

BetterLife FSHD

Input today, impact tomorrow


Amanda Hill


Senior Director of Research, FSHD Society

What is BetterLife?

A patient-driven health platform and research registry

- 
- ✓ *Designed by and for people living with FSHD*
 - ✓ *Personal articles and recommendations*
 - ✓ *Be your own citizen scientist*

- 
- ✓ *Track symptoms over time*
 - ✓ *Access all your health data*
 - ✓ *Learn about FSHD and your own health*

- 
- ✓ *Find and be notified of trials and studies*
 - ✓ *Health data shared securely with researchers*
 - ✓ *Be part of advancing research, including future treatments*

What is BetterLife?



Our Mission: Be the transformational platform for all people with FSHD to take control of their health journey

Inside BetterLife: Your dashboard

- Dashboard
- Available Activities
- Community Polls
- Insights & Recommendations
- Genetic Testing
- Research Opportunities
- Achievement Badges
- Profile
- Inbox

Dan Jones's Dashboard

[+ Add Family Member](#)

Available Activities

[View All](#)

Sleep and Fatigue (Version: 1)

Estimated Time: 5 min - 10 min

This survey asks questions about sleep and fatigue and how they affect your life. We'll ask these questions every 3 months so that we understand how your sleep and fatigue change over time and so that you can track the information for yourself.

[Begin Survey](#)

Mental Health (Version: 1)

Estimated Time: 5 min

This survey asks questions about how you feel about your life. We ask these questions to understand how FSHD affects mental health. We'll ask these questions every 3 months so that we understand how your mental health changes over time and so that you can track the information for yourself.

[Begin Survey](#)

Diagnosis Journey (Version: 1)

Estimated Time: 10 min

This survey asks questions about your experience getting diagnosed with FSHD. We ask these questions to better understand your personal journey with FSHD, and so that doctors and researchers can learn how to improve the diagnosis process.

[Begin Survey](#)

Insights and Recommendations

[View All](#)

Using HIPAA to Make Sure You Are Treatment Ready

Make sure your doctor adds G71.02 to your medical record

Advocacy

Clinical Research

Drug Development

Show More Tags

Read more

Muscle fatigue in muscular dystrophies

Research study on the nature of fatigue in FSHD and other NMDs

Fatigue

Read more

Achievement Badges

[View All](#)

Apprentice

Citizen Scientist

Research Superhero

Health Diary

Today's Check-In

How would you rate your overall muscle weakness today, if any?

1

2

3

4

5

6

7

8

9

10

No weakness

Worst imaginable weakness

How would you rate your overall pain today, if any?

1

2

3

4

5

6

7

8

9

10

No pain

Worst imaginable pain

How would you rate your fatigue today, if any?

1

2

3

4

5

6

7

8

9

10

No fatigue

Worst imaginable fatigue

Submit

My Stats

[View All](#)

No, I don't have this problem: 50.00%

Inside BetterLife: Personalized feeds

Research Opportunities:

Insights and Recommendations:

Search

Active filters

Unread Only

Categories: English

Tags: Breathing Problems

Filter

Emergency considerations for FSHD patients

Reviewed by Dr. Joshua Benditt, a guide for EMTs and ER doctors on how to correctly manage a person with FSHD who is in respiratory distress.

Breathing Problems

Read more

Treating FSHD: A Broader View with Nicol Voermans, MD PhD, and Nathaniël Rasing, MD

Treat all aspects of FSHD to optimize your well-being

Breathing Problems

Diet and Nutrition

Drug Development

Show More Tags

Read more

Breathing with FSHD

Excellent overview on breathing issues for people with neuromuscular disease

Breathing Problems

Sleep Problems

Read more

Abdominal and breathing exercises for FSHD

Frank Hanley's Qi Gong exercises for breathing and core strength

Breathing Problems

Core Weakness

Exercise

Read more

Search

Active filters

Personal Matching: Good Match & Possible Match

Countries: CA

Study Status: Active, not recruiting, Enrolling by invitation & Recruiting

Good Match

Dietary Protein Requirements in Adults With Facioscapulohumeral Muscular Dystrophy

McGill University

Age: 26 - 60 years

Status: Recruiting

Study Type: INTERVENTIONAL Phase: NA

Facioscapulohumeral muscular dystrophy (FSHD) is one of the most common types of muscular dystrophy, affecting about 4 out of 100,000 individuals. The diseas...

