



1st International Fibromuscular Dysplasia Research Network Symposium May 15th-16th Cleveland, OH. Chaired by Doctors Heather Gornik and Jeff Olin

This meeting was nearly two years in the making and was met with great excitement. The meeting gathered key researchers and clinical thought leaders in the field of FMD for a state-of-the-art review of the existing knowledge base and current research activities related to FMD in the United States and abroad. Topics covered, ranged from advances in imaging and diagnosis to an evaluation of connective tissue features recently published on FMD patients. A large proportion of the meeting was focused on the creation of an FMD research network, comprised of four focused working groups on various aspects of FMD research (epidemiology, genetics, research registries, and imaging and clinical therapeutics). The meeting was a great success! Multiple international research projects as well as continued collaborations were fostered during the two day event.

To view all abstracts presented and learn more about the Symposium and working groups, [click here](#).



Clinical and biochemical profiles suggest fibromuscular dysplasia is a systemic disease with altered TGF- β expression and connective tissue features

These findings were published April 14th in the Journal of the Federation of American Societies for Experimental Biology (FASEB) to view the full abstract and data, please visit their website [@www.fasebj.org/content/early/2014/04/12/fj.14-251207.abstract](http://www.fasebj.org/content/early/2014/04/12/fj.14-251207.abstract)

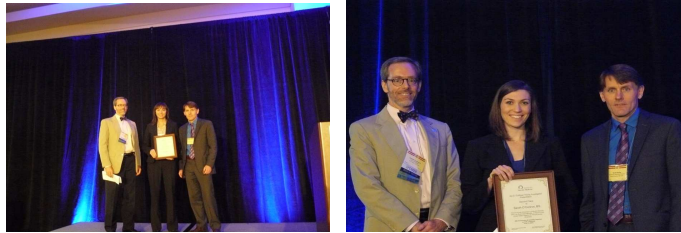
Rare Disease Report Coverage

On June 11, Rare Disease Report spoke with Dr. Javier Romero of Massachusetts General Hospital regarding the development of an FMD image bank. The idea for an image bank was developed at the 1st International Fibromuscular

Dysplasia Research Network Symposium, where physicians from around the world collaborated to improve the care of FMD patients. You can view Dr. Romero's comments on the image bank [here](#).

Society of Vascular Medicine (SVM)

Every year the SVM hosts a Young Investigators Award Competition and we are excited to announce that two of the three posters that won this year's competition were on FMD. Congratulations to Ms. Sarah O'Connor, Cleveland Clinic for taking 2nd Place – Outcomes of FMD, with mentor Dr Heather Gornik and 3rd Place went to Dr Erin K Moore, Greenville Health System – Mesenteric FMD, with mentor Dr Bruce Gray. Winners pictured with doctors Jim Froehlich (SVM President) and Scott Kinlay



Congratulations to State Representative, Pat Somerville

Michigan, Rep. Somerville received an Award of Appreciation for his efforts in designating March 11th Fibromuscular Dysplasia Awareness Day in the State of Michigan. He is proudly wearing the FMDSA Cleveland Marathon shirt that our runners wore this year. In a few months we will be sharing information on how to get your state representatives involved in designating March 11th as Fibromuscular Dysplasia Awareness Day in your state.



Seventh Annual FMDSA Patient Meeting – Reflections

On May 16th and 17th, physicians, researchers, patients, and family members gathered in Cleveland, Ohio for the seventh annual FMDSA patient meeting. The meeting took place at the Wyndham Hotel in the Playhouse Square district, and was an overwhelming success thanks to all who support the Society. Most importantly, we would like to thank our sponsors and donors for their support, without whom this important annual meeting would not be possible. It was a pleasure to attend the conference, hear a wealth of engaging patient stories, and meet patient advocates of this rare disease.

The meeting immediately followed the first ever meeting of the International Fibromuscular Dysplasia Research Network, which also took place in Cleveland, Ohio on the 15th and 16th of May. Researchers from as far as Paris, France attended the meeting and offered a unique vantage point in the process of researching and treating fibromuscular dysplasia. An important part of the research meeting was the working groups, which focused on genetics, data registries, imaging modalities, and epidemiology. Each group was tasked with solving a different facet of FMD, and each made great strides to collaborate further after the meeting.

