FMDSA Society Page

August, 2011

Working towards better diagnosis and treatment of Fibromuscular Dysplasia

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.etapess.com/hosted/FibromuscularDysplasiaSociety/OnlineForm.html

Thank you,
Rich Gould, President

Annual Conference is a Success
by Pam Mace

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

Table of Contents

2011 Giving Honor Roll
Save the Date...
FMDSA.RIVITY.ORG
FMDSA Amazon Wish List
"GO TO BAT" for FMDSA and Win Tickets to the World Series
Special iGive Promotion
Time to Renew Your Membership
Annual Conference is a Success
Biorepository Update, July 2011
Centers Participating in the Patient Registry
Meet Dr. Ganesh Research in Paris
Illinois Awareness and Fundraising Campaign
Napa Valley Fundraiser
Spreading the Word Australian Support Group

Quick Links
Our Website
Donate Now
Contact Us
Email Us

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.

**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
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.

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
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.

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

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 ship 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!
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.