

Physical activity, FSH Dystrophy, and you

By Ryan Levinson

When I was diagnosed with facioscapulohumeral muscular dystrophy (FSHD), a doctor advised me to “quit athletics and learn something useful like keypunch.” Another doctor told me to “not overdo it.” Sound familiar? Until recently the prevailing medical advice for people with our condition seemed to be that exercise is too risky, that being physically active might accelerate our muscle loss. Some people hear advice like this and think, “I guess I’m destined to sit around and passively watch life go by.” This article is for the rest of us.

If you are like me, then you believe humans are programmed to move. That we feel better and are ultimately happier when we get our blood pumping, when all our senses are stimulated, when we use our bodies. But how is that possible for those of us living with FSHD? What about the doctors’ warnings? Can people with FSHD live active lives?

When I was diagnosed, it took me about one day to decide that if I am going to lose my muscles anyway then I may as well lose them doing the things I love. I moved to Fiji to surf incredible waves on a remote island. When I came home I spent all my time in the water—surfing, kite boarding, kayaking, sailing, and



Specialized Factory Team Rider Ryan Levinson prepares for XTERRA off-road triathlons despite losing muscle to FSHD. Notice the pronounced rounding of his right shoulder, the winging in his right scapula, and the loss of muscle in his upper legs. Ryan compensates for his weaknesses by modifying his technique and equipment to focus on his strengths.

SCUBA diving. It was my work and my play. It was incredibly physical and incredibly fun.

Over those five years, I noticed that my muscle loss continued, but it did not seem to be happening at the catastrophic rate doctors warned. At the same time, it seemed my “healthy” muscles had gained significant strength. I was more aerobically fit, more flexible, and in many ways happier and more fulfilled than I had been before diagnosis. I decided to step things up a few notches and see what would happen.

If you want the details of what happened next, please check out my website, www.ryanlevinson.com, but the gist of it is that I ended up traveling extensively, competing successfully semi-professionally, first as a cyclist then as a triathlete, in both able-bodied and “physically challenged” divisions. In other words, and with all due respect to the doctors, I defined for myself what “overdoing it” means.

But that is easy for me to say, right? While I am living with some significant physical challenges, my symptoms are currently somewhere in the middle in terms of severity. Can those of us who are more affected by FSHD still enjoy physically active lives? Let’s meet someone whom I look to for inspiration and hope, a good friend of mine named Kristin Duquette.

Kristin is a young woman currently finishing high school in Connecticut. She began noticing the impact of FSHD at a younger age and her symptoms have progressed more rapidly than mine. Kristin uses a walker and other assistive technology. Yet Kristin is on her high school’s swim team and is currently competing for a spot on the USA Paralympics swim team.

A cause that propels a career:

Meet Patrick Reed, Ph.D., Department of Physiology, School of Medicine, University of Maryland, Baltimore

Patrick Reed, Ph.D., works in the laboratory of Robert Bloch, Ph.D., in the Department of Medicine at the University of Maryland, Baltimore. Dr. Reed is also a contributor to the Sen. Paul Wellstone FSHD Center Accessible Animal Models Core, and he is a recipient of the FSH Society Marjorie and Gerald Bronfman Foundation Post-doctoral Research Fellowship Award. Recently he shared with *Watch* his personal and professional motivation for launching a career in FSHD research.

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Please Join Us for a Special Concert to Benefit

The FSH Society, Inc.
 (Faciocapulohumeral Muscular Dystrophy)

Featuring:
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A Festive Evening of Music and Song

Members of the FSH Society, their friends and family plan a benefit concert in New York, Wednesday, March 25, 2009.

Tickets and sponsorship opportunities vary from \$125 to \$5,000. For more information, see the invitation at left or go to www.fshsociety.org.

Tides Foundation challenges the FSH Society and you!

Dear Friends,

Thank you, thank you, thank you for all your gifts in 2008 and for all the good work you do for the FSH Society!

Now I have another request of you: In



Nancy Van Zant

late 2008, the Tides Foundation awarded the FSH Society a \$30,000 matching grant. The conditions of the match are that we raise contributions from new individual donors or institutional funders, between December 15, 2008, and December 15,

2009. Funds are to come from new sources and cannot be from renewals or previous donors. The Tides Foundation wants to see the Society expand our "prospect pool."

