

FSH Watch

INCLUDING
DONORS
2011



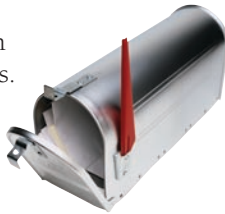
CONNECTING THE COMMUNITY OF PATIENTS, FAMILIES, CLINICIANS AND INVESTIGATORS

LIVING WITH FSHD

Wanted: FSH pen pals

by EMILY ANGELINI

FSH affects people in many different ways. Collin and I not only share some of the same symptoms of muscular dystrophy, we share a friendship.



I was 12 years old when I was officially diagnosed with FSH. At that time my mom thought it would be a good idea for me to meet other kids who also have FSH. She turned to the FSH Society, and Nancy Van Zant put my mom in contact with Lilleen Walters, a lady in Virginia who not only had FSH, but so did her son Collin.

I started corresponding with Collin by email. At the same time, my mom was beginning a friendship with Collin's mom. It turns out Collin and I have many more things in common besides FSH. We both like to camp, fish and play video games.

In April my family and I were invited to Collin's house for an FSH get together. I was nervous before I met the Walters' because I didn't know what to expect, I didn't know what they would think of me and I didn't know anything about the other people who were attending the party. But, the day I met Collin changed my life forever! I kept thinking "I'm not the only kid with FSH. I have a friend who is also affected by this disease." During the visit, Collin and I played X

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Fran and Marsha Sverdrup and family

RESEARCH

My journey to FSHD research

by FRAN SVERDRUP, PH.D., SENIOR RESEARCH SCIENTIST
Center for World Health & Medicine, Saint Louis University, St. Louis, Missouri

My journey into FSHD research began in early 2011 when my daughter was diagnosed with the disorder at the age of 10. As my wife, Marsha, and I digested the news of the diagnosis and began furiously reading about FSHD, I was slowly overcome by the realization that my own research background put me into a posi-

tion of potentially contributing to research towards a therapy. Though such a career shift was daunting to consider, how could I not seize the opportunity to add my efforts to the cause?

To explain my situation I need to start with my daughter, Naia, who was born on October 4, 2000, in Kalamazoo, Michigan. She was born six weeks premature, but at 34 weeks of gestation she was far enough along that no major problems were anticipated. She appeared fine and healthy at birth, but a couple of medical issues arose early on. The first was alarming as

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WINTER 2012

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MY JOURNEY TO FSHD RESEARCH

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Naia stopped breathing while she nursed. She was clearly having difficulty coordinating feeding and breathing. It was apparent, even at this early age, that her facial muscles were weak, a condition later diagnosed as facial palsy. Over the course of a couple of weeks in the hospital with careful observation, Naia was able to master the suck-swallow-breathe reflex and we were cleared to take her home. During the hospital stay, she also participated in a newborn screening program for hearing loss, which picked up mild to moderate sensorineural hearing loss. My wife Marsha, a genetic counselor, immediately suspected a neurological disorder that may connect the facial palsy and the hearing loss. Naia's physicians, however, were unable to identify a genetic syndrome at that time that matched her symptoms. In any case, we honestly thought that these were relatively manageable issues and that Naia was an otherwise healthy baby. Of course we had never heard of facioscapulohumeral muscular dystrophy, nor did we suspect that we would be challenged by a degenerative muscle disease.

We had moved to Kalamazoo just before Naia was born when I accepted a job with Pharmacia & Upjohn, a pharmaceutical research and development company. My training was in biochemistry and molecular biology, and I was enthusiastic to apply my skills towards discovering anti-viral drugs. I had expertise in the regulation of gene expression, and over the course of the next ten years I would expand my interests and research to include the epigenetic control of gene expression, controls on whether a gene is turned on or off based upon a very particular set of mechanisms. As a drug discovery scientist I was particularly focused on how environmental factors (e.g. diet, drugs) might alter the epigenetic control of genes in the immune system. This experience would

later prove to be significant in terms of my ability to understand the science around FSHD and my decision to tackle this new research area.

