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

FRAN and MARSHA SVERDRUP and family

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 position 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...
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 low 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. 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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Articles may be edited for space and clarity. Every effort has been made to ensure accuracy in the newsletter. If you wish to correct an error, please write to the above address.

Look for us on the internet at: www.fshsociety.org

Editors: Daniel Paul Perez and Nancy Van Zant.
Editorial assistance: Howard Chabner
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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 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.
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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*Gifts received January 1, 2011 through December 31, 2011, continued*

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

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John L. Stephenson
Prasanna Swamy
Nancy Taillie
Thelma I. Van Aller Corradino
Jo Ann Wido
Henry T. Wiggins

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Amy Bekier
Greg and Tanya Bergstein
Howard Chabner and Michele DeShah
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

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 DeShah
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
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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)

► Saturday, June 30
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:
• 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
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
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

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

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.”

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 $__________

_____ 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 ENCLOSURED $__________

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

October 5
Golf Tournament
Abilene, Texas

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

Request more information at info@fshsociety.org