This is an excellent opportunity for

those of you working to cultivate new sources, to encourage them to give in this time period. In recent weeks, we have received contributions that fit these criteria and the Society is on the way to satisfying the match.

Further, if you are a reader of *Watch* but you are not a member and do not support the FSH Society, this is a great time to join. YOUR GIFT WILL BE MATCHED! Use the enclosed envelope, or go to www.fshsociety.org and click on Contribute.

I shall keep you posted on our progress toward the \$30,000 matching opportunity!

Sincerely,

Nancy Van Zant
 Executive Director

Physical activity, FSH Dystrophy, and you, *continued from front page*

Here are some resources that may prove helpful:

- Challenged Athletes Foundation - <http://www.challengedathletes.org>
- International Paralympic Committee - <http://www.paralympic.org>
- Adaptive Snow Ski Programs - <http://www.sitski.com/pg3.htm>
- AcesSurf Hawaii - <http://www.accessurfhawaii.org>
- SCUBA Diving - <http://www.scuba-doc.com/divdis.htm>
- Waterskiing - <http://www.usawaterski.org/pages/divisions/WSDA/DisabledHistory.htm>
- Sailing - http://www.ussailing.org/swsn/adaptive_programs.asp

Recently Kristin came to visit me in San Diego to take part in the Challenged Athletes Foundation's annual triathlon. We were both doing the swim as part of relay teams. Kristin had someone carry her down the staircase leading to the beach. While we were waiting to start, a large wave came and washed over all of us waiting in the sand. There was talk about canceling the swim due to the fog and large surf. But they decided to let it happen, and Kristen swam the half Ironman open ocean cold-water swim unassisted. For more information about Kristin, check out her website at

www.kristinduquette.com

It's not just Kristin and me. There's a woman in Washington who trained for, and then raced in, an off-road triathlon last year. She crashed hard during the mountain bike portion, but she still completed the ride in 100 degree mid-day desert heat despite her injuries. There's a guy who rode his bike across Canada to raise awareness about FSHD. There's a guy with FSHD in England who plays rugby. There's a woman in Hawaii with MD who uses a power chair fulltime but

who surfs every chance she gets (someone pushes her into the waves and she rides them lying down).

Trust me, if you want to live a physically active life you can. It doesn't matter what level of physical ability or prior experience you have, there is a place for you.

This may sound trite, but the first step is to dream. Just put on some music, stare out your window, browse the web, or read a magazine, whatever it takes to get your mind flowing. Find an idea that makes your spine tingle and grab it. Own it. Don't be afraid of challenges, you will be AMAZED at what is possible.

Yes it's true that if you don't have any leg muscles you're probably not going to run a marathon, but before you dismiss an idea, remember that the adventure is in the process, not the result. It takes a lot of adaptive technique and training for me to succeed at what I do. The same may be true for you and those techniques take time to discover. It's worth it, I promise you.

For what it is worth, and this is important, I do not believe that exercise

has somehow reversed the progression of FSHD in my body. The affected muscles are still affected and the atrophy seems to continue progressing in stages. But that is not the point. To paraphrase Viktor Frankl, "you cannot always choose what happens to you but you can choose how to respond." It is incredibly meaningful to live on your own terms doing what you love. It can be immensely rewarding to define your own limits rather than be pigeonholed by other people. I hope you choose to join Kristin, me, and all the other active FSH'rs in redefining what is possible for people living with our disorder.

SEND YOUR SUGGESTIONS: 2010 International Patient/Researcher Network Meeting

In the coming months, FSH Society staff and the board of directors will begin to plan the next patient/researcher network meeting, expected to be held in summer 2010.

The choice of a location has several objectives, and these objectives are not always compatible with each other:

- convenient to major airports
- wheelchair accessible venues
- family vacation destinations
- clinical and/or research interests
- reasonable costs for attendees and for the FSH Society

With any or all of these considerations in mind, please email your suggestions to 2010meeting@fshsociety.org. Please name a city, state, or general region of the country to which you would travel for a meeting. Give us your thoughts and tell us if you have ever attended a patient meeting and, if so, which one(s). We want to sample as many interests of likely attendees as you are willing to share.

