time so don't do that many fun things with children, feel like I'm failing them

---

Walking/Running is more difficult  
Stairs and Lifting objects off the floor is difficult Swallowing food causes choking regularly

---

Not being able to walk or stand  
Unable to lift my arms to brush or wash my hair Lack of facial expressions

---

Leg weakness Shoulder weakness  
Progression of condition

---

Unable to walk,  
unable to stand up from a toilet seat if low,  
It's hard to do tasks while standing because it takes all my strength to hold up the upper part of my body.

---

the loosing of ability to walk/and stand , the fact that i need to support the 1 arm that works with the other to be able to lift the arms. the fatigue when overdoing activity, (but doing time you learn a lot of tricks to cope with practical problems)

---

loss of muscle strength in legs  
unable to lift arms over my head  
Chronic Body Pain

---

weakness, range of motion in arms, fatigue

---

Extreme walking difficulty Arm/shoulder weakness Muscle ache/pain

---

losing the ability to walk - facial weakness - weakness in both hands.

---

Balance  
Foot drop  
Loss of hamstring strength

---

not being able to walk no facial expression weak hands poor grip

---

shoulder weakness/scapular winging, arm weakness, upper leg weakness

---

Not being able to raise arms above shoulder as makes it hard to get dressed. Foot stop as constantly fear falling.  
Weakness in legs as hard to stand up without something to help me up.

---

1 – Not being able to transfer, including to the toilet – I use a shower/commode chair and require 100% assistance from caregivers. 2 – Not being able to walk at all – use an electric wheelchair 100% of the time  
3 – I can no longer feed myself; I need assistance.

Weakness in legs Fatigue Weakness in arms

Unable to stand and walk. Muscle weakness in legs. Muscle weakness in arms.

Fatigue.  
heart rate slowing,  
time & pain making drinks/sandwiches - just getting about

Cant Exercising Constant pain Social life

Legs weakness. Standing up from a chair.

walking and falling

Walking distances

Fatigue, shoulder weakness, unable to use arms above head

Not being able to lift arms,

Very difficult to get from sitting to standing Difficulty walking and standing  
Difficulty carrying anything

1. Abdominal weakness,  
2. ankle weakness/foot drop.  
3. Balancing issues. Can't stand without leaning against something

Leg weakness Arm weakness Lordosis

Pain Uncomfortableness Fatigue

Sleep, pain, leg weakness

Foot drop, unable to stand up alone. unable to walk alone

---

-weak legs (fear of falling, no stairs, no walking without assistance)  
-constant fatigue  
-muscle aches

---

Can't get off toilet without pushing off sink or door knob. Can't get up from floor or chair without leaning on something. Unable to walk outside the home without a cane and/or support of another person.  
Can't get up and down stairs without a handrail.

---

Hip weakness Arm weakness  
Abdominal weakness

---

fatigue, knee and hip soreness, shoulder pain

---

Extreme difficulty with steps  
Right leg significantly weaker than right - I now limp and without a stick, I have fallen many times Back pain

---

Pain, loss of energy and weakness.

---

Arm movement. With the muscles weak in the shoulders, it is hard to reach high shelves and to hold a phone to the ear for any longer than 1-3 minutes  
Having adjusted to reaching high things over the years my posture has changed to a 'leaning back' stance which gives me a funny walk and at times back ache

---

can't raise my arms even to shoulder height, in a wheel chair full time and need support to transfer

---

Leg weakness

---

Shoulders weakness, belly weakness

---

Both legs and 1 arm dysfunction

---

Foot drop, inability to smile/wrap lips around a straw, and not being able to lift my arms above my head

---

Fatigue

---

Tired  
No energy always tired

---

High fatigue and pain from pushing muscles to accomplish simple tasks (so muscle weakness) skeletal pain from the weight our muscles can no longer carry. Slowly losing use of arms and hands.

Inability to get up from seating position, inability to walk, pain

Breathing muscle weakness Core muscle weakness Arm/shoulder weakness

I was a pianist but can no longer play.

Ability to be independent (I now am dependent on care givers) I couldn't care for my babies/young children alone. Facial weakness, Can't raise arms above shoulder height, Severe scapular winging, At least one muscle in my arm can lift against gravity but not against additional resistance, foot drop, Unable to stand up from a chair unless supported on just one side, I can walk unaided at all times but worry about stairs, fatigue, and falling, Other (please specify): Eyes not closing completely leading to consistently dry eyes, especially when I first wake up.

1. Difficulty getting myself up off the floor/ground. 2. Stability and fatigue when walking. 3. Inability to carry things and walk for fear of falling, and not strong enough core muscles.

Foot drop Fatigue  
Inability to walk without a walker

Difficil

Not being able to raise my arms, not being able to run, pain

Severe atrophy in one thigh, both calves and foot drop means I cannot walk and must use a wheelchair, preventing my free and independent use of public transport, preventing me from visiting the homes of family and friends and limiting the places where I can work when I finish my studies. Beyond the practicalities, the bodily experience of the atrophied and atrophying muscles is both discomfoting and uncomfortable to live with, causing pain and fatigue that are severe enough that they often stop me from doing very everyday tasks.

Stiff back and thighs. Weak muscles in back and thighs. Aches and pains in lower back and torso.

PAIN, FATIGUE and Limits my mobility in doing the things I once could.

weakened limb girdle, foot drop and breathing( which impacts fatigue)

dysarthria  
requiring mechanical ventilation  
total dependence on others for virtually all ADLs

---

Tiredness, lack of mobility, frustration

---

I can hardly go up stairs, I can't raise feet well while walking, I often feel very unstable while standing

---

arm lift, foot drop, winging

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foot drop, weakness in balancing muscles, loss of power in legs

---

Not being able to lift my arms. Not being able to walk for very long. Being too tired or sore, or just unable to do certain things for myself.

---

Inability to walk without a walker; unable to get from a fall.

---

Coats Disease (totally blind), hearing loss, low muscle tone

---

Inability to walk distances, inability to stand for more than a couple of minutes, inability to lift

---

Limited arm use and lack of leg strength

---

Muscle weakness, facial weakness, muscle endurance

---

1. Breathing - using ventilator 24/7
  2. Muscle pain - especially low back and shoulders
  3. Shoulder weakness - unable to do many activities
- 

Loss of capacity to weight bear (i.e. stand up); Loss of capacity to lift arms to 45 degrees; Incapacity to lift and carry items

---

Pain, (all over body pain due to the FSHD) Mobility, (Takes 30 minutes longer to go anywhere, I cannot walk without walking sticks and leg brace for foot drop, weakness) Tired all the time...spend more time in bed just to recoup for a morning activity

---

Can't stand  
Limited reach with arms Reduced finger dexterity

---

Weakness in the arms and now the legs

---

1. loss of skeletal muscle

2. pain
3. depression

---

(1) winging (2) foot drop (3) eye lids

---

raising arms above head getting fatigued  
long walks

---

Inability to lift arms above my head Facial weakness on one side  
Pain in right shoulder area

---

Pain, weakness, unable to walk without assistance

---

Slowly losing strength and mobility in my upper body.

---

1. Unable to stand from seat or toilet. 2. Unable to get to bathroom in time because move so slow. 3.  
Can't maneuver in bed anymore. Now sleep in a lift chair

---

Difficulty raising my arms Fatigue

---

1. fatigue from increasing muscle weakness while performing everyday tasks, especially walking
  2. chronic muscle pain
  3. progressive reduction in mobility reduces my quality of life
- 

1. Lordosis (trunk weakness) 2. Leg weakness 3. Arm strength
- 

inability to stand and walk Scoliosis

---

The ability to lift my arms, the look of the winged shoulders and my facial weakness.

---

Walking

---

Bicep not able to lift with resistance. Calf muscle does not allow me to do toe raises. Not being able  
to lift hand above head

---

Weakening hip girdle and arm muscles lessening strength  
needing to take time to rest between activity

---

Not being able to walk  
Not being able to use both arms together

---

---

shoulder pain and weakness

---

Dropped foot Fatigue  
Lifting arms above head

---

Pain, weakness, not able to walk

---

Arm lift restriction  
Leg muscle weakness Foot drop

---

Scapular winging, and upper back weakness, because it prevents me from doing daily activities without feeling incredibly fatigued or in danger of getting weaker. These activities include ordinary things such as doing the laundry, cooking, cleaning the house, or exercising (running, lifting weights, etc.).

---

Foot drop, Arm and shoulder weakness.

---

arms and hands

---

1. Inability to walk
  2. Speech impairment
  3. Lack of facial expression
- 

Shoulder pain

---

unable to stand or transfer respiratory

---

1. Loss of hand function (source of lost independence),
  2. Shoulder/arm strength
  3. Abdominal strength (needed for respiratory and standing/walking)
- 

Walking and lifting objects are the two most difficult. I was an independent woman until FSHD made regular activities impossible to perform without help from my husband.

---

Weakness Fatigue Unbalance

---

**Respondent skipped this question**

Losing the ability to walk Losing the ability to drive safely Footdrop



---

Fatigue

1. Leg weakness
2. Arm weakness

---

losing muscle mass

---

Difficulty walking  
Difficulty/inability to get up after falling Biceps weakness

---

Chronic pain, physical limitations, and depression.

- 
1. Pain
  2. Walking
  3. Arm weakness

- 
1. Cannot use my hands.
  2. Can only walk 10 feet using a walker.
  3. Often feel like a quadriplegic.

---

Not having use of my arms. I have no strength in my right arm at all and fear what will happen if I lose strength in my left. I fall a lot and trip very easily

---

Walking Falling Balance

---

**Respondent skipped this question**

---

Walking and balance issues

- 
1. Have to use a walker to walk safely.
  2. Fatigue easily after working several hours.
  3. Back pain and difficulty sleeping

---

Ability to stand and walk.  
Ability to raise arms to face/head Hand dexterity and weakness

---

Weakness Drop foot Arm lifting

---

Need 2 canes to walk!!!! Trouble swallowing solids and choking on liquids...General lack of stamina i.e., fatigue

Fatigue, Scapular Winging, Leg Weakness

Leg and core weakness, causing need to use a power wheelchair Facial weakness  
Inability to lift arms up greater than 45 degrees

Muscle weakness, Pain from activity, and fatigue or exhaustion from overuse of weak muscles

Walking long distance Heart palpitations  
Can't get my arms up to do hair etc....

Arm weakness Leg weakness Core weakness

Fatigue with walking long distances, inability to raise my arms, facial weakness: Inability to show expression/feelings

Foot drop  
Facial weakness belly

Weakness that causes falling Difficulty rising from toilet (chair) Raising drink and food to my mouth

Walking. Reaching above my head. Putting on my clothes. Taking a bath without help...

Weight Lifting, Respiratory, Fatigue

Leg weakness, shoulder weakness and foot drop

Foot drop, calf atrophy, overall heavy feeling

Weak legs, core, arms Fatigue/lack of energy Weight gain

#1. Fatigue leg weakness  
shoulder weakness

can't walk far or safely, arms can't perform many daily living tasks, can't smile

---

Fatigue Chronic pain  
Inability to walk or take stairs

---

Can't lift objects above my head, difficult to hold objects directly out from my torso for short periods, hand weakness makes gripping difficult.

---

facial weakness, inability to walk well (i.e. leads to trips/falls due to foot drop, no ability to run or even walk quickly, easily slipping on icy/wet surfaces), inability to work with arms overhead.

---

I use a ventilator all the time to breathe. I'm completely wheelchair bound. i don't hear well, 60 percent deaf in both ears. all around severe muscle loss including vital organs

---

Unable to raise arms above shoulder height, fatigue keeps me from doing all I want to do, weak legs and foot as fatigue sets in

---

Leg weakness  
Weakness in arms, neck and shoulders Weak wrists

---

Can't raise arms above shoulder height Severe scapular winging  
Foot drop

---

Walking, lifting arms and pain

---

Use of hands (gripping, writing), raising arms (overall strength) & balance

---

dry eyes, foot drop, balance

---

FOOT DROP, INABILITY TO EASILY RISE FROM A SEATED POSITION, NEED FOR A  
ROLLATOR TO WALK

---

My core is weak and walking standing up straight is difficult without a support, and arms and shoulders can't lift to reach or to carry much weight. I am 77 years old. Diagnosed at 14.

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- 
- 1) Not being able to get up from a regular chair without help.
  - 2) Not being able to walk outside
  - 3) Not being able to get out of bed without support
- 

1. Not being able to climb stairs/steps
  2. Footdrop
-

### 3. Difficulty in standing up from a seating position

---

unable to walk

---

walking

---

Mobility speed, fear of falling and fatigue

---

Unable to Raise arms over my shoulder, lift simple household items

---

Hips back arms

- 
- 1) Complete dependence on wheelchair due to weakness
  - 2) Daily pain and fatigue management
  - 3) Long-term effects of inactivity
- 

---

Not being able to move fast, not being able to climb stairs or walk a short distance, not being able to carry or hold anything more than 10 lbs. Not being able to pick up household items and put them away in cupboards, i still try. My shoulder muscle and scapula are the only muscles in my right arm that work still and let me pick things up. Luckily my right hand still works. But very shaky. Im more left hand/arm dominant now, my arm muscles are still halfway there, thank goodness!

Q3 Are there specific activities that are important to you but that you cannot do at all or as fully as you would like because of your condition?

List the three most important activities that have been impacted.

Answered: 600 Skipped: 9

Showering Dressing. Going out unassisted

hiking, going to concerts, commuting.

Physically everything is impacted and compensations and choices a 9 year have to be made that a 9 year old should not have to face. Not being able to run as a 9 year old is hard, life is about running at that age. Stairs for a school age child makes also living life a challenge and just basic walking to keep up with peers is a huge struggle. All things that limit a child's life as we all know it and leads to isolation.

walk and do stairs get out of a chair pucker my lips

Working more efficient is not easy because I cannot do all activities easily

building/woodworking/heavy gardening activities (limited) tennis (cannot play anymore)  
playing the piano (cannot play anymore)

There are no such activities

dressng myself, washing my hair, cooking

Hoiding my brand new grandchildren, inability to waik any significant distances and Limitations on my abiility to play piano for any length of time.

1. Golfing
2. Throwing a ball with my kids
3. Jogging, hike, work out, carry groceries

Taking care of kids Household work. Typing and presentation skills at work

- I can't effectively
- 1) bowl
  - 2) play darts or pool
  - 3) work without a back brace and stretching and rest breaks

Going to a full time working job, exercising for health and happiness, living independently

Travel, walk, bathe on my own

exercise, travel, self confidence

jogging, swimming,

---

Walking, participating in sports, reduced socialising

I love to coach baseball. That has become a lot more taxing for sure. There is nothing I want more than to coach young people and impact lives in a positive way through baseball. Playing golf with my wife is becoming more and more of an issue. It is something we share together and I fear it will be taken away. Simple tasks with out pain or trying to think it through so I can limit my possibility of pain and increase my possibility of success.

Fishing Golf and walking

1. Going upstairs
2. Skiing
3. Cycling

Work around the house (cleaning, laundry, yardwork), golfing, and difficulty brushing teeth/shaving.

Running, walking, lifting

Climb stairs

Need scooter for long distance Unable to lift or carry

1. Ability to travel
2. Walk without fear of falling
3. Virtually every physical activity as simple as billiards or table tennis are impossible.

walk, cook (I can do it but it's uneasy and tiring), hold my grand-daughter

cannot drive my adapted van anymore personal grooming  
playing board games or any sports

Carry my kids (especially daughter still in crib), use right hand (texting, typings, writing), walking long  
distances (walking kids around in stroller and doing errands)

correr  
fuerza en las manos subir escaleras

So far, the disease has not limited my life.

skiing, running, playing

Yard work / landscaping  
Walking In sand / going to the beach Unable to get up from the ground by myself

Working full-time.

walking, horse riding and dancing

Freedom to explore & be spontaneous etc. I miss bush walks and walking in general Climbing stairs

Stairs

Pronouncing perfectly which leads to miscommunication, shoulder weakness which makes it hard to carry  
both light and heavy things, and sudden fatigue that can be a burden during my daily activities.

Working and lifting overhead and lifting with strength. Showering without contorting to reach. Getting off  
the floor after lying down.

Some woodworking tasks, hiking, intimacy

limited range of motion, not being able to pick up things over a few pounds and activities with my family

Going anywhere without anxiety, going to the bathroom (at home but especially out in public spaces) by myself and without pain and anxiety of falling or not being able to get up, dancing/exercising

1. Can't do at all: Sports - Tennis, Skiing, basketball, running
2. Walking with friends - too worried about falling to enjoy the experience
3. Enjoying the outdoors and being active

The Mountains:

I will never be able to go on a hike again on a beautiful summer day the smell of the pine trees with just the sound of squirrels maybe a bird in the distance, the peaceful feeling you get. Or setting by a campfire enjoying a cold beer with a hobo dinner and then in morning heading down to the closest river or lake to take in Some fishing.

Grandchildren:

The ability to get on the floor letting the kids climbing on me, rolling around and chasing them. The happiness it brings when your hearing the laughter. Or when they reach their arms out for you I am unable to pick them up and lift them to the stars. Let me put it like this I won't be receiving the world's greatest grandpa tee shirt I not able to enjoy all the things grandpa's should.

Taking a Bath:

I am 58 years old and haven't been able to relax in a tub for 13 years and with FSH I get a lot of aches & pain what I would give to lay in a tub and just forget about everything for a little while.

There is so many things that FSHD has taken from me that it would've been easier to say what I can still do.

1. Can no longer ski
2. Can no longer hike.
3. Can no longer swim in the ocean.

Cannot do elliptical or many arm bar weights at gym

daily activities like cooking, cleaning, bathing, dressing and being social - travel and going to other homes (inaccessible)

Walking Lifting Running

Walking, playing with grandkids (can't get off the ground), baking or cooking (requires standing for long periods which hurts)



Ability to handle tools for home repair, etc.  
Ability to travel for work or pleasure without fatigue  
Ability to lift and carry large or heavy objects requiring both arms

1) Running and playing with my kids. 2) Hiking, backpacking, and other strenuous exercise. 3) Household duties that used to be easy.

lift weights, shoot basketballs, outdoor activities

I cannot run so I cannot play with my daughter. I cannot walk quickly so I feel like I slow a group down. I cannot play tennis.

Walking Showering Driving

Ride a bike outside or take long walks without having to stop constantly. Walk the stairs somewhere like a lighthouse or just in general where there are staircases. Fatigue quickly - I wear out quicker throughout the day and almost need a nap to re-energize, not that I wouldn't mind a nap but I feel like I'm missing out on stuff.

Walking unaided Smiling  
Raising arms

Simply being able to get something out of the cupboard, walking long-distance to get to the fishing is that I love and being able to work

Running, lifting anything heavy, games with balance

Walking, playing with my kids, doing my hair

1- Sports ( Walking freely / Playing Basket Ball / Dancing ) 2- Painting / Taking shower  
3-Working ( I work as Architect )

Standing at gigs Walking

Can't go to my kids events.  
Can't swim.  
Can't travel

Long hikes, being able to carry a back pack for walks or travel. Struggling to carry bags.

Lifting, pushing, pulling, carrying addy work, reaching above my head, walking up stairs

Ride a bike. Cheering, soccer

Cannot golf. Cannot walk, thus impossible to access relatives home. Do not travel and stay overnight.

Working, just light house keeping, and not been so depressed cause I know what is coming in my future.

Walking. Holding objects in front of me while I walk. Using my arms above my head

drive a car  
take a bath or go to the toilet by myself walking

EVERYTHING required walking - can't hike , camp, access to some buildings, carry food on trays at cafeteria, shop, try on clothes in a store, find appropriate shoes to fit AFOs, museums, cocktail parties, pot lucks with friends, sit in conference chairs for education at work, take coffee to my desk....

Group traveling as on buses or walking tours, playing neighborhood Bunco because I can't get up steps to homes, playing with my grandchildren cause I can't run, sit on floor or lift them.

Sports Talking  
Walking long distances

Sex, exercise, travel

Walking-anywhere. Social events in the evening - cannot manage due to fatigue, even with a nap during the day. Shopping for clothes.

Walking any distance. House cleaning meal prep

Independent shopping, holding grandchildren, Dependence on daily living activities

Gainful employment, gardening, walking

Walking long distances or length of time Riding a bike  
Lifting objects

Typing, sitting comfortably, sleeping while laying flat (hip muscles shortened due to sitting all day).

Cooking Cleaning Climbing stairs

Traveling.  
Needing someone to help me get my wheelchair out of the car.  
Riding a bike, exercising, house chores

Standing up from floor, Stairs, walking longer distances, lifting stuff off floor

Sooooo many!  
Skiing with my family  
Limitations on traveling as hard to walk thru airports and long distances Swimming in ocean

Yes. Shopping, drawing, socialising

I can't play volleyball anymore  
I love doing renovations, but I can barely swing a hammer  
I'm approaching the season of life where grandkids could happen in the next 5 years, but recently realized  
I can't pick up a baby

Exercising like I used to, work ( had to change careers), skiing

Running, walking days out, house maintenance

walking comfortably and climbing stairs

1- visiting friends' homes that have stairs at the entrance 2- chores around the house now being done by spouse 3- disinterest in traveling due to mobility problems

Dancing, swimming & walking

Sleeping exercise and using left arm to do things like sanding scrubbing etc.

Physical activity at work Walking for extended periods Walking up and down stairs

walking stairs

Running, being social with friends, playing sports

Swimming, sports shooting & picking up my son

Work Golf Travel

Yoga, work, food preparation

Walking stairs  
Outdoor walking on the beach Cleaning

Yes, marathon running , can't jog anymore more than 50m, windsurfing is too painful and Motorcross

Playing soccer or baseball, doing mechanic work on my own car, carpentry (remodel and building new things)

Cannot walk without AFOs (even with them, distances are limited). Cannot engage in sports or any physical recreational activities.  
Travel is difficult

Walking too far, Working, feeling awake

Kickboxing, walking long distance

Difficulty attending my kids school events. Seating is either bleachers, which I can not climb or small chairs that I cannot rise from. Any events with a lot of people. I lose my balance easily. I am also not comfortable going most places by myself because if I fall I cannot get myself up.

### **Respondent skipped this question**

Change my own clothes Use the restroom  
Take shower

Changing a light bulb and other raising arms tasks. Walking uphill in the country. Carrying heavy items

Eating out. Concerts. Just being in public is hard

Long distance walking. Playing snooker.

Raise eating utensils to mouth Lift with dominate arm  
Walk for any later Nigeria distance

- 1) routine tasks that involve reaching upwards (changing lightbulbs, reaching things from the top shelf, etc)
- 2) sports (snowboarding was my favourite sport but, I no longer have the strength in my quads to participate)
- 3) general physical well-being (it is difficult to remain active and keep my overall fitness up when I can't do the large majority of types of physical exercise)

Exercising, picking up my children, photography

1. Play guitar and sing live for more than 30 minutes.
2. Work. My children's activities. Social gatherings.
3. Walk dogs.

I can do all these things but in a severely limited fashion, yet they give me great meaning in life.

Walk long distances at a decent pace Run

Carry items

Work. My children's activities. Social gatherings.

It would be nice to throw a ball with my son without pain. I would like to be able to do basic upper body exercise without worry (pushups, shoulder exercises).

Traveling, rock climbing, Sex

Cannot play piano Difficulty in cooking Cannot do gardening

general house maintenance. walking .. working

Running

Caring for grandkids Home projects/cleaning

Play sports, mainly basketball and table tennis. Work in the computer for longer periods.  
Play the piano.

EVERYTHING in my life that I'd like to do is impacted by my condition. It's like asking the parent of 3 children to pick their favourite.

Sports with my kids

Ability to do cardio exercise for heart health Rugged outdoor activities (skiing, fishing, etc.)  
bike, snowboard, hike

walk long distances, play soccer, run

Going out meeting new people/finding new partner Social interaction  
Sport

Dancing, picking up my niece, putting away dishes

I can't walk more than a mile used to be able to walk 2.5 miles. I can't swim anymore.  
I have a hard time lifting anything more than a few pounds.

Holding my new born daughter. Running  
Working out

1. Long daily walks with my dog. 2. Cooking fabulous meals for friends. 3. Being able to do the work — mostly sitting for long periods — to earn a M Theology so I could teach.

Walking, exercise, travel

doing simple house hold chores

Yes. Daily chores such as cooking, laundry and general shopping

Drive. Visit friends. Do gardening.

Hiking or walking, golf and the ability to do heavy house projects like remodeling.

Picking up my son. Helping around the house

play piano, walk long distances (e.g. go on walks with family), do housework (putting dishes or towels away, reaching for things, carrying things)

Everyday living tasks unable to complete. Fear of falling, walking.

To be honest, I can't think of an activity in my life that isn't affected. 1- all social activities, including attending grandchildren's events

2 - use a bathroom toilet without a lift

3 - take a shower

1. Getting to be on the beach. Basic independence.
2. Not being able to fully go where I would like.
3. Be on the floor and play with my grandchildren. Everything that encompasses mobility basically.

walking, getting up and down from toilet; dressing myself

Running long distance races. Despite being asymptomatic, my doctor does not want me to run longer distance races like 1/2 or full marathons for fears that the strain might cause muscle damage that might not be restored or might trigger other symptoms I don't currently have.

1. Ability to live and work independently. Since I fall regularly and cannot get off the floor by myself, I am dependent on others for help. Plus this has stopped me from finding work outside of home, as I cannot risk going outside is snowy, icy or high wind conditions. So I remain on SSDI with a reduced income.
2. Loss of physical strength to perform chores, duties and enjoyable activities. I no longer hike, bike, ski, run, even walk on uneven ground. I struggle to roll over in bed, let alone be the physical mate I'd like to be. I can't play catch with my grandson or pick up a baby.
3. Fear of falling and loss of strength have changed how I consider myself. I now think of myself as fragile. So how I present myself to the world and how I am perceived has changed.

Bird Hunting with my father and brothers Hiking in the mountains

Working in my garden and yard

- social life is difficult because I need assistance to load/unload my wheelchair from the car, so I can not move independently whenever I want.
- bathroom accessibility is big problem for me, because even if a bathroom is big enough (accessible stall) it doesn't mean I'm able/strong enough to move on/off the wheelchair
- walking on a beach

Having a normal workout routine. Walking for long periods and everyday chores (supermarket errands or anything that requires lifting)

capacity to lift and carry everyday items like groceries is waning. upper body posture affecting mobility comfort.

Everything. I would love to be able to go on walks, ride a bike, live life.

Playing piano, making art, sports I had to quit.

I cannot run, so I cannot play any of the sports I used to, or go for runs. I can't go for walks because I start to get pain and fatigue.

Walking



Walking

Getting up from seat unaided Climbing stairs

1)inability to walk 2)unable to drive 3)unable to work

Would love to cook, play golf and hike.

Walking upstairs, dancing, exercising for my health.

Running is important to me but muscle weakening is making that harder. I also feel generally weaker with my arms. The limit of my arm movement hampers me playing sports like tennis, badminton and squash which I used to enjoy more.

Work

Leave the house independently Hobbies

Playing with my children would be the most important activity that I cannot do fully. As I've aged, running is impossible. I also have difficulties climbing most things. I have to hold onto an item whether it's a piece of furniture etc. to get up off the floor.

Ability to participate fully in certain forms of exercise.  
Ability to go on long hikes or walk uphill for extended periods of time.

Participate in active activities with my children , bending up and down ,walking

Can't travel long distances. I can't exercise as much as I used to. I don't get enough sleep due to pain

Climbing up anything  
Lifting anything bigger than a toothbrush above my waist  
Bending over to pick something up and feeling that I'll just keep going down to ground

Housekeep, take walks/hikes, carrying things

Sailing, walking any distance, climbing stairs

inability to walk  
inability to stand from sitting position occasional difficulty with speaking

driving, walking, sport

1. ADLs such as bathroom transfers, bed positioning
2. Driving

Walking, swimming, cooking

walking in the woods, canoeing, hugging

Bathing/grooming, general household chores, gym workouts

- 1.)anything requiring bending over
- 2.) lifting anything
- 3.)standing for any amount of time.

Carrying things upstairs, lifting thing above my head, riding a bike.

No.

cleaning my house, dancing and riding a bicycle.

Спортивные занятия, обучение, питание

Walking even médium distances, eating without having to be aware all the time about the swallowing, having to look at the floor when walking so as not to trip

Inability to bathe, transfer or toilet independently.

Food prep (standing, lifting, carrying anything) Paper work i.e. filing, lifting, management  
Travel, socialization, just to local restaurants or gathering. Transferring into/out of vehicle to travel  
wheelchair as powerchair is too large. Isolation is almost overwhelming and expensive.  
Laundry and daily chores very difficult.

Difficulty getting dressed. Taking a shower and washing my hair is a challenge. Unable to go anywhere that has steps, including neighbor and friends houses. Any form of shopping takes twice as long due to mobility limitations.

Lifting above my head working out  
Exercise without exhaustion

#### Respondent skipped this question

Independence.  
Walking unaided by back brace or AFOs. Reaching for and opening things.

Walking to shops Going on holiday  
Visiting friends and relations

Walking, reaching, swimming

play sports, hike in the outdoors, compete academically

Use the restroom by myself Walk

#### Respondent skipped this question

Walking -I used to enjoy walking on the mountain I live and in the surrounding countryside -now it takes me all my time to get around a shop -so that is a joy which has disappeared, as is the ability to dance, I no longer can

Personal maintenance (i.e. hygiene, getting dressed); transferring on/off toilet or bed or shower seat;  
cooking

Pick up and carry a baby, hiking with rucksack on the back, bending over to pick up things from the floor



Walking Cooking Gardening

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Social outings, shopping and climbing stairs

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Run hike  
kneel down

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Get round the airport and on the aircraft unaided  
Not being able to go out and socialise or attend events  
Nothing able to go to friends houses with steps into the house or without a downstairs bathroom

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RUNNING, HIKING, YARDWORK

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1. Not being able to go anywhere due to not having a vehicle that can transport my power wheelchair and not being able to sit in my wheelchair for long periods of time because of pain and stiffness
  2. Yard work
  3. Not being able to play any sports
  - 4.
- 

Walking, breathing, exercising

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Holding my son, volunteer fire fighting, and detailing cars-- i do that for a living

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Driving - recently had to give it up due to pain levels. Flights longer than 3 hours - travel is a passion of mine. Social activities such as dancing and swimming.

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Can't walk up stairs  
Can't exercise to stay in good health  
Hard to hug family members without almost falling

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Walking, work, house and garden maintenance

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Socializing (inability to smile makes it more difficult to socialize).

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Facial drooping (causes strangers to rub their eyes, a sign that they see something unpleasant). Swimming (self-conscious about body asymmetry).

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Golf  
Canoeing  
Fishing

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Traveling, Housework, just getting up and going without thinking about the impact on my body

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**Respondent skipped this question**

#208

COMPLETE

#218

COMPLETE

Pick up things on the floor

Use stairs without assistance (cane) Stand for more than several minutes

Lifting and carrying grandbaby, travel

Basic daily task, grooming, putting stuff away above shoulder height. Fatigue.

### Respondent skipped this question

I can't walk as much. Doing household things Keeping a healthy mind  
leg weakness, foot drop, inability to go up stairs

shopping, building access, fishing/walking on uneven ground

working/having a job, I'm 60 yrs old and have been on disability for 6 yrs. Again, just because a building says that it is accessible, doesn't mean that it truly is. Many do the very minimum to be compliant. I would love to be able to drive a car again. Arm weakness does not allow me to be able to hold or care for young family members. Not being able to hold an infant is kind of sad...

Anything active with my adventurous three-year-old  
Travel confidently; every new environment brings unknowns and the logistics often overwhelm the opportunity at hand

Music and doing creative woodwork with my hands. I used to play classical guitar and lost that ability 35 years ago now when the extensor muscles of my hands stopped working. This also has affected other hobbies such as woodworking, leatherwork, etc. The function of my hands also made it much more difficult to do important elements of my job - writing. Luckily in recent years, Voice recognition software has improved to the point that I can be more productive writing again.

Outdoor physical activities. Sports activities such as golf, tennis, end basically diminished and then ended over the last 30 years. Being outdoors hiking, walking around cities with my wife, going on long bicycle rides, these are all gone. At this point, I am far more isolated, and alone then add any previous point in my life.

Travel. My wife and I retired two years ago hoping to do more travel again. FSHD makes everything much more challenging and expensive. The challenge of using an electric wheelchair to get around airports in cities. The extra costs of having to choose very specific seats on airplanes. The intense planning required to make sure that vehicle transportation and accommodations are accessible. By and large, the world does not pay much attention to the needs of those who have mobility difficulties.

Gardening Yoga  
General exercise

#233

## COMPLETE

1. Working: Loss of career as a violin maker restorer/wood worker - inability to translate my skills and find the energy to begin another career
2. Getting Exercise: Inability to participate in favorite physical activities such as biking, hiking, camping, yoga, and going for long walks.
3. Social Impact: Inability to continue playing musical instruments (cello & electric bass) going to concerts, visiting friends houses/apartments, and limiting travel with family and friends due to inaccessible venues and/or the high cost of mobility equipment/vehicles.

Walking easily, getting up from a chair, getting up from the floor.

Looking after and playing with my grandchildren Walking my dog, most household chores

Walking, driving, and doing things around the house

Winging, raising arms, shoulders

Can not golf anymore Can't walk on beach  
Can't walk up stairs so can't see grand child at her house

hiking  
traveling to remote places  
being able to do things independently around the house ie: lifting, reaching higher spots changing alight  
bulb etc.

Socializing with friends. Doing household chores.

1. I used to play golf but cannot anymore.
2. I used to run 5K races but cannot anymore.
3. I used to do yard work and got to the point I could not do near as much as I used to.

4.

