February 2009

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FMDSA 2009 Annual Board Meeting
June 13, 2009

Speakers:
Dr. Jeffery Olin, Dr. Nazli McDonnell & Dr. Heather Gornik

On February 12, FMDSA and the Cleveland Clinic Heart & Vascular Institute took part in a special live web chat offered to members of FMDSA.

Dr. Gornik along with Dr. Kim and Pamela Mace answered a variety of questions about FMD. We are pleased to announce over 65 people participated in the live chat from all around the world! Many questions were submitted prior to going live. Over 225 questions were submitted. Because of the overwhelming response another web chat will be scheduled in the future. Unfortunately because of limited time and the large amount of questions submitted not all questions were addressed, please check back on the transcripts for additional information. We would like to thank those who participated in the chat. For those of you who could not make it to the chat the transcript should be ready in two weeks.

sponsored by:

Cleveland Clinic
RARE DISEASE DAY

FMDSA will participate in a Global Rare Disease Day on February 28th, 2009. As a Rare Disease Day Partner, we will join hundreds of other patient organizations, government agencies, medical societies and companies in focusing attention on rare diseases on that day.

This will be the Second Annual Rare Disease Day. The first was observed in Europe last year and was organized by EURORDIS, the European Rare Disease Organization, and the national alliances of rare disease patient organizations in each country.

This year, EURORDIS invited NORD, the National Organization for Rare Disorders, to organize a similar observance in the United States. Activities are also being planned in some other countries. The ultimate goal is to have a global Rare Disease Day on the last day of February each year.

The theme is that rare diseases are a public health issue, affecting millions of people around the world. The hope is that Rare Disease Day will increase awareness of rare diseases, the special challenges encountered by those affected, and the need for research to develop safe, effective treatments or cures.

FMDSA invites you to write to your state governors to request that Feb. 28, 2009, be designated Rare Disease Day in the state. (A sample letter and resolution are posted on the NORD Rare Disease Day web page.)

For more information on these and other activities:

U.S. Rare Disease Day page on the NORD website: http://www.rarediseases.org/rare_disease_day/rare_disease_day_info

Global Rare Disease Day website: www.rarediseaseday.org.

FMDSA will be attending the International Stroke Conference in February!

The International Stroke Conference is a two-and-a-half-day educational forum highlighting the most recent advances in the treatment, prevention and outcomes of cerebrovascular disease and stroke.

Unfortunately because of limited funding this will be the only conference FMDSA will be able to attend in 2009. With the patient registry around the corner FMDSA is in need of funds to keep programs like (GAP) Grassroots Awareness Program & (PEP) Physician Education Program going. These programs are vital in bringing awareness to FMD.

For more information on Discovery Health & Mystery Diagnosis:

Discovery Health Channel will be featuring Pamela Mace’s story on its TV show: Mystery Diagnosis. This is a giant step in bringing awareness to FMD.

FMDSA wants to thank Pam for being courageous in sharing her battle with diagnosing FMD. Taping for Mystery Diagnosis begins in February. Mystery Diagnosis new season begins in March, watch our web site for details.

Dr. Nazli McDonnell from The National Institutes of Health is currently requesting artery pathology samples from those FMD patients who have had a carotid graft or replacement or renal graph or nephrectomy. For more information please contact Dr. McDonnell at:

Dr. Nazli McDonnell
NIA-ASTRA Unit, 5th Floor
3001 S. Hanover Street
Baltimore MD 21225
mcdonnellna@mail.nih.gov

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http://www.rarediseaseday.org/rare_disease_day_info

PEP / Physician Education Program

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**FMD Clinic**

The University of Illinois FMD Clinic is a multidisciplinary clinic based out of their Stroke Center. The clinic is staffed by the following specialties:

- **Dr. Aslam Khaja**, Stroke Institute (No Photo Available)
- **Dr. Kaylani Perumal**, Nephrology Dept. (No Photo Available)
- **Dr. James Bui**, Interventional Radiology
- **Dr. Eunice John**, Pediatrics
- **Dr. George Hoganson**, Genetics Department

For appointments contact:

Clinic Coordinator Maureen Hillmann:

- (P)312-355-3863 or (F)312-413-8215
- or email at hillmann@uic.edu

Every effort will be made to do same day office visits and radiographic imaging to accommodate patients traveling from a distance.

