

FSH Watch

INCLUDING
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2012



CONNECTING THE COMMUNITY OF PATIENTS, FAMILIES, CLINICIANS AND INVESTIGATORS



New Study Pinpoints Genetic Source of FSHD Type 2

by MARK MICHAUD, SCIENCE WRITER

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A new study appearing on November 12, 2012, in the journal *Nature Genetics* by an international team of researchers has solved the complex genetic mystery behind a form of muscular dystrophy. The scientists have discovered that a rare variant of facioscapulohumeral muscular dystrophy (FSHD), called type 2, is the result of two unrelated genetic flaws that come together to ultimately produce toxins that damage muscle cells and trigger the symptoms of the disease.

“The discovery of the complex and elusive source of FSHD type 2 is the result of not only a unique international partnership of scientists, but also the extraordinary cooperation of the families who are burdened by this disease,” said University of Rochester Medical Center (URMC) neurologist Rabi Tawil, MD, a senior co-author of the study. “Here in Rochester, we have evaluated many patients – often for several years – who clearly suffered from FSHD, but did not meet the common genetic profile of the disease. This discovery will help us better diagnose these patients and help guide research that could lead to new treatments.”

The study was conducted by a team of researchers from URMC’s Fields Center
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Karungyi—a female mountain gorilla. FSHD patient Scott Sawa climbed for hours through steep, densely forested slopes to visit these amazing animals.



LIVING WITH FSHD

The Mountain Gorillas of Uganda – An FSHD journey

by SCOTT SAWA

Oshawa, Ontario, Canada

I always believed that my life was measured in how many goals I scored, how fast I could run or the number of times I could juggle a soccer ball... that was until my body started to fail me.

When I was finally diagnosed in 2007 with FSHD after 14 months of countless doctor visits and testing I was both relieved

and devastated. I was relieved that my foot drop wasn’t cancer or multiple sclerosis, but devastated because my life was not going to play out the way that I had envisioned. I struggled with this realization and quickly found myself dealing with depression. The physical symptoms I could manage, but I was not prepared for the mental toll associated with my diagnosis.

Initially I was embarrassed and too proud to admit that I was hurting. I couldn’t ask for help and suppressed my feelings of pain and sorrow. My physiatrist suggested a number of aids to help with the
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FSH Society Annual Donor Report



Steps Forward



Dear Friends,

We at the FSH Society are launching into 2013 with renewed energy and excitement. Last year, we broke all previous records, raising over \$1.4 million, including \$586,000 during the Year-end Challenge. Our heartfelt gratitude to all who donated, especially to the wonderful benefactors who contributed to the matching gift challenge: Duncan and William R. Lewis Sr., MD, Corinne Bronfman, PhD, Michelle and David Mackay, William R. Lewis III, MD, Barbara and James A. Chin Sr., and William S. Herzberg.

In this issue of the FSH Watch, you will learn how your past gifts led to major milestones, including the discovery of a second gene for FSHD and a genetically engineered fish that provides a compelling new animal model for the disease. You can also read about the new grants that have just been approved by our Scientific Advisory Board. Your dollars are paving the way, step by step, to drug discovery and clinical trials.

Speaking of going step by step, Scott Sawa shares the gripping story of his adventure of a lifetime, trekking up rainforested slopes in Uganda to visit the mountain gorillas. After years of feeling his world shrink, he decided to no longer let FSHD prevent him from reaching for his biggest dreams.

We also wanted to share the stories of the many volunteers who have dedicated their time, wits and energy to fundraising. These are inspiring tales of individuals who turned their genetic roll of the dice into something positive and empowering. They are building communities and networks to raise awareness, support one another, and have a great time while pursuing a worthy purpose.

Imagine if a hundred of you set out to each raise \$10,000. That's \$1 million right there. What if 200 leaders stepped forward? That's \$2 million. Or raise your sights to \$20,000 per event. The math takes care of itself. But we need boots on the ground. What if you've never done this before? Just take the first step, and then the next, the way Scott Sawa did, and you may be pleasantly surprised by what you are capable of doing.

With best wishes,

June Kinoshita
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It is our editorial policy to report on developments regarding FSHD, but we do not endorse any of the drugs, procedures or treatments discussed. We urge you to consult with your own physician about any medical interventions.

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

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2012 FSH Society Edward M. Schechter Fellowships

Lindsay Wallace, PhD **Postdoctoral Fellow, The Research Institute at Nationwide Children's Hospital, Columbus, OH**

The Edward M. Schechter memorial research fellowship I received from the FSH Society was used to attend the 17th International Congress of the World Muscle Society held in Perth, Australia, in 2012. These funds were imperative because they covered the cost of my flight. Without these funds I would not have been able to attend the meeting and present my work on FSHD.

The aspect of FSHD research that I shared was our findings on the expression pattern of the *DUX4* promoter. Specifically I shared our data on an experimental mouse model that uses the putative *DUX4* promoter to drive the reporter gene green fluorescent protein (*GFP*). We use this model to look at the potential expression of *DUX4* in a non-toxic way. We found the *DUX4* promoter directed *GFP* expression in the face and limbs of newborn and adult mice, as well as the retina. Strikingly, these mice also showed asymmetrical expression and variable penetrance, all of which is consistent with known FSHD clinical characteristics. We concluded that our mice faithfully recapitulate expected *DUX4* expression patterns in regions of FSHD pathology, and further support the role of *DUX4* as a pathogenic insult in FSHD.

During the poster presentation I spoke with many muscle researchers and clinicians who were able to give good insight and suggestions to advance this project and our knowledge of the disease. Because this particular congress is attended strongly by clinicians I was able to gain a lot of insight into the more subtle clinical features that are not always discussed at basic science meetings. Due to the descriptive nature of this project, this was a particularly important learning experience for me.

In turn I believe other attendees also benefited from my presence at the meeting. I had in-depth conversations with many researchers about the rapidly changing views of the field and I also presented to a few people who had never heard of the disease. In that light I believe this fellowship was necessary to broaden the awareness of FSHD and FSHD research.

In general, the field was greatly under-represented at this international meeting. In total there were 317 presentations. Of those six were related to FSHD and only four were related to the disease specifically. Of the four presentations specifically on FSHD, two belonged to my colleague and me, both of us recipients of the FSH Society Travel Fellowship. Without the Society's support, only 0.6% of the presentations at a muscle-specific meeting would have been dedicated to FSHD research.

I am genuinely grateful for the funds the FSH Society provided under the Edward M. Schechter memorial research fellowship program, and I am proud to say I was awarded the Elsevier WMS Membership Award for the research I presented.

Jacqueline Domire **Graduate Research Associate, The Research Institute at Nationwide Children's Hospital, Columbus, OH**

I recently returned from the 2012 World Muscle Society Congress in Perth, Australia, where I presented a poster describing my work on deciphering *DUX4*'s role in FSHD. Since there is not much consistency between dysregulated gene pathways identified by different research studies, we set out to identify these pathways by a novel method in the field in hopes to elucidate a potential target for disease therapy. Since this project is in its infancy, it is important to share our findings with other researchers to facilitate a transfer of knowledge and cross-fertilization of ideas between research groups. Indeed, many of the presentations about research in other muscular dystrophies provided valuable insight into some technical aspects of my project, which will hopefully lead to faster and more significant results.

In addition to the scientific benefit to my research provided by this Congress, it also strengthened the motivation behind my research. Working in a research laboratory does not offer much direct exposure to patients and clinicians, and this Congress is an inspiring annual reminder of the lives that my research has the potential to impact. Research careers can be a long and daunting road, but these interactions at meetings keep me pushing towards the goal of a treatment for individuals affected by FSHD.



Lindsay Wallace and Jacqueline Domire glam it up for the World Muscle Society Congress gala!

I am early in my career and I am new to the field, so these interactions also provide the chance to network with more senior career scientists. The more contacts I make early in my career will lead to more opportunities for the next step in my training after I receive my PhD.

An FSHD presence at these meetings also increases interest in research efforts for those in the muscular dystrophy community. FSHD is underrepresented in muscular dystrophy research, despite its estimation as one of the most common dystrophies. Indeed, out of the 400 posters presented at this year's World Muscle Society Congress only four were on FSHD.

FSHD representation at these multidisciplinary meetings is imperative for exposure to other scientists and clinicians, and will hopefully lead to quicker advancement of research efforts than we have seen in the last 20 years. In fact, many clinicians with limited knowledge of current research in the disease were intrigued by the work of our lab. Hopefully this will lead to a larger representation of FSHD research at subsequent meetings as these research efforts become more publicized. Indeed, another private research foundation, FSHD Global, was hosting an event in Perth in concurrence with the WMS Congress. The research of our lab was represented at this event also, and allowed for collaboration with others involved in advocating for FSHD research.

Without the funds provided by the FSH Society under the Edward M. Schechter memorial research fellowship program for the flight to Australia, attendance at this meeting would have been cost prohibitive since our current grant funds cannot be used for international travel. I'm grateful to the FSH Society and its donors. FSH Watch

The FSH Society funds advances in understanding and treating FSHD

by THE FSH SOCIETY
Lexington, Massachusetts

FSHD research has come a long way since the FSH Society was founded 22 years ago. The evidence was there for all to see at the FSH Society's 2012 International Research Consortium & Research Planning Meeting held on November 6, 2012, in conjunction with the annual meeting of the American Society of Human Genetics in San Francisco, California.