Corporate mergers and reorganizations are part of life in the pharmaceutical industry, and I was introduced to this fact quite suddenly in 2003 when I was transferred from Kalamazoo to St. Louis, Missouri. Our family of four (now including Cora, one, in addition to Naia, three) moved to St. Louis to start a new chapter in our lives. Both girls thrived, and we soon added a third daughter, Lila. All three grew like weeds and were healthy and happy. As corporate reorganizations continued, the closure of the research site in St. Louis and the loss of my job in 2010 forced us into contemplating a possible move from St. Louis. However, a new opportunity arose. I joined forces with a group of 12 similarly displaced drug industry scientists with complementary skill sets encompassing a range of those required for discovering drugs, and we marketed ourselves to Saint Louis University. Long story short we became the Center for World Health & Medicine. Our focus would be discovering medicines for orphan and neglected diseases, thereby largely avoiding competition with large drug companies that tend not to invest in these areas. We began to chart our own course in terms of choosing which diseases we thought we could make a significant impact on with our research expertise. This was a relatively new freedom for us, having recently transitioned from "big pharma" to a more academic environment. For me personally, this was extremely rewarding at the time and would become even more so.

While our children continued to grow, we did notice that Naia was generally weaker in her upper torso than others her age (by the age of five) but continued to remain fully active, playing basketball, softball

It is our 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: Daniel Paul Perez and Nancy Van Zant.
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and swimming. Between the ages of seven and ten we noticed a more pronounced weakness in Naia's arms. When she was having trouble shooting a basketball, I worked with her to strengthen her arms and discovered a rather striking lack of strength and muscle mass in her triceps. I realized that some awkward movements we had noticed with her arms were actually compensatory movements caused by the loss of strength in particular muscle groups. This sent off warning bells in our minds (should they have gone off sooner?) and Marsha and I brought Naia in for a neuromuscular evaluation. At our first evaluation, we were surprised by a tentative diagnosis of FSHD. We had never considered that Naia's symptoms could possibly be related to a muscular dystrophy. Of course this started Marsha and me on a crash course of reading on every aspect of FSHD we could find.

As the confirmation of the diagnosis by genetic testing came back several weeks later, I was becoming engrossed in the

recent literature on the genetic basis for FSHD and the role that epigenetic regulation plays. It really seemed an amazing coincidence (or fate) that I had spent a significant part of my career developing skills and understanding in a particular area of biology that would relate so closely to my daughter's newly diagnosed condition. Although I had little experience with muscle biology, the concepts around the control of genes by epigenetic mechanisms are completely analogous to other systems I had studied. Fortuitously, my new position at the Center for World Health & Medicine allows me to venture into new areas where our drug discovery expertise might be utilized. For me it turned out to be less of a question of whether there was anything I could contribute, and more of a question of how I was going to contribute to the search for potential therapies for FSHD.

In November, 2011, I attended the "FSH Society Facioscapulohumeral Muscu-

lar Dystrophy [FSHD] 2011 International Research Consortium & Research Planning Meeting" held in Boston. Since I was new to the field, Nancy Van Zant and Daniel Perez were obviously curious as to my interest in FSHD research. I thank them tremendously for immediately welcoming me into the FSH Society and making sure that I was introduced to other researchers and research supporters. The relatively small meeting and the fact that I was on a mission made it easy for me to meet many of the researchers at the meeting and to find common ground in understanding how drug screening efforts could potentially push forward the search for new therapeutic options for FSHD. I'm just now getting started with FSHD research, but I certainly have a profound sense of motivation to add my efforts to those of the many fantastic researchers who have made the tremendous strides in understanding FSHD that you have witnessed in recent years. I only hope that my efforts will be fruitful. FSH Watch

WANTED: FSH PEN PALS

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During the visit, Collin and I played X Box for hours. It was also enlightening to meet adults with FSH. That is, someone other than my dad. I didn't feel like people were watching me because of how I walked. I felt like I belonged.

Last summer Collin and his family went camping with my family. I was so happy to see Collin again because he was someone like me. Collin and I went fishing (we didn't have any luck), sat around the campfire and played cards. We had a chance to talk about how the disease had progressed in each of us. It made me feel very compassionate towards him. It made us stronger friends. Our families had so much fun that we went camping again.

