

## FMDSA Society Page

August, 2011

*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. 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/FibromuscularDysplasiaSociety/OnlineForm.html>

Thank you,  
Rich Gould, Presiden

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### Annual Conference is a Success by Pam Mace



The 4th Annual FMDSA Conference was held at the Doubletree Hotel in

### Quick Links

[Our Website](#)  
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### 2011 Giving Honor Roll

**Champion - \$5,000**  
 Tracey Toto  
 Cheryl Golden

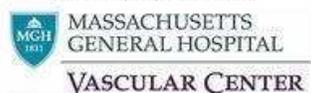
downtown Cleveland on May 13th and 14th of 2011. Over 60% of those who attended were new to FMDSA. The conference would not be possible without the support of our speakers and sponsors. We want to extend our thanks to them for their support and making the annual conference a huge success.

For more information on the annual meeting and the power point presentations that we are permitted to post, please [click here](#).

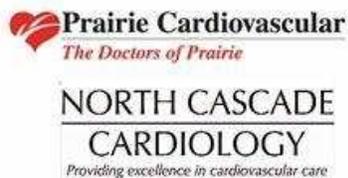
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**Hero - \$1,000**

Jodi Roth  
 Manchester Family Dental  
 Angeline Young  
 Virginia Fundraiser  
 (Maureen Womack)  
 Night at the Races  
 Fundraiser (Kellie Smiddie  
 and Pam Mace)  
 Dorine Catherine Secrest  
 Molly Clark & Kay Tanner  
 Martha Clark  
 Napa Valley Fundrasier  
 (Betty Conway and Mimi  
 Petersen)

**Benefactor - \$500**

Ron Vinder  
 Johnson & Johnson  
 Peace Unique  
 Douglas & Mariruth Webster  
 Eve Brooks  
 Maureen Womack  
 Kara Arthur  
 Nikki Esserman Wolpe

**Patron - \$250**

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 Google  
 Alice Faye Hubbard  
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 Nancy Pook  
 Mike Miller Auto Park  
 Nicole McCombie  
 Fith Third Bank

**Founder - \$100**

Monique Ravazzani  
 Wright Motor Company  
 Donna Lanza  
 Cathy Wolfersberger  
 Tracy VanDenBerg  
 Michelle Koty  
 Louise Arends  
 Patricia Brock  
 Thomas Edward Stone, Sr.  
 Lisa Foster

**Biorepository Update, July 2011**

**by Angela Dalenberg, The Mayo Clinic Biorepository for Individualized Medicine**

Thank you to all of those that participated in our study at the FMDSA 2010 and 2011 annual conferences. The Cleveland Clinic provided staff at the annual meetings to consent and draw blood from patients and first degree family members who were interested in participating.

To date:

- Nearly 150 patients with FMD have been recruited in our biorepository project
- 115 Mayo Rochester FMD participants
- 34 FMDSA 2010 conference attendees
- 10 FMDSA 2011 conference attendees

FMDSA would also like to acknowledge that 142 FMD biorepository patients have been enrolled at the Cleveland Clinic. We would like to thank all participants, the Mayo and Cleveland Clinics for their continued support and we look forward to sharing new developments.

For more information regarding the biorepository and the Mayo Clinic

brochure, please [click here](#).

## Centers Participating in the Patient Registry

by Pam Mace

We are thrilled to announce that ten centers are currently participating in the Fibromuscular Dysplasia Patient Registry. Additional centers will be included in the registry once they receive approval to participate. To date, more than 400 medical histories have been entered. To be evaluated at one of the centers, please contact them directly.

Please [click here](#) for more information

## Meet Dr. Ganesh



Santhi Ganesh is the Assistant Professor of Medicine at the University of Michigan. Dr. Ganesh received her medical degree from Northwestern University and training in Internal Medicine at the University of Michigan. She then trained in Cardiology at Johns Hopkins and went on to do postdoctoral fellowships in vascular biology at the National Institutes of Health (NIH) and in human genetics at the Johns Hopkins Institute of Genetic Medicine. Dr. Ganesh moved to the University of Michigan last year where she has established a lab focused on the genetics of vascular remodeling, funded through two National Heart, Lung, and Blood Institute (NHLBI) awards.

## Research in Paris

by Pam Mace

During the International Stroke Conference earlier this year, Dr. Emanuel Touze approached the FMDSA booth and discussed his groups research of Fibromuscular Dysplasia which provided an open door of opportunity. FMDSA has since been in regular contact with Dr. Touze and his colleague Dr. Pierre Plouin. We are excited to announce that Dr. Jeffrey Olin was invited to speak at the Fifth HEGP Meeting on Fibromuscular Dysplasia in Paris later this year. Dr. Olin, along with Pam Mace, will also participate in a round table discussion with the Paris group.

## Illinois Awareness and Fundraising Campaign

It was a great month in Central Illinois for the "April FMDSA Awareness and Fundraising Campaign". Terri Wetzel and Karen Hartman worked on several events in their community for FMDSA including soliciting donations and participation in the Illinois Marathon. The entire campaign raised over \$4,000 for FMDSA.

