

Connective Issues

Heartworks Gala Photos Inside

National Marfan Foundation: Education, Research and Support for the Marfan Community

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NMF Receives \$45,000 from Chase Community Giving

Chase Community Giving started out with hundreds of thousands of charities, and people on Facebook voted to narrow the field down to the top 100 which each won \$25,000 in Round 1. In Round 2, voters again determined the outcome, with the top 25 charities winning grants of \$20,000 to \$500,000.

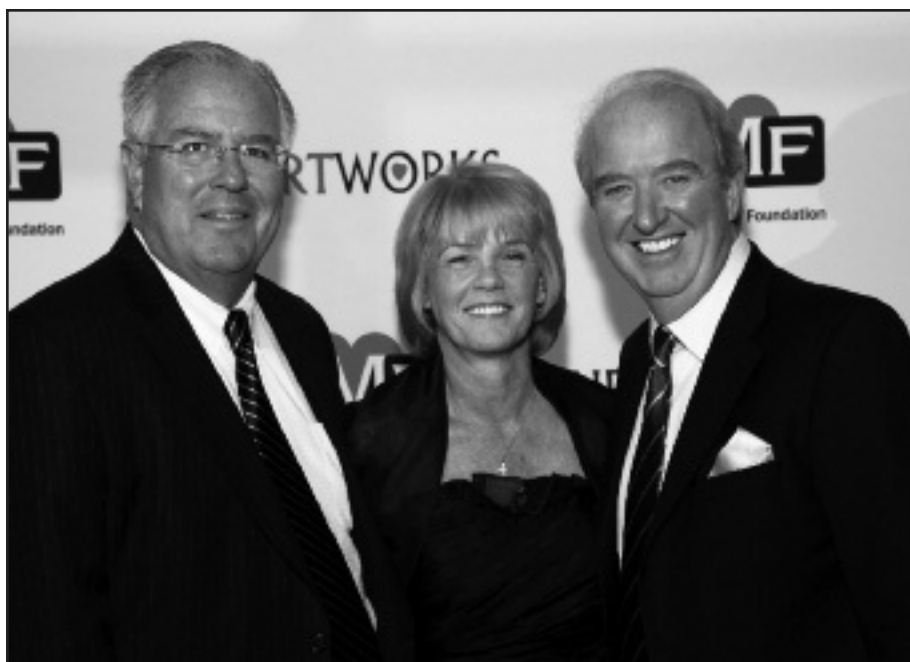
Thanks to the tremendous support of the Marfan syndrome and related disorders community, the NMF finished in the top 100 (#28) in Round 1, resulting in a \$25,000 grant. The Foundation has earmarked these funds to support the 27th Annual Conference in Portland, OR.

In Round 2, the Marfan community ramped up its efforts to win even more funding for the NMF's life-saving programs. When voting ended on May 25, the NMF finished #22, good for an additional \$20,000 grant.

The NMF did not do it alone. The Foundation had support from a variety of places including the local media; other nonprofit organizations, such as the Loeys-Dietz Syndrome Foundation and Ehler Danlos Syndrome Network C.A.R.E.S.;

Continues on page 21

Heartworks Galas Show Commitment to the Marfan Community



The 11th Annual Heartworks gala in New York City, held on April 7, the 3rd Annual Heartworks St. Louis, held February 26, and the 4th Annual Heartworks Westchester on May 14 demonstrated again this year the passionate dedication of so many people to advancing the mission of the NMF and helping people with Marfan syndrome and related disorders.

The New York City event, again held at Cipriani 42nd Street, continues to combine the excitement provided by high profile speakers with the heartfelt powerful stories of NMF members. Adding to the sparkle of the evening, Broadway star Megan Hilty (*9 to 5*, *Wicked*) performed.

Nearly \$1 million was raised for the NMF through sponsorships and ticket sales, as well as through the silent auction,

Continues on page 22;

more photos on pages 12-13

Gala Dinner Chairs Susan Falco, NMF Board member, and Michael Weamer, Executive Vice President, American Heart Association (left), with NMF Board member Steve Crombe.

Dates & Deadlines

July

July 14-17	NMF 27th Annual Conference, Portland, OR Contact: Maggie Hogan, 800-8-MARFAN, ext. 38 or mhogan@marfan.org
July 22	13th Annual JAFGO Golf Outing Mill Pond Golf & Catering, Medford, NY Contact: Glenn Stidham, 631-676-6706
July 23	New Hampshire/Vermont Marfan Network Group Meeting Dartmouth Hitchcock Medical Center, Lebanon, NH, 2pm Contact: Rene Jones, 603-769-1263; coordinator@nhvtmarfan.org
July 23	3rd Annual Jonathan Superman Pawell Fundraiser Morabito Community Center, Cortlandt Manor, NY Contact: Todd and Marisa Pawell, 914-528-9054
July 29	Heart of Iowa Chapter 4th Annual Moonlight Stroll The Shores, Pleasant Hill, IA Contact: Teri Dean, 515-371-5633; tkdean11@q.com
July 30	Heart of Iowa Chapter's 11th Annual Have Heart for Marfan Walk/Fun Run, Pleasant Hill, IA Contact: Teri Dean, 515-371-5633; tkdean11@q.com
	Chapter Quarterly Financial Form and Year-End Summary Due

September

Sept. 9	Mid-Atlantic Chapter 2nd Annual Golf Tournament South Riding Golf Club, South Riding, VA Contact: Rob or Kelly Berklite, rberklite@verizon.net; 571-345-6480
Sept. 10	New Hampshire/Vermont Marfan Network Group Meeting Dartmouth Hitchcock Medical Center, Lebanon, NH, 2 pm, Contact: Rene Jones, 603-769-1263; coordinator@nhvtmarfan.org
Sept. 14	Annual Heart of Iowa Chapter Social Event (Rain Date September 24); Corn Maze, Geisler Farms, Bondurant, IA Contact: Teri Dean, 515-371-5633; tkdean11@q.com
Sept. 24	Massachusetts Chapter Annual Get Together, Winthrop, MA, 1-5pm Contact: Jon Rodis, 617-846-4975; jmarfan58@aol.com

October

October 22	Annual New England Marfan Syndrome and Related Disorders Symposium Dartmouth Hitchcock Medical Center, Lebanon, NH, 9am-4pm Contact: Rene Jones, 603-769-1263; coordinator@nhvtmarfan.org
October 8	Northeast Indiana Network Group Meeting Parkview Women's Health Center, Fort Wayne, IN, 1pm Contact: Ellen England, 260-925-4041; eeengland@gmail.com
Oct. 8-9	Heart of Iowa Chapter Marfan Corn Maze Weekend Geisler Farms, Bondurant, IA Contact: Teri Dean, 515-371-5633; tkdean11@q.com

For more details about upcoming events and meetings, be sure to check the NMF Calendar on our website, www.marfan.org.

Thank you to photographer Tim Joyce, of Cape May, NJ, for his ongoing dedication and commitment to the NMF (www.timjoyce.com).



National Marfan Foundation • 1981-2011

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Register Now for the 27th Annual Conference on Marfan Syndrome and Related Disorders

There's still time to register for the 27th Annual Conference in Portland, OR, July 14–17. The conference is being co-hosted by Shriners Hospitals for Children and the Oregon Health & Science University. The program truly has something for people of every age—those who are affected and those who are the family member or loved one of someone who is affected.

For full conference details and online registration, visit the NMF web site at www.marfan.org.

Early Bird discount registration and registration for children and teens end on June 13. Adults may continue to register after June 13; on-site registration is also available for adults, but pre-registration is preferred.

“It’s been 18 years since our annual conference was in Portland. Since then, the NMF annual conference has expanded exponentially, and we are thrilled to work with our Professional Advisory Board member Lynn Sakai, PhD, to bring the excitement back to the Pacific Northwest,” said Carolyn Levering, NMF President and CEO.