Our most recent hang out was this past December. My family traveled from Pennsylvania to Virginia for a FSH Christmas party at Collin's house. Collin and I played an intense game of electronic Monopoly. He won. Our families got a chance to spend time together, laugh, eat lots of great food and strengthen our friendship.

I have since been in contact with a girl from Brazil who has FSH. It's been very exciting to talk to another friend that has



Pen pals Emily and Collin

muscular dystrophy. Both of these special friends have something in common with me that none of my other friends share. I'm so grateful that Nancy was able to find these two friends for me!

Emily turned 14 earlier this year; Collin is 15. FSH Watch

The 2011 Fundraising Challenge for FSHD exceeds its goal!

February 2012

Dear Friends,



In November, Duncan and William R. Lewis, Sr., M.D., Chairman of the Board of Directors, together with Barbara and James A. Chin, Sr., David and Michelle Mackay (Jim and Michelle are members of the Board), and Corinne Bronfman, Ph.D., a major donor to the Society, joined together to

offer a challenge to the Society's members and friends to support promising new work that may lead to a treatment for FSHD. They asked you to make gifts to the **2011 Fundraising Challenge for FSH Muscular Dystrophy**, and they agreed to match your gifts up to a total of \$217,000, on a dollar-for-dollar basis, if you sent them by December 31, 2011.

I am delighted to report that hundreds of individuals, foundations and businesses in the FSHD community contributed **\$272,000** to the Challenge. The Challenge Team has made their matching gifts in recognition of all of you who have made gifts large and small. Together, you have all contributed **\$489,000**.

Notwithstanding the extraordinary economic environment in which we find ourselves, the FSH Society has concluded our most successful fundraising year ever, raising over **\$1,070,000** from generous friends like you. You help the Society make important progress. Thank you for supporting advances in research, education, outreach and advocacy.

The list that follows includes donors to the FSH Society in 2011. We hope you will continue to support this work by joining the Society again in 2012. Thank you and all good wishes to you and your families for the New Year.

Sincerely,

Nancy Van Zant
Executive Director

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 Tony Norskog and Sarah Woerner,
 M.D.
 Jackson Wong and Kami Wright
 Pamela M. and Matthew D. Wright
 Christiane Wyckoff
 Milton and Joanne Yatvin
 Ray Yee
 Michael York
 Phyllis and Paul Young
 Christine Zakrajsek
 Violet Zeitlin
 Liqin Zhu
 Angela P. and Drew L. Zielinski
 Linda and Kendall Zigler
 Tracy and Bart Zitnitsky
 Zitter Group
 Michael A. Zukowski

In Honor

Family and friends of these individuals made gifts in their honor in 2011

Joseph Alburnio, Jr.
 Jean Marie Allen
 Frank Aurich
 Jeffrey Bache
 Marie Bagot
 Carol & Horace Barsh
 Sandy Batkin
 Amy Bekier
 Geoff Bello
 Douglas Berg
 Ann Biggs-Williams
 Steven Blier
 Janelle Blom
 Tyler Brookbank
 Mimi Brown and Bill Burns
 Rachel Brusseau
 Ashley Bryan
 Edie and Bruce Campbell
 Howard Chabner
 Michele Chauvin
 Haley Cohen
 Harriet and Stuart Cohen
 Justin Cohen
 Stuart Cohen
 Ken Colosi
 Matt Comfort and Susan Ziegler
 Betsy Conron
 Grace Corradino
 Marianna Daly
 Rosalind Devon
 Julie Devore
 Robin Ettinger
 Maureen Eye
 Frank Fitzmaurice
 Emily Flanigan
 Sixto Garcia
 Catherine Gibson
 Eric Gibson
 Samuel Gillespie
 Mel Gonzalez
 William E. Grieder, Sr.
 Jessica Ryley Hammond
 Adele Hantman
 Mike Harrison
 Joseph Donald Hawkins
 Scott Heakin
 Ruth Hereford
 Donna Hersh
 The Herzberg Family

