

VIVA10, Las Vegas!



In November, Pam Mace was asked to speak at the Vascular Interventional Advances (VIVA) Conference in Las Vegas. It was an amazing opportunity to raise awareness among the 2,000 physicians and medical professionals about Fibromuscular Dysplasia. The title of Pam's talk was "A Plea to Vascular Specialists: Don't Forget about Fibromuscular Dysplasia".

Pam jumped at the opportunity and was very grateful for it. What Pam didn't know was that the VIVA Board of Directors had gotten together and agreed to donate \$50,000 to FMDSA to help further our mission. After Pam spoke, Dr. Michael Jaff presented her with the check for \$50,000! As you can tell by the picture, Pam was very surprised and it was a very emotional moment.

FMDSA would like to express our deepest gratitude to the all of the VIVA Board of Directors and Staff, including Gaylene Horst, Gary Ansel, Michael Dake, Tony Das, Michael R. Jaff, James Joye, John Kaufman, John R. Laird, Manish Mehta, Krishna Rocha-Singh, Kenneth Rosenfield, Peter Schneider and Tmothy Sullivan. There is no way to fully express our gratitude. Everyone at FMDSA is truly moved and inspired by your generosity!

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A note from Dr. Michael Jaff
VIVA has always been committed to philanthropic
efforts for the medical field and the public who are in
need. We have provided philanthropic grants to
the Vascular Disease Foundation, Hurricane
Katrina, and the Haitian Relief Effort. The
Fibromuscular Dysplasia Society of America is a
natural extension of our efforts to support initiatives
dedicated to our patients.

Thoughts from one of our members Mimi Petersen

On November 9th, Pam Mace spoke at Peninsula Medical Center in the Bay Area. Just a few short years ago it would have been hard to believe that a hospital on the west coast would ask someone from FMDSA to speak at their facilty. But there it was! Pam's talk enthralled the room filled with medical professionals. When the talk concluded many questions were asked. I heard one doctor say "now this is something I will consider in the future"! Amazing that the word is now spreading coast to coast!

Since Pam was in the area she offered to see if local FMDSA members were interested in meeting. A wonderful time was had by all. Several patients had never met another person with FMD and were overwhelmed with emotion. We shared our personal journeys about living and dealing with Fibromuscular Dysplasia. There really is not enough time in the day to say all that we wanted to say to each other. We broke bread, toasted our strength and hugged each other long and hard before we said goodbye. But our goodbyes will be short lived. We intend to meet again and on a regular basis.

All of us agreed that we not only benefit from time shared together, but that we have the desire to spread the word about FMD. Together we can make a difference. Ideas were bantered around with great enthusiasm. We have shared e-mails looking forward to our next meeting. Of course we hope that others in the area will be able to meet with us in the future and enjoy the benefits of the support we derive from one another. So we will spread the word to our doctors and health care providers that there are others with FMD and no one has to deal with this disease alone. FMDSA has been there for us as an organization, and we can be there for each other. We will also do our part to support the organization that helped to bring us into each others lives.

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FMD Patients United: April 2011 National Fundraising Event

We are pleased to announce the first national and hopefully international fundraising event for FMDSA. In April 2011, we are asking members to become involved and sponsor a fundraiser for FMDSA. It can occur anytime in the month of April and can be any type of fundraiser you choose.

Right now, we have received commitments from members in the following states: California, Florida, Illinois, Kansas, New York, Oregon, Ohio, Rhode Island, Texas, and Virginia! Some members are planning large events; others will be planning smaller events.

Our goal is to include as many states as possible. If you don't see your state listed we would love to have you join us. Or, if you see your state listed and would like to become involved; please contact Kellie Smiddie at kellie.smiddie@fmdsa.org

Stay tuned for updates on this exciting event!

Gwinnett Medical Center's Stroke Conference

On November 5th, Nurse and Executive Director Pamela Mace was one of several speakers at the Gwinnett Medical Center's Stroke Conference.

"Advances in Stroke Care 2010:Complex Causes of Stroke and Research Update". The conference was attended by nurses and physicians as well as Jeffrey a 15 year old FMD stroke patient and his family. The evaluations showed that FMD was the #1 topic in order of importance that attendees felt they learned.

