



3rd Annual Conference

May 21 - 23, 2010

Doubletree Hotel Downtown

1111 Lakeside Ave. E

Cleveland, Ohio 44114

Direct: 216-928-3234 | Fax: 216-241-1831

www.clevelanddowntownlakeside.doubletree.com

We are pleased to announce the above date has been set for the 3rd annual conference. We heard your concerns/feedback and made the decision to remain in the downtown area for patients who need to be seen at the Cleveland Clinic.

This hotel has a pool and parking is free! Rooms will be \$89 a night when you mention the conference. As more information becomes available, it will be posted on the website. Please address questions and concerns via email to Kellie at kellie.smiddie@fmdsa.org.

2nd Annual Conference

The 2009 FMDSA conference in Cleveland this past June 13th was a huge success. In addition to attending the conference, many patients/members

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also enjoyed site seeing in Cleveland and seeing the Cleveland Indians play...and of course a stop at the Rock and Roll Hall of Fame.

It was also an opportunity for many patients to be seen for a consultation/assessment at the Cleveland Clinic FMD Clinic, which was booked solid with out of town patients the week of the conference, including some from out of the country.



Guest speakers included Dr. Jeff Olin, Dr. Heather Gornik, Dr. Kevin Meyers (all members of our Medical Advisory Board), and Dr. James Froeclhich who discussed the new patient registry.

We would like to thank them for their informative presentations. Dr. Olin once again held our attention with a comprehensive lecture about what is known and what isn't known about FMD. Dr. Gornik's session offered patients the opportunity to participate interactively in "FMD Jeopardy" via an audio response system. Dr Meyer's presented interesting insight to pediatric FMD, for the first time at an FMDSA conference. After each speaker finished, they allowed time for a question and answer period with their audience. The time passed quickly and each presentation was very enlightening.

A big thanks also to all patients, family members, and medical personnel who attended our 2nd Annual Conference, hosted at the Wyndham Hotel in downtown Cleveland. Your support of this event is greatly appreciated and sends a message about how important it is to spread awareness about Fibromuscular Dysplasia. This year's conference also included a photographer from the Wall Street Journal who was on hand to take photographs for the June 27th front page story on Fibromuscular Dysplasia.

Friday night's social was a great way to meet new people and reconnect

FirstGiving

www.firstgiving.com/fmdsa

Thank you to the following FMDSA members for opening FirstGiving pages and raising more than \$15,000 for FMD awareness, education, and research.

Pamela Mace - \$4,650
Kari Ulrich - \$3,527
Rochelle DesRocheres - \$2,370
Tracy Vandenberg - \$2,280
Mimi Petersen - \$2,230
Cheryl Bailey - \$225
Emily Diggs - \$145
Susan Gould - \$100
Patricia Smith - \$50

Giving Honor Roll

Hero - \$1,000
Cheryl Golden
Elizabeth Willmore
Manchester Family Dental
Martha Clark
Maureen & William Murley
Molly Clark & Kay Tanner
Robert & Lisa Zborowski
Tana Busch DDS

Benefactor - \$500
Charlotte Rosenberg
Doug & Mariruth Webster

Patron - \$250
Kellie Smiddie
Liz Augusta
Michelle Paxton
Ronni Herrick
Tracy Vandenberg

with old friends. Saturday was a full day starting at 8am with breakfast, followed by conference presentations until 3pm, and ending with a social and raffle that were a fun way to spend the last of our time together.

Photos from the conference are available on our website.

Thanks to all of our sponsors and volunteers!!!

New Executive Director

FMDSA Makes Another Big Step Forward

In our most recent letter campaign, we announced some significant news. We have reached a stage in our development where demands were quickly outstripping the capabilities of our completely volunteer staff. We are thrilled to announce that we have hired our first employee, Executive Director Pamela Mace. A very familiar face to FMDSA, Pam has served two terms as Board President and has been a force of nature for FMD awareness. As Executive Director, Pam will dedicate her time to developing additional programs and funding for FMDSA.



