

*Working towards better diagnosis and treatment of
Fibromuscular Dysplasia*



FMDSA
Fibromuscular Dysplasia
Society of America

FMDSA PATIENT REGISTRY

The FMD Patient Registry is funded by FMDSA at a cost greater than \$40,000 a year. For the past two years data from the registry has been released and the findings have caught the attention of the medical community and researchers. To date over 655 patients have enrolled in the registry and we have 12 participating centers. As long as we can continue to fund the registry we will continue to learn and find answers. Thank you to the FMD patients who have participated and also to those who donate, together we can make a difference.

**6TH FMDSA Annual Meeting
May 17-18, 2013**

Cleveland, Ohio



Registration and a welcome reception will be held the evening of May 17th and the Conference will start early morning on May 18th at the Wyndham Cleveland Playhouse Square Hotel in Cleveland, OH. Our speakers will discuss the latest Fibromuscular Dysplasia patient registry findings and other related topics. Following our speakers there will be a panel discussion where everyone will have the opportunity to ask questions. On line registration is now available, see link below.

Confirmed speakers include:

Dr Jeffrey Olin, Mount Sinai, NY Update from the FMD Patient Registry; Dr Jacqueline Saw, Vancouver General Hospital Sudden Coronary Artery Dissection and Fibromuscular Dysplasia; Emma Greenwood, Founder Whooshers.com, New York, NY; Dr Heather Gornik, Cleveland Clinic, Ohio; Dr John Angle, University of Virginia Radiation dose exposure and implications. Additional speakers to be announced.

To register for the 6th Annual Meeting, [click here](#)

To book your hotel room please contact the Wyndham Hotel directly and mention FMDSA to receive the discounted hotel rate of \$109.00 216-615-7500



FMDSA Appreciates the Generous Contributions of the Annual Meeting Sponsors. Our 2013 meeting is going to be the biggest and most informative meeting yet. We can truly make it a fulfilling event for attendees through the help of our members and other sponsors.

FMDSA is seeking sponsorship for our 6th Annual Meeting, donations are tax-deductible.

Table of Contents

- [FMDSA PATIENT REGISTRY](#)
- [Save the Date...](#)
- [2012 GIVING HONOR ROLL](#)
- [FMDSA Amazon Wish List](#)
- [Special iGive Promotion](#)
- [Spreading the Word](#)
- [Cafe Press](#)
- [6TH FMDSA Annual Meeting](#)
- [Annual Meeting Raffle](#)
- [2012 Annual Letter Campaign](#)
- [ABSTRACT ON FIBROMUSCULAR DYSPLASIA](#)
- [Australian Society for Ultrasound in Medicine](#)
- [NORD REGIONAL MEMBERSHIP MEETING](#)
- [New Zealand Organization for Rare Diseases](#)
- [Whooshers.com](#)
- [SCAD](#)
- [FMDSA Thanks Petersen Plumbing Services](#)
- [FMDSA Mosaic Wall Fundraiser](#)

Quick Links

- [Our Website](#)
- [Donate Now](#)
- [Contact Us](#)
- [Email Us](#)



2013 Cleveland Marathon

FMDSA is an Official Charity of the 2013 Cleveland Marathon

This will be held the same weekend as the FMDSA Annual Meeting. We are putting together teams of runners and walkers to participate in the marathon, half marathon, 10K, 5K and kids run.

FMDSA is also looking for 25 volunteers to

Sponsorship levels available:

- PLATINUM - \$5,000.00 or more
- GOLD - \$2,500.00 or more
- SILVER - \$1,000.00 or more
- BRONZE - \$ 500.00 or more

Please consider helping our patients and us by supporting our event.

Two free registrations are included with the platinum, gold and silver levels of sponsorship, and we encourage you or any of your staff to attend as this will be a very informative meeting. FMDSA will also recognize your contribution in our event program and on our web site.

For more information on sponsorship, please contact: Pamela Mace, RN, Executive Director FMDSA @ pam.mace@fmDSA.org or call the FMDSA office.

Annual Meeting Raffle

We have always had a great response from our members interested in donating items to the annual meeting raffle. This year FMDSA members, Linda Williamson and Mary Jo Bajc have teamed up to work on the raffle together. If you are interested in donating or helping out with the raffle please contact Mary Jo at: danmary@windstream.net

2012 Annual Letter Campaign

As only one in five members donate, we will not be able to continue or expand all of our current programs without your donations.

