

Donor Impact

REPORT

FOR THE YEAR 2016



Greening the landscape

Living with a rare disease can feel terribly lonely, all the more so when one is faced with the world's indifference to the patient's plight. So when Susie Kanewske, a busy fashion stylist from Portland, Oregon, was diagnosed with facioscapulohumeral muscular dystrophy (FSHD) in 2014, "understanding that I had this disease and not knowing if my children or grandchildren might have it, too," she recalled, "I didn't think there would be a solution during my life."

Stunned to learn the cause of the leg weakness that she had first noticed five years earlier, Kanewske searched the Web to learn everything she could about her condition. "A few months later," she said, "I was at my first FSH Society conference." The experience changed her life.

The Society's Patient Connect conference, one of the essential programs made possible by your donations, is the premier networking event for the FSHD community. Every two years, patients, families, researchers, and clinicians gather to learn from one another and emerge with new ideas and a powerful sense of purpose to work toward solutions. For Kanewske, "The Society is a lifeline. It is a place I can go to for answers."

Your support has enabled the FSH Society to sustain a 26-year effort to transform the FSHD landscape from an outback into an ecosystem ripe with opportunity. Biotechs today see world-class scientists who have made impressive headway toward understanding the disease. They see engaged, motivated patients eager to volunteer for studies. They see essential tools—FSHD cell lines, bioengineered mice, repositories of patients' tissue and DNA—to aid in testing drugs and gene therapies. And the result is that today more than a dozen companies are pursuing treatments for FSHD. This is unprecedented.

Thank you—our donors, volunteers, Board of Directors, and Scientific Advisory Board—for giving genuine hope to Kanewske and thousands like her. Today, your support is more important than ever. With your generous contributions, the FSH Society can continue to have an outsized impact on FSHD research and on the lives of patients and families everywhere.

A handwritten signature in black ink, appearing to read 'June Kinoshita'.

June Kinoshita

Executive Director and Chief Operating Officer



“The change is huge. I know there will be a treatment in my lifetime.”

— SUSIE KANEWSKE

INVESTING IN THE ECOSYSTEM

Over the past three years, two experimental treatments have been tested in patients, and more than a dozen companies have joined the field to work on the next generation of FSHD drugs, many of which are targeting the DUX4 gene thought to lie at the core of the disease. These are dramatic advances, and they did not happen overnight. They are the result of the FSH Society carefully cultivating and nurturing the conditions needed for research and drug development efforts to thrive. Signature achievements in 2016 include the following:

Support for understanding the cause of FSHD

- A record-setting \$1,383,892 in FSH Society commitments to new research projects.
- Coriell Institute makes available a biorepository of FSHD cell lines generated out of 607 samples collected from 43 multi-generational families.
- Creation of a nationwide FSHD tissue donation registry.
- Development of a new FSHD mouse model, now available from Jackson Labs.

