FMDSA welcomes Dr. Heather Gornik, Medical Advisory Board

Dr. Heather Gornik from the Cleveland Clinic joins the Medical Advisory Board. She is the Medical Director of the Non-Invasive Vascular Lab at the Cleveland Clinic in Cleveland, Ohio. We appreciate her expertise and willingness to help FMDSA.

2008 FMDSA Annual Board Meeting

Cheryl Golden, Pamela Mace, Rochelle DesRocheers, Dr. McDonnell & Kari Ulrich

Dr. Olin’s Top 10 List, Page 2

Cleveland Clinic Foundation announces first ever FMD CLINC!

Starting January the Cleveland Clinic Foundation will be holding a FMD clinic on Fridays in their Vascular Department. This project will be headed by our own Dr. Heather Gornik along with colleagues Dr. Bartholomew Section Head in Vascular Medicine, Dr. Kim & Dr. Al Solaiman. FMD patients will have access to multiple specialists to manage their disease. For more information please contact the Cleveland Clinic at: 1-800-223-2273

International Patient Registry

The International Patient Registry is expected to be operational January 2009. Members of the steering committee are meeting at the American Heart Association in New Orleans this November to work out final details. According to a recently published article Current Opinion in Cardiology 2008, 23:1 – 10, “Contemporary management of fibromuscular dysplasia” by Jeffrey W. Olin and Matthew Pierce, “... there has been virtually no new research in this disease over the past 40 years. The literature consists of single case reports, small case series and review articles. The FMD Society of America (www.fmdsa.org) is a lay organization that has made impressive advances in awareness of FMD and in raising money to fund an international registry for FMD. The first step for this registry is to allow the collection of information by centers that see a large number of patients with FMD and analyze the data with the hope of gaining new information about FMD and the most appropriate treatment. The second step will be to collect blood to study the genetics of FMD in a large cohort of patients.”
Dr. Olin’s Top 10 List

Top 10 Mistakes in FMD Diagnosis & Treatment

10. Not listening to the neck with a stethoscope during physical examination

9. Not performing an MRA of the brain in patients with carotid artery FMD

8. Performing an angioplasty and telling the patient the artery is normal by looking at it

7. Telling the patient (and their doctors) that they can determine the degree of narrowing of an artery by looking at an angiogram

6. Telling patients with severe headaches with FMD that there is nothing that you can do for them

5. Telling patients that the symptoms are all in their head

4. Telling patients there are no experts in FMD

3. Telling the patients that FMD is a rare disease

2. Telling patients that FMD is a fatal disease with no treatment

1. Not contributing SOMETHING to FMDSA so this important work can continue!

FIRST FMDSA CONFERENCE

Westlake, Ohio

The 2008 Annual Board Meeting took place on June 21, 2008 in Westlake, Ohio. The Annual Board Meeting & Conference was well attended with over 100 participants! This was the first time in history where members & FMD experts: Drs. Olin & McDonnell were in the same room educating one another.

The weekend started out on Friday with registration and an informal social gathering. For many of the members this is the first time they had ever met others with FMD. The event continued on Saturday morning with the annual board meeting. Re-election results were announced by our secretary Cheryl Bailey. Pamela Mace & Rich Gould presented the latest FMDSA updates including, our mission, goals and financial information on our organization.

Dr. Jeffrey Olin spoke on Fibromuscular Dysplasia and what this disease entails, including a “Top 10 Mistakes in Caring for Patients with FMD”. Members had the opportunity to ask questions in a panel discussion with Dr. Olin, Pamela Mace RN & Kari Ulrich RN. Dr. McDonnell gave an update on her genetic findings from the NIH study, we have exciting news to look forward to in the future. Dr. McDonnell also participated in a panel discussion and collected saliva samples from participants for DNA analysis. After lunch was served, Dr. Michael Ulrich presented “Coping with FMD” which gave validation to those diagnosed with FMD and their loved ones...remember to eat the fudge! At closing remarks awards of recognition were given out to those who have made an impact with FMD.

Founders awards were presented to Dr. Olin & Dr. McDonnell and Pamela Mace for there contributions they have made. Pamela Mace presented awards to FMDSA founders Rich & Susan Gould, and Maria Yeh. FMDSA Volunteers were presented with certificates of appreciation for their valuable contributions to FMDSA. The conference ended with another social and raffle with proceeds benefiting FMDSA.
A few memories from the conference...

2009 FMDSA Conference Details Coming Soon...
PEP/Physician Education Program

**FMDSA attended ACC Conference**

ACC08 – Booth 15086, home to the FMDSA Exhibit March 29th through April 1st 2008 in the “windy city” of Chicago. What a wonderful experience this was for Cheryl Bailey, a patient with FMD and a member of the Board of FMDSA and her husband David. The Conference itself featured many hot topics and sessions, and our goal was “networking”, spreading awareness of FMD, which is what we did from our booth sharing information on FMD and making some new contacts. Medical specialists and students as well as other Exhibitors all stopped by our booth, asking questions and walking away with valuable handouts on FMD to help them better diagnose patients in the future who could have FMD.

**Dr. Michael Ulrich brings awareness to Colleagues.**

During a trip to Whistler BC, Dr. Ulrich had a chance to formally speak on FMD to his Med School Alumni. This was a very successful talk in bringing awareness to FMD and FMDSA to multi-specialty doctors located in Canada.