Laurie Heyman
 Richard W. Holmes
 John Hosp
 Betty and Bob Humphreys
 Victoria Insley
 Lauren Jacobs
 Isabel Jeffares
 Preston Jeffares
 Beth & Jeff Johnston
 Katherine and Neil Judell
 Glenn Kalmus
 Family Katz
 The Kelly Family
 Christi & Paul Kembrecos
 Timothy Kerrigan
 Bob Kirsch
 Daniel Krasner
 Kryn Krautheim
 Michele Langer
 Stanley Lapidow
 Rubin Laskoff
 C. Larry Laurello
 Aubrie Lee
 Hon Lee
 Richard Lefebvre
 Duncan and Bill Lewis
 Danielle Liptak
 Lokerson Triplets
 Brian Luoma
 Myra Marantz
 Ginny and Charley Maxwell
 Linda McClay
 Kathy McCoy
 Hilary Michels
 Mel Minsky
 Jennifer Moore
 Leon Morales
 The Narayan Family
 Marvin Neiditz
 Elizabeth Niner
 Amanda Norskog
 Edward O'Dell
 Ann O'Leary
 Kyle Pablo
 Carl Parker
 Linda Passon
 Denise Patapa
 Jessie Pease
 Carol & Charlie Perez
 Dan & Sue Perez
 Susan Perez
 Sal Picone
 Jacqueline Pierangelo
 Nicolas Pogony

► 2011 Donors

The Polonsky Family
 Jeff Rennell
 Darryl M. Richards
 Jo Ann Roesler
 Emily and Alan Rosenfeld
 Jane Rowlett
 Jessica Ryley Hammond
 Kelly Sanderfoot
 Eli Schindelheim, Sr.
 Deborah Schwartz
 Adi Segal
 Adi & David Sullivan Segal
 Judy Seslowe
 Clint Shack
 Vincent Shirk
 Allan Silverstein
 Kristin Simmons
 Gina and Dana Simone
 Todd Skiles
 Robert F. Smith
 Monti Staton
 Chris Stenmon
 Erin Taylor
 Doris and Henry Walter
 Benjamin Watson
 Sandy Weeks
 Wilt Family
 Carden Wyckoff
 Helen Younger

In Memory

Family and friends of these individuals made gifts in their memory in 2011

Rex Babcock
 Ruth Batkin
 Elvina and George Baxter
 Foley Bernard
 Barbara Birnbaum
 Alice Bowser
 Christine Bridges
 Helen Burnham
 Bernard Chabner
 Diane Chapman
 Dr. Christopher Chow
 Barbara Christman
 James Colagiovanni
 Bea Cox
 Robert Cranford
 Doug Davies
 James Davis
 Karen Detch
 Jane Douglas McCoy

Audrey Falk
 Barbara Ferullo
 Fuerstein Family
 Hurley Fulmer
 Cindy Gilman
 Elaine Golub
 Joe Grech
 John R Gregory, Jr
 Lady and William E. Hall, Jr.
 Robert Stark Henderson
 F. Peter Herzberg
 Dotty Hiehle
 Dr. John Holmes, III
 Marcella Jarosz
 Karen Johnsen
 Alex Kanter
 Miles Kerrigan
 Elaine Lancaster Kolakowski
 Irene Lai
 Dr. Harvey Larson
 April Levin
 Evelyn Levine
 Beverly Levy
 Richard Markel
 Frank Kenneth McKinney
 Marilyn Meisel
 Carol Melvin
 Billy Michael
 Edward J. Morris
 Dave Nelson
 Lillian Orinick
 Godfrey Padberg
 Panter Family
 Daisy Paynter
 Aida & Harold Purowitz
 Andrew Quigley
 Edith Rastellini
 Gertrude Reil
 Janet Rodano
 Edward Schechter
 Leonard Schwartz
 Edwin Seiberlich
 John Shimkus
 Ralph Skiles
 Russell E. Smith
 Jean E. Soldan
 Frederick Steinmann
 John L. Stephenson
 Prasanna Swamy
 Nancy Taillie
 Thelma I. Van Aller Corradino
 Jo Ann Wido
 Henry T. Wiggin

