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