The biggest buzz at the meeting was generated by the discovery of a new gene for FSHD by scientists from the U.S., Netherlands and France (see related story on page 1). The study appeared in the prestigious science journal *Nature Genetics* on November 11. The newly found culprit, a gene called structural maintenance of chromosomes flexible hinge domain containing 1 (*SMCHD1*), may account for the majority of the five percent of patients who have FSHD type 2. The new finding will provide them with a genetic test. The interaction between the new gene and the D4Z4 deletion associated with FSHD type 1 will be a topic of intense interest.

As important as it is to pinpoint the genetic causes of FSHD, it is also essential to validate methods to measure the progression of the disease. To conduct a clinical trial, researchers need a "therapeutic biomarker", something that changes to show that a treatment is working. Without a proven therapeutic biomarker, the Food and Drug Administration will not allow a clinical trial to go forward. And unless a biomarker can show change over one or two years, pharmaceutical companies are not going to be willing to invest in a clinical trial, especially for rare diseases with small markets.

The search for a therapeutic biomarker has been very challenging for FSHD, which typically progresses slowly over many years and decades. So attendees at the San Francisco meeting were heartened by a report from George Padberg, MD, and his colleagues from the Netherlands. In the small study of 30 Dutch patients with genetically confirmed FSHD, magnetic resonance imaging was used to measure fat, which invades and replaces muscle as the disease progresses. The investigators reported that once the disease process sets



into a muscle, the rate of fat infiltration is rapid enough to be detected over a period of as short as four months, making it potentially useful as a therapeutic biomarker. This finding needs to be replicated in a larger group of patients, Padberg noted.

The discovery two years ago of the role of the D4Z4 deletion and *DUX4* is starting to produce new insights that could lead to treatments. An exciting study, reported by Greg Block, PhD, and his colleagues at the University of Washington School of Medicine and University of Rochester Medical Center, pointed to a possible role for apoptosis ("programmed cell death") in FSHD muscle. Skeletal muscle cells, or myotubes, that express *DUX4* undergo apoptosis, and are rescued from death by chemicals that block apoptosis. The group was also able to reduce myotube death by manipulating biochemical pathways that regulate *DUX4* expression.

Additional insight into future biomarkers and drug targets could emerge from a study at Boston Children's Hospital, Johns Hopkins School of Medicine and the NIH Senator Paul D. Wellstone Muscular Dystrophy Research Center in Boston. First author Fedik Rahimov, PhD, described the identification of a "molecular signature" based on gene expression in muscle biopsies from FSHD patients. This signature was accurate 90 percent of the time in distinguishing FSHD bicep muscle from normal control muscle. The study,

which has been submitted for publication, also identified a dozen biological pathways that are altered in FSHD. Restoring these pathways to a more normal pattern might be a strategy for developing future treatments.

Last but not least, investigators reported on the latest advances towards treatments. Collaborators from Belgium, France, Australia and the U.S. presented an "exon skipping" approach similar to one used recently with promising results in Duchenne muscular dystrophy, to inhibit *DUX4* in human muscle cell cultures and mice.

These latest findings are generating a wave of optimism, but much remains to be done. As important as the work in laboratories is the work of educating patients and their families about the critical role they play as volunteers for studies.

"It is asking a lot of people to sacrifice their time and energy, not to mention give blood and muscle samples, for research, especially when there is no treatment today," said FSH Society Executive Director June Kinoshita. "But patients and their families who do volunteer are manifestly moving the field forward, as was so clear at this meeting. None of these discoveries would have been possible without them." FSHWatch

Editor's note: You can read the abstracts presented and the priorities developed at the meeting by the FSHD research community for *FSHD Research: 2013 and Beyond* at <http://www.fshsociety.org/pages/sciConsortium.html>

FSHD Champions meet in San Francisco

by **KEES VAN DER GRAAF, PRESIDENT, STICHTING FSHD AND FSHD EUROPE**
Wassenaar, The Netherlands

Early in 2012, Dan Perez, President and CEO of the FSH Society, and I developed the idea to bring together all the organizations that raise funds for FSHD research. It seemed a good opportunity to hold a meeting at the occasion of the general meeting of the American Society of Human Genetics on November 8, 2012, in San Francisco. As the FSH Society would hold its annual gathering of FSHD scientists earlier that week, also in San Francisco (see story on page 4), many of the potential participants for a Champions meeting would already be in the same location.

The purpose of the meeting was many-fold. We wanted to get to know all the players in the FSH research funding world. We wanted to get a feeling for the projects the different organizations were funding. We felt there was a real need to exchange information and a possible willingness to learn from one another. This appeared to be a good assessment, as all of the invited organizations participated.

Each organization sent a high-level officer, either the chairman, the general director or a senior executive. From North America, we had representatives from the Muscular Dystrophy Association, FSHD Canada, the Pacific Northwest Friends of FSHD, the FSH Society, the National Institutes of Health, and the Shaw family. From Australia we had the FSHD Global Research Foundation, and from Europe the Association Française Contre les Myopathies (AFM), FSHD Europe, the Stichting FSHD, the Prinses Beatrix Fund, and the Vereniging Spierziekten Nederland VSN (Netherlands Neuromuscular Diseases Association), a Dutch patient organization. The Chris Carrino Foundation's Jennifer Burgess had planned to attend but was unable to due to

Hurricane Sandy.

The meeting was co-chaired by Dan Perez and Kees van der Graaf. In the first round each organization introduced itself briefly. Immediately the enormous amount of motivation came across, as most representatives of the FSHD organizations were either affected themselves or were a parent of a child with FSHD. Ria Broekgaarden of VSN gave a fascinating and cautionary account of the Pompe muscular dystrophy experience. Here a therapy exists and people with the disease are being successfully treated. Important lessons for FSHD were learned.


An initial analysis of research funding of FSHD projects indicated that well over 10 million dollars were granted annually by the participating organizations. A significant portion of this goes to the "Fields" group, with Silvere van der Maarel (University of Leiden) as one of the largest recipients of grants. The Champions organizations agreed to share information about their grant funding per year and per institution, to obtain a better overview of global investments in FSHD research.

Given the significant progress made in explaining the genetic mechanism behind FSHD1 and FSHD2, there was a quick agreement on the most important objective of the coming years: to identify potential therapeutic targets, develop a way to stop the progression in FSHD, and by doing so, gain time to develop a complete cure.

It was also considered extremely important to get global agreement on the description of FSHD, its severity, its prevalence and its occurrence. With the help of the research community, we will develop a white paper, which we will publish in one of

the scientific journals.

Other topics which we agreed to pursue were: formulation of the 10 most important research areas, identification of the right output measures (including biomarkers), magnetic resonance imaging (MRI/MRS) for measurement of progression of FSHD in the muscle, trial readiness and natural history data analysis.

As so often happens with successful meetings, we ran out of time, and would have loved to cover more subjects. It was a no-brainer to agree upon an annual meeting, immediately after the FSH Society's annual research meeting. All participants of the Champions meeting will attend the FSH Society meeting. In the meantime a working group has been formed to drive all the agreed actions to completion. This group will meet at least monthly by conference call. We will also use webinars for presentations on particular topics of mutual interest. We concluded that huge progress has been made, that we have the fortune of a large number of excellent researchers working on the discovery of a treatment, that we have accumulated an impressive amount of expertise around the Champions table, and that we as a group can have a significant impact by working more closely together. To be continued! 

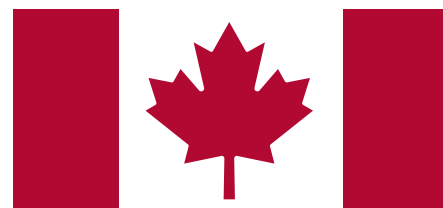
Editor's note: *The first Champions webinar was held on January 28, 2013; it was a fascinating presentation by John Porter, PhD, Program Director for the muscular dystrophies at the National Institute of Neurological Disorders and Stroke (NINDS), about the need for rigor and reproducibility in preclinical studies, and the initiatives at NINDS and NIH about this critical subject.*

COLLABORATION WITHOUT BORDERS

The FSHD Canada Foundation and FSH Society are working together to direct funding to the highest quality, most impactful research on FSHD. The newly formed Canadian foundation will be offered opportunities to fund grants for research projects recommended by the FSH Society's world renowned Scientific Advisory Board. The first FSH Society-FSHD Canada Foundation fellowship grant has been awarded to Dr. Gabsang Lee, D.V.M., PhD, of Johns Hopkins University, for his project "Derivation of human induced pluripotent stem cells from FSH patient fibroblasts."

This collaborative approach enables FSHD Canada to retain a lean, efficient operation and leverage the FSH Society's resources to fulfill the aims of Canadian donors. If you have any questions, please visit the FSHD Canada website (<http://www.fshd.ca/>)

Canada



THE MOUNTAIN GORILLAS OF UGANDA - AN FSHD JOURNEY

... from page 1



Scott Sawa says goodbye to some of the school children from the Bigodi Progressive School. Many of the children have lost their parents to HIV.

pain including AFOs, a back brace and a cane. I was embarrassed to show the world what I was dealing with, which meant the cane was out. I would wear my AFOs to assist with my drop foot, but I had to wear long pants regardless of the temperature. I honestly believed that if I hid supportive aids and did not talk about FSHD, then somehow I was not affected.

As the weeks turned into months, and the months into years, I realized I was simply getting through life. I was not living life to the full because I was too busy feeling sorry for myself. My wife had a lifelong dream to travel the world and would ask me “if you could go anywhere in the world where would you go?” I had stopped having dreams, so this question was very difficult for me to answer.

