

2024

\$5.9 MILLION

TOTAL MISSIONAL
INVESTMENT



FSHD SOCIETY
LIGHTING THE WAY TO A CURE
2024 IMPACT REPORT

EXPANDING & DEEPENING OUR COMMUNITY

Through **119** support gatherings, podcasts, and educational webinars, we provided opportunities for connection and learning.

These activities generated over **18,000** points of engagement, helping families find the support they need.

DRIVING CHANGE THROUGH ADVOCACY AND REGULATORY ENGAGEMENT

Through our comprehensive advocacy and regulatory engagement efforts, the FSHD Society is *accelerating the path to effective treatments*. By fostering collaboration among researchers, clinicians, pharmaceutical companies, regulators, and insurers, we ensure that the patient voice is central in every phase of therapy development.

RESEARCHERS & CLINICIANS

Over **400 individuals** contributed to advancing clinical research and therapy development for FSHD by donating data, bio-samples, and time to Natural History and biomarker studies.

PHARMACEUTICALS

Dozens of individuals participated in advisory meetings, guiding companies on the patient journey, treatment protocols, and trial design to ensure the patient voice is represented.

EXPANDING & DEEPENING OUR COMMUNITY

(CONTINUED)

REGULATORS

Advocates amplified the patient voice and raised awareness in Congress, while others provided testimony at an FDA listening session, *attended by over 40 regulators*, on the critical importance of upper body mobility.

INSURERS

Through our Navigator initiative, we are launching a *targeted, data-informed advocacy strategy* to ensure adequate reimbursement and access as effective treatments become available.

BUILDING A STRONGER NETWORK

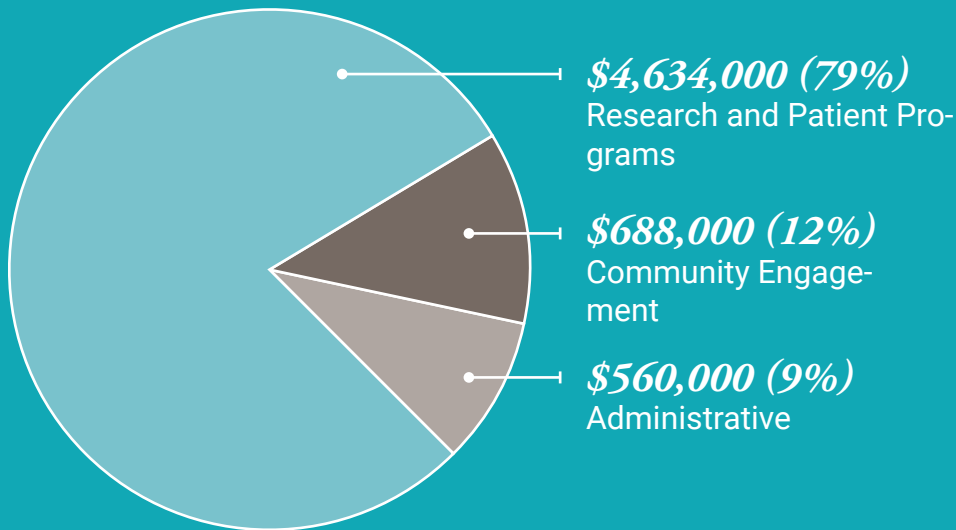
The Society's newly launched *FSHD Navigator Program* profoundly enhances our mission by providing personalized assistance to individuals and families affected by FSHD. By connecting them with essential resources, local support groups, and clinical trials, the Navigator ensures that no one faces FSHD alone, empowering our community to live their best lives.

33 active chapters held **98** meetings, engaging over **900** members across the country.

Volunteer Impact: In the past year, **120 volunteer** leaders guided and supported an army of advocates working to advance awareness, education, and advocacy. Thousands of volunteers mobilized in their communities, driving meaningful change and raising **\$1.5 million in mission-driven funds** to support the FSHD Society.

FINANCIALS

\$ 5,882,000
total missional investment



ADVANCING RESEARCH

INTERNATIONAL RESEARCH CONGRESS

Brought together **246** participants from **98** organizations, **33** countries, and **24** companies, driving research forward.

CLINICAL TRIAL RESEARCH NETWORK:

Expanded to **32** sites globally, covering **11** countries and **5** continents, ensuring more patients can join studies that bring us closer to a cure.

BETTERLIFE FSHD: A GAME-CHANGER FOR PATIENTS AND RESEARCH

- This new health and research platform was built to help people with FSHD *live better lives* while pushing research forward.
- In its first few months, BetterLife enrolled **388 people in 42 states**.
- Participants completed **1500 surveys**, sharing valuable data to support research.

PAVING THE WAY FOR FUTURE BREAKTHROUGHS

Global FSHD Innovation Hub:

This new platform, launched by the FSHD Society, is helping the research community prepare for more clinical trials. By expanding trial sites and streamlining enrollment, *we are moving faster toward treatments and a cure.*

YOUR SUPPORT HAS PROPELLED US FORWARD

Scan to
access our
financial
information



75 North Main Street, Suite 1073, Randolph, MA 02368 • fshdsociety.org