





Transforming the landscape

FOUNDED IN 1991 BY TWO INDIVIDUALS WITH FSHD, THE FSH Society has forever altered the world for the 870,000 people living with this condition.

Where before, there was a black hole of mystery about this genetic disorder, we now have identified two genes and are unraveling one of the most complex disease-causing genetic mechanisms known to science. Where before, people diagnosed with FSHD had nowhere to turn, they are now a phone call or mouse click away from a worldwide network of experts and fellow patients.

Over our 24-year history, we have funded a cumulative \$5.5 million in research grants—about what a single major cancer lab spends in a single year. Yet this modest sum, much of it awarded as seed grants to support young scientists and young ideas, has led to breakthrough discoveries and launched the field into the era of drug development. Since 2014, a new biotech firm has been founded and a second has embarked on a clinical trial for FSHD.

Without question, your donation to the FSH Society is the most powerful investment you will ever make to advance medical research.

*“This is an investment,
not a contribution. I
have strong confidence
that it will be used to its
maximum benefit for all of
us affected by FSHD. It is
truly a blessing to invest in
an organization that does
it right.”*

— WILLIAM MACLEAN,
PENNSYLVANIA





Our achievements

IN 2014-2015 YTD, THE FSH SOCIETY GREATLY ACCELERATED its efforts around our strategic goals to drive research forward, empower patients, and connect and strengthen our network. Here are some of the most significant impacts of our work:

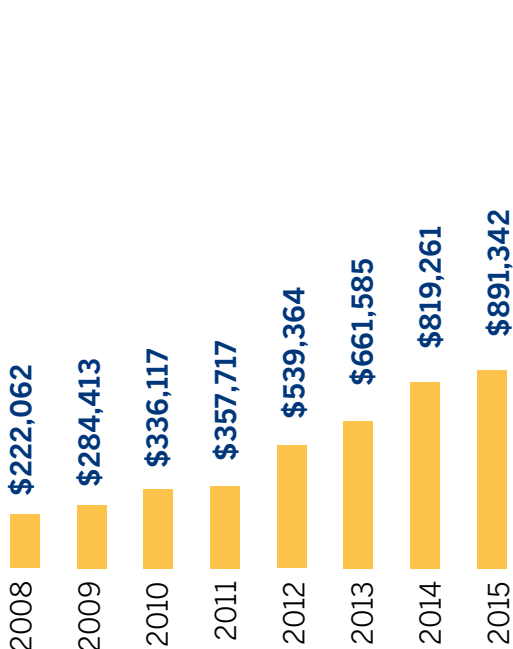
Driving Research Further

- In 2014 and 2015 to date, the FSH Society awarded \$1,710,603 to basic and translational research projects.
- FSH Society-funded projects have harnessed genomic engineering to silence DUX4 (the gene causing FSHD), developed new methods to measure disease progression, and identified novel targets and compounds to interfere with DUX4 expression.

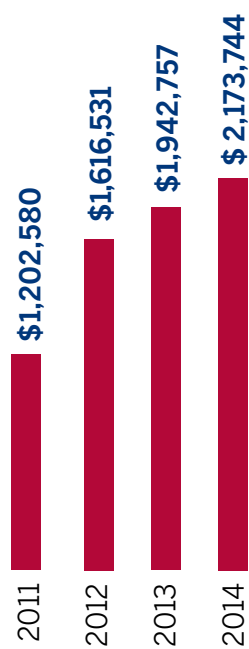
Empowering

- The first evidence-based care guideline for FSHD was published by the American Academy of Neurology in July 2015.
- President Obama signed the MD-CARE Act 2014 into law, ensuring continued federal resources for all muscular dystrophies.
- Our #FSHDselfies and #CureFSHD campaigns drove thousands of images and facts about FSHD to be shared over social media.

New Grants Awarded



Total Revenue





Our achievements

Connecting and Communicating

- We launched our new website in January 2015, attracting 41,000 unique visits.
- Our biennial FSHD Connect conference in Boston drew 200 patients and family members, researchers, and clinicians. Massachusetts Senator Elizabeth Warren delivered a special keynote.
- More than 15 FSH Society member meetings have been held across the country including in California, Colorado, Maryland, Massachusetts, Michigan, New Jersey, North Carolina, Oregon, Virginia, and Washington.

Funding

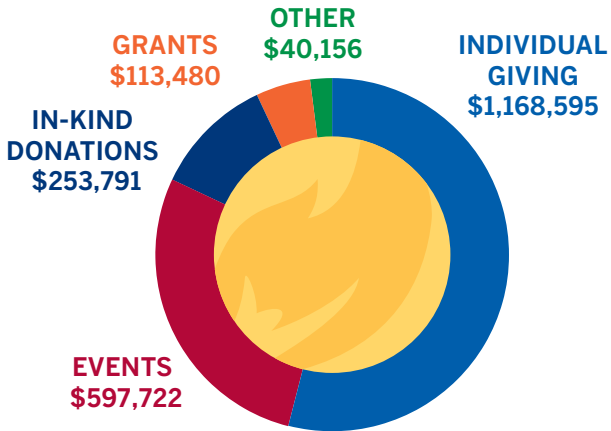
- In 2014, FSH Society fundraising events and campaigns inspired 3,195 gifts totaling nearly \$2.17 million.
- For every dollar raised, the FSH Society directs 91 cents to mission-critical programs designed to advance us toward our goal of treatments and a cure for FSHD.

