

Lessons from the



FSHD
NAVIGATOR



Provide Support &
Guidance

Make Connections

Journeying
together

Identify Resources

Engage patients
in research

Using a relationship-centered approach to connect the FSHD community to resources, information, guidance, and opportunities to contribute, empowering patients to live their best life possible with FSHD.

A stronger, more interwoven network





FSHD NAVIGATOR

We'll help you find the resources you need, no matter where you are on your journey with FSHD.

 **CONNECT VIA EMAIL**

Navigator@fshdsociety.org

 **CONNECT VIA PHONE**

781-301-6060 x4000

 **SUBMIT YOUR QUESTION(S)**

www.fshdsociety.org/Navigator

Who are the Navigators?

- Fellow FSH'ers!
- Dedicated volunteers
- Passionate community members
- Have an area of expertise
 - Need some “generalists”



What have we learned?

Most frequently asked question: Do you know a doctor in my area who sees other FSHD patients?

Coming soon: web tool you can browse (and add to!)

Find Doctors & Resources

Use this tool to find resources and providers near you. If you need guidance, see our category guides below. Asterisk (*) indicates required field.


* Category

* Support Type

* Zip Code

* Distance

Search

Financial Resources

- Gap: Funding for ongoing/recurring expenses
- Many grant programs are state-based
 - Also search within your city & county
- ABLE accounts
- Vocational Rehab Office – one in every state!
 - Client Assistance Program (CAP)
 - Can help subsidize training & college tuition
- JAN: Job Accommodation Network

Are you our next Navigator?

- Training
- Breaking news
- Giving back to your community

“Thank you for all of the background information you sent and all of your answers to my questions. You encouraged me when I was having a challenging time getting help and I am so very grateful.

I know you impact a lot of people. You were truly a godsend and I thank you for all of the time you gave to help me.”

- Want in? Email: Navigator@fshdsociety.org

Government Advocacy

- **Legislative**
- **Regulators**
- **Payor system**

Thank you to Daniel Paul Perez

- Started advocating for research funding in 1994
- Has testified before congressional committees nearly 50 times
- Provides regular written testimony to ensure ongoing NIH funding for FSHD research
- Photo cred: Don Burke



May 8th, 2024: FSHD Day on Capitol Hill!





Thank you KPM Group DC for preparing us!







Inaugural
Successes:

- 12 FSHD families
- 4 groups
- 15 meetings



Thanks to all who supported these efforts!

Attendees:

- Don Burke
- Chris & Laura Carrino
- Mark & Renee Christman
- Debbie & Maggie Eggleston
- Mollie Garrett
- Gregg & Ellen Lichtenstein
- Amy & Chris Lowden
- Laura Maffei
- Ally Roets & Sam Ray
- Gary Lauck
- Lexi Pappas-LeVine
- Vera, Rich, Isla, & Siena Treonze

Supporters:

- Ann Areson
- Abby DeVisser
- Len Goldberg
- Roy Stang
- Jim Wilkinson
- Kristin Zwickau

The latest update:

Rep. Debbie Dingell (MI-6) and Rep. Mike Kelly (PA-16) have agreed to co-sponsor a Resolution to recognize World FSHD Day!



What YOU can do now:

- www.fshdsociety.org/advocacy
- Find your Congressional Representative
- Ask them to support this resolution!

FDA Listening Session: Upper Body Mobility

August 23rd, 2024



- Get FSHD back in front of the FDA
- What's important in a future treatment?
- Better understanding = More effective review & regulation of future treatments



Why Upper Body
Mobility?

Tell us YOUR story



EMAIL:
NAVIGATOR@FSHDSOCIETY.ORG



SUBMIT FORM VIA:
WWW.FSHDSOCIETY.ORG/ADVOCACY



Timeline

- Content due: Mid-July
- Meeting: August 23rd
- Report published:
Late September – Early
October



Looking Ahead:
Insurance
coverage for
future therapies

*Stay tuned for how you
can get in on the action!*