When I finally stopped to think about it, I told her I wanted to go to Africa and see the mountain gorillas. My answer definitely surprised her but she used it as the seeds that would grow into our trip of a lifetime, one that took us to 23 countries spanning four continents. The trip became a reality when we sold our house and boxed up our most treasured possessions. After that, things happened very fast and before I knew it we were flying from Istanbul to Nairobi.

I was filled with a lot of questions and doubts about what we were doing. I was trying to balance my physical limitations with the negative voice telling me that I couldn't do it. What I found surprised me.

Our plan was to spend the first three weeks volunteering in western Uganda near the Congo border before traveling to Bwindi National Park to track the critically endangered mountain gorilla.

We arrived in Bigodi and met our host Tinka and his family. The village of Bigodi is located in the western highlands of Uganda

and a community-run organization, KAFRED, oversees the operation of a wetland sanctuary where tourists come to see primates, birds, snakes and plant life. This eco-tourism organization was established to generate funds for community projects such as the local school and HIV/AIDS orphan care. It was amazing to see how the community benefits directly from the tourist dollars.

All of the comforts we had at home were gone – no running water, no hot water, no electricity and no indoor plumbing. I was initially focused on the negatives and all the things that the village didn't have, but as the weeks passed I began to see the positives. There was such a sense of community and family. The people of the village were so generous and kind to us it was hard not to come around.

Into the Mountains

At the end of our volunteer commitment, we arranged to make the trip to see the gorillas. Our driver David picked us up for our journey south. Crossing the equator, we arrived at Bwindi Impenetrable National Park. We camped at the base of the mountain and after I processed that I was actually there, I began to doubt that I could complete the trek. I was caught between the idea that we were fulfilling a dream of mine while I was physically capable and the idea that I couldn't do it because of my foot drop and muscle fatigue.

The mountain was steep and it had been raining, which would make it much more difficult to trek. My other concern was that these wild mountain gorillas, of which there are fewer than 800 left, could be anywhere on the mountain. This meant that it



The Silverback Mwirima. "I caught him staring directly at me and was able to capture the moment in a photo. I was astounded by how muscular and powerful he was. He was very protective of the baby gorillas and actually charged very close to our group to let us know he is the boss."



Scott Sawa with Catherine, who guided his group on their trek to see the mountain gorillas. "She was curious about my FSHD and made sure that I was accommodated throughout our journey. This photo was taken after I received my official certificate for completing the trek. This has to be one of the proudest accomplishments of my life."

could literally take 12 hours to track them down and even this was not guaranteed. My anxieties were temporarily relieved at dinner as I listened to the tales of the adventurers who had returned from the mountain that day. The relief didn't last as I tossed and turned in my bed. Doubts and excitement danced in my head.

The morning of our trek was eerie. The mist rolled down the mountain and then my AFO strap snapped! I quickly found some duct tape and improvised a quick fix which I hoped would hold until day's end. We received our permits while enjoying our breakfast overlooking the Impenetrable Forest. These permits are like gold. They only issue eight permits per gorilla family and with just three families in Uganda that means we were two of 24 privileged people who would have the opportunity to come face-to-face with mankind's closest animal relative. The permit allows you 60 minutes with the family if/when you find them and you must keep a distance

of seven metres at all times due to the fact that we share 98% of our DNA with them and can wipe out a population with a common cold. The only time this is not applicable is if the gorillas approach you!

After our orientation was complete we separated into three groups, each assigned to track a different gorilla family. As we waited in the group slated to follow the Habinyanja family, our driver David approached and informed us that we would now be tracking the Rushegura family. David had listened to me speak about my FSHD and managed to get us into a group with a shorter anticipated trek.

I made sure to hire a local porter to help me along the way, and with walking stick in hand, we set out. The weather was favourable but I was not prepared for the steepness of the ascent. We stopped every ten minutes to catch our breath and grab a drink. It was hard going and after about an hour one of our group members had to turn back because it was physically too much for her. I could feel my legs burning and I really struggled to keep up, but I was determined to see the gorillas.


Our ranger called us to a halt about 90 minutes into the journey and informed us that the lead trackers had located the gorillas and that we were roughly 30 minutes away from them! Although that last leg of the hike was the most difficult, it was all worth it when we finally slashed our way into a tiny opening on the side of the mountain and first laid eyes on these amazing animals. They were in the trees just "hanging out" and enjoying the beautiful, peaceful day. Many thoughts were rushing through my head but I wanted to stay in the moment and fully appreciate the experience. Within a few minutes of arriving the gorillas started to make their way down from the branches above and carried on with their day as if we were not there. We saw the dominant silver back Mwirima, a powerful and intimidating creature. At one point our eyes met and we shared a moment. It was a moment that I will never forget and one that makes me smile every time I think about it.

Of the 19 gorillas in the family we were lucky enough to see them all and this included a blackback, some juveniles and five babies. The gorillas became interested in us and decided to come in for a closer look. A man in our group almost had his pocket picked by a curious juvenile and Mwirima actually charged in our direction at one point. The hour went by far too quickly, but the journey back to basecamp was a joyous one. My legs were heavy and my body was hurting from numerous falls, but it was a life-changing experience for me.

I am grateful to our driver David for recognizing that I needed help. His kind and graceful gesture was ultimately why I was able to make the full trek to see the gorillas. As it turned out, our original gorilla family had not been located by the time we returned to basecamp. This meant that they were hiking for five hours, something I would not have been able to do.

In the past if I perceived something to be too difficult I simply avoided it. My gorilla experience made me realize that I can dream, I should not label myself or set limits on what I can't do without trying. If it doesn't work out or it is too demanding at least I know I tried.

The people I met in Africa taught me about resiliency and how to appreciate the simple gift of being alive. My FSHD may have closed some doors for me but ultimately it has provided me with the opportunity to truly experience life. I am grateful every single day and I am already planning my next big adventure.

If you want to read more about our round-the-world adventure visit www.aroundabout.ca. 

One man's decision to have surgery

by RICH HOLMES

Hyannis, Massachusetts

Some surgical decisions are clear cut: Gash your hand; sew it up.

Break a leg; put it in a cast.

Develop acute appendicitis; remove said appendix.

Then there are those medical decisions that require balancing risks and benefits and determining not only whether to have a procedure done, but choosing from more than one surgical option.

How do you make up your mind?

The answer, for me, consisted of finding enough information from which to make an intelligent decision, and possessing the willingness to accept the possibility of a partially successful or unsuccessful outcome because the research showed favorable odds. Nothing ventured, nothing gained, they say.

The process began two years ago and the full results remain to be seen, but early indications seem encouraging. If my recuperation continues to go well, more surgery lies ahead.

A Promising Option

Two summers ago I attended a patient-researcher conference sponsored by the FSH Society. I have FSHD. There is no cure or medical treatment for this chronic muscle-wasting disease. There is, and has been for decades, a surgical option of attaching the scapulas — or shoulder blades — to the rib cage to stabilize the shoulders, thereby allowing patients to raise their arms above their heads.

I had dismissed this procedure as barbaric carpentry, until a presentation at the conference convinced me of its benefits and how recent refinements had improved results and reduced complications. I also met people at the conference who had undergone the surgery and were thrilled with the results. I became a convert.

How could I get this operation? Was I even a candidate?

A year went by before I seriously began pursuing the surgery. I had not visited my neurologist at Brigham & Women's Hospital in Boston for several years, because there was no treatment for my muscular dystrophy. My previous visits had consisted of cataloging the genetic disease's slow progression and participating in a test drug pilot study. Now I

“Because I live alone, I thought about how might I take care of myself with both an arm and a leg out of commission. I would need some help, but how much and from whom?”

was back seeking information.

Was there anyone in the Boston area that did scapular fixation surgery?

The surgeon who gave the presentation worked in Baltimore. Would I benefit?

My neurologist, Dr. Anthony Amato, and his colleague, Dr. Erik Ensrud, a physiatrist, assessed my physical state.

Yes, my shoulders had full range of motion if supported. Surgery would supply that support.

Amato said he would investigate if any local surgeons performed this procedure.

A few days later, he e-mailed me a name: Dr. Laurence Higgins, of Brigham's orthopedic surgery department, a specialist in shoulder surgery. I made an appointment.

Higgins examined me and said he, too, thought my range of motion indicated surgery would allow me to raise my arms over my head again for the first time in years.

Other than my dystrophy, I was healthy, so I would probably be a good surgical risk. He did caution that most patients he had done this operation on were in their 20s and 30s. I was 56 at the time; I might heal more slowly.

Another issue: The benefits of the operation would fade somewhat with time. I was close to being too old for him to accept me as a candidate.

It was now or never.

Higgins called me a week or so later. He thought my biceps were so withered that although the surgery might allow me to reach a jar on the top shelf of my kitchen cabinet, I might drop both the jar and my arm from lack of muscle strength. He said he had discussed my case with a colleague in Chicago who had a patient similar in age and condition to me. That man was unhappy with the results of the surgery because he could not do as much as he had hoped, Higgins said.

Downcast, I thought, well, it's not for

me. I'll just continue on as I am, slowly getting worse.

A New Plan

But there was another twist and turn. Dr. Higgins contacted me again, asking me if I wanted to see another orthopedic surgeon who might have a way of bolstering my biceps.