Expanded Details

Good Match

Motor Outcomes to Validate Evaluations in FSHD (MOVE FSHD)

University of Kansas Medical Center

Age: N/A - N/A years

Status: Recruiting

Study Type: OBSERVATIONAL Phase:

The primary goal of this proposal is to collect motor and functional outcomes specific to FSHD over time. By collecting measures specific to FSHD, this will help ensu...

Expanded Details

Good Match

Study to Evaluate the Efficacy and Safety of Satralizumab in FSHD1

Centre Hospitalier Universitaire de Nice

Age: 18 - 65 years

Status: Active Not Recruiting

Study Type: INTERVENTIONAL Phase: PHASE2

Facioscapulohumeral muscular dystrophy (FSHD) is characterized by clinical diversity, with FSHD1 being the most common form. It is associated with a toxic gain of...

Expanded Details

Good Match

Phase 1/2 Study of AOC 1020 in Participants With Facioscapulohumeral Muscular Dystrophy (FSHD)

Avidity Biosciences, Inc.

Age: 16 - 70 years

Status: Active Not Recruiting

Study Type: INTERVENTIONAL Phase: PHASE1

A Randomized, Double-blind, Placebo-controlled, Phase 1/2 Study to Evaluate the Safety, Tolerability, Pharmacokinetics, Pharmacodynamics, and Exploratory...

Expanded Details

Inside BetterLife: Data visuals

Health Diary

Today's Check-In

How would you rate your overall muscle weakness today, if any?



No weakness Worst imaginable weakness

How would you rate your overall pain today, if any?



No pain Worst imaginable pain

How would you rate your fatigue today, if any?



No fatigue Worst imaginable fatigue

Submit

Average response for "How would you rate your overall muscle weakness today, if any?"

6.3

Average response for "How would you rate your overall pain today, if any?"

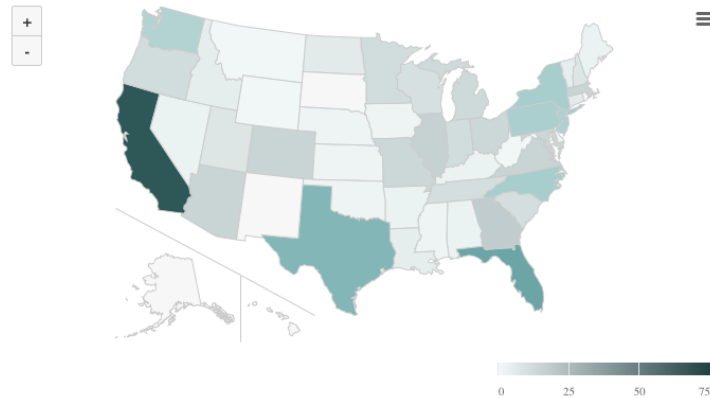
4.0

Average response for "How would you rate your fatigue today, if any?"

6.0

Who are the BetterLife FSHD participants?

