

FSHD SOCIETY



2025



What we did,
together.



Moving Forward in Turbulent Times

Despite a tumultuous year, 2025 brought extraordinary momentum for the FSHD Society and proved what's possible when generosity meets purpose. While national uncertainty and shifting policies created challenges, our community held fast. Supporters across the United States and Canada invested in initiatives that laid the groundwork for a transformative 2026.

Industry partners, individual donors, and hundreds of volunteer fundraisers contributed millions of dollars to advance our mission. The community gathered and gave, and we gained critical ground as a result.

In fact, 2025 marked our most successful year of event fundraising ever. Supporters turned out for Walk & Rolls in record numbers, logged miles in endurance events, and created unique fundraisers to turn hope into action.

Donor generosity and advocacy opened new federal research funding pathways, engaged regulators shaping future clinical trials, and expanded global trial networks. You strengthened our community through chapters, support groups, volunteer leadership, and trusted education for families and clinicians.

From enhancing platforms like BetterLife to launching the Care Connector and hosting the largest International Research Congress on FSHD to date, your partnership accelerated progress worldwide.

Thank you for believing in this moment and in this community. We celebrate the achievements of 2025 and look ahead to a 2026 poised to power the path toward treatments and a cure.

Forward Together,



Mark Stone FSHD Society CEO



Scan to review the Society's financial information & meet the Board of Directors.

Financials

\$3,979,000

Research, Education, Global Initiative

60%

\$1,479,000

Advocacy, Community Engagement, Awareness

22%

\$831,000

Fundraising

13%

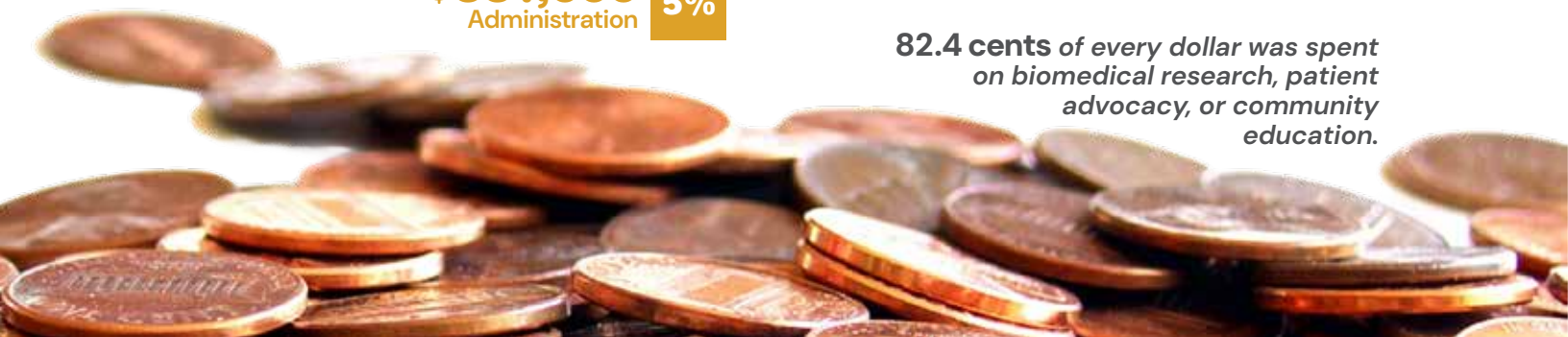
\$331,000

Administration

5%

2025 EXPENSES
TOTAL: \$6,620,000

82.4 cents of every dollar was spent on biomedical research, patient advocacy, or community education.



Research, Education & Global Initiatives

Research

- ▶ **BetterLife FSHD**, the Society's unique health and research platform, celebrated its first full year of participant support and data collection.



In 2025, BetterLife supported 642 individuals with FSHD in 48 different states across the U.S. (a 65% growth in users from 2024).

- Participants completed 5,000 surveys which have supported 9 research opportunities so far.

- ▶ **The 2025 International Research Congress** on FSHD, hosted in Amsterdam, marked the Society's largest and most globally engaged research meeting to date, with 345 total attendees representing 30 countries.

Attendance continued its upward trajectory from 2023 and 2024, reflecting growing global momentum in FSHD research, with the U.S., the Netherlands, and Italy leading participation.

