

FMDSA Society Page

November 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/FibromuscularDysplasiaSociet/OnlineForm.html>

Thank you,
Rich Gould, President

Paris Update

by Dr. PF Plouin



The fifth HEGP (Hopital Europeen G Pompidou) meeting on FMD was held on October 21st. This annual meeting brings together physicians from Bordeaux, Caen, Clermont-Ferrand, Grenoble, Lille, Saint-Etienne, Marseille, Nancy and Toulouse participating in a national network on FMD. The French network is coordinated in Paris by PF Plouin (Hypertension Unit, HEGP) E Mousseaux (Department of Radiology, HEGP) and E Touze' (Stroke Center, Hopital Saint-Anne, Paris). A registry designed to document phenotypic

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2011 Giving Honor Roll

Champion - \$5,000

Tracey Toto
Cheryl Golden

Hero - \$1,000

Jodi Roth
Manchester Family Dental
Angeline Young
Virginia Fundraiser
(Maureen Womack)
Night at the Races
Fundraiser (Kellie Smiddie)

and genetic traits in patients with renal and/or cervical artery FMD is used for a national cohort study evaluating the progression of FMD lesions and for pathophysiological and genetic studies.

J. Olin and P Mace (USA) as well as P De Leeuw (The Netherlands), A Morganti (Italy), and A Persu (Belgium) were invited to participate in this year's meeting in order to exchange information and data and to consider harmonizing the US and the French registries. This would be a first step for organizing cooperative or complimentary studies in this rare condition.

Research update by Marja Wessels, who also attended and participated at the HEGP Meeting in Paris.

Dr Marja Wessels (MD, PhD), clinical geneticist, Dr Rob Willemsen (PhD) and Prof J Kros (MD, PhD), pathologist at the Erasmus Medical Center Rotterdam, the Netherlands are continuing their work on histopathology studies including immunostaining for TGFB pathway components to describe in more detail characteristics of FMD pathology. We hope to finish these studies by the end of this year.

5th FMDSA Annual Meeting

May 18th and 19th 2012

The Fifth FMDSA Annual Meeting to be held at the Wyndham Hotel in Downtown Cleveland. We would like to thank Cardiomems and the Cleveland Clinic Foundation for being the first to sponsor our 2012 meeting at the Platinum Level! Confirmed speakers include Dr Jeffrey Olin, Mt Sinai New York; Dr Heather Gornik, Cleveland Clinic Foundation and Dr Kevin Meyers, Children's Hospital of Philadelphia. To register for the meeting, please [click here](#)

To make hotel reservations please contact the hotel directly at 216-615-7500, mention Fibromuscular Dysplasia Society to receive the discounted rate of \$95.00/nt plus tax. We suggest you book your room early as the hotel sold out for the last meeting. As we have more details, they will be posted on Facebook and the FMDSA web site.

ABWA chapter hosts meeting, focuses on good cause!

by Cheryl Bailey

The Atlantic City Charter Chapter of the American Business Women's Association recently hosted Cheryl Bailey, Vice President of the Fibromuscular Dysplasia Society of America to present her program "Recent Accomplishments of the FMDSA" during the Chapter's September meeting, held in Egg Harbor Township, NJ. Mrs. Bailey detailed the society's launch of an International Patient Registry for patients with FMD, through the University of Michigan. Cheryl advised which centers are participating in the Registry, and what data is presently available. Cheryl stressed how important annual renewal of membership is, and the ABWA members were given the website address for renewing their membership, learning more about FMD and how to help further support FMDSA. The Chapter awarded Mrs. Bailey with a \$100.00 check to FMDSA, which was immediately matched by ABWA member Virginia Quickmire for a \$200.00 donation that evening.

and Pam Mace)
Dorine Catherine Secret
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

Robert and Brenda Brodrick
Chesser Financial
Liz Schimmel
Richard and Susan Gould
Bernard Ray Koogler
Karen Hartman
Liz Augusta RN
Bonnie McClinton
Elizabeth Pancoe
Jason Wrone
Google
Alice Faye Hubbard
Bronte Sterk
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
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





Patricia Hackett, President ABWA (left); Cheryl Bailey, VP FMDSA (right)

Important DATE!

Save the Date...

December 14th is the next Cleveland Clinic FMD web chat with Dr. Heather Gornik and FMDSA Executive Director Pamela Mace. For more information [click here](#)

1st Annual US Conference on Rare Diseases and Orphan Products by Lisa Foster

The FMDSA was represented by Lisa Foster, volunteer, at the NORD conference in Washington DC. The conference was held October 11-13th at the Omni Shoreham Hotel. The DIA, Drug Information Association and NORD, National Organization of Rare Disorders, presented a \$1000.00 scholarship to the FMDSA to be used towards the meeting expense. To view the PDF document, please [click here](#):