Adult Program

The adult program includes a general session with topics in orthopedics, cardiology and cardiac surgery, ophthalmology, pulmonary issues and pain management, as well as more than 50 medical and psychosocial workshops.

CONFERENCE AT-A-GLANCE (Subject to Change)	
Friday, July 15	
12 noon	Registration Opens
4:00 – 4:45 PM	Orientation for First-Time Attendees
5:30 – 7:00 PM	Welcome Reception
Saturday, July 16	
8:30 AM – 12:15 PM	General Session
12:30 – 2:15 PM	Awards Lunch
2:30 – 6:00 PM	Medical Workshops
Sunday, July 17	
8:30 AM – 12:45 PM	Psychosocial Workshops
1:00 – 3:00 PM	Farewell Lunch and Living Successfully Program

Conference Programs for Children and Teens

The weekend features special programs and fun activities for children (ages 5–12) and teens (ages 13–19). This year’s children’s program includes a day-long field trip to the Oregon Museum of Science

and Industry and the Oregon Zoo as well as a class with staff from the Northwest Children’s Theater and School. Teens will enjoy a river trip aboard the Willamette Star, a talent show and dedicated workshop sessions on heart health, related disorders, genetics and other age-specific topics.



National Marfan Foundation
27TH ANNUAL CONFERENCE
JULY 14–17, 2011
PORTLAND, OR



HOSTED BY SHRINERS HOSPITALS FOR CHILDREN AND OREGON HEALTH & SCIENCE UNIVERSITY



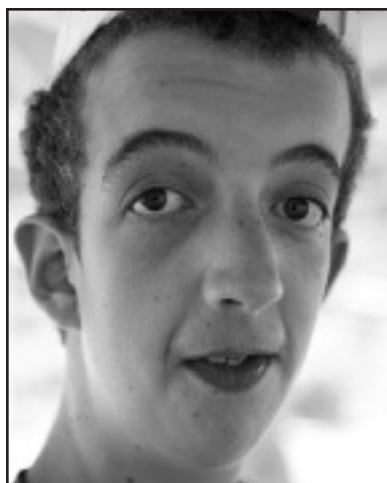
Lynn Sakai, PhD (seated), with Allison Gregory, genetic counselor, OHSU, and Victor D. Menashe, MD, Professor of Pediatric Cardiology, OHSU.

New Young Adult Program

The Portland conference kicks off the new Young Adults program for ages 19–30. Conference participants in this age group have the opportunity to register for a special workshop track just for them, a group trip to Portland’s well-known Powell’s Bookstore and Café, and a river cruise aboard the Portland Spirit.

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In The Eyes of Our Members: A 30 Year Perspective



The NMF provided relief for my family when I was diagnosed with Loeys-Dietz in 2006. They helped provide the guidance we needed to adjust to this diagnosis. The NMF's Massachusetts Chapter helped us find doctors and kept us up-to-date on the NMF world.

For me, the NMF has become a great place to meet new people with the same disorder and the same problems. Conference is the best part of the NMF because it's where you can go and not feel alone. People get to express

themselves in ways they might not be able to back at home.

Without the NMF, I would not be who I am today. I would probably be scared not knowing who to go to and what is going to happen next. I would not be an inspiration to other people or as outgoing as I am now. I wouldn't have the same outlook on life as I do now. Thank you NMF for helping me, my family and friends get through this. You have made it 30 years and you're going to make it another 30. Happy Birthday, NMF!

– Peter Donato, 16, Framingham, MA

I was diagnosed in 1959 after completing kindergarten. Thanks to the material and knowledge I gained from the first NMF conference I attended in 1987, when I was 34, I started my drive to enlighten others. A colleague of mine, a registered nurse who taught in the nursing program at Salem State College, had never heard of Marfan syndrome until she met me. Using the material I got from the conference, we wrote a thesis that she could use in her curriculum.



In 1988, I went to the conference in Baltimore and continued to increase my knowledge. When I went to the 1989 conference in L.A., I talked to an orthopedist and found out I needed to see a doctor as soon as I got home for my scoliosis. The following June, I was in New England Medical Center for a month due to an anterior and posterior spinal fusion. Every morning I would have a different group of residents come in on rounds. They would get a crash course on Marfan from me.

Since then, I have been committed to informing the medical community about Marfan syndrome through my experience. I would not be able to do this without the knowledge and support I have received from the NMF. I know what it was like when I was young, when doctors did not know about Marfan syndrome. I remember what it was like—not knowing what was going on with my body—and I don't want anyone else to have to go through that, especially with all that is known about Marfan syndrome today. Through the NMF, I am doing my part.

– Kaddie Ackroyd, 57, NH

A Look at Some of the NMF's Accomplishments



- The NMF has provided approximately \$10 million as part of its research program, funding grants, fellowships and symposia, and is now supporting a critical clinical trial that is being funded by the National Heart, Lung, and Blood Institute and conducted by the Pediatric Heart Network.
- The Foundation has a comprehensive support network, including a toll-free Information Resource Center, 52 chapters and support groups nationwide, and its own on-line social network, NMFconnect. It also holds an annual conference where affected people and their families can learn from experts in the field.
- The Foundation's education and awareness efforts among the medical community and the general public have led to better diagnosis of affected people. This has enabled people to get the treatment they need to avoid a sudden early death from a tear or rupture of their aorta, the large artery that takes blood away from the heart. Most recently, the NMF launched www.MarfanDX.org, a mobile website for smartphones that puts the diagnosis criteria directly into the hands of doctors, thus facilitating diagnosis for people with Marfan syndrome and overlapping conditions (see page 6 for details).

NMF Annual Membership Drive Kicks Off

A True Story of Membership and Friendship



Janice McCarthy

When doctors suspected that Janice McCarthy's 18-year-old daughter might have Marfan syndrome, she didn't know where to turn. Her search for information led her to the NMF website and to Catherine, an NMF member who ran support groups in her area. Catherine assured Janice that there was a strong sense of community around this syndrome, and that help, information and compassion in abundance were all available.

Catherine answered many questions and educated Janice about Marfan syndrome. Determined to put up a strong fight for her daughter, Janice went with Catherine to the 2006 NMF Conference in Philadelphia.

"Attending the NMF Conference was a blessing," said Janice, "The educational opportunities certainly increased my knowledge of Marfan syndrome and options for evaluation and treatment. I was deeply touched by the people I met and my experience at the conference."

At Catherine's urging, both Janice and her daughter decided to be evaluated by Dr. Reed Pyeritz, one of the NMF Professional Advisory Board members.

"We were both diagnosed with MASS Phenotype, a related disorder. I am forever grateful to Catherine and the NMF for the difference both made in my life," said Janice.

This story encapsulates what's so amazing about NMF membership. Being a member connects you to a strong community—people who truly understand—along with a treasure trove of resources.

How Membership Fuels the NMF

A lot of the progress we've made in the last 30 years has come about because our members found each other. The activism of our members has helped changed the course of history of this disorder.

In many ways, it has all been leading up to this moment. We have just reached the enrollment goal for a major clinical trial and are optimistic about potential breakthroughs in science that could open the door for new potential therapies.

For the first time, we now have the capability to reach every emergency department doctor in America with information about how to differentiate a patient with Marfan syndrome undergoing aortic dissection from patients having a heart attack—and what to do to save a life.

And with modern social networking, we are doing all we can to make sure that every person in this country—in the world—has information at their fingertips about Marfan syndrome and related disorders.

Now's The Time: Become a Soldier for our Cause

Our goal is to raise \$175,000 from this year's membership campaign—so we need each and every one of you to join or renew. At the very moment when the NMF can do more than ever before, we're also facing enormous financial pressures related to the continuing economic slump.

Our annual drive is so important because Marfan syndrome and related disorders are more common than most people think. Through our day-to-day work, the NMF has a tremendous impact on the lives of so many people.