The clinic is located at:

University of Illinois Medical Center Outpatient Care Center
1801W. Taylor St.,
Chicago, Illinois 60612

**FMD Clinic**

Dr. Gornik started an FMD Clinic dedicated exclusively to seeing patients with FMD. The Cleveland Clinic FMD Clinic is a multidisciplinary clinic based out of their Vascular Center. Please click on the links below for more information on participating physicians:

- **Heather Gornik, MD**
  [http://my.clevelandclinic.org/staff_directory/7/Staff_6671.aspx](http://my.clevelandclinic.org/staff_directory/7/Staff_6671.aspx)

- **John Bartholomew, MD**
  [http://my.clevelandclinic.org/staff_directory/1/Staff_998.aspx](http://my.clevelandclinic.org/staff_directory/1/Staff_998.aspx)

- **Esther Kim, MD**
  [http://my.clevelandclinic.org/staff_directory/10/Staff_9319.aspx](http://my.clevelandclinic.org/staff_directory/10/Staff_9319.aspx)

- **Firas AlSolaimain, MD**
  [http://my.clevelandclinic.org/staff_directory/8/Staff_7671.aspx](http://my.clevelandclinic.org/staff_directory/8/Staff_7671.aspx)

**To make an appointment click here:**

[http://my.clevelandclinic.org/patients/appointmentsrecords/default.aspx](http://my.clevelandclinic.org/patients/appointmentsrecords/default.aspx)

**Cleveland Clinic**

1-800-223-2273
FMDSA has signed The International Patient Registry Contract!

After a lot of planning and anticipation, the FMD Registry is now ready to begin enrolling patients. In the first phase, there are nine sites that are going to participate in the registry, including seven that are in the United States. The sites are:

- Mount Sinai School of Medicine, New York, New York USA
- University of Michigan Health System, Ann Arbor, Michigan USA
- Mayo Clinic, Rochester, Minnesota USA
- Ochsner Clinic, New Orleans, LA USA
- The Cleveland Clinic Foundation, Cleveland, Ohio USA
- Dr. Thomas Zeller, Germany
- Dr. Joerg Radermacker, Netherlands
- North Central Heart Institute, South Dakota USA
- Institute of Vascular Health, Greenville South Carolina USA

Since funding to support the registry is very limited, these sites were chosen by a multidisciplinary committee because they treat a large enough number of patients with FMD and thus will be able to rapidly accumulate as much information as possible. As soon as additional monies become available, more centers will be added.

Each person agreeing to participate in the registry must first sign a consent form. The consent forms are often lengthy and detailed because they are formatted similarly to those used in clinical research. It’s important to remember that the FMD registry is a data registry only – no experimental research is being conducted. Clinical data is collected in a de-identified manner and placed into a database. Clinical data includes elements such as date of diagnosis, types of tests conducted and results of these tests, past medical history, family history, subsequent clinical events and any clinical outcomes. All of these data elements are important to determine the natural course of the disease and to determine which procedures are more effective to relieve symptoms and reduce adverse outcomes.

Since patient privacy laws were enacted in 2003, physicians must have individual patients’ consents to place data in a central registry. No names, addresses, social security numbers, or any personal information are included in the registry. Each patient is assigned a unique ID number which identifies individual patients to the treating physician. All staff involved with the registry can identify sites and patients by numbers only. Many measures are taken to secure the information including multiple firewalls, encryption codes, and de-identifiers.