Did you know that more than 50% of rare diseases have no foundations, advocacy groups or community support? For almost ten years, the FMDSA has been a source of awareness, advocacy and support for patients. After nearly 10 years we continues to grow and succeed far beyond our original hopes and dreams. One of our most important and impressive accomplishments is funding the much-needed FMD patient registry. The patient registry is an enormous undertaking and is currently our largest program expense.

In addition to our research and education focused efforts, we are also very focused on building public awareness and improving patient support. The FMDSA Facebook page and our online FMD Inspire support group have been very successful. FMDSA also has Regional Network Groups throughout the US so that patients have the opportunity to meet others that live locally.

If you have donated, thank you. We still need your donations to fund research, operate our current programs and be a physical presence in the medical community.

Our campaign challenge this year is to reach \$50,000 in donations! If you haven't previously donated to FMDSA, please do so today.

Thank you,
The FMDSA Board of Directors

ABSTRACT ON FIBROMUSCULAR DYSPLASIA

Presented Thursday November 8, 2012 at the American Society of Human Genetics

Redefining Fibromuscular Dysplasia of the Arteries as a TGF- β Pathway Disorder. R. Morissette¹, S. Ganesh², B. Griswold¹, L. Sloper¹, N. McDonnell¹ 1) National Institute on Aging, National Institutes of Health, Baltimore, MD; 2) Division of Cardiovascular Medicine, University of Michigan Health System, Ann Arbor, MI.

Please visit the American Society of Human Genetics web site to view the

work at a water station on Sunday May 19th, the day after the annual meeting. All 25 people will stay together and we can be as creative as we would like with our water station. For more information please contact volunteer Tammy Porter at: tammyporter@fmDSA.org.

Tammy will also be able to provide you with the FMDSA registration code.

For specific information on the race, please visit:
http://www.clevelandmarathon.com/263_Mile_Rock_Party/

Save the Date...

December 13, 2012 is the next Cleveland Clinic FMD web chat with Dr. Heather Gornik and FMDSA Executive Director Pamela Mace.



2012 GIVING HONOR ROLL

June 16, 2012 thru September 30, 2012

Member (Up to \$100.00)

Cardinal Health*
Gwendolyn Androw*
Carolyn Kim Kost*
Kristy Koberna
BJ Purdum
Margaret Mudge
Claudia Redden
Judith Brown
Rosann Mann
Donna Maggiotto
Donna Bunce
Aimee Johnson
Jeremy Woolman
Dena Lane
Linda Williamson
Elizabeth Long
Ronni Herrick
Maureen Salinas
Susan Schesno
Barbara Bond
Diane Adams
Jacqui Schmind
Maryann Hall
Diane Delgrosso
Ojas Pradhan

Founder (\$100.00 +)

Karen Hartman*
Petersen Plumbing Services*
Nancy O'Hara*
Chester Hope Chrch Fundraiser
Dianne Griffith
Anna Labatut
Kimberly Abold

abstract: <http://abstracts.ashg.org/cgi-bin/2012/ashg12s>

Australian Society for Ultrasound in Medicine

Last month, Dr. Michael Jaff spoke at the Australian Society for Ultrasound in Medicine. Dr. Jaff included in his talk, some of the recent data from the FMD patient registry, educating physicians from around the world on what we are learning. We are very fortunate to have dedicated doctors supporting our cause. The FMD Patient Registry and the data continue to open doors that a few of us alone could not. Dr. Jaff was also kind enough to meet with a local patient and FMDSA member to discuss how to raise awareness of FMD in Australia.

<http://www.asumcongress.com.au/scientific-meeting-program/international-speakers/>

NORD REGIONAL MEMBERSHIP MEETING

September 21 and 22, Phila, PA
Cheryl Bailey, President FMDSA

I attended NORD's second year of Regional Membership meetings in Philly this year, and over 30 nonprofit organizations were in attendance. It was great to connect with other organizations, who like us, have a Mission that also includes research, diagnosis, treatment and cure's for their rare disease. This year's meeting provided the platform for us to hear about innovative programs our fellow member organizations are in the process of running, gave us the opportunity to discuss challenges as rare disease patient organizations, and we shared insights as to how our organization along with the others can continue to move the rare disease agenda forward.