While in town, Pam invited local patients to meet with her which provided patients the opportunity to meet with others also diagnosed with FMD. Everyone really enjoyed meeting and a few also had the opportunity to speak with staff at Gwinnett Medical and get referrals for local physicians.

We Need Your Story



Please take the time to view the "Patient Story" section of our website and see the many faces of FMD. The stories are very informative. To add your story, please contact us.

Support Groups



The FMDSA board recently approved the addition of volunteer support groups for individuals and family members of those diagnosed with FMD. California, Florida, Georgia, Illinois, Massachusetts, North Carolina, and Virginia have volunteer support group leaders ready to go. More information will be sent out soon. Please let us know if you have any questions!

Save the Date: Annual Meeting - May 13 - 14, 2011



Save the date: The FMDSA Annual Meeting will be held May 13 - May 14, 2011 in Cleveland, Ohio.

Confirmed speakers are Dr. Jeffery Olin of Mt Sinai in NY; Dr. Heather Gornik of the Cleveland Clinic; and Dr. Chris Buller will be coming from Canada to discuss coronary FMD; Dr Rishi Gupta from Emory Hospital System to discuss Neuro Intervention for Carotid FMD.

Registration will be available starting mid January. The Cleveland Marathon is the same weekend so book your hotel early. We are also happy to announce that the Cleveland Clinic is a proud sponsor of our meeting for the fourth year in a row! Other confirmed sponsors are Massachusetts General Hospital, North Cascade Cardiology, and Greenville Health Systems.

Hotel: Doubletree Hotel Downtown

Please note: Each individual guest must make their own reservations by calling 1-800-222-TREE or 216-241-5100. You must identify yourself as a member of the FMDSA.

Akron Marathon



FMDSA served as the Akron Marathon escorts. Our team members cleared the way for the lead runners and the lead wheel chair racers.

If you would like to display your FMD pride, you can also own one of these uniforms. This is not a fundraiser, but an opportunity to show off you FMD pride. A standard jersey and shorts are \$58 each. FMDSA is the lead sponsor on the jerseys. The shorts have a different title sponsor, but they look good when macthed with the jersey.

If you are interested in ordering, please contact Rich Gould at rich.gould@fmdsa.org and he will send you an order form and additional information. All orders must be received by January 26, 2011.

Congratulations Dr. Gornik!

The American Red Cross of Greater Cleveland honored 25 Heroes at its "Hero Award Luncheon" on November 16, 2010 at the Renaissance Cleveland Hotel.

Dr Heather Gornik received her Hero Award in the medical category and she also received a Certificate of Recognition from the Mayor of Cleveland for her work and commitment to changing the lives of those diagnosed with FMD.

Kim Eagle, M.D., M.A.C.C. Joins FMDSA Advisory Council



FMDSA is introducing a new arm to our organization called the "Professional Advisory Council". The purpose of the council is to gather experts together that can provide advice and assistance on our business functions. We are very pleased to have Dr. Eagle join our organization. He is currently the Albion Walter Hewlett Professor of Internal Medicine and Director of the Cardiovascular Center at the University of Michigan Health System and has been one of the catalysts behind the FMD International Patient Registry.

In addition, Dr. Eagle has a tremendous amount of experience in charity work. He is the founder of Project Healthy Schools (fight against childhood obesity) and the founder of Project My Heart Your Heart (heart disease in special populations and reuse of pacemakers in third world nations). We look forward to learning from Dr. Eagle's past experiences and we are grateful to have him as part of our team.

Robert Kubic, MBA Joins FMDSA Advisory Council



We would also like to welcome Bob Kubic to the Professional Advisory Council. Many of you already know Bob as he has been lending his experience and expertise to FMDSA for many years now.

For those of you who don't know Bob, he is currently the Chief Operating Officer and member of the Senior Management Team of the Honigman Law Firm in Detroit and has over 20 years of experience in senior leadership positions with National and International law firms. Bob earned an MBA from the Weatherhead School of Management at Case Western Reserve University and also holds degrees from Hiram College. Bob was recently identified by *Corp!* magazine's as one of Michigan's 21 Top Executives for 2010!

We want to thank Bob for all his past support and we look forward to learning more from Bob.