Hiking Hunting Scuba diving

Working, swimming, doing sit ups

Hiking, fishing, rock climbing

1. Being able to work a full day without pain later that day
2. Being as spontaneous
3. Having to cancel plans (social and work-related) due to pain

Walking Balance Sports



#233

COMPLETE

walking

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#247

COMPLETE

wash hair, carry my grandbaby, brush my teeth, eat without lowering my head or putting my elbows on the table.

Buttoning my jeans, getting in and out of equipment used to run my business.

1. Walking
2. Getting up from seated position.

walking/ running, working, carrying (pregnancy) and caretaking for a child

Walking, hiking' climbing stairs, running Carrying and lifting  
Speaking for long periods of time

Participate in Sports, Run, Climb Stairs

Walking: in a mall, at the grocery store, walk the dog  
Carry things: groceries into the house, laundry basket to/from the laundry room, items into the garage  
Home tasks: change lightbulbs or smoke detector battery, hang curtains, put dishes away, put food in microwave

Walking freely, swimming hard (can still swim, but very slowly and difficult to get my heart rate up), going out with friends

Driving.  
Hiking.  
Riding a bike.

General walking for pleasure or exercise is a thing of the past. even with AFOs, walking is extremely taxing. Running--can't run even if I try. Carrying light to moderate weight when walking is extremely difficult.

Lifting my Granddaughter. Some gardening activities

driving, being able to go out of the house without causing much work for my husband, shopping, going out at all if there is any snow on the ground (slip and fall easily) visiting friends who have stairs and don't have disability equipment in their bathrooms

Playing sports full contact Sit ups  
Serving in the military

Caring for dogs and all pets

#264

COMPLETE

I've never known the feeling of running. I would now love the ability to enjoy a simple walk. For the future, I hope to maintain sufficient strength to manage my own self-care, independently managing activities of daily living.

Walking--Going out--Being a Grandfather

Play fetch with my dogs, ballroom dancing, typing for work

Working in the yard. Skiing. Just going for a walk....

Walking around, climbing stairs, traveling by myself, exercise, sexual activities,

Work, I no longer work due to the all day long muscle fatigue. Visit with family. Alone time with my husband.

my fatigue is limiting

Hiking in the woods with my family. Playing sports like softball, track, and soccer. Being able to access the play equipment at my school playground.

DRIVING/DOING ERRANDS/HOUSE AND YARD WORK

I cannot work at a computer for long periods Gardening  
Sport including walking and cycling long distances

- walking more than one or two miles
- typing on a keyboard with more than two fingers
- eating soup without spilling

Walk Cook Bathe

Stairs  
Putting things on top shelves

Most sports and exercises; travel is difficult because of carrying heavy bags; dancing and just making normal body movements and gestures instead of being stiff.

Martial arts; Walking; working out

working full time and socializing

#264

COMPLETE

Walk confidently Pick up loved ones Dance

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#277

COMPLETE

Fishing. Golf. Sex.

Can't walk as far, or fast as I want

Had to change jobs as no longer able (physically) to work with nursery age children

Can't stand for long periods which affects everything that involves standing for any length of time

Cleaning the house Washing the car Jazzercise!

Cooking, anything involving lifting arms over head, walking

Stairs Running

Walking for long time due to foot drop

Cooking is problematic (I do it but it is getting dangerous). Cannot exercise (walk) safely. Housework difficult (often straining muscles doing simple cleaning).

## WALKING BATHING TOILET

1. Any exercise that involves significant leg strength. I can still walk for exercise which is good. But it would be nice to be able to play tennis like I used to or baseball or just about anything that requires running.

2. Swimming - I can still swim and even with shoulder weakness could still swim long distances which is great exercise and I swam for many years with FSHD. The eventual foot drop pretty much eliminated my swim kicks so even swimming isn't what it used to be and I'm not longer as comfortable in the water as I once was. Before foot drop, I could still swim in the ocean and surf waves. Even walking in the sand now is difficult. Legs are a big deal!

3. Social situations - I'm mostly an introvert anyway, but would be more comfortable in social situations without FSHD.

Dad always attended sporting events ... too weak with the breathing problems

Tying up my hair/washing hair. Putting things away on high shelves. Standing up straight.

Carry children (being pregnant, holding small nieces/nephews), my job as a PTA, group gym workout classes

walking, sex, unable to lift

basic daily life~ walks, walking normally without feeling stared at, being able to lift or carry anything.

#292

COMPLETE

Attending social events with family (parties, child's sports/music programs) and travel.

Many. I can't participate in the activities I love most like playing with my children or sports. I struggle to help around the house and feel like a failure to my family at times.

Family time out - I look disgusting! Can't lift or manage daily tasks Can't shower/ bathe myself properly

Going out alone, drinking without a straw, driving

Rowing machine. Painting ceilings and lifting things up. Walking long distances

Walking, swimming, hiking

Walking Exercising at gym  
Cross country skiing

Playing sports Running Lifting. weights

ability to rock climb, paint, cook, surf, swim, and be active which limits who I hang out with and my social life.  
At time, the depression gets bad.

exercise; hanging clothes; lifting boxes

Coaching Hunting Housework

1. I cannot get down on the floor to play with my grandkids.
2. I will not be able to play catch with my grandkids.
3. Driving.

Playing guitar, lifting and carrying things and walking in the mall or going to a fair...or any event that isn't  
handicap friendly

Cook and do housework Fix my hair and dress Do handwork of anykind

- 1- Working
- 2- Visiting friends and relatives. They don't live in wheelchair accessible homes. 3- fishing

#307

COMPLETE

keep up with my grandchildren, get up from floor or chair, ability to carry things

Healthy Food Preparation Travel  
Weight control

Limits sexual activities, walking & hiking with family, travel

JUST WALKING IN GENERAL, HUNTING AND FISHING AND DOING MY JOB

Can no longer go out without help.  
Can't fix my own food.  
Can't lift a cup or glass

Sailing

Walking in countryside Swimming

Gardening Long walks Socializing

cannot run easily; can no longer dance; can no longer hike

take a walk in the woods  
stairs  
hold my grand baby

1. going out in public alone - shopping, restaurants, doctors, etc. I need help with my scooter and a variety of other factors that may present themselves (not being able to reach things when shopping, parking on a wet surface or a slope, opening doors for example).
2. Being able to participate/see my children's activities due to location - maneuvering sports fields, field trips, award ceremonies, etc.
3. visiting friends houses and restaurants which are inaccessible to scooter and/or don't have bathrooms I can use (toilet height, grab bars, etc. ).

Traveling (due to standing in lines, sitting on an airplane, walking long distances). Work (due to sitting in same chair for long periods, standing, walking, fatigue). Cooking (due to standing for long periods, moving arms a lot).

Walking/hiking. All sports I used to play. Household chores

Toileting, climbing stairs, getting up from low chairs

Shaving, walking and making sports

#307

COMPLETE

Walking long distances or jogging.

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#321

COMPLETE

I take the survey for my mom the most impacted for her when she stand up she don't need help but she can't stand up as those as old as she is and her scapular winging she can not reach out to pick up distant objects so she Avoid going to events.

1. League bowling
2. Daily hygiene and chores - putting dishes on the shelf, doing my hair and makeup, taking the trash out, etc...
3. Walk and/or run

Playing soccer, playing volleyball, running around with my kids

Combing my hair Playing basketball Running

Daily activities such as drying my hair with a round brush, being able to style my hair in the back of my head, comfortably and confidently working out on an elliptical.

My sex life with my wife I no longer work  
I can't contribute to house work as I would like

fitness - unable to walk or swim like the old me showering and washing my hair  
eating - unable to reach my mouth and need to bend my head down to meet the fork.

Doing my own hair without using a wall for support.

Going to workout classes, many of the workouts I cannot do. Most sports

Hiking, throwing balls/beanbags during sport activities, swimming

Fishing. Yard work. General home maintenance.

being able to go anywhere without worrying whether I can actually get there, and / or get through the front door.

DIY, exp above shoulder height. Strimming as stoop forward. Arms ache swimming, grass cutting, most arm actions

Walking, gardening, daily house chores

Walking  
Breathing well—diaphragm is partially paralyzed limiting my breathing capacity. Stability—too wobbly and unstable on feet.

#336

COMPLETE

Cannot get any form of physical exercise except warm water workouts which compromise weight management.

Playing sports with our children. Going to the beach and swimming.  
Taking the family to outings like sporting matches, parks, amusement parks etc.

Brush my hair. Tired when I am cooking

Lifting a fork. Can no longer drive. Need caregiver to dress and bathe

1. 1-cooking/baking
2. holding my grandchild 3-personal care

My job as an X-ray tech is difficult to do. Exercise class is very curtailed for upper body exercises. Shoes are very, very difficult to buy. Can't have any heel or I trip

Running

Skiing - water or snow Golf

1. I used to be a very active tennis player and horseback rider, but I am now unable to participate in those sports.
2. I now act and dance, but long rehearsals exhaust and tire me out very quickly, and I often have to sit out from rehearsals due to fatigue.
3. My family loves hiking, especially when we go to the mountains, but, although I would love to, I am unable to hike the long trails.

Walking long distance playing sport day to day chores

Combing my hair  
Lifting things and holding it Sitting and getting up from there

Walking around easily, physical exercise

Exercising, socializing, travel

Exercise, playing with my kids, house work, hobbies

Mobility due to legs weakness.

Wrist weakness affects typing and writing. Breathing problems

Lifting heavier things/carrying children and even lighter things for an extended length of time Working out (a lot of yoga and Pilates moves I used to love, running)

#336

COMPLETE

Anything requiring hands over head (hand ball, tennis, a lot of sports)

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#350

COMPLETE

Shopping. Working a full work day. Vacations to the city.

bicycling, yard work, being an active participant in many worthy activities formerly done.

Outdoor activities, running, sports

Before the scapular surgery, I couldn't sit down and study because my neck and shoulders hurt too much. I would study standing up, and later on studied while lying down on my stomach. Since the surgery, luckily I can do desk work all day long (I'm currently in medical school, and study a lot). I feel that I still can't do manual labor, or do any weight lifting that involves the arms, because I fear I'll snap the achilles tendon graft that holds my scapulas together, and regardless of it snapping, I'd have pain. I wish I could go rock climbing.

1. Hiking & backpacking (not at all)
2. Unable to climb stairs if over 10 steps
3. Can't pickup my grandchildren

Running, doing outdoor activities with my family and walking long distances

unable to walk (wheelchair bound), need help with transfer to wheelchair from bed, need help showering such as washing hair

Playing saxophone, my job, sports

Cycling Swimming Sports in general

Carrying anything is impossible due to walking sticks or canes. Bending down to do anything. Walking on uneven surfaces.

Use to play tennis but can no longer. Love to hike and ballroom dance, but now that is limited if I am able to do those activities. Love to do adventure travel, but now just walking long distances is difficult

1. Can't walk without support as i have to attend office.
2. Office work affected.
3. Problem in using public toilet.

work exercise  
every day tasks

Dancing

#364

COMPLETE

Taking long walks make my shoulders cramp horribly Standing too long  
Cant wave in my right hand

Active sport, mountain walks.

Walking anywhere.  
Using the toilet.  
Staying up for more than 6 hours (I need to lie down and rest a lot).

Cleaning house. Grocery shopping. Going out daily to do anything.

Used to do quite a bit of sport, but now unable to play golf or cricket. Also unable to go on long walks in the country due to the unknown topography of areas (i.e., if i come across a big/steep hill it would take along time to ascend and would tire me/my legs a lot)

Walking, running, sports.

The ability to do home odd repairs or renovations. Typing/keyboard.

Cycling with friends and family outdoor activities with family ability to keep fit

Employment

Going to bathroom unaided.  
Bending over to feed self.  
Walking.

I cannot stand up to cook or do dishes. I can't fold or put away laundry, or do house work.

Everything

Being able to lift and play with my daughter is number one it's a strong mental downer at times  
Second sports activities I was very active and healthy as a kid now I get worn out just grocery shopping

Last hobbies like racing riding motorcycles and working on vehicles has all been affected do to the loss of mobility of arms legs and feet it makes the tasks much more dangerous

Not able to wash or dry myself Not able to wash or comb my hair Not able to dress myself

- travelling
- cycling, driving a motorcycle
- doing any kind of sports activity or things like dancing

#381

COMPLETE

cooking more than an easy, simple, quick meal; gardening; walking/hiking

GOING IN MY BOAT, GOING ON TRIPS, AND NOT BEING ABLE TO WORK

Visit places of entertainment or culture such as theatre or museums; visit family and friends; visit places of interest where walking would be involved

Need for all normal activity help. So there is no special thing to note.

Taking a bath Wiping my bottom  
Being able to get up from the floor or a chair

Art/Drawing Eating/drinking Masturbation

Walk or stand for any length of time. Sit without arm and back support Play with my grandchildren

Walking on the street or in stores.  
Cannot "clean" my home.  
Need assistance getting dressed with anything over my head.

Inability to run which took away ability to play sports. Skiing  
Hiking if path is steep and not paved.

**Respondent skipped this question**

self care and having to rely on others

Walking out in the countryside

Climbing stairs as part of visiting places Dancing/going to gigs/clubs

Can't drive

Can't visit friends Can't travel

Tennis, bike riding, hiking.

Cooking, having to deal with my clothes on hangers in the closet is terrible ( getting them and putting them back on the bar) . Getting dressed in general and it is worse with heavier clothes in the winter.

1. Inability to work anymore
2. Travel is much more difficult and, therefore is more limited

#381

COMPLETE

3. Sex is much more complicated, which is annoying

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lifting much of nothing above waste, sit without slouching to maintain eye contact for extended periods of time, getting winded during activities

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#395

COMPLETE

1. Limiting how I can be with my kids (lifting into crib, carrying) 2. My right hand is atrophied so I can hardly write or type. Can't lift heavy pots etc. 3. Exercise-- I used to exercise and maintain a healthy body and image. Now I can't do so many exercises and I am scared to do anything that I am losing my body and have poor self-esteem.

Walking/hiking Typing/driving

Activities in general(Working around the house), golfing, walking.

Getting up from the floor/chairs/bed unaided, walking without aids, lifting/carrying items

I cannot work or engage in regularly scheduled activities because my energy levels are so inconsistent. By the time I shower and dress I'm usually exhausted, so morning events and activities are out of the question. I feel cut off from society.

Limits to opportunities for Exercise, e.g., classes /sports as most use arms in ways I can't or which cause me significant pain afterwards.

Walking around, I'm terrified I'll fall over and hate that people stait at how I walk. Dancing or going on night out. I just can't do it any more for risk of falling and fatigue. Shopping, being unable to be on my feet for longer than five mins

1. Hiking
2. Traveling / Visiting locations with stairs
3. Dancing and other enjoyable exercise

hiking, sight seeing, socializing

Walking Lifting  
Talking so that I can be heard

Running

Driving Cooking Working

Shopping. Cooking, Going to doctors. (Cannot get up out of a regular chair so it is challenging when going places to take a cushion high enough to get you up.)

Cooking.  
Working(used to work in an office).  
Being able to socialize and/or go to baseball games due to not being able to walk up/down stairs to get to seats.



#414

COMPLETE

Shopping, standing to cook, enjoying the beach since I live at the coast

Walking. Sewing . Energy to do things

walking working playing

Daily tasks Working out Driving

Walking

Basically just physical activities. I've never been a runner, so that isn't an issue but I used to like to bowl and can't do that any more, long walks for sightseeing purposes and hiking in general.

Walking, cooking and going out alone

Bodybuilding Rock climbing  
Some regular every day things like carrying small but heavy items

Dancing, walking the dogs, going places like new restaurants without worry of stairs

travel; working/volunteering in community, painting/art

Being able to walk/hike, cooking/baking, independently being able to go somewhere

Walking  
Using my arms above waist level (washing hair, cleaning)

Anything involving arm strength (opening jars, carrying anything, scrubbing) Adding a fourth. I have a grandchild on the way that I will have difficulty holding.

Cycling, dancing and general exercises

Carrying/ taking care of my baby Working out at the gym/ running/ sports

Holding a baby, hiking/walking trails, bathing/grooming my dogs, swimming in cold pools in the summer, bumper or go cart riding, horseback riding, rollercoasters, etc.

Some yoga poses.

Outdoor activities, beach, hiking, sight seeing. Extended vacations.

#414

COMPLETE

Exercise Quilting Yoga

Walking/hiking Gardening Biking

#430

## COMPLETE

Holding my kids, picking up my dogs, embarrassing myself at work because I can't even lift a laptop, or anything for that matter.

Going to stores to shop. I shop online and do a grocery pick up. I don't go anywhere by myself. I am not able to work.

Sports are really not possible. I would love to do my hair up or elaborately but in order to put my hair even in a pony tail I have to lay on my bed. I can't get down on the floor or even a low sofa. I was at a friend's place to the other day and sat on her low couches. I couldn't get up. It was so embarrassing. I had to have lots of help to get up.

1. Used to play drum set. Can't now.
2. Used to dance. Can't.
3. Used to drive. Can't.

I can no longer keep my house clean. I cannot go shopping on my own anymore, and I need assistance now in getting dressed and undressed.

Smiling, eating, running

Doing my hair

impacts on my ability to do karate ironing the clothes

walking more than a mile in under an hour would be nice to do again. picking up and walking with a weighty object. sex.

Walking. Playing with grand children. DIY

walking and visiting places; lifting and carrying things; Going out in adverse weather (ie windy, icy, snowy weather)

Self care, self management of home environment, shopping

Outside activities. Not going places because too much walking. Less activities with my teenagers.

Walking

Walking, driving and lifting items.

walking with thinking about every step

Walking stairs/ not being able to come into most buildings in a wheelchair. Walk in the woods/ take a bath in

#430

COMPLETE

the ocean.

Difficulties taking on clothes and being by myself.

---

#462

COMPLETE

gardening, cooking, housework

Leaving my home where I have assistance devices  
Going to church and shopping  
Going with friends to activities

Sports of ALL kind Climbing

Skiing Running

Bike riding Hiking Any sport

Walking (long) distance Being creative  
Sporting like Snowboarding, dancing,...

Daily task such as reaching for things up high Grooming: washing/brushing hair, brushing teeth, etc.  
Playing tennis...I was a competitive tennis player on my way to playing NCAA Div 1

work i used to love to skateboard and was pretty good at it and holding my son

Currently only doing exercises such as press-ups or planking are affected by causing pain, therefore cannot fully achieve what I would like to

Housekeeping tasks

Outdoor exercise such as hiking, walking on beaches Spontaneous activities with family - theme parks, theaters, parties

Can't reach above my shoulders.  
No more golf game.  
Can't shoot a bow anymore and need a rest to shoot rifles.

Walking Standing  
Carrying anything

Cooking, cleaning, holding my children.

Smile. I wish I could smile.  
I can't lift my kid I wish I could  
Being able to stay awake all day without feeling like I'm so tired and weak and sore I'll pass out.

Doing anything above my shoulders/head (changing light bulbs in ceiling fixtures, reaching anything on a shelf higher than shoulder height, etc.)  
Carrying anything of moderate to heavy weight, especially up any stairs

Visiting my son in Colorado because I have to be on oxygen at high altitudes. Walking distances.  
Playing with my grandchildren.

#462

COMPLETE

Working, exercising and everyday life chores around the house.

Fitness, work, walking

sports such as volleyball, horseback riding, skiing

Walking, stairs and inclines, loss of stamina

Walking distance and steps.

Cooking, moving heavy objects, walking long distances, stairs and other mobility impediments in stores etc.

Hiking, long walks

Regular home activities such as gardening, painting, fixing things.

Basic personal hygiene activities like brushing teeth and shampooing hair. Sports

Sports Walking Travel

Walking  
Being independent

Walking, golf

**Respondent skipped this question**

Running Hiking

Hug my children Sleep with my spouse Ride a bike

Walking Standing up Lifting arms up

Toilet Walking Drive

I used to dance- traditional folklorist - very sad -mentally to give up - slowly during the proses of losing

#462

COMPLETE

walking ability.

I am Girlguide - still hang along caring for the children - but no more camping - etc. though with the wheelchair its still possible to join partly. I used to Cook and bake and knitting embroidering etc. all this Things I cant do anymore due to no strength in the arms - its hurting tiring out the muscles. that is also very sad to give up on all kind of being your hobbies.

---

#477

COMPLETE

Outdoor Sports Activities   Walking Unaided   sitting for a period of time example   out to dinner, at a sports event, at a FSHD meeting - Painful to sit   Lifting more than 5lbs

baseball, gardening, and working is becoming difficult

Concert going

Hill walking/climbing travelling

walking - standing up - driving a car

Running

Standing for over 20 mins Walking long distances

biking skating  
playing the piano / hand writing

lifting, scooching, climbing

Unable to lift my grandchildren when they want a hug. Unable to go for walks in country.  
Unable to dance with my wife.

Same answer as question #2. Those are important activities that I cannot do.

Unable to work full-time Socialising  
Daily chores

Unable to help around the house.  
Unable to drive a car.  
Unable to walk.

Participate in sport, Golf, football, swimming Activities, Walking outside, holidays abroad  
Not being a hold up when out, being walked past by OAPs

Walking Exercising  
Moving faster at work

Running. Riding a bicycle

used to be a competitive pistol shooter...shoulders are gone carpentry...can't climb ladders  
just general life



#493

COMPLETE

Cleaning Shopping Walking distances

ADLs such as doing makeup or doing my hair due to inability to raise arms above shoulder level

Golf, bowling, or cheer

Pick up children/hold babies Walk/ dance  
Cook  
So many more things

Hiking, Going to concerts and standing to watch the show. Walking on the beach

Walking

Using my arms Standing

Cooking Racquetball Basketball

Stand to perform dressing

Walking, holding a grand baby,visiting friends in homes with steps.

-walking (the beach shell hunting/in the ocean, walking my dog)  
-babysitting my first newborn grandson  
-cooking

I don't go out for fun or errands without someone to lean on or a place with a shopping cart - I'd love to just go out for a cup of coffee BY MYSELF and feel safe. Travel on an airplane because it's too hard to get up from the seat. Go to the movies by myself or lie on the beach/ground and get back up.

Walking  
Independent use of the bathroom  
Being able to lift things with hands/arms

Can not run or even walk fast. Can not stand for very long without feeling the need to sit down. Going down stairs can be painful and upstairs very tiring.

Anything involving balance - e.g.  
Walking, sports

Gardening / decorating Dancing

Driving is getting more difficult. Wife has to sponge bathe me and wash my hair.

#493

COMPLETE

Tennis

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#508

COMPLETE

Walking, going anywhere, not enough money to live and get a vehicle to go places

Walking up stairs, can't walk well and carry something in front of me, standing for long periods

Abs strengthening Raisings arms

Walking, eating, dressing

Running, playing piano, and picking up things such as pets or babies

I wish I had more energy towards the end of the day to go out with my husband.

Cooking and wash my hair

Being social outside of my home.  
Holding longer conversations, but can't because pain will make me loose train of thought. Self care.

Lead independent lifestyle (every day things)

I was a pianist but can no longer play.

Ability to be independent (I now am dependent on care givers) I couldn't care for my babies/young children alone.

1. Running, playing tennis, or walking my dog. 2. Teaching preschool. It's too physically demanding for me.  
3. Picking things up off the floor unassisted.

Walking

Not able to lift objects Getting up from a chair

Trabajo me adapto cada día a mis limitaciones.

Limited to what exercise I can do, not being able to lift heavy things or reach high places, not being able to climb on chairs to do things like change lightbulbs

1. Cooking for more than just myself. Now I cannot lift more than the smallest, lightest pots and pans and even then this is increasingly difficult.
2. Travelling about London and visiting art galleries. Many places are not accessible and it is very difficult to even get to many places without lots of organisation. Spontaneity is impossible.
3. I used to enjoy ice skating and had my own skates. I can no longer skate at all.

#523

COMPLETE

Longer quicker walking

Lifting heavy bags for shopping and travelling Playing table tennis and other activities

Going to the park to play with my toddler, leisurely walks and running.

walking, playing with my child ( kicking a ball, enjoying trips to park etc), swimming

Speaking Breathing Ambulation

Walking, lifting/carrying, sport.

Dancing, running, taking things up

sometimes uncomfortable sitting for long periods of time due to scapula, heaviness in right side (asymmetrical wasting), trip often due to foot drop

walking any distance, climbing stairs, staying in hotels

Taking walks in the park. Going to the mall with friends. Running. I can't do any of these anymore.

Walking; holding a child; using t arms as I would like

Everything that requires vision and hearing.

Bicycling, standing (like to cook in the kitchen), typing on the keyboard

Have not been able to play golf for the last two years. Certain travel locations are not accessible anymore.

I was poised to be a high school varsity track star, soccer mvp, and long distance runner. I had to stop sophomore year because my body could no longer handle it. I also was a bass player in my high school's award-winning band. However I had to stop that too as my hands could no longer play with the dexterity required for a high level musician. I am young - 20 to be exact - and I was very very athletic before I started to feel the symptoms of FSH, which is why I am not as affected as others but it would be very nice to play the game of life on the same playing field as anyone else.

1. Cooking - cutting vegetables, cooking unaided, transferring food off stove
2. Playing piano
3. Gardening

#536

COMPLETE

Cannot hug or cuddle loved ones very well; Social activities, such as meals out, drinks out, theatre, cinema (mainly due to access issues at venues such as lack of accessible toilets with right-hand transfer); Holidays with friends and family (again due to access issues)

Walking, I wish I could walk without 30 minutes of putting on special equipment; leg braces. Walking is the most important one - Holds me back from so many activities. I do not use a wheelchair I am not there yet, but I cannot keep up with the group, spouse Walking keeps your independence Your Pride...Your right frame of mind

Socializing Travel Boating

Walking - DIY - gardening

Difficult to work, to move and to sleep.

Yes... 1- Practicing Martial Arts (Kung Fu), 2- Taking walks

biking running  
balance in general. it's tricky

Workout Play sports Cooking

Landscaping, household outside chores, remodeling interior of home

Mountain biking

Put right arm around my wife Wave and give high fives

Social isolation. Going to peoples homes. Can't get in bc always a step, then can't sit.

Activities that require lifting my arms. I can't do many activities that everyone else can in phys ex class (such as push ups and pull ups) and it is frustrating and humiliating. Basic activities like getting dressed (putting on/ taking off a shirt) are impacted. I am not able to participate in some sports.

1. aerobic activity like running or walking fast
2. because of fatigue I have to limit other personal activities outwith work and parenting - too tired by evening to join social groups like book group, choir, art classes, etc.
3. playing more actively with my daughter & when she was younger, carrying her & playing with her more actively

#551

COMPLETE

1. Climbing stairs 2. Lifting/carrying things 3. Walking more than short distances

Difficulty going to lavatory Inability to dress myself  
Inability to transfer from chair to chair or chair to bed independently

1. Dance
2. Hot Yoga

I cannot baby sit my grandson alone.

Running Dancing

-lifting/picking up young grandchildren  
-limiting social time with family and friends if stairs are involved  
-can't travel independently anymore

Cooking and baking  
Getting in and out of other peoples houses

lifting son up into the air.

Running (as I have a child aged 7)

Lost two jobs

Cannot hold a camera any more Cannot hold my grandchildren

Automotive repairs Walking/hiking  
Job limitations because I can't lift much weight or take things on/off shelves.

1. Running / Exercising
2. Doing the laundry
3. Cooking

Shopping, Queuing.

eating drinking defending self

- Travel
- Drive a car
- Smile back at people passing by

#565

COMPLETE

Ride my bike, some yoga poses, pain at night

drive auto use my boat travel

1. Self-care (dress/undress/bathe/toilet)
2. Grasp, hold, and use objects (pen/pencil, cooking utensils, glass/cup, tools)
3. Cook and clean

Dressing, cooking, doing things around the house

Hiking

Walk Bike  
Squash.....

Being able to stand and mingle at social events. To carry household items like laundry from point A to B. To pick up household items from the floor.

Play sports  
Walk on the beach  
Traveling-(don't do as much because of fear of the unknow, (bathroom "accessible, especially the toilet to go from sit to stand)

1. Be active - run, walk up stairs, exercise, etc.
2. Lift children/heavy objects in general
3. Clean the house more thoroughly

doing outside work, house improvement project, energy lost

Typing, as I work with computers all day Playing with my kids  
Walking

Outdoor sporting activities with my family, shopping, exercising.

1. ADL's take twice as long to accomplish
2. Walking my dog.
3. Reaching up to get things in cabinets.

Eating.

Personal hygiene Getting out of the house

#584

COMPLETE

wood working raising my daughter running

Sex Walking Steps

**Respondent skipped this question**

Inability to hold grandkids while standing up due to instability and balance issues.

Walking. Sleeping. Working.

Drive the car Bathe and dress Cook

Walking long walk Sports  
Caring heavy weight

Walk with grand children!!!! Play any sports (golf and tennis) Afraid of choking when eating.

Lifting anything. Drawing, Cycling, Walking

-I miss being able to hug people while standing  
-I drop things constantly due to wrist weakness  
-Would love to hike and run again

Walking, Climbing stairs, Reaching above my head

Swimming Walking Horse riding

Stairs Skiing Hiking

Exercising and walking long distances, household chores, showing full facial expressions.

Frequent falls and impossible to get up alone. Impossible doing housework.  
Need help for my personal hygiene.

Work, can't do it. I am an attorney Visiting at peoples houses (steps) Traveling alone

Showering, washing dishes, cooking



#584

COMPLETE

I didn't play with my children, Friends laughing when I eat and swimming with them. I can't hold food plate in my hand.

---

Walking, reaching up high and general getting about

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#597

COMPLETE

Walk evenly without a limp, jog/run, tap my foot

I struggle with having the energy to take care of my family. I barely have the energy and strength to perform my own basic hygiene/daily living tasks.

I spent a lot of time and energy advancing my education and career. I was quite successful and had been earning a great salary. Due to my FSHD, I have had to give this all up much earlier than I had hoped.

Public outings are difficult as everything needs to be prepared for and planned in detail. Will I have access to a wheelchair accessible bathroom? What happens if I can't raise off of the toilet and get stuck? What if I can't get inside the building I need to go to because they do not have automatic doors? What if I can't maneuver inside because the space is too tight? What if I can't find an accessible wheelchair van parking stall?

my career, social life, driving

clean house, garden (hobby), vacations are limited because can't sightsee or hike

Hiking or walking outdoors with family and friends Running  
Team sports

Sports such as fencing and climbing are very difficult for me, working is very tiring due to arm fatigue, maintaining good posture can be very difficult.

riding bikes and other sports such as skiing, ice skating, bowling, baseball, etc. running.

drawing, video gaming, and eating

can no longer lift grandchildren or play with them easily, lack of strength in arms and fatigue limits time spent driving (short drives fine), no longer work in garden

Can no longer use my left arm for strenuous activities Cannot keep my head lifted for short or long times  
Walking is becoming a struggle. If I do any if these - I am in pain for the next couple days

hang the clothes

put luggage in overhead bin fall frequently due to foot drop

Exercise, long walks, housework

sewing, shopping, sailing

#608

walking - keeping up with others

COMPLETE

WALK, RUN, PLAY GOLF

Walking far without assistance. Walker or cane Dancing. More of a normal social life.

Attending cultural events by myself

Get out of a car and walk into house, store, anywhere. Etc.

- 1) Get into and drive a tractor
- 2) Get out of bed, or anything, without fear of falling....

Outdoor recreation (fishing, camping, hiking)

Traveling to foreign countries  
Work-related tasks.

House work, exercise, cooking

daily chores

Walking long distances, getting up off the floor, getting in and out of a boat/ kayak

Holding and lifting my 3 year old sister

Walking playing sport gardening

- 1) Owning and caring for a house
- 2) Driving, cannot afford wheelchair accessible van
- 3) Being active outdoors

I can't run, i use to be strong

I can't lift, so I don't cook because I drop heavy items heavier than 7-8 lbs. (Casseroles, spaghetti, batter, dishes)

#608

COMPLETE

#1

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, January 29, 2020 4:03:21 PM  
**Last Modified:** Wednesday, January 29, 2020 4:05:48 PM  
**Time Spent:** 00:02:26  
**IP Address:**

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain relief Fall prevention

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Tramadol

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

PT OT  
CBD Oil Ibuprofen

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It dampens the pain but it is chronic  
PT balance training can only go so far in fall prevention

---

## #2

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, January 29, 2020 8:55:27 PM  
**Last Modified:** Wednesday, January 29, 2020 9:10:42 PM  
**Time Spent:** 00:15:15  
**IP Address:**

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

All of them! We are going to PT 2x's a week, swim 1 a week, Pilates 1 a week, monitor steps everyday of the week. Stretch nightly. Watch and monitor intake for a high protein diet to help with some muscle growth. Bi-weekly massage to help the overworked muscles. In summary every day we wake up to make sure that there is just enough physical activity to keep what we have and try and grow what we can if anything at all.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None. We are trying to control progression of the disease with a high protein diet.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Mobility - keeping our daughter moving is the number one way we are working to keep her as strong and healthy as possible. 2. Monitor and make sure all food is real food and not processed to minimize the free radicals, 3. PT and OT weekly plus bi-annually we see a team of doctors to monitor and make adjustments if necessary to the care program.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Time and money. We have to be so planned out in order to fit in the care that we think is needed into life. It's a very hard balance and weighs on our whole family every single day. There is not a day that goes by where we can be carefree or just live without this disease impacting us. As much as we try and say the disease will not define us it does due to our care program. End result we hope that all of this is paying off with slowing the course of progression, however it's not proven it will slow, it's just what we can control and what the care team THINKS will help.