I met with Dr. Philip Blazar at Faulkner Hospital in the Boston neighborhood of Jamaica Plain in late 2011. He discussed ways of relocating muscles to improve my ability to flex my elbow. A muscle in my forearm could have one end reattached further up my arm, but I would not be able to fully straighten my arm. Or, my pectoral muscle could be flopped from my chest to my upper arm, although I would have to relearn how to command it. Perhaps something similar could be done with my one of my lats (latissimus dorsi muscles) on the side of my torso?

I rejected all of these options as the tradeoffs seemed too big, and anything that would further weaken or destabilize my shoulders didn't make any sense to me.

Blazar thought for a moment, then offered another suggestion: Why not transplant the gracilis muscle from my thigh to my upper arm? Would it worsen my gait or make me less stable on my feet, I asked? No, he said. In fact, the muscle was redundant; its function could be taken over by other thigh muscles.

Hmmm.

I went home and researched the operation on the Internet and found that it was done for people who had injured the brachial plexus, the bundle of nerves leading from the spine to the upper arm. In those cases, not only was the gracilis transplanted, but a nerve from the chest was connected to it.

In my case, the operation would be

simpler. My nerves were fine, so only the muscle would be transplanted and then hooked up to my arm's nerves and blood vessels. Recovery rates for the operation looked good in a study I read. The vast majority of patients had considerable to some improvement, although about 20 percent did not.

I also found other papers backing up Dr. Blazar's description of the gracilis as a "spare part" that could be safely moved to the arm or face in plastic or reconstructive surgery. One caveat: He could find no mention in medical literature of the operation being done on someone with muscular dystrophy. He couldn't be certain how I might heal or how the disease might affect the gracilis after transplant. I would be a bit of test case.

Before meeting with Dr. Blazar, I had not heard of a "free muscle transplant." Now I was hoping to have one.

Getting Ready

In anticipation of the surgery and a lengthy recovery away from work, I took several steps.

First, I checked my medical insurance to

see if the surgeons were "in network," and therefore the work done would be covered more fully than "out of network" doctors. I checked my policy for hospitalization, home care and physical therapy, did some math and saw I would fare better financially if I switched to the costliest health insurance plan offered by my employer. The amount coming out of my paycheck would go up considerably, but less than the maximum out-of-pocket expenses I would be hit with if I stuck with my mid-level coverage. Plus more of the total cost would be spread through the year via paycheck deductions.

The opportunity to change health insurance plans occurs at year's end at my workplace, so I needed to make up my mind in a month or so if I wanted surgery in 2012.

I talked to the woman who oversees the human resources office at work and my boss and her boss about taking a medical leave of absence. I considered what two to three months away from work would mean to me and the staff of page designers I oversee.

Then came more personal decisions. Would a leave disrupt progress on the annual FSH Society charity event I oversee that

takes place in early autumn? I thought about the weather, and wanted to have surgery after winter had passed — no need to fall on the ice and ruin all the work that had been done on my arm. I weighed whether to go to a rehab hospital on Cape Cod (close to work friends and my daughter) or in Boston (excellent reputation and close to my surgeons). Because I live alone, I thought about how might I take care of myself with both an arm and a leg out of commission. I would need some help, but how much and from whom? Should I rely on the local Visiting Nurse Association or take up the offer of my girlfriend, a registered nurse, to live with her for a few weeks? There was a lot to pore over.

I also visited a lawyer and had a health care proxy and new will drawn up, naming who should make decisions on my behalf should I become incapacitated.

I was ready.

Surgery and a Complication

I had the transplant on April 27, 2012. Drs. Blazar and Matthew Carty, a plastic

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NEWS AND EVENTS

2012 Celebrity Walk 'n' Roll

by **AMY BEKIER, CO-CHAIR**


Irvine, California

You've heard the saying: Charity begins in the home and Have Fun while raising funds. The Celebrity Charity Walk 'n' Roll was all of that and more.

Over 20 celebrities and athletes joined attendees at Heritage Park, Irvine, CA, on October 7, 2012. Max Adler, who starred as Dave Karofsky on the television series *Glee*, served as the celebrity host. Many others also brought their star power to a fun-filled day, which ended up raising \$56,000 in donations and in-kind sponsorships.

How did the event grow from its humble beginnings? Three years ago, Mimi Garcia and I, both FSHD patients, met at an FSH Society conference and decided that we "could no longer sit and cope, but must get active and hope."

Even modest beginnings can compound into large sums. People are more likely to donate when they know someone with the disease. Most family, friends, and coworkers are delighted to help. Believing that the mission is more important than the messenger will help you ask for donations and support. What keeps me going is the warmth, appreciation and love I feel from the people who attend. The journey begins with asking.

Save the Date: The 2013 Celebrity Walk 'n' Roll will be on October 6 in Irvine. If you would like to help, please contact me at amyzoart@gmail.com. Thank you! 



Max Adler shows off a hat made for him by Simone Taverna, who traveled from Italy to attend the 2012 Celebrity Walk 'n' Roll.

A Fish for FSHD

by JUNE KINOSHITA, EXECUTIVE DIRECTOR, FSH SOCIETY
Lexington, Massachusetts

A renowned laboratory has genetically engineered a fish that develops the hallmarks of facioscapulohumeral muscular dystrophy, providing an important new animal model for understanding FSHD. Congratulations are in order to our Scientific Advisory Board member Louis Kunkel and FSH Society Fellow Hiroaki Mitsuhashi, who are co-authors on the paper published in *Human Molecular Genetics*. Both Drs. Kunkel and Mitsuhashi are at the Division of Genetics at Boston Children's Hospital.

The scientists worked their genetic wizardry on the zebrafish, a tropical minnow with dapper blue stripes. Around two inches in length, the creature migrated from the remote, Himalayan headwaters of the Ganges River into the fish tanks of biologists around the world, and has become the aquatic counterpart to the laboratory mouse. The fish's body is transparent during its embryo phase, enabling biologists to map the development of its organ systems in meticulous detail. The creature's entire genome has been sequenced, and bodily and behavioral abnormalities catalogued and linked to genetic mutations. The zebrafish has even traveled into outer space!

Back at Boston Children's Hospital, the little minnow is helping humanity by revealing the role genes play in disease. One mystery about *DUX4*, the current leading suspect in FSHD, is that the gene is expressed in only one in a thousand muscle cells. It's challenging to explain how such a low level of expression can lead to such



Four-day-old zebrafish expressing DUX4-fl. Arrows point to fish with eye abnormalities.

Photo courtesy of Hiroaki Mitsuhashi and Louis Kunkel.

dramatic muscle degeneration. Animal models to date have not fully mimicked the disease, characterized by an asymmetric progressive weakness and wasting of the facial, shoulder and upper arm muscles, and often, later, those of the legs, ankles and trunk. These symptoms are sometimes accompanied by hearing loss and disordered blood vessels in the retina of the eye.

Mitsuhashi and his co-workers injected small amounts of human full-length *DUX4* messenger RNA into fertilized zebrafish eggs. These fish developed asymmetric abnormalities such as less pigmentation of the eyes, altered ear structure, abnormal fin muscle, disorganized facial musculature and degeneration of trunk muscle later in development – everything one would expect if a fish could have FSHD.

“These results strongly support the current hypothesis for a role of *DUX4* in FSHD pathogenesis,” the authors write. But there's a twist: “Our hypothesis is that FSHD is a developmental disorder,” says Kunkel, meaning that the disease arises from the

impact of genetic events in the developing embryo or fetus. He hypothesizes that the aberrant expression of *DUX4* during development triggers a cascade of changes that set up the individual to be susceptible to FSHD.

“This changes our thinking about therapeutics,” he observes. “Knocking down *DUX4* in adults may not work. The real targets may be the downstream genes that are affected by developmental expression of *DUX4*.”

A fascinating and important hypothesis, and one which shows how vitally important it is to keep an open mind and study FSHD at the most fundamental biological level. With a little help from a fish with FSHD. [FSH Watch](#)

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ONE MAN'S DECISION TO HAVE SURGERY

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and reconstructive surgeon, performed the operation.

I spent five days post-surgery at the Brigham before transferring to Spaulding Rehabilitation Hospital in Boston for physical therapy and rehab. It wasn't all smooth. I kept bleeding from my leg wound — a lot.

The day I was discharged my thigh started aching and accelerated to intense pain by the time my girlfriend and I reached Buzzards Bay on Cape Cod, MA. I ended up at Faulkner Hospital the next day where

a liter of fluid was taken out of my leg and a new drain installed. After two weeks at home, Dr. Carty determined a persistent infection was keeping my leg from healing. I was admitted to Faulkner where the thigh-long incision was reopened and scraped out and I was put on two heavy-duty IV antibiotics for a week. That ended the problem with my leg, and I healed rapidly afterward, returning to work on July 3.

My arm never gave me any medical problems. It was difficult having it in a bulky

sling for months. I did weaken overall from inactivity during my hospitalization and recovery.

But the hardest part was and is trying to be patient. The nerves in my arm need to grow into the transplanted muscle for it to function. Otherwise, it would be useless and waste away. There was no guarantee the nerves would grow into the muscle. The doctors had connected the nerve sheath as closely as they could to the muscle to

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SANDY COULDN'T STOP ME!

by ANNE CATERINO
Malvern, Pennsylvania

After four months of fundraising for the FSH Society, and one major hurricane, my husband Darren, who has FSHD, and I were finally in New York, checked in and at the New York City Marathon Expo on Friday, November 2. I picked up my marathon bib, took photos, enjoyed perusing the booths, spotted some elite runners, and mentally prepared myself to run for the FSH Society in two short days, through one of the greatest cities in the world, despite some angry opposition to the race so soon after "Sandy" tore through the region.