With Pam moving into the Executive Director role, we needed to elect new officers to the Board of Directors. The new officers are as follows:

President: Richard Gould
Vice- President / Secretary: Cheryl Bailey
Treasurer: Cheryl Golden

Founder - \$100
Amy Fisher
Andrea Bettoni
Anne Karmon
Antoina Keg
Bernice Rydell
Brad & Mary Robbins
Bronte Sterk
C. Hope Poindexter
Carla Uss
Coastal Physicians
Edwin & Anne Bergamo
Hitchcocks
Jack & Sheila Claxton
Jack Fleig
Jo Hicks
Jo Soderberg
Joe Goldenberg
Louis Troilo
Lydia Mackey
Kadi Hodges
Karen Hartman
Margaret Webster
Nancy Darragh
Pam Bowser
Philip Verveer
Rick & Kathleen George
Robert Hachey
South Jersey Surgical
Stacey Fischer

"Donate A Car"

Help us raise money by donating your old car.

When it is time to get rid of your old car...Donate It!

- * *Fast, free towing.*
- * *Get a tax deduction*
- * *Quick, easy, and hassle free.*
- * *Help FMDSA*

FMDSA has recently completed the necessary paperwork to allow members to donate their used cars. From each car donated, 70% of the proceeds will be contributed to the FMDSA. It's fast and easy! Simply call the number below and staff will assist with arrangements seven days a week. They will even pick up the car for you!

For more information contact:
Donate A Car 1-800-237-5714
www.donateacar.com

Thank you to FMDSA Member Cecile Pileggi for bringing this program to our attention.

The Doctor's Channel

Dr. Heather Gornik

Dr. Heather Gornik (FMDSA Founder's Award Winner) has made tremendous strides in educating the patient population through her online web chats. She is also making great strides within the medical community through a series of short streaming video clips available on the Doctor's Channel.



The Doctor's Channel www.thedoctorschannel.com is a Web site that allows doctors to learn from each other – fast. The time-saving site includes short one- to two-minute streaming video clips designed to get to the point, with insights and opinions from experts in 35 different specialties, as well as community and lifestyle features that help doctors stay on top of the latest news, ideas and information.

Public Service Announcement Produced

Terri Provost-Daar and Brad Daar

Thank you to Terri Provost-Daar and Brad Daar as well as Dr Jeffrey Olin for their efforts in having a highly effective Public Service Announcement made about Fibromuscular Dysplasia. So far this PSA has been shown on local cable stations in CT and Ohio and is available for anyone who wants to help promote awareness about Fibromuscular Dysplasia. If you would like to approach your local cable television station or area service group or hospital to show this informative clip, please contact Chrissy Gribble at chrissy.gribble@fmdsa.org.

You can view the PSA from our website at <http://fmdsa.org/fmdsageneralnews.html>

Fredericksburg News

Kathy Beaver



Thank you to Kathy Beaver for helping us spread awareness. Kathy contacted her local newspaper, The Free Lance Star, and on August 2, 2009, her story was published on the front page under the title: "Nurse Surprised by Unusual Diagnosis". The story was also published on The Fredericksburg.Com. Way to go Kathy, for taking the time to get the word out about FMD.

CheckOrphan

December 11th at 9AM ET

Tune into CheckOrphan (www.checkorphan.org), a website dedicated to rare, orphan, and neglected diseases on December 11th at 9AM ET for their NewsFlash broadcast. You will notice that the host is wearing a FMDSA T-shirt. This program is called "Spotlight", which is designed to promote nonprofit organizations that are working with rare, orphan or neglected diseases.

Florida Fundraiser

Ronni Herrick

Congratulations to member Ronni Herrick of Florida. She held a raffle fundraiser at Midwest Feed Store on October 17. She hit the pavement and received over 40 donations from local businesses. The raffle proceeds, along with several donations made in her name, came close to \$500! Thank you to Ronni for all your hard work.



Fundraiser - Cafe Press

Rochelle DesRocheres

FMDSA volunteer Rochelle DesRocheres has applied her talents to not only build and operate our elegant website, but also to design and offer FMDSA merchandise through our Café Press store. Help us spread FMD awareness by proudly wearing and displaying the FMDSA logo. A portion of each purchase is also donated to FMDSA.

Please visit the links below to support the FMDSA by visiting our online store, or by purchasing a bracelet, key chain or other jewelry.

Also, please consider using [iGive](#) when you shop online. Click on the iGive link to learn how your online shopping can benefit the FMDSA.

Please visit our website at www.fmdsa.org.