---

#3

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, January 30, 2020 3:06:38 AM  
**Last Modified:** Thursday, January 30, 2020 3:10:02 AM  
**Time Spent:** 00:03:23  
**IP Address:**

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

walking and climbing hill can be problem in future and because of that I am everyday active and working to avoid that condition

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Being active in daily life  
some rest when tired too much be careful what I am eating

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

progressive disease is making me think everyday for future.  
before doing any activity like going somewhere plan everything even road and stairs, etc thinking that disease make my work life bad in future

---

#4

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, January 30, 2020 3:50:15 AM  
**Last Modified:** Thursday, January 30, 2020 3:57:44 AM  
**Time Spent:** 00:07:28  
**IP Address:**

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**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

no

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

limit activities before any muscle fatigue sets in  
constantly look for uneven surfaces when walking and reminding myself to always pick up my left foot use  
handrails when going downstairs

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

have limited endurance for any activity that requires arm or leg strength (which is pretty much affects all the  
things I love to do) my walking speed is slow  
can't carry medium to heavy things going up or down stairs.

---



#5

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, January 30, 2020 11:38:59 AM  
**Last Modified:** Thursday, January 30, 2020 12:05:28 PM  
**Time Spent:** 00:26:28  
**IP Address:**

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Doing physio therapeutic exercises, going to massage or osteopathy to relieve the symptoms of scapular winging.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Going to psychologist to deal with my concern of the disease.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

There are no downsides right now.

---

#6

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, January 30, 2020 12:06:01 PM  
**Last Modified:** Thursday, January 30, 2020 12:11:32 PM  
**Time Spent:** 00:05:30  
**IP Address:**

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I do physiotherapy for flexibility and reducing the pain of the sore muscles, and swimming to exercise my breathing

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

only vitamin D

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I use a bi-pap, physiotherapy, avoid sweets in my dietary.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

my situation is constantly deteriorating, I get very tired by physio and swimming.

---

#7

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, January 30, 2020 6:54:15 PM  
**Last Modified:** Thursday, January 30, 2020 6:59:06 PM  
**Time Spent:** 00:04:51  
**IP Address:**

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**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Psoas muscle hurts me constantly. Use a deep tissue percussion gyn on neck, shoulder, back, buttocks.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Over the years, yes.

Lyrica, terrible medicine, not appropriate for fsh. Tramadol. Since June 2019, I use tylenol and motrin only.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Percussion gyn. Rest, positioning.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It is hard to use the gun on myself. I'm down so much of the day. I feel pretty useless.

---

#8

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, January 30, 2020 10:28:29 PM  
**Last Modified:** Thursday, January 30, 2020 10:36:18 PM  
**Time Spent:** 00:07:49  
**IP Address:**

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**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

The symptoms I try to address are fatigue, weakness, and imbalance. I address these symptoms through a low impact, low weight workout each morning (5-10 minutes) of basic pilates exercises. These help tremendously to exercise the muscles that I have and to enable better posture to begin the day.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No. However, I do experience back pain to varying degrees on a routine basis. I use Motrin and Alleve routinely.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Daily 5-10 minute (light) pilates routine
2. Once/week elliptical machine at low intensity level
3. Diet and routine movement during the day, as much as possible (use a standing desk, walk around a lot)

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. The exercises do not result in the strengthening of muscles as much as they help to maintain posture and "awaken" the muscles.
  2. Any intense exercise will result in a mild "crash" 24-48 hours later.
  3. Diet is helpful, as a general rule, but it does not seem to slow disease progression
-

#9

COMPLETE

**Collector:** Web Link 1 (Web Link)

**Started:** Friday, January 31, 2020 1:17:59 AM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

fatigue, weakness, pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Oxycontin, amitriptyline, CBD tinctures, muscle relaxers

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

PT manual manipulation of cervical and lumbar spine,  
water aerobics, acupressure, acupuncture, electrical stimulation, L-Serin Amino Acids,

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

none have lasting benefits, cost of services not covered by insurance, some are painful but balance by short periods of reduced pain

---

#10

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Friday, January 31, 2020 12:25:39 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Respiratory issues - BiPap Foot drop - AFO

Lack of ability - Adjusted work area

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Pain - Ibuprofen, Hot water shower Multi Vitamins

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Disease progression makes a continuous change of adjustments

---

#11

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Sunday, February 02, 2020 1:09:31 PM  
**Last Modified:** Sunday, February 02, 2020 1:14:00 PM  
**Time Spent:** 00:04:28  
**IP Address:**

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I don't understand question

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Rolfing, acupuncture, vibratrim, diet, supplements, exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Cost, winter and ability to leave house on my own

---

#12

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Sunday, February 02, 2020 4:58:32 PM  
**Last Modified:** Sunday, February 02, 2020 4:59:27 PM  
**Time Spent:** 00:00:54  
**IP Address:**

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

exercise supplements

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no\

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

nothing

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**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

lack of progress

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#13

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 11:19:01 AM  
**Last Modified:** Monday, February 03, 2020 11:25:36 AM  
**Time Spent:** 00:06:35  
**IP Address:**

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**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Walking and climbing stairs is difficult, I am trying to maintain these abilities by attending weekly hydrotherapy sessions.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Hydrotherapy
2. Regular exercise (walking/stationary bike)
3. Maintaining a healthy diet

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. It is not effective - in spite of regular exercise/hydrotherapy, my physical abilities continue to decline.
  2. It does not treat the cause of the disease - eating a healthy diet is not stopping my muscles from producing DUX4.
  3. It is not helping to stop disease progression and so it does not improve my quality of life.
-

#14

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 11:32:24 AM  
**Last Modified:** Monday, February 03, 2020 11:33:37 AM  
**Time Spent:** 00:01:13  
**IP Address:**

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Use a walker and battery scooter

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I continue to weaken

---

#15

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 11:28:58 AM  
**Last Modified:** Monday, February 03, 2020 11:39:45 AM  
**Time Spent:** 00:10:46  
**IP Address:**

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Arm and leg weakness. A well as arm mobility.

I have tried yoga and light exerciser. you have to be in motion but not too much stress on the body. It is a tight line to walk. The yoga works in stretch things out for a short time. Then it will of course tighten again. It helps more in regards to meditation and being in a better mindset.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I have never used prescription medications. I would prefer to avoid that, unless it is a cure or a proven treatment that will help substantially.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Light to moderate activity.
  2. Being positive and consonantly feeding my mind with positive things. This disease affects me more emotionally than physically. Not because the physical issues are not bad, because the mental state is that much worse.
  3. Volunteering to help. That has been the best intervention.
- 

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. Being down and felling a lone. There is no escaping it, no rest from it. It is constant and unrelenting.
  2. Getting tired when you are trying to stay active. Feels counterproductive.
  3. My family worries and they see me with FSHD not only me. FSHD is a companion. It is part of my identity, unfortunately.
-

#16

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 11:40:18 AM  
**Last Modified:** Monday, February 03, 2020 11:48:43 AM  
**Time Spent:** 00:08:25  
**IP Address:** 12.36.67.45

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain and fatigue. I've tried a few different pain medications but none have been worth the side effects. I also was prescribed Adderall to help with loss of focus during the day that seemed to help but again, didn't seem worth the side effects in the long run.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Different levels of Tylenol, another medication that was an antidepressant but also helped with pain management, and diclofenac gel.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Ongoing visits to my neurologist to track progression, participating in any clinical studies available, and riding a stationary bicycle for light cardio. Attempted to do physical therapy but was turned away as they didn't have a program for FSHD - their focus was more on repairing/restoring muscle loss.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Most physical therapy is targeted at restoring or repairing muscle loss after injury - that doesn't fit with FSHD. Limited avenues for physical therapy or general exercise for wellness due to asymmetrical muscle loss.

---

#17

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 1:08:17 PM  
**Last Modified:** Monday, February 03, 2020 1:09:11 PM  
**Time Spent:** 00:00:53  
**IP Address:** 174.18.106.140

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Physical therapy, massage, water exercises

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Respondent skipped this question

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Respondent skipped this question

---

#18

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 1:13:42 PM  
**Last Modified:** Monday, February 03, 2020 1:18:11 PM  
**Time Spent:** 00:04:29  
**IP Address:** 107.77.230.84

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I try to walk instead of using scooter when I can to try and preserve leg functioning.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Mobic, Toradol, Tylenol 3

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Use walker or scooter  
Several safety rails in bathtub  
Try to have support for arms when trying to raise above head.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Scooter hassle to transport

---

#19

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 1:56:01 PM  
**Last Modified:** Monday, February 03, 2020 2:03:19 PM  
**Time Spent:** 00:07:18  
**IP Address:** 107.77.235.38

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Constantly looking for any product or tool that might help me, such as foot drop braces or things to help me stand.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Just Ambien to help me sleep when muscle spasms are too unbearable.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Low fat Mediterranean diet Exercise bike

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

The realization that working hard will never improve your health, never make you stronger. It might slow down the progression, but nothing else.

---

#20

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 3:54:20 PM  
**Last Modified:** Monday, February 03, 2020 3:58:01 PM  
**Time Spent:** 00:03:41  
**IP Address:** 2.10.34.198

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

eyes open during the sleep > ointment - physical shape > some physical exercise

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

ointment for eyes, vitamin D

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

try to walk as often as I can

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

can't do anything alone, for example can't walk without my husband arm - and physical exercise is very tiring

---



#21

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 4:40:42 PM  
**Last Modified:** Monday, February 03, 2020 4:44:44 PM  
**Time Spent:** 00:04:02  
**IP Address:** 47.157.91.240

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

core weakness facial / speaking hands

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Daily physical therapy meditation visualization

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

slow irregular response time consuming

---

#22

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 6:34:25 PM  
**Last Modified:** Monday, February 03, 2020 6:40:55 PM  
**Time Spent:** 00:06:29  
**IP Address:** 209.153.245.3

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am trying to improve overall strength and balance in the muscles-- get as strong as I can before DUX4 gets activated more. I am really focused on the core and gait as I am noticing this is starting to hurt my mobility. I am trying to improve my diet using anti-inflammation approach. I also did surgery to release a nerve in my arm, hoping that is why my right hand atrophied so aggressively.

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes-- using the pill with a regular and consistent dose of estrogen and progesterone. Also looking at taking prescription CBD (I live in Canada).

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1) Rest-- I am trying to ensure I get sleep and rest my body if I have had a long day (2) I got a nanny to support me with my young children and to help with housework and cooking (3) Mindset-- keeping my mind positive with meditation, positive affirmations

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I have only been diagnosed for 3 months, so still figuring it out. Downsides of too much rest is I feel sore, and my symptoms are amplified. Exercise and stretching and healthy diet is imperative.

#23

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 7:02:24 PM  
**Last Modified:** Monday, February 03, 2020 7:08:02 PM  
**Time Spent:** 00:05:38  
**IP Address:** 201.103.168.98

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

improve leg strength ... i'm doing a stationary bike

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

stationary bike walk  
swim

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

the difficulty of getting up from the floor or the bed the difficulty of climbing stairs  
tiredness and back pain

---

#24

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 9:20:48 PM  
**Last Modified:** Monday, February 03, 2020 9:21:45 PM  
**Time Spent:** 00:00:57  
**IP Address:** 73.149.119.82

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

continue to work out to stay active and fight muscle loss

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

yoga, stretching, pilaties

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

time

---

#25

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 9:44:26 PM  
**Last Modified:** Monday, February 03, 2020 9:49:11 PM  
**Time Spent:** 00:04:45  
**IP Address:** 174.57.61.56

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Overall muscular/ skeletal health by taking supplements Participating in clinical trials

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Using a scooter Using AFO's Supplements

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Supplements don't seem to have much effect Scooters are logistically challenging to travel with

---

#26

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 03, 2020 10:36:43 PM  
**Last Modified:** Monday, February 03, 2020 10:43:50 PM  
**Time Spent:** 00:07:06  
**IP Address:** 96.2.65.87

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle shortening, decreased range of motion, sore/burning/fatigued muscles.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Some stretching, standing in a stand aid, taking ibuprofen for soreness, resting at some point during the day, drinking high protein shakes.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not much changes, resting feels like a waste of what could be productivity, ibuprofen is terrible for the kidneys but aspirin isn't as effective.

---

#27

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 04, 2020 2:15:32 AM  
**Last Modified:** Tuesday, February 04, 2020 2:16:26 AM  
**Time Spent:** 00:00:53  
**IP Address:** 124.176.31.169

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I just try to keep as active as possible

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

**Respondent skipped this question**

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**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

**Respondent skipped this question**

---

#28

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 04, 2020 4:20:24 AM  
**Last Modified:** Tuesday, February 04, 2020 4:23:39 AM  
**Time Spent:** 00:03:14  
**IP Address:** 150.107.174.111

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am attending the pool x3 a week to combat weight gain and muscle tone

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No none at all, only natural vitamins and herbs

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Mental work - EFT (Emotional Freedom Techniques) Mediation and Mind movies to remain positive and optimistic Eating balanced meals and the pool

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Tiredness  
I'm still gaining weight

---



#29

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 04, 2020 7:27:46 AM  
**Last Modified:** Tuesday, February 04, 2020 7:29:44 AM  
**Time Spent:** 00:01:58  
**IP Address:** 24.144.188.151

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Try to keep moving Taking collagen peptides

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physical therapy

Exercising

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None

---

#30

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 04, 2020 8:38:28 AM  
**Last Modified:** Tuesday, February 04, 2020 8:43:45 AM  
**Time Spent:** 00:05:17  
**IP Address:** 118.137.180.95

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Shoulder and facial weakness. Trying to maintain shoulder muscles by doing pilates weekly, and trying to talk slowly often to maintain facial muscles stay strong.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Moving around and being more productive everyday to maintain muscles. Using facial muscles often to maintain its muscles from weakness.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Unable to workout like I used to, unable to smile wide that people often think I'm faking it, unable to do activities that require strength like hiking and travelling.

---

#31

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 04, 2020 8:53:32 PM  
**Last Modified:** Tuesday, February 04, 2020 9:02:44 PM  
**Time Spent:** 00:09:11  
**IP Address:** 174.194.20.11

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Improvising to get around the weakest musculature. Propping arms up and then doing work. Getting a "running" start to roll over in bed etc.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Slowing down and being more deliberate with movements to prevent falls and injuries. Using abdominal binders to improve abdominal weakness symptoms and help swayback. Occasionally taking OTC pain and inflammation medication to treat flares in pain.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

No real improvement in symptoms.

Tedious binder application with difficult application due to the underlying weakness.

Anti inflammatory medications not recommended in significant amounts with co-morbid conditions (ex: diabetes)

---

#32

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 04, 2020 9:31:58 PM  
**Last Modified:** Tuesday, February 04, 2020 9:35:51 PM  
**Time Spent:** 00:03:52  
**IP Address:** 107.218.168.54

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness and pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes - Cymbalta Have since quit taking because it left me feeling fatigued

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise, supplements

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Only moderately successful in slowing the progression

---

#33

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 04, 2020 11:37:31 PM  
**Last Modified:** Tuesday, February 04, 2020 11:41:37 PM  
**Time Spent:** 00:04:05  
**IP Address:** 97.113.198.178

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Since I don't really have noticeable symptoms yet, I'm basically just working hard at eating a healthful diet, getting regular exercise, and getting regular massage therapy.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Diet, exercise, massage  
Thinking about trying weekly sessions in a hyperbaric chamber.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None

---

#34

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 05, 2020 12:38:05 PM  
**Last Modified:** Wednesday, February 05, 2020 12:40:45 PM  
**Time Spent:** 00:02:40  
**IP Address:** 104.51.182.228

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

message my shoulder muscles for the pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

yes but I have not taken them in years due to side affects. Neurontin

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

move heavy items like pans to bottom shelf, avoid lifting

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

still in pain daily no matter what I do

---

#35

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 05, 2020 11:20:19 PM  
**Last Modified:** Wednesday, February 05, 2020 11:24:08 PM  
**Time Spent:** 00:03:49  
**IP Address:** 47.133.230.177

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I take anti-depressants and Ritalin. I do not have ADD/ADHD. I was prescribed Ritalin by a doctor the 2nd time I went to a psych ward for trying to kill myself because I mentioned fatigue and inability to focus. It helps immensely

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

CBD, I smoke weed (best thing I've found so far to help but its illegal in my state), and eating healthier

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Can't/don't want to smoke during the day/while I'm working, Ritalin is NOT good for you, hard to eat healthy sometimes when I'm tired and sore

---

#36

COMPLETE

Collector: Web Link 1 (Web Link)

Started: Thursday, February 06, 2020 12:27:42 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

lack of strength

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Prednisone - tested for muscle response Prozac - depression and fatigue

Ambien - restless sleep

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Massage - keep blood flow through muscles
  2. Counseling - to help with the catastrophizing progression thoughts
  3. Wear braces and/or use walking sticks to assist with stability
- 

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. No matter what I try, nothing has slowed the progression
  2. Mental anguish continues to be a top issue regardless of counseling or peer support since there's no trajectory
  3. Even with added physical support, there's no going back to doing what I loved doing.
-



#37

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Friday, February 07, 2020 4:07:50 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Taking a number of dietary anti-oxidents to try to slow progression.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Investigating the use of a stance control brace to ehlp with my stability standing and walking.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Expense.

---

#38

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Saturday, February 08, 2020 9:31:56 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Trying not to go up stairs, not standing in chair or ladder, conscious of foot drop and fallung

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Fatigue

Limitation to carry groceries

Very slow with any leg movement

---

#39

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Sunday, February 09, 2020 11:12:08 AM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Steroids

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Using wheelchair all the time, cbd lotion for aches, Tylenol PM or Benadryl to sleep soundly

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Steroids cause hunger and weight gain, unknown to body on others

---

#40

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 10, 2020 12:25:35 PM  
**Last Modified:** Monday, February 10, 2020 12:29:21 PM  
**Time Spent:** 00:03:45  
**IP Address:** 23.31.84.90

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle deterioration seems to be increasing. Continuing to try and keep as active as I can be.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Chair lift on stairs.

Rollator or walking stick in crowds to help guard against falling. Keeping as active as I can. Continuing to try whether successful or not.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Walking is very fatiguing and I am required to rest more which means I don't get as much done as I need to.

Having to choose events or things I go to in order to limit walking/standing.

Chairlift is an easy out when I'm tired. Need to keep climbing stairs as much as I can.

---

#41

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 10, 2020 3:28:48 PM  
**Last Modified:** Monday, February 10, 2020 3:31:02 PM  
**Time Spent:** 00:02:14  
**IP Address:** 50.203.198.21

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain management Fatigue Management Clinical Trials

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Regular check ups with Neurologist.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Muscle loss can't be reversed Getting appointments scheduled Side effects of medications

---

#42

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 10, 2020 3:46:04 PM  
**Last Modified:** Monday, February 10, 2020 4:18:31 PM  
**Time Spent:** 00:32:26  
**IP Address:** 198.241.174.15

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

My lower back muscles were consumed by FSHD, causing lumbar lordosis, which led to a bulging disc between L4-L5, pinching the nerve that runs down my left leg. Over the past year, I've been receiving quarterly lumbar injections to combat pain and discomfort. I also perform resistance training to keep core muscles and other muscles from weakening.

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I take one 15mg Meloxicam daily for pain. I'll supplement that with ibuprofen on particularly bad days.

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1) Regular exercise regimen of light resistance and core strength training, walking and stationary bike. 2) Medications listed above. 3) Try to stay positive.

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1) I'm always subject to pain and fatigue, which often leads to incomplete or no workouts. 2) I try to stay upbeat, but I battle occasional bouts of depression, which also benches me from my workout regimen. 3) I feel like I'm starting all over again, even after missing just a few workouts. I'm former athlete, football player and U.S. Marine, so I'm not accustomed to this AT ALL.

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

**Respondent skipped this question**

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

**Respondent skipped this question**

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

**Respondent skipped this question**

#43

COMPLETE

Collector:	Web Link 1 (Web Link)
Started:	Monday, February 10, 2020 6:02:47 PM
Last Modified:	Monday, February 10, 2020 6:03:07 PM
Time Spent:	00:00:20
IP Address:	199.247.42.215

---

#44

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 10, 2020 6:41:41 PM  
**Last Modified:** Monday, February 10, 2020 6:46:51 PM  
**Time Spent:** 00:05:09  
**IP Address:** 108.65.108.201

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Weakness in left leg

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

- 1) "Cocktail" of supplements .... CoQ10, Zinc ....etc.
- 2) Wearing an AFO
- 3) Water exercises in pool during the summer months

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Value of supplements unknown in addition to being expensive.  
Can not drive with the AFO on. ....So constantly taking it on and off.

---



#45

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 9:57:21 AM  
**Last Modified:** Tuesday, February 11, 2020 10:01:38 AM  
**Time Spent:** 00:04:16  
**IP Address:** 174.21.42.147

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Sleep disorder, dry eyes, loss of strength

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Gabapentin at night for pain and to help with sleep. Eye drops

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Walking, tai chi, just completed sleep study and will probably have a CPAP machine

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Recovery time needed interferes with work

---

#46

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 11:18:35 AM  
**Last Modified:** Tuesday, February 11, 2020 11:20:55 AM  
**Time Spent:** 00:02:20  
**IP Address:** 45.49.141.28

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle strength all over body Fatigue

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No - there are none

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Yoga

Water fitness

More sleep to combat fatigue Diet

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Extreme muscle fatigue later in day and day after exercise. Can't exercise every day due to it

---

#47

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 11:29:17 AM  
**Last Modified:** Tuesday, February 11, 2020 11:30:49 AM  
**Time Spent:** 00:01:31  
**IP Address:** 89.241.19.199

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Foot drop but no with any great success

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

co codamol paracetamol and codeine

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

walking

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

exercise makes my muscles ache for days after

---

#48

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 11:31:17 AM  
**Last Modified:** Tuesday, February 11, 2020 11:35:59 AM  
**Time Spent:** 00:04:41  
**IP Address:** 86.159.2.184

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

General light exercise cycling machine light weights

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Diet, vitamins and exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not knowing if anything is working ,no current medication , not meeting anybody else with it, doctors all don't seem to know or understand what it does to the body

---

#49

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 11:37:13 AM  
**Last Modified:** Tuesday, February 11, 2020 11:39:27 AM  
**Time Spent:** 00:02:14  
**IP Address:** 81.144.224.34

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Poor walking - trying carbon fibre orthotic

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Continue to work. And trying to get back swimming and gym as was going so well just 6 months ago before walking became an issue

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Cost (self funding) and lack of benefits so far

---

#50

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 11:50:02 AM  
**Last Modified:** Tuesday, February 11, 2020 11:53:19 AM  
**Time Spent:** 00:03:16  
**IP Address:** 195.158.79.26

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Back to the gym , I walk 6km daily and to gym 5 times a week

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise, exercise and exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not joining friends doing some extreme sports such as racing bikes and sailing

---

#51

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 11:53:53 AM  
**Last Modified:** Tuesday, February 11, 2020 11:57:37 AM  
**Time Spent:** 00:03:44  
**IP Address:** 79.67.201.107

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Go to the gym to try to keep moving

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Fatigue

---

#52

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 11:55:46 AM  
**Last Modified:** Tuesday, February 11, 2020 11:58:24 AM  
**Time Spent:** 00:02:37  
**IP Address:** 51.6.159.215

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Breathing

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

A CPAP machine

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Regular exercise and diet to keep weight down.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Carrying and installing the CPAP equipment when travelling.

---



#53

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 11:56:49 AM  
**Last Modified:** Tuesday, February 11, 2020 12:00:11 PM  
**Time Spent:** 00:03:22  
**IP Address:** 80.189.39.174

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Trips and falls. Right shoulder

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Regular gym work, including active circuit class. Improving fitness generally. Care with diet. Have bought orthopaedic boots.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Cost of boots - £3000.

---

#54

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 12:04:33 PM  
**Last Modified:** Tuesday, February 11, 2020 12:10:29 PM  
**Time Spent:** 00:05:56  
**IP Address:** 74.133.22.63

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

All symptoms

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I am a participant in the Fulcrum Losmapimod clinical trial. Started Dec. 17th 2019

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercising daily Eat well  
Use AFO on left leg for drop foot

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None, Doing all that I can

---

#55

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 12:15:55 PM  
**Last Modified:** Tuesday, February 11, 2020 12:17:42 PM  
**Time Spent:** 00:01:46  
**IP Address:** 69.120.2.144

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Walking

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing except working on a exercise bike

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

**Respondent skipped this question**

---

#56

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 12:14:31 PM  
**Last Modified:** Tuesday, February 11, 2020 12:19:48 PM  
**Time Spent:** 00:05:17  
**IP Address:** 5.62.43.109

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Occasional Hydrotherapy to help movement Acupuncture to help pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Tramadol Nefopam Pregabalin Paracetamol Oramorph

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Using an assisted cycling machine Upperbody exercises

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Cannot be bothered as such an effort sometimes Relying on friends/carers  
Cost in monetary terms

---

#57

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 12:12:14 PM  
**Last Modified:** Tuesday, February 11, 2020 12:20:13 PM  
**Time Spent:** 00:07:59  
**IP Address:** 88.110.37.239

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Paracetamol to ease back ache.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Keep moving to maintain flexibility. Tried CBD but it's not strong enough.

Build friendships to keep my mind off my own issues.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

The condition steals my ability to move.

More powerful prescribed drugs have negative side effects.

The condition stops me from getting out and getting involved in events and activities.

---

#58

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 12:33:57 PM  
**Last Modified:** Tuesday, February 11, 2020 12:36:36 PM  
**Time Spent:** 00:02:38  
**IP Address:** 78.151.50.184

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle strength in arms. Overall strength

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no prescriptions

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

mild exercise Supplements like coQ10 creatine

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

They're nothing really but then we have nothing, there is no therapy for FSHD, we need a medicine that tackles the root cause of the disease.

---

#59

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 12:37:54 PM  
**Last Modified:** Tuesday, February 11, 2020 12:45:06 PM  
**Time Spent:** 00:07:11  
**IP Address:** 86.161.204.176

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Weakness in leak muscles.

Try to continue walking with specific walking aids in order to keep remaining muscles useful.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Keep as active as possible Eat sensibly

Keep weight down

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Risk of falling heavily whilst trying to remain active

---

#60

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 12:43:07 PM  
**Last Modified:** Tuesday, February 11, 2020 12:46:33 PM  
**Time Spent:** 00:03:25  
**IP Address:** 132.185.160.121

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am trying an ankle brace to help my foot drop when running and have an orthotic insole for my trainers.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Only Ibuprofen occassionally if muscles are aching

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Trying to keep fit and active

Seeing a specialist physio once a year

Doing Pilates weekly to try to keep flexible and to stretch muscles properly

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None of it will stop the disease progressing and I can't rebuild muscles that have stopped working.

---



#61

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 12:50:22 PM  
**Last Modified:** Tuesday, February 11, 2020 12:52:13 PM  
**Time Spent:** 00:01:50  
**IP Address:** 94.173.29.57

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

pain management with physiotherapy

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

cocodamol Paracetamol

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

none

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

difficult to access treatment e physio

---

#62

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 12:52:29 PM  
**Last Modified:** Tuesday, February 11, 2020 12:56:04 PM  
**Time Spent:** 00:03:34  
**IP Address:** 92.30.237.109

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

None

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Never been given anything just told there is no treatment.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I try and exercise IE exercise bike but very difficult.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

getting on and off the exercise bike alone

---

#63

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 12:55:35 PM  
**Last Modified:** Tuesday, February 11, 2020 12:57:49 PM  
**Time Spent:** 00:02:14  
**IP Address:** 82.132.212.163

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness Lack of flexibility

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Resistance train x3 a week Eat healthily  
Swim twice a week

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Fatigue in the evenings

---

#64

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 1:01:19 PM  
**Last Modified:** Tuesday, February 11, 2020 1:04:28 PM  
**Time Spent:** 00:03:09  
**IP Address:** 95.24.27.164

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Плавание , без результатов

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Карнитен, цитофлавин, витамины В ,Е ,

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

ЛфК

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Прогрессирование на останавливается

---

#65

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 1:10:00 PM  
**Last Modified:** Tuesday, February 11, 2020 1:16:23 PM  
**Time Spent:** 00:06:22  
**IP Address:** 77.103.55.46

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness but no current treatments apart from stretching exercise one per day.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No. There are none recommended.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Buying disability equipment  
Adapting house  
Annual visits to see Consultant at Queens Square

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None

---

#66

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 1:15:14 PM  
**Last Modified:** Tuesday, February 11, 2020 1:20:32 PM  
**Time Spent:** 00:05:17  
**IP Address:** 130.132.173.189

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Taking supplements (Vitamin E, B1, creatine, lecithin), had scoliosis surgery

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Vitamins have not been proven to work or slow the progression and there are no treatments available

---

#67

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 1:19:09 PM  
**Last Modified:** Tuesday, February 11, 2020 1:23:23 PM  
**Time Spent:** 00:04:13  
**IP Address:** 86.24.82.10

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Strengthen hips and legs to prevent falls

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None have been offered

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Foot drop aid Physio  
mobility scooter

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Foot drop aid is uncomfortable and can only be worn with lace up shoes Scooter is too heavy to manage without help  
Physio is tiring and if too fatigued I can do it that day

---

#68

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 1:30:00 PM  
**Last Modified:** Tuesday, February 11, 2020 1:34:21 PM  
**Time Spent:** 00:04:20  
**IP Address:** 109.146.186.213

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I have exercises given by my Physiotherapist to address my weakness and fatigue

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Ibuprofen for pain management Pacing myself through the day Resting frequently

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I cannot contribute as I would like to running the house and garden. I can become depressed at my incapacity

---



#69

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 1:32:38 PM  
**Last Modified:** Tuesday, February 11, 2020 1:35:07 PM  
**Time Spent:** 00:02:29  
**IP Address:** 86.4.244.163

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Nothing

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Anti-inflammatory drugs to help with the pain

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Nothing

---

#70

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 1:26:24 PM  
**Last Modified:** Tuesday, February 11, 2020 1:37:00 PM  
**Time Spent:** 00:10:35  
**IP Address:** 86.171.197.119

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain  
Dry eyes

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Amitriptyline Co-codamol Gabapentin Viscotears

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Adjustable bed to provide the best support and aid independence. Occasional physiotherapy.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Medication side-effects - e.g. constipation, drowsiness.  
Only able to do limited range of physio exercises - most physiotherapists struggle to help me.

---

#71

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 1:47:59 PM  
**Last Modified:** Tuesday, February 11, 2020 1:51:15 PM  
**Time Spent:** 00:03:16  
**IP Address:** 81.155.22.33

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

for muscle weakness I do various exercises, visit physio, have massages, starting pilates again, short walks

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I am literally self caring and maintaining my independence by volunteering, which I have always done

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

do too much so get tired

---

#72

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 1:49:18 PM  
**Last Modified:** Tuesday, February 11, 2020 1:53:06 PM  
**Time Spent:** 00:03:48  
**IP Address:** 90.217.173.245

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Trying to keep my muscles strong in arms legs and shoulders

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Painkillers ibuprofen, co codamol, paracetamol

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Trying to get a good night's sleep Keep moving so I don't "set"  
Eat properly

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Nothing really makes much difference whatever I do u think it will deteriorate anyway

---

#73

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 1:54:43 PM  
**Last Modified:** Tuesday, February 11, 2020 2:01:44 PM  
**Time Spent:** 00:07:01  
**IP Address:** 109.150.64.172

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

no

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Not on medication

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

ignoring as much as possible Go to a gentle exercise class  
keep trying to go to social activities

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

hard to ignore when trying to walk etc when feel fine sitting down. The class is getting more difficult as I get worse Have to rely on others to get me around

---

#74

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 2:04:54 PM  
**Last Modified:** Tuesday, February 11, 2020 2:06:31 PM  
**Time Spent:** 00:01:37  
**IP Address:** 176.250.94.1

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

weight going swimming and watching what eat

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

resting trying to only do what can

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

its not always working, getting harder to walk about

---

#75

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 2:10:28 PM  
**Last Modified:** Tuesday, February 11, 2020 2:16:17 PM  
**Time Spent:** 00:05:49  
**IP Address:** 174.27.218.84

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle fatigue, weakness and tight muscles

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No. I dont believe there are any.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Mild exercise, especially yoga for stretching

Taking Reliv powder supplements and protein shakes Staying hydrated and getting adequate sleep

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It is only helping to alleviate the symptoms but not stopping it.

---

#76

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 2:27:03 PM  
**Last Modified:** Tuesday, February 11, 2020 2:32:46 PM  
**Time Spent:** 00:05:42  
**IP Address:** 86.163.42.120

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

**Respondent skipped this question**

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Recognise when I need to rest my muscles. Trying to keep a positive outlook

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Sometimes it is not possible to rest my muscles when they need it.

When you are tired and your muscles won't do what you would like them to it is not always possible to remain upbeat and positive.

---



#77

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 2:58:28 PM  
**Last Modified:** Tuesday, February 11, 2020 3:01:26 PM  
**Time Spent:** 00:02:58  
**IP Address:** 86.150.188.59

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Neck stiffness and tightening of other muscles

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Stretching, physiotherapy and Hydrotherapy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

They take time.

I have to travel for my treatments Cost

---

#78

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 3:51:09 PM  
**Last Modified:** Tuesday, February 11, 2020 3:57:14 PM  
**Time Spent:** 00:06:05  
**IP Address:** 86.180.113.152

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain in neck, shoulders, legs and back.  
Try to do yoga on good days to strengthen core muscles.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Bought steps to help with cooking and housework. Bought lightweight seat to help with showering.  
Bought gardening kneeler to help me get up from floor after yoga.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Aids have problems (e.g. other people move lightweight seat out of my reach (tidier they think).

---

#79

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 3:56:07 PM  
**Last Modified:** Tuesday, February 11, 2020 4:02:23 PM  
**Time Spent:** 00:06:15  
**IP Address:** 84.64.3.47

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Trying to improve neck pain (that is caused by muscles overcompensating for the weakened ones) Trying to improve raising arms.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physiotherapy.

Wearing racerback bras so that the straps don't keep falling off due to sloping shoulders.

