



Leadership Connection

September 2010

Volume 4 .No. 3

THE IDEA SOURCE FOR NMF NATIONAL VOLUNTEER NETWORK LEADERS

Published by the National Marfan Foundation
22 Manhasset Avenue, Port Washington, NY 11050
800-8-MARFAN - www.marfan.org

Fall/Winter Volunteer Leadership Seminar Schedule

**One-hour Conference Call Seminars are
Open to All Group Leaders and Telephone Support Contacts**

Please make every effort to participate, or appoint a key person in your group who demonstrates leadership qualities.

Time schedules relate to Eastern Time.

To Register:

E-mail Kathy Jeffers, *Manager of Volunteer Development*,
at kjeffers@marfan.org, or call 1-800-8-MARFAN X 11.

MANDATORY TRAINING on NEW DIAGNOSTIC CRITERIA FOR ALL GROUP LEADERS AND TELEPHONE SUPPORT CONTACTS!



Understanding the New Diagnostic Criteria

Since you are representing the NMF at the local level, it is imperative that you understand the new diagnostic criteria and their implications. How are the new criteria different? How do they work? What do they mean for Marfan syndrome and related disorders? How can we be a resource for our doctors? What resources are available? Why it is important for us all to be on the same page? All questions will be answered by the presenters, accompanied by full discussion with participants. **Please choose one day and time that is most convenient for you from the following list, and sign up by October 15.** NOTE: You will need phone and computer access for this webinar format.

**Presenters: Jennifer Buffone, Director of Support and Volunteer Development
Josephine Grima, Vice President of Research & Legislative Affairs
Jonathan Martin, Director of Education & Awareness**

Wed. Oct. 20	8:00 pm	Jonathan Martin
Tues. Oct. 26	2:00 pm	Josephine Grima
Thurs. Oct. 28	1:00 pm	Jennifer Buffone
Mon. Nov. 8	8:00 pm	Jonathan Martin
Wed. Nov. 17	2:00 pm	Josephine Grima
Wed. Nov. 24	3:00 pm	Jennifer Buffone
Wed. Dec 8	8:00 pm	Jonathan Martin
Thurs. Dec. 9	10:00 am	Jennifer Buffone
Wed. Dec. 15	2:00 pm	Josephine Grima

Network Group Leaders Open Forum: Strategies for Building Group Participation

Moderator: Kathy Jeffers, Manager of Volunteer Development

Date: Thursday, October 14

Time: 8:00 pm ET

Sign up by: 10/5

Description: Designed as a forum for peer consultation, Network Group leaders come together to discuss what's working and what's not in managing their group. Here is the place to share your prized successes, challenges, solutions and new ideas with other group leaders. Specific staff members can be invited as needed, with advance notice. Please submit any other topics or questions by 10/5, to Kathy Jeffers at kjeffers@marfan.org.

Telephone Support Contact Open Forum

Moderator: Jennifer Buffone, Director of Support and Volunteer Development

Date: Wednesday, October 20

Time: 1:00 pm ET

Sign up by: 10/12

Description: Do you feel disconnected from other NMF volunteers across the country? Would you like to find out how other Telephone Support Contacts answer a particular question? Would you like to get support from your fellow Telephone Support Contacts? If you answered yes to any of these questions the Telephone Support Open Forum is for you. It's the place to share thoughts and ideas, support each other and learn from each other.



Introduction to Using the NMF Style Guide On-line

Presenters: Eileen Masciale, Communications Director

Date: Monday, October 25

Time: 12:00 pm ET

Sign up by: 10/18

Description: Here is the NMF identity tool kit you have been waiting for, with practical tips for using it. Before you design your next meeting invitation, or do your group's flyer or brochure, become familiar with this easy to use tool that is now available on the NMF website. This seminar is a pre-requisite for "How to Create a Winning Brochure/Flyer" on 11/16. If you want to participate, but this date/time is not possible for you, please let Kathy Jeffers know.

Medical Office Outreach Project

Presenter: Jennifer Buffone, NMF Director of Support Services and Volunteer Development

Date: Wednesday, October 27

Time: 1:00 pm ET

Sign up by: 10/20

Description: Learn about a new exciting way you can get involved, raise awareness of NMF services, attract new people to your group, and build collaborative relationships with local Marfan and related disorders doctors' offices.



"TOWN MEETING" With Carolyn Levering, NMF President and CEO

Presenter: Carolyn Levering, President & CEO

Date: Wednesday, November 3

Time: 1:00 pm

Sign up by: 10/20

Description: All group leaders and chapter board members are invited to meet with Carolyn to hear the latest NMF news and trends, ask your questions, and brainstorm on advocacy, awareness, and fundraising to benefit the Marfan community. **NOTE: You will need phone and computer access for this webinar format.**



How to Create a Winning Brochure/Flyer for your Chapter or Network Group

Presenter: *Eileen Masciale, Communications Director*

Date: Monday, November 8 **Time:** 1:00 pm

Sign up by: 10/28

Description: A brochure or flyer can be an effective marketing tool for your group, highlighting who you are, what you do, and where you are located. You are encouraged to develop a promotional piece to give to doctor's offices and local clinics that deal with Marfan syndrome and related connective tissue disorders. Groups that have done this find it a good way to attract new members. Using the new NMF Style Guide and a design template, you will leave this session with the knowledge and tools to develop your group's brochure or flyer. You must have taken the 11/12 seminar "Introduction to the New NMF Style Guide" to participate in this session. If you want to participate, but this date/time is not possible for you, please let Kathy Jeffers know.