FSHD Future Fund

Members of the FSHD Future Fund are individuals who have included the FSH Society in their estate planning

Anonymous
 Sanford Batkin
 Amy Bekier
 Greg and Tanya Bergstein
 Howard Chabner and Michele DeSha
 Barbara and James A. Chin, Sr.
 JoAnn P. Forance
 Judy and William Herzberg
 Jeffrey and Christine Jacobs
 Duncan and William R. Lewis, Sr., M.D.
 Donald and Judith Lokerson
 William A. Maclean
 Joseph J. Matt, III
 William and Virginia Michael
 Jennifer Moore
 Elizabeth Schrauder
 Deborah Schwartz
 Robert and Patti Smith
 Thomas A. and Kathy Stewart
 Helen and Marc Younger

Family Fundraising, 2011

Chabner Family
 Gillespie and Gibson Families
 Herzberg Family
 Jacobs and Conners Families
 Kelly Family (Lucero, Wing, Paladino,
 Cuoco, Gregorio, Owens,
 MacDonald)
 Tim Passon

Gatherings of Members and Fundraising Events, 2011

April

13th Annual After Tax Season
 Celebration
 Dorchester, MA
 Ellen & Chris Stenmon, Chairs

May

Festive Evening of Music and Song
 New York, NY
 Judy Seslowe and Beth Johnston,
 Chairs

June

Fulmer Family Dinner
 McDonough, GA
 Rod and Brenda Fulmer, Chairs

Quilt Raffle
 Hopewell School Kindergarten
 Class
 Taunton, MA
 Ann Marie McKenney, Teacher

September

End of Summer Pool Party for FSH
 Muscular Dystrophy
 Atlanta, GA
 Kevin Kirby, Host

October

2nd Annual Walk 'n' Roll
 Irvine, CA
 Amy Bekier and Mimi Garcia,
 Chairs

3rd Annual Walk 'n' Roll
 Cape Cod, MA
 Rich Holmes, Chair

Nike Half-Marathon
 San Francisco, CA
 Paula Birnbaum running in memory
 of her
 mother, Barbara Birnbaum

Chili Cook-off
 Lambertville, NJ
 Jen Hunter and Josh Bobrovcan,
 Hosts

November

ING New York City Marathon
 Geoff Bello, Runner
 Jeff Johnston, Coach

December

Silpada Designs Evening
 Stuarts Draft, VA
 Jill Browning, Hostess

We deeply regret any errors or omissions.



FSH Society 2012 International Patient/Researcher Network Meeting

Saturday, June 30 and Sunday July 1 • Atlanta Marriott Marquis, 265 Peachtree Center Avenue NE, Atlanta, Georgia 30303

Tentative Program (February 2012)

► Friday, June 29

4:00-6:00 p.m. **Registration**
6:30 p.m. **Informal dinner(s)**, to be arranged (optional)

1:30-2:30 and
3:00-4:00 p.m. **Small breakout sessions;
Concurrent and repeating**

Possible topics

- Caregivers; sharing triumphs and trials
- Maintaining a good diet and good nutrition
- Leisure time and the freedom to travel
- The expert patient: managing dialogue with your physician
- Parents: preparing for the education and work life of your children
- Taking stock of your future in the workplace
- Advocacy and disability rights
- Teenagers: Dating and forming lifelong relationships
- Adults of any age: Dating and finding relationships
- Deciding to have children

► Saturday, June 30

Breakfast on your own

8:00 a.m. **Registration continues**

9:00 a.m. to noon **Keynote address and panel discussion**
The State of FSHD research and what patients might expect in the decade

Noon **Lunch** (included in registration)
Luncheon speaker

2:00-3:30 p.m. **Concurrent sessions**
Getting to know each other:
Introducing ourselves

- Teenagers and young adults
- Parents of teenagers and young adults
- FSHD adults
- Spouses and partners of FSHD adults
- IFSHD parents
- Brothers and sisters of FSHD patients

4:00 p.m. **Conclusion**

3:30-4:00 p.m. **Break**

4:00-5:00 p.m. **Speaker or panel:**
Yoga, massage and other relaxation therapies
Dinner on your own