Using walls as props for my elbows when I need to reach up (to tie my hair/do up a dress at back on my heck).

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Doing exercises tire the muscles and my posture is more likely to deteriorate.

---

#80

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 4:18:51 PM  
**Last Modified:** Tuesday, February 11, 2020 4:22:56 PM  
**Time Spent:** 00:04:04  
**IP Address:** 92.237.169.222

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am trying my best to stay active and as fit as I can - dr said it was worth doing to stay ahead of the weakness so I mountain bike as much as I can but recovery lasts longer

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I've been told there are none that will help - is this not true ???

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

ibuprofen and pain relief  
Cold/heat creams and sprays and packs Rest

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Nothing helps ! It just eases the symptoms a little but they still have to take the days to go - the pain relief doesn't fix it just eases it slightly

---

#81

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 4:13:22 PM  
**Last Modified:** Tuesday, February 11, 2020 4:27:21 PM  
**Time Spent:** 00:13:59  
**IP Address:** 82.35.233.188

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Just getting up and moving around are hard enough but trying to cope with some decorating to keep me going but fatigue always wins wife got me a dog to get me out of the house

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Just pain killers as and when it gets bad just live with the constant aches

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Hot shower every day to warm up body to get it moving exercise stretching out arms to keep them going sleep pattern terrible sleep when I can any time of day to relive pains

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Lack of support from all old work colleagues so struggle need more money to be able to go to have acupuncture washing and dressing very hard need help really

---

#82

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 4:36:46 PM  
**Last Modified:** Tuesday, February 11, 2020 4:39:23 PM  
**Time Spent:** 00:02:36  
**IP Address:** 86.162.96.69

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain. I am going to try CBD oil.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Amitrytline. Paracetamol. Ibuprofen.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Keep as active as possible. Try to stay positive. Know when to rest

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not recognising when I may need help

---

#83

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 5:43:53 PM  
**Last Modified:** Tuesday, February 11, 2020 5:45:16 PM  
**Time Spent:** 00:01:23  
**IP Address:** 50.50.101.14

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I use a teeter elliptical every day to try and strengthen my legs.. it's a seated machine.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise Eat healthy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Keeping motivated

---

#84

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 6:09:38 PM  
**Last Modified:** Tuesday, February 11, 2020 6:11:13 PM  
**Time Spent:** 00:01:35  
**IP Address:** 31.125.22.117

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

General mobility

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Hydrotherapy Physiotherapy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Unable to do at home

---



#85

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 6:26:23 PM  
**Last Modified:** Tuesday, February 11, 2020 6:29:07 PM  
**Time Spent:** 00:02:43  
**IP Address:** 213.205.194.92

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

The pain in my feet and shoulders. I train hard to keep walking.  
I try to stay fit and lose weight anytime.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Naproxem

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I try to keep fit and to make sport

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I cannot run, I walk very slow and I cannot climb the stairs

---

#86

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 7:14:57 PM  
**Last Modified:** Tuesday, February 11, 2020 7:17:41 PM  
**Time Spent:** 00:02:43  
**IP Address:** 174.228.135.139

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Shoulder mobility and lower back pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Continued use of muscles that are weak through daily activities Physical therapy exercises  
Ibuprofen

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Limited success for each Discouragement

---

#87

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 7:40:57 PM  
**Last Modified:** Tuesday, February 11, 2020 7:45:39 PM  
**Time Spent:** 00:04:42  
**IP Address:** 24.17.37.47

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Eye drops for dry eye.

Exercise to maintain strength and range of motion.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Watch my weight.

Eat healthy.

Take OTC supplement called NADH to reduce fatigue.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None at this time.

---

#88

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 7:58:12 PM  
**Last Modified:** Tuesday, February 11, 2020 8:06:47 PM  
**Time Spent:** 00:08:35  
**IP Address:** 76.115.210.5

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Lately experiencing difficulty breathing even walking short distances

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Not at present, no pain meds. Just blood thinner for DVT, anti-depression, and blood pressure.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Moderate exercise (swimming), moderate ADLs, eating healthy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1) Working even part-time was hardest as I didn't have any energy left over to exercise. I just retired, so that will help), 2) Takes so much energy to just move that so tiring to do usual activities of daily living without my guy's help; 3) too tired to make healthy dinners and go shopping.

---

#89

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 9:24:18 PM  
**Last Modified:** Tuesday, February 11, 2020 9:29:41 PM  
**Time Spent:** 00:05:23  
**IP Address:** 172.58.140.83

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Physical therapy for right shoulder. OT to be fitted with a brace for the right shoulder.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Only advil, but I have sleep issues which possibly are Fshd related and I take seroquil for sleep

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise and diet to assure no weight gain and keep healthy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I still can not run without stress of falling. (constantly watching the ground) my exercise routine doesn't make my shoulder feel better.

---

#90

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 10:32:07 PM  
**Last Modified:** Tuesday, February 11, 2020 10:41:15 PM  
**Time Spent:** 00:09:07  
**IP Address:** 69.117.139.194

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am trying not to do too much activity so that my muscles will not deteriorate faster yet I have heart issues that I am told to increase activity for..seems like an uphill no win battle!

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I have been offered pain killers. I do not want to deal with opioids! No, I have not.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Massage helps but I have to massage myself soooo it also harms the muscles that I am using to massage.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Muscle deterioration, weight gain, depression due to missing out on things that I would have loved to do if I could.

---

#91

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 11, 2020 10:43:00 PM  
**Last Modified:** Tuesday, February 11, 2020 10:54:32 PM  
**Time Spent:** 00:11:32  
**IP Address:** 136.56.160.153

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

For weakness and pain I exercise in the water. I eat extremely healthy, I take vitamins and supplements that are supposed to grow muscle.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Cymbalta for pain. Amitriptyln for migraine headaches related to neck strain.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise, rest, conserve energy as much as possible for things that have to be done.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I have no idea if anything I do helps. Frustrating

---

#92

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 1:31:06 AM  
**Last Modified:** Wednesday, February 12, 2020 1:36:00 AM  
**Time Spent:** 00:04:53  
**IP Address:** 69.47.101.252

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

muscle weakness and loss of function

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

taking frequent breaks and laying down, go swimming to help preserve muscle function, trying to stay as active as possible to preserve muscle function

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

no matter what I do the disease keeps progressing

---



#93

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 4:49:52 AM  
**Last Modified:** Wednesday, February 12, 2020 4:55:31 AM  
**Time Spent:** 00:05:39  
**IP Address:** 82.10.52.251

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am as active as possible. Keep fit, walking. Trying to stay one step ahead. Keep using as many muscles as possible.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Listening to my body, resting when needed. Planning my week with breakes.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

N/a

---

#94

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 5:05:37 AM  
**Last Modified:** Wednesday, February 12, 2020 5:13:37 AM  
**Time Spent:** 00:07:59  
**IP Address:** 86.143.76.53

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No. I did daily physio exercises for about 40 years till it became too difficult to continue. I eat a healthy diet, don't drink alcohol or smoke.

There's nothing else I know of that I can do.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

For pain relief

Paracetamol, Ibuprofen, Pregabalin, Oxycodone.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Resting

Aromatherapy gel and Deep Heat spray on painful areas

I have learned to ask for help when I need it instead of wasting energy in struggling to do something.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Can't answer this

---

#95

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 5:28:27 AM  
**Last Modified:** Wednesday, February 12, 2020 5:34:43 AM  
**Time Spent:** 00:06:16  
**IP Address:** 193.117.160.74

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness is my main symptom. I have been given exercises to help keep my legs, back, and core mobile and hopefully 'keep' the strength that is still present.

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Pain killers from time to time (co-codomol). I can go months without any issues, then could easily spend a week or 2 on pain killers as 'something has gone in my back' ?!

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I have a positive outlook on things. 'Shit' happens. There is nothing that i can do about it so no point in being all 'doom and gloom' about it. What will be will be.                      que sera sera!

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Dont think my 'approach' has any downsides (see above answer :-) )

#96

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 5:32:35 AM  
**Last Modified:** Wednesday, February 12, 2020 5:35:05 AM  
**Time Spent:** 00:02:30  
**IP Address:** 81.157.37.2

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle waste Exercise

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Keeping mobile..

Eating healthy.

Keeping positive.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Fighting a losing battle.

---

#97

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 6:00:35 AM  
**Last Modified:** Wednesday, February 12, 2020 6:04:29 AM  
**Time Spent:** 00:03:53  
**IP Address:** 176.27.174.26

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

General muscle twitchy feeling and aching. General joint pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

N/A

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I try to exercise but feel very limited in what I can do.

I take selenium to help with the muscle twitching feeling. I take pain killers if my joint aches are particularly bad.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Trying to exercise can make the muscle aches and joint pain worse. The selenium seems to be a bit inconsistent as to how effective it is.

---

#98

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 6:28:31 AM  
**Last Modified:** Wednesday, February 12, 2020 6:29:58 AM  
**Time Spent:** 00:01:26  
**IP Address:** 86.24.248.38

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

A little exercise to maintain ability to stand

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

N/A

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

N/A

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#99

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 7:23:50 AM  
**Last Modified:** Wednesday, February 12, 2020 7:25:35 AM  
**Time Spent:** 00:01:44  
**IP Address:** 90.200.61.74

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Been told nothing can be done

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Only painkillers to try to ease it so I can try to sleep

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing. Everything hurts. They say physio but it gives me days or extra pain

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Everything is a downside. Neurologists haven't given me any positives

---

#100

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 10:22:49 AM  
**Last Modified:** Wednesday, February 12, 2020 10:30:51 AM  
**Time Spent:** 00:08:02  
**IP Address:** 86.165.219.152

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I try doing exercises to maintain or improve strength in legs, lower back, hands and arms

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I have had some co enzyme Q10 prescribed by an NHS hospital.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

As well as static exercises mentioned before, I do some walking indoors with a rollator

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Doing exercises is boring and there is no obvious or immediate pay off

---



#101

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 10:58:26 AM  
**Last Modified:** Wednesday, February 12, 2020 11:02:57 AM  
**Time Spent:** 00:04:31  
**IP Address:** 86.138.205.25

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Adapting to lifestyle change.

Being positive.

Occupying my brain.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None

---

#102

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 11:00:03 AM  
**Last Modified:** Wednesday, February 12, 2020 11:14:00 AM  
**Time Spent:** 00:13:56  
**IP Address:** 86.171.145.89

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I do stretching exercises set out by a physiotherapist to try and maintain my inner core strength

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Have bought an adjustable bed Have bought an adjustable chair  
Modified my kitchen so that everything is close at hand

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

They are effective at present but may need modifying if my illness progresses  
Going to visit anyone makes me feel very anxious as to whether I will be able to access their building, bathroom  
Going on holiday- I worry about all aspects including the airport home & abroad and the facilities available when I get to my destination

---

#103

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 12:56:03 PM  
**Last Modified:** Wednesday, February 12, 2020 1:00:34 PM  
**Time Spent:** 00:04:30  
**IP Address:** 90.248.15.180

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Fatigue  
Physical strength

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Taking nutritional supplements Taking physical exercise  
Avoiding eating dairy produce to eliminate muscle cramping

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not knowing if they are making an impact or having any medical advice on their efficacy

---

#104

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 1:01:16 PM  
**Last Modified:** Wednesday, February 12, 2020 1:07:36 PM  
**Time Spent:** 00:06:19  
**IP Address:** 109.152.225.102

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Cocodomol

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Painkillers, exercises, trying to keep busy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Painkillers do not work so I have now stopped taking them. Exercises help a little bit, but my very good physio.  
Left some time ago. I am unable to do the things I would like to, eg. Walking, cycling, swimming

---

#105

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 1:31:15 PM  
**Last Modified:** Wednesday, February 12, 2020 1:34:53 PM  
**Time Spent:** 00:03:37  
**IP Address:** 201.175.135.3

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Exercise for the shoulder weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I didn't had a diagnosis before. I would take anything to stop the problem

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

None

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It's not resolving just maintenance

---

#106

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 4:21:48 PM  
**Last Modified:** Wednesday, February 12, 2020 4:36:00 PM  
**Time Spent:** 00:14:12  
**IP Address:** 92.238.116.74

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Maintain a healthy diet

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes pain killers, Naproxen, Paracetamol. prescribed other drugs but didn't agree with me.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Wheat bag, stay positive, not to let the disability get the better of me!

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Persistent aches & pains, walking is tiresome,

---

#107

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 4:48:56 PM  
**Last Modified:** Wednesday, February 12, 2020 4:52:55 PM  
**Time Spent:** 00:03:58  
**IP Address:** 108.74.220.119

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Breathing difficulties.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Weight management.

Bipap at night.

Maintain activity.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Difficulty eating due to GERD.

---

#108

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 5:08:35 PM  
**Last Modified:** Wednesday, February 12, 2020 5:10:24 PM  
**Time Spent:** 00:01:48  
**IP Address:** 81.129.105.85

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No. Nothing helps really

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing. Nothing suggested to me.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I don't think about downsides

---



#109

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 5:21:05 PM  
**Last Modified:** Wednesday, February 12, 2020 5:33:09 PM  
**Time Spent:** 00:12:04  
**IP Address:** 213.205.198.233

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I try to exercise to keep all symptoms at bay but it's so hard to fund things I can actually do and get past the back pain.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Naproxin but to no positive effect.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Eat healthy  
Stay at a healthy weight Regular massage  
Purchasing special office chair to support back

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Expensive!  
Finding exercises that I'm able to do  
Limited success is depressing, at the end of the day it feels like nothing I do has any impact what so ever on the progression of the disease.

---

#110

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 5:34:06 PM  
**Last Modified:** Wednesday, February 12, 2020 5:46:53 PM  
**Time Spent:** 00:12:47  
**IP Address:** 24.185.202.164

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Talking Walking

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No prescription other than over the counter Tylenol and Lidocaine patch and sleeping pill every night

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

My husband. He does all shopping and cleaning, goes to library to get me recorded books so I don't dwell on how badly I feel or start to feel sorry for myself.

The FSHD clinic at Temple in Philly and their wonderful staff

Over the counter pain medications.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

My Husband is 81 with a heart condition

The FSHD clinic is in Philadelphia and it takes us at least one and a half hours to get there with traffic

I worry about taking Tylenol so frequently that it's going to harm my liver.

---

#111

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 8:36:50 PM  
**Last Modified:** Wednesday, February 12, 2020 8:39:10 PM  
**Time Spent:** 00:02:19  
**IP Address:** 67.38.9.36

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Don't know of anything that can improve my muscle weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Take supplements daily Walk daily  
Reduce stress

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None

---

#112

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 12, 2020 9:22:10 AM  
**Last Modified:** Wednesday, February 12, 2020 9:20:44 PM  
**Time Spent:** 11:58:34  
**IP Address:** 93.204.123.109

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

- muscle weakness in legs, arms, shoulders - physiotherapy and gait training
- arm-, hand coordination - ergotherapy
- pain management - physiotherapy, massages

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

none

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

- eating healthier
- taking additional vitamins, zinc and iron
- using heating pads for muscle pain

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

- the first two things are very expensive, because there are no significant studies, the health insurance doesn't cover it
  - with the vitamins you have to be very careful, get checked by your GP regularly and ideally get your blood tested once a month to see if your levels are normal
-

#113

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, February 13, 2020 6:25:47 AM  
**Last Modified:** Thursday, February 13, 2020 6:31:55 AM  
**Time Spent:** 00:06:07  
**IP Address:** 86.172.226.1

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Occasional ibuprofen.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Rollator. Mobility scooter. Reclining /lifting chair.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Cumbersome. Restricting. Expensive.

---

#114

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, February 13, 2020 6:37:03 AM  
**Last Modified:** Thursday, February 13, 2020 6:42:30 AM  
**Time Spent:** 00:05:26  
**IP Address:** 88.106.190.203

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness- keeping active and doing gentle exercise Fatigue- getting plenty of sleep  
Isolation- getting out and doing things with other people

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise & keeping active  
Taking OTC painkillers to ensure sleep Attending physio appointments

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Balancing exercise without getting too fatigued Would prefer not to take painkillers  
Takes up a lot of time (would struggle if I was still working)

---

#115

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, February 13, 2020 11:31:19 AM  
**Last Modified:** Thursday, February 13, 2020 11:32:47 AM  
**Time Spent:** 00:01:28  
**IP Address:** 92.2.143.254

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

None

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

None

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Don't know of any

---

#116

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, February 13, 2020 5:12:43 PM  
**Last Modified:** Thursday, February 13, 2020 5:15:45 PM  
**Time Spent:** 00:03:01  
**IP Address:** 86.129.96.253

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

**Respondent skipped this question**

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Keep active

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

**Respondent skipped this question**

---



#117

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, February 13, 2020 9:56:59 PM  
**Last Modified:** Thursday, February 13, 2020 10:01:30 PM  
**Time Spent:** 00:04:31  
**IP Address:** 68.134.139.62

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Exercise, try not to loose muscle mass. Creatine supplement.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Creatine supplement.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise.  
Keep active.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

weakness, tiredness,.

---

#118

COMPLETE

Collector: Web Link 1 (Web Link)

Started: Friday, February 14, 2020 5:30:50 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

My bad back, flexibility and bad knee.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Co codamol 30mg. Horrible Co codamol 8mg useful Amatriptline horrendous stuff Pregabalin ok  
Ibuprofen tolerable with omeprazole

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Stretches, yoga, keep moving

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Tiredness, can't sit still for long, everytime I try new exercises something else goes wrong

---

#119

COMPLETE

**Collector:** Web Link 1 (Web Link)

**Started:** Saturday, February 15, 2020 9:40:51 AM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Exercising hands to try to maintain dexterity

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

#119

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Saturday, February 15, 2020 9:40:51 AM

Respondent skipped this question

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

#119

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Saturday, February 15, 2020 9:40:51 AM

Respondent skipped this question

---

#120

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Saturday, February 15, 2020 12:04:15 PM  
**Last Modified:** Saturday, February 15, 2020 12:14:14 PM  
**Time Spent:** 00:09:58  
**IP Address:** 71.171.89.244

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Respiratory- breathing exercises Strength- PT, aquatic therapy Weight control- healthy eating

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

#120

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Saturday, February 15, 2020 12:04:15 PM  
**Last Modified:** Saturday, February 15, 2020 12:14:14 PM  
**Time Spent:** 00:09:58  
**IP Address:** 71.171.89.244

---

**Respondent skipped this question**

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Massages Tens unit  
Physical therapy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

relieves the pain only temporarily

---

#121

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Saturday, February 15, 2020 12:21:54 PM  
**Last Modified:** Saturday, February 15, 2020 12:25:44 PM  
**Time Spent:** 00:03:50  
**IP Address:** 88.104.247.93

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Bladder sensitivity Finger weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Oxybutinin, Solefinacin & Tolterodine

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Keeping moving

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not aware of anything I can do to improve my symptoms.

---



#122

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Saturday, February 15, 2020 1:11:11 PM  
**Last Modified:** Saturday, February 15, 2020 1:34:11 PM  
**Time Spent:** 00:22:59  
**IP Address:** 109.57.58.196

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I go to fysiroly training try to stand and move along a rip to keep strengt in legs, and do arm training to maintain strengt in arms to be able to keep as mutch streingt as possible  
 somtimes taking Water driven medicin to help legs not to be swelling or sometimes if too tired get migreen i take head ace .

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Furix and iboprofen

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I got a car opel movana with lift where the scoter can come into - and the ni can drive myselfe and go to Work - I use the gliding pad to move arrond from bed to chair to scoter or weel chair to toilet etc. (greathelp).  
 I have a dayly rutine doing Things Places where I know I can cope with situation, avoid too many unforeseen events where disability get in it way . at Work I have an agreement where person can help with Things I cant manage lifting , feching open dors etc. so that way I can manage.

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

most problems with steps and stairs , as weelchair can't manage , and then I can't manage without help from others.

#123

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Saturday, February 15, 2020 2:36:52 PM  
**Last Modified:** Saturday, February 15, 2020 2:52:02 PM  
**Time Spent:** 00:15:10  
**IP Address:** 97.118.234.86

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Leg Weakness, I walk with walking sticks on soft surface to keep my muscle sparked Leg braces help with using my legs

Arm Weakness, rubber band work out

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Methocarbamol Gaoapentin oxycodone all for Pain Testosterone injections for muscle strength and energy

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

walking with walking sticks on soft surface      Posture Brace for pain and leg and drop foot brace

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Takes 3 x long to do anything Slower taking all the medication to tolerate daily full body pain

---

#124

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Saturday, February 15, 2020 6:39:46 PM  
**Last Modified:** Saturday, February 15, 2020 6:43:14 PM  
**Time Spent:** 00:03:27  
**IP Address:** 5.81.240.174

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

General physiotherapy to help maintain mobility

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercises  
keeping as active as possible

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None

---

#125

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Sunday, February 16, 2020 7:34:36 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I try to save my energy by parking close to where I need to be and trying to go places where I know there no stairs to toilets etc

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Etodolac, Amitriptyline, Naproxen

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Conserving energy by planning where to go so I can get parked close. Ensure disabled toilets are available.  
At home I try to keep the use of the stairs to a minimum by ensuring I have got everything I need downstairs

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not everywhere has disabled access.  
A few places i used to visit don't have disabled toilets.

---

#126

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 12:30:07 AM  
**Last Modified:** Monday, February 17, 2020 12:34:31 AM  
**Time Spent:** 00:04:24  
**IP Address:** 24.6.40.178

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I use a BiPAP all night, every night, for breathing. I use a standing frame as frequently as possible.  
I do some light exercise, but I am unable to do anything beyond light exercise. I do meditation.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Many years ago I tried albuterol for several weeks, but had some negative side effects. I don't remember what the side effects were, but they were severe enough that I stopped the medication.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I require assistance from caregivers or my wife for activities of daily living. This is not really "managing" the symptoms, but managing their impact.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None that I can think of.

---

#127

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 7:49:24 AM  
**Last Modified:** Monday, February 17, 2020 7:55:25 AM  
**Time Spent:** 00:06:01  
**IP Address:** 148.252.129.201

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Excruciatingly painful muscle spasms/flare in neck and both shoulders

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes. Naproxen

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Homeopathy Exercises

Natural supplements

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Cost

---

#128

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 8:44:55 AM  
**Last Modified:** Monday, February 17, 2020 8:55:14 AM  
**Time Spent:** 00:10:18  
**IP Address:** 86.18.81.191

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

House adapted on ground floor with wet room and bedroom to facilitate wheelchair access and sideways transfer for personal washing and sleeping.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

House rooms would ideally be larger as wheelchair manoeuvring takes up more space than normal human movements.

---

#129

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 9:32:56 AM  
**Last Modified:** Monday, February 17, 2020 9:46:55 AM  
**Time Spent:** 00:13:58  
**IP Address:** 95.149.163.20

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Keeping as active as possible to maintain muscle mass as long as possible.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

OxyContin, Pregabalin, Naproxen, Amitriptyline, Paracetamol, Codeine, Tramadol,

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Pacing Meditation Health diet

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I'm just managing the degenerative disease, so no matter what I do I'm just slowing down at best the process.  
But in my mind I remain as positive as I can

---



#130

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Monday, February 17, 2020 12:21:04 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Falls -- started using a walker and scooter to avoid falls.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Have someone pull up using the back of my pants/belt to assist getting me to a standing position Shower stool to avoid falls in the shower

Freestanding mirror to enable shaving when sitting

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Still have mobility limitations that constrain what I can do relative to everyday activities Significant reliance on my caregiver which constrains their life

Falls can occur even with a focus on avoiding them

---

#131

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 1:19:22 PM  
**Last Modified:** Monday, February 17, 2020 1:20:29 PM  
**Time Spent:** 00:01:06  
**IP Address:** 173.88.68.66

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Been told nothing helps.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Afo

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Nothing improves

---

#132

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 4:25:33 PM  
**Last Modified:** Monday, February 17, 2020 4:37:04 PM  
**Time Spent:** 00:11:30  
**IP Address:** 86.26.175.193

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

To maintain leg muscles and lose weight I attend a gym twice weekly and go swimming once a week

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes. I was prescribed inbrufen and have continued a daily dose to reduce arthritis in my lower back.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Avoid standing for long periods - for example I remain seated when I teach or do chores like the ironing

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Unable to engage as effectively as I would like with my students. Having to use disabled changing facilities I find embarrassing.

---

#133

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 4:54:26 PM  
**Last Modified:** Monday, February 17, 2020 4:57:59 PM  
**Time Spent:** 00:03:32  
**IP Address:** 32.208.217.248

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

walking, PT  
getting in and out of chairs, PT  
overall strength, adaptive fitness center

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

positive attitude - helping others, therapy staying active - getting outdoors, PT  
using devices when needed, (scooter, chair lift, etc)

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

access to some public places  
ability to participate in activities at the level I would like being a burden and concern to others

---

#134

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 5:09:01 PM  
**Last Modified:** Monday, February 17, 2020 5:12:21 PM  
**Time Spent:** 00:03:19  
**IP Address:** 50.80.226.45

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

weakness in arms, hands and legs, and back to stand

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

taking amino acids, and other vitamins and minerals physical therapy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

therapy gives you exercise to do and send ya home therapist don't know what to do for FSHD  
not sure on the vitamins and minerals yet

---

#135

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 5:10:01 PM  
**Last Modified:** Monday, February 17, 2020 5:12:21 PM  
**Time Spent:** 00:02:20  
**IP Address:** 146.198.50.95

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

The posture with the 'leaning back effect' - having seen a physio he suggested a aerobics ball to 'lean over' as a way to TRY and counter the leaning (which to my mind seems natural now)

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

#135

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 5:10:01 PM  
**Last Modified:** Monday, February 17, 2020 5:12:21 PM  
**Time Spent:** 00:02:20  
**IP Address:** 146.198.50.95

---

**Respondent skipped this question**

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

#135

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 5:10:01 PM  
**Last Modified:** Monday, February 17, 2020 5:12:21 PM  
**Time Spent:** 00:02:20  
**IP Address:** 146.198.50.95

---

Respondent skipped this question

---



#136

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 5:27:52 PM  
**Last Modified:** Monday, February 17, 2020 5:31:00 PM  
**Time Spent:** 00:03:08  
**IP Address:** 72.80.58.216

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Arm weakness, right hip weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Gym 2x week, elliptical or walking 5x week, at home fitness therapist 1x week

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Tire easily, arm exercises extremely difficult, afraid to fall while walking and have done so 3x

---

#137

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, February 17, 2020 9:14:07 PM  
**Last Modified:** Monday, February 17, 2020 9:18:52 PM  
**Time Spent:** 00:04:45  
**IP Address:** 108.78.169.61

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain. Regular physical therapy and massage.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

NSAIDs, narcotic pain meds, other muscle pain meds

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physical therapy Massage  
Icy-hot like creams

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

These help somewhat but are temporary (pain comes back) Couldn't stay on medication due to side effects.

---

#138

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 18, 2020 7:02:24 AM  
**Last Modified:** Tuesday, February 18, 2020 7:06:59 AM  
**Time Spent:** 00:04:34  
**IP Address:** 2.123.17.61

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I'm trying to lose weight and do more exercise to reduce strain on my joints.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Diclofenac, co-codemol, co-dydremol for pain.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Danger of overdoing exercise or choosing the wrong ones

---

#139

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 18, 2020 7:19:05 AM  
**Last Modified:** Tuesday, February 18, 2020 7:34:22 AM  
**Time Spent:** 00:15:17  
**IP Address:** 77.103.55.46

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

1. I have physiotherapist prescribed exercises for shoulders, arms, legs, core stability etc. and I keep up with them to maintain the strength I have as much as possible. I go back for an updated opinion every few years as the condition changes.
2. I have been trying electrical stimulation for the muscles in my legs to try and improve any non effected muscles.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Oral contraceptives to stop additional fatigue and pain.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Keeping weight very low so my muscles are not having to lift much mass.
2. Keeping active where possible but also...
- 3 Pacing myself and not taking on so much that I injure myself.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. Being careful with my activity levels while maintaining health through exercise can be isolating as physiotherapist mandated activity is not like the shared gym or football activities my fellow students take part in.
  2. Continuing to do a particular movement for years as an exercise as your ability to actually complete it withers away is incredibly dispiriting.
  3. Trying to keep active and trying to pace myself are actively in conflict and because the condition is a moving target, it feels like as soon as you've got the balance right it all falls apart again.
-

#140

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 18, 2020 8:28:03 AM  
**Last Modified:** Tuesday, February 18, 2020 8:32:38 AM  
**Time Spent:** 00:04:34  
**IP Address:** 51.6.208.230

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Stiff muscles Weak muscles

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No, other than occasional pain killers.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Pacing activities at home and out and about Group exercise class  
Resting when needed

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Sometimes difficult or embarrassing to stop joining in something Pacing is difficult on some days  
Can't always stoo and sit or lie down in some places

---

#141

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 18, 2020 11:58:17 AM  
**Last Modified:** Tuesday, February 18, 2020 12:01:17 PM  
**Time Spent:** 00:02:59  
**IP Address:** 78.148.163.20

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

fatigue, limb girdle and leg weakness, breathing

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

keeping my body as stress free via physical impact .

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

i feel i am not getting anywhere beyond sheer basics if at all before being fatigued or unwell

---

#142

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 18, 2020 3:09:46 PM  
**Last Modified:** Tuesday, February 18, 2020 3:12:16 PM  
**Time Spent:** 00:02:29  
**IP Address:** 82.39.206.219

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Weakness.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Some stretching and exercise. Stubbornness. Keeping going, use it or lose it.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Exercise makes me tired, recovery time if too much is done.

---

#143

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 18, 2020 3:33:48 PM  
**Last Modified:** Tuesday, February 18, 2020 3:38:39 PM  
**Time Spent:** 00:04:51  
**IP Address:** 73.231.79.93

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I use a sleep mask and eye drops to keep my eyes from drying out. I do cardio on a stationary bike 4x a week.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Stretching and hydrotherapy like hot tubs and cold baths.
2. OTC pain killers
3. Natural medicines like CBD/THC to mitigate pain

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. It doesn't change the progression of the condition.
  2. It doesn't always alleviate the pain
  3. The mental stress and anxiety of having a progressive disease is oftentimes more present when trying to deal with symptoms. Makes it more real when forced to manage the pain/increase mobility.
-



#144

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 18, 2020 6:52:34 PM  
**Last Modified:** Tuesday, February 18, 2020 6:56:46 PM  
**Time Spent:** 00:04:11  
**IP Address:** 125.237.134.121

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

i do some training to try to build strength in unaffected muscles and to slow onset of disease

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Use of rowing machine to strengthen legs, floor exercises to try to strengthen arms, shallow squats

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It does help but not enough, it is tedious to do, can be depressing as performance weakens

---

#145

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 18, 2020 10:38:52 PM  
**Last Modified:** Tuesday, February 18, 2020 10:51:43 PM  
**Time Spent:** 00:12:51  
**IP Address:** 64.53.140.157

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Trying to maintain the health of the eyes- even though vision is lost, making sure pressure remains stable. This requires anesthesia at the hospital because I cannot be checked in the office.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Dorzolomide, Dorzolomide Timilol, Latanoprost (all eye drops)

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I have done physical and occupational therapy in the past.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Having no vision and hearing loss, makes it difficult to understand and trust the therapist. Often therapists want to grab my hands to show me how to do things, but that is scary as a blind person. Additionally, I have autism and am non-verbal. I am unable to tell people when I am hurting.

---

#146

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 18, 2020 11:07:42 PM  
**Last Modified:** Tuesday, February 18, 2020 11:10:32 PM  
**Time Spent:** 00:02:49  
**IP Address:** 75.51.148.13

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

no

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

use voice recognition for working on computer electric wheelchair

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

lifting the chair in and out of the car and in and out of the house. If I fall, what will happen?

---

#147

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 19, 2020 7:03:15 AM  
**Last Modified:** Wednesday, February 19, 2020 7:09:04 AM  
**Time Spent:** 00:05:49  
**IP Address:** 92.29.202.0

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Private physiotherapy to ease pain and stiffness in muscles; use medical sheepskin in my wheelchair to prevent skin sores; electric bed to sit me up.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Oxybutynin to assist with bladder control; citalopram to reduce anxiety

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Accessible home environment including electric WC, wider doorways, lower switches etc.,; Private physiotherapy with neuro physiotherapist; Private personal assistant to assist with washing etc.,

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Cost Cost Cost

---

#148

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 19, 2020 10:15:14 AM  
**Last Modified:** Wednesday, February 19, 2020 10:33:10 AM  
**Time Spent:** 00:17:56  
**IP Address:** 207.167.47.64

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I try to walk on soft service feels better on my muscles Keep what muscles I have sparked But its hard I am 62 and feel and look like I am 72 The disease ages you quickly Its hard to try to improve when each day brings another problem of strength

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

oxycodone only thing that really helps with the pain

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Sleep More cut back on work hours I am now down to 9 hours a week PT disability and my wife works full time with her insurance covering any new issues

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Keeps me in a state of dormant Do not do much other than a few hobbies to keep my mind in tack as best I was an athlete I played sports. Now I have a hard time just throwing the ball with my dog

---

#149

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, February 19, 2020 11:41:44 AM  
**Last Modified:** Wednesday, February 19, 2020 11:44:49 AM  
**Time Spent:** 00:03:04  
**IP Address:** 81.158.139.127

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No idea how I could improve my situation

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing that I am unaware that I could do to manage my symptoms

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I have no current approach

---

#150

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Wednesday, February 19, 2020 4:25:07 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Shoulder weakness, attempting to strengthen the muscles in that area

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

n/a

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Stretching Massaging

Strengthening exercises

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not sure if it helps

Good days and bad days

Not going to prevent it worsening

---

#151

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, February 20, 2020 12:00:20 AM  
**Last Modified:** Thursday, February 20, 2020 12:02:46 AM  
**Time Spent:** 00:02:26  
**IP Address:** 73.78.200.223

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I lift eights hoping that I can gain muscle strength elsewhere to compensate for the muscle loss elsewhere

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise Good nutrition

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Can't really say they are changing the progression of my symptoms

---



#152

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, February 20, 2020 8:11:32 AM  
**Last Modified:** Thursday, February 20, 2020 8:23:53 AM  
**Time Spent:** 00:12:21  
**IP Address:** 66.153.214.232

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Yes... Foot drop, weak shoulders, weak core (abdominals)

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No. I have not been prescribed any meds.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1-Practice martial arts to help with balance, muscle tone, core and shoulder weakness. 2-Weight training for overall strengthening. 3- Qi Gong practice for breathing and overall positive mental attitude.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

My overall approach is an effort to maintain and possibly slow the disease and maintain a positive mental attitude. The downside is that I invest a significant amount of time daily with no measurable result. I still stumble, I still can't reach the top shelf, I still can't get out of a chair without help.

