

*Working towards better
diagnosis and treatment of
Fibromuscular Dysplasia*



FMDSA
Fibromuscular Dysplasia
Society of America

Time to Renew Your Membership

Membership is very important to FMDSA and keeping our membership numbers high gives us a louder voice in the medical community and within the media. FMDSA relies heavily on membership fees for our operation, however, if you are not able to make a donation at this time, we do offer a free membership. It is easy to renew your membership. Please follow the link below and complete the simple form to renew your membership. Renewing now will ensure that you continue receiving FMDSA updates and newsletters.

<https://app.etapestry.com/hosted/FibromuscularDysplasiaSociet/OnlineForm.html>

Thank you,

Cheryl Bailey, President

FMD Patient Registry Data Released

"The United States Registry for Fibromuscular Dysplasia: Results in the First 447 Patients" published in *Circulation* (a journal of the American Heart Association).

This is a very exciting day for all of us. New data has been released on the first 447 adult patients who participated in the FMD Patient Registry

Some of the findings were:

- Cerebrovascular FMD occurred as frequently as renal FMD;
- The mean age of diagnosis for women was 51.9 years and for men 54 years;
- 5.6% of patients were asymptomatic when diagnosed;
- Hypertension was present in 72% of the patients;
- Headaches in 60%;
- Plusatile tinnitus in 27.5%;
- Dissections were reported in 19.7% and aneurysms in 17% of patients.

To view the article abstract or to purchase the article, [click here](#)

This is the most up to date article published on FMD. You do have to pay for the article, sorry we have no control over that.

Thank you to every one who participated and to those that donate to FMDSA, your donations fund the FMD Patient Registry.

Patient Registry Update

Currently we have 12 Centers participating in the Patient Registry with over 580 patients who have participated.

The newest centers to receive approval to participate are the Children's Hospital of Philadelphia, Dr. Kevin Meyers and Miami Baptist, Dr. Barry Katzen.

To view a complete list of participating patient registry centers and to learn how to participate in the FMDSA Patient Registry [click here](#).



FMDSA Annual Conference Recap

THE 2012 FMDSA CONFERENCE

by Cecile M. Pileggi, MD

The Fifth Annual FMDSA Conference was held at the Wyndham at Playhouse Square in Cleveland, Ohio, May 18th and 19th, 2012 thanks in great part to our sponsors Cardiomems, the Cleveland Clinic Foundation, Greenville Hospital, the University of Virginia, University of Michigan and Minneapolis Heart Institute/Abbott Northwestern Hospital, and to all our volunteers who all helped to make this Conference a great success!

Festivities began with a welcome reception Friday evening, providing an opportunity to acquaint with old friends and meet new ones. For half of the 150+ attendees, it was their first Conference. Many FMD patients were accompanied by family members, who were also interested in expanding their knowledge of FMD, as well as continuing to be a vital source of support.

After a welcome from President Cheryl Bailey, Saturday morning opened with Executive Director Pam Mace providing a presentation of the history of FMDSA, beginning with its founding by the Gould Family in 2003, and following it through its development and expansion into the worldwide resource that it is today. Additional medical centers continue to be added to the list of FMD participants, media awareness increases, and physician understanding and interest expand through exposure at conferences and in journal articles. All of these have resulted in a growing excitement about the future of our organization.

Esther Soo Hyun Kim, MD began the lectures with "The ABCs of FMD", a basic introduction for the audience. Santhi Ganesh, MD followed with her studies into the "Genetic Aspects of FMD". Heather Gornik, MD continued with an "Update on the Biorepository". Kevin Myers, MD educated us about "Pediatric Renovascular Hypertension".

The afternoon session was opened by Jeffrey Olin, DO with much anticipated data on the "Patient Registry". Mark Stillman, MD contributed his expertise on "Headaches and Treatment Options". Bruce Gray, DO educated the audience with "Taking the Fear out of Catheter Based Procedures".

