

## FSH Society Makes Notable Progress in Funding, Research and Patient Engagement in 2013

After wrapping up what was a busy first month of 2014, we finally have a moment to look back on 2013 and acknowledge what a busy – and successful – year it was!

Throughout 2013, we expanded our networks locally and nationally, [partnering](#) with the University of Massachusetts' Wellstone Center for FSHD Research and Training. The Society is proud to have participated in several FSHD studies as well, contributing to noteworthy developments in research of the disease. We took part in the [discovery](#) of the first disease-modifying gene for FSHD Type 1, which turned out to be the SMCHD1 gene that causes FSHD Type 2. Additionally, our funding of the first MRI studies on FSHD patients led to the publication of a [PLOS ONE paper](#), which outlined the distinct disease phases in muscle of those living with FSHD. We are also thrilled to have partnered with SHIFT Communications, a Boston-based public relations firm, who is helping us build strategic PR and social campaigns to spread FSHD awareness.

The 19<sup>th</sup> [FSH Society's Annual International Research Consortium](#), held in October at MIT (Cambridge, MA) drew in a record number of attendees. We are thrilled to announce our 20<sup>th</sup> annual research consortium will take place in October 2014 in San Diego, CA. Check our website in the coming months for more information.

The acknowledgement of our achievements by the greater non-profit community was also notable. The FSH Society was [honored](#) with a prestigious 2013 Top-Rated Award by GreatNonProfits, the leading provider of user reviews about nonprofit organizations, and was also [named](#) one of "Ten Charities Worth Watching" by Charity Navigator, a leading national charity watchdog organization.

In 2013, the FSH Society raised a record amount – more than \$1.779 million – a 24% increase over 2012. The Society also disbursed a record amount in grant funding (\$541,000), as well as approximately \$106,000 due on grants issued, as we continue raising funds to better treatment and find a cure. As 2013 drew to a close, we received a generous holiday [donation](#) of \$10,000 from Adveq, a leading asset manager. The company was inspired by the courage of employee Angela Farkas in sharing her family's journey with FSHD.

To maximize awareness and funds raised, the Society took part in several events throughout the year, including our 4<sup>th</sup> annual [Celebrity Walk 'n' Roll](#) (Irvine, CA); the 5<sup>th</sup> annual Cape Cod Walk 'n' Roll for FSHD (Harwich, MA); the 2<sup>nd</sup> annual Hustle for Muscle Golf Tournament (Abilene, TX); our annual [Festive Evening of Song](#), which featured pianist Steven Blier and Broadway veteran Judy Kaye (New York, NY); and a [lakeside fundraising event](#) hosted by Michelle Mackay and retired Kellogg's CEO David Mackay (Gull Lake, MI). We are thrilled to announce the following 2014 events – just the first of many, we're sure!

- [Phil's Jam for FSH](#): February 26 – Nashville, TN
- [St. Patty's Dining for Charity](#): March 17 – Rancho Bernardo, CA
- [Celebrity Walk 'n' Roll](#): October 12 – Irvine, CA

As we look forward to what's sure to be a productive and momentous 2014, we thank you all for your continued support. If you have any questions regarding any of the research, awards or events included above, [reach out](#) and let us know!

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[www.fshsociety.org](http://www.fshsociety.org) | Charity Navigator 4-star award, listed in "10 Charities Worth Watching"

The FSH Society is a 501(c)(3) public charity dedicated to solving facioscapulohumeral muscular dystrophy (FSHD), one of the most prevalent forms of muscular dystrophy. We would not exist without members' donations to carry out our mission, and thank you so much for your interest and support.