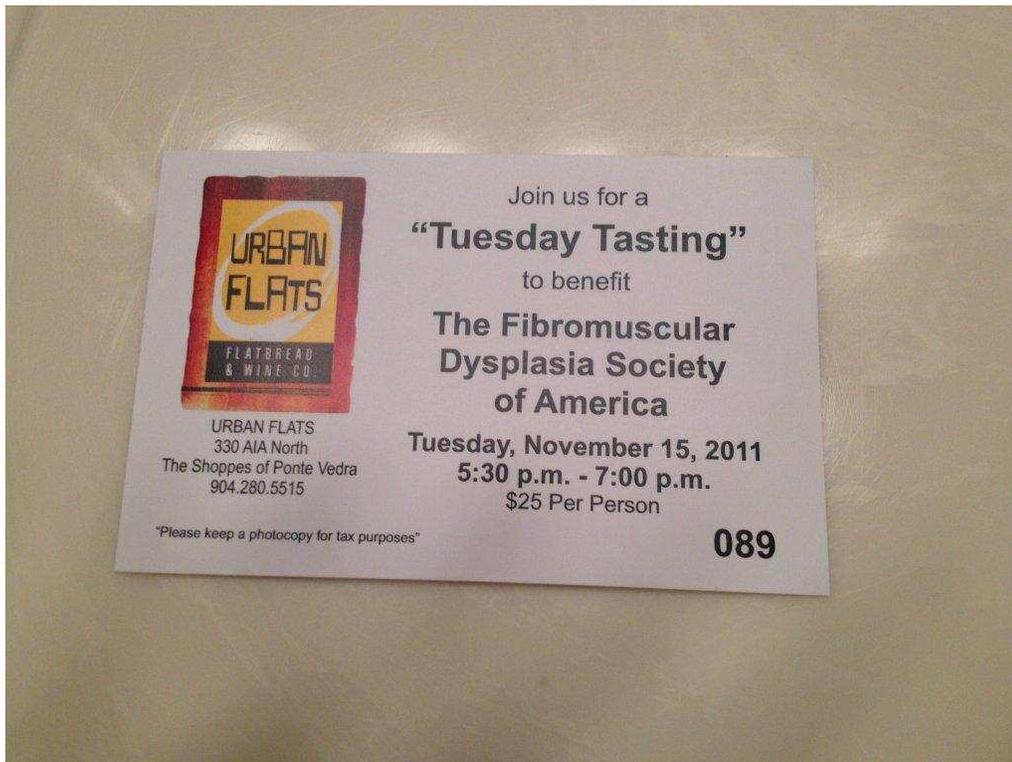


FMDSA.RIVITY.ORG

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](#).

Florida Group Meeting and Fundraiser



The newly formed FMDSA group in Florida will gather for a meeting and fundraiser on November 15th, 2011 at Urban Flat's in Ponte Vedra Beach, FL.

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.

The fundraiser will include a wine tasting and 50-50 raffle. Several FMD patients living in northeast Florida are selling tickets for the event at \$25.00 each.

This includes 3 glasses of wine, appetizers and live music. The restaurant will keep only \$5.00 from each ticket that is turned in the night of the event. The restaurant has provided printed tickets to the FMDSA for sale too. The Florida group would like to thank Applebee's Corporation for their donation to the FMDSA.

Watch the next newsletter for pictures and more information about this event.

Spreading the Word

Inspire FMD Support Group Page

Be the first to post on our new Inspire FMD Support Group Page. We have added discussion topics so that you can go right to your area of interest. <http://www.inspire.com/groups/fibromuscular-dysplasia-society-of-america/>.

FACEBOOK

We have updated our Face Book page to be able to add events and causes. visit our new page: <https://www.facebook.com/pages/Fibromuscular-Dysplasia-Society-of-America/259831044055679>

Support

FMDSA is in the process of organizing Regional Network Groups across the country.

To learn more [click here](#)

If you do not see your City or State listed please check back soon as we are in the process of adding more groups. Please note these groups are informal and run by volunteers, many who also have FMD.

FMDSA TO HOLD ON-LINE AUCTION (eBay)

NOVEMBER

FMDSA will be holding our FIRST on-line auction (on eBay) to raise money for our great organization.

We are looking for donations such as jewelry, electronics, gift cards and one of a kind experiences (ie... cooking lessons, weekend get away). We request that the minimum value of items be \$50 please. We hope to solicit 25-30 items for this fundraiser.

We continue to receive beautiful donations, such as but not limited to, a beautiful pearl necklace, dinner and movie certificates, digital camera, web consulting, teeth whitening and massage therapy.

Contact Kellie at kellie.smiddie@fmdsa.org for more information and to donate. Thank you in advance for your support.

Thank you to the Oregon Group & Vie de Boheme

On November 10th the newly formed Oregon group teamed up with Portland's newest urban winery, Vie de Boheme, to support the FMDSA.

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

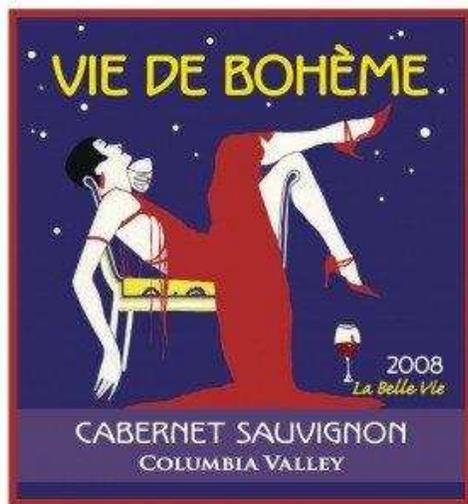
Special iGive Promotion

Join iGive for free and a portion of everything you purchase online will be donated to FMDSA at no additional charge to you! 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:

- Shopping more means helping more. Over 900 great stores participate.
- No pop ups, ads, toolbars, special search engine, or unwanted emails.





The winery donated 10% of proceeds from all purchases of food and wine for anyone attending the evening of November 10th, to the FMDSA.

Vie de Boheme also donated a bottle of wine for the Oregon group to raffle.

Please visit our website at www.fmdsa.org.