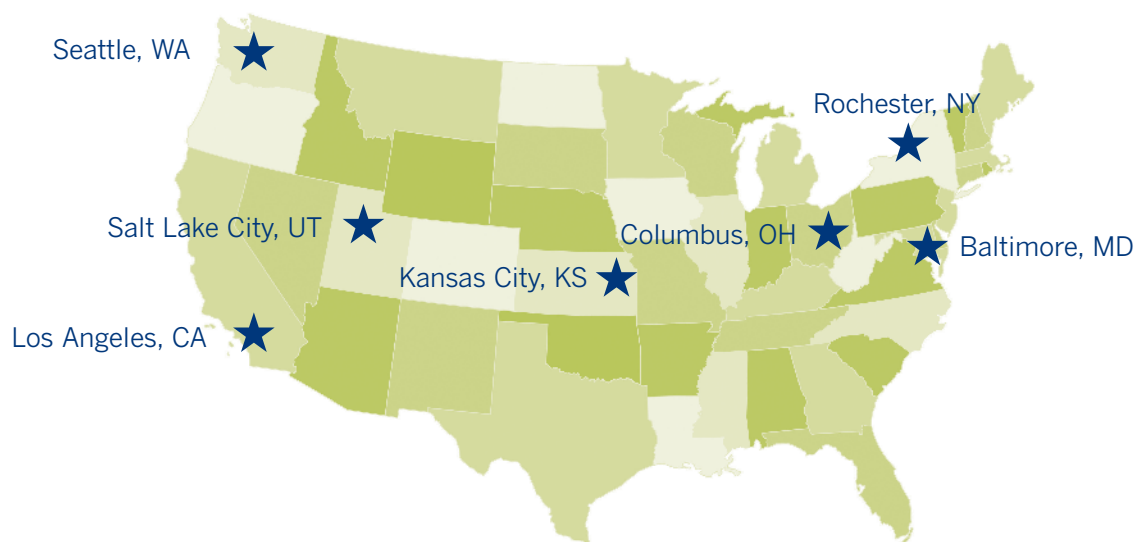
Getting ready for clinical trials

- Helping to launch the seven-center FSHD Clinical Trial Research Network (CTRN) through an FSH Society grant, with support from the Gerald Norton Foundation and an anonymous donor.
- Co-organizing an international workshop on global FSHD patient registries.
- Collaborating with Acceleron Pharma to make sure outcomes measured in Acceleron's clinical trials will be meaningful to patients.

Building a strong network

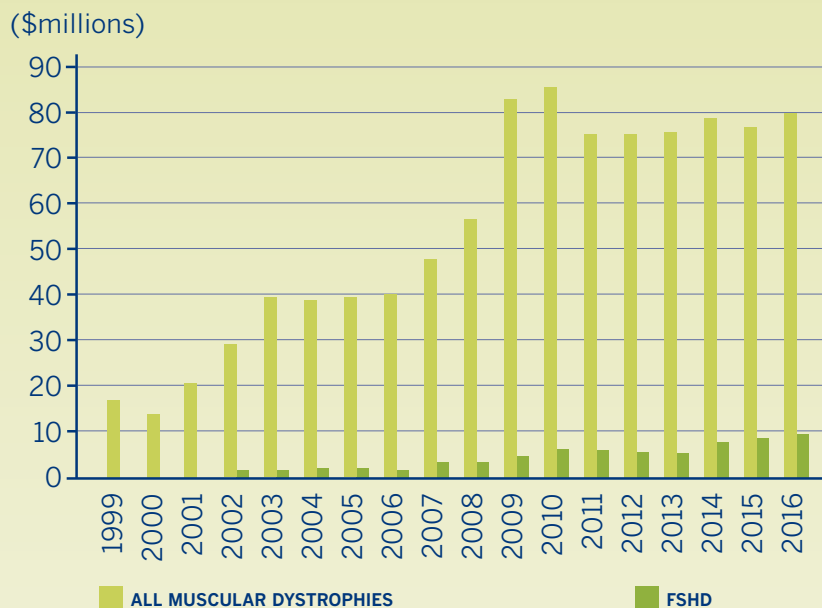
- Our first joint FSH Society international research and patient networking conference attended by more than 350 researchers, patients, families, and other stakeholders.
- Participating in three FSHD Family Day conferences at leading centers and organizing member support group meetings at 16 sites across the US.

Clinical Trial Research Network members



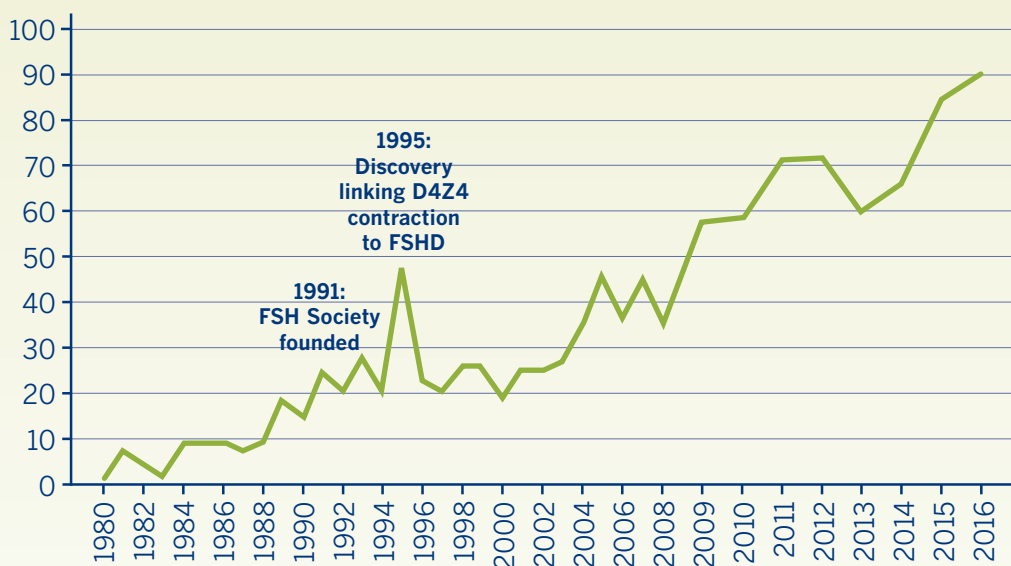
OUR IMPACT

NIH funding: 1999-2016



Since the FSH Society's work to pass the MD-CARE Act in 2001, National Institutes of Health funding for FSHD (dark green) has grown from 2 to 11 percent of total NIH funding for muscular dystrophy (light green).

