

**Development
& Creative Fundraising**

2014 FSHD CONNECT

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BOSTON

August 16, 2014



Our Vision & Mission

- Deliver treatments and a cure for FSHD
- Be the catalyst for connecting all of the stakeholders
- Promote research focused on FSHD, through thought leadership, networking and funding

Strategic Imperatives

- **Empower**

- Mobilize patients and communities to take action.

- **Connect & Communicate**

- Serve as the leading source of information and support for all patients and families with FSHD

- **Finance**

- Grow & diversify revenue to invest in research, education, patient support & operational capacity.

- **Knowledge**

- Act as a driving force in the development of research directed towards treatment and cure of FSHD.

Achievements

- Funded over \$5 million in research grants, seeding discoveries that have transformed the field.
- Created a global research program when none existed, by recruiting and funding scientists to undertake FSHD research.
- Convened international research meetings to coordinate a global effort to cure FSHD.
- Empowered a worldwide network of patients and families through education, peer-to-peer support and access to care.

Achievements

- U.S. government funding for FSHD research.
 - MD-CARE Act 2001
 - MDCC Action Plan 2006
 - MD-CARE Act Re-authorization 2014
- NIH Funding for FSHD research in 2001: \$400,000
- NIH Funding for FSHD research in 2013: \$5 million
- \$5 million of FSH Society grants leveraged into \$78 million of NIH funding

FSHD remains underfunded

- 2013 NIH funding for diseases with similar or lesser prevalence:
 - ALS \$39 million
 - Ataxia Telangiectasia \$11 million
 - Cystic Fibrosis \$78 million
 - Duchenne Muscular Dystrophy \$33 million
 - Myotonic Dystrophy \$10 million
- Progress in FSHD is all the more remarkable given the relative lack of funding!!

Challenges & Opportunities

- Cost to develop a new drug: \$100 Million +
- FSH Society has a vitally important role to play in helping to reduce risk for biotechs and pharmas:
 - Patient + Family network
 - Improving FSHD care standards through education & outreach
 - Driving efforts to mobilize volunteers for clinical studies and future clinical trials
 - Coordinating stakeholders for initiatives that will speed up clinical trials
 - Continuing to support basic research!!

Your support is more important than ever!

- Donations
- Join the FSH Society's Legacy Circle
- Organize or participate in fundraisers
- Awareness raising
- Telling family and friends
- Volunteer – your skills are valuable!

What we can accomplish TOGETHER



- Treatments to slow or stop FSHD
- Improve health care and quality of life through better understanding of FSHD
- Ensure that the pipeline for new drugs is replenished
- Secure more funding from governments, NGOs & industry

At FSHD Connect

- Pick up event flyers
- Talk to Development Committee members
Contact list available
- Creative fundraising Breakout Session
Harbor Ballroom I
- Up next, event chairs



THANK YOU FOR YOUR SUPPORT

