**Working towards better diagnosis and treatment of Fibromuscular Dysplasia**

**FMDSA PATIENT REGISTRY**

The FMD Patient Registry is solely funded by FMDSA at a cost greater than $40,000 a year. To date we have spent close to $200,000 on this project. The registry is ongoing, and we need your support to continue funding it.

For the past two years data from the registry has been released and the findings have caught the attention of the medical community and researchers. To date over 700 patients have enrolled in the registry and we have 12 participating centers. To be evaluated at one of the centers, please contact them directly, [click here](#) for more information.

As long as we can continue to [fund](#) the registry we will continue to learn, and find answers.

**Thank you** to the FMD patients who have participated and to those who donate, together we can make a difference.

**6TH FMDSA Annual Meeting**

**May 17-18, 2013**

**Cleveland, Ohio**

Registration and a welcome reception will be held the evening of May 17th and the Conference will start early morning on May 18th at the Wyndham Cleveland Playhouse Square Hotel in Cleveland, OH. Our speakers will discuss the latest Fibromuscular Dysplasia patient registry finding's and other related topics. Following our speakers there will be a panel discussion where everyone will have the opportunity to ask questions.

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Confirmed speakers include:

Dr Jeffrey Olin, Mount Sinai, NY  Update from the FMD Patient Registry; Dr Jacqueline Saw, Vancouver General Hospital  Sudden Coronary Artery Dissection and Fibromuscular Dysplasia; Emma Greenwood, Founder Whooshers.com, New York, NY; Dr Heather Gornik, Cleveland Clinic, Ohio; Dr John Angle, University of Virginia  Radiation dose exposure and implications. Additional speakers to be announced.

To register for the 6th Annual Meeting, click here

To book your hotel room please contact the Wyndham Hotel directly and mention FMDSA to receive the discounted hotel rate of $109.00 216-615-7500.

FMDSA Appreciates the Generous Contributions of the Annual Meeting Sponsors.

The 2013 Platinum level sponsors to date include:

The 2013 Silver level sponsor includes:

FMDSA is still seeking sponsorship for our 6th Annual Meeting, donations are tax-deductible.

Sponsorship levels available:

2013 Cleveland Marathon

FMDSA is an Official Charity of the 2013 Cleveland Marathon

Once again our annual meeting coincides with the running of the Cleveland Marathon. In the past this was merely an additional distraction to our event. This year we are going to be highly involved in the race and spreading awareness for our cause.

We will be setting up a water station along the course, to hand out water bottles to the runners. Our area will be well labeled and give us a good opportunity for exposure in the community. We are looking for 25 volunteers for this event, on Sunday, the day after the annual meeting.

Those interested need to contact Tammy Porter at tammyporter@fmdsa.org. If you are looking for more information on the race, go to clevelandmarathon.com for information.

To further put our organization in the spotlight, we are putting together teams of runners and walkers to participate in the marathon, half marathon, 10K, 5K, and kids run. People involved in this event may ask their friends, families, and co-workers to sponsor them with donations. When signing up to register for the marathon you can use the following codes:

- FDS3HALF for the half marathon
- FDS3Track for the 10K and 5K

These codes are then entered into the "coupon code" section of the allocation form. For those of you in town for the event, this is a great way to help our organization. We are looking forward to seeing you out there!!

We would like to encourage our runners to create a firstgiving fundraising page, it's fast, easy and secure. Create your page here!
PLATINUM - $5,000.00 or more
GOLD - $2,500.00 or more
SILVER - $1,000.00 or more
BRONZE - $ 500.00 or more

Please consider helping our patients and us by supporting our event.

Two free registrations are included with the platinum, gold and silver levels of sponsorship, and we encourage you or any of your staff to attend as this will be a very informative meeting. FMDSA will also recognize your contribution in our event program and on our web site.

For more information on sponsorship, please contact: Pamela Mace, RN, Executive Director FMDSA @ pam.mace@fmdsa.org or call the FMDSA office.