Using Online Resources To Enhance Your Group

Presenter: *Jennifer Buffone, NMF Director of Support Services and Volunteer Development*

Wednesay, November 17

Time: 1:00 pm ET

Sign up by: 11/10

Description: NMFconnect. Facebook. Youtube. The possibilities are endless. Learn how to use online resources/services to promote your group and enhance your groups' activities.

Chapter Leaders Open Forum

Guest Consultant: *To be announced, depending on your submitted requests*

Moderator: *Kathy Jeffers, NMF Manager of Volunteer Development*

Date: Monday, November 30

Time: 8:00 pm ET

Sign up by: 11/11

Description: This is a forum for peer consultation, where chapter presidents and board members come together to discuss what's working and what's not. Make every effort to participate and get feedback on your challenges, create solutions and share new ideas from this select group of key NMF leaders. Please submit any specific needs or questions by 10/9 to Kathy Jeffers' e-mail at kjeffers@marfan.org, so we can invite appropriate guest consultants for this session.



Generating Media Coverage for NMF 30th Anniversary

Presenter: *Eileen Masciale, Communications Director*

Date: Thursday, December 2

Time: 12:00 pm E.T.

Sign up by: 11/25

Description: As the NMF's 30th Anniversary approaches in 2011, we are preparing for extensive media coverage across the nation. Find out how to become a part of this special opportunity to support your group and your organization!

REMINDERS! DATES & DEADLINES!

Reminder:	Chapter and Network Group Web Pages on the NMF web site are available for all Chapters, Network Groups and Support Groups. Remember to update your page as necessary. To create/update your page, contact Kathy Jeffers.
September	Sign up for conference call workshops
October 30	Chapters: First Quarter Financial Reports Due
November	Family Volunteering Month
January 1	Deadline for Leadership Connection submissions: send your contributions to Kathy Jeffers at kjeffers@marfan.org
February	NMF Conference 2011 information available on-line
July 14-17, 2011	NMF National Conference in Portland, Oregon

KUDOS

Kudos: *n* 1. *syn* see EMMINENCE; 2. *syn* see HONOR

Thanks to Houston and San Antonio Network Groups for NMF Conference 2010

Invaluable support for the NMF National Conference in Houston came through Pam Bryson, Local Volunteer Coordinator and Chair of the Houston Network Group, who coordinated volunteers from all over the city. San Antonio Network Group Chair, Kathy Magee, and her team created a fabulous Heart Mart that raised over \$4,000 for conference scholarships!

Mid-Atlantic Chapter Status Approved

At the July meeting of the NMF Board of Directors, the Mid-Atlantic Provisional Chapter was given full chapter status. Congratulations to Mary Ahearn, President, and her board.

North Dakota Network Group Applies for Chapter Status

In April, the North Dakota Network Group, chaired by Selma Kerzman, applied to become a chapter. After six months as provisional chapter, the group will be presented to the NMF Board of Directors for approval. We look forward to good news in October!

Bruce Klein Retires as Northern Illinois Chapter President

After 12 years of outstanding service, Bruce Klein, of Hanover Park, is "retiring", and handing over the reins to Rhonda Barranco, an experienced board member. Bruce will still be active with the Chapter, and is already helping to organize for the 2012 NMF Conference in Chicago.

New Chapter Leader

Rhonda Barranco – President, Northern Illinois Chapter

New Network Group Leaders

Leah Goodman – Chair, Houston, Texas
Cheryl Gross – Chair, Bloomington, IL Network Group
Melissa and Nathan Shera – Co-chairs, Milwaukee Network Group
Jacki Stone – Co-chair, Cleveland, Ohio
Rebecca Stroda – Chair, Portland, Oregon Network Group

New Telephone Support Contacts

Pam Bryson, Houston, TX
Michael Hart, Los Angeles, CA
Amanda Jungkuntz, Milwaukee, WI



NVN VOLUNTEER SPOTLIGHT:

Selma Kerzman, President

North Dakota Provisional Chapter

701-221-2063; skerzman@live.com

Hi, my name is Selma Kerzman. I've recently remarried and have two wonderful adult children, two adult stepchildren, two grandchildren and two step grandchildren. Until last year I worked at home doing medical transcription. Now I'm enjoying my grandchildren, crafting, reading, and am a Mary Kay beauty consultant.