- ▶ Growth continued across the **FSHD Clinical Trial Research Network** and the **European Trial Network**, with 21 sites in North America and 11 throughout Europe, South America, Australia, and Asia, for a total of 32 sites globally.

Education

- ▶ The Society hosted four **FSHD 360 Regional Conferences** across North America — in Ontario, Vancouver, Philadelphia, and Atlanta — bringing together 208 participants for a full-day of presentations, connection, and resources. With presenters from academia, industry, clinics, and the patient and caregiver community, our FSHD 360s continue to equip individuals with the knowledge and tools they need to navigate FSHD while strengthening care across the FSHD ecosystem.
- ▶ The Society delivered 18 **FSHD University** webinars, covering critical topics such as mental health, exercise, research advances, and day-to-day care management.
 - 23 experts, including leading clinicians, researchers, and community voices, engaged directly with audiences, answering 358 community questions and reaching more than 1,300 live participants throughout the year.



- ▶ **FSHD Frontline:** In August, the Society launched FSHD Frontline, a dedicated newsletter designed to keep clinicians and researchers informed, engaged, and connected to the evolving FSHD landscape. Each month, Frontline reaches more than 900 healthcare providers and researchers. Featuring research updates, clinical care insights, and practical tools to support patient care, FSHD Frontline strengthens our ability to equip the medical and research community with the knowledge needed to deliver high-quality, evidence-based care.

Global Initiatives

- ▶ Hosted quarterly, **World FSHD Alliance meetings** united leaders from 36 FSHD organizations across 30 countries. The Alliance fosters the growth and development of FSHD patient advocacy organizations worldwide.
- ▶ The FSHD Society was proud to support **FSHD Europe's first Connect Conference** as they brought together patients and families. The event quickly reached full capacity, and everyone is already excitedly planning for the 2027 gathering.
- ▶ **Project Mercury** achieved several significant milestones this year in its efforts to accelerate clinical trials globally and establish the foundation for patient access to future treatments:
 - Over 10,000 FSHD patients are now enrolled in registries across the 10 Project Mercury countries.
 - FSHD clinical trial sites have doubled since the launch of Project Mercury in 2023.

"FSHD Spain joined Project Mercury with the belief that collective action can lead to real progress for patients.

For us, every step we take as part of Project Mercury is fueled by the voices and hopes of our community—and that makes this collaboration feel urgent."

Ricardo Gerpe FSHD Spain



Global FSHD Innovation Hub

- ▶ The Hub advanced the **Industry Collaborative**, a clinical research initiative bringing together drug development companies to execute projects to understand and validate biomarkers and clinical trial measures.
 - 2025 was a building year focused on significant investments in technology and partnership infrastructures.
 - We began analyzing Fulcrum clinical trial data and building clinical tests to measure biomarkers to improve potential accelerated drug approval pathways.
 - Results from these clinical tests also have the potential to shorten clinical trials and expand treatment label criteria.
 - Worked with > 6 companies to support future potential FSHD clinical trials testing muscle regeneration therapies for FSHD.
- ▶ The Hub also launched **FOCUS**, the world's first FSHD clinical data warehouse. This virtual database provides access to and learnings from highly valuable patient clinical data to improve drug development and accelerate research.
 - FOCUS data will be crucial to the Industry Collaborative's biomarker and outcome measures validation work.
 - FOCUS launched with data available from more than 10 clinical trial endpoints.

BIOMEDICAL ENDPOINT EXAMPLES

- Muscle biopsy transcript data
- MRI results

FUNCTIONAL ENDPOINT EXAMPLES

- Reachable workspace
- Timed up-and-go measurement

Advocacy, Community Engagement, Awareness

Advocacy

► Peer Reviewed Medical Research Program

In collaboration with the MDA, the FSHD Society pursued this new source of research funding within the Department of Defense. Volunteer advocates called, wrote, and emailed legislators, and participated in more than 10 meetings with Senators to ask for access to this grant program. Thanks to their openness and persistence, FSHD is one of 52 conditions eligible to access this \$370 million pool.

► **Engagement with the FDA** for a second year in a row led to a meaningful conversation about FSHD, this time through a scientific workshop covering three main topic areas – Clinical Outcome Assessments, MRI, and Biomarkers. The goal was to help the FDA understand the challenges and opportunities in clinical research in FSHD. Success means that regulators will better understand and interpret future clinical trial data.