CLEVELAND CLINIC ART TOUR

The Cleveland Clinic Art Tour has been set for the morning of the 17th of May. This is a 1-1/2 hour tour. If you are interested, please contact maureen.womack@fmdsa.org to register, space is limited. The tour is free. Following the tour we will stop at the Vascular Department and see Dr. Gornik and D.r Kim. Transportation available via shuttle from the Hotel to the Cleveland Clinic. The Wyndham Shuttle will provide service to the Cleveland Clinic during the annual conference week. For guests who have specific appointment times at the clinic, shuttle reservations are recommended to ensure that the appointments are kept in a timely fashion. Shuttle reservations are taken 24/7 and can be arranged up to one-month in advance. Call the hotel directly at 216-615-7500.

Whooshers.com
Learn more at the 2013 FMDSA 6th Annual Conference

People who experience pulsatile tinnitus (a.k.a. "whooshing") hear a sound that whooshes, pulses, clicks, screeches or makes another rhythmic sound. Sometimes others can hear it (objective pulsatile
tinnitus) and sometimes only the patient can hear it (subjective pulsatile tinnitus). The key that distinguishes a pulsatile tinnitus sound from a regular, far more common tinnitus sound is that it is in constant sync with the heartbeat.

This year we are proud to announce that Emma Greenwood, Founder of whooshers.com will be speaking at the 2013 FMDSA meeting in Cleveland Ohio. We welcome Emma and are looking forward to learning more about whooshes.com.

**FMDSA Memsaic Wall Fundraiser**

**SUPPORT FMDSA...BUY A BRICK!**

WE STILL HAVE A FEW BRICKS AVAILABLE to purchase on our Memsaic Wall where you can post your picture, the picture of a loved one or post a message for other FMD patients to see. The bricks are only $15 each and you can buy more than one, only 210 bricks will be sold. Help us to build a Beautiful FMD Wall, while supporting our programs. It's fast and easy.

As you scroll across each brick, you can see who has purchased the bricks.

To be directed to the fundraising page, click here.

**Rare Disease Day USA**

**Alone we are rare.**

**Together we are strong!**

The last day of February each year is the celebrated date of Rare Disease Day throughout the world.

This year it fell on February 28th. If you are reading this article, you are more than familiar with the fact that FMD is classified by many as a rare disease.

Throughout the United States, and the world, persons of all persuasions recognized their various rare diseases in many
ways. The challenge we face not only on this special day each year, but every day, is to spread awareness. Only through education of the public and the medical community can the battle against these illnesses be fought effectively.

Many of you know that feeling of isolation and fear upon being beset with symptoms of illness that are debilitating, yet Doctors can’t put a name on it. Then when they do tag it as Fibromuscular Dysplasia (FMD, you are no more comforted, as there seems to be no one else with neither the illness nor anyone to treat it. Our organization (FMDSA.org) has grown exponentially since its inception and it continues to be a presence on many continents helping patients to feel that they are not alone. In addition, this worldwide effort aids in determining treatment modalities and giving Doctors a better chance and diagnosing FMD.

This year’s theme “Rare Disorders without Borders” exemplifies the need for reaching out to people throughout the world to let them know that they are not alone. There are over 6000 rare diseases recognized throughout the United States and Europe alone. The purpose of this and every rare disease day is for patients, Doctors, family members and friends of those with a disease, to create awareness in their own way.

Whether it is a fundraiser, or simply spreading the word to your community, awareness is the goal. If you were not involved this year, you now have an entire year to plan your event or activity to let everyone know about FMD. If you would like some ideas, and more information about Rare Disease day you can check out the website RAREDISEASEDAY.US.

Knowledge is power. By creating awareness and recognition of a disease it can more effectively be battled. Through information gained from as many patients as possible we can learn much more about its origin and how to treat it. Our patient Registry does just that by collecting data on patients at centers throughout the country. This international campaign of awareness stresses the importance of reaching out to all those afflicted with FMD not only in the US but on every continent. The last few years of research have shown that FMD may not be as rare as previously determined. Only through campaigns such as Rare Disease Day can the world be better educated on diagnosis and treatment of the disease.

We all play a small part in this education, but our single efforts add up to a worldwide effort to combat a rare disease.