Thursday night began with a reception where representatives from NORD, Mary Cobb, Senior VP, Peter Saltonstall, CEO, Diane Dorman, VP, Public Policy and Paige Bingham of the Medtronic Foundation, welcomed everyone. Friday morning following breakfast, we spent the day in the meeting room and were welcomed by Mary Cobb. We heard from Jason Barron, Associate Director, Public Policy followed by several organizations that spoke on Patient Leader Perspectives (Friedreich's Ataxia Research Alliance and Friedreich's Ataxia Research Alliance to name a couple), and following a short break resumed with The Power of Patient Voices. Following lunch Anna Kole, Associate Director spoke on the Patient Registry Program. We heard from many other organization leaders who spoke on their struggles and how they were able to work through them. An open conversation was then led by Mary Cobb and Mary Dunkle on Leveraging Change to Empower the patient.

It was a great day of dialogue, learning and sharing. I personally connected with two organizations that spearheaded "groups" over the past year, and they readily shared printed resources with me to share with our Group Leaders. It is important to stress that NORD provides information, advocacy, research, and patient services to help all patients and families affected by rare diseases and they are committed to the identification, treatment, and cure of rare disorders. Being a member of NORD helps FMDSA remain a "visible member" of a large, collective voice on behalf of patients with rare diseases, and we all know, there is "strength in numbers"!

New Zealand Organization for Rare Diseases

We have been in contact with the New Zealand Organization for Rare Diseases and they are willing to list information on their web site about FMD. If they have a local contact that would also be listed for other FMD patients to contact. If anyone from New Zealand would like more information please contact:

Pam Mace at: pam.mace@fmDSA.org
 or visit
<http://www.nzord.org.nz/>

Whooshers.com

What's a Whoosh?

People who experience pulsatile tinnitus (we call ourselves "Whooshers") we hear a sound that whooshes, pulses, clicks, screeches or makes another rhythmic

Lylia Cramerotti
 Marica Speer

Patron (\$250.00 +)

Patricia Brock*
 Denise Laman*
 Cherylann Bailey*
 Mary Wright Baylor

Benefactor (\$500.00 +)

Carolyn Cusick
 Dr. Douglas & Mariruth Webster

Hero (\$1000.00 +)

Manchester Dental

Celebrity (\$5000.00 +)

Kay Tanner & Molly Clark

{*= recurring monthly donations}

FMDSA Amazon Wish List

A special thank you to all who have donated through our Amazon Wish list. **Please note:** when we receive a donation, **we do not always know who made the donation.** We appreciate the support and want to acknowledge your donation, and we are working with Amazon to resolve this issue so please while we work out the details, **send an e-mail to kim.blakemore@fmDSA.org advising us of your donation.** These donations are very valuable to our day to day operations and allow us to focus on our other programs. THANK YOU again for supporting our mission!

Kim Blakemore, Office Manager

To donate with an Amazon Wish List item... Simply [click here](#) and search through our "wish list" and find an item that you would like to donate to FMDSA, add it to your shopping cart, pay, and Amazon ships it to FMDSA. It's that simple.

Thank you again for helping support FMDSA via our Amazon.com wish list.

Special iGive Promotion

Join iGive for free and a portion of everything you purchase online will be donated to FMDSA at no additional charge to you! Using iGive.com means a donation of at least \$10 for FMDSA- \$5 for using iGive & \$5+ for your 1st purchase. The donations keep growing as you keep shopping. Just [click here](#):

Some Quick iGive Celebration Details:

- Shopping more means helping more. Over 900 great stores participate.
- No pop ups, ads, toolbars, special search engine, or unwanted emails.

sound. Sometimes others can hear it (objective pulsatile tinnitus) and sometimes only the patient can hear it (subjective pulsatile tinnitus). The key that distinguishes a pulsatile tinnitus sound from a regular, far more common tinnitus sound is that it is in constant sync with the heartbeat.

Since whooshing is not that common, it's not unusual for patients to feel isolated, anxious, confused, frustrated and depressed as they search for answers. To some, the volume and pitch of the sound may be debilitating. Regardless of its impact, it's a symptom that warrants special medical attention and evaluation. There is hope and support.