Our members know that when it comes to comforting individuals and families dealing with Marfan syndrome and related disorders, to providing information that saves lives, to funding the cutting edge research that leads to big breakthroughs down the road, the NMF is the only organization to turn to.

With government and foundation sources cutting back dramatically, we need to increase the number of NMF members now, more than ever. Participation is key. **Every member makes a difference.**

To learn more about becoming a member visit www.marfan.org, call 800-8-MARFAN or email staff@marfan.org

NMF Launches Mobile Site to Put Diagnosis of Marfan Syndrome and Related Disorders Directly into the Hands of Physicians

This Spring, the NMF launched a new mobile site—www. MarfanDX.org—to facilitate diagnosis of Marfan syndrome and related disorders. The site content is based on the new diagnostic criteria for Marfan syndrome that were published last year in the *Journal of Medical Genetics*. The site is compatible with Droid and iPhone smartphones.

“The new mobile site is an innovative use of new technology for doctors who are concerned about the possibility of underlying Marfan syndrome or a related connective tissue disorder,” said Mary Roman, MD, Professor of Medicine, Weill Cornell Medical College, and a member of the NMF Board of Directors. “Marfan syndrome is a condition that has a varied expression and requires a multi-system clinical examination for diagnosis. The revised criteria simplifies the complex process for diagnosis and provides insights into the diagnosis for conditions with overlapping features. The NMF’s new mobile site facilitates instantaneous access to diagnostic criteria for Marfan syndrome and provides diagnosis and management information for related disorders. This is a real benefit for busy doctors.”

Features of the Mobile Site

According to a study conducted last year by Manhattan Research, a full 72 percent of U.S. physicians now use smartphones, and the number is expected to jump to more than 80 percent by 2012.

“With so many physicians utilizing smartphone technology,” says Dr. Roman, “it makes sense to provide a resource that is compatible with the latest trends.”

“The NMF’s new mobile site facilitates instantaneous access to diagnostic criteria for Marfan syndrome.... This is a real benefit for busy doctors.”

The mobile site features a summary of the new diagnostic criteria, including seven simple formulae for diagnosing Marfan syndrome. Expandable text provides a detailed explanation of each formula. The site also features:

- Interactive Systemic Score Calculator used to consider the lesser characteristics of Marfan syndrome that can be key in making the diagnosis. This too has expandable text and graphics, as well as the ability to email results for the patient file.
- Interactive Z-score calculator, used to determine the size of the aorta compared to body surface area. This can also be emailed for the patient file.
- Key points about the role of genetic testing and family history.
- Important information on differential diagnosis and related disorders.
- Helpful links and resources.



The mobile site is also viewable on a desktop computer; it is compatible with Safari and Firefox browsers.

The NMF is promoting the mobile site to healthcare providers in numerous ways.

“We are promoting MarfanDX through exhibits at medical conferences, targeted email marketing, and print ads in key medical journals which will include a QR code (short for Quick Response) so users can load the site onto their phone by scanning the code,” said Jonathan Martin, NMF Director of Education and Awareness.

“Once the link to MarfanDX.org is saved on their smartphone home screen or bookmarked, the diagnostic criteria for Marfan syndrome are never more than a tap away.”

You can scan the QR code on this page with your smartphone to open MarfanDX on your phone (a free scanner is available from your phone’s App store).

This mobile website was supported by the CDC Cooperative Agreement Number 1H75DD000703-01. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.



Retinal Detachment in Marfan Syndrome

A detached retina is one of the potential eye problems in Marfan syndrome. Retinal detachments consist of separation of the retina from its underlying layers. Such separations may be partial or complete and may occur in all parts of the eye. They typically originate in the far periphery away from the macula or the area of sharpest vision in the back center of the eye. This separation is a medical emergency and requires rapid attention.

Suzanne Kouri, NMF member from Lexington, MA, knew little about retinal detachments until one was diagnosed in her 10-year-old son Yamil last fall. She knew that Yamil, who has Marfan syndrome, was at risk of a retinal detachment, particularly after head trauma, and had talked to her son, as well as his teachers, the school nurse and his friends' parents, about informing her immediately if there was ever any head trauma. Yamil was also instructed to let an adult know if he saw the "black veil" or "raining of lights" typically associated with a detached retina or, of course, if he had any pain after a blow to the head.

Yamil did not report any of these features, which is not surprising as patients between the ages of 5 and 15 typically do not realize that there is a problem when their retina detaches. Like other children who have a detached retina, Yamil had one relatively good eye to compensate and was unaware of the problem in the other eye. The detachment was diagnosed during a routine eye examination.

Once a detachment is suspected or detected, time to treatment is very critical. It is vital to get to surgery as soon as possible and particularly before the area including the macula is detached.

"I wish I had taught Yamil the simple habit of covering each eye and checking for visual changes in each eye on a weekly basis," said Suzanne. "We are fortunate to have had the retinal detachment discovered before it was too late to operate with optimal results."

In people with Marfan syndrome, the combination of severe myopia and subluxated (dislocated) lenses increases the risk of a spontaneous retinal detachment. Similarly, the presence of a retinal detachment in one eye or in family members with Marfan syndrome increases the risk. Immediate treatment is recommended: the longer the wait, the greater the chance that the retinal detachment will become more severe or even total. The more severe the detachment, the more complicated is the surgery and the less vision may be recovered. Any surgery has its risks; however, an untreated retinal detachment usually results in permanent, severe vision loss or blindness.

Here are important questions to ask the eye surgeon about repairing the detachment:



Yamil Kouri

- How much of the retina is detached and does this include the macula?
- What are the different procedures for reattaching the retina and how will we know if it works?
- What is the recovery period?
- Will normal vision return?

"Visual impairment, while not life threatening like an aortic dissection, has profound impact on the quality of life and learning," said Suzanne. "Our retinal surgeon is now an important part of Yamil's health care team."

Following a retinal detachment and surgery to repair it, regular retinal evaluations are just as important as your echocardiograms that evaluate your aorta. Talk to your doctor about the long-term schedule for evaluations, criteria for wearing protective eye wear, and lifestyle changes that may need to be considered.

For more information about eye issues, click on Living with Marfan Syndrome on the NMF website, www.marfan.org.

MedQuest: The Marfan Lung

People with Marfan syndrome are usually most focused on problems related to the heart and blood vessels, eyes and bones. In many people with the condition, the lungs are also affected. If you are experiencing any breathing problems or are being treated for any type of pulmonary (lung) problem, it is important to make sure that your doctor knows that you have Marfan syndrome. Here is some information about lung disease in Marfan syndrome provided by Dr. Enid Neptune, Johns Hopkins.

■ What is restrictive lung disease?

How is it treated?

Restrictive lung disease occurs in about 70 percent of people with Marfan syndrome. This could be due to structural issues, such as a severely indented chest bone, severe scoliosis or severe kyphosis. Marfan syndrome is also associated with skeletal muscle weakness, which can also be the cause of restrictive lung disease.

Restrictive lung disease is characterized by reduced lung capacity. This leads to decreased lung volume, which, in turn, makes it harder to breathe. To diagnosis this, a lung doctor (pulmonologist) conducts special tests for inhaling and exhaling, called pulmonary function tests, which assess the lung capacity.

Early surgery of moderate to severe scoliosis may not only improve lung function, but also may prevent further deterioration in lung capacity. Although the sternum or chest bone in those with Marfan syndrome may curve in (pectus excavatum), this feature in isolation rarely causes significant breathing problems. However, surgical correction of the chest bone can result in dramatic cosmetic improvement.

■ What is a spontaneous pneumothorax?

How is it treated?

Another lung problem common in Marfan syndrome is a spontaneous pneumothorax (lung collapse or detachment from the chest wall). The Marfan lung can have over-expanded lung air sacs, called apical blebs, which can be seen on a chest x-ray. These weakened areas can make the lungs more prone to collapse, similar to an over-expanded balloon. A pneumothorax can be diagnosed by chest x-ray or CT scan.