► Sunday, July 1

Breakfast on your own

9:00-10:15 a.m. Improving the quality of patient living
Speakers: Clinician on best practices and three patients speak about their lives

10:15-10:45 a.m. **Break**

10:45-noon Improving the quality of patient living, continued: Physical therapy and exercise, and Breathing and respiratory health

Noon **Lunch** (included in registration)
Luncheon panel
Psychological, spiritual and social dimensions of FSHD

► SOCIETY CONTINUES PROGRESS IN UNDERSTANDING AND TREATING FSHD

Grant awards for August 2011 cycle

1. Identification of the epigenetic mechanisms that regulate DUX4 activity in skeletal muscle
Richard J.L.F. Lemmers, Ph.D. / Silvere van der Maarel, Ph.D.
Leiden University Medical Center
Department of Human Genetics
Leiden, Netherlands
\$80,000 over 2 years
2. Resonance Imaging and Spectroscopy Biomarkers in FSHD
Doris G. Leung, M.D. / Kathryn R. Wagner, M.D., Ph.D.
Hugo W. Moser Research Institute at Kennedy Krieger
Baltimore, Maryland
\$43,650 over 1 year
3. Additional Support for Medicinal Chemistry Developing anti-DUX4 therapeutics for FSHD
Michael Kyba, Ph.D.
Lillehei Heart Institute, University of Minnesota
Minneapolis, Minnesota
\$25,000 over 2 years



FSH Society 2012 International Patient and Researcher Network Meeting

Date:

Saturday and Sunday, June 30–July 1, 2012

Location:

Atlanta Marriott Marquis
265 Peachtree Center Avenue NE
Atlanta, Georgia 30303

Cost for meeting registration and lunches:

- ▶ \$190 per adult (with current membership)
- ▶ \$210 nonmembers
- ▶ \$105 per young adult age 12–18
- ▶ no charge for children under 12

The **International Patient and Researcher Network Meeting**, sponsored by the FSH Society, is a partnership among patients, families, clinicians and scientists. The June–July 2012 meeting in Atlanta will include lectures by and question and answer sessions with leaders in the field of FSHD, including contributions from major clinical centers and research centers, and educational sessions on breathing and respiration, exercise and physical therapy and other quality-of-life topics. Popular breakout sessions include topics that participants have requested as well as the interests of teenagers and young adults.

Overnight accommodations are available at Atlanta Marriott Marquis. The FSH Society has a special conference rate of at \$109 per night (single or double occupancy), plus taxes. The hotel guarantees 25 accessible rooms, 9 with roll-in showers. For the best selection of accessible rooms and showers, please make your reservations early. The closing date for the Society’s block of rooms is Thursday, June 7. For reservations, call (800) 266-9432 or (506) 474-2009, or reserve online at https://resweb.passkey.com/Resweb.do?mode=welcome_ei_new&eventID=6304468

Confirmation for the meeting will be mailed/e-mailed to you upon receipt of your registration. Please mail this form in the enclosed envelope or register online at www.fshsociety.org by June 1. Credit card or checks payable to “**FSH Society**.”

▶ FSH SOCIETY PATIENT NETWORK MEETING AND LUNCH

REGISTRATION FORM

Saturday–Sunday, June 30–July 1, 2012

Please mail in registration by: **June 1, 2012**, to:

FSH Society, Inc.
64 Grove Street • Watertown, Massachusetts 02472
Phone: 617-658-7878 • Fax: 617-658-7879
E-mail: 2012Meeting@fshsociety.org
Register online at www.fshsociety.org

NAME(S): _____

ADDRESS: _____

DAYTIME PHONE: _____

E-MAIL: _____

| | | |
|------------------|--|---------------------|
| Conference Fees: | _____ adults at \$210 each (non FSH members) | \$ _____ |
| | _____ adults at \$190 each (FSH members) | \$ _____ |
| | _____ young adults \$105 (12 to 18 years) | \$ _____ |
| | _____ children under 12 no charge | \$ <u>no charge</u> |
| | _____ 2012 FSH Membership \$50 per household | \$ _____ |

