

Study Name:	Motor Outcomes to Validate Evaluations in FSHD (MOVE FSHD)
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Introduction and Purpose of the Study	The primary goal of this study is to hasten drug development in FSHD and improve care delivery (in-person or telehealth). This study will collect motor and functional outcomes specific to FSHD over time. It will help us understand how FSHD impacts motor function and other health outcomes, and how these changes are clinically meaningful.
How many people will participate?	We are seeking 450 volunteers to participate in this study.
If I am eligible, what will I do?	If you have genetically confirmed FSHD (Type 1 or 2) or diagnosed by a doctor with FSHD AND an affected parent or child, then you will be eligible. Participants of all ages are accepted. Visits will take place on or near the date of your standard clinic visit. If you are not seen in clinic, you can still participate. Each visit will include health-related questionnaires, strength and motor function assessments, and a physical exam. There is an optional blood draw and saliva test. There will be at least 3 visits over 3 years.
How much will this cost me?	There is no cost to participate in this study.
Can you help me with my travel expenses?	This study is designed to coincide with your regular clinic visits, so there will be no reimbursement for travel costs.

THANK YOU FOR YOUR CONSIDERATION.

Who can I contact for more information?

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