

FMDSA Society Page

March 2012

*Working towards better
diagnosis and treatment of
Fibromuscular Dysplasia*



FMDSA

Fibromuscular Dysplasia
Society of America

5th FMDSA Annual Conference

May 18th and 19th 2012

The **FIFTH FMDSA ANNUAL CONFERENCE** will be held at the Wyndham Hotel in Downtown Cleveland.

We would like to thank **Cardiomems, the Cleveland Clinic Foundation, Greenville Hospital, the University of Virginia, University of Michigan and Minneapolis Heart Institute/Abbott Northwestern Hospital** for sponsoring our 2012 meeting.

To hear Dr. Gornik discuss last years meeting, [click here](#)

Friday May 18th there will be a reception and registration starting at 5:30 pm, and the conference starts early Saturday morning.

Confirmed speakers:

Dr. Santhi Ganesh, University of Michigan - Genetics.

Dr. Bruce Gray, Greenville Hospital SC - Taking the Fear Out of Catheter-Based Procedures.

Dr. Jeffrey Olin, Mt Sinai New York - Things We Have Learned from the Patient Registry.

Dr. Heather Gornik, Cleveland Clinic Foundation - Quality of life, Genetics and Physical Exam.

Dr. Kevin Meyers, Childrens Hospital of Philadelphia - Genetic causes of Renovascular Hypertension in Children.

Dr. Esther Kim, Cleveland Clinic Foundation- Fibromuscular Dysplasia 101.

Dr. Mark Stillman, Cleveland Clinic- Headache and treatment options.

Dr. James Stanley, University of Michigan - Operative Treatment of Children with Renal Artery Fibromuscular Dysplasia.

Dr. Chris Buller, St. Michael's Hospital, University of Toronto - Coronary FMD.

To register for the Conference, or to download a printable form to mail in your registration, [click here](#)

To make hotel reservations please contact the hotel directly at

216-615-7500, mention Fibromuscular Dysplasia Society to receive the discounted rate of \$95.00/nt plus tax. We suggest you book your room early as the hotel sold out for the last meeting. As we have more details, they will be posted on facebook and the FMDSA web site.

Cleveland Clinic Art Tour May 18th, 11:00 AM prepare for a wonderful and informative 1-1/2 hour art tour at the Cleveland Clinic. The Wyndham Hotel will have shuttle service that can be reserved well in advance. More information is available on the web site and you can contact Maureen Womack at maureen.womack@fmdsa.org.

FMD in the NEWS

This has started out to be a great year, and for all of you that have participated in the registry and donated to FMDSA to support the Patient Registry, the impact we are having is obvious!

Table of Contents

[Save the Date...](#)

[FMDSA.RIVITY.ORG](#)

[FMDSA Amazon Wish List](#)

[Special iGive Promotion](#)

[5th FMDSA Annual Conference](#)

[FMD in the NEWS](#)

[James C. Stanley, MD](#)

[NEW CHAIR NAMED TO FMDSA BOARD](#)

[California FMDSA Support Group](#)

[Registering Hope](#)

[Spreading the Word](#)

[HOLIDAY BENEFIT TO SUPPORT the](#)

[FMDSA](#)

[FMD PATIENTS UNITED](#)

[Raise Money on eBay](#)

Quick Links

[Our Website](#)

[Donate Now](#)

[Contact Us](#)

[Email Us](#)

Save the Date...

April 18th is the next Cleveland Clinic FMD web chat with Dr. Heather

Gornik and FMDSA Executive Director Pamela Mace. For more information [click here](#)



FMDSA.RIVITY.ORG

Everyone shops online, right? Well, enjoy your shopping expeditions while a portion of your purchase goes right to FMDSA ... how you ask? Simply follow the link, pick your store, and shop. It's that simple. Rivity takes care of the rest. You can see how much each store donates to FMDSA by hanging your cursor over the store name. Thank you

Fibromuscular Dysplasia Registry Results presented at the ISET Meeting in Miami by Dr Jeffrey Olin: [click here](#)

FMD makes the Cover of Endovascular Today. Thank you Dr Olin and colleagues! [click here](#)

Clinical Neurology News: [click here](#)

It's amazing just how frequently FMD is making headlines and is in the News. "Images and Case Reports" [click here](#) Thank you Dr Gornik and Colleagues

Dr. Jackie Saw on Coronary Dissection and FMD: [click here](#)
Hear Dr. Saw discussing the data. She is introduced about a minute into the Podcast: [click here](#)

The National Stroke Association features Stacey an FMD patient with a very inspiring story. [click here](#)

The TV Show **House** did a segment in late February and fibromuscular dysplasia was mentioned as a possible diagnosis. One of the writers for the show is Lisa Sanders who also writes for the New York Times. Recently Lisa also featured an fmd patients story in the New York Times. [click here](#)

James C. Stanley, MD

New to the FMDSA Medical Advisory Board



Dr. Stanley joined the FMDSA Medical Advisory Board in February of 2012.