Since FMD is not commonly recognized and often misdiagnosed, the only way to gather enough information to learn how to better diagnose and treat patients is to form a data registry which allows collection of many cases from multiple institutions. With large numbers of cases, physicians can create statistical models that can accurately predict which tests/procedures/medications result in the best outcomes. It often takes time to gather enough information in order to adequately analyze the results. Based upon the current number of sites involved (which is limited by the funding available to coordinate the registry), it will most likely take a year before enough data is gathered to adequately analyze.
Now you can fundraise for FMDSA with Firstgiving!

Firstgiving lets people donate to non-profits online. It’s quick, easy and safe.

**How it works:**
- You can make your own fundraising page on Firstgiving to raise money for any nonprofit organization.
- Email your page to friends, family and colleagues, who donate by credit or debit card in an easy, secure online transaction.
- Firstgiving will send all the donations to your nonprofit, minus our small transaction fee.

**Log on NOW and start raising money for FMDSA!**

http://www.firstgiving.com/

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FMDSA MEMBERS MAKE A DIFFERENCE!

Introducing FMDSA member:

**Sandi Pileggi**

Sandi made a difference in the fight against FMD by raising over $11,000 in a Pennsylvania fundraiser!

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Exciting news from Manchester, Connecticut!

**Manchester Family Dental** recently held a patient education day to present the advantages and functions of Invisalign clear braces. In addition to providing the attendees with individualized consultations, those wishing to pursue treatment were offered both financial and treatment incentives. More importantly the event kicked off the offices pledge to give a portion of each treatment to their chosen non-profit organization, FMDSA.

**Dr Bradley Daar, owner of Manchester Family Dental** will donate $200 (two hundred dollars) of every Invisalign treatment from this event and future cases, to help educate and seek a cure for Fibromuscular Dysplasia (FMD)

Dr Daar and the FMDSA have the common goal of creating an awareness campaign to aid in the proper diagnosis of the disease. Donations and grants are a necessity in order to maintain the registry, support the education effort, and allow studies to understand the causation of the disease and ultimately the cure.

The organization could not exist without the financial support of the community. Through the Invisalign program and future fund raising events Dr Daar plans to raise money and educate the community, local hospitals, and Physicians.

As an incentive for his patients to share in this effort, Dr Daar is allowing them to write a check for $200.00 (two hundred dollars) directly to the FMDSA as a portion of their payment towards Invisalign treatment. By doing so they can reap the benefits of a $200.00 tax break and help a worthy cause.

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Log on to [www.drdaar.com](http://www.drdaar.com) to keep updated on future fundraising efforts and how you can help the cause.
You are invited to participate in a Study:

**Fibromuscular Dysplasia: Quality of Life for People with a Poorly Studied Chronic Illness**

At the end of February, people with fmd will have the opportunity to participate in the study entitled “Fibromuscular Dysplasia: Quality of Life for People with a Poorly Studied Chronic Illness.”

**Alaina Murley** will be conducting research as part of the requirements to earn her master’s degree in nursing this June. She hopes to identify issues and emphasize the need for support and education for patients with fmd.

FMDSA will be cooperating in the study by supplying a link to a website where participants will fill out an online questionnaire. If you wish to participate in the study, please watch for the survey posting on FMDSA’s website.

**FMD Patient from Australia participates in NIH Study!**

Bronte, Australian native travelled all the way to Baltimore to participate in the Connective Tissue Study at NIH. Hats off to Bronte for participating!

**Board of Directors**

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Richard Gould - Treasurer
Cheryl Bailey - Secretary
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Glenn Graham, MD- Executive Committee
Cheryl Golden, CPA- Board of Directors
Caroline Fultz-Carver, PhD- Board of Directors
Kari Ulrich, RN- Board of Directors
Office Manager:
Kim Blakemore

**FMDSA Wish List:**
We are looking for volunteers with experience in Grant Writing & Fundraising
Donations Needed: MacBook Pro Laptop, All in One Printer, Scanner, Fax, Computer Paper & Printer Ink