

How the FSHD Society Serves the FSHD Community

Amanda Hill, MBA, ACRP
Director of Clinical Research



**Partner
Family
Friends**



**Others
w/FSHD
Doctors
Health
Partners**

Vision: a world free from suffering caused by FSHD



Research

Clinical Trials

**Approval &
Access**

Health & Care



Research

Clinical Trials

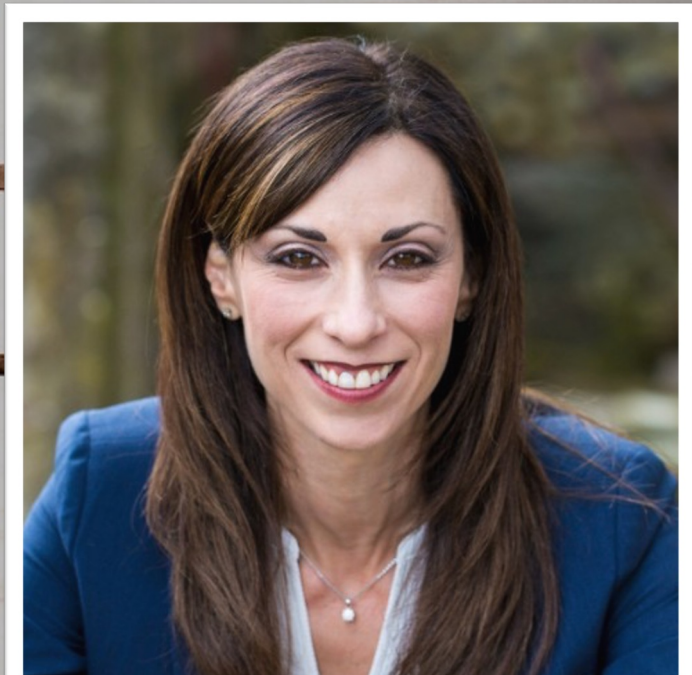
**Approval &
Access**

Health & Care

**Lucienne Ronco, PhD
Chief Scientific Officer**



**Michelle Mellion, MD
Medical Advisor**



CONNECT ~ LEARN ~ TAKE ACTION

360 Events

Local Chapters

FSHD Navigator

Walk & Roll to Cure FSHD

BetterLife FSHD

FSHD Straight Talk

Gathering Place

FSHD University

Advocacy



BetterLife FSHD:
A patient-driven health
and research platform

Amanda Hill, MBA, ACRP
Director of Clinical Research



What barriers do you face in living your best life with FSHD?

*Constant loss and
adaptation*

*Understanding my own
body*

Information overload

*Access to clinical trials
(and therapies)*

*Doctors don't
understand FSHD*

A cure!

BetterLife FSHD: a patient-driven health and research platform

Goal 1: Help you live a better life with FSHD


- Personalized resources and data tracking
- Match to research opportunities

Goal 2: Speed and improve FSHD research and therapeutic development

- Securely use and share data
- Research to advance disease understanding, clinical trials, clinical care, access, and advocacy





How does BetterLife FSHD work?





Create your account


Enter your email and password to create your account

Thomas 

Spratt 


Thomas.spratt@mail.com 

Thomas.spratt@mail.com 

***** 

Passwords must:


- ✔ Have at least 8 characters in length
- ✔ Lower case letters (a-z)
- ✔ Upper case letters (A-Z)
- ✔ Numbers (i.e. 0-9)
- ✔ Special characters (e.g. !@#\$%^&*)



Check your email

We sent you an email with instructions on how to complete your sign up

If you do not see an email in your inbox, please check your spam or junk folder

 sample@mail.com

[Resend email](#)

[I've verified my email](#)

[Back to create your account](#)

1

Create your account

- Adults create an account for themselves and/or children
- Informed consent process
- Fill out a profile(s)

How does BetterLife FSHD work?

The screenshot displays the 'Activities' section of the BetterLife FSHD interface. At the top, there are tabs for 'CURRENT', 'UPCOMING', and 'PAST', along with a 'FILTERS' dropdown. Below the tabs, the page is organized into two main sections: 'Due Immediately' and 'Due This Week'. Each section contains a list of activities. The first activity in 'Due Immediately' is 'Survey 2', which is marked as 'OVERDUE' and 'REQUIRED'. The second activity in 'Due This Week' is 'Survey title', also marked as 'OVERDUE' and 'REQUIRED'. The third activity in 'Due This Week' is 'Share Your Medical Records', which is marked as '3 DAYS LEFT TO COMPLETE'. Each activity card includes a title, a description, an estimated time, and a 'Start' button.

