Lessons from the



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.





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







Navigator@fshdsociety.org

781-301-6060 x4000

www.fshdsociety.org/Navigator



Who are the Navigators?

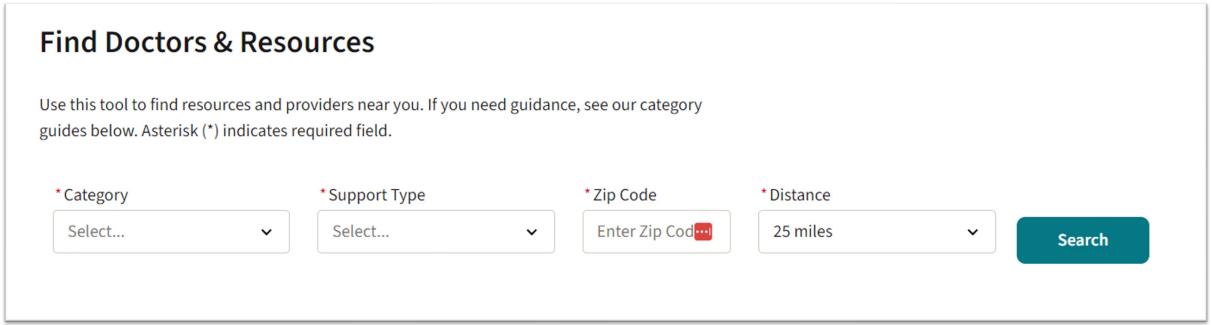
- Fellow FSH'ers!
- Dedicated volunteers
- Passionate community members
- Have an area of expertise
 - Need some "generalists"



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!)





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.

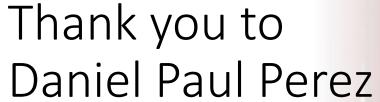
I know you impact a lot of people. You were truly a godsend and I thank you for all of the time you gave to help me."

Want in? Email: <u>Navigator@fshdsociety.org</u>









- 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







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!



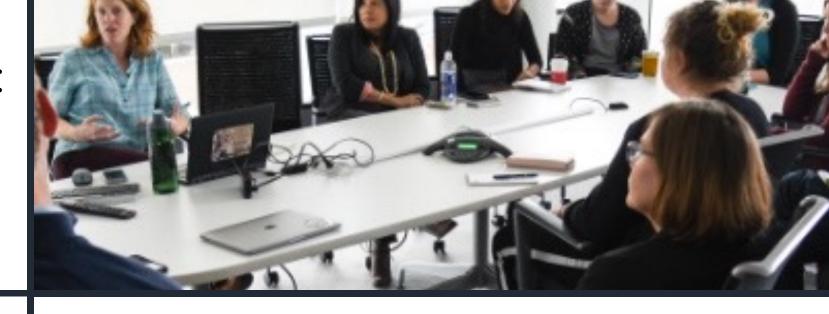
What YOU can do now:

- 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



Tell us YOUR story





EMAIL: NAVIGATOR@FSHDSOCIETY.ORG

SUBMIT FORM VIA: WWW.FSHDSOCIETY.ORG/ADVOCACY



Looking Ahead: Insurance coverage for future therapies

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