I am unable to attend but wish to support the conference with a fully tax-deductible contribution \$ _____

TOTAL AMOUNT ENCLOSED \$

Please make checks payable to **FSH Society** or, bill my:

CREDIT CARD: AMEX VISA MASTERCARD DISCOVER

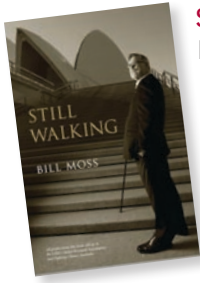
ACCOUNT NUMBER: _____

CARD EXPIRATION DATE (MM/YY): _____ / _____

SIGNATURE: _____



New books



Still Walking
By Bill Moss
Sydney, 2011
\$40.00 US, plus shipping
www.stillwalking.com.au

“These memoirs are the inspirational, moving, blunt and at times very funny account of how a senior and seemingly all-powerful Macquarie banker struggled for years through physical discomfort, pain and the many barriers thrown in the path of people with physical disabilities...to come to terms with his disability.” The author is affected with FSHD and the founder of FSHD Global Research Foundation, Australia. He has generously offered net profits to the FSH Society, from books purchased by FSH Society supporters.

To purchase, email info@fshsociety.org

MATCHING GIFTS AND OTHER WORKPLACE GIVING

Many employers offer workers options for directing the company’s funds to a charitable organization of their choice. When this opportunity is available to you, please consider how your workplace might make a gift to the FSH Society.

DO YOU FOLLOW THE SOCIETY’S FACEBOOK AND YAHOO! GROUP PAGES?

Go to www.facebook.com and sign up. It is free and easy. Search on FSH Society and join the discussion. You can also join FSH Society Yahoo! Groups forum,



online since the 1990’s and with tens of thousands of searchable posts. Bookmark them and come back often. You can also access the FSH Society Facebook page and Yahoo! Groups by going to www.fshsociety.org clicking on the “Community & Reference” menu tab at top of page and then selecting “Online Community” in the left vertical navigation menu.



IT IS NOT TOO EARLY TO MAKE A GIFT TO THE SOCIETY IN 2012

Please help now. The FSH Society is a world leader in combating muscular dystrophy. It has provided over \$3 million in seed grants for pioneering research worldwide and has developed an international collaborative network of patients and researchers. If you are not already a 2012 member, won’t you join in this effort? Please return your membership gift, or another gift, in the enclosed envelope. Or contribute online at www.fshsociety.org. Go to Contribute, and select the gift category you wish to make. Thank you.

VOLUNTEERS ARE STILL NEEDED FOR MUSCLE BIOPSY STUDY

To date, 68 individuals in 34 groups of FSHD-affected volunteers and their unaffected relatives have participated in the FSHD-NIH-Wellstone Muscular Dystrophy Cooperative Research Center’s research study. Muscle samples are in extremely short supply and tissue donors are most needed. The study is in particular need of patients with suspected FSHD-related hearing and retinal involvement, and from minority races and ethnicities, but all are welcome. In order to determine eligibility, you will need to provide a .copy of your gene test result and medical records indicating FSHD diagnosis. For more information, please contact Doris Walsh at the FSH Society 617-658-7877 or doris.walsh@fshsociety.org or Genila Bibat, M.D., Johns Hopkins, 443-923-2697.

Save the Date!

April 28
14th Annual “Friends Supporting Hope”
Fundraiser for FSH Muscular Dystrophy
Dorchester, MA

June 30-July 1
FSH Society International Patient and
Researcher
Network Meeting
Atlanta, Georgia

September 24
A Festive Evening of Song
New York Botanical Garden
Bronx, New York

September 29
Walk ‘n’ Roll for FSH Muscular Dystrophy
Harwich (Cape Cod), MA



Walkers and Rollers at Harwich, Massachusetts, enjoy their October 2011 success, and they are planning another event for 2012. Rich Holmes, Walk chair, second from right in back; Bob Smith, member Society board of directors, front left.

October 5
Golf Tournament
Abilene, Texas

October 7
Third Annual Celebrity Charity Walk ‘n’ Roll
Irvine, CA

Request more information at
info@fshsociety.org