The keynote address, "Operative Treatment of Children with Renal Artery Disease" was given by James C. Stanley, MD from the University of Michigan. He was also the recipient of the Founders Award for this year, presented by Dr. Olin and Richard Gould, commemorating the contributions he has made to the study of FMD.

The lectures were followed with a panel discussion by the physicians, including Dr. Alan Matsumoto from the University of Virginia, with questions from the audience. A concluding reception followed, with continued insight from Kamal Gupta, MD about his experiences with FMD patients.

Dr Olin summarized our Fifth FMDSA Annual Conference with a quote from Sojourner Truth (1797-1883):

"We ain't where we wanna be,
We ain't where we oughta be,

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We ain't where we gonna be,
But we sure ain't where we was."

We would like to thank Lisa Foster and the Cleveland Clinic staff for tweeting from the annual meeting. For nurses who attended, the Cleveland Clinic provided CEU's, thank you to Kathy Petrarca for all of her efforts in applying for the CEU's. It was wonderful to see all of the research nurses from the different participating registry centers attend. At the end of the meeting, FMDSA received \$10,500 in donations from members who attended. FMDSA has been working very hard since 2003 and our efforts are paying off thanks to your continued support and donations.

Finally, we would like to thank member Terry Wetzel, who generously donated back to the FMDSA her winnings from the 50/50 Raffle!

Bio Repository Update

Mayo Clinic and Cleveland Clinic Biorepository ...by Ruchi Sanghani, Cleveland Clinic Foundation

The current total for FMD patients participating is 438 and for family members 51. 180 FMD patients and 35 family members are currently participating at the Cleveland Clinic site, and 212 patients are participating at the Mayo Clinic site. 12 patients and 2 family members were enrolled during the FMDSA conference this year, in addition to the 34 patients and 14 family members that were enrolled at the conference in previous years. We are continuously enrolling new patients and first-degree family members into the study at both the Mayo Clinic and Cleveland Clinic site.

FMD in the NEWS

Executive Director Pam Mace speaks in London

Executive Director Pam Mace was asked to speak at the European Meeting on Hypertension in April in London. Pam, along with Xavier Jeunemaitre (Paris, France), Pierre Plouin (Paris France), Peter DeLeeuw (Maastricht, The Netherlands) and Andrew Persu (Brussels Belgium) presented on FMD during the two hour session dedicated to Fibromuscular Dysplasia. This was a great honor and demonstrated that FMD is being recognized and getting the attention it deserves.

Dr. Bradley Daar interviewed by Pamela Sawyer:

Bradley Daar DDS recently produced and aired a 30 minute segment on FMD. Hosted by Connecticut State representative Pamela Sawyer, the interview was shown on the community access channel for almost two months. Questioning was aimed at creating awareness of the disease and its clinical manifestations. Coinciding with rare disease month, the talk presented a very basic description of the disease so that the general public would be more capable of recognizing those affected by FMD. In addition much of the newer data was presented to illustrate that FMD may be more prevalent than previously thought; and not a rare disease.

Local Awareness on NBC 40, South Jersey

President Cheryl Bailey recorded a 90 second video on April 20th on FMD which ran every day for one week on the Health Update show on NBC40 (South Jersey's local NBC Affiliate).

University of Kansas Hospital/Kansas City, KS

The hospital's Fibromuscular Dysplasia program provides patients with specialized care for FMD. Our multidisciplinary team of specialists, led by Kamal Gupta, MD, offers advanced diagnosis, treatment and long-term management of FMD. For more information, call 913.945.1227 or [click here](#).

Everyday Health

FMD is mentioned again! [Read the article](#) under the videos, its great to see all of the awareness of FMD.

American Heart Association

In May, Circulation a journal of the American Heart Association published a Patient Page on Fibromuscular Dysplasia. The article was written by Stacey L Poloskey, Dr Jeffrey Olin, Pamela Mace and Dr Heather Gornik. The view the entire article which is free, Please follow the link to the [Circulation Page](#)

National Fibromuscular Registry Offers New Insights into Fibromuscular Dysplasia

May 2012

The FMDSA Funded Patient Registry in the news, again! [Click here](#) to read article.