A couple of hours later, relaxing at our hotel, the calls and text messages started coming: "Heard about the cancellation," "I'm sorry about the marathon." Quickly I looked at the race website – no change. But there had been a press release. Friends and family around the U.S. who had supported our fundraising all knew what the runners in NYC did not: that the 2012 NYC marathon had been cancelled.

An emotional roller coaster. What do you do when you are running for charity? You run ANYWAY. That weekend in Central Park, many charity runners came out to run. People yelled out "Ándeale Annie!!" my way due to my "Running to cure FSHD" shirt. There were photos at the finish line. Most important – we raised \$7,338 for the FSH Society ANYWAY!

I was able to run the Trenton half marathon the following weekend, where I chatted up some fellow runners about our cause, and the finish line announcer informed the crowd inside Arm & Hammer Park that I was running for the FSH Society for treatment and a cure for FSH muscular dystrophy.



Anne Caterino with daughters Megan and Julia at the Trenton half marathon.

Musical Stars Shine for FSHD

by JUNE KINOSHITA, EXECUTIVE DIRECTOR, FSH SOCIETY
Lexington, Massachusetts

For years, Steven Blier has occupied the limelight as a celebrated pianist and advocate for the art song. He has toured with opera superstars like Renée Fleming. Singers line up at his door to be coached to greatness. As Artistic Director of the New York Festival of Song, he brings songs from diverse genres to the stage and to nationwide radio audiences.

But on September 24th, 2012, Blier stepped into the spotlight as an advocate for a different cause, starring in a benefit concert at the New York Botanical Gardens to raise funds for FSH muscular dystrophy (FSHD). FSHD has left Blier unable to walk. Sharing the stage with him was his friend Kelli O'Hara, a multi Tony award-nominated singer and actress who has entranced audiences in such Broadway hits as *South Pacific*, *The Pajama Game* and, currently, *Nice Work If You Can Get It*.

The pair captivated the audience with Gershwin, Sondheim and other classics from the American songbook, but they also had an urgent message to deliver through a new video (<http://www.youtube.com/watch?v=FljYUMTr3IM>). "We no longer just live in some vague, undefined hope," Blier tells viewers in the video. "We now live in the knowledge that with your generosity and our music, we will actually reverse this disease and get out of our wheelchairs for good." The event was a smash success, raising \$250,000 for the FSH Society.

For Blier, FSHD had been a lonely, unending battle. Even as his musical career took flight, he carried on stoically as the strength ebbed from his upper arms and legs. Eventually, the disease confined him to a wheelchair, but his arms and hands remain strong, and he can still tickle the piano ivories and fill the air with melodies. Several years ago, Blier decided he needed to do more. He became a champion for FSHD research and lent his star power to the FSH Society, performing at the Society's New York concert every year since, and recruiting his friends in the music world to the cause as well.

Speaking to the nearly 300 donors who attended the New York concert, Blier shared a remark made to him by scientist Peter Jones about the profound impact the FSH



Steven Blier and Kelli O'Hara

Society has had. "It's all about numbers [of patients], and there's a lot of competition for those federal dollars...and FSHD was getting left in the dust," Jones told Blier. "But you guys...wow. You are a tough bunch to keep down. The breakthroughs are really because of the FSH Society. And they're tremendous. They're bigger than just FSH Dystrophy."

An international team of scientists recently completed the first map of the junk DNA genome in a scientific landmark that made headlines around the world. The breakthroughs in understanding FSHD in particular have prompted National Institutes of Health (NIH) Director Francis Collins to proclaim that "If we were thinking of a collection of the genome's greatest hits, this would go on the list."

Blier was filled with pride and joy when he realized the impact he and thousands of patients have had. "Musicians don't always know dreams from reality," he told the New York benefit audience. "But it seems that this time, my dreams—and those of so many other people with FSH Dystrophy—might finally be coming true."

The FSH Society thanks Steven Blier and Kelli O'Hara for lending their artistry to our cause; event co-chairs Judy Seslowe and Beth Johnston, and all of the event committee and volunteers for their passionate and tireless work; Abigail and Bob Kirsch for providing the elegant venue and catering; and Bill Milling, Susan Egert-Milling and the staff of the American Movie Company, who donated their time and resources to the writing and production of our FSH Society video. [FSH Watch](#)

NEW SOURCE PINPOINTS GENETIC SOURCE OF FSHD TYPE 2

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for FSHD & Neuromuscular Research, the Leiden University Medical Center in the Netherlands, the University of Washington, and the Fred Hutchinson Cancer Research Center in Seattle.

FSHD is one of the most common forms of muscular dystrophy. The first symptoms of the disease usually appear in the form of muscle weakness in the upper body – including the arms, shoulders, and face. Eventually, these symptoms spread to the rest of the body. The disease can lead to significant disability and many patients end up in a wheelchair. An estimated 500,000 people worldwide suffer from this disease.

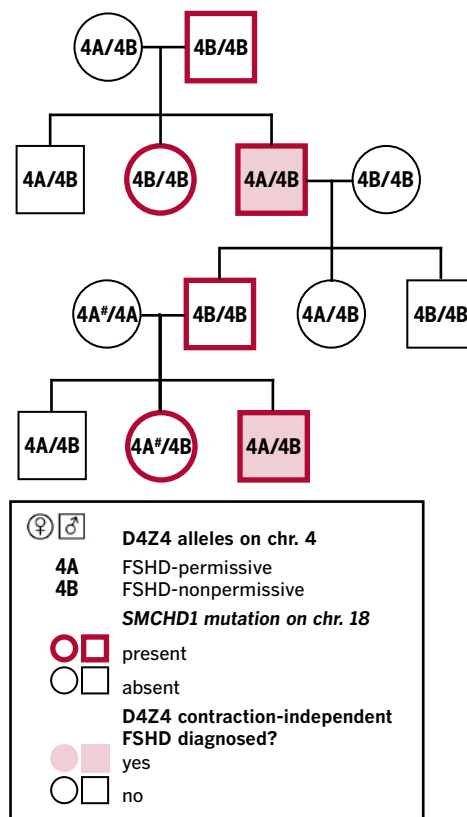
The genetic cause of FSHD type 1 – the more common form of the disease – was first revealed by the same group of researchers in a study that appeared in the journal *Science* in 2010. In that paper, the scientists zeroed in on a specific segment of genetic code called a macrosatellite repeat that appears at the end of chromosome 4, essentially a genetic “stutter” that results in a section of code being replicated multiple times.

The human genetic code was thought to be full of “junk” or inactive genes often contained in macrosatellite repeat sequences such as the one seen in FSHD. However, these regions of repeated genetic code are now understood to be actively switched on and off and help regulate the function of many other genes. When the normal regulation of gene expression is disrupted, such as occurs in FSHD, the effect is devastating.

People without the disease actually have a large number of repeats. Consequently, this section of the code is longer and folds tightly back upon itself like a ball of twine. This prevents an active piece of code – called *DUX4* – which is bound up within the macrosatellite repeat, from being accessed. *DUX4* carries instructions to create a protein that – while found in other parts of the body – is toxic to muscle cells.

By contrast, people with the disease possess a small number of repeats (fewer than 10). The *Science* study found that in these instances the DNA is more loosely bound and exposed, allowing the genetic instructions in *DUX4* to be used by the muscle cells to build proteins. People with FSHD also possess a snippet of genetic code adjacent to the repeats – called an A allele –

FSHD2 Pedigree



Idealized composite FSHD2 pedigree, showing independent segregation of a muscular dystrophy-permissive D4Z4 allele (4A) and any of several mutated forms of the SMCHD1 gene (red outline), which segregate with D4Z4 CpG hypomethylation. Only individuals with digenic inheritance of both the FSHD-permissive D4Z4 allele and a mutated SMCHD1 allele develop D4Z4 contraction-independent, type 2 FSHD (i.e., FSHD2). The 4B allele of the D4Z4 array is not permissive of FSHD. Rare subtypes of the 4A allele (marked with #) are also considered to be FSHD-nonpermissive. (Figure courtesy of Stephen Tapscott.)

that serves to stabilize the message from the *DUX4* code. In people with this unfortunate set of conditions (short number of repeats followed by an A allele), the result is the production of a protein that breaks down muscle cells causing the symptoms of the disease.

“Most genetic mutations reduce the production of a protein, or a mutated gene might produce a detrimental protein,” said Daniel Miller, MD, PhD, and associate professor of pediatrics at the University of Washington. “FSHD is unusual because it is most often caused by genetic deletions that paradoxically result in the production of *DUX4* in the wrong tissue at the wrong time.”

While this phenomenon explained

the trigger for the vast majority of FSHD patients, there remained a small number of individuals – 5 percent of patients with the disease – that did not meet this genetic profile. These patients, dubbed by researchers as exhibiting FSHD type 2, possessed the longer D4Z4 repeats found in healthy individuals, however, their symptoms were identical to other FSHD patients.

To understand the cause of this FSHD variant, researchers analyzed the genetic profiles of 12 families with the disease. The genetic mutations that cause FSHD are inherited. By examining the code of patients with FSHD type 2 and that of their unaffected parents and siblings, the researchers could then identify the common genetic factors and begin to understand how they may impact each other.

