Introducing New Medical Advisory Board Member

Warren D. Lo, MD  
Associate Professor of Pediatrics  
Associate Professor of Neurology  
Nationwide Children’s Hospital  
Columbus, OH  

Dr. Lo is a wonderful addition to our Board with his specialty not only in Neurology but Pediatrics as well, giving us expertise for our represented patient population. Thank you Dr. Lo for your willingness to serve.

MARCH 11, 2008 FMDSA CELEBRATED 5 YEAR ANNIVERSARY

FMDSA Welcomes Kim Blakemore  
Our new Office Manager

May is Stroke Awareness Month
May is the month nationally dedicated to stroke awareness so take this opportunity to contact your local healthcare facilities and newspapers and ask them to focus on stroke awareness and FMD. Local reporters would love to highlight patients so get your stories ready and out there.

OUR FIRST FMDSA CONFERENCE

June 21, 2008

HOLIDAY INN WEST LAKE, OHIO

 Speakers: Jeffrey W. Olin, DO, FACP, FACC, Nazli McDonnell, MD, PhD, Michael Ulrich, MD

FMDSA will be holding it’s Annual Board Meeting in Westlake, Ohio. The event will be held at the Holiday Inn. We are excited about this event because it would be the first time Patients and Physicians will be coming together to bring awareness and education to this disease. We are honored that both Dr. Jeffery Olin, DO, Director of Vascular Medicine Mount Sinai Medical Center and Dr. Nazli McDonnell MD, Genetics National Institute of Health, Baltimore have volunteered to speak at this event. The target audience includes FMD patient’s, family and friends. Anyone interested in learning more about FMD and FMDSA. Physicians, Nurses and healthcare providers are welcome, no CME or CEU will be provided.

See Page 4 for Registration Information

Event Sponsored By:

Cleveland Clinic

2008 International Stroke Convention

New Orleans

Pam Mace RN FMDSA President

Kari Ulrich RN Board Member

We are meeting our Mission to Educate

The 2008 International Stroke Conference was held this year in New Orleans. The conference was a big success at bringing awareness to physicians thanks to the help of member Maureen Murley.

Other conferences FMDSA have attended can be viewed at www.fmdsa.org
PATIENT REGISTRY IS OUR FOCUS FOR 2008

FMDSA is working on the contract phase of our International Patient Registry. We are working with the University of Michigan to host our registry and Dr. Jeffery Olin will be heading this project. This milestone will enable FMDSA to further our mission to ultimately establish research. The Registry is estimated to cost between $50,000.00 to $60,000.00 a year for the first three years. FMD has been considered a rare disease but many physicians, including Dr. Olin feel that it is often overlooked or misdiagnosed. The FMD Patient Registry will enable us to keep records on patients which will eventually help in research and hopefully help us find a cure. The HIPAA Privacy Act makes sharing information very difficult and therefore we have been unable to collect correct data on patients and store information. The cost of this project is high and the FMDSA is working diligently to apply for grants and establish additional fundraising opportunities. If you are able to assist FMDSA in grant writing or can contribute financially toward this project please contact us at admin@fmdsa.org

2007 FMDSA ACCOMPLISHMENTS

• FMDSA’s President, Pam Mace RN, makes the cover of “Stroke Connection” Magazine, by the American Stroke Association, March/April 2007 with a feature article “The String of Beads No One Wants” by Jon Caswell. The American Stroke Association Recognizes Fibromuscular Dysplasia as a Cause of Stroke

• AAKP Renalife, March/April 2007 does a cover story on FMD patient Lexi Martinez

• FMDSA’s Medical Advisor, Dr. Jeffery Olin, DO Vascular Medicine, writes for Cleveland Clinic Journal of Medicine “Recognizing and Managing Fibromuscular Dysplasia” and presents at Medical Grand Grounds at the Cleveland Clinic April 2007

• FMDSA’s President, Pam Mace RN, writes a personal essay for Cath Lab Digest, September 2007 writing “My Experience with Fibromuscular Dysplasia and Stroke”

• FMDSA’S Medical Advisor, Dr. Kevin E. Meyers, MD Pediatric Nephrologist makes the cover of Cath Lab Digest, October 2007 writing “Fibromuscular Dysplasia in Children and Adolescents

FMDSA on Education

Professional Awareness Committee: FMDSA’s secretary, Cheryl Bailey, has completed her article in “Health & Wellness”. Cheryl was diagnosed with advanced FMD during a routine exam for a bladder infection three years ago. Her disease affects both carotid arteries with a carotid aneurysm, both vertebral arteries and her right renal artery. Cheryl’s physicians at Shore Memorial Hospital follow her every 6 months with CTA’s and carotid ultrasounds, she takes aspirin as an anti-platelet, and monitors her blood pressure daily. Cheryl joined FMDSA shortly after being diagnosed and joined the Board of Directors this year to work with other FMD patients and volunteers, to help spread awareness. Cheryl Bailey’s article can be viewed at www.fmdsa.org

Nephrology Conference: ASN (American Society of Nephrology) Conference took place at the Moscone Convention Center in San Francisco, California from November 1st to 5th, 2007. Susan Bell and Mimi Petersen attended the conference for FMDSA and had additional assistance from Shirle Meyers, wife of Dr. Kevin Meyers of our Medical Advisory Board. Dr. Meyers attended the conference and was a keynote speaker for the ASN during their business meetings.