We will make a decision by late summer 2009! Thank you.

It is the editorial policy to report on developments regarding FacioScapuloHumeral Muscular Dystrophy (FSHD), but not to endorse any of the drugs or treatments discussed. We urge you to consult with your own physician about the procedures mentioned.

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Editors: Nancy Van Zant and Daniel Paul Perez. Editorial Assistance: Carol Perez, Jenny Lazzaro, Howard L. Chabner & Charles C. Perez. Graphic design & editorial assistance: Susan L. Stewart, StewartBusinessStrategies.com

Meet Patrick Reed, Ph.D., *continued from front page*

Q. Can you share a bit about what motivates you to study FSHD?

Dr. Reed: Both of my brothers, Mike and Bill, have FSHD. There is not any effective treatment so I want to try to find potential drug targets that may be used to treat the disease. My brothers are somewhere in the middle in terms of the FSHD effects they experience. One is a police dispatcher and the other is employed by a contractor for the U.S. Senate. They have meaningful lives, the support of our large family, and satisfying work.

Q. What academic path did you follow to the University of Maryland?

Dr. Reed: I took courses, which included chemistry and biology, at Montgomery College. From there, I transferred to the University of Maryland in College Park and studied biology, which led to a bachelor's degree. After getting my degree, I started to take graduate courses in molecular biology at the University of Maryland's Shady Grove campus. In the meantime, I had taken a job at a biotech company in Rockville, Maryland, mapping the changes in the proteins that occur in vital organs in response to the top 50 drugs prescribed at the time. I had hoped to do some work on FSHD then but never had the opportunity. While working there, I learned about the Interdisciplinary Muscle Biology Program at University of Maryland, Baltimore. I contacted Martin Schneider, Ph.D., about the program and learned that it was exactly what I was looking for. Schneider and Robert Bloch, Ph.D., were both working on muscular dystrophy and I took laboratory rotations in both of their labs during my coursework. One Friday during my rotation in Dr. Bloch's lab, I asked him if I could work on an FSHD project. The following Monday, he had drafted an application for a grant to the FSH Society to study the sarcolemma (a component of muscle tissue) in FSHD! I was very surprised and impressed by this and asked if I could finish my entire thesis project in

his laboratory. I have been in his laboratory ever since.

Q. Your brothers must be very grateful to you for your personal and professional commitment to this work.

Dr. Reed: Yes, they're glad I have chosen to work on this disease and I'm sure they are grateful. I am also grateful to them for making it possible for me to continue doing this work. Members of my whole family have picked up the tab on many things over the years when I was trying to pay my way through school.

Q. Are other people in your extended family affected with FSHD?

Dr. Reed: With the exception of my brothers, no other person in my entire family has FSHD and there is no family history of the disease. The disease affects the whole family, though. Of course, you do not want anything bad to happen to your family members. It is very hard to accept that there is no effective treatment for the disease.

Q. When did you first become aware of the FSH Society?

Dr. Reed: I first became aware of the FSH Society after attending a patient support group meeting at Karen Johnsen's house in Bowie, Maryland. I did not know that so many people had FSHD in the Washington, D.C., area. There were 10 to 20 people present, all of whom lived within convenient driving distance of Karen's house.



The Reed brothers—Mike, Pat, and Bill

Q. Is the FSH Society filling an appropriate role?

Dr. Reed: The FSH Society is the central clearinghouse for information about FSHD. Patients with FSHD are put in touch with important resources and receive the latest information regarding research progress on FSHD through the FSH Society. It is also very important to realize that the FSH Society funds small research grants to initiate studies in new directions or using new approaches that would not be funded by other agencies. Many labs have been able to establish a research program specifically working on FSHD that was made possible by funds from the FSH Society. As far as the FSH Society's role in raising awareness about FSH muscular dystrophy and the need for federal funding, it has been extremely successful in the establishment of the Boston Biomedical Research Institute Senator Paul D. Wellstone Muscular Dystrophy Cooperative Research Center for the study of FSHD. Now that the Wellstone center has been funded for FSHD research, I think it is very important to make sure all patients and family members with FSHD know that they can contribute to the success of this center by volunteering to have muscle biopsies taken for research.