The race week started off strong with an interview of Pam Mace and Terri Wetzel on the local CBS morning news. Provena Covenant Medical Center hosted a presentation about FMD to over 30 physicians and

Robert Kubic  
 Rosann Kahn Mann  
 Philip Gorelick, MD, MPH  
 Mimi Petersen  
 Walter Tenley  
 Diana Clark  
 Linda Kinnear  
 Terri Jo Wetzel  
 Teresa Marie Seim  
 Steven A Kizis  
 Evie Bogis  
 Gail Calandrino  
 Marilyn Coleman  
 John Williamson



Save the Date...

December 14th is the next Cleveland Clinic FMD web chat with Dr. Heather Gornik.

## 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](#).

medical staff as part of their continuing education. The finale of the awareness campaign included a FMD booth at the Illinois Marathon Health and Fitness expo, where Cathy Wolfersberger and Fran Saplis assisted in educating others about FMD.



It was an amazing week. We were able to touch so many people by sharing our stories and we know the community will benefit from the awareness campaign. We believe it's important to educate everyone, including the physicians in your local community, in order to effectively promote awareness of FMD.

## 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 shipped it to FMDSA. It's that simple.

Thank you in advance for helping support FMDSA via our Amazon.com wish list.

## "GO TO BAT" for FMDSA and Win Tickets to the World Series

FMDSA has been chosen as one of 43 charities to participate in this fundraising program! State Farm will donate \$18,000 to the winning charity each week. A \$25,000 grand prize will be awarded at the conclusion of the contest.

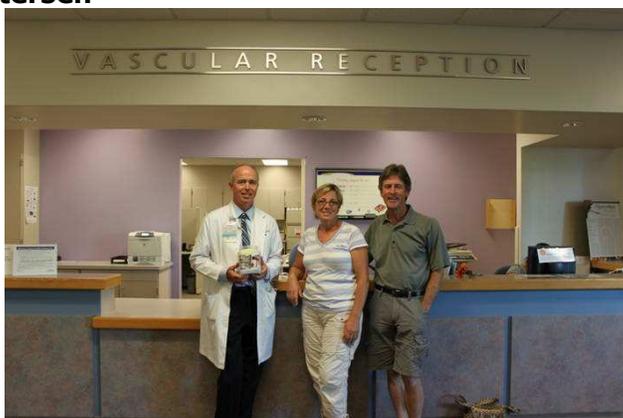
[Click here](#) to learn how you can help FMDSA and win tickets to the World Series.

## 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!

## Napa Valley Fundraiser

By Mimi Petersen



The California FMDSA fundraiser was a great success!!!! This wonderful raffle item: a three night four day stay for two in a cozy cottage was donated by Bob and Betty Conway. In addition to the stay, the winner won a gift certificate for \$100.00 to a fine Napa eatery, a bottle of BV's George's De Latour Private Reserve Cabernet, golf for two at Napa Valley Golf Club, and tickets for two on the Napa Valley Wine Train.

The winner is Donna Lanza from Lake of the Pines California and her

husband Larry!

The Fundraiser was put on by Betty and Bob Conway and Mimi Petersen. Special thanks go to ticket sellers: Linda Bradley (who was a ticket selling machine!), Kimberly Abolt (thank you!) and the winner Donna Lanza! All three FMDSA members are also part of the California Support Group!

Dr. Laird of UC Davis pulled the winning ticket. Thank you Dr. Laird for taking time out of your busy schedule

## Spreading the Word

### World Stroke Organization Features Patient Stories

Several members of FMDSA have had their stories added to the World Stroke Organization web site raising awareness of FMD all around the world! [Click here](#) to view the page.

### Kudos to Member Lisa Foster and Dr. Kevin Barrett

Kudos to member Lisa Foster and Dr. Kevin Barrett for such a great interview! Lisa Foster and her doctor shared Lisa's story with Fox News in Florida. Lisa has been a huge advocate in raising awareness of FMD. [Click here](#) to see Lisa's story.

### FMD: An Overlooked Diagnosis

Our thanks to Jodi Roth and Dr. Jeff Olin for the highly informative video clip and story about Fibromuscular Dysplasia, as reported by "myFox New York". Please [click here](#) to read the story and see this excellent video about Jodi's experience with FMD and Dr. Olin's discussion of treatment and diagnosis.

## Australian Support Group

Member Chris Pitman-Jones has proactively created a [website](#) on Google for FMD patients in Australia where they can participate in a support group sharing their experiences, ideas, and names of local physicians to promote further awareness of FMD in Australia and New Zealand.



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:

- \$5 is donated just for using iGive through 10/31/11. No purchase necessary.
- Another \$5 (or more) is donated if the new member also makes a purchase by 10/31/11.
- Shopping more means helping more. Over 900 great stores participate.
- No pop ups, ads, toolbars, special search engine, or unwanted emails.





Please visit our website at [www.fmdsa.org](http://www.fmdsa.org).