James C. Stanley attended the University of Michigan as an undergraduate and medical student. He received his Medical Degree in 1964. To read more, [click here](#):

NEW CHAIR NAMED TO FMDSA BOARD



We would like to take this opportunity to Congratulate Cheryl Bailey who is now acting Chairperson of FMDSA. Rich Gould will remain on the board but due to personal reasons could no longer commit to the time required as Chairperson. Cheryl has been with FMDSA for many years and will do a great job!

California FMDSA Support Group

by Mimi Petersen

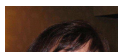


The California FMDSA support group had their third meeting on February 4th. In order to facilitate the long distance between members, the meeting location is decided on by the members. Our meetings usually run about two to three hours. Of course we hate to part, but given the distance members drive we laugh, hug, say goodbye and look forward to our next meetings.

While we enjoy sharing our stories, discussing our treatment and referring doctors, we are all committed to contributing to the mission of FMDSA. We are exploring ideas on how we can contribute to spreading awareness about FMD. We discussed simple steps to inform our medical providers about the resources FMDSA has to offer patients. One such step is to hand out a current copy of the FMDSA Newsletter when we visit our medical facilities, letting providers know that FMDSA is the leader in research and awareness and a great source for their FMD patients. Spreading the word is something we all agreed we could contribute to.

Registering Hope

Vascular Disease Foundation, Winter 2012 magazine article with Dr. Heather Gornik and our own Cheryl Bailey



In December 2004, Cheryl Bailey sought treatment for a simple bladder

for supporting FMDSA.

To start shopping, simply [click here](#).

FMDSA Amazon Wish List

The Amazon Wish List allows organizations such as ours to defray the cost of many items we would otherwise need to purchase, and allows benefactors the opportunity to make a donation to FMDSA in the form of an item that we need in our office or for a conference.

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 to all who have donated to date, 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.  [iGive.com](#)



infection. Soon after that, she found out she had something far more serious to deal with: fibromuscular dysplasia (FMD), a rare vascular disorder. To read the full article [click here](#)

Spreading the Word

Inspire FMD Support Group Page

Be the first to post on our new Inspire FMD Support Group Page. 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 Face Book page to be able to add events and causes. visit our new page: <https://www.facebook.com/pages/Fibromuscular-Dysplasia-Society-of-America/259831044055679>

HOLIDAY BENEFIT TO SUPPORT the FMDSA

Tampa, FL



A huge thanks goes to Cheryl Golden, FMDSA Board Volunteer Treasurer & friend, Debra Koehler.

Debra opened her historic home in Tampa, FL on December 9th for a holiday benefit to support the FMDSA.

Pam Mace was flown in to speak at the benefit about fibromuscular dysplasia. Lisa Foster attended to represent the Florida FMD Group. Approximately \$30,000 was raised to support the FMDSA.

FMD PATIENTS UNITED

Spring 2012 National/International Fundraising Event

We are pleased to announce the second annual FMD Patient United fundraising event for FMDSA. This spring, we are once again asking members to become involved and sponsor a fundraiser for FMDSA. It can occur anytime in the months of March, April or May and can be any type of fundraiser you choose. Last year, we raised over \$12,000 and had members participate in the states of Ohio, California, Florida, Illinois, Kansas, Rhode Island and Virginia. Examples of fundraisers included a raffle for a weekend at a cottage, a "jeans day for FMDSA", selling our awareness bracelet, and members who participated in the Illinois marathon and managed an awareness booth.

You can plan a large event or a small event. Our goal is to include as many states as possible, and to double the funds raised last year. We have also partnered with Hip Chix Fundraisers (<http://www.hipchixfundraisers.com/how-it-works.php>) to make fundraising as easy as possible. This on-line fundraiser will give members an option to help raise money without planning an event. Please contact Kellie Smiddie at kellie.smiddie@fmdsa.org for more information. Stay tuned for updates on this exciting event!

Raise Money on eBay

Some time ago, FMDSA registered with the non-profit arm of eBay, referred to as MissionFish. eBay + MissionFish equals ebaygivingworks. To date we have raised approximately \$420. This money was raised by members who are "sellers' donating a percentage of their profits as well as our recent on-line auction.

eBaygivingworks allows sellers to give a portion of the proceeds from their sales (10%-100%), buyers can add a donation to their purchase during checkout, and anyone with a PayPal account can donate to FMDSA right away-without buying or selling anything!

This is another great way to raise awareness for FMDSA, and remember that we are a tax-deductible organization.

For more information, please go to <http://www.ebaygivingworks.com/about.html>

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