PLEASE DONATE

Your Donation is vital to promoting FMD research and awareness programs. Remember that all contributions are tax deductible. Contact us at:

FMDSA
20325 Center Ridge Road, Suite 620
Rocky River, Ohio 44116

www.fmdsa.org
FMDSA THANKS YOU FOR YOUR DONATION:

FMDSA HERO $1000
- Jesse Paul
- Thomas and Sandra Pontikis
- John and Mary Sanders

Bernard and Ruth Madoff
- Robert Kubic
- Katie Likander
- Karen Sciff

Kevin and Cheryl Golden
- W. Eric Casey
- Danielle Carroll
- Karen Shelly

Dell Corporation
- Michael and Kari Ulrich
- Kevin Lundholm
- Kenneth Gross and Leslie Mark

Lisa and Robert Zborowski
- Michael and Kari Ulrich
- Adelaide Dibenedetto
- Mark Murley

Maureen Murley
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- Allen Jordan
- Mary Beth Smith-Chibe

Kevin and Joy Burns
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Lehman Brothers
- Marilyn McCabe Reidy
- Beth Sperber
- Michael Connolly

Tri-Star Transport Corp
- McLeodUSA
- Brian Lammert
- Pacific Coast Cardiac and Vascular Surgeons

FMDSA BENEFACCTOR $500
- Carolyn Cusik
- Charles and Karen
- Robert and Dawn Gutierrez

- Janet Walker
- Daisy Margolin
- Ruth Cline

- Universal Solutions Inc
- Diane Smith
- Thomas Kelley

- FMDSA PATRON $250
- Stephen Kelly
- Douglas and Mariruth Webster
- Tom and Pamela Wieland

- Mimi Petersen
- Elizabeth Pancoe
- William and Janet Oliver

- Patricia Brock
- George Cumpata
- William McLean

- Elizabeth Willmore
- Jan Schneider

NEW JEWELRY FROM PEACE UNIQUE

Designer Katie Janoch of Peace Unique Jewelry Designs has teamed up with the Fibromuscular Dysplasia Society of America to make a beautiful key chain & blue Swarovski crystal earrings. These earrings were made to compliment the "String of Beads" bracelet that was designed to help unite the people who are afflicted with FMD.

Price $17.00
Price $26.00
Price $40.00

A Portion of the Proceeds goes to FMDSA for more information visit: www.fmdsa.org

FMDSA Wish List
We are looking for volunteers to help with Grant Writing & Fundraising
Donations Needed:
- Computer, Laptop, Computer Paper, Printer Ink

Please Call us at 1-888-709-7089 or email us at admin@fmdsa.org

FMDSA is “Going Green”
Help FMDSA be more of a “Green Society”. Make sure we have your email and let us know if you want us to use it for future newsletters.
Please go to www.fmdsa.org today and fill out the form to be included in our newsletters.
FMDSA will never misdirect or sell your personal information.
2008 FMDSA Annual Board Meeting
June 21, 2008
Holiday Inn
West Lake, Ohio

Complete the form below, and mail by May 31, 2008
The registration fee includes Pre-event
gestation and snack / Event day speakers,
continental breakfast & sandwich lunch. The cost
is $40.00 per person.
Raffle will be held during the event, proceeds to
go toward FMDSA and Patient Registry.

For additional information, contact:
FMDSA
20325 Center Ridge Rd., Suite 620
Rocky River, Ohio 44116
1-216-834-2410
Toll Free: 1-888-709-7089
Web site: www.fmdsa.org

Registration Form

Contact Information:

Name of Registrant

Address- street address

City State or Province

Zip or Postal Code Country

Home Phone Work Phone

E-mail Address

Payment Information:
$40.00 x _______ Registrants
Payment Total $

Enclose check payable to FMDSA

Schedule of Events

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friday, June 20</td>
<td>Pre-registration and Social</td>
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<tr>
<td>4:00pm–6:00pm</td>
<td>Pizza will be provided</td>
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<tr>
<td>Saturday, June 21</td>
<td>Introductions: Pam Mace</td>
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<tr>
<td>8:00am–9:30am</td>
<td>Annual Meeting</td>
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<td></td>
<td>Continental Breakfast</td>
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<tr>
<td>9:30am–10:30am</td>
<td>Jeffrey Olin, DO Patient Registry Funding FMD</td>
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<tr>
<td>10:30am–11:00am</td>
<td>Break</td>
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<tr>
<td>11:00am–12:00pm</td>
<td>Nazli McDonnell, MD PhD Medical Genetics</td>
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<td>12:00PM–1:00pm</td>
<td>Lunch Provided</td>
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<tr>
<td>1:00pm–2:00pm</td>
<td>Panel Discussion with Dr. Olin &amp; Dr. McDonnell</td>
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<tr>
<td>2:00pm–2:30pm</td>
<td>Michael Ulrich, MD Mayo Health Systems</td>
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<tr>
<td>3:00 PM</td>
<td>Raffle and Social</td>
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FMDSA
Fibromuscular Dysplasia Society of America, Inc.
20325 Center Ridge Rd., Suite 620
Rocky River, Ohio 44116
Phone: 216-834-2410
Toll Free: 1-888-709-7089
www.fmdsa.org

Board of Directors: President: Pam Mace RN, Richard Gould, Susan Bell, Cheryl Golden, Dr. Doug Webster, Cheryl Bailey, Dr. Glenn Graham, Kari Ulrich RN
Not pictured: Michelle Moran, Caroline Futz-Carver