A small pneumothorax is treated in the hospital with supplemental oxygen. A moderate to large pneumothorax is treated by chest tube insertion and possibly pleurodesis, if the lung does not re-inflate. Pleurodesis involves scarring the lung surface to re-attach the lung to the chest wall. It is important for doctors to know that the preferred pleurodesis method for individuals with Marfan syndrome is the mechanical rather than chemical type, as the former makes cardiac surgery easier, should this be necessary in the future.

■ What other lung problems affect people with Marfan syndrome?

Other pulmonary conditions that can occur with Marfan syndrome include emphysema (about 5–10 percent of affected individuals have this), asthma and sleep apnea. Symptoms of emphysema can include shortness of breath, recurrent bronchitis and pneumothorax. It is important that individuals with Marfan syndrome be correctly diagnosed if they are thought to have asthma, as beta agonists (Albuterol, Combivent), standard treatments for patients with asthma, can neutralize the effects of beta blockers which are frequently used to prevent further aortic root enlargement. A preferred asthma regimen is the use of anticholinergics, such as ipratropium for quick relief, and inhaled corticosteroids as a maintenance medication. Sleep apnea is thought to be under-diagnosed in Marfan syndrome. If you are experiencing persistent daytime sleepiness and interrupted sleep, you should ask your doctor about having an evaluation by a pulmonologist or sleep specialist. Be aware that patients with Marfan syndrome can develop sleep apnea in the absence of excess weight or obesity.

As the Marfan lung is prone to collapse, people with Marfan syndrome are advised to avoid activities that risk rapid changes in atmospheric pressure, such as scuba diving and flying in unpressurized aircraft.

■ Does shortness of breath indicate a lung problem?

Sometimes lung problems have symptoms that are similar to heart problems. For instance, shortness of breath during activity is a primary symptom of restrictive lung disease; however, this can be also a symptom of a faulty heart valve or congestive heart failure. Symptoms of a spontaneous pneumothorax (lung collapse or detachment from the chest wall) include shortness of breath and chest pain, which can mimic a heart attack or aortic dissection. Thus, chest pain should always be thoroughly evaluated in Marfan syndrome.

Both pharmacologic (drug-based) and nonpharmacologic treatments should be considered for people with Marfan syndrome who develop lung disorders punctuated by shortness of breath with activity. A highly effective intervention is pulmonary rehabilitation (physical therapy for the lungs). This plan of care can be prescribed by any physician, but consultation with a pulmonologist is recommended.

Shortness of breath with Marfan syndrome is common and deserves careful evaluation with consideration of cardiac, pulmonary and muscle contributions.



27th Annual Conference

Continued from page 2

HeartMart

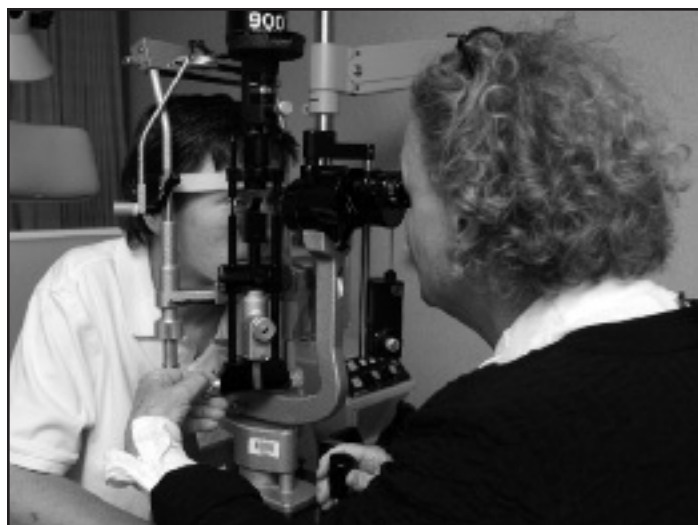
HeartMart, a fun raffle at the annual NMF conference, raises funds to support the NMF Conference Scholarship Program. Please help! Donations of clean, new items are being accepted. Suggestions include gifts cards, electronic items and things for children and the home. Fashion, jewelry and beauty items that can be combined to make gift baskets are also appreciated. The value of donated items/packages should be at least \$30. Higher-end items with a value of \$150 or more are also appreciated. Please send your items to the 2011 HeartMart Chair by June 30:

Kathryn Thompson
HeartMart Donations for NMF
P.O. Box 760
Brush Prairie, WA 98604

If you have questions, please contact Kathryn at kgert.kt@gmail.com or Cathie Tsuchiya at the NMF at ctsuchiya@marfan.org.

Our Conference Co-Hosts

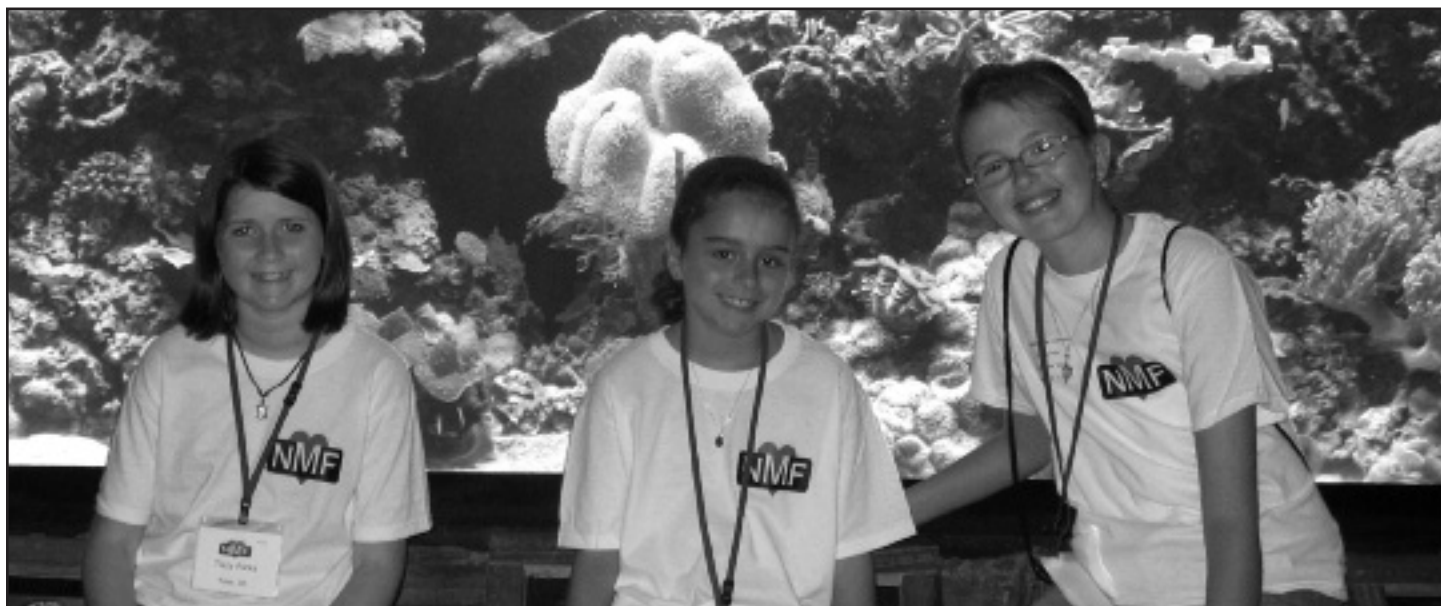
Shriners Hospitals for Children® is a network of 22 hospitals specializing in medical care for children. Each year, Shriners Hospitals spend millions of dollars on specialized research and the development of new treatments for diseases that affect children. A leader in the field of orthopedic medicine, Shriners Hospital in Portland provides a full spectrum of pediatric care using the latest and best therapeutic modalities and state-of-the-art equipment. The hospital offers special expertise in areas important to the care of those with Marfan syndrome and



A young NMF member is examined by NMF Professional Advisory Board member Irene Maumenee, MD, at the conference clinic.

related disorders, including scoliosis, skeletal growth abnormalities, and chest wall deformities. An interdisciplinary team approach is used in patient care programs to ensure comprehensive care for each patient. Children up to age 18 with orthopaedic conditions or cleft lip and palate are eligible for care and receive all services in a family-centered environment, regardless of the patients' ability to pay.