---

#153

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, February 20, 2020 12:08:41 PM  
**Last Modified:** Thursday, February 20, 2020 12:13:11 PM  
**Time Spent:** 00:04:29  
**IP Address:** 82.69.50.246

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Tiredness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Swimming

Night time ventilator Healthy diet

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None of the approaches stop or reverse the progression Night time ventilator is intrusive, more than inconvenient etc

---

#154

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, February 20, 2020 6:30:08 PM  
**Last Modified:** Thursday, February 20, 2020 6:38:56 PM  
**Time Spent:** 00:08:47  
**IP Address:** 73.215.234.10

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Yes, Trunk, arm and leg strength via NeuroKinetic Therapy

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No, none.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. NeuroKinetic Home exercise and breathing 2. Short walks 3. Arranging my schedule to allow breaks to move around

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. Making time for home exercise 2. Making sure I stick to planned breaks in my day 3. Weather can play into any outside walking

---

#155

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Thursday, February 20, 2020 9:10:56 PM  
**Last Modified:** Thursday, February 20, 2020 9:18:57 PM  
**Time Spent:** 00:08:01  
**IP Address:** 24.69.202.15

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

-neck and shoulder impingement (affected by two car accidents / not my fault / caused soft tissue injury that's slow to heal and has affected FSHD progress negatively)  
 -weakening hip girdle and leg muscles making it harder to get up from seats / move in bed etc)

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No. Just over the counter tylenol and voltaren gel

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

-some gentle exercises and stretches along with (reduced) walking  
 -resting with legs stretched out between times of activity / trying to pace myself  
 -staying involved with people as this helps me mentally and emotionally (from getting too focused negatively on myself)

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

-trying to find a physiotherapist who has an understanding of my limitations / weaker muscles as a result of having FSHD  
 -not always being able to take a break when needed  
 -my husband has medical needs also and isn't always able to help

---

#156

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Friday, February 21, 2020 7:05:04 AM  
**Last Modified:** Friday, February 21, 2020 7:06:32 AM  
**Time Spent:** 00:01:27  
**IP Address:** 82.69.88.212

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Other than using a scooter to get around my solutions all revolve around paying other people to do the things I need but can't do.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It's expensive.

I hate the loss of independence.

---

#157

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Friday, February 21, 2020 10:41:35 AM  
**Last Modified:** Friday, February 21, 2020 10:42:14 AM  
**Time Spent:** 00:00:39  
**IP Address:** 86.168.122.137

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

no

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

massage

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

only immediate relief

---

#158

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Friday, February 21, 2020 11:23:42 AM  
**Last Modified:** Friday, February 21, 2020 11:24:28 AM  
**Time Spent:** 00:00:46  
**IP Address:** 86.170.78.146

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

None

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Walking/exercise daily

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not sure if it is working

---

#159

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Friday, February 21, 2020 12:47:48 PM  
**Last Modified:** Friday, February 21, 2020 12:52:15 PM  
**Time Spent:** 00:04:27  
**IP Address:** 80.229.165.207

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain - using many pain killers although prescribed cannabis is the best. Weakness in my legs - getting physio and doing home exercises

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Prescribed cannabis MST  
Paracetamol Tegretol Salbutamol tabs Calciferol tabs

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Using mobility aids  
Using heat to; relieve pain Getting physio

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Distance to travel for physio - Round trip 150 miles Not getting enough support  
Lack of medical understanding

---



#160

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Friday, February 21, 2020 2:16:37 PM  
**Last Modified:** Friday, February 21, 2020 2:24:21 PM  
**Time Spent:** 00:07:43  
**IP Address:** 209.249.190.124

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Just the discomfort that comes from having severe scapular winging when lying down - I lie down with a pillow under my right arm so my scapula doesn't dig into the surface I sleep on, which would produce a lot of discomfort.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I try to walk as often as I can.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I am constantly worried about the limits of my body, and it is easy to make mistakes and make myself weaker by pushing my limits of walking accidentally.

---

#161

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Friday, February 21, 2020 6:21:00 PM  
**Last Modified:** Friday, February 21, 2020 6:25:49 PM  
**Time Spent:** 00:04:49  
**IP Address:** 72.208.48.192

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Losing muscle mass and balance.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise, eating healthy, taking nutritional supplements.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Finding the exercises and eating habits that work the best.

---

#162

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Saturday, February 22, 2020 8:38:41 AM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

#162

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Saturday, February 22, 2020 8:38:41 AM

Respondent skipped this question

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Wearing foot supports.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

none

---

#163

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Sunday, February 23, 2020 1:22:23 AM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No. Not possible to improve

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

- Maintain my current level of ability for as long as I can by doing the things I can do on my own for as long as I can
- Stretch
- Be wary of overexerting myself

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

- It's easy to push myself too far by accident
- Doing things on my own takes too long
- Difficult to remember to keep up stretching

#164

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 25, 2020 1:12:45 PM  
**Last Modified:** Tuesday, February 25, 2020 1:14:14 PM  
**Time Spent:** 00:01:28  
**IP Address:** 66.170.14.226

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

n/a

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

n/a

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Ankle-foot orthotics (AFOs)

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

AFOs are difficult to put on and uncomfortable

---

#165

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 25, 2020 1:14:20 PM  
**Last Modified:** Tuesday, February 25, 2020 1:16:29 PM  
**Time Spent:** 00:02:08  
**IP Address:** 172.76.3.130

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I do daily stretching to try to help with the pain.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Doctors have given me narcotic pain meds and muscle relaxers, but I can not take them and function on a daily basis, so I mostly just live with the pain.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

No management, just tolerance.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I am living in pain everyday, not active with my family and depressed.

---

#166

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 25, 2020 1:41:32 PM  
**Last Modified:** Tuesday, February 25, 2020 1:44:11 PM  
**Time Spent:** 00:02:39  
**IP Address:** 72.38.125.194

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

drop foot I wear a foot brace  
I cannot lift my right arm at all so I use my left to help

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I am very careful walking and lifting things

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I can't do anything to help. It is very depressing and at times I feel like giving up.

---



#167

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 25, 2020 6:40:46 PM  
**Last Modified:** Tuesday, February 25, 2020 6:44:45 PM  
**Time Spent:** 00:03:59  
**IP Address:** 107.202.149.37

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Just stretch exercises to maintain some flexibility.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise bike 3X a week.

Managing my alcohol intake to avoid falls.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None really. Just time and discipline.

---

#168

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 25, 2020 10:14:01 PM  
**Last Modified:** Tuesday, February 25, 2020 10:18:47 PM  
**Time Spent:** 00:04:45  
**IP Address:** 71.235.249.140

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Apply eye drops nightly for dryness  
Attempting to keep what ability I have by doing seated/chair yoga

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Gratitude journal, prayer  
Manage what I eat (fewer carbs, minimal sugar, lots of water) Appreciate my power wheelchair and wheelchair accessible van

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I don't have prescriptive guidance. Have always felt it's hard to balance doing too much vs. doing too little re: exercise

---

#169

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, February 25, 2020 11:06:46 PM  
**Last Modified:** Tuesday, February 25, 2020 11:51:32 PM  
**Time Spent:** 00:44:46  
**IP Address:** 69.181.242.90

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I'm trying to keep my muscles along side the weak ones strong by swimming, riding a stationary bike, home exercises from my PT and walking with exerstrider walking poles

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I was told there were no prescriptions to improve muscle weakness. I am taking a perscription for anxiety and depression. The perscription is Duolxetine

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

For pain, I take Tylenol and I ice my lower back. For fatigue or exhaustion, I rest (or sleep). For anxiety and mood, I swim, and I take Tai Chi Chih

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

The pain never goes away, the fatigue never goes away, and the exercises (along with daily activities) don't improve muscle strength.

---

#170

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Wednesday, February 26, 2020 10:58:10 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

None

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Occasional painkillers to help with pain but the side effects stop me using them

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Try to keep as active as possible, try to eat healthy and try to keep a positive attitude

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Nothing really helps

---

#171

COMPLETE

Collector:

Web Link 1 (Web Link)

Started:

Friday, February 28, 2020 5:44:25 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Fatigue

Keeping healthy muscles strong Pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

PT exercises, eating healthy, acupuncture/Chinese medicine

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

#1. cost

preparing healthy food when I am fatigued

---

#172

COMPLETE

Collector: Web Link 1 (Web Link)

Started: Saturday, February 29, 2020 12:38:58 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Fatigue Chronic pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes - Hydrochodone, Flexeril, Ibuprofen, Diazepam

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Hot baths with Epsom salt Heating pad

Stretching exercises

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Medicine effects on my body Inability to work full time

---

#173

COMPLETE

Collector: Web Link 1 (Web Link)

Started: Saturday, February 29, 2020 1:44:23 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am trying to improve my strength and range of motion by training the healthy muscles surrounding the atrophied muscles. I am also taking any supplements recommended by healthcare professionals that can improve muscular strength and health.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No prescription medication has been used.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Strength training muscles surrounding atrophied ones, taking supplements that can improve muscle health, being open and honest with people about my condition.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It is merely providing a intermediate coping mechanism, some day I will progress to a stage of the disease where I can no longer strength train at the level I do now.

---

#174

COMPLETE

Collector: Web Link 1 (Web Link)

Started: Monday, March 02, 2020 8:59:51 PM

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain and fatigue

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Gabapentin

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise Sleep Rest

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Pain

---



#175

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 03, 2020 12:14:52 PM  
**Last Modified:** Tuesday, March 03, 2020 12:22:35 PM  
**Time Spent:** 00:07:42  
**IP Address:** 108.14.78.211

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Strength & mobility. I am doing Pilates & Myofascial Release.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Cannot use due to allergic reactions.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Pilates, Myofascial Release & mobile activity.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Things get better ( I have a core, again & biceps, a smattering of triceps & lats). Other areas lose strength, muscles die & there is not a damn thing I can do to regain them.

---

#176

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 03, 2020 12:24:40 PM  
**Last Modified:** Tuesday, March 03, 2020 12:29:37 PM  
**Time Spent:** 00:04:57  
**IP Address:** 63.105.50.19

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No. I should be exercising more to help with core/balance.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Yoga. Should be doing cardio and light weights too.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

As I progress I will no longer be able to do Yoga.

?

---

#177

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 03, 2020 12:30:52 PM  
**Last Modified:** Tuesday, March 03, 2020 12:36:52 PM  
**Time Spent:** 00:06:00  
**IP Address:** 199.90.35.10

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Swim therapy to assist with my foot drop and hip issues occurring more so on my right side, which is over-compensating for my left side.

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Cymbalta. More so to manage fibromyalgia but helps my chronic/debilitating pain and honestly don't know how I have gone so long without it. Another member of the FSHD chapter meeting attested to the same medicine doing wonders for her as well. Not everyone has pain associated but if you are like me, it is CONSTANT with no relief until I started this medication.

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

- 1) Not pushing myself beyond my means and listening to my body.
- 2) Turning in early in attempt to get plenty of rest.
- 3) Stretching and use natural remedies to help with pain.

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

- 1) Extreme, debilitating and chronic fatigue.
- 2) Extreme, debilitating and chronic Pain.
- 3) Takes away from allowing me to do activities or have enough energy to participate in doing things with my family and limiting my quality of life.

#178

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 03, 2020 12:37:10 PM  
**Last Modified:** Tuesday, March 03, 2020 12:38:15 PM  
**Time Spent:** 00:01:05  
**IP Address:** 73.166.76.255

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

NO

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

NO

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

NOTHING

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

CONTINUED DETERIORATION

---

#179

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 03, 2020 1:43:19 PM  
**Last Modified:** Tuesday, March 03, 2020 1:47:40 PM  
**Time Spent:** 00:04:20  
**IP Address:** 162.244.227.146

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I get in a pool for Water Therapy once a week. I have been doing this for 1 1/2 years and has been very beneficial for overall ability to maintain my strength.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Prescription Hydrocodone helps get me through feeling of fatigue late in the day.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

- 1) Stay as active as I can
- 2) Maintain a strong faith in God
- 3) Stay as active as I can

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

#179

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 03, 2020 1:43:19 PM  
**Last Modified:** Tuesday, March 03, 2020 1:47:40 PM  
**Time Spent:** 00:04:20  
**IP Address:** 162.244.227.146

---

Respondent skipped this question

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#180

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 03, 2020 1:57:41 PM  
**Last Modified:** Tuesday, March 03, 2020 2:04:00 PM  
**Time Spent:** 00:06:18  
**IP Address:** 207.140.42.154

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Trying to improve standing balance to prevent falling.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Eat healthy, avoid consumption of fast-food services.
2. Twice-3x pool exercise.
3. Be involved with research activities.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. Science in what is healthy eating is specific to the individual therefore one is not certain they are taking the best approach.
  2. Fine balance between over exercising and under. Resources and equipment tailored for my needs not readily available in most gym clubs.
  3. Living far away from FSH-specific health clinics makes it difficult to participate in various studies.
-

#181

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 03, 2020 3:00:25 PM  
**Last Modified:** Tuesday, March 03, 2020 3:01:35 PM  
**Time Spent:** 00:01:09  
**IP Address:** 24.23.239.165

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Inability to walk

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

nothing

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Exercise not possible

---



#182

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 03, 2020 7:59:02 PM  
**Last Modified:** Tuesday, March 03, 2020 8:00:50 PM  
**Time Spent:** 00:01:47  
**IP Address:** 209.81.9.175

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Trying to improve holding cups/heavy plates for longer period than normally I am able to do.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes, cannot recall at the moment.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercising regularly

Eating healthy and trying to ovoid over burdening my arms.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Daily chores require me to lift things and I find it hard to do so.

---

#183

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 03, 2020 8:29:29 PM  
**Last Modified:** Tuesday, March 03, 2020 8:32:38 PM  
**Time Spent:** 00:03:08  
**IP Address:** 138.130.82.196

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Inflammation

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Naproxen

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Taking natural tablets Pilates physio

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Finding time to go to appointments fatigue money buying natural tablets

---

#184

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 03, 2020 11:08:43 PM  
**Last Modified:** Tuesday, March 03, 2020 11:37:16 PM  
**Time Spent:** 00:28:32  
**IP Address:** 75.51.148.13

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Exercise (indoor bicycle) to maintain leg strength and cardio. Weight reduction to put less burden on my muscles.

Voice control for writing/computer use to relieve pain in my hands/wrists

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No - just over the counter pain relievers

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Limiting outdoor activities or using wheelchair to prevent falling.

Sitting in tall chairs that have a sturdy table (or arms) so that I can stand up from the chair.

Making extensive use of grab-bars in the bathroom and shower, and taking extreme care in stepping into the bathtub. I desperately wish for some sort of effective intervention to slow or stop the progression of my symptoms.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It limits my activities and cuts me off from enjoyment and friends. It reduces my Quality of life.

---

#185

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, March 04, 2020 2:06:16 PM  
**Last Modified:** Wednesday, March 04, 2020 2:11:42 PM  
**Time Spent:** 00:05:26  
**IP Address:** 142.132.20.130

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain management through physiotherapy, massage, acupuncture and cannabis oil.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Medically prescribe cannabis oil, refuse to use prescription pain killers due to risk of addictiveness and over dependence.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Prescription medication to manage depression and anxiety associated with having to confront physical and attitudinal barriers in everyday life

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

No FSHD-specific treatments available, lack of connection to others with FSHD, financial barriers to accessing mobility equipment to increase health and independence.

---

#186

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Wednesday, March 04, 2020 4:46:00 PM  
**Last Modified:** Wednesday, March 04, 2020 5:00:32 PM  
**Time Spent:** 00:14:32  
**IP Address:** 68.96.209.17

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Im taking medication (lyrica and tramadol, and flexorill)

Lyrica and tramadol give me a little boost of energy which helps me stand up and walk better, helps me climb stairs more easily. I just want to be able to get up and live daily life without body restrictions. People need muscle to do MOST EVERYTHING.

I wish WISH i could run. But theres no medication for that.

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes Lyrica Tramadol Flexorill

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I try and eat healthy. Exercising is OUT THE QUESTION, my muscles tense up and i get weak abd fatigued easily.

I get up every day even though it is difficult. I am very tired in the morning but i get up despite gravity and sleepiness and drink coffee & take meds, thats helps me

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It wears off. Medication i take only helps temporarily.

Medication doesnt give everything i want. And i hate relying on a pill for energy and strength.

Even tho im walking up stairs and still moving, i dont get muscle, i actually lose it. Thats depressing and sometimes a drawback for me. No matter how hard i try i wont ever get stronger

#187

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Friday, March 06, 2020 10:20:36 AM  
**Last Modified:** Friday, March 06, 2020 10:25:04 AM  
**Time Spent:** 00:04:27  
**IP Address:** 24.0.65.29

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain & Weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Voltarin Gel

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Stretch & Exercise to relieve pain & retain as much strength as possible. Use a wheelchair when my back starts to hurt. Use a walker to avoid falls.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I can't avoid all pain. Wheelchairs are a pain in the butt for the user and those around me (everyone trips over my back wheels when I'm in public). My walker hurts my shoulder when I try to lift it into my van so I can't go anywhere alone with it.

---

#188

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Friday, March 06, 2020 10:26:57 AM  
**Last Modified:** Friday, March 06, 2020 10:30:02 AM  
**Time Spent:** 00:03:05  
**IP Address:** 86.132.18.200

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness. I do light weights, swimming etc..

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None at all

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Bicep specific exercises

Bench press with light weights to try and strengthen pecs Shoulder presses to help lifting above head height

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I don't think any exercise is really helping

---

#189

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Friday, March 06, 2020 3:56:56 PM  
**Last Modified:** Friday, March 06, 2020 4:01:47 PM  
**Time Spent:** 00:04:51  
**IP Address:** 99.6.41.158

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Weak legs and arms Balance

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Walking
  2. Exercise classes
  3. Chair Yoga
- 

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.



#189

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Friday, March 06, 2020 3:56:56 PM  
**Last Modified:** Friday, March 06, 2020 4:01:47 PM  
**Time Spent:** 00:04:51  
**IP Address:** 99.6.41.158

---

Respondent skipped this question

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#190

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Friday, March 06, 2020 9:35:37 PM  
**Last Modified:** Friday, March 06, 2020 9:40:30 PM  
**Time Spent:** 00:04:53  
**IP Address:** 73.205.43.101

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Light strength exercises 2. Swimming for aerobic exercise 3. Eat healthy and take vitamins

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I don't think it will have very much impact

---

#191

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, March 09, 2020 12:42:58 PM  
**Last Modified:** Monday, March 09, 2020 12:46:00 PM  
**Time Spent:** 00:03:01  
**IP Address:** 73.19.19.93

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Walking

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Testosterone

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Mental attitude

Getting enough exercise Watching immune system

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Nothing seems to help Again, nothing out there Losing mental ability to cope

---

#192

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, March 09, 2020 1:57:20 PM  
**Last Modified:** Monday, March 09, 2020 2:00:34 PM  
**Time Spent:** 00:03:14  
**IP Address:** 204.136.116.12

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Overall body strength. I'm trying to keep the muscles I DO have strong and loose. Especially my shoulders, which are predominantly affected, I'm trying to maintain the muscle I do have by using it.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Weight lifting, running, walking.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I can only build muscle as much as my body will let me. If the muscle is dead, then there's nothing I can do to bring it back. I'm limited in what I can do since my first priority is keeping safe. And the last downside is that there isn't anything I feel I can do to stop the progression of FSHD. So kind of like a hopeless feeling that no matter what I do, the disease will win.

---

#193

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, March 09, 2020 5:49:53 PM  
**Last Modified:** Monday, March 09, 2020 5:51:03 PM  
**Time Spent:** 00:01:09  
**IP Address:** 68.2.94.243

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise Vitamin Creatine

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

They don't work that much

---

#194

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, March 09, 2020 5:59:30 PM  
**Last Modified:** Monday, March 09, 2020 6:01:51 PM  
**Time Spent:** 00:02:20  
**IP Address:** 71.226.123.67

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Inability to take a deep breath- cough assist machine Abdominal weakness- binder

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Rest NSAID

BiPap

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

NSAID don't always work

---

#195

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, March 09, 2020 7:51:10 PM  
**Last Modified:** Monday, March 09, 2020 7:55:59 PM  
**Time Spent:** 00:04:49  
**IP Address:** 74.122.53.161

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Shoulder weakness, facial weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

-Supplements from a Naturopath including creatine  
-physiotherapist  
-occupational therapist

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

-Not sure if it is helping or not  
-cost  
-time to go to all appointments

---

#196

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, March 09, 2020 8:01:24 PM  
**Last Modified:** Monday, March 09, 2020 8:11:21 PM  
**Time Spent:** 00:09:57  
**IP Address:** 104.33.225.104

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Fatigue: albuterol PO 4mg BID, cpap, exercise but it's difficult

Pain: motrin, tylenol, skelaxin, take prn 2-3 times a day. Have tried physical therapy, massage, accupuncture and chiropractor.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Motin, tylenol, skelaxin, albuterol, occasionally norco but md does not like to prescribe it

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Keep moving

Take the motin, tylenol, skelaxin and albuterol Cpap

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Keep moving- do to much end up loosing a day to recover

The medications, especially motrin and tylenol everyday, i am killing my kidneys and liver and some days there is no relief from the pain

Cpap dragging it when traveling, not wearing, getting upper respiratory infection if I didn't clean it throughly

---



#197

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, March 09, 2020 9:43:55 PM  
**Last Modified:** Monday, March 09, 2020 9:45:36 PM  
**Time Spent:** 00:01:41  
**IP Address:** 73.60.179.170

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain in legs

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No unless you count medical marijuana

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

- 1) exercise
- 2) over the counter pain meds
- 3) stretching and massage

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Sometimes I get sore and it makes the pain worse

---

#198

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Monday, March 09, 2020 10:54:09 PM  
**Last Modified:** Monday, March 09, 2020 11:05:08 PM  
**Time Spent:** 00:10:59  
**IP Address:** 99.129.137.214

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Tendinitis, muscle spasms, weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Celebrex and muscle relaxants

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Ice packs, heat, and exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Balancing the right amount of exercise, Pain,  
Temporary results

---

#199

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 4:02:30 AM  
**Last Modified:** Tuesday, March 10, 2020 4:06:50 AM  
**Time Spent:** 00:04:19  
**IP Address:** 92.167.147.97

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain in shoulders, weakness in legs

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no medication

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

physical therapy (kinesitherapy in french), hot showers, hot cushion

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

not 100 % effective, need to visit a therapist (time)

---

#200

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 4:00:29 AM  
**Last Modified:** Tuesday, March 10, 2020 5:50:12 AM  
**Time Spent:** 01:49:43  
**IP Address:** 138.130.82.196

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Hip pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Naproxen

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Reformer Pilates stretches and walking

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Pain time and fatigue

---

#201

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:04:23 AM  
**Last Modified:** Tuesday, March 10, 2020 10:05:27 AM  
**Time Spent:** 00:01:04  
**IP Address:** 172.58.62.144

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Fatigue and muscle pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Accupuncture, laser therapy, infrared sauna

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not a complete solution

---

#202

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:08:04 AM  
**Last Modified:** Tuesday, March 10, 2020 10:11:05 AM  
**Time Spent:** 00:03:00  
**IP Address:** 109.252.182.21

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Weakness, pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Swimming, HIT on bicycle

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I think it doesn't help

---

#203

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:16:47 AM  
**Last Modified:** Tuesday, March 10, 2020 10:19:54 AM  
**Time Spent:** 00:03:07  
**IP Address:** 73.198.245.221

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

loss of strength in my legs; difficulty walking; pain and numbness running down my arms, caused indirectly by the MD

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

exercise: biking machines, yoga, stretching, strengthening exercises

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

very time consuming; some machines (bike, legs), I only have access to through Physical therapy appts. and insurance limits the number of visit; some exercises are very difficult to do;

---

#204

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:18:27 AM  
**Last Modified:** Tuesday, March 10, 2020 10:20:04 AM  
**Time Spent:** 00:01:36  
**IP Address:** 174.192.207.110

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Soreness, muscle fatigue

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Steroids, naproxen

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise, diet, supplements

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Time, cost, not completely effective

---



#205

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:06:20 AM  
**Last Modified:** Tuesday, March 10, 2020 10:20:54 AM  
**Time Spent:** 00:14:33  
**IP Address:** 173.184.97.79

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

My disease has taken away most of my muscles. Cannot move my legs. Can still use arms in an awkward fashion.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Take heart medicine for irregular heartbeat. Metamucil for bowels.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing. What can I do??

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I have pain in my hip when in my wheelchair so seldom use it. Spend my time in bed or a recliner. I have a sporadic case of fsh. Am

47. Diagnosed at 15. In a study at Rochester with Dr Tawil for many years along with my parents.

---

#206

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:19:53 AM  
**Last Modified:** Tuesday, March 10, 2020 10:25:21 AM  
**Time Spent:** 00:05:27  
**IP Address:** 96.81.231.137

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Neck pain, shoulder pain, and shoulder instability

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Antioxidants, because there has been one study for FSHD suggesting disease-modifying effect

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. I am 10 months post-op from a scapula-to-scapula scapulopexy that I had done at Mayo Clinic. Essentially, my scapulas were tied together into a retracted position with an achilles tendon, a more conservative intervention than scapulothoracic fusion. This intervention I got is unpublished and unproven, although it has turned my life around, allowing me to return to medical school.
2. Trying to rehab my shoulders with swimming and pushups

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. The scapulopexy feels unnatural and I still have some pain, although now I am functional.
  2. If I do even 30 wall pushups, my upper body feels bad for a few days. This might improve as I get further out from the scapulopexy I got 10 months ago.
-

#207

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:23:55 AM  
**Last Modified:** Tuesday, March 10, 2020 10:27:37 AM  
**Time Spent:** 00:03:42  
**IP Address:** 67.191.112.52

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain in lower legs and shoulders going for physical therapy helps a little.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

none available

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

#207

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:23:55 AM  
**Last Modified:** Tuesday, March 10, 2020 10:27:37 AM  
**Time Spent:** 00:03:42  
**IP Address:** 67.191.112.52

---

Respondent skipped this question

---

#208

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:25:18 AM  
**Last Modified:** Tuesday, March 10, 2020 10:28:31 AM  
**Time Spent:** 00:03:13  
**IP Address:** 82.30.53.222

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Don't know

---

#209

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:25:23 AM  
**Last Modified:** Tuesday, March 10, 2020 10:28:38 AM  
**Time Spent:** 00:03:14  
**IP Address:** 206.80.128.10

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am currently seeking the help of a chiropractor because of my lack of movement and do massage therapy to help ease the muscle pain.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Have used muscle relaxers but nothing seems to work. Currently using medical marijuana seems to be the only thing that eases the pain.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing, currently my doctor can not find anything more that will help me with muscle loss.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It doesn't help with muscle loss or the ability to gain it back, just eases the pain which isn't very helpful.

---

#210

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:23:07 AM  
**Last Modified:** Tuesday, March 10, 2020 10:29:41 AM  
**Time Spent:** 00:06:34  
**IP Address:** 207.29.45.2

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am trying to keep up with cardio workouts to keep my leg muscles active. I do have a back brace for my shoulderblades, they do cause a lot of pain especially when sitting for long periods, which I have to do at work.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No, only over the counter pain medication

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

cardio exercise, back brace

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Everything is a temporary fix, the pain still exists.

---

#211

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:29:03 AM  
**Last Modified:** Tuesday, March 10, 2020 10:30:43 AM  
**Time Spent:** 00:01:40  
**IP Address:** 178.148.56.192

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Not much can be done

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It's a progressive illness I am told, so no known cure

---



#212

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:31:36 AM  
**Last Modified:** Tuesday, March 10, 2020 10:35:29 AM  
**Time Spent:** 00:03:53  
**IP Address:** 75.64.190.239

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Self-massage of arms with focus on elbows and wrists. Cannabis.

Coffee and cigarettes to deal with pain and fatigue.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

My body keeps going downhill, regardless.

---

#213

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:23:01 AM  
**Last Modified:** Tuesday, March 10, 2020 10:35:50 AM  
**Time Spent:** 00:12:48  
**IP Address:** 69.139.32.214

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Loss of use of legs  
Total body weakness and pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Done with taking meds. Nothing works.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

- 1- Getting adaptive equipment.
- 2- Medical marijuana.
- 3-?

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

- 1- Would like - be able - to do more
  - 2- miss being able to help others
  - 3-No support system
-

#214

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:26:27 AM  
**Last Modified:** Tuesday, March 10, 2020 10:36:00 AM  
**Time Spent:** 00:09:33  
**IP Address:** 129.100.255.34

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am not doing anything to try to improve my condition other than regular exercise.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I'm not really doing anything other than exercising. Other than that, I'm just hoping for treatments or a cure to be made available at some point.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I'm not really being pro-active, which is a bit of a downside of my strategy. At the same time, my symptoms aren't very severe and don't require a lot of intervention.

---

#215

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:35:20 AM  
**Last Modified:** Tuesday, March 10, 2020 10:36:54 AM  
**Time Spent:** 00:01:34  
**IP Address:** 37.142.104.60

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

no

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

just live my disabled life ;)

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

#215

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:35:20 AM  
**Last Modified:** Tuesday, March 10, 2020 10:36:54 AM  
**Time Spent:** 00:01:34  
**IP Address:** 37.142.104.60

---

Respondent skipped this question

---

#216

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:35:30 AM  
**Last Modified:** Tuesday, March 10, 2020 10:37:30 AM  
**Time Spent:** 00:01:59  
**IP Address:** 96.233.73.67

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

no

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

crutches, braces, wheelchairs

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

increased weakness

no solutions to improve weakness

---

#217

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:35:18 AM  
**Last Modified:** Tuesday, March 10, 2020 10:37:31 AM  
**Time Spent:** 00:02:13  
**IP Address:** 162.234.170.97

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Widespread pain that feels like I'm on fire

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Amitriptline

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Rest. Water. Meditation

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Never have energy. Afraid to leave the house because it's hard to walk. Getting up from chairs is impossible

---

#218

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:27:54 AM  
**Last Modified:** Tuesday, March 10, 2020 10:38:58 AM  
**Time Spent:** 00:11:03  
**IP Address:** 144.160.131.231

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

leg weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

yes, Norco

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise, Diet, Rest

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Exercise, its easy to over do it.

Diet, often doesnt help with pain

Rest, rest does not strengthen muscles

---



#219

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:26:40 AM  
**Last Modified:** Tuesday, March 10, 2020 10:42:10 AM  
**Time Spent:** 00:15:29  
**IP Address:** 24.118.84.44

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain  
Sleeplessness from pain Fatigue and tiredness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Medical marijuana Advil

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physical therapy to manage strength and hopefully decrease pain

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Muscle pain and fatigue after therapy for about 1 or 2 days

---

#220

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:39:06 AM  
**Last Modified:** Tuesday, March 10, 2020 10:43:06 AM  
**Time Spent:** 00:03:59  
**IP Address:** 65.175.195.34

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

muscle spasms, pain, soreness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no, just medical marijuana and cbd

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

occasional tylenol

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

expense of medical marijuana

---

#221

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:39:24 AM  
**Last Modified:** Tuesday, March 10, 2020 10:43:29 AM  
**Time Spent:** 00:04:04  
**IP Address:** 65.144.7.114

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I have weakness in my upper body (arms and shoulders) and my right leg. Currently, because there are no approved treatments, I simply do my best to workout and stay active to try to impede the progression of weakness.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Workout, eat healthy, try to keep my mind mentally strong by getting in nature and reducing stress

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Knowing that whatever I do currently has very little impact , knowing that trying certain things may actually have a negative impact given the lack of information out there.

---

#222

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:36:11 AM  
**Last Modified:** Tuesday, March 10, 2020 10:45:55 AM  
**Time Spent:** 00:09:43  
**IP Address:** 67.6.69.78

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Trying to improve physical strength and endurance. Trying to maintain health and function of ankles and feet.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Fulcrum drug trial participant -- Losmapimod or placebo.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physical therapy and recumbent bike exercise; orthotic and brace; OTC supplement and healthy diet

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Poor efficacy

---

#223

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:43:17 AM  
**Last Modified:** Tuesday, March 10, 2020 10:45:56 AM  
**Time Spent:** 00:02:38  
**IP Address:** 73.215.140.118

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Excercise

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Prednisone

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I am confined to a walker I fall a lot  
Must depend on someone to go out.

---

#224

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:41:24 AM  
**Last Modified:** Tuesday, March 10, 2020 10:46:19 AM  
**Time Spent:** 00:04:55  
**IP Address:** 24.27.9.165

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I use a vibration platform and an infrared sauna for muscles, bones, circulation and inflammation. I also take supplements like COQ10, zinc, selenium, vitamin C

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I tried vyvanse for energy in the past as well as Lexapro for depression.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Meditation, vibration and sauna

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

No downsides but nothing directly helps the symptoms. It's obviously expensive to buy an infrared sauna and vibration platform

---

#225

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:44:56 AM  
**Last Modified:** Tuesday, March 10, 2020 10:48:14 AM  
**Time Spent:** 00:03:17  
**IP Address:** 47.37.225.213

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

staying active in community to avoid isolation and depression.