Meet Patrick Reed, Ph.D.

Q. Are you optimistic about the development of treatments for FSHD?

Dr. Reed: Absolutely—it would be crazy to do this work if I did not believe FSHD could be treated. It is a physical problem and it has a physical solution. FSHD has a complex mechanism and it may be difficult to treat the primary cause of the disease. Then again, our understanding of the disease can be improved overnight with the right experiment, so it is impossible to say how long it will take to find a treatment. We all want to see a treatment for this disease in our lifetime. There are potential treatments that are less specific for the disease but that I find very exciting. I am most optimistic that one of the new approaches to modifying the myostatin pathway will work out. Even though these do not specifically address the cause of FSHD, they may lead to increased muscle mass and strength in patients with FSHD.

Q. How does your research impact the future of the disease?

Dr. Reed: The research that my colleagues and I are doing is designed to detect the changes that occur at the protein level in FSHD muscle compared to normal healthy muscle and to other muscle diseases. Proteins showing

misregulation in muscles from patients with FSHD specifically are the ones that are most likely to be involved in the specific disease mechanism of FSHD. I have been using the protein analysis technique that has the highest available resolution—large format, non-equilibrium, two-dimensional gel electrophoresis—and have recently expanded the resolution of the method even further. Combining this technique with the use of special dyes will enable us to resolve and quantify the greatest number of proteins, perhaps even all of the 6,000 different proteins found in muscle. This will almost certainly lead to the detection of more proteins that are specifically misregulated in muscles from patients with FSHD. The difficult part in this approach, as in many others used to study FSHD, is in the follow-through. You have to study the proteins misregulated in the disease and to learn if they actually play a role in the disease to have any chance of using your results to design possible treatments for FSHD. I have been studying the most obvious candidate protein to date, mu-crystallin. It is not linked to chromosomal position 4q35, the primary disease locus, but seems likely to act downstream of the primary mutation to cause muscle pathology. Mu-crystallin has binding sites for two important chemicals in muscle cells and so is a potential drug target.

DVDs available 2008 International Patient and Researcher Network Meeting

The set of three DVDs, totaling 263 minutes, contains material from the 2008 patient meeting held in Coralville, Iowa. They include presentations from six experts in FSHD and a workshop session for teenagers and young adults on living with FSHD.

The cost of the DVD set is \$25 including USPS Priority shipping *for orders in the continental U.S. only*. A shipping fee will be added to international orders.

Please email

jennifer.lazzaro@fshsociety.org
for an order form and purchase instructions.

Visit our website, www.fshsociety.org, to

- Volunteer to provide tissue samples
- Read about new research
- Make a gift online
- Learn more about FSHD
- Get involved!

Jacobs Family Post-doctoral Research Award established

Through the gifts of Jeff and Chris Jacobs and their family and friends, the FSH Society has established the Jacobs Family Post-doctoral Research Award.

The first recipient is Scott Q. Harper, Ph.D., Center for Gene Therapy, The Research Institute at Nationwide Children's Hospital and Department of Pediatrics, The Ohio State University. The award was approved by the Society's Scientific Advi-

sory Board (SAB) at its meeting in fall 2008.

Dr. Harper's interests and expertise (his work was reported in the Spring 2008 *Watch*) are in developing gene therapies for muscular dystrophy and neurodegenerative disease. He proposes more studies in DUX4, a gene that has recently emerged as a potential FSHD gene. His lab's preliminary data, funded

in part by the FSH Society, show that FSHD tissue appears to have greater levels of DUX4 than normal muscle tissue. Next the lab is using mammal cell culture and zebrafish to try to understand the biochemical function that causes DUX4 toxicity, a necessary step for ultimately developing treatments.