A Message from NORD
The 30 million Americans who have one or more rare diseases are concerned that cuts in the budgets of NIH and
FDA will delay medical progress and the availability of new treatments. The research done at NIH and the regulatory oversight at FDA are essential government functions that need to be fully funded. Even temporary cutbacks will adversely affect our patient community. While we support the need for careful budget controls, medical research and regulation deserve exceptions from cuts that will be severely detrimental to people with rare diseases. Follow the link below to let Congress know your personnel story and ask them to stop budget cuts for medical research! [http://www.capwiz.com/rarediseases/issues/alert/?alertid=62248156](http://www.capwiz.com/rarediseases/issues/alert/?alertid=62248156)

**Patients United 2013**

**Spring fundraiser**

It is that time of year again when we are looking forward to our spring fundraiser "Patients United".

To date we have had 10 States participate in this event. Our hope is to one day have all 50 States participate!

The event is held during the months of March, April and May. Individuals can have an event, or groups can work on one together. Events have been large or small in size. Whatever the size, every dollar raised for FMDSA helps us to continue to support the FMD Patient Registry **funded solely by FMDSA**.

If you are a group leader or member of an FMDSA support group, perhaps your group might want to jointly work on a fundraiser. Or... if you are an individual member and have not yet met others with FMD, this might be a great way to reach out to someone and work on a fundraiser together.

For information on participating in Patients United, or if you have any questions, please contact Maureen Womack at [maureen.womack@fmdsa.org](mailto:maureen.womack@fmdsa.org).

Let's make this the most successful fundraising year yet!

**Support Group Leaders**

**FMDSA Welcomes Our Newest Support Group Leaders**

The FMDSA would like to welcome three new Support Group Leaders in the states of South Carolina, Washington and Nevada. Welcome Diane, Susie and Barbara. Watch for our “Support Group” posts on inspire.com and facebook.com for dates on group meetings and FMDSA fundraisers in your area.

Teresa Seim

{ *= recurring monthly donations}

**FMDSA Amazon Wish List**

A special thank you to all who have donated through our Amazon Wish list. **Please note:** when we receive a donation, **we do not always know who made the donation.** We appreciate the support and want to acknowledge your donation, and we are working with Amazon to resolve this issue so please while we work out the details, **send an e-mail to kim.blakemore@fmdsa.org advising us of your donation.** These donations are very valuable to our day to day operations and allow us to focus on our other programs. **THANK YOU** again for supporting our mission!

Kim Blakemore, Office Manager

To donate with an Amazon Wish List item... 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 ships it to FMDSA. It's that simple.

Thank you again 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.

**Spreading the Word**
state.

Contact your support group leader by email via: http://www.fmdsa.org/patient_support/support_groups

**DIANE DUMIT:** Diane is a lifetime resident of the state of South Carolina and has lived Greenville for 31 years.

She has worked in the travel industry in sales, marketing, and account management for over 20 years, retiring in 2010. She has experience in meeting/event planning and has been active in various charitable organizations.

Diane was diagnosed with FMD in 2001 at age 39. Initially, the diagnoses was bilateral carotid and right renal FMD, then, in 2009, FMD of the Superior Mesenteric Artery. Since inception, the FMDSA has been a great source of information and support in the management of the disease. Diane began the South Carolina group to help provide support to patients in her area. In addition Greenville Hospital System's Vascular Alliance is one of the 12 patient registries for the FMDSA.

**SUSIE GOLDSMITH:** Susie was diagnosed with FMD in late 2008 and had a renal artery bypass in 2010 after being unable to control her blood pressure with medication and several angioplasties. Susie has been a health care advocate for her entire career. She has an MSW degree and has been licensed as a clinical social worker since 1980 in Oregon now in Washington. She also is a nationally Board Certified Diplomate in Clinical Social Work. She pioneered the field of private geriatric and long-term care management in 1979 as a social worker/Trust Officer with US Bank, managing special needs clients, one of four bank social workers in the nation working with trust clients. She then owned a private geriatric care management firm for around 20 years. She’s served on the National and Western Regional Board of the National Association of Professional Geriatric Care Managers, now boasting 2,000 members.