Oregon Health & Science University (OHSU) is Oregon's only health and research university. As part of its multi-faceted public mission, OHSU strives for excellence in scholarship, research, clinical practice and community service. OHSU includes four schools, two hospitals, numerous primary and specialty care clinics, multiple research centers and institutes and dozens of community service programs. OHSU's fundamental purpose is to improve the well-being of people in Oregon and beyond.



Age-appropriate programming for younger children creates friendships that last a lifetime.

Social Security Disability: A Primer

Many people with Marfan syndrome or a related disorder are unable to work and file for social security disability. This is often a challenging process. Jon Rodis, president of the NMF's Massachusetts Chapter, became disabled due to Marfan syndrome ten years ago and went through the process of attaining social security disability along the way. As part of this journey, Jon and his wife, Katherine Kane Rodis, were determined to learn as much as they could about the process and then help others. Here's what they learned and have shared over the years to help other people achieve benefits.

Is Marfan syndrome considered a disability under the Social Security Disability listings?

Marfan syndrome is listed in the Social Security's Listings of Impairments within the cardiovascular section. However, it does not address all the disabling factors of the disorder. It does give some needed guidance on the evaluation of Marfan syndrome.

What is the difference between Social Security Disability and Supplemental Security Income?

Social Security Disability Insurance (SSDI) is based on your prior work (social security taxes paid into the system). Supplemental Security Income (SSI) is based on the financial need of adults or children who are disabled and have not paid into the social security system.

Does it make a difference in outcome whether I apply on-line or in-person?

The decision to apply on-line or in person is mainly one of choice or what might be easier or more comfortable for the applicant. Some people prefer the comfort of filling out forms at home while others would prefer to meet and talk to a person.

Should I retain the services of an attorney when I start the application process?

The best time to hire an attorney is when you have reached the hearing stage of the process. Before this point, there is a chance of approval so there would be no need to pay an attorney.

What questions should I ask in selecting a disability attorney to handle my case?

It would be in your best interest to ask the attorney if they have ever represented a client who had Marfan syndrome or a related connective tissue disorder and had success. If they

did not, then it's a good idea to find out how many cases they have handled and won for people with a rare disorder. It's also important for them to have several years of experience representing disability cases.

Is there a way to clearly explain my symptoms so that my doctor will understand that I am unable to work anymore?

A great way to help explain your symptoms to your doctor and why they are a major part of your inability to work is to give examples. For example: When I want anyone to understand



Gary Bennett and his wife, Brenda

I have been a member of the National Marfan Foundation for about six years. I would like to extend a sincere thank you to Jon Rodis and the team at the National Marfan Foundation for their efforts working with the Social Security Administration to get them to recognize Marfan as a disabling condition. I want to thank Jon for his counseling and support before my heart surgery at Brigham and Women's Hospital in Boston in 2008 and for his guidance as I worked through the disability process over the past five months. Thank you to the NMF for the letter of support and the literature you provided as I began my battle.

Those efforts finally paid off. I was just approved for Social Security after the five month minimum disability period was fulfilled. Last week, I also prevailed in my disability appeal. My wife and I both agree that, if not for the efforts of the National Marfan Foundation, this quick resolution would not have been possible.

Gary Bennett
Oakland, ME



for Approval

what it is like to have constant pain and fatigue and why it is disabling, I ask them to think back to the last time they had a bad cold and how weak they were and remember the aches and pains they had, but they still may have gone to work. I tell them that is how I feel two days a week. Next, I ask them to think back to when they had a bad flu. They were extremely fatigued, had a lot of pain all over their body and they definitely couldn't go into work. That is how I feel five days a week.

The majority of applicants get denied on their first decision. If you are denied, you will be asked to appeal and you should do so immediately.

What documentation should I include with my application? Are letters of support helpful? What information should be included in my doctor's letter of support?

Along with your fully completed application and all the required financial documentation, it is extremely beneficial to have a support letter from your doctor(s). It is very important that your doctors state in their letter of support that you are disabled and express all the symptoms of your condition and all your limitations. In addition, a support letter from the National Marfan Foundation that is written on your behalf may increase your chances of approval.

Do most applicants get approved on the first try? How long will it take to get notice of the first decision?

The majority of applicants get denied on their first decision. It can take from two to three months on average for approval from the date you apply. If you are denied, you will be asked to appeal and you should do so immediately.

The government's website for social security disability is located at www.ssa.gov/disability/

The information provided in this article is not legal advice, but general information on legal issues commonly encountered by persons that became disabled due to Marfan syndrome and are considering going through the process of attaining social security disability benefits. The National Marfan Foundation cannot provide legal advice and can only provide general information. Although we go to great lengths to make sure our information is accurate and useful, we recommend you consult a lawyer if you want professional assurance that our information, and your interpretation of it, is appropriate to your particular situation.

Social Security Disability Checklist

- Complete the form accurately and in full and then file it with your local Social Security office. Make sure to keep copies as back-up.
- Call your local department of social services regarding state disability funds and services.
- Make appointment(s) with your personal physician(s); advise the doctor of your filing and request a letter of support.
- Compile information to support your claim, including materials from the NMF, research papers on Marfan syndrome and your particular complications, letters of support from the NMF and anyone else who can support your claim.
- If possible, make an appointment with a doctor who has special expertise and experience with Marfan syndrome for additional support, such as a letter about a specific complication of Marfan syndrome that can become disabling.
- Make sure you have copies of all your medical records. Keep them in a folder or on a CD in case the social security office misplaces your materials.
- Look for people with Marfan syndrome within your state who have been approved. They can provide you with emotional support, as well as serve as a resource for other doctors familiar with Marfan syndrome who can support your claim.
- If you are denied on your appeal and have reached the hearing stage, find a disability attorney who has several years experience and speak to the attorney immediately.
- Make sure the attorney has all of your medical records and support materials, as well as any information you can gather about other people with Marfan syndrome in your state who have been approved.
- Most important: Keep a daily health journal that lists all your symptoms, appointments, results, INR's, daily notes, and how your life is impacted.

Provided by Jon Rodis and Katherine Kane Rodis, Massachusetts Chapter of the NMF

HEARTWORKS

GALA ♥ 2011

Hero
with a
Heart



Peter L. Spadaro, Divisional Vice President, Cardiac Surgery Sales, St. Jude Medical (R), accepted the Hero with a Heart Award on behalf of St. Jude Medical from Dr. O. Wayne Isom, Terry Allen Kramer Professor of Cardiothoracic Surgery, Weill Cornell Medical College. St. Jude is a major supporter of the critical multi-center study, "Aortic Valve Operative Outcomes in Marfan Patients."

Hero
with a
Heart



Hero with a Heart Award recipient Jeff LeSage, U.S. National Managing Partner, KPMG (R), with KPMG Chairman and CEO John Veihmeyer.



WNBC-TV's Jane Hanson (L) served as master of ceremonies and led the live auction with her colleague Janice Huff.



NMF members Alix McLean Jennings and Ezra Jennings. Alix spoke about their daughter, Cassie, during the evening's special Fund-a-Need Appeal.



NMF Senior Vice President Judy Gibaldi and her husband, Rocco (center) with (R-L) NMF Board members Teri Dean, Ray Chevallier, Gary Kauffman and Gary's wife, Mary.



(L-R) NMF President and CEO Carolyn Levering; Ann Reinking, Dinner Chair; Mayor Michael Bloomberg, Honorary Chair; NMF Board member and Heartworks Corporate Host Karen Murray; and NMF Chair Jon Tullis.