Kelly Family Fundraiser—A reason for hope

By Julie A. Kelly

Last year, I wrote to *Watch* readers about my family's commitment to raise funds for FSHD research. Our work began Labor Day weekend, September 2006, as our family joined together from Boston to Florida in raising contributions for the FSH Society. We knew that every contribution counted so we set forth to get a fundraiser done. It was a true family effort lead by the matriarch of our family, my mother Pauline, down to my youngest nieces, Yan Ni and Lia. Just over two years later, I am pleased to tell you that we have successfully completed three fundraiser letter campaigns, and we have established the Kelly Family Research Fund.

I have been living with FSHD all my life; however, not until the 2006 FSH Society Patient Conference in Cambridge, Massachusetts, did I (and my family) realize just how many families are living with FSHD. Those who are patients are not the only ones who live with this disease—the entire family is impacted. Like most families with FSHD, my family has more than 50% that carry this disease. But as I mentioned, 100% of us live with it each day. We left the 2006 conference wondering: how can we help raise funds and awareness?

As a family, we wanted to give back to the FSH Society. Our family and friends stretch across the Northeast, to the sunny state of Florida, to the big state of Texas. We elected to do a letter campaign because we wanted to reach out to as many relatives and friends as possible. Who knows, maybe we will upgrade to the marvels of modern technology and use the internet next year. Either way, the goal is simple, raise awareness and give back to the FSH Society.

In October of last year, I attended the ribbon cutting for the Sen. Paul Wellstone Center for FSHD Research with my mother and other family members. Once again, we were left wondering: what else can we do to help in the FSHD fight?

To all the families living with FSHD, think about starting your own family fundraiser. If you are not sure what to do, reach out to Nancy Van Zant at the FSH Society. Think about the impact we could all have for the effort of the FSH Society. It doesn't matter if each family raised \$500 or \$5,000 — the collective effort is what will have the most impact. And the



The Kelly Family – 2006 family wedding celebration

research efforts—the search for treatments—in the Wellstone Center for FSHD Research will accelerate.

The FSH Society started at the hands of another family, the Perez family. This grassroots efforts lead by Carol Perez and Daniel Perez has grown and flourished due to their dedication and hope for families living with FSHD. I am in awe of their dedication and hope. So this year's article in the *Watch* is in dedication to all families touched by FSHD. I have hope! My family has hope! Your family also has a reason to hope!

We are grateful to all our family and friends for their gifts, their work and their prayers. We look forward to report to you about the Kelly Family Research Fund and the work it will undertake in the coming months.

From picnic to the laboratory— Family picnic raises funds for FSHD fellowship

Generous and energetic friends of the FSH Society in suburban New York, led by Beth Johnston and her committee, held a picnic to raise funds for a post-doctoral research fellowship in summer 2008. These funds have been awarded to Frédérique Magdinier, Ph.D., Laboratory of Molecular Biology of the Cell, Ecole Normale Supérieure de Lyon, France, by the Society's SAB at its meeting in fall 2008.

Dr. Magdinier is an expert in epigenetics and FSHD. Epigenetics is the study of gene expression caused by mechanisms other than changes in a person's DNA. In

France, she has established an impressive library and range of high fidelity cellular models to study epigenetic aspects of FSHD. Her work shows evidence that the D4Z4 repeat(s) involved with FSHD have an anti-silencing activity on genes involved in FSHD. Normal "repeats" keep genes "silenced" and muscle healthy. A reduction of "repeats" causes the loss of "silencing" and FSHD results. Capturing this data, and explaining these epigenetic control mechanisms in models of FSHD, will rapidly give clinicians a rationale to attempt treatments in FSHD, especially using compounds to modify gene

expression. Most FSHD is linked to a decrease in the number of "repeats," or adjacent copies of a DNA sequence called D4Z4 located at the end of chromosome 4. The D4Z4 area on the chromosome contains no genes but it may influence genes nearby, perhaps activating a gene or "silencing" it.

Thanks again to all the good work by Beth Johnston, Ken and Judy Seslowe, and all our friends in New York for making this research fellowship happen!

NIH Wellstone Center for FSHD officially launched

October 10, 2008, members of the FSH Society and friends of the Boston Biomedical Research Institute (BBRI) gathered to recognize the establishment

of the first Wellstone Center in New England and first research center in the world to focus exclusively on FSHD.