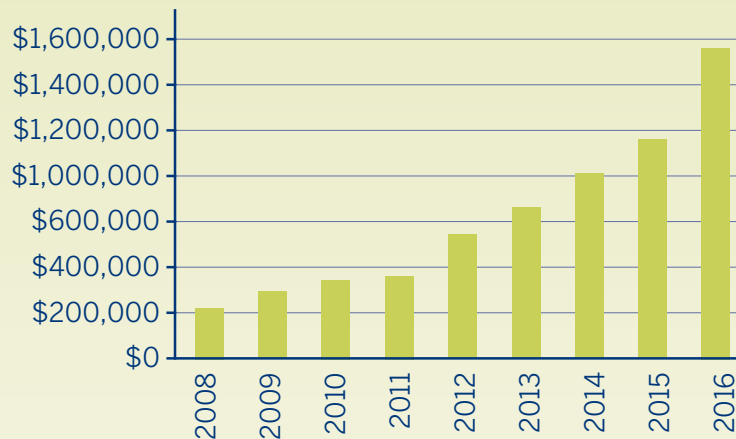
Scientific publications: 1980-2016



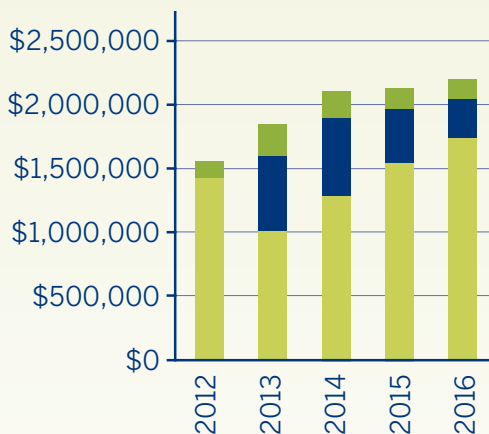
The FSH Society's investment in research is reflected in the steady increase in scientific publications on FSH muscular dystrophy since 1991. A spike in publications occurred in 1995 due to the discovery that contraction of D4Z4 repeats on chromosome 4 causes FSHD, and the value of p13e11 for genetic testing was observed. This came on the heels of the 1990 discovery genetically linking FSHD to region 4q35 on chromosome 4.

ACCOUNTABILITY

FSH Society's investment in research



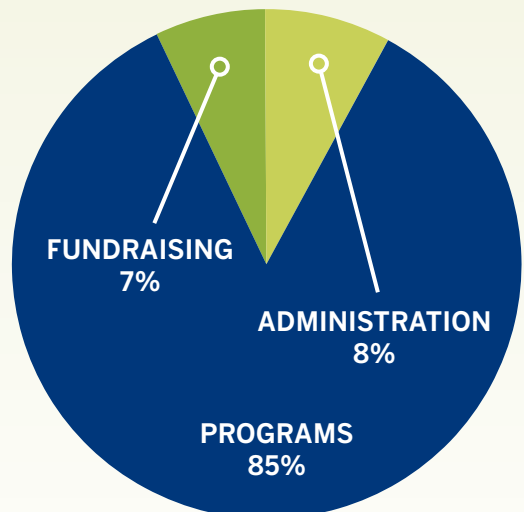
Support & revenues



- DONATED GOODS & SERVICES
- SPECIAL EVENTS
- GIFTS, GRANTS & CONTRIBUTIONS

Since 2012, the FSH Society's revenue has increased steadily. The Society is determined to expand its capacity in fundraising in order to invest in the research and education needed to build upon our track record of progress and success.

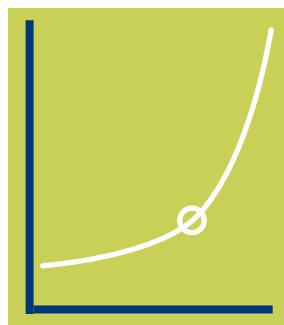
2016 FSH Society expenditures



- Programs—\$2,153,601
- Fundraising—\$177,819
- Administration—\$209,103

The knee of the curve

Progress can seem excruciatingly slow when a technology revolution is viewed in real time. And the fact of the matter is, finding a treatment for FSHD is a daunting task for which there are no shortcuts. Do not be disheartened. It is a heady time for biotechnology in general and FSHD research in particular as we approach the “knee of the curve.” The very nature of the technology acceleration curve is that the seemingly impossible becomes inevitable if you can keep to the course. I thought it to be impossible before, but my true hope today is that in our lifetime, we will be able to look back and reflect on how we all witnessed and profited from an amazing time of progress and success. So stay tuned in, buckle up, and join us in all ways that you can to keep us all on the acceleration curve!