The Alaska contingent—including former NMF Board member Mary Witte (second from right), her husband John (behind her) and her mother Rita Sholton (third from right)—enjoyed the gala.



Randy and Susan Falco (right), with Keith and Catherine Turner, got involved in the lively auction, and won great trips and a celebrity chef dinner.



NMF Board member Cory Eaves and his family.



Jon Tullis, NMF Board chair, opened the evening with a special welcome. As part of his comments, he noted that Heartworks' ongoing success is due to the loyal and effective hands-on commitment of gala committee leaders Susan Falco and Karen Murray. He also expressed appreciation for the ongoing advice and support from Artistic Chair Ann Reinking and Board Advisor Michael Weamer.



NMF member Ben Carpenter participating in the evening's Fund-a-Need Appeal.



Karen Murray with Peter Hunsinger, publisher of GQ Magazine.

TAD Coalition Receives Grant to Reach Doctors with Aortic Dissection Treatment Guidelines

The TAD (Thoracic Aortic Disease) Coalition, convened in 2009 by the NMF to increase awareness of aortic disease, has received a \$75,000 educational grant from W.L. Gore & Associates.

The grant will make it possible for the TAD Coalition to print 25,000 copies of the *Physician Pocket Guide* version of the guidelines for diagnosis and treatment of aortic dissection published last year and disseminate it utilizing various strategies. It will also enable the TAD Coalition to have a presence at the American College of Emergency Physicians meeting in the Fall, where Coalition representatives can meet in-person with emergency physicians from all over the country.

“We are thrilled to be working with W.L. Gore & Associates on this medical education initiative, which will certainly benefit those with Marfan syndrome and related disorders,” said Carolyn Levering, NMF President and CEO. “We hope this is the beginning of a long partnership that will result in changes in the practice of emergency medicine that will save the lives of those who are having an aortic dissection.”

The TAD Coalition was established in advance of the new diagnosis and treatment guidelines for aortic dissection that were published in 2010 by the American College of Cardiology (ACC), American Heart Association and several other medical organizations in order to maximize the impact of these guidelines. In addition to public awareness and medical education, the Coalition desires to change the processes in hospital emergency departments so that people with aortic dissection are diagnosed quickly and treated correctly. This will save lives.

The NMF continues to take a leading role in the TAD Coalition as part of its commitment to the Foundation’s Emergency Medicine Campaign, its long-standing initiative to prevent avoidable deaths from aortic dissection in hospital emergency departments.

Several TAD Coalition members have also been involved with raising awareness of aortic disease:

- Amy Yasbeck (wife of the late John Ritter) continues to make appearances discussing Ritter Rules, which provide simple guidelines for people to learn about risk factors, symptoms, and diagnosis of aortic dissection.
- Nebraska Methodist Health System continues to encourage improvements in hospital systems via its video “Aortic Dissection at Any Age: The Tyler Kahle Story” which can be viewed online at www.bestcare.org/tyler.
- Additional awareness events have been held by Jade Carabajal in Kansas, Patty Peterson in Minnesota, and Robert Epps in New Jersey.

This year, new members have been added to the Coalition, including:

- Steering Committee—Turner Syndrome Society of the United States, Ehlers-Danlos Syndrome Network C.A.R.E.S.
- Associate Members—Dr. John Elefteriades (Yale Center for Thoracic Aortic Disease), Dr. Kevin Harris (Minneapolis Heart Institute), Robert Epps and Patty Peterson.

Professional and Scientific Advisory Boards News

Dr. Alan Braverman (PAB) is the senior author of the chapter on Diseases of the Aorta in Braunwald’s *Heart Disease*, 9th Edition, Elsevier and another study on Aortic Involvement in Patients with a Bicuspid Aortic Valve in the journal, *Heart*.

Dr. Richard Devereux (PAB) was named the principal investigator for the National Registry of Genetically Triggered Aortic Aneurysms and Cardiovascular Conditions at Weill Cornell Medical College.



Hal Dietz, MD

Dr. Hal Dietz (PAB) was elected to the National Academy of Sciences, an honorary society that advises the government on scientific matters.

Dr. Dianna Milewicz (PAB) has joined the Professional Advisory Board for the Canadian Marfan Association and the Ehlers Danlos Syndrome Network C.A.R.E.S.

Dr. Reed Pyeritz (PAB) has been elected a senior fellow of the Center for Bioethics and the Leonard Davis Institute of Health Economics at the University of Pennsylvania. He is currently on sabbatical at the Fondation Brocher in Hermance, Switzerland until September 2011.

Dr. David Rimoin (PAB) was awarded the Mayo Soley Award for Lifetime Achievement in Research by the Western Society for Clinical Investigation.

Dr. Bjorn R. Olsen (SAB), Harvard School of Dental Medicine’s dean for research and professor of developmental

Continues on opposite page

Researchers Gain New Clues about How to Prevent Aortic Aneurysm in Marfan Syndrome

A new study by Hal Dietz, MD, a Howard Hughes Medical Institute investigator at the Johns Hopkins University School of Medicine, builds on his team's earlier discovery that blocking signaling from a molecule called TGF-beta halts the progression of aortic aneurysm in a mouse model of Marfan syndrome. Losartan dampens TGF-beta signaling by blocking one of its partners, the angiotensin II receptor. Dr. Dietz's new work, described in two papers published April 14, 2011, in the journal *Science*, clarifies which molecules in the cell work with TGF-beta to drive aneurysm progression.

The findings have implications both for how losartan works relative to other existing drugs and for how researchers might focus future drug development efforts.

"I really think we're going to be able to make more informed choices regarding which medication to use now [to protect against aortic aneurysm] and which medications to test in the future," Dietz says.

Five years ago, patients with Marfan syndrome received new hope when laboratory studies suggested that losartan, an FDA-approved drug used to treat high blood pressure, might prevent the potentially deadly enlargement of the aorta that the syndrome can cause. Now, researchers have a clearer picture of the cellular signals that contribute to progression of aortic aneurysm in Marfan syndrome and how losartan alters those signals. The new information—which is based on mice studies—is expected to help guide future treatment decisions, as well as efforts to develop therapies that might offer benefits that losartan does not.

Advisory Boards News

Continued from opposite page

biology, was recently named a fellow of the American Association for the Advancement of Science. Olsen, who is also the Hersey professor of cell biology at Harvard Medical School, was honored "for distinguished research contributions to cell, matrix, and developmental biology and to dental academics through innovative leadership."

Dr. Craig T. Basson (SAB) has moved to Novartis Institutes for BioMedical Research as head of Translational Medicine – Cardiovascular.

Dr. John Carey (SAB) was awarded the Gary Schoenwolf Mentoring Award from the Division of Medical Genetics, University of Utah Health Sciences Center.

Medications to Treat the Cardiovascular (Heart and Blood Vessel) Problems in Marfan Syndrome

Cardiovascular (heart and blood vessel) problems are common in people with Marfan syndrome. In fact, cardiovascular problems affect about 9 out of every 10 people diagnosed with Marfan syndrome. It is important that people with Marfan syndrome know about cardiovascular problems and ways to prevent or manage them.

Here is an update on the medications used to manage the cardiovascular problems of Marfan syndrome.

Beta-blockers. These help lower blood pressure and reduce the force of heartbeats. These medications may help prevent or slow down aortic dilation (enlarged aorta) and can reduce the risk of aortic dissection (tears between layers of the aorta). For many people with Marfan syndrome, beta-blockers are a first choice medication.

Angiotensin receptor blockers (ARB's). Recent research has shown that one ARB drug, losartan, can prevent aortic growth in special Marfan mice. A clinical trial is now underway to compare this medication to beta-blockers in people who have Marfan syndrome.

