

# 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.

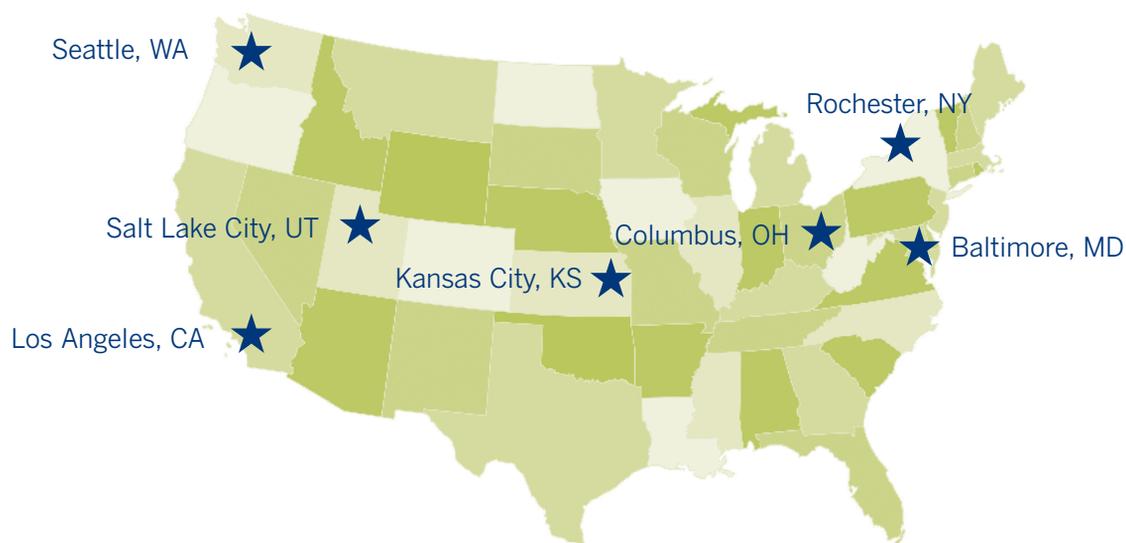
## Getting ready for clinical trials

- 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



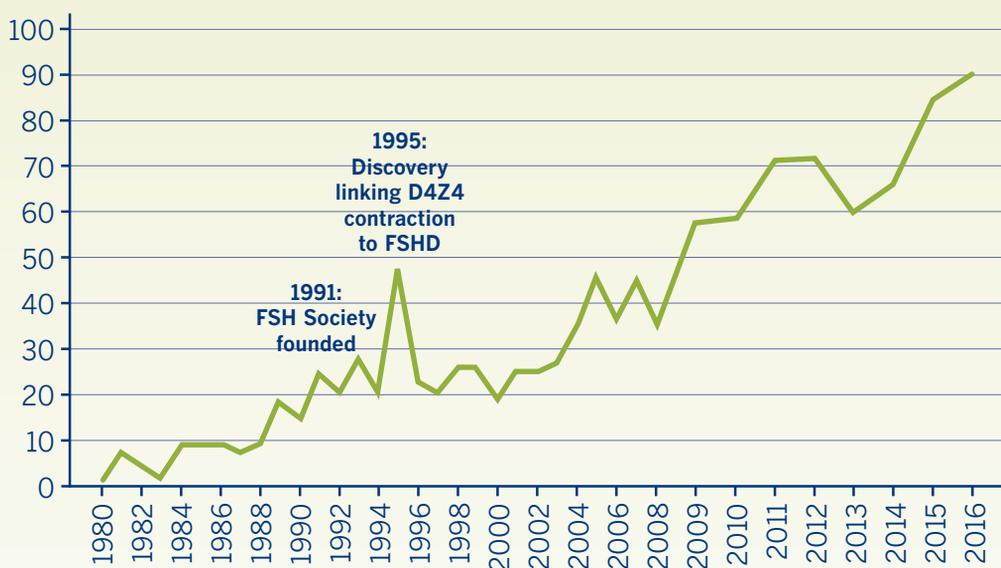
# OUR IMPACT

## 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).

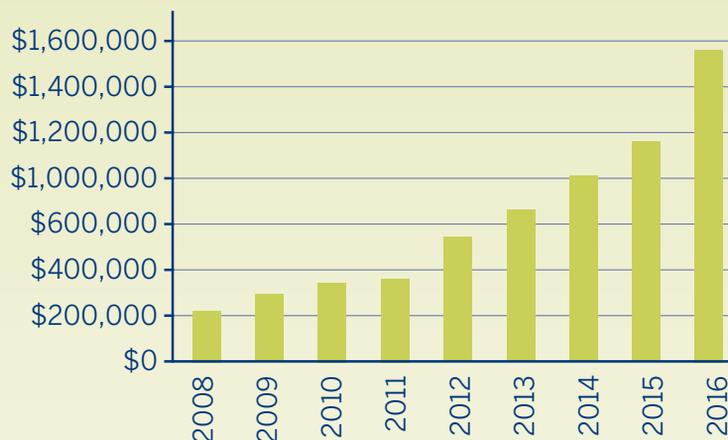
## Scientific publications: 1980-2016



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



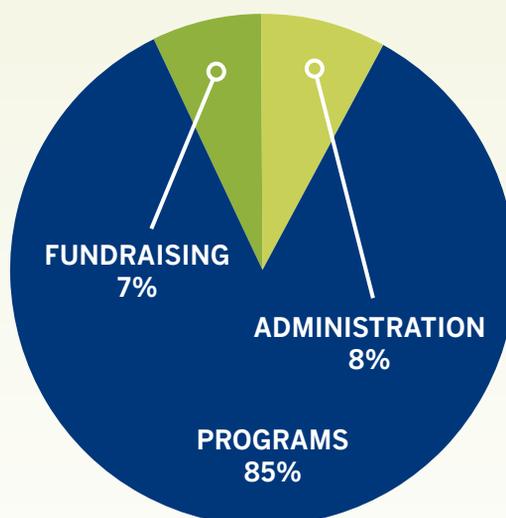
## Support & revenues



- 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](mailto: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  
William J. Connors III & Barbara  
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  
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David Rosenberg  
Marsha & Jerry Seslowe  
Allan C. Silverstein, DDS, & Pauli  
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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  
 Chabner  
 Thomas Dempsey  
 Julie & Mitchel Dye  
 Stephen & Jennifer Elia  
 Betty Ettinger  
 Carlos & Beatriz Garcia  
 Genomic Vision  
 GlobalGiving Foundation  
 Leonard & Linda Goldberg  
 Eugene & Emily Grant  
 Idera Pharmaceuticals, Inc.  
 Christine & Jeffrey Jacobs  
 Jewish Communal Fund  
 Jacqueline Kates  
 Timothy Kerrigan & Catherine  
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 Ann & L. Frank Kolakowski, PhD  
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 Joanne Maguire  
 Christine & Conway Mcdonald  
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 Group  
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 Ralph & Cherie Gorenstein  
 Charitable Foundation, Inc.  
 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
<b>\$1,000-\$2,499</b>	<b>179</b>	<b>\$233,619</b>
<b>\$500-\$999</b>	<b>203</b>	<b>\$119,295</b>
<b>\$250-\$499</b>	<b>269</b>	<b>\$81,729</b>
<b>\$100-\$249</b>	<b>616</b>	<b>\$80,147</b>
<b>Under \$100</b>	<b>654</b>	<b>\$27,658</b>

# 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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[www.fshsociety.org](http://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