On Friday evening, the annual FMDSA raffle was held, and many wonderful prizes were awarded including portable

music players, massage packages, and more. More importantly, Friday night was an opportunity for FMDSA members from all over the country to reconnect. Observing the FMD patient network for the first time was an incredible experience. Never before have I seen such a dedicated group of people committed to finding an answer to this absorbing, frustrating, and often overwhelming medical condition. The compassion and selflessness of the members of the FMDSA was inspiring and uplifting.

With opening remarks from Dr. Jeffrey Olin of Mount Sinai and FMDSA Executive Director Pamela Mace, the meeting began in earnest on Saturday morning. Exciting presentations included those of Dr. Esther Kim, who gave us all an overview of FMD with "FMD 101," as well as a report from Dr. Kevin Myers on pediatric FMD. Investigator Dr. Pierre-Francois Plouin gave an update to the FMDSA on the status of the French projects ARCADIA and PROFILE, which consist of patients from throughout Europe. Drs. Minnie Bluhm and Sherry Bumpus were on hand to listen to the stories of FMD patients, whose research will help us understand what it really means to live with FMD. Dr. Jackie Saw of Vancouver, gave an important talk regarding a potential correlation between Spontaneous Coronary Artery Dissection (SCAD) and FMD. Dr. Saw was awarded the FMDSA Founder's Award for this work, which will hopefully elucidate the mechanisms of FMD and ultimately improve patient outcomes.

Although the meeting concluded officially on Saturday afternoon, many FMDSA members remained in Cleveland to participate in the 2014 Cleveland Marathon, either as participants in the race or as volunteers. It was a perfect morning for running; sunny, crisp, and cool weather made for an exciting yet tiring race. As a half-marathon participant, seeing the FMDSA members at the aid stations raised my spirits and helped me finish the full 13.1 miles. We hope that more runners will participate in the race next year in support of team FMDSA!

I would like to thank all of the donors, sponsors, patients, and volunteers who put in their time and effort to make this meeting a success. It opened my eyes to how far patient advocacy can really take an organization. With your continued support, determination, and optimism, we can continue to investigate into the underpinnings of this disease.

Steven Heidt
FMD Student Team Leader
Michigan Clinical Outcomes Research and Reporting Program

Video Spreecast covering the International Research Meeting with Dr Heather Gornik and Pam Mace

For those of you who were not able to participate in the Spreecast on June 19th, you can view the video at your convenience. Topics discussed included the International Research Meeting, FMDSA Annual Meeting and they also responded to questions from patients who participated. To watch the video, [click here](#)

2014 Founders Awards Recipient's

The Founders Award is awarded to an individual or institution, who has taken extraordinary measures to advance awareness, research, or treatment of Fibromuscular Dysplasia.

We wish to express our sincere gratitude to our FMDSA Founders Award recipients for their outstanding achievements in promoting research and awareness of Fibromuscular Dysplasia.



Santhi Ganesh, MD University of Michigan



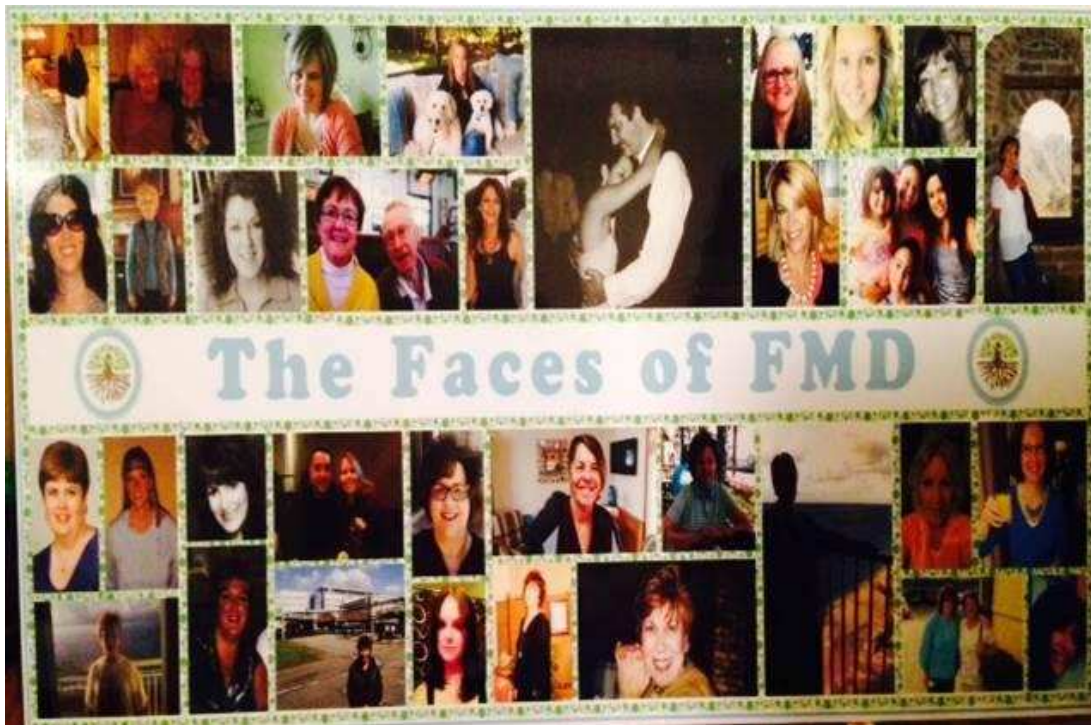
Jackie Saw, MD Vancouver General Hospital, Canada