Quick Links

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To view the April transcripts from the Cleveland Clinic FMD web chat with Dr. Heather Gornik and FMDSA Executive Director Pamela Mace [click here](#)



SAVE THE DATE

May 17-18, 2013

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

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 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:

Coastal Pediatric Symposium 2012

Wilmington, NC, March 19-20, 2012

Dr. Kevin Meyers was a guest speaker at the Coastal Pediatric Symposium in Wilmington, North Carolina. The symposium was organized by SEAHEC, part of the NC AHEC (Area Health Education Center) Program. Dr. Meyers spoke on Hypertension, Obesity and Our Children on the 19th. On the 20th he spoke on Ambulatory Blood Pressure Monitoring in Children and Adolescents, and his last case study was a boy with Fibromuscular Dysplasia. He ended his talk with a slide of information on the FMDSA with Pam Mace's picture and noted that he is on the Medical Board and supports all the work of FMDSA. The FMDSA slide was up for his question and answer session as well. The symposium was attended by approximately 150 health care providers. On hand for both days was Carol Rogers, RN, MSN, a volunteer for FMDSA. There were posters, flyers on both adult and pediatric FMD and plenty of pens. Dr. Meyers did an outstanding job and was very well received.

University of Michigan Research Project

Santhi K. Ganesh, MD...

...and colleagues at the University of Michigan are conducting research on the genetic basis of arterial dysplasia, and enrollment is currently underway. If you agree to participate we will gather pertinent information from you or your medical records, and you will be asked to provide a blood sample. We are also interested to know if any of your family members have been affected by FMD, and we may ask for your assistance in contacting family members who may or may not have FMD for participation in this study. Details of the study may be obtained by emailing Dr. Ganesh at:sganesh@umich.edu. For more information [click here](#)

Spreading the Word

Inspire FMD Support Group Page

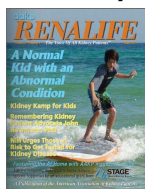
Be the first to post on our new Inspire FMD Support Group Page. We have added discussion topics so that you can go right to your area of interest. <http://www.inspire.com/groups/fibromuscular-dysplasia-society-of-america/>.

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>

FMD Patient Hayden makes cover of RENALIFE!

That is Hayden surfing!



Thank you Hayden for sharing your story and raising awareness of FMD. To view the full article, [click here](#)

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 \$486. 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>

FMDSA Board of Directors

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



Northern California Group Meeting

July 28, 2012

1:00 PM PST

PLACE: Jacks in San Bruno
ADDRESS: 1050 Admiral Court
 Suite A
 San Bruno, CA 94066

CONTACT: Kimberly Abold
akimbalee@comcast.net



GIVING HONOR ROLL

MEMBER – Up To \$100

Janie Heath
 Helen Lee Lodge
 Eunice Miles
 Donna Bunce
 Janet Fitzgerald
 Renee Marie Petroskey
 Cecilia Petroskey
 Pauline Standley
 Susan Begelman
 Linda Shattuck
 Judy Lynn Brown
 Tom & Joanne Korsmo
 Mary Piepergerdes
 Betty B Davis
 Nancy Jo Pierce
 Harold C Huang
 Linda Jeannette Bradley
 David & Sheryl Wiener
 Marcia Purdy
 Alexandra Am Vrachas
 Eija Endersen
 Toni Bracey
 Tejon Builders
 Becky (Pelfrey) Ramsey
 Ruth Winston
 Martin Dale Mick
 Susan Amy Goldsmith
 Rebecca & Oliver Janney
 Sandra Jeanette Garver

New Appointees



Dr. Brad Daar, Vice President

Born and raised in the Chicago suburbs, Dr. Daar has been practicing Dentistry in Manchester, Connecticut since 1983. Always having an interest in fitness and health Dr Daar received his Masters degree in Nutrition from St Joseph College in West Hartford CT. In addition he holds a Bachelors of Science and Masters Degree in Biology. His motivation to help with the FMDSA organization is not limited to his interest as a medical practitioner. Dr . Daar is also the husband of an FMD patient. Involvement as a Board member is a natural progression for Dr. Daar in his efforts to spread FMD awareness among the Medical community, not just for Dentists, but all Health Care providers and the general public.



