

194

+

community engagement opportunities and events

\$

3,330,000

TOTAL REVENUE RAISED

\$ 3

million

Approximately \$3 million invested in research projects and Therapeutic Accelerator initiatives

FSHD SOCIETY
LIGHTING THE WAY TO A CURE

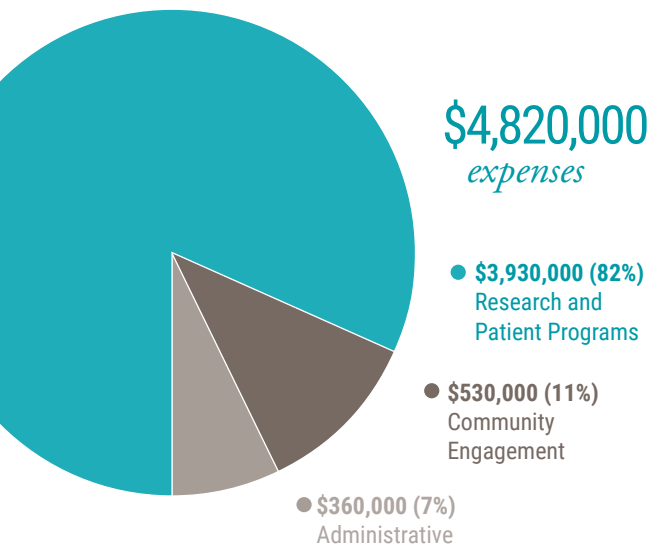
2022 IMPACT REPORT

FINANCIALS

\$3,330,000

total revenue raised

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ADVANCING RESEARCH

Our ability to advance research grew, through continued investment in specific research projects, advancing Therapeutic Accelerator initiatives, and by bringing together an ever-growing network of stakeholders to collaborate, problem solve, and chart the best course forward.

- Direct research funding was utilized to validate blood biomarkers and use AI to identify risk factors for symptom progression.
- The TestFSHD initiative advanced trial-readiness for our community by providing free genetic testing for 150 patients.

- The True Cost of FSHD study gathered information from over 300 households about FSHD-related expenses, so that we can better advocate for insurance coverage of future treatments. Data is currently being analyzed; results are expected to be published in 2023.
- The 29th annual International Research Congress on FSHD brought together researchers and clinicians from all over the world for collaboration and inspiration.
- The Industry Collaborative Workshop congregated key stakeholders to review progress in therapy development and agree on the best course forward.

Our worldwide community grew by 15%, including nearly 600 patients, who've self-identified as being ready and willing to participate in research.

EXPANDING AND DEEPENING COMMUNITY

194+ opportunities to engage with your community and build meaningful connections through a variety of channels, including:

- Gathering Place virtual affinity groups, meeting monthly
- Twice monthly FSHD Radio podcasts
- Local Chapter meetings (including in-person, virtual, and hybrid gatherings), connecting people in their home region
- Monthly educational webinars through FSHD U
- The bi-annual FSHD Patient Connect Conference and quarterly regional FSHD 360 conferences

25% of mission funding was raised through volunteer-led events and local efforts.



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