Trying to adjust as muscle loss progresses by making changes in the way I do things to remain as independent as possible.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Muscle loss if progressing faster than I can plan.

---

#226

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:43:09 AM  
**Last Modified:** Tuesday, March 10, 2020 10:48:32 AM  
**Time Spent:** 00:05:22  
**IP Address:** 47.213.225.109

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Yes, muscle soreness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Just Ibuprofen

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Walking Aids, Scooter, Staying Active

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Getting tired, and being sore

---



#227

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:46:21 AM  
**Last Modified:** Tuesday, March 10, 2020 10:49:22 AM  
**Time Spent:** 00:03:01  
**IP Address:** 102.65.67.248

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Weakness - gentle strengthening and walking

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Only antiinflammatories when muscle spasms kick in

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Only strength and moderate activity

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not having enough power to train in the gym / participate in exercise classes in the same way as the norm

---

#228

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:50:07 AM  
**Last Modified:** Tuesday, March 10, 2020 10:51:32 AM  
**Time Spent:** 00:01:24  
**IP Address:** 76.110.198.196

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle loss

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Doesn't always help

---

#229

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:49:14 AM  
**Last Modified:** Tuesday, March 10, 2020 10:52:26 AM  
**Time Spent:** 00:03:12  
**IP Address:** 71.208.87.245

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I AM DOING PHYSICAL THERAPY FOR MY SORE BACK AND LEGS.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

NO

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I DO NOT DO MUCH BECAUSE THERE IS VERY LITTLE THAT CAN BE DONE

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

ANYTHING I HAVE TRIED OR AM TRYING REALLY DOES NOT SEEM TO HELP

---

#230

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:43:22 AM  
**Last Modified:** Tuesday, March 10, 2020 10:53:38 AM  
**Time Spent:** 00:10:15  
**IP Address:** 173.8.1.217

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I've found stretching helps with cramping and muscle pain and stiffness and just an overall feeling of well-being. Moderate exercise and walking help as well. CBD also helps with muscle pain.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I use a testosterone gel prescription for a urological problem. It would not be approved solely for a neuromuscular problem, but I do believe the testosterone therapy does provide benefits to still healthy muscles in terms of strength and endurance.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Sufficient sleep.
2. Healthy diet with adequate protein.
3. Stay busy... dwelling on problems you can't control is not healthy.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None of them address that my body is still producing DUX4 which is strongly believed to be the root cause of FSHD.

---

#231

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:51:27 AM  
**Last Modified:** Tuesday, March 10, 2020 10:53:57 AM  
**Time Spent:** 00:02:30  
**IP Address:** 68.62.255.72

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Ability to stand for long lengths of time

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Oxycodone Gabapentin Medical Marijuana

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Water therapy
2. Massage therapy
3. Use of cane

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. Intense tiredness/exhaustion after exertion
-

#232

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:44:26 AM  
**Last Modified:** Tuesday, March 10, 2020 10:54:16 AM  
**Time Spent:** 00:09:50  
**IP Address:** 68.75.2.161

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

When my foot drop worsens, I do a lot of stretching and that helps some.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

In the past I used a muscle relaxer for pain but now I try to manage with ibuprofen.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

My worst symptom right now is anxiety and depression. I am taking prozac and wellbutrin to help.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. I'm not really doing anything
2. I'm not really doing anything
3. I'm not really doing anything

It's difficult to know what to do so I end up doing nothing.

---

#233

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:52:32 AM  
**Last Modified:** Tuesday, March 10, 2020 10:54:42 AM  
**Time Spent:** 00:02:09  
**IP Address:** 47.210.82.55

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

no

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

we have none

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

not knowing what is available

---

#234

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:53:44 AM  
**Last Modified:** Tuesday, March 10, 2020 10:54:55 AM  
**Time Spent:** 00:01:11  
**IP Address:** 73.89.111.118

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Flexibility and strength

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Swim Gym

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Slow progress

---



#235

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:43:52 AM  
**Last Modified:** Tuesday, March 10, 2020 10:57:19 AM  
**Time Spent:** 00:13:27  
**IP Address:** 73.70.92.156

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

My legs and feet are swollen from lack of movement since I use a wheelchair so I wear compression stockings and I'm getting a special machine that helps push fluid back up

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I don't know of any medication that can help me

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I wear a custom back brace every day to help hold me more erect for extreme back pain. I wear booties to keep my feet flexed to prevent pain on top of feet from stretching too far from foot drop.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Compression stockings are difficult to put on. My aid helps me but time consuming. Back brace falls apart often and requires constant sewing for repairs and proper fit. Booties are hard to get on from swollen feet and often hurt.

---

#236

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:54:10 AM  
**Last Modified:** Tuesday, March 10, 2020 10:57:51 AM  
**Time Spent:** 00:03:41  
**IP Address:** 179.242.27.120

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Weakness, fatigue, unbalance

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physiotherapy, gym, massage

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Time, weakness, price

---

#237

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:41:10 AM  
**Last Modified:** Tuesday, March 10, 2020 11:00:56 AM  
**Time Spent:** 00:19:46  
**IP Address:** 23.119.33.33

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle and joint Pain. Muscle tightening & contracture, Spine pain and curvature. Frequent occipital & tension migraine from weakened head & neck muscles overworked. Eye dryness, sleep.

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Pain medication occasional muscle relaxer and anti inflammatory medications for spasms.

None really combat the issue

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Heat

Massage ( I cannot afford and Medicare does not cover but they absolutely helped when I had a friend who could rub our tight muscles for free)

Without these over past 10 years I've gotten more contractures and angry muscles that just will not release.

Stretching as much as possible

OTC Advil, CBD oil & melatonin for sleep, natural tears for my eyes and intermittent rest as needed.

It's very frustrating massage is not a luxury as considered by medical coverage. It should be mandatory prescription for Fshd just as Ongoing physical therapy

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Results of heat are short lived Side effects of medications

Unaffordable or not covered by insurance

Adds to frustration of daily life in pain and weakness.

No 'treatment' is anything but short temporary relief. Nothing mitigates the ongoing atrophy which is ultimately root cause. Lack of support from medical community unfamiliar with Fshd also adds to emotional impact of living with such a rare disease

#238

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:01:42 AM  
**Last Modified:** Tuesday, March 10, 2020 11:05:23 AM  
**Time Spent:** 00:03:40  
**IP Address:** 166.181.80.14

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

NA, I take no medication for treatments

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise Eat healthy

Plenty of rest

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

My muscles do not regenerate. Once the muscle mass is lost, it continues to affect my everyday life.

---

#239

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:54:31 AM  
**Last Modified:** Tuesday, March 10, 2020 11:09:59 AM  
**Time Spent:** 00:15:27  
**IP Address:** 71.87.241.86

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am actually trying to maintain my current level of muscle strength by regular exercise at my local YMCA.  
Recumbent bike and REX cycles.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Grab bars, Electric wheel chair (extended outing), leg braces, ramps, raised seating, illuminated shoes,  
buttonless shirts, elastic waisted pants, power lift chair, and the support of loving friends & family.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Imposition on my wife Loss of opportunities Fear of the future

---

#240

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:08:28 AM  
**Last Modified:** Tuesday, March 10, 2020 11:10:54 AM  
**Time Spent:** 00:02:25  
**IP Address:** 99.203.121.132

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness and fatigue

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise... walking

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I get tired quickly so I'm not confident the little I am doing is actually helping

---

#241

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:08:45 AM  
**Last Modified:** Tuesday, March 10, 2020 11:13:32 AM  
**Time Spent:** 00:04:46  
**IP Address:** 73.125.128.74

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle pain and overtired muscles

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physical therapy and over the counter Advil for when I have sore muscles.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Won't really help much with the root cause of muscles aching. Simple, everyday tasks are harder for me and sometimes my body gets overworked and tired easily.

---

#242

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:02:02 AM  
**Last Modified:** Tuesday, March 10, 2020 11:13:39 AM  
**Time Spent:** 00:11:37  
**IP Address:** 94.25.173.102

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I try to improve the dystrophy of the calf muscles with gymnastic exercises

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes

- L carnitine
  - coenzyme Q10
  - idebenon
- 

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

- massage
- 

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

-

---



#243

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:11:38 AM  
**Last Modified:** Tuesday, March 10, 2020 11:14:31 AM  
**Time Spent:** 00:02:53  
**IP Address:** 107.77.212.116

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Getting up from sitting. Lifting my hands to my mouth and head. Walking safely

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Weight lifting, treadmill

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Motivation when progress is slow or not at all. Scary to know what to do. Not consistent

---

#244

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:09:59 AM  
**Last Modified:** Tuesday, March 10, 2020 11:19:53 AM  
**Time Spent:** 00:09:53  
**IP Address:** 173.164.10.141

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

My symptom of upper back pain and weakness is always a work in process. My symptom of abdominal weakness. My symptom of foot drop. My symptom of depression/anxiety.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

The only prescription medication I use is Zoloft to help with depression/anxiety. I have not found any prescription medications to help with the muscle weakness and pain.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. I finally found a great mattress to help with my upper back pain. It is a Purple mattress. It allows my upper back muscles to fully relax at night, which gives them a better chance at recovering from the day.
2. I use ice packs on my upper back to reduce swelling which helps reduce pain.
3. I use ibuprofen as needed to help with pain.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

The biggest downsides of my approach is they are all just about managing pain. None of my approaches will actually improve my condition. They just make it tolerable.

---

#245

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 10:51:40 AM  
**Last Modified:** Tuesday, March 10, 2020 11:21:40 AM  
**Time Spent:** 00:29:59  
**IP Address:** 24.168.78.21

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain, inflammation, stiffness & loss of range of motion

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I was prescribed Naproxin, Ultram and Vioxx. Naproxin worked the best of all 3 but caused digestive issues. Vioxx was taken off the market but it didn't work as well as the Naproxin. Ultram didn't work but I didn't take it long enough to notice any side effects.

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

- 1) Daily stretching: range of motion & realignment stretching - similar to some pilates exercises
- 2) Diet: avoiding processed & inflammatory foods, and increasing medicinal foods & teas (blueberries, turmeric, dandelion/camomile/mint teas, garlic, pineapple, etc)
- 3) Medicinal Marijuana - made into butter

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

- 1) Marijuana is illegal where we live yet it works best.
- 2) I'm not able to control exactly what I'm getting like I would at a store/dispensary. Good quality Indica, which has been rated for pain relief, is not always available and I must take what I can find, hoping it is organic. I am unable to separate the anti-inflammatory/pain relief phytochemicals from the psychoactive ones in the plant and the FDA prohibiting true research on the subject, means that I may be clouding my mind more than necessary in a bid to avoid the pain without stomach ulcers from Aleve or addiction from opioids.
- 3) It's all palliative care. FSHD is progressive and the best I can hope for is slowing the disease, managing my pain and discomfort. Exercising too much in a bid to stay strong has sped up my atrophy on numerous occasions.

#246

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:16:39 AM  
**Last Modified:** Tuesday, March 10, 2020 11:26:36 AM  
**Time Spent:** 00:09:56  
**IP Address:** 96.8.168.191

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Doing deep-water aerobics 3x/week for generalized strength and flexibility.

Wish I had direction from specialized physical therapist, too.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Nothing with regularity.

I take one Tramadol as needed when I have multi-hour outing (or using my rollator for several hours),

Supplements: trying NAD per article in FSHD Society bulletin.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Water aerobics

Prayer and reading research Bi-pap at night

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

No help from insurance

Distance and cost to indoor pool in colder weather Little communication with specialist doctors

---

#247

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:26:09 AM  
**Last Modified:** Tuesday, March 10, 2020 11:30:12 AM  
**Time Spent:** 00:04:02  
**IP Address:** 99.76.33.55

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Yes. Bi lateral foot drop (wear AFO's daily). Upper body symptoms I just deal with

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

In the past, gabapentin (not effective). I currently use Advil, which I found to be more effective than Meloxicam which I've used in the past

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Watching my weight and overall health

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

AFOs are cumbersome and uncomfortable Pain and discomfort is a constant Decreased mobility

---

#248

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:26:15 AM  
**Last Modified:** Tuesday, March 10, 2020 11:31:59 AM  
**Time Spent:** 00:05:44  
**IP Address:** 75.85.206.168

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

my most difficult symptom is loss of strength in my lower legs. PT focused on balance and AFO for foot drop help me manage but so far nothing that helps improve.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Non prescribed.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

PT AFO  
Positive attitude

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It never gets better, I only slow the progression.

---

#249

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:28:14 AM  
**Last Modified:** Tuesday, March 10, 2020 11:32:53 AM  
**Time Spent:** 00:04:39  
**IP Address:** 75.69.180.168

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Walking. I use walking sticks.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I take ibuprofen occasionally, mainly for elbow pain.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

The biggest downside is that there is no treatment or cure.

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#250

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:27:21 AM  
**Last Modified:** Tuesday, March 10, 2020 11:33:47 AM  
**Time Spent:** 00:06:25  
**IP Address:** 63.157.193.130

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I just try to move when I can so I am still using the muscles I have left,

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No. However, I am a part of the clinical trial with losmapimod, but I don't know if I am taking the placebo or drug.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Get enough sleep.
2. Stop when my body says I have done enough,
3. Keep moving.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I don't know that I have three disadvantages I could name just because I am not doing much to help the symptoms. I'd like to do yoga but I don't feel I am strong enough to. I'd also like to do physical therapy, meditation, swimming, etc. My biggest disadvantage of what I'm doing now is just not doing enough.

---



#251

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:38:53 AM  
**Last Modified:** Tuesday, March 10, 2020 11:39:56 AM  
**Time Spent:** 00:01:02  
**IP Address:** 130.250.255.226

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

muscle weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

aerobic exercise lift weights stretch

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

over use some pain

---

#252

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:39:11 AM  
**Last Modified:** Tuesday, March 10, 2020 11:41:27 AM  
**Time Spent:** 00:02:16  
**IP Address:** 199.181.136.170

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Weakness. Just cycling and using resistance bands to keep strong as possible and flexible.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Stretching, resistance bands, cycling

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Can't work out very hard, probably not slowing things down much, fatigue

---

#253

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:38:20 AM  
**Last Modified:** Tuesday, March 10, 2020 11:42:33 AM  
**Time Spent:** 00:04:13  
**IP Address:** 96.2.146.11

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Neck pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Aleve, pool therapy, heat

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Only works sometimes

---

#254

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:45:09 AM  
**Last Modified:** Tuesday, March 10, 2020 11:46:07 AM  
**Time Spent:** 00:00:58  
**IP Address:** 165.225.50.92

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

pain, fatigue

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Massage
2. Exercise
3. Supplements

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. Time away from family
  2. Cost
  3. lack of confidence on benefit vs risk
-

#255

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:41:08 AM  
**Last Modified:** Tuesday, March 10, 2020 11:46:19 AM  
**Time Spent:** 00:05:11  
**IP Address:** 24.59.58.39

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Neck weakness, shoulder and knee pain, incontinence

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Oxycontin, myrbettiq, tolterodine tartare er

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physical therapy, injections for pain relief

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Too many meds. PT only works for a while.

---

#256

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 11:47:15 AM  
**Last Modified:** Tuesday, March 10, 2020 11:53:07 AM  
**Time Spent:** 00:05:51  
**IP Address:** 157.48.88.100

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Driving tractor  
To vibrate total body

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No  
Not even single medicine

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Not using any equipment to overcome fshd

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Shoulder Hip, thigh

---

#257

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 12:04:26 PM  
**Last Modified:** Tuesday, March 10, 2020 12:06:37 PM  
**Time Spent:** 00:02:10  
**IP Address:** 213.205.198.47

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Hydrotherapy, heat pads, massage

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Hydrotherapy- cost, availability, travel time

---

#258

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 12:04:53 PM  
**Last Modified:** Tuesday, March 10, 2020 12:09:28 PM  
**Time Spent:** 00:04:35  
**IP Address:** 174.255.76.140

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Fatigue, weakness, pain.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Ibuprofen. Medical Marijuana. Stretching. Have Hydrocodone but haven't taken it.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

PT, stretching.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Have Major Depression and have a hard time motivating. Nothing really works.

---



#259

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 12:12:46 PM  
**Last Modified:** Tuesday, March 10, 2020 12:14:43 PM  
**Time Spent:** 00:01:57  
**IP Address:** 174.229.1.131

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain and tendon and ligament weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

PRP

Massage Chiropractic

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Cost !

---

#260

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 12:13:56 PM  
**Last Modified:** Tuesday, March 10, 2020 12:20:43 PM  
**Time Spent:** 00:06:47  
**IP Address:** 174.20.188.111

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Standing strength, strength in muscles used to stand up

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Occasionally I use Aleve or narco for pain

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Rest,

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I don't see progress

---

#261

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 12:18:42 PM  
**Last Modified:** Tuesday, March 10, 2020 12:21:54 PM  
**Time Spent:** 00:03:12  
**IP Address:** 76.126.192.230

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

eye dryness pain tendonitis

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

eye drops pain reliever  
topical antiinflammatory cream

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

CBD cream sleep  
drink water, hydration helps

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

nothing really works. all are temporary fixes. the pain subsides for a short while, and then returns...

---

#262

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 12:22:58 PM  
**Last Modified:** Tuesday, March 10, 2020 12:27:57 PM  
**Time Spent:** 00:04:59  
**IP Address:** 67.44.240.65

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Dropped head, overall pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Lyrica, Aleve

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Stretches, resistance exercises, water exercises

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Minimal pain reduction, minimal strength improvement

---

#263

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 12:13:21 PM  
**Last Modified:** Tuesday, March 10, 2020 12:28:39 PM  
**Time Spent:** 00:15:17  
**IP Address:** 71.125.82.247

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No. I manage my symptoms, but I have no thoughts of improving or reversing my symptoms.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I use Mucinex and Sudafed daily to help prevent and mobilize respiratory secretions. I use Senna and a stool softener daily to prevent constipation. I take a daily diurectic to prevent water retention and edema.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I tape my shoulders to reduce subluxation pain. I sleep on a low-air-loss mattress to prevent skin breakdown.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I cannot think of anything.

---

#264

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 12:31:11 PM  
**Last Modified:** Tuesday, March 10, 2020 12:33:35 PM  
**Time Spent:** 00:02:24  
**IP Address:** 75.115.57.191

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Make sure to rest, not push myself too much, use a wheelchair when necessary

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Its all maintenance. Im not doing anything to improve my situation

---

#265

COMPLETE

**Collector:** Web Link 1 (Web Link)  
**Started:** Tuesday, March 10, 2020 12:39:53 PM  
**Last Modified:** Tuesday, March 10, 2020 12:42:14 PM  
**Time Spent:** 00:02:20  
**IP Address:** 73.108.62.71

---

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

weakness in raising arms drop foot

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

only over the counter

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Homeopathy exercise massages

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

can't exercise as much as I could last year

---

## Survey 4 | Current treatments

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain!

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Tramadol HCL, 50 mg as needed Hydrocodone-Acetamin 5-325 mg

Hydrocodone-Acetamin 7.5-325 mg

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Heating pad

250mg CBD Muscle & Joint Heat Relief Roll On with Capsicum Prayer

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Nothing works

I still live in excruciating pain I get depressed

---



#267

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

COMPLETE

I am working to improve muscle health and function in neck, deltoid, and, hips and calves. These have been atrophied, that is reduced in size and strength.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Eleven years ago, I was told that an antibiotic I was taking for autoimmune disease would also improve my FSHD by the Rheumatology Dept. head at a university medical center( he was not the prescribing doctor, but a second opinion). I asked why and he said they were seeing those improvements in another patient with my FSHD and my autoimmune disease. Within two weeks of initiating the antibiotic, muscles that had not responded to physical therapy began functioning, and 60 days later I did a five-mile uphill hike with my family.

Subsequently, while still on the antibiotic (doxycycline) I needed to take acyclovir for cold sores, and I noticed improvement with muscle health and function. Over the last ten years, whenever I have taken the two medications at the same time, my muscle function improved for the duration of the overlapping use.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

The impetus for my diagnosis with FSHD was taking myself to a highly recommended Physical Therapy office, Folsom Physical Therapy (certified time teach Jan Eventh's Physical Therapy in US). On my first appointment they gave me a Philadelphia collar, and asked me to see a neurologist, who done months later received the results of my DNA test. I had appointments every two weeks, but FPT invites patients to work out as often as they wish, and I decided I didn't want to 'leave anything on the table' so I went in five days a week. In less than a year I was part of a workout class that scaled my participation to my abilities, nevertheless, I kept up with the class in 75% of the actives, and also my own activities. I continue to workout and progress at FPT.

A year and a half ago, I began going to Acupuncture once a week. The progress has been gradual, but in the last month I have regained strength and used of my neck muscles. I have observed that on days when physical therapy and acupuncture are both done, I observe substantial improvement I my muscle function that I sustain.

My regimen was interrupted in the last year due to divorce and moving, and I felt that I had lost quite a bit of what I had accomplished, however; in the last three months, I have improved substantially. In the areas of muscle mass and strength I have regained neck muscle mass, strength and function, and the same in calf muscles, hips, upper arms, and back muscles.

As to diet, I was raised in my mother's Mediterranean tradition, and I eat mainly unprocessed foods, animal protein at all meals (salmon, bison, chicken, eggs) and lots of greens, fruit, nuts and fewer grains and dairy, but still consume those. I take calcium, magnesium citrate, D-3, B12, and Omega 3.

I am part of the Resolve Study at the University of Utah Medical Center, and will be returning June 3 for my final testing. I did well last year, but I am hoping to best my prior measures in June.

Yes, I have always been competitive with myself.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I can't think of any. FPT is a culture of encouragement and celebrating each other's improvement. They haven't given up on me, and when I say I think I can improve more they find ways for me to accomplish that. I feel fortunate to have the options and support I have. Vi wish my primary care doc was as supportive.

---

#268

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

no

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

staying active as possible, antidepressants, OTC pain medication

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

none

---

#269

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Lower back and leg nerve pain.  
arm extension, flexibility and mobility

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Gabapentin and tramadol - no longer taking ineffective Medical Marijuana - some benefit but did not like side effects amlodipine 10 MG some minor help

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Using laser light therapy Computer based spine alignment PT

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

A lot of time and effort minor improvement availability of process

---

#270

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Upper and lower extremity weakness. Muscle and joint aches.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

NSAIDs

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Staying active to my abilities.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It does not stop the disease.

It causes significant fatigue.

It causes significant muscle and joint aches.

---

#271

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain in lower & upper back, neck and hamstrings. Scratching and icing Lots of icing where ever I need it. And on a daily bases

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Tried opioids for the 1st year then stopped. When the pain hits II found that getting off me feet ad icing works the fasted

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I'm taking a 2 exercise classes at a local Jr college spherically for people with disabilities. One is stretching the other is an aqua /pool

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Even with my best effort over 3 years. It hasn't stop the inevitable decline in the over strength. But I at least feel in I'm trying something

---

#272

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Foot drop, muscle weakness in legs and arms (try to improve all of these with physical therapy)

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physical , massage

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not paid for by insurance for long periods of times (though would be needed constantly) or not paid for at all (massage), potentially only small impact

---

#273

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?  
back problems due to gait changes (which are due to FSHD)

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.  
(none)

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.  
--Using wrist braces to address tendinitis, caused by FSHD-caused arm/wrist weakness  
--Using a rollator, modified to allow upright walking

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.  
--rollator only allows for limited walking distance (I am currently considering powered chair/scooter for longer distance trips outdoors)

---



#274

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?  
mobility/leg strength, day tiredness/fatigue

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.  
Provigil for day tiredness

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.  
sleeping in night splints for my legs, resting when I can, massage

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.  
they don 't always help, they take time, and I can't do all of them independently

---

#275

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle Atrophy - No Treatment Known. Muscle Fatigue - Rest.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I am using Albuterol Sulfate - tablets. Seems to help with strength.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Use of cane when walking. Frequent rests while walking. use of mobility scooter. Justo leg braces to combat foot drop.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Loss of Independence. Loss of strength / abilities. Loss of being able to protect my family.

---

#276

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Maintaining the strength I have through exercise and diet

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Not now - in the past I've tried Oxandrolone, Albuterol (trial), and Creatine.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Swimming, diet, meditation

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

#276

COMPLETE

Respondent skipped this question

---

#277

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain in my shoulders, arms and hips. I do light physical therapy and take Tylenol.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Gabapentin

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Rest, put my feet up, positive attitude.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I don,t always have the energy to do my physical therapy exercises. Sometimes the pain is overwhelming.

---

#278

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

At this point it's all about exercising to try and maintain some strength to be able to walk

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Eating healthy and exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

#278

COMPLETE

Respondent skipped this question

---

#279

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I receive monthly massage therapy to help with tight muscles. I also do stretches regularly for lower back pain.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Anxiety medication to deal with the emotional toll

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Water/swimming therapy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Massage therapy is expensive and not covered by insurance. Access to a pool is also expensive and requires a membership to a health club facility.

---



#280

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

The only symptoms I am trying to improve are weakening of my legs.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercises in a therapy pool: walking, stretching, and resistance training.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Time consuming, getting into and out of pool, getting to the pool.

---

#281

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Generally I am doing moderate exercise several times a week to help with flexibility and hopefully improve strength.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

In 2006 my neurologist put me on Prednisone (weekends only). I took it regularly for a few years but got no benefit that I could tell. Thankfully no obvious side effects either.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I wear a knee brace to help with hyperextension, and ankle braces to help with overpronation. Nothing else.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

The braces are effective but clearly imperfect, and taking them on and off each day is a pain in the &\$%@.

---

#282

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Strength

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Deterioration

---

#283

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

MANY DETERIORATED NON-FUNCTIONAL MUSCLES. SERIOUS NECK PAIN---LIMITED HEAD MOVEMENT. CAN'T WALK OR STAND.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

YES BUT NONE CAN NOW HELP. BEST IS 1 1/2 HR. DAILY EXERCISE/PHYSICAL THERAPY 7 DAYS/WEEK. CBD CREAM ON THE NECK TO REDUCE PAIN.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

SEE ABOVE. ALSO MUST USE WHEELCHAIR AND SALLIFT TO TRANSFER. PLUS MANY HOME HANDICAP IMPROVEMENTS TO ENABLE STAYING AT HOME

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

JUST DELAYING DECLINE. NO CHANCE OF RECOVERING ANY MUSCLE FUNCTIONS AT THIS STAGE

---

#284

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Symptoms keep getting worse. Needed shoulder replacement, now I am diagnosed with arthritis in both shoulders.

Have lymphedema in left foot. Use bag pump and compression stockings. Do not think these are related to FSH, however not sure about that. Also diagnosed with Sjogrens syndrome. Having a difficult time .

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Prednisone,

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

At my stage, just trying to live with my pain.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

#284

COMPLETE

Respondent skipped this question

---

#285

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Core weakness, fatigue, joint muscle pains do weakness, clumsiness,

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise (aerobic, strength, stretching) Diet  
Supplements

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Fatigue during exercise  
Diet changes must be pretty strict Supplements can't be sure if their helping

---

## Survey 4 | Current treatments

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Achey hunched scapula area.

Achey lower back from weak abdominal area.

Hips that twist out causing pidgeon toed walk& "winging" walk. Damaged right scapula muscles causing right arm weakness. Headaches from muscles pulling on bottom back of skull.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Lyrica - too many side effects and just numbs pain, nothing for weakness. Muscle relaxers, helps when combined with stretching & heat.

Ibuprofen- helps with headaches.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Hot baths- soaking submerged for an hour. Massage - full body every other month.

Stretching.

Avoiding lifting heavy loads above the waist level.

Avoiding actions requiring rubbing, scraping or pushing with hands in front or above body. (Most household cleaning g tads) Practical walking with hips/buns squeezed together.

Swimming with light arm motion.

---



## Survey 4 | Current treatments

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

House does not get cleaned.

Swimming is not readily available.

Massage is expensive.

Nothing helps bladder control except relaxing muscles by laying down, to readjust pressure against inner organs.

---

#287

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Adapting daily life and finding ways to cope with physical limitations

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I have adapted to many limitations but these make me more dependent on my personal environment at the house. Could not handle public transportation or hotels.

---

#288

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Arm, leg and foot weakness. Daily moderate walking, yoga and biking

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Over the counter Aleve

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Unknown if exercise is effective. May be doing more harm. Slows degeneration of muscles but does not reverse the damage

---

#289

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

muscle weakness in left leg. Doing PT, massage, yoga, swimming to keep muscles strong

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Lots of stretching

Staying active with exercising Massage and PT

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Fatigue

Possible over stretching Cost

---

#290

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain, weakness, fatigue, muscle cramping

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Advance Biostructural Correction (ABC) chiropractic Muscle Activation Technique (MAT)

Combination supplements: vitamin c and E, Omega 3, CoQ10, turmeric

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. Does NOT treat the root cause of FSHD and symptoms
  2. Not medically-proven methods for FSHD
  3. Do not know if it is working
-

#291

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes, a variety. Some in the past some current. Ibuprofen  
Tylenol Percocet Lortab Fentanyl Cymbalta Robaxin

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Lying down Massage Hot tub

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Time (takes too much time) Money (too expensive to keep up) Not effective enough

---

#292

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I go to physical therapy. I try to strengthen the muscles in my arms, legs, core, back and neck for posture. I work on my balance and gait.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I have not used prescription drugs. I do use Aleve when necessary.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I get at least 8 hours of sleep a night. When fatigued I do not over do. I have totally limited my daily activities and can no longer work.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I feel depressed that I am not functioning as I did before. Some days it does not matter that I have slept well, or exercised. I do everything in slow motion and need assistance with all I do.

---

#293

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Walking on treadmill

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Hydrocodone 5 mg and muscle relaxers.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Stretching and very minimal weight lifting. Try to walk as much as I can

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I have very low energy. I stay extremely stiff most of the time . I have a lot of chronic pain.

---



#294

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Weakness and pain in legs

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Ibuprofen

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physical Therapy Targeted exercises Walking

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Insurance limits # of visits they will cover and won't cover things that do work — like massage/myofascia release therapy, pool therapy or gym memberships.

Can cause pain/intense fatigue if I don't go slow enough.

---

#295

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

back and neck muscle pain - PT twice a week with massage

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

none have helped

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. staying active
  2. swimming
  3. stretching
- 

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

N.a

---

#296

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness, pain and exhaustion are my main issues

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Paracetamol Diclofenic Pregablin Gabapentin

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physiotherapy

Staying as active as possible Massage

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None of them are really helping to any significant amount

---

#297

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Building leg / quad strength by weight lifting, treadmill, and exercise bike use 3X week at local gym. Also do weight lifting to strengthen my back, scapula.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes, but none have helped - primarily tramadol 50 mg and diclofenac 75 mg.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I mentioned going to the gym 3 X week, drinking lots of water, being extra aware of my walking, sitting, posture positions. I also wear a right leg AFO at times.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Need more relief, strength, sleep.

---

#298

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I get Bowen Therapy every 5 weeks which helps simulate the muscular.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Keep moving as much as possible Bowen treatment

Don't over work the weak area of the muscles

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not be able to afford more Bowen treatment

---

#299

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

PT weekly to keep stretching

Cough assist machine to excercise my lungs

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

PT

Swimming

Wearing my hearing aides to help get thru the day

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

#299

COMPLETE

Respondent skipped this question

---

#300

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Yes, trying to keep muscles from atrophying quicker by doing walking and exercises in a pool and riding a recumbent bike on alternate days. It does wonders physically and mentally!

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No. I feel blessed I do not have any pain with FSHD.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Standing (in a mobility scooter most of time), walking, core exercises.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I'm getting better at listening to my body - some days I don't do as much so I can preserve energy to make it through the day.

---



#301

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I work on balance at physical therapy doing stepping and balancing exercises. I also work on decreasing strength through PT exercises involving a band. I try to improve pain by doing stretches from my physical therapist and doing a stationary bike 3-4 times per week.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no. We have talked about pain medication but at this point I made a decision that I rather rest more and be in pain than take prescription pain medications.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

energy conservation by using an electric wheelchair to prevent pain and falls, weekly physical therapy to treat pain and work on strength where I can, lifestyle changes (I had to stop working and I closely manage my schedule to make sure I am not doing too much and factoring time for plenty of rest)

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1)None of these interventions improve my symptoms. All of my symptoms keep getting worse but these interventions help manage it by helping me 2) While energy conservation of using an electric wheelchair and lifestyle changes (i.e. stopping working and going on disability) have helped decrease falls and provided the needed time to manage fatigue, I wish I could have continued walking and working vs. having to drastically change my life to protect my health

---

#302

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

drop foot, wear a afo

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

PT OT

AFO/KAFO

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Always tired

---

#303

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

#303

COMPLETE

Respondent skipped this question

---

#304

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

It was my understanding that there is no treatment. I swim 3 times a week with the hope that it strengthens the muscles I have.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Once again I was not aware that there was anything I could do.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Have to travel 40 minutes to pool

---

#305

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Shoulder weakness (exercise )

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

There is none

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Therapy yoga and exercise at my possibility

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

There is no improvement

You never know your future muscle weakness Affects your face expression (you look sad)

---

#306

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

BREATHING ISSUES. LUNG CAPACITY

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

NO

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

PULMONARY REHAB PT

WEIGHT MANAGEMENT

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

LACK OF THERAPIST AGGRESSIVE APPROACH NEED TO GET TO GYM MORE OFTEN

NOT BUILDING STRENGTH FAST ENOUGH

---

#307

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Yes, muscle tightness, physical therapy and weights for strenght.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Np

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Diet and supplements. Protein drinks. Excercise, Sauna. General wellbeing.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Diet restrictions/ gluten free, having to take so many supplements.