Pr Pierre- Francois Plouin, Hospital European G Pompidore, Paris France

THE FACES OF FMD

This wonderful collage poster of our beautiful FMD family was proudly on display at the FMDSA Annual Meeting. It was well received by all and everyone enjoyed seeing the photos. We are all on this FMD journey and together we can make a difference ...



NORD Portrait of Courage Celebration (National Organization For Rare Disorders)

NORD (National Organization For Rare Disorders) hosted a "Portraits of Courage Celebration" on Thursday, May 8,

2014 at the National Building Museum in Washington DC. FMDSA's very own Executive Director, Pam Mace was one of the honorees at this gala as a patient/advocate who is the personification of courage.

The centerpieces of the gala were portraits of the honorees– large photos of patients/advocates – on display with beautifully written text explaining why the individuals are the personification of courage.

Congratulations to Pam for receiving such a special honor from Nord! Please click on this link for more information about the event <http://www.raredr.com/articles/NORD-Portrai-Courage-Celebration>



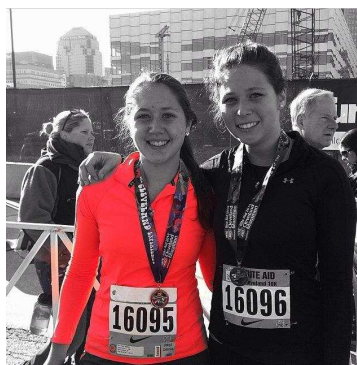
FMDSA AND THE CLEVELAND MARATHON

FMDSA had a large group of runners this year, young and old in the Cleveland Marathon Races Sunday, May 18th. We also had many volunteers and supporters manning water stations and cheering our runners on! A great time was had by all and we raised much needed funds for FMDSA.

We are already putting together teams of runners and walkers to participate in the 2015 Cleveland Marathon on Sunday May 17th. We need runners for the full marathon, half marathon, 10K, 5K and kids run. FMDSA is also looking for 25 volunteers to work at a water station on Sunday. 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 Karen Prcela at karen.prcela@fmdsa.org, For specific information on the race, [click here](#).

For runners, the coupon code for all races is: RUN4FMDSA. This code should be entered into the COUPON CODE section of the application form. We would like to encourage our runners to create a Firstgiving fundraising page, it's fast, easy and secure. Create your page, [click here](#).

Here are some fun photos of our supporters from this year's Marathon:





CIRCLE OF FRIENDS AWARDS

2014 "Circle of Friends"

Sending a very big THANK YOU to our 2014 "Circle of Friends" Award recipients: Jodi and Peter Roth, Molly Clark and Kay Tanner, Terri Provost and Bradley Daar, Pam Mace and Bob Kubic and Cheryl Golden.

The FMDSA's "Circle of Friends" is a group of committed benefactors with an interest in supporting the patient registry. By making a gift or pledge of \$5,000 or more annually, you can help FMDSA ensure that the registry continues. Without the registry, we are just a group of patients. With the registry, we are a voice that has gotten the attention of the medical community.



We want to thank you for your continued support. Our organization and the registry are funded primarily through your contributions. Without your help there would be no registry.

Thank you.



Please visit our website at www.fmdsa.org.

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

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