Activities **CURRENT** UPCOMING PAST | FILTERS

Due Immediately

Survey 2 ESTIMATED TIME: 15 MIN
Survey
Magna non feugiat fermentum non. Porta elit orci, varius nunc elementum lectus.
Gravida fermentum risus et arcu.
OVERDUE REQUIRED Start survey >

Due This Week

Survey title ESTIMATED TIME: 15 MIN
Survey
Magna non feugiat fermentum non. Porta elit orci, varius nunc elementum lectus.
Gravida fermentum risus et arcu.
OVERDUE REQUIRED Start survey >

Share Your Medical Records ESTIMATED TIME: 5 MIN
Medical Records
Magna non feugiat fermentum non. Porta elit orci, varius nunc elementum lectus.
Gravida fermentum risus et arcu.
3 DAYS LEFT TO COMPLETE Start Sharing >

2

Start taking surveys

- Clinical and genetic diagnoses
- Establish what your symptoms are
- How FSHD affects you now

How does BetterLife FSHD work?

Fatigue Tracker

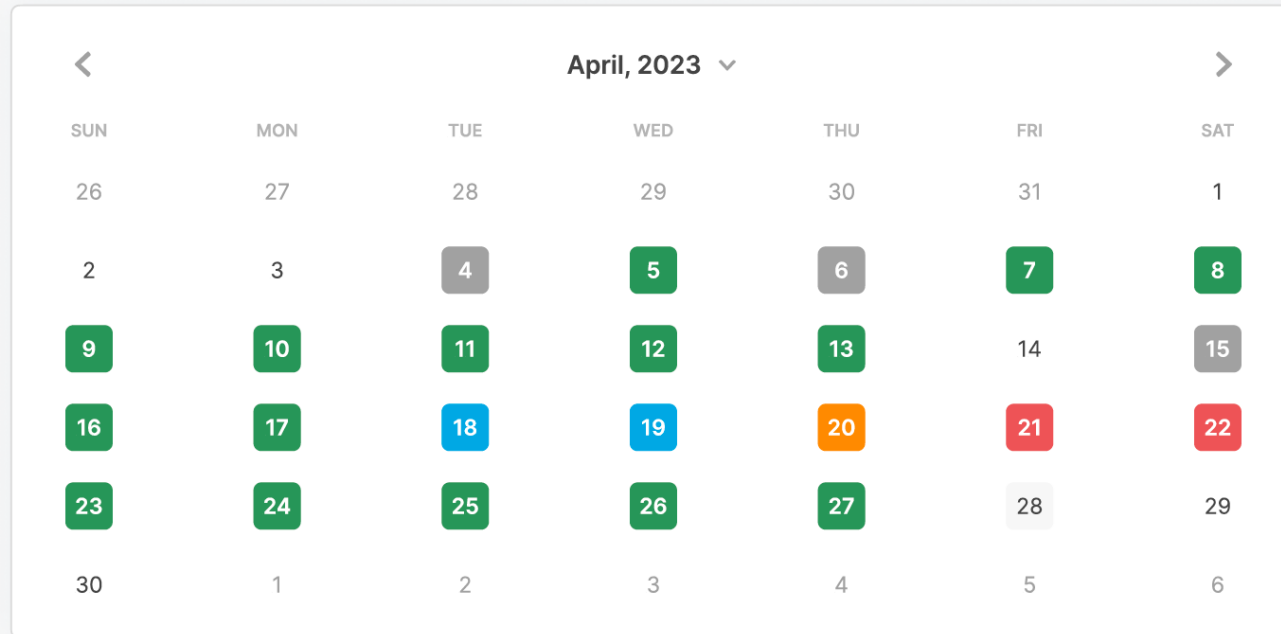
+ Add

FILTERS

Keep track of your pain and the fatigue impacts on your life over the calendar year.

By answering these questions each time you log-in, we'll be able to fill in the heat map to the right and organize your responses into a report. We hope this will help inform conversations with your doctor.