Whooshers.com was launched several years ago with an aim to help patients and their doctors, and to demystify pulsatile tinnitus, an annoying and alarming symptom that, especially for those of us who experience it, is very real.

On Whooshers.com, community events are organized, links to medical reports about various causes are collected so patients may share them with their doctors, and stories of "Cured Whooshers" are posted regularly to bring hope to the rest of us.

We welcome members of the FMD community to join our community of Whooshers from all over the world so we may continue to increase awareness of the symptom that could very well be a significant clue toward the next FMD patient's diagnosis. Because prompt and proper diagnosis of any condition depends on an evaluation of each symptom, even if it's a whoosh!

Emma Greenwood
 Founder
 Whooshers.com
<http://www.whooshers.com>
 whooshers@gmail.com

SCAD

Spontaneous coronary artery dissection

SCAD and FMD Vancouver Canada Support group was started this past year with the assistance of the VGH Cardiac Rehab program. Dr Saw and case manager, Taira Mast Birnie have invited all the known SCAD's and FMD women patients together in the same exercise class to connect and focus on issue that are specific to our disease.

The SCAD Vancouver group keeps in touch with SCAD and FMD women who graduate from the program providing a point to connect, articles of interest and they currently working on our first fundraising event which is taking place on November 19th in downtown Vancouver.

To Connect with SCAD Vancouver, please email: SCADVancouver@gmail.com.

FMDSA Thanks Petersen Plumbing Services

Monthly Donation Program

FMDSA would like to acknowledge and thank PPS for being the first Business to join our Monthly Donation Program.

Taylor Petersen Owner and President of PPS says of his donations " I wanted to contribute to research as I am personally affected by this little understood disease. My mother has been a long time volunteer of FMDSA and has always shared the importance of volunteering and donating to worthy causes. My company prides itself on community involvement, donating and fundraising. Donating to a National Organization is just a broader scope of our community. Petersen Plumbing services is Proud to support FMDSA help to fund the FMD registry that FMDSA Funds"

We would like to also thank the other business who have donated to FMDSA in the past.

If you are interested in being part of our monthly donating team, please contact



Spreading the Word

Inspire FMD Support Group Page

The Inspire FMD Support Group Page, to date, has over 300 members participating. We have added discussion topics so that you can go right to your area of interest.
<http://www.inspire.com/groups/fibromuscular-dysplasia-society-of-america/>.

FACEBOOK

We have updated our Facebook page to be able to add events and causes. To date, over 466 members have "Liked" our Facebook page. Please visit our new page:
<https://www.facebook.com/pages/Fibromuscular-Dysplasia-Society-of-America/259831044055679>

Cafe Press

Spread awareness of FMD and support our research fund!

Please visit our Café Press store to make a purchase for yourself or others. Our Café Press store has recently been updated and includes over 60 products with our current FMDSA logo! You will find men's, women's and children's apparel, drink ware, bags, pins and much more on the Café Press site.

All money raised assists the research efforts for FMDSA and assists in spreading awareness. When you wear or use these items with our logos you are helping to raise awareness and maybe even initiate a discussion about fibromuscular dysplasia. Check out our site today!

If you have any questions or suggestions for our FMDSA Cafe Press Store please contact Kelly Seifried at pedsobrn@gmail.com

our office manager kim.blakemore@fmdsa.org or call the FMDSA office at 1-888-709-7089 for more information.

Additionally we also have individual members who donate on a monthly basis. Ten dollars a month is \$120.00 a year to help fund research! Thank you to those that are utilizing this donation feature!

FMDSA Mosaic Wall Fundraiser

Buy a Brick!

Buy a brick on our Mosaic Wall and post your picture or a message for other FMD patients to see. The bricks are only \$15 each and you can buy more than one, only 210 bricks will be sold. Help us to build a Beautiful FMD Wall, while supporting our programs. It's fast and easy. "

As you scroll across each brick, you can see who has purchased the bricks.

To be directed to the fundraising page, [click here](#).

Please visit our website at www.fmdsa.org.

[Remove my name from all future email correspondence](#)

Address postal inquiries to:
Fibromuscular Dysplasia Society of America - FMDSA
20325 Center Ridge Road Suite 620
Rocky River, OH 44116

Powered By