Charles Emerson, Ph.D., director of the new center and president of BBRI, "We have recruited the best minds in basic and clinical research and have an extraordinarily committed patient advocacy group to help us focus on this problem." Emerson invites William R. Lewis, Sr., M.D., chairman of the board of directors of the FSH Society, to cut the ribbon and launch the new center. Louis Kunkel, Ph.D., co-director of the new center, and Daniel Paul Perez, president of the FSH Society, also pictured.

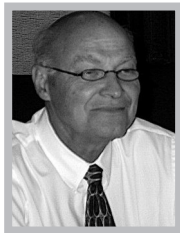
FSH Society Annual Donor Report 2008

The Challenge for the Wellstone Center for FSHD reaches its goal!

From the Chairman, Board of Directors, FSH Society

February 2009

Dear Friends,



William R. Lewis, Sr., M.D.

In November, I wrote to ask you to participate in the Challenge for the Wellstone Center for FSHD Muscular Dystrophy, a collaboration of the Boston Biomedical Research Institute, the FSH Society and others important to this work. Board members joined together to offer to match your gift and the gifts of others, up

to a total of \$117,200 on a dollar-for-dollar basis if you made your gift by December 31, 2008.

I am pleased to report that 280 individuals, foundations and businesses in the FSHD community contributed \$123,856 to the Challenge. Board members have made our matching gifts in recognition of all of you who have made gifts large and small. Together, we have all contributed \$241,056.

Notwithstanding the extraordinary economic environment in which we find ourselves, the FSH Society has concluded one of our most successful fundraising years ever, raising \$750,000 from

generous friends like you.

You helped the Society make important progress. Thank you for supporting advances in research, education, outreach and advocacy.

The list that follows includes all donors to the FSH Society in 2008. We hope you will continue to support this work by joining the Society again in 2009.

Sincerely,

William R. Lewis, Sr., M.D.

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 Arnold Shkolnik, M.D.
Stephen Shotland
Cathy and Steve Shuster
Rod Shuster
Kenneth L. Siegel, D.D.S., P.C.

Gifts received January 1, 2008 through December 31, 2008

Gifts to Membership, Research and Education

Robert and Marian Simon
Lois Ann and Brent Skinner
Glenora Kelly Smith
Keri Smith
Lorraine and Kenneth Smith
Rolf and Trudie Soderstrom
Paul and Geraldine Spillane
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Thomas Wix
Patrick and Mary Yost
Anthony and Joan Zaccani
Susan and Joseph Zacherman
Steve Zawrotny
Angela Zielinski
Helen Zimmer and Karen Prill

In Memory

Family and friends of these individuals have made gifts in their memory in 2008.

Elizabeth A. "Betty" Black
Salvatore R. Bonanno
Roger Brown
Judy A. Burke
Francis Cameron
James Carr
Paula Sulzman Cartoun
Bernard Chabner
Elizabeth Coar
Eleanor H. Falenski
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Marsha Resnick
Susan Rice
Pearl Rosenblatt
Ethel Russom
Pauline Seslowe
Jeffrey Shook
Henry E. Smith
Dr. Russell E. Smith
Jean E. Soldan
Jean E. Soldan on Father's Day
George Stangas
Charlyne Deeg Stasiuk
Benjamin L. "Ben" Stout
Adelyn Tyll
Joseph Vengelar

In Honor

Family and friends of these individuals have made gifts in their honor in 2008.

Joseph Daniel Albumio, Jr.
The Jeffrey Bache Family
Carol and Horace Barsh on
their marriage
Sandy Batkin on *Father's Day*
Sanford Batkin on *his 85th birthday*
Ann Biggs-Williams
Barbara Birnbaum
Steven Blier
John Bowden
Marge S. Brchan
Corinne Bronfman
Mimi Brown
Don Burke
Brian Cavanaugh
Howard Chabner
Howard Chabner on *his 50th birthday*
Justin Cohen
Justin Cohen on *starting*
Tufts University
Gary Cohen on *his 50th birthday*
Haley Cohen
Betsy Conron
Betsy Conron on *her 50th birthday*
Grace Corradino
Pauline Cuoco
Rosalind Devon on *her birthday*
Charles Emerson, Ph.D.
Richard T. Fields and family
Frank Fitzmaurice