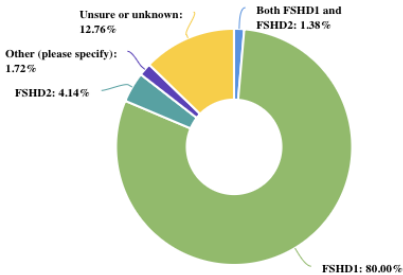
Location



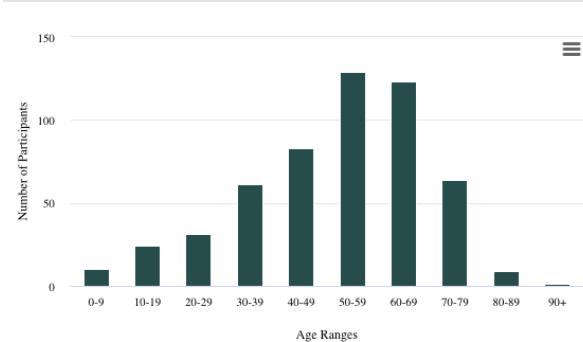
Total Participants

536

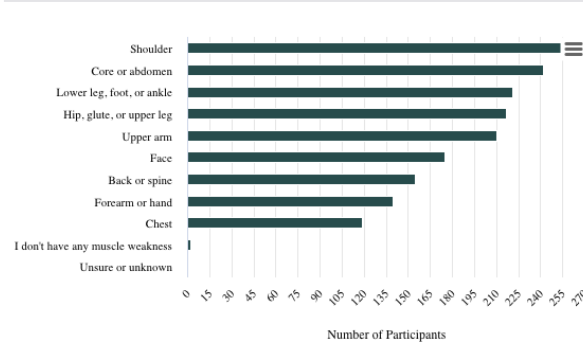
Type of FSHD (if genetically tested)



Age



Areas of Muscle Weakness



What users are saying so far

INFORMATIVE

It's the first place I've seen some answers.

It has information we don't get elsewhere.

I have learned a lot of information from this website.

SENSE OF COMMUNITY

Makes you feel like you're not alone.

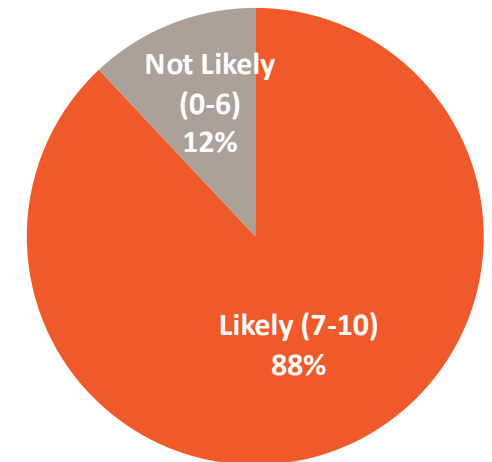
I just think it's always a good idea to try to stay together as a community and share information.

EXCITED TO CONTRIBUTE

It feels like am contributing to the cause with a professional group I trust.

I think the platform is an interesting opportunity to contribute data!

How likely are you to recommend BetterLife?



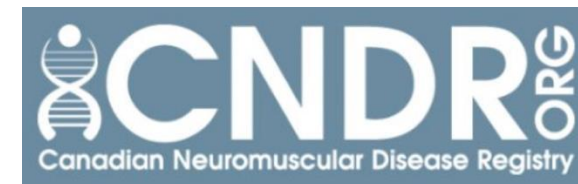
Coming soon...



Late summer 2025

Linked to clinical data in CNDR

→ **Register with CNDR now!**



How BetterLife speeds research



Core Dataset

- Demographics, health history
- Clinical and genetic diagnosis
- FSHD weakness and other symptoms



Health Tracking

- Pain, fatigue, sleep, mental health
- Physical activity, exercise, diet
- Daily activities, falls

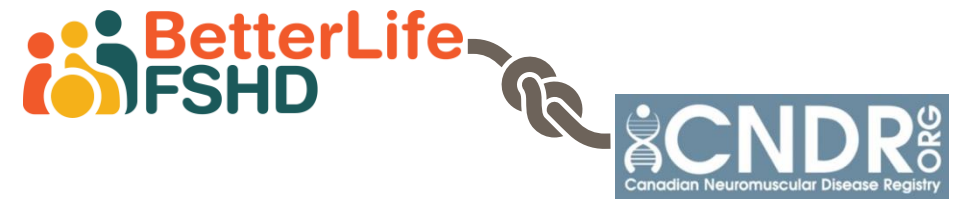


Additional Research Topics

- Clinical trial preferences
- Diagnosis journey
- Healthcare interactions

Sharing data securely:

1. Your personal information is removed from your health data.
2. Researchers make a request to use the health data.
 - Used to plan clinical trials, understand natural history, study genetics, etc.
3. Researchers can use the platform to run new surveys or studies.
4. Researchers can ask the BetterLife team to notify you of trials and other studies.