- In September Dr. Ulrich attend the Minnesota EMS Medical Directors Conference in Alexandria, Minnesota. Over 100 of our brochures were picked up by Emergency Physicians, EMS and Emergency Department Directors. Dr. Ulrich had the opportunity to discuss FMD & FMDSA one on one with Emergency Personnel.
- Later in September Albert Lea Medical Center hosted a Grand Rounds talk by Cardiologist Dr. Birchem, along with Dr. Ulrich. The lecture that day was on Stroke and causes. Dr. Ulrich covered FMD being a cause of stroke.

**FMDSA attends the 2008 Vascular Society Annual Meeting**

The Society for Vascular Medicine held its 19th Annual Scientific Sessions & 4th Annual Board Review Course May 29-June 1, 2008 in Minneapolis, MN. Kari Ulrich, RN attended this conference for FMDSA. Our goal to educate and inform physicians of the upcoming patient registry was met with great enthusiasm from many of the top physician leaders in the vascular field. This was the first Vascular Conference FMDSA has attended. Physicians from all over the nation attended this conference.

**PAC / Professional Awareness Committee**

**Cheryl Bailey Speaks on Behalf of FMDSA**

On Monday April 7, 2008, Cheryl Bailey spoke to the Atlantic City Charter Chapter of the American Business Women’s Association on FMD and the importance of FMDSA. Following Cheryl’s talk, and a brief Q&A session, Cheryl was awarded a Certificate of Appreciation for speaking as well as a donation toward FMDSA’s June 21, 2008 Annual Meeting (a sponsorship in the amount of $500.00)

“Keeping in Circulation” the official publication of the Vascular Disease Foundation featured Fibromuscular Dysplasia in their summer 2008 newsletter. The article titled: Finding Fibromuscular Dysplasia: Trying to Diagnose an Illusive “String of Beads”, highlighted Pam Mace’s battle with FMD. Keeping in Circulation is the largest lay publication in America focused on vascular diseases. For more information please visit: www.KeepingInCirculation.org or www.vdf.org
Board members Elected
The following board members were re-elected for another 2 year term:
Dr. Doug Webster: Director-at-Large
Cheryl Golden: Director-at Large
Rich Gould: Founder, Treasure
Kari Ulrich RN: Director-at-Large

FMDSA MEMBERS MAKE A DIFFERENCE!

Introducing April Langmeyer FMDSA member.
April is making a difference in the fight against FMD. April organized a bake sale and the proceeds went to FMDSA! April did not stop at the bake sale, she also designed a t-shirt for MedTees.com. April states, “I have been working with co-founder, qa Westby Fisher MD, FACC. He is the Director, Cardiac Electrophysiology at Evanston Northwestern Healthcare and Associate Professor of Medicine at the Feinberg School of Medicine, Northwestern University.” (Co-Founder of MedTees.com)
MedTees.com will be donating 10% of the proceeds received from the sale of the “My Disease Needs a Celebrity” tee shirt to FMDSA!
Get your tee’s at:
http://www.cafepress.com/medtees/643511
and bring more awareness to FMD. Remember Christmas is around the corner, this would make a great gift!
Thank you April from all of us at FMDSA! We appreciate all the effort you have made to benefit others!

FUNDING FMDSA
We need your help now more than ever! With the patient registry around the corner FMDSA is in need of funds to keep programs like (GAP) Grassroots Awareness Program & (PEP) Physician Education Program going. These programs are vital in bringing awareness to FMD.

FMDSA FOUNDERS
Maria Yeh, Richard Gould, Susan Gould

FMDSA Wish List
We are looking for volunteers with experience in
Grant Writing & Fundraising
Donations Needed:
Laptop, All in One Printer, Scanner, Fax, Computer
Paper & Printer Ink
Please Call us at 1-888-709-7089 or email us at admin@fmdsa.org

Board of Directors
Pamela Mace RN, -President
Richard Gould- Treasurer
Cheryl Bailey -Secretary
Doug Webster, DO - Executive Committee
Glenn Graham, MD- Executive Committee
Cheryl Golden, CPA- Board of Directors
Caroline Fultz-Carver, PhD- Board of Directors
Kari Ulrich, RN- Board of Directors
Office Manager
Kim Blakemore
You can make a difference...

Fibromuscular Dysplasia does not discriminate against age, gender or nationality. It’s impact on quality of life can be devastating...

... but everyday the Fibromuscular Dysplasia Society of America is striving to improve the lives of those impacted by FMD. FMDSA provides advocacy to those newly diagnosed and their families. Our volunteers spend countless hours supporting FMDSA’s mission, by raising awareness and developing funds to promote research towards new medical treatments and diagnostic tools.

Every dollar that you provide to FMDSA goes toward fighting FMD.

Did you know that monthly giving is an incredibly efficient way to support FMDSA? With your monthly gift to FMDSA you provide a consistent, reliable income stream, allowing us to focus more resources on our programs. Members like it because it's easy to budget and it feels great to be making a difference every month of the year.

FMDSA is the only organization that has a presence in the fight against FMD. Together we can make a difference, your generosity allows us to continue our programs, fund our registry and improve the lives of mothers, fathers, sons and daughters... It only takes a few minutes, please donate now at [www.fmdsa.org](http://www.fmdsa.org)

Your Donation is vital to promoting FMD research and awareness programs. Remember that all contributions are tax deductible. Contact us at:

FMDSA
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