“The breakthrough came when we realized that in some of these FSHD type 2 families this open macrosatellite structure segregates in the family independently of the length of the repeat,” said Silvere van der Maarel, PhD, professor of human genetics at the Leiden University Medical Center. “This observation allowed the identification of the genetic flaw that causes this opening of the repeat structure.”

This investigation ultimately led the team to yet another culprit on a different chromosome. In healthy cells, one of the factors that helps bind long strands of the chromosomes tightly together is a chemical process called methylation. In FSHD, the absence of these chemical links enables the macrosatellite repeat structure to unravel or open up – regardless of its length – exposing the *DUX4* code. The researchers found that this occurred in patients who also possessed a mutation in a gene called *SMCHD1*, which regulates the methylation process and consequently how tightly genetic structures are bound together. In patients with FSHD type 2, just as in FSHD type 1, this flaw works in concert with the A allele code to create the conditions in which the toxic proteins that are the source of the disease are mistakenly produced.

“Many diseases caused by a single gene mutation were identified over the last several decades, but it has been more difficult to identify the genetic basis of diseases caused by the combination of more than one genetic variant,” said Stephen



Members of the team that discovered the genetic cause of FSHD type 2. Standing (left to right): George W.A.M. Padberg, Silvère van der Maarel, Daniel G. Miller, Rabi Tawil, Sabrina Sacconi. Kneeling (left to right): Greg Block, Richard J.L.F. Lemmers

Tapscott, MD, PhD, a co-investigator at the Fred Hutchinson Cancer Research Center. “Recent advances in DNA sequencing made this study possible and it is likely that other diseases caused by the inheritance of multiple genetic variants will be identified in the coming years.”

This understanding of the source and mechanisms of the disease has helped researchers identify junctures during which the disease process could be intercepted or altered. The findings also indicate that similar treatments could be developed that impact patients with both types of FSHD.

In addition to Tawil, Van der Maarel, Tapscott and Miller, other authors of the *Nature Genetics* paper include:

- University of Rochester Medical Center: Colleen Donlin-Smith;
- Leiden University Medical Center: Richard Lemmers, Judit Balog, Patrick van der Vliet, Kirsten Straasheijm, Yvonne Krom, Rinse Klooster, Yu Sun, Johan den Dunnen, Jessica de Greef, Annemieke Aartsma-Rus, Rune Frants, Quinta Helmer, Bert Bakker;
- University of Washington: Lisa Petek, Gregory Block, Amanda Amell, and Michael Bamshad
- Radboud University Nijmegen Medical Centre (Netherlands): George Padberg and Baziel van Engelen;

- Academic Medical Center (Amsterdam, Netherlands): Marianne de Visser;
- Nice University Hospital (France): Claude Desnuelle and Sabrina Sacconi; and
- Fred Hutchinson Cancer Research Center (Seattle): Galina Filippova.

Funding to conduct the study came from the National Institutes of Neurological Disorders and Stroke, the National Institute of Arthritis and Musculoskeletal and Skin Diseases, National Human Genome Institute, National Genetics Institute, the Muscular Dystrophy Association, and the URMCC’s Fields Center for FSHD & Neuromuscular Research.

The FSH Society awarded fellowship grants to three of the co-authors of this study: Richard J.L.F. Lemmers, Yvonne Meijer-Krom and Silvère van der Maarel.

Additional funding came from Pacific Northwest Friends of FSH, Netherlands Genomics Initiative, the Gerald Norton and Eklund family foundation, European Union Framework Programme 7, Stichting FSHD Netherlands and China Scholarship Council. [FSHWatch](#)

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GENETIC TESTING FOR FSHD TYPE 2

In 2010, an international team of researchers discovered the cause of FSHD in over 90 percent of patients: a loss of “D4Z4 repeat” DNA near the tip of chromosome 4 together with a DNA snippet called the “A allele”. This variant of FSHD, called type 1, can be diagnosed through a commercial genetic test ordered by a doctor.

Now a genetic cause has been found for patients with FSHD type 2: a mutation in a gene with the tongue-twisting name “structural maintenance of chromosomes flexible hinge domain containing 1” (*SMCHD1*), which when combined with the “A allele” causes symptoms identical to those of FSHD type 1.

For FSHD patients who have tested negative for D4Z4 deletion, what does this finding mean?

A test for *SMCHD1* is not yet available from commercial diagnostic laboratories, but it can be ordered through Leiden University in the Netherlands. The test requisition form is available from the FSH Society (e-mail info@fshsociety.org). The test costs 770 euros and takes around eight weeks for results to be reported.

The University of Rochester’s Rabi Tawil, MD, a senior co-author of the study, emphasizes that researchers still have much to learn about *SMCHD1*’s role in the disease. “It is crucial at this point to carefully study individuals with FSHD type 2 as well as their unaffected family members, so that we may increase our understanding of the clinical and molecular similarities and differences between FSHD types 1 and 2,” he says.

The University of Rochester has ongoing research studies of individuals suspected of having FSHD type 2, as well as their family members. The studies involve clinical evaluations, collection of biological samples and genetic testing for FSHD type 2. To be eligible for this study, the patient must have tested negative for FSHD type 1, and the evaluating neurologist must rule out other possible muscular dystrophies. The study covers the cost of DNA testing and travel expenses, but due to limited resources, is able to accommodate only a limited number of individuals per year. Qualified patients can contact Colleen Donlin-Smith at 585-275-7680.



BBQ and soulful sounds - Fulmer Family Dinner

by **ROD FULMER**
McDonough, Georgia

FSHD is a strange disease. It sometimes affects just one or maybe two people in a family, but in our case FSHD has affected several beginning as far back as my grandfather, dad, uncles, cousins, my two sisters and me.

My dad passed away in 2005, and I wanted to do something in his honor. But with very little funds, I decided to try to start a tradition that could go on for years – maybe even after I am gone. That is how the Annual Fulmer Family Dinners to benefit the FSH Society got started. I wanted to do something to try to help stop this disease that has taken a toll on so many of us.

Each year we have an all-volunteer event that involves a meal and live entertainment. This event is chaired by my wife and me, and with the help of many dear friends and family we are raising money and making a difference. Each year the event gets larger and we raise more money and for some reason it seems to get easier as well.

This past year we were blessed to use a wonderful facility at Sharon Baptist Church as well as to have some wonderful BBQ donated by Shane's Rib Shack, a chain of restaurants started right here in McDonough, Georgia. We were also blessed with some wonderful talent from as far away as Alabama and Tennessee and some local people as well. I so much look forward to our daughter Savannah singing at these dinners. Special thanks to Phil Bennett and Nia Stivers, both with FSHD, who performed their music as well. Phil brought his guitar all the way from Tennessee.

None of this could've happened without some very talented and dedicated volunteers. It is with great pleasure that I not only thank my immediate family but also Barbara and Richard McMichen, Mark and Deborah Mathis and their family, Joyce Jacks, Patsy and Rick Joyner, June and Paul Pitney, and so many others. I have to give a huge Thank You to my wife Brenda who has worked tirelessly and is already planning the 2013 dinner.

I hope I speak for all of us when I say that we have a great time doing these dinners. There are times when things get a little frustrating, but there are more often times of much laughter and it really touches your heart when people donate money, time and door prizes for these dinners. I can't thank these people enough. I know these dinners benefit the FSH Society and so much research. I have to thank Nancy, June and Doris for their never-ending support.

If you are considering a fundraising event please do it. It really is fun and it helps you forget about your aches and pains for a little while. FSH Watch



The Fulmer Sisters entertained with sweet harmonies.

CAPE CRUSADERS—CAPE COD WALK 'N ROLL

by **RICH HOLMES**
Hyannis, Massachusetts

Through the hard work of volunteers and the generosity of sponsors and FSHD families and friends, the fourth annual Cape Cod Walk 'n' Roll raised more than \$20,000 – our highest amount yet!

The September 29, 2012, event at the Harwich Community Center combined a walk along a bike trail, a raffle, silent and live auctions, and a hot meal. The Cape Cod Cheer Academy kicked off the event with an energetic display. AnnMarie Richard, Fred Thys, Jake Holmes, and Freya Hoffman-Terry collected auction items.

I'd like to thank co-chair Bob Smith and all donors and sponsors, especially Cape Air, Cardi's Furniture, Tuckerman Brewing, Harley-Davidson of Cape Cod, Coastal Sun Self-Storage, Cape Cod Times and WBUR.

AnnMarie, Roger and Karen Debenham, Melanie Lauwers and Maureen Hourihan created an amazing meal. Melanie and Susan Eastman held a successful bake sale. Tom and Karen Mansir, Tim Miller, MaryJo Wheatley, Bill Mills, Natalie Holmes, Tom Lorge and others lent helping hands.

FSH Society President Daniel Perez, Executive Director June Kinoshita and scientists Peter and Takako Jones told the audience of the advances being made. Peter Jones told me that FSHD is more complex than previously thought. Rather than seeing this as a reason to despair, Jones said there are more opportunities to interrupt the disease process – truly something to celebrate.

Two milestones were noted: the passing of Dan's mother, Carol Perez, and the retirement of the organization's first full-time executive director, Nancy Van Zant. Both women's leadership helped make the Society what it is today. Nancy and Doris Walsh also volunteered as cashiers at the event.