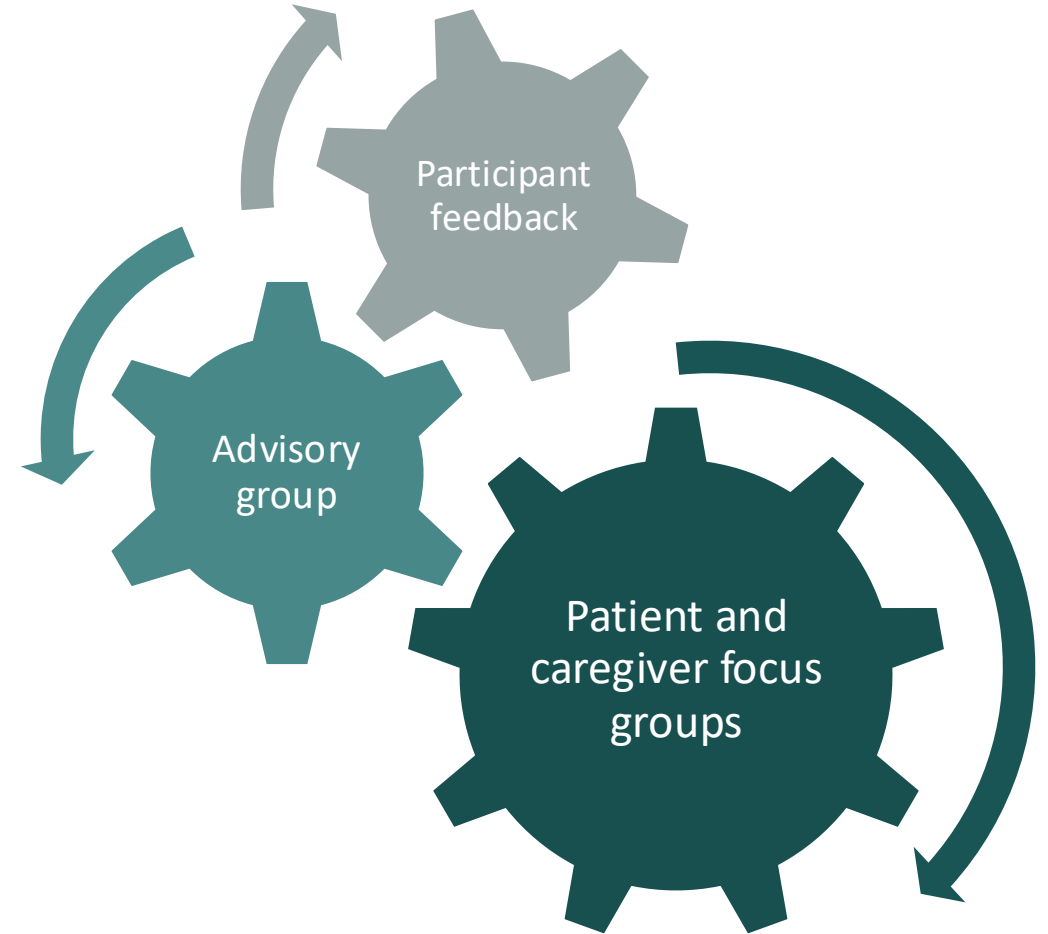
Making BetterLife better, together

Personal data tool +
resources to help your
doctors understand
FSHD

More ways to visualize
your data and track
over time

AI-driven insights and
information

Expanded health diary
features



Questions?