“Your work makes a real difference for people living with FSHD and their families, people all across the country.”

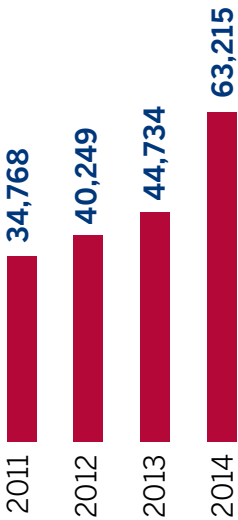
— SENATOR ELIZABETH WARREN



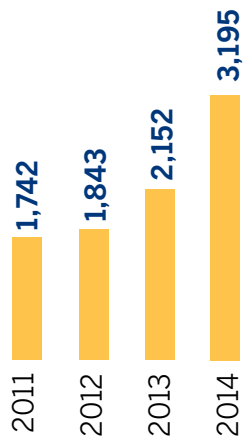
2014 Sources of Revenue



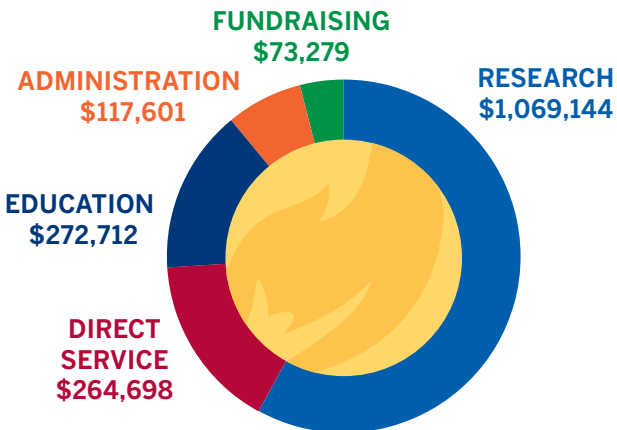
Number of Unique Website Visitors



Number of Donors



Where the Money Went in 2014



Strategic initiatives and funded research

Improving Care Nationwide

Now that the evidence-based FSHD care guideline has been published by the American Academy of Neurology, we will be putting this information into the hands of doctors and patients at neuromuscular disease specialists' offices across the country. They will be receiving summaries of the newly published FSHD care guideline for patients and clinicians along with a toolkit of resources and educational material to make sure FSHD patients have access to optimal care and support.

Building Critical Infrastructure

Discoveries about FSHD cannot happen unless researchers can collaborate with patients and family members. The FSH Society facilitates these collaborations and is actively investing in patient registries, model organisms, and systems to deliver tissue and DNA recovered from surgeries, from biopsies, and postmortem to researchers who need them.

“We believe there will be a cure one day for our son Noah, and we know the FSH Society will play a huge role in finding one.”

— KRISTEN AND DAN LINSKY



Identifying Disease Mechanisms

Under the direction of our world-class Scientific Advisory Board, the FSH Society's fellowship program funds the highest-quality, most needed projects. This program has transformed FSHD research and led to breakthrough discoveries. We will continue to push the envelope to advance outstanding research, and work to recruit and retain researchers who otherwise may have to abandon the field under the current difficult NIH and MDA funding environment.

Paving the Way to Clinical Trials

Working in close collaboration with academic scientists, medical researchers, industry, regulators, and other stakeholders, the FSH Society is helping to build the tools and partnerships for clinical trials. We are funding research to discover and validate diagnostics, biomarkers, imaging markers, and clinical outcome measures.

FSHD in Children

The FSH Society co-funded the international CINRG study of early-onset FSHD and, with a grant from the John W. Alden Trust, provided families with support to travel to study sites. This study will shed much-needed light on this severe form of FSHD affecting an estimated 20,000 to 30,000 children around the world.

2014 Donor List

\$2,500+ Individual, Corporate, and Foundation Donors

We are grateful to every one of our donors for lighting the way to the future through your generous support!

\$100,000+

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GE Foundation Matching Gifts
Program

“Working with the FSH Society has been one of the most exciting and important experiences in my life ... I am positive that this organization will lead us rapidly to the day where we find a treatment or a cure and finally rid the world of this disease.”

— MAX ADLER



John W. Alden Trust
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“The FSH Society has served as the focal point for vetting of the science of FSHD, providing seed money for new ideas and ... fostered a consensus understanding of disease mechanism.”

— FRAN SVERDRUP



We are stronger than FSHD



Buy the campaign T-shirt and wear it proudly to raise awareness; 100 percent of the profits will go to the FSH Society. Visit the online store at <http://teespring.com/stores/FSHsociety>.

Information is power



Be sure to sign up for email alerts—the fastest way to keep up on the latest research, advocacy initiatives, campaigns, and community news.



Our end-of-year challenge

OUR BOARD OF DIRECTORS HAS PLEDGED A TOTAL OF **\$384,805** and challenges our supporters to match this. From now through December 31, 2015, every gift will be counted toward our year-end challenge. Please stretch a little—13 percent over last year's gift—to help us meet this challenge and reach our ultimate goal for this year!

OUR 2015 GOAL:

\$2,445,000



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FSH Society, Inc.

450 Bedford Street
Lexington, MA 02420 USA
781-301-6060
info@fshsociety.org
www.fshsociety.org



YOUR TRUSTED PARTNER. In 2015 the FSH Society earned its seventh consecutive 4-star award from Charity Navigator, placing us among the top 2 percent of U.S. charities.