Other Medications: Other classes of medications are considered for the treatment of people with Marfan syndrome who do not tolerate beta blockers including angiotensin converting enzyme inhibitors (ACEi such as enalapril). There are only very small studies of ACEi in people with Marfan syndrome. While recent work in mice with Marfan syndrome suggests that ARBs provide greater protection to the aorta than ACEi, more experience is needed in people with Marfan syndrome. While some have considered calcium channel blockers (CCB) as an alternative to beta blockers in the treatment of Marfan syndrome, currently there is simply too little information to infer either efficacy or safety of CCBs in Marfan syndrome. You should discuss these issues with your doctor.

For more information, please visit the NMF website (www.marfan.org), specifically the Heart of the Matter Fact Sheet entitled: Marfan Syndrome: How to Care for Cardiovascular Problems.



Chapter & Local Network

Here are some highlights of recent chapter and network group activities.

New Hampshire/Vermont Network Group



Network group members Nancy Nelson, Rene Jones and Kaddy Ackroyd (L-R) distributed Marfan materials at the Wellness Fair at the Londonderry (NH) High School on April 14.

Mid-Atlantic Chapter



Chapter members supported Daniel Speck, 12, and his mom, Amy, who organized Heart & Soul, a benefit concert that raised more than \$3,500 for the NMF. (Back row L-R, Kay Goad, Daniel Speck and Amy Speck; front row L-R, Lois Kuhn, Sarah P., Meghan C., Phyllicia M. and Jessica Berklite)
Photo courtesy of Audra Haddock-Martenot

Massachusetts Chapter



On April 7, the Chapter held a meeting at Brigham and Women's Hospital in Boston to hear the latest medical information from NMF Professional Advisory Board member Ron Lacro, MD, and his colleagues Dr. Michael Murray and Dr. Michael Singh. Clinic Coordinators Martha King and Monica Giovanni were also on hand to talk about the Marfan care they offer.

More online at
www.marfan.org

Visit the NMF website, www.marfan.org, to read about activities of these groups: Central Indiana Network Group, Eugene Network Group, Northern California Chapter, Omaha Network Group, Portland Network Group, South Central Pennsylvania Network Group and Southeast Florida Network Group.

Group News **Each One Reach One**



Please go to the NMF website (www.marfan.org) to read more!

Northern Illinois Chapter



Northern Illinois Chapter members, Jason and Jennifer Aguayo, hosted a four-day fundraiser in March at Choo Choo Johnny's in honor of the 5th birthday of their twin boys, Aaron and Joshua (pictured here with their grandpa, Gus Aguayo). They raised \$218.

North Dakota Chapter



Dena Kemmet, ND Chapter Vice President (pictured above left with Kent Vernon, Courtney Kemmet and Lynnae Weidner), and members of the chapter held the 2nd Annual Movie for Marfan on New Year's Day at the Cinema Twin in Hazen, ND. They raised \$302.50.

Northeast Indiana Network Group



Dr. Patricia Bader of Northeast Indiana Genetics Counseling spoke to the group, using her grandchildren's building blocks to explain the revised diagnostic criteria for Marfan syndrome.

Heart of Iowa Chapter



NMF member Marty Dostalík (center) and friends enjoyed the chapter's 2nd annual Drink for a Cure event on January 29 at OverTime in Urbandale. They raised nearly \$1,000.

Mid-Atlantic Chapter



The Mid-Atlantic Chapter distributed information at the NBC4 Health & Fitness Expo, held at the Washington Convention Center on January 15-16.



People People &



Karen Collins (center) organized the 3rd Cookson Snow Trek in Colorado and raised \$1,659 in memory of Kevin Cookson.



Sharon Nasutovicz, of Utica, NY, raised more than \$2,000 from local businesses as part of the Hang-a-Heart Campaign.



Alix McLean Jennings (second from left), of Madison, NJ, and her team members ran the Superhero Half Marathon and Relay in Morris Township, NJ in honor of Alix's four-year-old daughter, Cassie. They raised more than \$43,000.



Ten-year-old Emma Ingraham of Elroy, WI, conducted a successful Hang-a-Heart campaign through local businesses and raised \$1,000 for the NMF.



Jeannie Marve, of Bay Shore, NY, celebrated her 30th birthday with a party (attended by Mr. Met) and asked her friends to make a donation to the NMF in honor of her father, Rodney Marve. They raised \$2,145 for the NMF.



Samantha Morrison at the Marfan awareness fundraiser she arranged at Rogers State University.



Meaghan Joyce, of Cape May, NJ (center) raised \$1,300 for the NMF at her Sweet Sixteen party.

Events Events



Andi Solero (left), representing Jonnie's Goodguys, presented Amy Miller, widow of Jonathan Miller, with an honorary medal after raising \$800 for the NMF by completing the Indianapolis Monumental Marathon.



NMF member Bruce Klein and Miss Tall International Joy Dawson at the Paramount Tall Club of Chicago weekend in January. Fundraising for the NMF resulted in a \$2,000 donation.



Kathy Magee, of San Antonio, TX (pictured here with son Aidan), held her 6th annual Have Heart Quilt Fundraiser in March, raising \$1,230.



Music teachers at Mendham Township Middle School in New Jersey, including Karen Schaberg and Russell Branch (pictured above with members of the orchestra) held a Have Heart fundraiser, resulting in a donation of \$324.

More online at www.marfan.org

Visit the NMF website, www.marfan.org, to read about more People & Events:

- Supercuts fundraiser (AZ)
- Cynthia Ramirez's memorial fundraiser (CA)
- Laura Cockerham's candle fundraiser (FL)
- Ellen England's fundraiser (IN)
- Jane Brandt's Learn-to-Skate fundraiser (NH)
- Ridge High School's RENT fundraiser (NJ)
- March for Marfan at Case Western University (OH)
- Andrew and Stephen Melin's Change of Heart fundraiser (OR)
- Kathleen Cadden's jewelry fundraiser (PA)
- PeoplesBank Dress-Down fundraiser (PA)
- Larie Beck's Scentsy Fundraiser (WA)
- Tall Club fundraisers in New Jersey, Wisconsin and Nevada



NMF On the Road in Florida: Mobilizing Local and State Action

In April, NMF President and CEO Carolyn Levering and Manager of Volunteer Development Kathy Jeffers blazed a trail around the state of Florida, holding Town Meetings in Fort Myers, Sarasota, Tampa, St. Augustine, Orlando and Hollywood. Carolyn and Kathy were thrilled to meet face to face with more than 150 members, sharing the latest NMF news plus hearing members' views.

Results of the Town Meeting discussions were consistent and compelling. Members want to meet each other and create a Marfan community that gathers regularly to share their experiences and to support each other. Additionally, all groups have a common interest in sharing resources for medical care and creating opportunities for educating themselves, as well as the schools and medical communities on the local and state level.

According to Kathy, "The trip was most gratifying because members were so enthusiastic and responsive. I think the initiation and growth of Florida's Marfan communities can become a model for developing NMF Network Groups and activities in other geographic areas."

New Network Groups Developing

Florida was targeted for Network Group development because there is a critical mass of more than 1,600 NMF members in the state, with many who are interested in participating. A key factor is also that there are individuals who are willing to take leadership roles and others who will play active supporting roles. Five new groups are forming in the state.

There is currently one active group, the Southeast Florida Network Group in Hollywood, which has had tremendous



Sarasota Network Group

success in its first year. Led by M.J. and Max Freeman and Stacey Tabacco, the group has linked with a local hospital, Memorial Regional Hospital South (MHS), in a mutually beneficial relationship.

"The reality of creating a local group that will be integrated with a dynamic statewide Marfan community is fulfilling a dream for everyone," said Betty Carr, of Sanibel Island, who has been a long-time Telephone Support contact and will now lead the Southwest Florida Network Group.

Involvement of the Local Medical Community

Carolyn, Kathy, MJ, Stacey and NMF Board Member Gary Kauffman met with Frank Sacco, President and CEO of Memorial Healthcare System, Dr. Stanley Marks, Senior Vice President and Chief Medical Officer of MHS and a team of

Memorial physicians to discuss organizing a coordinated clinic for care of patients with Marfan syndrome and related disorders. They also explored the possibility of hosting the NMF Annual Conference in the future.