Stuart Lai

—Stuart Lai, co-founder, REDI trading systems
FSH Society Board of Directors

Add value to your philanthropic investment

The FSH Society empowers you to invest in the best scientific and medical research for a cause that is important to you: FSH muscular dystrophy. You can rely on the FSH Society to provide the following valuable services to our donors:

- Solicitation of research proposals from hundreds of researchers worldwide.
- Rigorous scientific review of grant applications by world-class experts.
- Administration of grant contracts with research institutes.
- Progress reports from grant recipients.
- Reporting back to you on the impact of your philanthropy.
- Requiring grant recipients to publish their data.
- Publicity for research findings and funding sources.
- Networking with academia and industry to advance the research.
- Stewardship of research resources resulting from funded work.
- Stewardship of intellectual property.
- Good governance, transparency, and accountability.

With the FSH Society as your partner, your philanthropy will have a powerful impact on our shared quest to improve health and find effective treatments for all who live with FSH muscular dystrophy.

TO LEARN MORE about how to have an impact with your philanthropic investment, contact June Kinoshita, Executive Director and COO of the FSH Society, by phone at (781) 301-6649 or email (june.kinoshita@fshsociety.org).

2017 DONOR REPORT

\$2,500+ individual, corporate, and foundation donors

We are grateful for each and every gift. Large and small, they add up to a powerful force!

\$200,000+

Duncan & William R. Lewis Sr., MD

\$100,000-\$199,999

Delta Railroad Construction, Inc.
Michelle & David Mackay

\$50,000-\$99,999

Anonymous
Barbara Finlay Trust
Barbara & James Chin Sr.
Christopher Eklund & Gerald
Norton Foundation
Joseph Friedman
Paul & Stacey Laurello
New York Community Trust
SHIFT Communications

\$25,000-\$49,999

Adveq Management AG
William R. Lewis III, MD
S & L Marx Foundation
Wasily Family Foundation, Inc.

\$10,000-\$24,999

Anonymous
Acceleron Pharma, Inc.
aTyr Pharma, Inc.
Sanford Batkin
Benevity Community Impact
Fund
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S. Connors Charitable
Foundation
Michelle Dodd
Finkelstein Foundation
Roslyn Goldstein
Google Foundation
Graham Family Charitable
Foundation
Glenn & Petrina Hasman

Karen & Darrin Jewell
Andy Johnson-Laird & Kay
Kitagawa

Stuart Lai
Local Independent Charities of
America
William Michael
Muscular Dystrophy Campaign
Michael & Melissa Penwell
Jane & Paul Rittmaster
David Rosenberg
Marsha & Jerry Seslowe
Allan C. Silverstein, DDS, & Pauli
Overdorff
Madeline & Dr. Lawrence
Weinstein
Helen & Marc Younger

\$5,000-\$9,999

Abundance Foundation
Battle Creek Community
Foundation
Kathleen J. Blakistone & Richard
C. Draut
Louis & Ruth Brause
Peter H. Catterall & Kim Toskey
Elizabeth & Joe Conron
Curtis Finlay Foundation, Inc.
Todd & Sian Defren
Mohammad Ehteshami
Christine & James Ford
Fulcrum Therapeutics, Inc.
Myriam & Carlos E. Garcia
GE Foundation Matching Gifts
Program
Sandra & Michael Hecht
Ida Laurello
Harry & Pamela Lewis
Tod Machover & June Kinoshita
William A. Maclean

Adam Manacher & Carol S.
Birnbaum, MD
Ray Miller, MD
Kevin Monahan & Ellen Hannan
Marie & Landon Morrell
Muscular Dystrophy Association
Jai & Jennifer Narayan
Craig Nation
Roy & Kristy Neilson
Susan Nordeen
O'Connor & Drew, PC
Daniel Paul & Susan Perez
Jane & George Pollock Jr.
Razoo Foundation
Gloria & Burton Richards
Beverly & Mike Rowlett
Joan & Alan Safir
Salesforce.org
Sarepta Therapeutics, Inc.
Shirley Family Charitable
Foundation
Kim Small & Norm Wesley
Neil Solomon & Paula Birnbaum
Gracia Toubia & Gregory Stucky
Susan & David Tunnell
Ultragenyx Pharmaceutical, Inc.
United Way of Battle Creek &
Kalamazoo Region
Aileen & Ken Wyckoff