▶ Do It Yourself Wine-Holding Support



Here's a "handy" tip from FSHD Canada's founder Neil Camarta. He says, "With my upper arm strength petering out – I've had lot of trouble doing the simplest things like carry around a glass of wine at a party or a plate at a buffet. So, I jury-rigged this contraption which helps a lot." He repurposed a device designed for "drop foot" by Dictus. (<http://dictusband.com/dictus.htm>)



Why I Missed School

by CUTTER COWART
Texas

I am writing this paper to explain why I missed school on Friday and about a great fundraiser that I got to be a part of. I was invited to play in the Hustle for Muscle Golf Tournament by our really close friends Wayne and Wendy Shack (see story below). The tournament was held to raise money for muscular dystrophy; their son Clint has FSHD.

The tournament raised almost \$80,000. I got to bid on something for the first time at a silent auction and I was the highest bidder on an autographed baseball signed by John Lackey, who graduated from Abilene and now plays for the Boston Red Sox. That was a lot of fun.

My family has known the Shacks since before I was born. They are like family to us and I was really sad when I found out that Clint had muscular dystrophy. Playing in the tournament made me feel like I was helping to find a cure for FSHD. There was a lady who flew in from Boston by the name of Nancy Van Zant. She brought a video to watch so all of us could learn more about how it affects people of different ages.

While watching the video I saw how Clint's wife Erin started crying and how much she loves and supports him. It made me really sad to think about what he might have to go through when he gets older and I hope that the FSHD will stop damaging his muscles. In the video, it also showed a young boy who I think was around nine years old who suffers from this type of muscular dystrophy. Wendy said that he is the youngest person in the United States who shows signs of FSHD. Since I am only 11 years old it really made me think about kids who suffer from diseases and how thankful I am to be healthy.

Wendy and her family spoke and said they are going to continue to do these tournaments so I will continue to play in them and help support raising money to find a cure for muscular dystrophy and get better at golf! Thank you for letting me miss school so that I could help support our friends and a lot of other people who are needing a cure. FSHWatch



Clint Shack and Cutter Cowart

HUSTLE FOR MUSCLE – REFLECTIONS

by WENDY SHACK
Abilene, Texas

The day had finally come that everyone had worked so hard for. The energy at the Hustle for Muscle tournament was so exciting. And what a turnout!!! We had 140 golfers and 33 volunteers. And I do need to mention we had 72, count them, 72 hole sponsors! What a sight to look out over the course and see all those signs.

Everyone who was there would just look around at all the people and say WOW! I cannot remember once during the day when there was not a smile on every person's face. The adrenaline was running high with the Hustle for Muscle team. And the steam just kept rising as the silent auction went on during the day. All I can say is we named the event right; we sure had a lot of Hustlers out there working that auction.

I could hear whispers during the day that someone from the FSH Society was there. Everyone was so impressed with Nancy, what she represented, and how far she had traveled. I was not sure how she would react to the Oilfield Beer Drinking Teams but she had a good laugh with all of them. I hope everyone goes to the Hustle for Muscle facebook page (<https://www.facebook.com/HuscleForMuscle>) to really get a sense of the spirit of the day.

As the day went on, all I could think about was, what a difference all these people have made in so many lives, with their giving hearts and



Golfers ready to take a swing against FSHD at the Abilene Country Club.

pocketbooks. As I sit and write this it brings tears to my eyes and such gratefulness to my heart. And to top all of it off we had one little secret we found out about the day before the tournament. Clint and Erin are going to be parents and that means a wonderful glorious grandchild for us to love and adore. It was too soon to tell everyone, but all I could think about was a little one being there next year. Yes God is good!

During the awards ceremony a video was shown that the FSH Society had created with the help of some amazing people.

When we wrote our letter explaining why we were doing this golf tournament, it reached many people. However, to explain FSHD is sometimes hard. After watching this video everyone was even more touched.

Nearly all of the golfers came to me afterwards and wanted us to do it again in the spring! All of the wonderful people from the Abilene Country Club that we had worked so closely with were in tears. Every one of them came up to me afterwards crying and telling me they wanted to be a part of this every year. We are approved for the 2013 tournament already, and they have arranged it so we can have a double shotgun. How blessed we are. So October 4th 2013, here comes the Hustle for Muscle 2nd annual golf tournament!

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| Adam D. Taylor | David Waldmann | Kabir Barday | Minna Fay Wolf | Thomas M. Guzik |
| Alex H. Hood | Dawn Counard | Karen Hamilton | Mirko Wienke | Thomas Marchetti |
| Alison Eill | Debora Otero | Karen Michalak | Monique Govostes | Timothy Harman |
| Aliza Shapiro | Donna Sanderson | Kate Mullen | Nadine Fagan | Tracey Greiner |
| Alyssa Lyons | Doris Walsh | Katherine Culbertson | Naomi D. Hillel | Walter D. Barrick |
| Amy E. Strolle | Edna Smith | Katherine Wade | Natie Kopelowitz | Yehudith Heiblum |
| Anat Harrel | Edward E Cormier | Katie Briggs | Nicholas D. Brandt | Yilin Shen |
| Andrea Kessler | Edwin Hu | Kayla Bruner | Nicholas H. OBrien | Zvi H. Harrel |
| Anisa Alhilail | Elia P. Demetri | Keith R. Johnston | Nicholas S. Langworth | |
| Anna Hawk | Elisa Koch | Kelly J. Geibel | Nikki Ament | |
| Anne Bridgers | Elise Correa Rocha | Kenneth L. Munroe | Olena Lyepyenina | |
| Annie Lyons | Elizabeth H. Weber | Kimberlee R Dieckhaus | Omid Dardashti | |



Helping to get the word out

by **RAYMOND HUML, DVM, RAC**
Durham, North Carolina

I recently volunteered to staff a Combined Federal Campaign (CFC) booth at the National Institute of Environmental Health Sciences (NIEHS) on behalf of the FSH Society. For those of you unfamiliar with the CFC, it is an annual fundraising drive that provides an opportunity for federal civilian, postal and military employees to donate to local, national, and international non-profit organizations - like the FSH Society. It is a philanthropic program that is employee-focused, cost-efficient, and effective in providing federal employees the opportunity to improve the quality of life for all.

I obtained some brochures and pamphlets from the FSH Society for those interested NIEHS employees too busy to talk to me, but most of the time I just talked about the disease and how it impacted me and my family since my daughter was diagnosed with FSHD in 2003. I'm quite familiar with the Society as I have been in regular contact with senior staff since my daughter's diagnosis, so it was easy for me to talk



Raymond Huml

about the good things that the Society does for persons with FSHD.

I was amazed that almost everyone I talked to knew about Duchenne MD, but only one person, out of 50 that I talked to, had ever heard of FSHD – one of the most common forms of MD!

I talked to senior level employees at NIEHS with PhDs as well as employees who worked in the cafeteria and the janitorial staff. I found them all to be pleasant, eager to learn more from the folks manning the booths, and they seemed glad that they had the ability to positively impact others.

I can't really define my ultimate CFC impact, but it made me feel that, at least in a small way, it helped get the word out about FSHD and, thinking optimistically, one step closer to a cure. **FSH Watch**



Editor's note: *The CFC is the world's largest and most successful annual workplace charity campaign.*

Pledges made by federal workers donors during the campaign season (September 1 to December 15) support eligible nonprofit organizations. The FSH Society's CFC identification number is 10239.



OUR EBAY CHARITY AUCTION SITE



The FSH Society is registered (as the "FSH Muscular Dystrophy Society") on eBay's charity auction site. If you have an eBay seller's account, you can put items up for auction and direct from 10 to 100 percent of the proceeds to the Society. <http://givingworks.ebay.com/charity-auctions/charity/fsh-muscular-dystrophy-society/76296/>

RAZOO ONLINE FUNDRAISING

Razoo provides an easy way for you to create an



online campaign. Your donors will enjoy the convenience of giving online and knowing that their gifts will go directly to the FSH Society. Razoo has built-in social media sharing, so you and your friends can help spread the word over Facebook, Twitter and other social media. <http://www.razoo.com/story/Facioscapulohumeral-Society>

ONE MAN'S DECISION TO HAVE SURGERY

... from page 10

speed the way, as nerves grow — if they grow — at a rate of about 1 millimeter a day. Results would first be seen four to six months after surgery, the doctors said.

Initial Success

On October 11, I saw Dr. Carty. I tried curling my arm, something I required some help to begin. He felt my transplanted muscle as I struggled to flex it. He said he detected the nerve impulse firing in the muscle! The nerve had grown into the muscle! Now it was no longer a matter of if I would improve, but how much.

Today, it seems much more likely that my educated gamble will pay off, though it may take another six months to see the full result. Plus, I may require a tightening of the transplanted muscle — basically, shortening the tendon on one end — so it's taut and not floppy, therefore better able to do its job of bending my elbow.

When Considering Surgery

Given my background, it's not surprising I would be willing to try a somewhat risky operation. I grew up in a medical family: my mother was a nurse, my father, a doctor. I love science,

particularly health and biology.

I believe in its promise.

As a journalist, I'm accustomed to researching and questioning. Since my diagnosis of FSHD, I have followed research developments and wondered about the disease's causes and expression. I've participated in two patient studies and donated muscle biopsies to research. I also volunteer on behalf of the FSH Society. So you might say I was predisposed to saying yes to the surgery if the risks weren't too high.

You need to know yourself, your finances and what you're getting into when considering a major surgery. Ask yourself, how much risk is too much? How big is the possible gain? Are there other options? Where should you go for the operation and who's the best choice to perform it? What will it cost you in lost time, discomfort and money? What can you afford? How will you cope during recovery? What if it doesn't work out?