Sacco confirmed, "We see the need for coordinated care for Marfan syndrome and related disorders, and are committed to serving patients in this region."

Said Carolyn, "Our resources are well spent when the outcomes are as significant as the results of this Florida trip. Members and staff are greatly energized by meeting face-to-face, discussing real issues and planning solutions."

More pictures of Florida network groups are online at www.marfan.org.



Hollywood Network Group

Volunteer Profile: Rebecca Stroda



The Stroda family (L-R): Kaitlyn, Rebecca, Kyle, Kylie and (in front) David

Rebecca Stroda, whose daughter, Kylie, 16, has Marfan syndrome, is the chair of the Portland Network Group. She is gearing up for the annual conference, which is coming to her city this summer for the first time in nearly twenty years.

How did you get involved in the Portland Network Group?
My daughter was diagnosed with Marfan syndrome in 2004. I was excited to receive a meeting notice from a support group in our state so I could connect with others. When the leader was stepping down, I thought about starting a local Portland Network Group. As leader of the group since the spring of 2010, my hope is to continue to connect with others who are affected or who support those affected and spread awareness and education. I have found the Marfan community to be supportive and educational, and they are some of the most amazing individuals who shine in not always the easiest of times.

How has your daughter inspired you?
My motivation to be involved with this group comes from my daughter and her love and beautiful heart that never cease to amaze me. She so generously puts herself out there in hopes of spreading awareness and support to others affected with Marfan syndrome.

What are some of the activities that your group and your family have organized?
My daughter Kylie and I have given five presentations with Shrine Clubs and Kiwanis groups to spread awareness about Marfan syndrome, as well as to let people know about the conference. At the presentation we did in Beaverton, Ron Stansell and Kathryn Thompson (HeartMart chair) also generously spoke. At the two Shrine Club presentations and at one Scottish rite presentation, we received \$100 donations

resulting in \$300 for conference. We have two events coming up, including a 5k run/1 mile walk that my daughter Kaitlyn is organizing for her senior project and a free screening of “In My Hands” at Shriners Hospital in Portland that we hope will bring in some donations.

What does your volunteerism mean to you?
Volunteering can be quite the juggling act at times with my other commitments and passions in life, but I have found it to be extremely rewarding. When you help others it truly can be a blessing to yourself, as well.

How is your group getting ready for the annual conference?
Our Network Group is so excited about the upcoming conference. We’ve made phone calls, held a joint fundraiser with the Columbia County Shrine Club, and made quilts for HeartMart. Some members have donated portions of proceeds from their home-based businesses. Many of our group members will be volunteering on-site. The excitement of the conference coming to Portland is growing as many people in this area have never had the opportunity to attend before.

Why should people come to Portland for the annual conference?
We are looking forward to welcoming NMF members to Portland. We have many attractions in and around the city. Conference attendees will be able to step outside of the hotel and walk across the street and along the beautiful waterfront. Those who will be attending the health fair appointments will be up on the hill and can take in some breathtaking views. Plus, if anyone has time to come before the conference or stay afterwards, there are many sights to see close by and within an hour or two from the city.

Chase Community Giving

Continued from page 1

celebrities who tweeted in support of the NMF, including Rosie O’Donnell, country music star Jason Aldean and Amy Yasbeck, of the John Ritter Foundation; gala supporters including KPMG; organizations such as the National Health Council and so many more.

Receiving this \$45,000 in funding was only possible because our own “Marfan Family” pulled together to make a statement that our work is important for companies like Chase to support.

Join the NMF’s email network (via the NMF’s website, www.marfan.org) and “like” the National Marfan Foundation on Facebook to get updates on opportunities to support the NMF.

Heartworks Galas *Continues from page 1*

live auction, and special Fund-a-Need appeal. The monies raised at Heartworks help secure core programs and services.

“Heartworks is a highlight for us every year. Our members and their families who attend, along with our partners and friends in the business community, are supremely supportive and demonstrate their commitment each year through their contributions to our programs of education, support and research,” said Carolyn Levering, NMF President and CEO. “They make it possible for us to continue to enhance the lives of affected people.

Heartworks St. Louis



(L-R) Lawrence Lenke, MD, Carolyn Levering, Rebecca and Alan Braverman, MD, and Keith Bridwell, MD

NMF Professional Advisory Board Chair Alan Braverman and his wife, Becky, hosted the 3rd Heartworks St. Louis at the exquisite Chase Park Plaza. The Hero with a Heart Award honorees were Keith Bridwell, MD, Chief of Spine Surgery in the Department of Orthopaedic Surgery and Asa C. and Dorothy W. Jones Professor of Orthopaedic Surgery, Washington University School of Medicine, and Lawrence Lenke, MD, Jerome J. Gilden Endowed Professor of Orthopaedic Surgery, Washington University School of Medicine.

The event attracted its largest crowd to date—more than 300 attendees—including many doctors from Washington University Medical Center, members of the NMF’s St. Louis Chapter, and NMF board members. Former Hero with a Heart Award recipients, Dr. Nicholas Kouchoukos and Dr. Gregorio Sicard, were also on-hand.

Nicole Elzea, mom of Kinley, a 10-year-old girl with Marfan syndrome, gave the most moving talk of the evening. She described Kinley’s difficult journey with Marfan syndrome and how Dr. Lenke has made it possible for her to be mobile.

There was not a dry eye in the room as Kinley joined her mom at the podium with a smile that inspired all.

Throughout the event, the guests enjoyed the entertainment provided by jazz vocalist Erin Bode.

The NMF is grateful to Dr. Braverman and Becky for their continued commitment to this event and to the St. Louis medical community for supporting the event again this year.

Heartworks Westchester

NMF member Barbara Lerman and her family and friends were planning for the fourth annual Heartworks Westchester as this issue went to press. The event is held in honor of Sydney Lerman, the eight-year-old daughter of Barbara and her husband, Jonathan (and granddaughter of NMF Board member Jerry Lerman and his wife, Judy). A fun-filled event is planned at Life the Place to Be, in Ardsley, NY, on May 14. Look for photos and highlights in the next issue of this newsletter.

In My Hands Named Best Short Documentary at the Garden State Film Festival



Ann Reinking and NMF member Dr. Douglas Richter participated in a panel discussion following a screening of the documentary “In My Hands: A Story of Marfan Syndrome” at the Garden State Film Festival in Asbury Park, NJ, on April 2, where the film was named Best Short Documentary. Ms. Reinking shared her experience as a parent of an affected son and her inspiration for making the film. Dr. Richter talked about his experience with Marfan syndrome; he is affected, as is one of his three daughters. Congratulations to filmmakers Ann Reinking, Brenda Siemer Scheider and Emma Joan Morris on these well-deserved recognitions and for their continued commitment to increasing awareness of Marfan syndrome and related disorders.

We Remember and Honor . . .

The National Marfan Foundation is grateful to its members and friends who have made contributions in memory of, or in honor of, the following individuals. These donations are fully appreciated and support our mission to save lives and enhance the lives of those affected by Marfan syndrome and related connective tissue disorders.

In Memory of:

Adrian Adame	Sarah Cayo	Dave Ingram	Christopher Paulsen
Carol Adame	Marie C. Cenac	Kevin Jolie	Roberta J. Pflieger
Elias Adame	Barbara Clark	Harriet K. Jones	Nolan Phillippi
Noreen Allaire	Jeffrey Martin Clark	Holly Justice	Ginger Preiss
Kaitlyn Anthony	Blake Ding	Cleo Moskowitz Karns	Joel Ramirez
Aunt Mary	Delores Ding	Mary A. Kerchner	Carolyn Lucile McEwen Rixie
Helen C. Austin	Roberta Dinwiddie	Hazel Knudson	Dylan Rohrer
Alison A. Bacchus	Clifton Stewart Durand	Jill Koepfel	Maryann Roney
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