---



#308

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I take over the counter Tylenol. My lower legs and hips pain me often.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Stretching exercises and Tylenol.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It's tough living with this dreadful disease.

---

#309

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Lack of muscle and strength in arms and back. I bought a brace that helped for a few months but my condition has progressed to a point that the brace no longer helps.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes, I am taking CBD oil orally to help with pain, I am also taking anti depression meds and a prescription anti inflammatory

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Just the meds that I listed in the previous answer. I am not aware if any other treatments that would help.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I have to pay for the meds so I need to continue to work to pay for my insurance. The brace no longer helps. Getting rest isn't helping at all.

---

#310

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Regain the muscles in my back

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I don't have any prescriptions I don't know of any

I was taking albuterol sulphate er tabs 8 mg three times a day by the company Milan in Pennsylvania but the quit making it and I keep calling them to get it started again but they keep putting the date off when it will be available. I can get 4 mg that I take 6 a day but they are not extended release and I find I'm not as strong as I was when I took the 8 mg extended release

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I do everything I can, clean, vacuum, wash clothes, rental property:clean kitchens, windows, bathrooms etc. I have a two story house that I maintain with bedrooms upstairs and laundry in the basement; I am very active but do get tired if I walk to much bent over, I do have a walker for long distances but I don't use it in the house, I lean on counters etc.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

See number 3

---

#311

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Core weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Swim

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Still declining

---

#312

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Cymbalta

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Resting, CBD oil, using a cane

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

They don't work well

---

#313

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Trying to control pain management through massage therapy and Physio routine each morning. I am unable to walk so have now purchased an electric wheelchair. Prior to that I used a scooter for Mobility before that AFOs [braces]. All of these expensive pieces of equipment help to keep me mobile, involved with my community and family which in turn is good "treatment" for the social isolation that occurs with any type of disability. My experience is that "mental/emotional health" aids in keeping the whole body healthy.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Only from time to time when I have broken multiple bones as a result of falls. At that time I was prescribed morphine until there was some healing. On occasion I use over-the-counter ibuprofen for daily pain control with massage therapy to supplement once a week. I have a constant level of "low-grade" pain that my body has adapted to.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

- 1) Massage therapy
  - 2) Physiotherapy routine each morning for 15 minutes that I do on my own in bed. The routine was established by a physiotherapist and is reassessed every six months or when there is a significant muscle loss requiring adjustments.
  - 3) I do a great deal of volunteer work and mentoring in the community which allows me to stay focussed on others rather than my own concerns. I have, with much effort, managed to keep many close friendships and this helps me to maintain emotional stability and strength.
- 

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Downsides of my current approach? I'm not sure I could list any. If I could think of some downsides I would probably spend time figuring out how to turn them into an "upside"! :)

Money for equipment and home modifications are always a concern as are attitudinal barriers within the community. Physical barriers that create isolation... The most obvious of which is the inability to visit most people in their home because of builders reluctance to build homes that are "barrier free".

---

#314

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Yes there are shoulder problems and mobility problems.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I am taking Gabapentin every night.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I also have a PT who has designed a program of exercises for me and has helped me somewhat as long as he continues to come.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

At the present time, I am stuck waiting for authorization for the PT to continue coming to my home, According to the Home Care Co, I have to see my doctor first who will then send the information even though they have that information ,although it is a few months old.

---

#315

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I do not

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I have none

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

None

---



#316

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Shoulder pain- I take astaxanthin Dry eyes - I take Macai Berry Fatigue - I take Modafinil

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Modafinil

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Massage

Diet (anti-inflammatory) Supplements: Vit D, B, Magnesium

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Peak relief relies on consistency and predictability. This limits spontaneity and travel. Anti-inflammatory supplements stop working after awhile.

Modafinil Rx interferes with sleep. Massage is not covered by insurance.

---

#317

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Hyperlordosis/Loss of abdominal strength Loss of hand dexterity and strength Stiffness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Stretching

Keeping weight low Mild exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

No visible or significant improvement Too tired to exercise

---

#318

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Yes. Trazadone, Naltrexone, Clonazepam, Duloxetine, NSAID's

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise. Have tried PT and acupuncture, not much success.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Only addresses the pain symptoms, does not affect natural history of disease

---

#319

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscular pain Muscle stiffness Unsteadiness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Not prescription medications but:

Coenzyme Q10 daily.

Ibuprofen or acetaminophen if required. (Creatine for muscle energy ineffective.)

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Pilates Stationary bike Physical therapy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Ineffective at preventing deterioration. Temporary benefit only with coenzyme Q10.

Transient increased fatigue and weakness can follow exercise.

---

#320

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

tylenol for pain, electric massager for pain and tightness in muscles

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

The relief doesn't last very long.

---

#321

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain, tight muscles, lordosis,

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Celebrex, amytriptiline, neurontin

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Aquatic exercise in a heated swimming pool. Massage.

Stationary bike. and stretching.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

During cold or stormy weather, getting to the pool is not an option. Stationary bike on porch due to space and too cold in cold weather. Downside of massage is cost. Not covered by insurance.

---

#322

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

None at this time.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No I am not on any medications to help my FSHD.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I do go to a chiropractor occasionally for a head to toe adjustment.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I see myself not being able to do things with my family as we use to be able to do.

---

#323

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Arm and leg strength.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Isometric exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Still losing strength and muscle mass

---



#324

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle deterioration. Exercise.. it still progresses anyway.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Vitamins

Creatine supplement

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Ineffective

---

#325

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Leg weakness has caused stress on my lower back. I take Ibuprofen for the back pain.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Stretching Exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Sometimes exercise makes muscles more tired and susceptible to falls.

---

#326

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am not doing anything to improve since muscle weakness is progressing. I still do some exercises I learned in PT to try to strengthen legs and trunk

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Use a cane and afos
  2. Avoiding obstacles like stairs and snow
  3. Arranging furniture
- 

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. Takes a lot of energy
  2. I don't think it is helping
  3. If I cannot avoid an obstacle I stay inside or abandon the activity
-

#327

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Weakness in arms and legs.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

none

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

exercises that physical therapists have left with me.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

don't seem to be helping.

---

#328

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Upper body and core weakness

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Walking 2 to 3 miles per day

Work out on upper body machines at gym 3 times per week Work out on exercise ball and hand weights 4 times per week

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

none

---

#329

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Leg and shoulder strength

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No, I'm not aware of any that are available.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Strength training, creatine and glutamine.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

While these interventions appear to be helping me, I'd much prefer an evidence based therapy which addressed the root cause of FSHD.

---

#330

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

loss of some functions such as raising arms above shoulders. Legs and trunk weakness. Primarily just keep as mobile/active as possible. Do some physical exercise at home. Don't stay immobile too long at a time.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Force myself to take stairs if there is a railing to hold and pull on, while using a cane to help in opposite hand.
  2. Use our exercise equipment lightly when I have time (not often enough). Brief time on treadmill and exercise bike. Seems to perk up agility and mental acuity.
  3. Stay positive, dwelling on the comfort of retirement and the many things that I am able to do, and spend much time on. Thankful for all the productive years I have had before becoming more restricted.
- 

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. Risk of falling, which I do at times
  2. Exercise equipment is not fun for me, preferring activity that is moving me about and productive, such as limited yard work with aid, auto/home maintenance etc
  3. Keepin a positive attitude can be difficult if one spends too much time dwelling on the previous productive yrs.
-

#331

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain is my regular companion. I use prescription Methadone and OTC Ibuprofen to control the pain.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Originally, I was prescribed various narcotic drugs that didn't really work all that well. Eventually I was prescribed Methadone and have used the same dosage of 10 mg twice a day.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Lots of rest, Take prescribed pain medication, Use Ibuprofen.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It doesn't always work.

---



#332

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Have not found anything that helps any symptoms

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Only Aleve for pain

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Trying to stay as active as possible

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not working very well

---

#333

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

The shoking, swallowing

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Not yet, will see speech therapist soon for suggestion on food, how to keep these scary situations happening.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Not moving enough

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Have to wait on people for advice, won't cure it,

---

#334

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Exercises attempting to keep strength

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No, but taking medication for Fulcrum trial.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercise, generally taking care of health, and positive thinking

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

No downsides

---

#335

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness, arms and legs

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Acupunturr,Exercise and stretching, weight baring,

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Limited effect

---

#336

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Neck, shoulder, lower back, and leg pain.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Only OTC pain meds like Tylenol and only on occasion.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

stretching, recovery resting when I've over done, and regular visits to a massage therapist.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

If stretching on the floor, it is getting harder and harder to get up from the floor. Sometimes I need to rest more than I am able. Would love to make more frequent visits to the massage therapist but I cannot afford to.

---

#337

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Exercise every affected muscle—probably not helping much.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

N/A

---

#338

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Inability to stand; inability to lift arms; head droop; constant drooling; difficulty in eating, chewing, swallowing

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

nothing at the moment; I have tried various physical therapy exercises in the past but the increase in the weakening of various muscles have discouraged me as they really didn't seem to help, and in fact, seemed to make the muscles even weaker.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

They don't work!

---

#339

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

no

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

AFOs for drop foot

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

**Respondent skipped this question**

---



#340

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

muscle pain, abdominal weakness, tingling & spasms in ankles, shoulder curving inward

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Amitriptyline to help with muscle pain and spasms/tingling in ankles

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

regular gentle exercise (swimming, walking, gentle yoga & qigong), regular application of heat on sore muscles, body treatments such as osteopathy, massage, shiatsu

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

difficulty finding enough opportunity to do regular physiotherapy & not enough time to exercise as much as I'd like (working widowed/single parent with no family in area)

---

#341

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Weakness and fatigue

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No - none available to my knowledge

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Stretching, pool walking, following a low oxalate diet.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Low oxalate diet is tricky to follow but muscle inflammation is tolerable when I keep to it.

---

#342

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Balance

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Losmapimod

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Walking slower. Getting new orthotics PT

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Time consuming

Frustration at loss of activity

---

#343

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

foot drop

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

orthotic braces

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1- it is time consuming and embarrassing

2- balance is difficult without a hand to hold on to 3-ice and stairs are near impossible

---

#344

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Neck pain, hip muscle pain, shoulder and bicep area pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Tramadol, medical marijuana

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Pool exercise in warm water at least 1 hr twice a week. Massage monthly. Wear back brace or cervical collar as needed for pain relief

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Cost of pool and massage not covered by insurance

---

#345

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

hip pain due to muscle atrophy that travels down to my knee. The pain is like a dagger poking. My leg kicks/shutters involuntarily

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

stretching hamstrings, quads, hip flexor sometimes I wear a patella band  
grin and bare it

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

relief doesn't always come  
never seem that I can stretch enough pain still there.

---

#346

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

winging scapula, foot drop, poor sleep

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

lyrica

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

gym, staying active, STAYING POSITIVE

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

could do with more support from govt to see allied health professionals to help me manage this condition before it becomes a full blown disability

---

#347

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

tiredness, weakness, discouragement, leg pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

vitamin D, L-Carnitine, B Complex

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physiotherapy, weight training, massages

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

**Respondent skipped this question**

---



#348

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I don't receive treatment but I wear a shoulder brace and an ankle-foot orthosis (AFO).

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No, I never used prescription medications in relation to FSHD.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. shoulder brace
  2. ankle-foot orthosis (AFO)
  3. swimming
- 

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

**Respondent skipped this question**

---

#349

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

So far, I don't seem to have symptoms. I suspect my eyes don't stay closed the whole night, so I use special drops for that. I work out, eat healthy, take supplements, and get massage therapy weekly in hopes that taking care of my body will help me fare better as symptoms increase.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

None so far.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Getting to and maintaining a healthy weight, exercise, massage.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Evidence as to whether exercise, supplements, and massage lessen the disease is unclear. It is also unclear what exercises and supplements are the right ones. Massage, supplements, and gym membership are costly.

---

#350

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle deterioration

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

-taking multiple types of antioxidants  
-looking into obtaining stance control braces.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Neither proven to be effective.

---

#351

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Yes. Fatigue. Joint pain. muscle pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Cymbalta 60mg Adderall xr 20mg Adderall xr 30mg Provigil 200mg

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Taking Advil as needed for pain.  
Stretching

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

It doesn't take care of all the pain.

---

#352

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Shoulder pain, hamstring pain, knee instability

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Used Naproxen for 3 months but stopped when I started to have digestive & intestinal issues. (Heart burn, Constipation, water retention, weight gain)

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physical Therapy and home exercises prescribed by PT, Swimming, Tylenol

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Fatigue, continue to feel weakness, sore

---

#353

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

weak legs

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I take Aleve at night to lessen leg pain

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Try to be more active--Use a scooter more to lessen leg pain---Use a cane more

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Most nights Im completely washed out.

---

#354

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Sports

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Nothing

---

#355

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

no

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

power wheelchair noninvasive ventilation

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

only maintenance with no real hope for improvement

---



#356

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain, mobility.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Paracetamol, ibuprofen, pregabalin, codeine - for pain, with varying success Creatine for muscle function with little perceptible effect

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Some physiotherapy, most hydrotherapy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Lack of effectiveness.

Lack of accessibility to get to exercise venues

---

#357

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Lose some weight

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Hard to exercise

---

#358

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Just exercise and staying as active as possible.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Nothing else

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Still losing the game

---

#359

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Shoulder and back strength

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Going to the Y Loosing weight

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I like to eat well and am a good cook.

---

#360

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

The only thing I really do is stretching for stiffness.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

There really isn't anything to do with the muscle loss.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

**Respondent skipped this question**

---

#361

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

General weakness - physio and exercise

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

None

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Time and cost

---

#362

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Shoulder pain.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Brace, Co enzyme Q10, healthy diet and exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not very effective.

---

#363

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Light exercise to maintain/improve muscle and flexibility.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Ibuprofen for pain.

CBD oil for pain.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I keep going. That's the best I can do.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Tire easily.

---



#364

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Breathing relief after doing anything.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Nebulizer with Albuterol Solution. Advair, Symbicort, Ventolin, VentoLater with Cpap, Symistatin.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Rest

Follow directions from pulmonary dr. Eat right.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

- !) Very short of breath.
  - 2) Lost upper body strength and can't lift arms over my head.
  - 3) Right leg is getting smaller than left.
-

#365

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

breathing using bi-pap

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

exercise, eat healthy, cough assist- using lung volume recruitment

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

dependent on husbands help. lack of medical professional knowledge, difficult to stay motivated

---

#366

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Sleep in stationary position the entire night: use an electric mattress frame to do minimal movement. Also helps with heat provoking skin rash.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I have used antihistamines to promote sleep.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Computer voice app due to non-functioning fingers.
  2. Use Miralax daily to help constipation.
  3. Pay out of cash flow for CNA assistance morning + bedtime.
- 

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. Expensive products and services.
  2. Weak arms/hands/legs cause difficulties with feeding and positioning.
  3. Drugs for bladder control are helpful but expensive.
-

#367

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?  
pain

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.  
yes, mainly NSAIDs. And Tylenol with codeine.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.  
Keto diet, CBD, massage.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.  
Cost. Availability of ingredients.

---

#368

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle degeneration

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Exercises of varying methods 3 times a week. Creatine and a collagen and amino acid supplement

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Biggest downside is that it is not working! I'm slowly getting weaker!

---

#369

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

All I am doing is trying to cope with life - fighting the pain - going to work or being social as much as I can otherwise I have nothing in hand to do ... just take vitamins and painkillers

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Injectons ( Vitamins Only and Pain Killers )

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1. Walking Less and driving automatic car
  2. not carrying anything at all
  3. taking rest periods in between any activity
- 

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I quite most of my hobbies I work less  
I can't sleep or interact with people normal because of the continuous pain

---

#370

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Balance and leg weakness. I do recumbent bike daily to lose weight and strengthen leg muscles.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Ibuprofen 800mg, occasionally cyclobenzaprine for extreme shoulder pain.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Daily light exercise, occasional ibuprofen, I use a cane for balance when I am not at home.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Exercise can be very draining, a cane doesn't always prevent falls, medications don't always help with the pain.

---

#371

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

pain in neck and shoulders

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

alprazolam

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

physical therapy focusing on myofascial release; "Bed Buddy" heat pack; daily prescribed stretching consistent with PT

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

extremely difficult to find PTs who use this approach and are willing to learn how to bill it to insurance

---



#372

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I have general stiffness in my shoulders and hips. Also reduced range of motion at each joint

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

I am currently in the redux4 clinical trial. I have not used other prescription drugs

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I get biweekly therapeutic massage and take creatine and CoQ10 supplements

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Aside from the the Fulcrum drug, none of these treatments slows the degradation of muscle. The supplements may not help either.

---

#373

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle weakness. Have tried muscle activation therapy which helped inactive muscles around the primary atrophied muscle.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Rest

Moderate exercise and stretching Eat healthy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Not sure if current approach is helping Can't tell if dystrophy is progressing Nothing seems to "cure"

---

#374

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am doing nothing at this time other than using a walking stick (tall stick, not a cane) to help me stand up straighter when I am walking and something to hang onto when I am standing still.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No, I have not.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I am involved in any clinical studies, going on at the University of Rochester, that are related to FSH treatments.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

**Respondent skipped this question**

---

#375

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I just try to keep moving, and using a static bike

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Painkillers

Codeine phosphate, paracetamol, ibuprofen diclofenac gel (all for knee pain and shoulder / back pain)

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Pain relief, and exercise

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Feel isolated

Not much incentive

---

#376

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

My biggest symptom is my right calf muscle atrophy. I just do my best to stay on the move.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

I take vitamins and try to stay active. There have been no other suggestions to me.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

There are no downsides other than I gradually get weaker because of the disease no matter what I do.

---

#377

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

I am trying to maintain the leg muscle mass that I currently have by walking two times a day. I have tried physiotherapy in the past for the scapula issues and have generally had increased setbacks because the treating professionals do not have a good understanding of our disorder and the exercises they recommend end up taxing the muscles more than they can tolerate.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Only Advil - nothing else has been recommended.

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Massage therapy and chiropractic care on a regular and continuous basis keeps things moving and unknotted.

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Currently with the Covid-19 pandemic - it's risky to get treatment, if the provider is even open for business. Similarly if the treating practitioner is on holiday for longer periods of time.

---

#378

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Acupuncture, rolfing, vibratrim. Strengthens muscles helps facial muscles, speech, eyelid closure, keeps bones, tendons and fascia straight and supple. Also IMRS , electro magnetic field and lmes which strengthens muscles

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Above in No 1 and supplements like Nads, fish oil, coq10, diet eliminating dairy, Glutino and sugar Going to start beetroot, creatine and a couple other things

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Cost, cost, cost most people can't afford

---

#379

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Recently noticed weakening of left arm flexion at elbow.

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

n/a

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Using high dose antioxidants per a research paper I recently found assessing their use in FSHD patients. Where possible, I chose supplements manufactured under USP standards ("USP" on bottle): 500 mg vitamin C, 25 mg zinc gluconate, 200 µg selenomethionine, and 400 mg dl-alpha tocopheryl-acetate per day.

[https://www.mda.org.nz/media/b1789279-9523-4c62-abb1-2ba0bf84f7b7/5F-](https://www.mda.org.nz/media/b1789279-9523-4c62-abb1-2ba0bf84f7b7/5F-WyA/About%20Neuromuscular%20Conditions/Neuromuscular%20Conditions/Vaccination%20Recommendations/FSHD%20Vitamin%20Research.pdf)

[WyA/About%20Neuromuscular%20Conditions/Neuromuscular%20Conditions/Vaccination%20Recommendations/FSHD%20Vitamin%20Research.pdf](https://www.mda.org.nz/media/b1789279-9523-4c62-abb1-2ba0bf84f7b7/5F-WyA/About%20Neuromuscular%20Conditions/Neuromuscular%20Conditions/Vaccination%20Recommendations/FSHD%20Vitamin%20Research.pdf)

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

No truly objective way to assess whether these supplements are helping. Perhaps there is a small strength increase, or no strength increase (but lessened decline -- which would still be good), or there could also potentially be harm if supplements are impure, etc. Expensive to purchase supplements as not covered by insurance. It is experimental, but worth trying as I am desperate to hold on to whatever strength I can.



#380

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Walking to stay mobile, doing any activities to stay mobile, massages for staying loose

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Walking, biking, light weights

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Afraid of falling

---

#381

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Muscle atrophy

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**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Working out Eating healthy

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Lack of information or studies

Vigorous exercise can hurt and/or make me more fatigued

---

#382

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

No

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

**Respondent skipped this question**

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**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

**Respondent skipped this question**

---

#383

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Yes, my left shoulder is tilted forward causing pain and weakness. I work with the band to strengthen my back muscles. The psoas muscle of my left hip is often inflamed and weak, and causes pain in my low back. I stretch a lot, but only helps for a little while.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

No

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Epsom Salt Baths Yoga practice Rest

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I often have trouble sleeping, so I don't get enough rest.

---

#384

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Pain and stiffness

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**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Naproxen

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

Physical Therapy, Tylenol, Exercising

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Stopped taking Naproxen after 3 months due to GI issues. Physical Therapy is limited to 20 visits per year.  
Exercise can sometimes cause more pain.

---

#385

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

Yes, pain, fatigue, weakness & sleep.

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

Lyrica, Cymbalta, Lunesta, Testosterone & Tramadol

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

1 & 2. I have been going to PT (three years, once a week) & therapeutic massage (12 Years, every two weeks). These help with pain management, fatigue and muscle maintenance. I also exercise on my own three times per week riding a recumbent bike, stretching and isometric exercises. 3. I rest a lot and use a Bipap machine to improve sleep. 4. Prescription Drugs for pain and sleep

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

1. I get fatigued, especially on days I exercise, therefore it puts more pressure on my wife to do everything: cooking, cleaning, laundry, shopping, etc. 2. I am totally dependent on prescription drugs such as Lunesta to sleep. If I don't take it, I do not sleep. Same with Bipap. Pain pills get make me tired. 3. I think the cocktails of drugs is also making my mind foggy.

---

#386

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

my foot drop my frozen smile my pains  
my fatigue

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

only for pains (tramadol)

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

fatigue = rest as much as I can frozen smile = grimace exercises foot drop = stretching exercises

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

Sometimes, I think it's useless as my situation is getting worse

---

#387

COMPLETE

**Q1** Are there specific symptoms that you are doing something to try to improve? Which symptoms?

no

---

**Q2** Have you used prescription medications to help with your symptoms? List all that you can recall.

no

---

**Q3** What else are you doing to manage any of your FSHD symptoms? List your top three interventions.

medical Marijuana for pain and to relax

---

**Q4** What are the biggest downsides of your current approach? List up to three disadvantages.

I use my muscles more then I should and it makes my pain worse

---



## Pre-Meeting Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Being able to remain in my home

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Preventing the disease from progressing

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Slow progression at a minimum. Slowing the disease will at least give our daughter the hope of living independent longer than letting the natural course take its path. Of course as she takes a medication that will at minimum slow the progression, we will support and work till that cure!

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To freeze the disease today! If we can just freeze where she is, then we can deal with modifying and creating a life that works. With continued progression, its next to impossible to see an independent future being possible for our 9 year old.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

walking and smiling

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stop the progression and maybe gain slight muscle mass to remain independent

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

improve my life style

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

increase my life quality and can work or take care of my family more easily.

---

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

drugs that stop/interrupt the generation of the DUX4 protein  
drugs that greatly reduces the harmful effect DUX4 protein has on muscle tissue

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

---

a treatment that stops the generation of the DUX4 protein could mean the difference between living the rest of my life being able to at least walk and never having to use a wheel chair. For others who have noticed little to no loss of strength, treatment would mean they would never suffer (nor have to worry & experience) the slow loss of muscle strength which affects almost every daily activity.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

a drug without side effects that can stop the progress of the disease

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

A treatment that can offer an improvement (even a slight one) to my muscle loss and fatigue.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

First to stop or slow down the progression of the disease. Second to regenerate the muscle I have already lost.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

At least to slow down the progression of the disease.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

My 4 kids all have it too. I would like to limit their symptoms. I'd like them to have long careers. I'd like to have grandkids that DON'T have it, guaranteed. I want technology to test sperm and eggs for the gene and select ones that are healthy.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Improving the quality of my life. A treatment for me would be a all terrain scooter, so I could go to parks and on hikes. To not be in pain all the time. I'm so tired of my life sometimes. It is what it is. Thanks for asking.

---

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop fatigue, pain and weakness.  
ability to gain muscle strength without harming self stabilize core strength to stop falling

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

---

stop muscle wasting which would allow me to gain strength in the remaining muscles I have left. lessen pain and fatigue

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Halting muscle deterioration so remaining muscles can be worked on to get better.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Reducing muscle deterioration to the most possible extent

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop progression, grow muscle, live my life without fear of future

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop progression

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

slow progression or improve symptom effects

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

slow progression

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

## Survey 5 | Future treatments

I want to be able to do every day tasks - notably go up and down stairs, walk at a normal pace. I desperately want to be able to play sports again.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

I want to ski again. Short of this, I want to be able to do normal things like get on the tube at a station with stairs - rather than waiting for a station that has a lift.

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop the muscle atrophy

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Restore muscles to allow walking and arm movement.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

A cure would mean the world for my sons, my wife and family and friends. A treatment would be a distant second. To stop the progression would be fantastic but a regeneration of muscles is a whole new me.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

It would allow for some hope when people are newly diagnosed. Instead of "You have FSHD, no cure, no treatment". You could have some plan of attack. It would help people physiologically in the disease. It would offer hope. Funny thing about hope is it is endless and bountiful. It can change everything.

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

An understanding of what the treatment will do. Whether it be stopping or even slowing progression... Or an actual "cure"... I'd be excited for anything that will help provide even the slightest bit of certainty for what the future holds.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slowing or stopping the progression. My symptoms are fairly confined to a specific muscle or two and it's difficult not knowing if and when it will spread to other muscles and how severely.

---

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Muscle deterioration stabilization

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

**Respondent skipped this question**

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To stop or slow the progression of the disease. I am constantly telling myself that I can live with my condition at it's current state, if I could just keep what i have left I would be happy. Therefore slowing or stopping progression is most meaningful

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To slow it down, so that life can be enjoyed longer.**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

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to be able to walk

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

making muscles strong stopping progression

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stopping progression giving energy

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

the sickness no longer progresses

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

improve the strength of the legs and hands

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

cure and reversal of muscle loss

---

## Survey 5 | Future treatments

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stopping existing progression

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Slow or even Stop disease progression Rebuild muscle / regain function Correct genetic disorder -aka full cure

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slow or stop disease progression - stop muscle weakening

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Having a more dependable body. Enjoying the physical activities I once loved.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Peace of mind.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

prevent it from getting worse, so I can keep active and independent

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

keep me active

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop muscle deterioration Have a cure for children

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

reduce ongoing atrophy of muscle

---

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Improvement of strength

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Strength

---

I would like to know why we're And more advanced in getting a cure when we've been raising money since Jerry Lewis fundraisers. Where does that money go and why isn't there more treatments out there.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Being able to be healthy and strong enough to travel and workout would be such a big outcome that might change my world. if it could cure my hearing and sight loss, it would change my life. Furthermore, no more winged scapula would be great for me to wear whatever I'd like to.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

able to raise my hand and being strong like normal people would be great for me to help those in need around me. hence, i'd fulfill my dream of becoming a lawyer and being able to hear and see things clearly.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Permanent treatment (cure) for the underlying problem.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping progression in all age groups including in utero.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Ideally as way to stop the progression and reverse its effects

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the progression

---

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping the progression of the disease or maybe even being able to keep it from starting. Being able to regenerate what the disease has destroyed.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

---

Stopping or at least slowing the progress would be the biggest benefit. At this point, I (and my undiagnosed children) don't have noticeable signs of the disease. Wouldn't it be great if we could keep it that way?

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

manage the pain

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

relieve the pain

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Cure, stopping progression, being able to have kids without it even if I still do

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Nothing, maybe pain management. Treatments cannot stop ADA violations and other things that go along with being disabled

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop the progression  
Reverse the progression  
Slow the progression

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slow the progression

---



**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping disease progression.  
Finding a way to enable myogenesis.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping disease progression.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To regain muscle for strength in legs and arms and to be able to lift arms over head. To be able to run especially during an emergency

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To be able to lift my arms all the way up

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Slow down progression, genetic testing before pregnancy, more money to help individuals diagnosed

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slowing progression

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop DUX4 from emitting protein that is toxic to our muscles. Regenerate deteriorated muscles.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Regenerate deteriorated muscles so we can regain use of what has been lost.

---

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping the progression of the disease. Reversing the effects of FSHD.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Pain/Fatigue Relief Stopping/Slowing the progression

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping FSHD from consuming any more of my muscles would be most meaningful. Ideally, reenabling and rebuilding the muscles I've already lost would be the best possible outcome, understanding that would be something short of a miracle.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

For me, going back to a normal, active life would be the most important benefit. For others, ensuring that people who have FSHD but have not shown symptoms would never suffer any of its symptoms.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

preventing progression of symptoms especially ability to walk and lift items, want to get married and have a family (love kids) but fearful of passing on condition

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stopping or slowing the progression of symptoms

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop the progression FSHD and repair / strengthen damaged muscle groups.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slowing down the progression of FSHD.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Increase in strength and mobility

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Increase in strength and mobility

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping the progression  
REVERSING AND IMPROVING muscle function ,strength, atrophy and balance

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Muscle strength function and balance Stopping progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Being able to walk about without footdrop, muscles being stronger, would not mind doing a lot of exercise if i knew my muscles were going to get stronger

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

getting rid of footdrop, could handle the weakness in the arms

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Body strength, and no pain

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Body strength, and no pain

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stabilisation of current state, maybe some improvement

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Return to unaided walking

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Anything that keeps me walking

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Anything that keeps me walking

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Cure

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Better mobility

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To improve affected muscle strength and mobility.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

to be more self sufficient

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Better mobility.

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## Survey 5 | Future treatments

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Improve strength of ankle and foot muscles.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

A cure that completely shuts down DUX4  
After therapies that improve or rebuilds muscle

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Shut down DUX4

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Restoration of physical ability.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Being able to use certain limbs.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

We need more doctors who know how deal with FSHD.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To slow down muscle loss.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

For me there is no real time left for any kind of future treatment, however for my son the chance to recover some muscle weakness and reduce pain would be good and hopefully for my grandson a treatment to reverse the effects of the faulty gene.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

A treatment to reduce the effects once diagnosed. A much quicker diagnosis

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

gaining muscle strength, being able to live a life.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

to at least halt the progression, things are bad now but just bearable, if it gets any worse I don't know what I'll do.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

A way of delaying the progress of the muscle wasting.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop or delay the muscles weakening

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

An effective accessible treatment leading to the ability to restore muscle strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

The ability to restore strength in leg muscles in order to be able to walk ,rise from a seated position and climb stairs all unaided.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Cure

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

prolonged mobility

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Reduced atrophy

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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Stop the progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I have not been given any treatment.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Being able to walk and not falling, being able to lift my arms to eat and wash my hair and body without help.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Выздоровление

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Восстановление мышц

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop decline and regain muscle strength.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop decline and improve muscle strength.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Restore muscle function and mass.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the progression and allow me to rebuild my muscle with exercise.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To stabilise me so I can remain independent

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Reduce degeneration and pain

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Being able to build strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Being strong enough to stop having falls or failing that being able to get myself up off the floor independently if i fall

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would like to improve my mobility  
I would like to improve my energy levels I would like to better accept my situation

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Improved energy levels

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping further advancement of the condition in an individual.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

No further muscle weakening and a strengthening of the remaining muscles in an individual.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

halting the disease and being able to stop it being passed through families

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

be independent

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

finding something to stop future generations getting fsh md

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

relief from pain

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would love it to not only stop progression but also reverse symptoms so that muscle rebuilds.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Reverse symptoms but at least stop progression or even slow it down

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

well treatment wont be in my life time and my children arent affected. But I hope one day there will be for future generations

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

working legs

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To stop the progression of muscle wasting. To slow down progression of FSH

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To slow down the progression of FSHD - to know and understand exactly what is making the condition get worse at a particular time.

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Keep me walking/upright.  
Manage pain better.

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Replace sense of inexorable decline with a bit of hope.

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping further deterioration of muscles. Rebuilding wasted muscles. Being able to have a family without passing FSHD on.

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping further deterioration of muscles.