In 1996, Susie bought a beautiful B&B in historic Long Beach, Washington. She moved there from her home in Portland to be an innkeeper with her sweetheart, Bill Verner. Following her renal bypass in 2010, she was recruited by the DaVita Dialysis Center in Long Beach, WA to be their clinical social worker. Susie developed an acute awareness of the

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**Inspire FMD Support Group Page**

The Inspire FMD Support Group Page, to date, has nearly 400 members participating. We have added discussion topics so that you can go right to your area of interest.


**FACEBOOK**

Have you "LIKED" our Facebook page yet? To date, over 589 members have!!!

Please visit us at: https://www.facebook.com/pages/Fibromuscular-Dysplasia-Society-of-America/259831044055679

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**Cafe Press**

Spread awareness of FMD and support our research fund!

Please visit our Café Press store to make a purchase for yourself or others. Our Café Press store has recently been updated and includes over 60 products with our current FMDSA logo! You will find men’s, women’s and children’s apparel, drink ware, bags, pins and much more on the Café Press site.

All money raised assists the research efforts for FMDSA and assists in spreading awareness. When you wear or use these items with our logos you are helping to raise awareness and maybe even initiate a discussion about fibromuscular dysplasia. Check out our site today!

If you have any questions or suggestions for our FMDSA Cafe Press Store please contact Kelly Seifried at pedsobrn@gmail.com
importance of kidneys since her FMD diagnosis and now advocates for dialysis patients on a local and national level.

BARBARA ANNE MCFEE: Barbara is a retired Registered Nurse with a Master’s degree in Administration and Deputy/Sheriff Coroner. She lives in Las Vegas, Nevada.

Barbara’s career encompassed acute care nursing and occupational nursing (COHN) and she was the Chief RN at the Nevada Test Site where underground nuclear testing is done for the United States.

She was diagnosed with renal artery FMD in 2005 and since then has had three angioplasties, a renal stent, an angiogram and is on several anti-hypertensive medications.

Her research of FMD, treatment and future advances (renal denervation) is ongoing. “I think all patients with FMD have a responsibility to learn, collect information on this rare disease to help others and ourselves. Education of health care professionals and being an advocate for FMD is crucial to FMD patients having appropriate treatment and hopefully leading to etiology and thus providing an earlier diagnosis for patients. I welcome the opportunity to meet with and share experiences with other FMD patients in the great state of Nevada.”

Medical Advisory Board.

FMDSA welcomes our newest additions to the FMDSA Medical Advisory Board

Bruce Gray, DO
Vascular Medicine,
Greenville Hospital System
Greenville, South Carolina


**FMDSA Celebrates 10 years**

**Our Greatest Accomplishment**

"As we celebrate our 10 year anniversary, FMDSA continues to grow and succeed far beyond our expectations. One of our greatest accomplishments is funding the United States Registry for Fibromuscular Dysplasia (FMD).

FMD was first diagnosed in 1938. To this day, the medical industry does not have protocols for treating this disease, nor is there a known cause or cure. The FMD registry has already produced new data with over 700 patients enrolled and 12 Centers participating. Last year, the most up to date findings from the registry were published in Circulation, The Journal of the American Heart Association "The United States Registry for Fibromuscular Dysplasia: Results in the First 447 Patients". This year we expect more data to be released as we continue to learn from the registry. As the data is analyzed, we all dream of the day that treatment protocols are established.

To help fund the United States Registry for Fibromuscular Dysplasia, we have created the FMDSA "Circle of Friends". The FMDSA Circle of Friends is a group of committed benefactors with an interest in supporting the patient registry. By making a gift or pledge of $5,000 or more annually, you can help FMDSA ensure that the registry continues. Without the registry, we are just a group
of patients. With the registry, we are a voice that has gotten the attention of the medical community. You can be a part of something great while making a difference in the lives of patients, not only today, but for generations to come. For many of our members, their daily activities of living are affected and they do not have the ability or means to give. It takes special individuals like you to help make a difference.

FMDSA has made substantial progress in raising awareness of this disease and educating medical professionals over the last decade as evidenced by the increasing number of patients that are newly diagnosed. We need your help to continue to be a voice! To learn more about the FMDSA Circle of Friends, please contact Pam Mace at pam.mace@fmdsa.org

Please visit our website at www.fmdsa.org.