“Now is a critical time for our community to work collaboratively with our regulatory partners to understand these important clinical trial endpoints that support the development of disease modifying or potentially curative therapies.”

Michelle Mellion
Medical Advisor for the FSHD Society



Thanks to the tenacity of volunteer advocate and fundraiser, Joanne Dalessandro, Illinois Governor JB Pritzker signed a state proclamation designating June 20th as FSHD Day in Illinois. This official recognition raises public awareness and encourages people to learn more about this rare genetic disease.



Community

Community engagement, the bedrock of Society success, continued growing and improving.

► Chapter Program

- 33 Active Chapters across the U.S. and Canada
 - 86 Local Chapter Meetings and 5 multi-chapter regional meetings connected more than 600 people.
 - 2 new Chapters launched, one in Iowa and one in Quebec, Canada.
- More than 100 community members found connection and support through eight virtual **Gathering Place** support groups. These volunteer-led groups bring participants together from around the world to share experiences, offer encouragement, and remind one another that no one has to navigate FSHD alone.
- **The Parents Roundtable** group participated in and guided research, and engaged with industry partners, driving advocacy on behalf of young people with FSHD.
- **Volunteer Leadership Summit**, for the seventh consecutive year, brought together Society volunteers from across the U.S. and Canada. Attended by nearly 100 virtual and in-person participants, this event educates and connects our volunteers, who generously give their time and talents to serve the FSHD community.



Care Connector

Launched in February, this online directory includes over 61,000 providers listed across 63 specialties with FSHD knowledge. Phase 2 features and Canadian expansion coming soon!

Awareness

- In May, the Society unveiled a brand refresh, adopting a new look, tagline, logo, and user-friendly website. Our new brand signals our readiness to power the path forward toward FSHD progress.
- We gained almost 5,000 followers, increasing our social media audience to nearly 20,000 across all our platforms.
- We gained 398 followers on YouTube. Viewers watched 4,102 hours of our content.
- Tim Hollenback hosted 35 guests across 24 episodes of the Society's FSHD Straight Talk podcast.

FSHD
SOCIETY
POWERING THE PATH FORWARD



Fundraising

Donor generosity demonstrated confidence in the Society's ability to make an impact and reflected the urgency and excitement of the moment we're in.

Individual Giving

- ▶ 921 donors contributed more than \$2.3 million to the Society's annual fund.
 - Of those donors, 169 gave 219 gifts of \$1,000 or more, providing crucial leadership dollars to ensure key initiatives continue without disruption.
- ▶ 130 donors gave monthly, providing reliable year-round support. As recurring givers, these Torchbearers collectively contributed more than \$77,000 – an impact few of us can make alone.
- ▶ 93 companies matched employee gifts, exceeding \$55,000 in additional dollars and community support.



The Society received donations from 31 countries and all 50 states.

Event Fundraising

Raising \$1,384,000, it was a record-setting year for special event fundraising, proving what's possible when our community rallies with purpose.

The Walk & Roll to Cure FSHD was hope in motion: Families and friends rallying to give support and spread awareness during a multi-month series of events.

Walk & Roll to Cure FSHD

- ▶ \$1,258,000 raised.
- ▶ 26 Walk & Roll events across the U.S. and Canada
- ▶ Participation grew by 28% with 2151 participants across 170 teams.
- ▶ \$576 raised on average per participant.
- ▶ \$7,284 raised on average per team.



Chicagoland Walk & Roll

The Chicagoland Walk & Roll set new records for attendance and dollars raised with an incredible 361 participants contributing \$209,000.



The extraordinary generosity and spirit carried through the year with our Endurance and DIY events, keeping the momentum going. Road races, golf tournaments, lemonade stands, and bracelet sales – the FSHD community used their time and talents to show up for one another in ways both big and small.

Endurance Events

► \$85,000 raised across many miles.

- Falmouth Road Race
- El Tour de Tucson
- Triple Bypass Bike Ride
- Twin Cities Marathon

DIY Events

► \$40,000 raised by people using their unique skills and passions to make an impact.



Tour de Tucson

Team FSHD raised a remarkable \$55K. These funds will support early onset initiatives, including a pediatric MRI study to help fill in the gaps in pediatric-focused natural history research.



North Carolina Walk & Roll