Weigh the pros and cons carefully. Get all the solid information you can. Personality and need powers the drive to pursue an operation like this, but knowledge should temper the decision. **FSH Watch**

The FSH Society funds advances in understanding and treating FSHD

FSH Society grant awards for the August 2012 cycle

► **Role of Polycomb Group Proteins in Facioscapulohumeral dystrophy**
Valentina Casà, M.S.

Fondazione Centro San Raffaele, Milan, Italy
\$45,000 over 18 months

Summary: The loss of D4Z4 “repeats” is involved in causing FSHD. Scientists suspect that the large numbers of D4Z4 repeats in people not affected by FSHD play a normal role in preventing harmful genes like *DUX4* from becoming active. This scientist proposes to understand how D4Z4 repeats work, in order to find ways to intercede in the process that gives rise to FSHD.

► **Derivation of human induced pluripotent stem cells from FSH patient fibroblasts**

Gabsang Lee, D.V.M., PhD
Johns Hopkins University, Baltimore, MD
\$49,705 over 1 year, FSH Society-FSHD Canada Foundation and Irene Lai Research Fund Fellowship Grant

Summary: This investigator proposes to develop “FSHD in a petri dish” using skin cells from patients. Using an emerging method to genetically “reprogram” skin cells to become stem cells with the ability to develop into other types of cells, including muscle, this project could lead to new insight into the disease process, and may also be a critically important tool for developing new therapies.

► **Autophagy defects in FSHD**
Sachida N. Pandey, PhD

Children’s National Medical Center, Washington, D.C.
\$99,599 over 2 years

Summary: Evidence from FSHD muscle cells suggests a possible role for autophagy, a natural “house cleaning” process by which cells degrade unnecessary or dysfunctional parts. Scientists hypothesize that, when misregulated, autophagy promotes disease and cell death. This investigator proposes to investigate whether defects in autophagy could play a role in FSHD.


► **Validating sensitive and accurate outcome measures needed for FSHD clinical trials**

Jeffrey Statland, MD
University of Rochester, Rochester, NY
\$59,185 over 2 years. FSH Society Marc & Helen Younger Fellowship grant

Summary: This investigator proposes to develop better ways to understand the changes over time in FSHD patients’ symptoms. This is vitally important for clinical trials, because in order to test a treatment for efficacy, one must be able to predict how symptoms will worsen within a given period of time. Validated outcome measures currently do not exist for FSHD, and without them, clinical trials cannot go forward.

► **Tissue-Specific Silencing of *FAT1*: Role in Pathogenesis of Facioscapulohumeral Muscular Dystrophy**

Angela K. Zimmermann, PhD
Centre National de la Recherche Scientifique IBDML – Development Biology Institute of Marseille, Campus de Luminy
Marseille, France
\$140,000 over 2 years

Summary: This researcher will investigate a promising novel idea about how muscles degenerate in FSHD. This research could lead to new ideas for treating the disease. Many scientists in FSHD research are currently focused on the *DUX4* gene and protein. It is very important to make sure that alternative hypotheses are also explored, as it’s never good to put all of one’s eggs in one basket, especially when it comes to developing drug treatments. 

Editor’s note: *The FSH Society continues to increase its funding in research and clinical research efforts. In 2012, we awarded ten grants totaling \$716,489. In addition, the Society awarded approximately \$20,000 in travel grants, small grants and funds for patient travel to participate in research studies and clinical research efforts. You have helped the FSH Society have the most successful grant-funding year ever. Thank you!*

YOU HAVE WILL POWER — JOIN THE FSHD FUTURE FUND

Express your appreciation for the Society’s leadership in FSHD research and education by directing a portion of your assets to the FSH Society by way of your will. Making a will is an important way to extend your love, care and gratitude to family, friends and the charitable causes you care about.

Members of the FSHD Future Fund are supporters who have remembered the FSH Society through a bequest or other estate-planning instrument. FSHD has touched your lives, and that is why your consideration of a

bequest to the Society is so important. Please contact the Society to discuss your interest. You can establish one of several types of bequests:

- Unrestricted bequests for the general use of the Society
- Restricted bequests for specific uses, such as patient education and outreach, FSHD research, or another particular program
- Endowed funds

If you have already included the FSH Society in your will, please let us know by contacting

june.kinoshita@fshsociety.org. If you will allow the Society to recognize your dedication in our publications, your example might inspire others. If you have questions about your planning and how it can support the work of the Society in the future, or if you would like a copy of the booklet “Questions and Answers about Wills and Bequests,” please contact us.

Always check with your advisors when making a will or before making changes in your plans, and learn how the latest changes in tax laws and other legislation may affect your plans.



Turning dreams into reality

Remarks at the Festive Evening of Song, September 24, 2012

by **STEVEN BLIER**
New York, New York

We musicians operate in a world of vibration. On a good day, we produce invisible “phenomena” — sounds — that have the power to move an audience to tears, or make a bunch of grown-ups get up and dance.

Since musicians dabble in the unseen, we are often guilty of a slightly tenuous grip on reality. Ever since the scientists cracked the code and located the “phantom gene” (how appropriate, I thought at the time) that causes FSH Muscular Dystrophy, my mind has been spinning fantasies of a hot-pink pill that will allow me to go hiking again, or buy a standing room ticket at the opera — or get up and dance along with everyone else. I could be the first senior citizen in a mosh pit.

But I try to keep a tight rein on my wild imaginings. I am not planning any trips to Mexican ruins until further notice.

And yet. The other day, I was at Bill Milling’s studio working on the public service announcement airing for the first time at tonight’s benefit. I sat in my piano chair for about four and a half hours, trying to look calm but not comatose, enthusiastic but not insane, and glowing but not sweaty. Kelli O’Hara nailed every take and looked as if she were on loan from Mount Olympus, but I was happy to settle for the basics—no fluffed words, and a general sense that I was neither suicidal nor on a dangerously manic high.

When we got done with our segment, I noticed that the room had filled up with the other players in the video, most of whom were on wheels like me, or walking with a cane. I knew many of them, but there were two nice-looking people sitting comfortably on stools, waiting their turn patiently. I drove up to them and said, “And what brings you here?”

“We’re the scientists.” I stopped dead in my tracks and tried to formulate an intelligent question that did not include the words “pink pill.” I managed to come up with, “So...?” Their answer lifted my heart. “The news is amazingly good. We can’t believe how fast things are going. One study



Steven Blier

fuels the next, and then the next. It seems that a treatment is not too far down the pike.”

“To stop the progress of the disease?”

“To stop the progress.”

“To...reverse it?”

“Well, maybe even that.”

I told them that a doctor friend of mine had told me that working with muscle tissue was an advantage.

“Why?” I had asked. “Because

muscle tissue is uniform. Basically, muscles are big and dumb,” he explained. “Like muscle-boys?” I pursued. He indulged me. “Well, yes. Like muscle-boys.”

The two doctors in Bill’s studio took this in, and gave a measured response. “Yes, muscle tissue is uniform, but it’s got its own way of behaving, its own laws, its own culture.” “Like muscle boys!” “Um, yes, I guess so. But we’re starting to learn our way around it.” This was more than I had ever managed, but I kept that to myself as they explained their research. Unfortunately, I reverted to my musician’s personality and was already off in fantasyland. Some of the details eluded me. But these two lovely people did share one more important fact with me. “It’s all about numbers, and there’s a lot of competition for those federal dollars. There was a lot of skewed polling, and FSHD was getting left in the dust. But you guys...wow. You are a tough bunch to keep down. The breakthroughs are really because of the FSH Society. And they’re tremendous. They’re bigger than just FSH Dystrophy.”

I was suddenly filled with pride at what the FSH Society has been able to accomplish, and overjoyed at being able to make a contribution to the work.

No, musicians don’t always know dreams from reality. But it seems that this time, my dreams—and those of so many other people with FSH Dystrophy—might finally be coming true. I am so grateful to the donors, FSH Society leaders and members, and research scientists for the possibility that my Golden Years might actually be golden. FSH Watch

DOES THE SOCIETY HAVE YOUR CURRENT E-MAIL ADDRESS?

If you want to be sure to receive breaking news and other up-to-the-minute information from the Society, please send us your e-mail address at info@fshsociety.org.

GET SOCIAL!

Join our online communities to get news, ask questions, seek advice and support from fellow FSHD patients and family members, and enjoy one another’s company. The FSH Society Yahoo! Groups forum, online since the 1990’s, has tens of thousands of searchable posts. Bookmark these pages and come back often. To find the FSH Society Facebook page and Yahoo! Groups, go to our homepage at www.fshsociety.org, click on the “Community & Reference” menu tab at the top of the page and select “Online Community” in the left hand vertical navigation menu. You’ll see links to take you directly to our Facebook page and Yahoo! Group. If privacy is a concern, you can use your account privacy settings to limit who can see your posts. You can also follow us on Twitter @FSHSociety.

HAVE YOU MADE A GIFT TO THE SOCIETY IN 2013?

Please help now! The FSH Society is a world leader in combating muscular dystrophy. It has provided more than four million dollars in seed grants for pioneering research worldwide and has developed an international collaborative network of patients and researchers. If you are not already a member, won’t you join in this effort? Please return your gift in the enclosed envelope. Or contribute online at www.fshsociety.org. Thank you!

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. This is a great way to double, triple or even quadruple your gift.

4-STAR RATING

The FSH Society has been awarded its fourth consecutive 4 Stars by Charity Navigator.