\$2,500-\$4,999

May & James Albert
Aviva Spring Foundation, Inc.
Brett Barlow
Amy Bekier
BioMarin Pharmaceuticals, Inc.
Josh Bobrovcan & Jen Hunter
Arlene & Dr. Gary Cohen
Stuart Cohen

Mitchell & Susan Coleman
 Freedman
 Combined Federal Campaign
 Assorted Chapters
 Cytokinetics, Inc.
 Michele De Sha & Howard
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 Thomas Dempsey
 Julie & Mitchel Dye
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 Idera Pharmaceuticals, Inc.
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 Jewish Communal Fund
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 Susan & Steven Rice
 Sanofi Genzyme
 Wendy & Wayne Shack
 Jeffrey Sherman

Steven Smith
 Staples Foundation

Carden Wyckoff

Legacy Circle

These individuals have arranged for a gift to the FSH Society in their wills or other estate plans. Their generosity helps to ensure that the Society will be able to sustain its mission for future generations. They have our deepest appreciation.

Michael & Ellen Aeling	Duncan & William R. Lewis Sr., MD
Anonymous	Susan Lipari
Barbara Finlay Trust	Donald & Judith Lokerson
Sanford Batkin	William A. Maclean
James A. Baxter	Joseph J. Matt III
Amy Bekier	Jennifer Moore
Greg & Tanya Bergstein	Roy & Kristy Neilson
Joette A. Black	Betty Schechter
Barbara & James Chin Sr.	Ellen Schechter Berger & Jeffrey Berger, MD
Michele De Sha & Howard Chabner	Elizabeth Schrauder
Thomas Dempsey	Deborah Schwartz
JoAnn P. Forance	Patti Smith
James Fox	Robin Stemple
Barbara Fulton & Ralph Blatt	Thomas & Kathy Stewart
William Herzberg & Judy Marantz-Herzberg	Madeline & Dr. Lawrence Weinstein
Christine & Jeffrey Jacobs	Helen & Marc Younger
George T. Kuykendall	

We are grateful to all of our donors. No matter how small or large, your gift has an impact!

Gift level	Number of donors	Total gifts
\$1,000-\$2,499	179	\$233,619
\$500-\$999	203	\$119,295
\$250-\$499	269	\$81,729
\$100-\$249	616	\$80,147
Under \$100	654	\$27,658

SPRING FORWARD

Double the impact of your gift!

Your donations are vital for helping the FSH Society overcome its challenges and meet its goals. We must invest in deciphering FSH muscular dystrophy so that we can aim treatments at the correct targets, even as we build the infrastructure to ensure that clinical trials will have meaningful results. A group of generous benefactors has pledged to **match your donations up to a total of \$50,000** during our spring campaign. Help us rise to this fundraising challenge!

Spring matching
gift campaign
deadline:
June 20
World FSHD Day



FSH SOCIETY

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info@fshsociety.org
www.fshsociety.org



YOUR TRUSTED PARTNER.

The FSH Society has earned its ninth consecutive 4-star award from Charity Navigator, which ranks us among the top 1 percent of US charities.

Barbara Chin's gift to the future

We at the FSH Society were deeply moved and inspired to receive a magnificent bequest of \$50,000 from the Barbara A. Chin Trust. This gift will enable the Society to fund work that Barbara cared deeply about: education and support for people with FSH muscular dystrophy, like herself and her late son Jimmy, and research toward treatments and a cure.



Barbara Chin

Barbara and her husband Jim Sr., who serves on the Society's Board of Directors, have supported the Society not only financially but through countless hours of volunteer service. Barbara changed the lives of many patients and families through her kindness and compassion as a peer counselor. The entire FSHD community owes her so much.

Barbara's bequest helps to ensure that future generations will enjoy lives free of the burdens of this disease. Individuals and families even of modest means can leave a powerful legacy by including the FSH Society in their wills or estate plans.

TO LEARN MORE please visit <https://www.fshsociety.org/planned-giving/>.

“After fighting this disease for 44 years, many times feeling like I was doing it alone, I now know that there are warriors out there to fight with me. I cannot express my gratitude and love for all of you who are in this battle.”

— BELINDA MILLER,
Author