Mimi Petersen

Mimi has been a member of FMDSA, as well as a volunteer, since the organization's beginning. Through the years, she has been involved in different aspects of FMDSA: patient support, fundraising, awareness programs, and assisting in facilitating UC Davis FMDSA Registry participation. An FMD patient, who has dealt with hypertension due to FMD since a young girl, Mimi is committed to making sure that others will not have to go years without being diagnosed. Retired from a career in Real Estate and the mother of two grown sons, Mimi has spent the last few years traveling with her husband of 30 years, Tony. She looks forward to her continued involvement with FMDSA and her part in helping to fulfill FMDSA's mission.

FMDSA Advisory Council

New Appointees



Joan M. Legraw, RN, JD, MPH

Joan M. LeGraw received a BS in Nursing, cum laude, from Fitchburg State College in 1983, a J.D., magna cum laude, from New England Law in 1989 and a M.P.H. from Harvard University in 2000. Currently Ms. LeGraw serves as General Counsel and Consultant for Ethical and Regulatory Affairs for the Cape Cod Research Institute in Hyannis MA. In addition, Ms. LeGraw practices with the Bourget Law Group, LLC a full service elder law and estate planning practice in Falmouth and Centerville MA and is on the Adjunct Faculty of Suffolk University Law School where she teaches Biomedical Law and Public Policy.



James Baranski, CEO-National Stroke Association

James (Jim) Baranski has been Chief Executive Officer of National Stroke Association since April 2003. Prior to joining National Stroke Association, he was an accomplished management consultant with expertise in organizational strategic planning and development, human resources and sales and marketing and has served as Managing Partner for a CPA & consulting firm in Chicago as well as serving as Interim Chief Executive Officer, Chief Operating Officer and Chief Financial Officer for a variety of for-profit businesses.

- Heather Campbell
- Lynn Lowecey
- Natali Pulver
- Microsoft Matching Gift Program
- Lynn Weill
- Donna Maggiotto
- Katjeleen Weibeler
- Ruth Kuertz
- Dennis G Durant
- Sr. Virginia M Kinsella
- Duane & Carol McGatha
- Pamela McPherron
- Maxine Hull
- Jim Kuertz
- Haeley Franklin
- Mary Karen Baukert
- Christiane Marie Mitchell
- Phyllis Labatut Barker
- Carol Soloman
- Glenda D. Nelson
- Heather Settle
- Milla Kay Workman
- Christa Saracco
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- Abbie J Levy
- Shep D. Brown
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- Robert & Linda Podojil
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- Taylor Womack
- Ann Barr Weems
- Richard & Susan Gould
- Rebecca Sue Wright
- Karen M McClellan
- Beverly Jo Parmed
- Ann Barr Weems
- Gwendolyn Androw
- Carolyn Kim Kost

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- Cindy Speck
- Dr Michael Mazowiecki
- Flordia Builders
- Jeanette Wilhelm
- Karen Schiff
- Nancy Darragh/Richard Buzby
- Lifecenter
- Barbara McFee
- Linda Lee Williamson
- Kathleen Martin
- Patricia Brock
- Denise Laman
- Karen Hartman
- Cherylann Bailey
- Taylor Petersen

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- Alice Faye Hubbard
- Terri Wetzel
- Kelly Connelly
- Samuel & Anne Oliver
- Mary Brodmerkel

Antonia Keg

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Clayton Foundation
Pamela Mace
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Michael Short
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HERO \$1000+

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Jodi Roth
Martha Clark

CELEBRITY \$10,000+

Debra Koehler
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