Sixto Garcia
Catherine Gibson
Omi Thea Giesen
Alan Gordon
Joseph Donald Hawkins
Ruth Hereford
Bill and Judy Herzberg
Harry Herzberg
Monica and Peter Herzberg on *their new home*
Dr. William Herzberg
William Herzberg on *his birthday*
The Herzberg Family
Andrew Hoffman on *his 21st birthday*
David E. Housman, Ph.D.
Lauren Jacobs
Shelley Jacobsen
Jeff Johnston
Beth and Jeff Johnston and *their Family Picnic for FSHD Fundraiser*
The Katz Family
Julie Kelly
Maureen Kelly
Pauline Kelly
The Kelly Family
Lewis M. Kunkel, Ph.D.
Berni Kuntzelmann
C. Larry Laurelo
Aubrie Lee
Mary and Man So Lee on *their 50th anniversary*
Richard Lefebvre on *his birthday*
Andrew Levinson on *his making Phi Beta Kappa*
Duncan and Wm R. Lewis, Sr., M.D. and family
Kathy Lucero
Myra Marantz on *her birthday*
Lin McClay
Marilyn Meisel
William Michael
John Milne
Michael Moffat
Nathan Morin
Camry Murdoch
Kyle Pablo
Pachx2
Linda Passon
Allison Patapa
Denise Patapa
Ron Paynter
Carol Perez on *her birthday*
Carol and Charles Perez
Dan Perez for *his great work*
Sue Perez on *her birthday*
Hilda Perez-Shafer
Sal Picone
Nicolas Pogany
Edward J. Reed
Valerie Renosto
Jennifer Rhatigan
Joanna Roberts
Zeke Ross
Jane Rowlett
Jessica Ryley
Edward Schechter
Eli Schindelheim
Deborah Schwartz
Rod Shuster
Gina, Dana and Lora Simone
Saul Smolar on *his 80th birthday*
Linda Stapleton
Monti Staton

Chris Stenmon and *his "Tenth Annual End of Tax Season Celebration"*
Jayne Turner-Hughes
Nancy Van Zant
John Weintraut
Jack and Debra Wilt
Dr. and Mrs. Glenn Wing
Matthew Worley
Dr. David Younger
Helen Younger on *her birthday*
Helen and David Younger

Gathering of Members and Fundraising Events, 2008

- Northport, NY, Tennis Fashion Show, March
Laura and Paul Kampa, Hosts
- Quincy, MA, 10th Annual After Tax Season Celebration, April
Ellen and Chris Stenmon, Chairs
- New York, NY, Gathering of FSH Society Members, April
New York Botanical Garden
- Pebble Beach, CA, 50th Birthday Party, April
Betsy Conron, Honoree
- Fire Island, NY, Yard Sale, July
Grace Corradino and Brian Kerr, Chairs
- Coralville, IA, FSH Society International Patient and Researcher Network Meeting
July
- Staten Island, NY, 50th Anniversary Party, August
Mary and Man So Lee, Honorees
- Mamaroneck, NY, Family Picnic for FSHD, Sept.
Beth Johnston, Chair;
Judy and Ken Seslowe, Hosts
- Spring Lake, NJ, Luncheon
December

Family Fundraising, 2008

- Biggs-Williams Family
- Chabner Family
- Gillespie and Gibson Families
- Herzberg Family
- Jacobs Family
- Kelly Family
- Perez Family

FSHD Future Fund

Members of the FSHD Future Fund are individuals who have remembered the FSH Society through a bequest or other estate planning instrument.

- Amy Bekier
- Greg and Tanya Bergstein
- Michele DeSha
and Howard Chabner
- Barbara and James A. Chin, Sr.
- JoAnn Forance
- Judy Marantz and
William Herzberg, M.D.
- Jeff and Chris Jacobs
- Donald and Judy Lokerson
- William and Virginia Michael
- Jennifer Moore
- Deborah Schwartz
- Robert Smith
- Helen and Marc Younger

Gifts received January 1, 2008 through December 31, 2008. We deeply regret any errors or omissions.