● Not bothered by fatigue ● A little ● Somewhat ● Very ● Extremely



3

Track your health over time

- New surveys every couple months
- Symptom tracking and data visualization

How does BetterLife FSHD work?

How is FSHD genetic testing done?

The individual being tested needs to provide a DNA sample, usually collected by a blood draw. DNA can also be obtained from skin, saliva (containing cells from the mouth), etc. But for genetic testing, a blood sample is standard.



READ



HELPFUL

[Learn more >](#)

Is There a Prenatal Test for FSHD?

Yes. Using the same technology as in the DNA test described above, prenatal testing is possible. Those who are interested in a prenatal test for FSHD should consult their physician and the genetic testing laboratories...



READ



NOT HELPFUL

[Learn more >](#)

How is FSHD genetic testing done?

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READ



FEEDBACK

[Learn more >](#)

4

Get personalized insights

- Relevant information and resources when you need it
- Matched to clinical trials and other research studies
- Personalized feed

How does BetterLife FSHD work?

Search FILTERS

FSHD biomarker study
by Dr. Leo Wong, University of Washington, Seattle
The University of Washington is seeking individuals to participate in a research study aimed at identifying biomarkers of Facioscapulohumeral Dystrophy (FSHD)...

+ STATUS Learn more >

Neurological and Psychiatric Comorbidities Patients With FSHD 1 and 2
Hospitalier Universitaire de Nice, France
The investigators propose to conduct a comparative pilot cognitive and psychiatric profiles of 10 patients FSHD) type 1 and 10 patients...

ENROLLED

The Wellstone Mus recruiting families t
Principal Investigators: Gen Kennedy Krieger Institute, etc.
The study is especially see

INELIGIBLE

Active Poll: Poll closes: 12-Jun-2024

Question:
How would you rate your stress level

Low

Moderate

High

Very high

None

Submit

5

Contribute to groundbreaking research

- Health data is securely shared with approved researchers while your privacy is protected
- Interactive community polling for our own community scientists

Who can join BetterLife FSHD?

- Anyone with FSHD
- Living in the United States
- 1 year of age or older

Anyone who is not an adult (18 years old in most states) must have permission from a parent or legal guardian to join.

If you are not an adult, your parent should sign up for BetterLife with their information, then create a profile for you in their account.



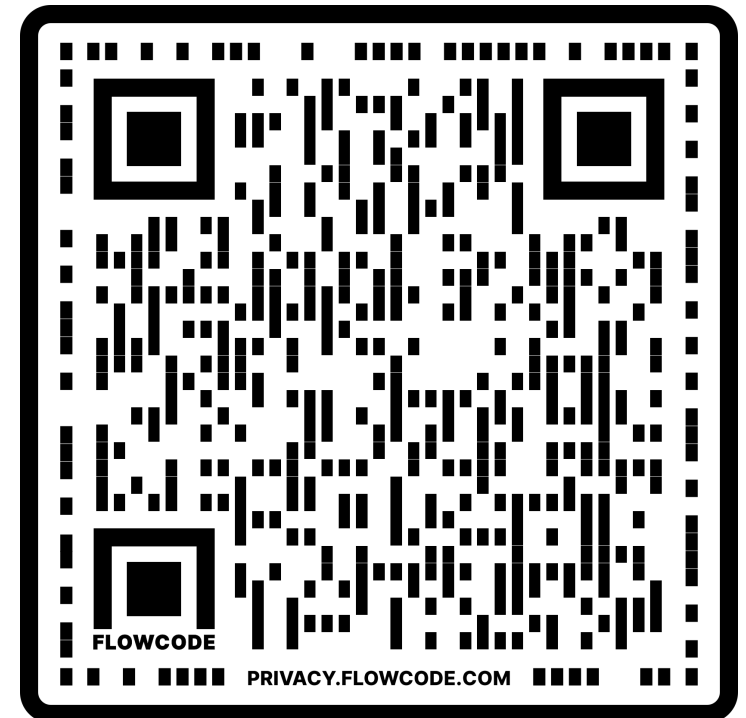
When can I join BetterLife?

BetterLife Launches Summer 2024!

Exclusive invitation to Connect attendees:

Volunteer for a chance to join the pilot group!

- Early access to BetterLife
- Provide feedback and user testimony
- Time commitment of 3-4 hours over ~2 weeks





BetterLife
FSHD