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Treatment for the symptoms A cure  
Improve my quality of life

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To stop the progression of the illness and treatment for the symptoms

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

What treatment I don't revive any only get a yearly check over now that's every 18months did have a bit of physio when they thought I had a bad neck then nothing

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Being able to eat wash dry dress my self lift and Carry things go back to work and do things that we all take for granted without a second thought

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

AIDS in keeping muscles. I'm afraid of drugs

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Mobility...independence

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Reduction of deterioration

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slowdown of deterioration

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To recover my walk and run skills

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To keep me walking till the end of my life.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping the progression in impacted muscles Preventing the impact to other muscles

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop progression

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Improve leg muscles for better balance.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Ability to walk safely.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Strengthen my muscles

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the progression and add strength

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To be able to be more active, to sleep well, and to be able to walk further without so much back, hip and leg pain.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stay out of a wheelchair! Be independent and not a burden. Return to hobbies I've had to give up.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Keep the muscle I have, stop the progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

No more muscle loss

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slow loss of muscle

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

slow or eliminate the progression of the disease, the ability of a treatment to slow the destruction of muscles.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stop the production of DUX4

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

If you can stop the “poisoning” deterioration of my body.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

That the muscles won't get weaker.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

There has never been any suggestion of a treatment being available for me but I would like future generations to be able to have effective genetic adjustment to prevent the disease taking hold as soon as it is diagnosed.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Prevention of muscle weakness as soon as it is diagnosed.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Getting my strength and mobility back

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Restoring my health back

---

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Sustaining/regaining muscle bulk and muscle strength in the areas where i have lost muscle. If there was 'something' out there that us FSH'ers could take to rebuild our lost muscles then that would be FANTASTIC.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To improve muscle strength and function as this would help with most other issues.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To allow me to participate in more activities with family and friends would give me a significant improvement in my overall well being.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Maintaining or improving current muscle.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Easing of pain/tiredness

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Daft question. Best outcome is a cure

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To walk

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Arresting and ideally reversing disease progression

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

## Survey 5 | Future treatments

Improving my ability to walk

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping the deterioration of my muscles. Not worrying about the future so much.  
Not having to get used to another disability every time another muscle wastes.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping the progress of the disease.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

The halting of the deterioration in my condition Any form of reversal in my condition  
Being party to the eradication or making it easier for younger people to survive/live with this condition

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Being able to enjoy walking without any discomfort and for any length of time

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Arresting the progression of the condition and/or reversing it.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Improving the fatigue and muscle pain Slowing or arresting the progression

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

That it would stop the disease progressing.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

That it would help my three children if any of them were to develop this disease.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

## Survey 5 | Future treatments

Treating the Origen of FSHD. (Urgently) I inherited my children and I don't know about my grandchildren. Unfortunately I learn I have FSHD 1 to late to prevent my children to have this terrible sickness

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Prevent the difficult of leaving without knowing what is the next symptom

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Repair affected muscles, stop the weakness

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Having full use of muscles that have been affected by muscular dystrophy

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Slow progression of the disease.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Increase in muscle function.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Prevention of further progression Potential to regain lost function  
Hope for my daughter if she has inherited it

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slowing or stopping progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping this horrible disease from getting worse.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping further deterioration

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Having a drug or treatment that will cure this disease

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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Slow down the progression of this disease.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Restore prior muscle strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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Increased muscle strength

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Preventing further progress.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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Minimising progression of muscle wasting.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop muscle wasting and increase muscle strength Reduction of fatigue and muscle ache

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stabilization of muscle wasting and/or increase in muscle strength

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To be able to walk again

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To prevent my condition from deteriorating.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Anything to improve the condition which will avoid surgery and scapula fixation

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Anything to improve the condition which will avoid surgery and scapula fixation

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

My own effected kids.  
Taking care of my own self.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Not to Become immobile.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

A treatment plan and drugs that work.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Pain and mobility improvement.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Muscles working again would be nice, mental health issues need addressing. Coping mechanisms need to be learned. How? I don't know

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Mental health and coping mechanisms. Acceptance. Physio

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Regain and/or maintain muscle strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Curb further deterioration

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Ability to stand supported - more independence

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Ability to stand while supported

---

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Of course a cure would be great but a treatment that would stop progression, and a second treatment that would help regenerate or reverse muscle loss

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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Stop the progression.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Halting progression of the disease & ultimately a cure.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Halt the progression and reduce bladder sensitivity

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping the progression of weakness...pain Regaining muscle strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping progression Stopping the Pain

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Increased muscle strength ache/pain relief

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Increased mobility

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Regaining my strength and muscles

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping muscle wastage and ending pain

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Regaining enough strength to transfer by myself. 2 – Regaining enough strength to walk.  
Regaining enough strength to feed myself.  
If none of the above are possible, I would be satisfied with stopping the progression.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Please see 1, 2 and 3, above.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Medication to slow down or stop progression of disease

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Independence

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Being able to stand and walk again.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Improvements in muscle strength throughout my body.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future

treatment?

Something akin to the latest MS treatment i.e. to halt it in its path, so although you can't improve you can halt the degeneration

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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See above , to stop further degeneration

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop the progression of atrophy. Regain the ability to walk independently  
Regain strength in my arms to support normal activities such as picking things up, eating normally, washing hair, etc.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the decline. This provides physical and mental benefits.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Walking unaided or without a limp. Having the confidence to visit places where the terrain may be uneven and difficult. Ascending and descending stairs

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

The downward progress of FSHD is halted or slowed down.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To walk, run, exercise and take care of myself again.  
To have a life and do things with family and friends or by myself. So people have a life again

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Give strength again to walk again

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Any thing that might slow or stop the condition - if it can be reversed with muscle growth even better

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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muscle support to alleviate muscle ache

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

More energy to do the tiring things I do bc of weakness, of course halting or reversing this condition

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

More energy

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

slow, stop or cure the disease

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

slow the progression

---

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Need something that enables rebuilding muscle to provide functional improvements.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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Partial functional improvement

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Something to help slow progression of muscle loss

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

---

Prevention of muscle loss

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

1. Regaining strength in thigh and other leg muscles so that I can walk.
  2. Halting the progression of the atrophy would be incredible but obviously also ideally reversing it and giving me the opportunity to work to get the muscles back.
- 

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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Stopping atrophy where it is so that I could stop having to read apt to a worsening condition and change my life about every few years.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stronger muscles or at least muscle weakness halted More flexibility of muscles  
Less pain from exercise

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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Halt the progressive weakening of muscles

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

to halt its progression. clinical trials not keeping to one specific /limited area when looking for results that suit only their idea of a positive outcome. To have better access to information and treatments

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

just stop it in its tracks.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Regain strength and independence. Help for future generations.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Independence by slowing it down or giving back some strength.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Ideally a correction at the genetic level that would stop the progression of dux4 and make it possible to regain strength. I'd happily settle for something that would slow the progression though.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

It'd be really nice to feel like I have some control over this disease. A huge part of the struggle with a condition like this is the feeling that there aren't any real options. A treatment option, even if not a full cure, would be huge mentally. Physically, I'd like to continue to be able to walk and be mobile as long as possible. Increased muscle strength or mass would be truly life altering.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Either halting advance of disease or, ideally, reversing it

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Halting progress

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Building muscle back up, staying out of a wheelchair, getting some vision back.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

An end to Coats Disease would be the most important to me. If that's not an option or even something that is being considered, then preventing the scapula from winging and using my arms with full range of motion.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

a cure for everyone!!

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stopping the increase of the weakness and inability to get around

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Gene/stem cell therapy to repair the faulty chromosome; Intervention to stop the progress of the disease, or slow it down; Free access to physiotherapy and other beneficial therapies.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

something that assisted me to weight bear again.

---

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To regain strength to be able to sustain what I have and possibly strengthen what I have now I feel too young for what is happening with my body We, those diagnosed with this disease need help, we need a drug that will help us sustain muscle and increase muscle

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Muscle improvement Strength so I do not have to be in..pay for a wheelchair, scooter I would rather put money into a "pill" then into a scooter

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop progression

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stop progression

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To stop the progress and improve muscle strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the progress of the symptoms

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Dependence  
Confidence in the treatment Seeing real benefits

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Ability to live independently

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Managing destruction of my muscle tissue, reaching my children /grandchildren before symptoms as severe as mine

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slowing down progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop disease progression  
Regain lost muscle mass and mobility

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop progression of the disease

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

First, to stop and reverse FSHD in all who are affected by it. Second, to end the disease.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Increased mobility, balance and strength. It would be nice not to struggle with a bag of groceries or climb steps without help.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping progression of the condition Reversing the condition

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping the progression of the condition

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

1. Halting or slowing disease progression 2. Curing the disease 3. Reversing disease symptoms

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slowing disease progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

-something that would work to prevent progression of symptoms would be wonderful (especially for the younger generations)  
-treatments with minimal side effects  
-being able to do physical activity without limitations-

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

-stop current progression in its tracks!!! And muscle repair!!!

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Regaining the muscle I have lost.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping the further decline.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

stopping progression improvement in strength improvement in mobility

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stopping progression. Keeping the ability to walk

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Seeing improvement

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Decrease of level of atrophy

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Relief of pain and weakness

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Relief of the pain

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

The most meaningful outcome for me would be to regain my strength in my upper back so I can do normal day to day activities again like:

1. cooking
  2. doing the laundry
  3. cleaning the house
  4. exercise
- 

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

The most important benefit for me would be to allow me to exercise again without making myself weaker.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping the progression of the disease and a cure.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping the progression of the disease.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

More mobility

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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Better balance

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

something

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

slowing it down

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

- Preserve longevity
  - Preserve independence
  - No side effects
- 

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Reduce biggest mortality risk factors

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Restoring muscle function Reduction in pain

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Increasing muscle strength

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would like to see a medication to stop the dux4 gene from attacking and killing my muscle tissue. And would like to see some non narcotic type of medication for pain.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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Pain treatment

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I want to be able to use my arms. I can handle the drop foot because I have a foot brace. I can't do anything about my arm weakness.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Use of my arms

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To stop progress for me and provide cure if my son has the disease.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop progression.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop progression of FSHD  
Would love to regain the ability to walk with confidence Able to smile

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop progression of FSHD and regain some muscle mass/ability

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

A percent reduction in my pain, fatigue, and emotional distress. And, a percentage increase in muscle strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Increase muscle strength

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Being able to manage daily life and be able to live independently and to be able to do things I haven't been able to do for years

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

A significant reversal of The weakness and be able to do things I haven't been able to manage for years

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Hope for an easier life for my daughter, for others now and in the future with FSHD, and for myself

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping cell death and increasing energy

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Ability to build muscle  
Ability to stop progression of the disease

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Not having future generations suffer with this terrible disease - my children and grandchildren can be active and enjoy life not trapped in their bodies

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Being able to have a fully functioning body.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Targeted muscle strengthening. I am mainly effected by the disease in my shoulders and hands at present. Something to assist with this muscle weakness would be ideal.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Prevention of muscle loss Regaining muscle loss

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## Survey 5 | Future treatments

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Prevent further muscle loss

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Muscle strength, even on a limited scale would be helpful.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

I do not expect a complete cure, but I would appreciate any muscular strength, especially in my arms & hands. I am tired of losing strength & continual adjustments. I would like to stop wasting, now.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop the progression of muscle loss and rebuild muscle.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the progression of muscle loss and rebuild muscle.

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

MEDICATION TO STABILIZE THE CONDITION

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

**Respondent skipped this question**

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To research and find a product that will regain muscle and strength so one can enjoy the fullest quality of life! Just to live and feel "normal" as the average everyday person does.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To give ENERGY and fight fatigue along with having NO PAIN at all!! Now, that would truly be a "CHRISTMAS MIRACLE!"

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop the progression of FSHD

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the progression of FSHD

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop progression of disease.  
Regenerate strength.  
New opportunities in hobbies/career based on strength renewal.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Providing hope in that people are "looking into" possible treatments. Not being forgotten.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop the progression of the disease and rebuild muscle

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the progression

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Being able to lift my arms and do chores as normal as anyone else

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Being able improve muscle strength

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

recuing or stopping the dux 4 from expressing

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Slowing or stopping the progression of my muscle weakness.  
Find a way to rebuild damaged muscle and increase physical strength.  
Cure the disease!!!!

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop or slow progressive degeneration of my muscle tissue.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Pain management, being strong enough to walk and exercise again.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Restore strength to core, legs and feet, other weakened muscle areas are 'easier' to live with.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To be apart of a medical trial treatment program that will help make people like me and myself get better. I want to be alive to see progress and treatment for FSHD.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Hope! Treatment means there's something being treated. So if it focuses on a little at a time even baby steps benefit out treatment. The simple fact that were close to a complete cure brings HOPE and faith that were important and they are working on fixing us. Closer now than ever is a huge benefit.

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Improved muscle strength. Protection of respiratory and cardiac muscles.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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More strength

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

That the treatment can help strengthen my muscles

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Any increase in muscle power would be a good thing

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Finding a way to maintain my present condition.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Maintain my quality of life

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Just to stop the progression

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping the progression

---

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping progression of the disease! Second would be to bring back the muscle that I've lost.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping progression of the disease! I can live with where I'm at now, but knowing that I won't get any worse would be a game changer.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

1. Disease progression slowing or halting
  2. Allowing me to exercise and use my body without having to worry about whether I'm doing more bad or more good.
- 

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Peace of mind, allowing me to put the idea of this disease to the back of my thoughts.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

that it won't spread to your children  
the pain would be diminished and there would be a medication other than opioids to relieve muscle burning pain.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

pain relief

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping the progression of the disease

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Mobility

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Cure, stop progression and regaining muscle.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stop progression

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Hope for a FSHD afflicted daughter and others like her. Cure, better mobility, or at least stop progression.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop progression of the condition.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Being able to stand and walk longer.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Energy to do more things .

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Living without pain - being able to walk and hold things normally

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Pain-Free - More strength to legs and arms

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Slowing or stopping the progression of deteriorating muscles.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Maintains current muscle and physical abilities as soon as possible.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

The ability to regain more functional use of my arms and legs.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Same answer as question 1.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

The ability to build muscle and gain movement back.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Increased muscle strength and ability to regain movement

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I just want my strength back. The lack of it is what causes all the other troubles.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

At the very least, stopping progression. Regaining some muscle strength would also be amazing.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

First, stop progression. The rebuild strength to be able to walk again, even if not at full strength. Using a walker would be a big improvement.



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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Be able to exercise more vigorously.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Increase in muscle strength to reverse foot drop and loss of ability to bend arm at the elbow

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Halt muscle loss and increase strength of existing muscle

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To not lose anymore strength or independence.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To not lose anymore strength or independence.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Any treatment that slows the progression would be amazing. If it stops the progression even better. If there is a drug that increases muscle strength, that would be fantastic too.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slow the progression of muscle weakness

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Decrease of how quickly muscle loss occurs (slower progression)

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slowing down how quickly muscle wasting occurs

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Slow the progression of muscle loss

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Hope that future generations won't suffer with this difficult disease

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Increased strength, ability to climb stairs, ability to lift heavier items, ability to smile, ability to work out, decreased fatigue, etc.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Increased endurance and strength

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I'd love to be able to build muscle again some day and return to a standard level of physical mobility. As a second best option, halting further deterioration would also be an amazing outcome.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

A halt of progression.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Mobility. Being able to walk without difficulty.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Regenerate skeletal muscle.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

walking, standing without difficulty and increased energy

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

ability to maintain my independence - physically

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Muscle strength and energy. Specifically torso, chest, neck, upper back and shoulders. No more fatigue.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Muscle strength

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Programming

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

I return my work (programmer)

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Ability to walk again without assistance.

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## Survey 5 | Future treatments

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Ability to walk again without assistance

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Ability to do the things I used to, no need for a wheelchair, to be able to go back to work!

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

No more restrictive lung disease!!!

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

At this point my symptoms are pretty minimal and I have children not yet showing any symptoms. Stopping or even just slowing the disease to maintain quality of life would be wonderful. Of course, treatment that could help rebuild muscle would be wonderful too.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping or slowing the progress would be most important. I think this would help many maintain whatever quality of life they still have. For example, it would keep my dad at the level of using a walker and still being able to care for his own hygiene rather than having to graduate to a wheelchair and hire help for toileting and bathing.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Greater muscle strength. Better control. More ability to do tasks around the house.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Increased muscle strength or being able to hold the strength I have.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Ability to improve, or at least maintain mobility and have independence

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Increase in strength enough to improve mobility and lessen pain due to overtaxed joints and weakened remaining muscles

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Increase in mobility

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slowing or halting muscle degradation

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Improvement in my walking ability, or at least that it not get worse.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Better functioning leg muscles.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Enable muscle rebuilding, prevent further muscle loss. I understand that the theory says muscle rebuilding is not possible, but my personal experience is otherwise. Preventive and corrective exercises would be more effective if the muscles responded better to them.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Prevent further decline, enable partial reversal for those patients willing / able to exercise to rebuild their strength.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

At least stop the progression.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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At least please stop the progression of this disease. Time is running out.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

stop progression and potential regeneration of muscle

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping progression

Able to exercise more , weight lift w/o fear of muscle damage Improving strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Preserve breathing function!

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

While total reversal is the ideal, a treatment that could significantly slow/stop the progression would be the answer to our prayers.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slow the progression to remain ambulatory and to maintain strength in hands to continue to work.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

GETTING BACK TO PHYSICALLY FUNCTIONAL

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

PREVENT FURTHER DECLINE AND BECOMING A TOTAL VEGETABLE

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

The ability of the effected muscles to be strengthened through exercise in stead of the steady decline.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

improvements in orthotics and devices that would improve independent movement and normal activities and delay the decline in strength.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I want deterioration to cease and muscle regrowth. I have the most muscle loss in my neck of anyone in the US, I am told, and I would like to be able to get in a car, airplane without the fear that I will be in an accident or turbulence, and become quadraplegic, or die.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Muscle function. Can the FSHD community contact J. Peter Rubin, MD, chair, UPMC Department of Plastic Surgery and, particularly Stephen Badylak, MD, PhD, DVM, McGowan Institute for Regenerative Medicine deputy director. Dr. Bladylak ten years ago pioneered muscle regeneration using pig bladder as an extracellular matrix. If we can halt the deterioration, this might be an option for regeneration of functioning muscle. What do we have to lose by asking, exploring, and opening a door to mitigate our muscle loss? In a video, Dr. Bladylak seven years ago stated that the surgery he's been teaching to many, many physicians 'will be done everyday, in every hospital in the country.' I think that if the deterioration can be halted, we should think outside the box and explore this as a therapeutic option. Because I have lost an extraordinary amount of neck muscle, I would really like to have this opportunity - my carotids, my ability to never have a tracheostomy, my ability to speak, and the protection of my spinal cord are at stake. Thank you, for asking what is most important. I don't want to be anonymous: Margaret M Mueller

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Of course, restoration of lost muscle would be the ultimate goal, having a treatment that would slow or halt the progression of the disease would be extremely meaningful.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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Halting progression and allowing me to live at home for as long as possible rather than being in a nursing home.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Able to maintain mobility and daily independence

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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Independence

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

That i can move and walk without pain. Lower my risk of falling. Feel more normal

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Move normally

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

independence

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stop the destruction of tissue and ability to manage pain

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Halting disease progression

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Improved lung function

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Slowing down or stopping the disease

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping the disease in the next generation

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping of disease at least

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Full cure or improvement

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

ability to perform daily living activities such as cooking, showering and dressing, driving. If I ever could gain back future strength to climb steps/stairs, I could participate in events in other people's homes

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

That the deterioration stop

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop disease and muscle wasting progression, treatment for pain and fatigue.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop disease progression.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Back to walk without a cane, wheelchair...

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Back to walk without a cane... gain muscles

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

- Stop the progression of the disease
  - Strengthen/regenerate weakened muscles
  - Control scapular winging
  - Eliminate pain
  - Significantly reduce fatigue
- 

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the progression of the disease.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Currently taking the Losmapimod drug in clinical study. Would love to see some sort of strength building drug with it as well.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To be able to have some sort of a live where I'm able to take care of myself while still striving to regain strength.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I'll take what I can get. Slow the disease... great... Stop the disease... fantastic... rebuild muscle... holy cow!! You've not only reached the moon... you're standing on Mars.

The process of treating FSHD is going to be a multi-phase process. Step 1. Stop or slow the disease.

Step 2. If Step1 only slowed, then work on a stop.

Step 3. Restorative treatment and therapy to regain any muscle or strength.

Certainly these can and are being worked in parallel, but steps 1 and 2 are likely to be completed first.

Steps 1 thru 3 equal cure.

However, for those recently diagnosed or not very severely effective.. Steps 1 and 2 could equal a cure.

Clearly stopping or even slowing the disease is the minimum requirement and certainly highly desirable and likely to be achieved first. Regenerative therapies will come in time, but should not be the only goal or mark of success given where we are at in finding an FSHD solution.

Proving a treatment is effective for Step 1 and Step 2 is going to be difficult in a clinical trial. We may have to trust the science and that the correct target has been found and if the target positively corrected and the treatment safe then go to phase 4 post approval and watch the results in the field over a decade.

However, it is important that we don't get an emotional FDA approval. Whatever treatment gets approved will likely be expensive and insurance companies will try to balk on payment and possibly jeopardize further commercial research. We need, at minimum, sound and accurate science backing up an approval.

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

I suppose for those on the highly severe scale something like improved breathing or heart health would be significant gains if not additionally restoring mobility and connective muscle strength.

For the majority, including me, where connective muscle is presently the only concern my answers to Question 1 apply.

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

enabling independent living

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

ability to lift arms against gravity, preferably with more strength

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Enough strength to be able to get in and out of chair, and if I can't have more strength, stopping the progression.

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping the progression.

## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping progression, reversing weakness and growing muscle

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would love to be independent and not need to ask for assistance from my husband who is my caregiver. daily needs are difficult for me to accomplish.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

If not curing it would be most helpful to stop the continuance of the disease spreading throughout your body.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would like to have the energy to begin living again. There are days when I sleep 15-20 hours, and that doesn't leave time for much quality of life.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

1. More energy
  2. Less pain
- 

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Gain strength to live independently, enjoy going out on my own, traveling, and feel confident that I can take care of myself and won't fall or get hurt.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Recover lost strength to be able to be self sufficient

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Improved function, no pain and increased muscle strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

restoration of normal muscle function, so I can live a full life

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop disease progression

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Restore some muscle function

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To reach as high a level of full physical activity as I would have had I not had FSHD.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Again, improvement / increase in overall activity, lessening of pain, which in turn would produce a great increase in emotional stress caused by FSHD.

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop the progression of the disease!! Within the next two years might keep me out of a wheelchair!

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping the progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would like to improve my capacity to swallow and prevent the choking Times.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

## Survey 5 | Future treatments

Help in breathing and swallowing.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop progression of muscle deterioration

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Decrease in pain or increase in function

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would like to have my strength back to be able to stand and walk and participate in physical activities.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To regain my strength and be able to control my motions.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

regaining strength and mobility

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stop muscular degeneration

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Gain more independence. More energy. Less pain.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop muscle deterioration.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Preferably reversal of weakness or mitigation of progression.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

mitigation of progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Halt the progress and cure

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Halt the progress

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would like to be able to use a regular toilet..I have to have arms to get up. I would like to stand in the shower. I want to be able to get up out of a chair without having to use the arms. I would like to be able to drive a car again.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Just stop the progression of the muscle loss.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

It would be great to get back my muscle strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the progression of the disease

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Halting progression of the disease will allow me to remain independent and active in the community.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping progression of muscle weakness and pain.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Increase in strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Increase in strength, decrease in inflammation.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Too find a cure so that others may not go through with the same problems and restrictions

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

A better quality of life that allows me to be more mobile

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Feeling better

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping the current advancement of fshd

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Being able to remain independent (walk, shop, drive, etc) and have access to more ongoing physical therapy to keep me going!

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To at least allow slow down, if not completely stop, the deterioration of my body. I would be happy even if I could just stay at the level I am at now.

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Of course, my first option would be a treatment that would roll back the effects of FSH and allow me to regain muscle strength. I would still be thrilled with the treatment that would just freeze it where it's at right now so at least moving forward I would know what I have to work with.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Think I answered his other question one, but a treatment that would freeze the disease in its current state and allow me to move forward knowing that I would not continue to deteriorate would be incredible.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stronger muscles

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stronger muscles

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping progression

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping progression

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Meaningful outcomes would be for me to be able to do all of the physical activities that I used to do. Be able to play catch with my son without having to stop after only a few throws. Running a 5K race again. Being able to go on longer hikes. Not being so tired all of them time. Being able to reach something on a high shelf.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Being able to regrow muscle in areas where I have lost it. And if I could not have that then at least stop the loss of additional muscle.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

At a minimum I would like to see my decline in strength stop. The ability to increase strength would have a huge positive impact on my day to day life.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Strength increases and the ability to continue daily exercise for overall health. A treatment that would do this would be fantastic even if it was time consuming or invasive.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

A treatment that would prevent genetic material from being passed on to offspring... I do not have children and my decision to remain childless was not related to FSHD but I think in the big picture this is probably the most important single achievement. My personal quality of life at the moment is very good in spite of

## Survey 5 | Future treatments

having FS HD but if pressed I would probably say it would be the ability to stand upright/walk.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

I believe I have answered this in the question above... A treatment that would prevent genetic defective material from being passed on to offspring... Personally the ability to stand upright and walk.

---

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Recover loss muscles & strength in areas that supports posture to ease the stress & pain; just standing too long results puts pressure to the shoulders and back.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Prevention of further loss of muscles and movement/function.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Anything to prevent me from getting worse or losing more muscle.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Halting the progression of the disease would be critical. I'm also very concerned about my partially paralyzed diaphragm and how that will impact my future.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Ability to get up from a fall would be meaningful

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Ability to walk or get up from a fall. I can still walk but not get up from a fall

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would love to have all the strength back in all the muscles that FSH took away.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To stop the disease and hope I could get back a % of my muscle strength back.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would like to be able to sit up straight (without lordosis) and have biceps and finger strength to eat, do my hair, etc. (I use a wheelchair so the little things matter)

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

I would be grateful for any strength improvement or even a slowing of muscle loss.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Strengthening of my back muscles and reduction of back pain

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Appropriate strengthening exercises

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

the halting or slowly of muscle deterioration would keep quality of life from continuing to diminish

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

early intervention after diagnosis to stop muscles from deteriorating

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To be able to halt the progression of the disease process  
To be able to gain back a bit of the muscle strength lost to the disease.

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## Survey 5 | Future treatments

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Halt disease progression.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Be able to do normal stuff like brushing my hair..... just want a normal Life... and be able to enjoy Time with my kids...

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Gain back some energy, muscle...

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Have my independence back

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the decease progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Increase in mobility and strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Increased mobility

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Improve my mobility. Gain strength back so that I could just keep doing daily chores.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Gain strength back in my torso area, very weak muscle to support my back.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

The ability to stop the decrease in muscle strength and the possibility to increase muscle strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the progression of muscle weakness

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Regain lost mobility.. speak clearer.. smile

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Being able to continue walking

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Prevent further deterioration.

Improve core/axial strength to improve mobility.

Impede muscle damage to allow strength training to improve lower limb strength and function.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Improve mobility via increases in core and proximal lower limb/hip girdle strength.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Normal/restored muscle function

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Treatment =cure for me. You can't really partially restore proper muscle function. So I'm not sure how to answer this.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop the progression.

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## Survey 5 | Future treatments

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slow it down.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Independence. Mobility. No pain. Visible signs of FSH eliminated. Minor or no side effects. The ability to gain muscle.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slow reversal of symptoms. If dux4 can be controlled it would give us a chance to build muscle and slow other conditions (tendonitis, arthritis, respiratory symptoms) from deteriorating quality of life

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would be happy if something could at least slow the progress of atrophy.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Strengthen core muscles

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Increased muscle strength for one. Anything to help with this awful and constant fatigue, we need more stamina, there ought to be a medication to help with that

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

I could accept the muscle weakness and pain and other things if I just had more energy to get things done. The greatest benefit would be something to give me stamina and endurance. The fatigue renders me unable to function.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Restoring lost muscle to improve function and mobility. Providing treatment to stop more atrophy.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that



## Survey 5 | Future treatments

a treatment could provide?

Treatment to strengthen and keep from more muscle loss.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I want a treatment that stops the progression of the disease ,if not improves it. At the moment I can still walk around the house unaided. Outside with a cane and longer distances with a Walker.. I have 5 very young grandchildren (7 and under) that I want to be able to enjoy time with at the park, zoo etc.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

No further deterioration

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To remain mobile and regain some of the function I have lost, which in turn may reduce discomfort

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop progression of the muscle wasting.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

less wasting of muscles and less muscle pain

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping or drastically slowing of muscle wasting.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping the progression of the condition.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Patients not getting worse.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To regain muscle strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

STRONGER HEALTH AND PROTECTION FROM THE DISEASE FROM MY CHILDREN

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

SAME AS ABOVE

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

That one day I will be able to do the things I did 10 yrs ago, like going up and down stairs, getting up off the floor without help and most importantly not have to use leg braces every day.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

A drug that can stop muscle loss so my symptoms don't get worse.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

If I could keep walking, even a little, enough to drive, I would be able to stay in my own home.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Prevent respiratory involvement to avoid invasive or non-invasive therapies. Also, future patients could have children without worrying about passing FSHD on as many of us diagnosed with the disease chose not to have children.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

increased muscle strength

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

deterioation of my condition

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

#1 priority: Stop the progression

#2: Reverse the disease as much as possible (re-grow or replace muscle tissue?)

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stopping the progression.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

To maintain some independence

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

To retain the ability to walk.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would like to be able to dress and toilet myself.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

It would be nice if my restrictive lung disease and my COPD improved.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Although the progression of muscle wasting on all parts of my body are important, the most meaningful thing that I miss is walking. Be able to stand and walk again without or little difficulty will surely make big changes and improvements in the quality of my life.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

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If not halted, at least to slow down dramatically the progression of muscle wasting to the point that restoring and building muscles can catch-up through the help of Physical Therapy or Rehab.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

detener la enfermedad y recuperar los músculos que sean posibles para tener una vida saludable de acuerdo a mi edad

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

poder recuperar la fuerza principalmente en brazos abdomen y piernas

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

STRENGTH GAIN. SLOW THE DEPLETION PROCESS. PAIN MANAGEMENT.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

REGAIN LOST MUSCLE AND STRENGTH

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Genetic therapy targeted muscle groups that could yield functional improvement to help with compensation of atrophied muscles.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

A partial improvement or cellular treatment to restore damaged or compromised muscle tissue via stem cell or transplant therapies

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

1 - stabilization (i.e., no further degeneration) 2 - some type of cure

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the progression.

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

No more muscle wasting.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Just to feel better and not to lose anymore muscle strength

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

reversing or stabilising muscle wasting, improving foot drop

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stabilising shoulder wasting

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

I would be glad if muscles did not continue to deteriorate

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

That it could reverse future muscle deterioration for our son and grandchildren and all others affected

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Reduction in pain without side affects.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Help for the muscles being used to compensate for the muscles that no longer work and a way to know which muscles are atrophying before they are too far gone.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

If damaged muscles were able to regenerate

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## Survey 5 | Future treatments

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Improved leg muscle strength, to be able to get out of a chair without assistance, walk without a gait, ride a bicycle.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Being able to take care of myself for the most part

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Slow down muscle atrophy

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

For me, getting the strength back in my right calf muscle would be life changing. I am a Physical Education teacher and to be able to get my movement back that would be huge. Also to be able to be more active with my two boys would be life changing.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Even just keeping me where I'm at with my strength would be life saving. Just maintaining my current level of strength and halting the disease.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

More mobility & ability to go back to being self-sufficient ie. showering without help, cooking, walking without tools.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

I do not believe there can be a complete cure for FSHD, because our skeletal systems are quite affected. However, anything that gives me more muscle strength & stamina would be fantastic.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Strength back in legs

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that

## Survey 5 | Future treatments

a treatment could provide?

Keep my muscle loss where it is. Not get worse

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

ability to stand and transfer to bed and toilet and get up off of toilet

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

at least keeping the strength that I have

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

It would be amazing if I were always able to live independently and not have to rely upon other people to have to do daily tasks that are required to maintain a home. Reduced fatigue would also be a big plus so that I could do more over the course of a day without requiring rest breaks.

---

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Halting the disease's progression. Also the ability to improve existing capabilities without the fear of causing yourself more damage in the process by over taxing the muscles.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Return of muscle function

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

stop progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Increased mobility and balance, less dependence on others.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

improved strength, less pain

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stopping DUX4

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Walking

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop progression, get stronger

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop progression

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Muscle strength, legs, hips, feet abdomen so I could walk again.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop it's progression.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

The most meaningful thing is to get back the mobility I have lost. Walking, getting out of a chair, going up and down stairs are necessary to live a full life. Second outcome would be to slow or stop the progress of this disease.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Most important to me is to get back the mobility I have lost due to muscle loss - the biggest thing that holds me back from social and work events, is getting up from a chair on my own. I can deal with the stairs and walk with a stick but there is nothing to help me get out of a chair without asking someone to pull me up. I can't do this out in public with strangers. If we can't get our muscles back, then I want something to strap on my legs that will help me stand up on my own. If we don't have a cure and we are already too far gone to bring back muscles, then a medical benefit has to be technology to mimic the muscles we have lost.



## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

1. Restore systemic muscle loss
  2. Stop future systemic deterioration
  3. Provide a pathway to Open trials to those over 65 to get actual treatments on a separate track from a study so it doesn't bias results yet allows those who are older and in good health an option to regain quality life
- 

**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

1. Restore muscle loss to core and legs with continued treatment even if treatment has long term potential side effects . People need to be mobile to maintain and extend healthy life. I am 72 and can walk with my hands in my pockets to support my core , can easily do 30-40 sit ups but because of weak core am limited to generally no more than 5 miles walking per day. While that sounds good to you, it is difficult To stand and make a meal with both hands in front of me. For those of us who are over 65, daylight is burning, we shouldn't be shut out of access to drugs under trial — ok to exclude us from study data but let us get the drugs to try with our own docs and report back to you so we can get a shot at having a better quality life.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Strength and energy to be physically active

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Improve strength

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

At least maintain where I'm at physically & hopefully gain strengths

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop progress or improve slightly

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Maintaining non-aided mobility

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Reduction in progression

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## Survey 5 | Future treatments

**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

The ability to participate in those activities that at this point are not possible. Playing catch, shooting baskets and hiking with my grandkids are just a few of the ones that come to mind.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop it from getting worse or at least slow it down to a point where exercising muscles would stay ahead of the downside.

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Fully take care of myself. Affordable treatment. Get off the pain and sleep medications.

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

Stop the muscle loss where it is now.....

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Stop the disease from worsening  
Recover muscle strength to walk normally again

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

recovering muscle strength no longer get tired all the time

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**Q1** What outcomes (changes and improvements to your quality of life) are most meaningful to you in a future treatment?

Trying to find a cure is all I wish would come out of anything I do to help the MD society

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**Q2** Short of a complete cure for your FSHD, what would be the most important medical or health benefit that a treatment could provide?

just to slow the progression of the muscle deterioration

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