I've been involved with Marfan syndrome for 30 years, through my first husband, Blake. His mother passed away at age 29 from Marfan complications. He was 9 at the time. Blake has two sibling: a brother not affected by Marfan syndrome, and one sister who is affected. Blake and I had two children: our oldest, Alicen is not affected, and our son, Andy, has Marfan syndrome. Blake was not officially diagnosed until after we were married. He was involved in sports and played in junior high and high school. He did not start the Atenolol regimen until his mid 20s, but not regularly. Blake's first surgery was at age 32 and he passed away at age 47 from complications after his last surgery. Our son, Andy, has had pectus surgery. He started Atenolol therapy at age 10, gets his checkups regularly and never played sports. His aortic size is fine and has not increased for several years.

Blake, Andy and I attended our first Marfan conference in 1993 after Blake's first surgery. We learned about NMF from the doctors in Minneapolis and became members. Living in North Dakota, we felt isolated and didn't know anyone else with Marfan syndrome. I always wanted to start a chapter, but Blake wasn't comfortable with a lot of people and open about his MFS. Also, I felt starting a group would be a lot of work, and I didn't know how to begin. In 2006 a friend asked me to contact a woman whose daughter had been diagnosed with MFS and wanted to talk to me. A friendship began with Dena Kemmet, who is now our Vice President. She also wanted to start a group, and we began planning our dream. We contacted the NMF, and the staff members were a tremendous help. Little did we know that all the things we were afraid of having to do were already being done by NMF, and we were grateful. Guidance for meetings, opportunities for outreach, education, awareness and support were already organized and laid out for us!

We started a network group in March of 2009. Our founding members were people we met locally – a classmate, a friend, a couple who lost their son from undiagnosed MFS and others who were invited through the NMF data base. My daughter and son and Blake's aunt are also members of our group. We all feel that education in this state is imperative. We brainstormed on how to get the word out through people we knew, local medical professionals and schools. One member, Dena, contacted her local EMTs about the Emergency Medicine Campaign and they got the packet and did the training. Dena and her daughter (who is affected with MFS) spoke about their experience with Marfan and acted as patient consultants at the training. We disseminated posters at a couple of clinics during the sports physical season, contacted several places about doing the Emergency Medicine program, and hope to initiate awareness programs with them. We have taken information to local school nurses and have done three fundraising projects raising a total of \$1200.00 last year; working with two restaurants. Several members contacted their local movie theater and had Movie for Marfan day. The theater donated proceeds from ticket sales and members set up an information table with a donation jar, and had sponsors for the Hang a Heart project. It has been so rewarding when someone listens, takes you seriously and wants to follow through and learn more. Everyone involved feels such a great sense of accomplishment!

The North Dakota Chapter's greatest desire, and biggest challenge, is Marfan awareness in this state. Since we are surrounded by many rural areas, most doctors don't see a lot of people with MFS, and do not know much about the condition. This is of great motivation to us. We know first hand of a young man who died from undiagnosed MFS, and we want to prevent that from happening again. We are determined to get information out to as many as we can about MFS and get them in contact with NMF to further their education. At conference we learned of doing symposiums and that is something that would be a great asset to this state.

This spring our Local Network Group made a unanimous decision to become a Chapter. We believe we can achieve more of our shared mission with the NMF as a chapter, and everyone is committed to participating in whatever capacity necessary to make this happen. Dena and I have been thrilled that our dream is coming to fruition, and are proud of the group's accomplishments, as well as the support we all give to one another.

We have learned through the group's development process that it is important to just keep going, to keep on making contacts, following up, and following through. With a high level of commitment and a great sense of purpose, we believe that if we continue to reach "just one more", we will achieve our goal, and save one more life.

Information Technology

Introducing Brian Polk, NMF Director of Information Technology

Brian Polk, IT Director

516-883-8712 x 19; bpolk@marfan.org

My name is Brian Polk, and I am the new IT Director at the National Marfan Foundation. I've had communication with many you via the phone or email. For those whom I have not communicated with yet, please feel free to send me an email at bpolk@marfan.org or call me on the phone at 516-883-8712 x19 if you have any questions.

One of my responsibilities is maintenance of the NVN web pages. If you go to the www.marfan.org web site, click on **Get Involved** and then **Chapter and Network Group Web Pages** you will see a list of all of the chapters and network groups that currently have web pages. If your particular group isn't listed, then you don't have a web page. While there, click through some of the links in order to see what others are posting to their web pages.

I would definitely encourage all of the network groups to have their own web page. It is a great central location where members and potential members can find out about your group, see what you've already done as well as what you are planning. Events also appear on the NMF calendar of events, providing another opportunity to gain exposure for your group.

For those who already have web pages – great! Just remember that it's also important to keep your page up-to-date with changes, new events and recaps of events which have already taken place. If you don't have a web page yet, now is the perfect time to get in contact with me or Kathy Jeffers to make it happen.

We are considering scheduling a web conference on this and related topics. Let me know if this is something you would be interested in.

Exemplary Leadership Skills

Communicating with NMF Staff Creates a Winning Team!

Kathy Jeffers, Manager of Volunteer Development

Teamwork requires regular two-way communication. Paid staff members need to keep volunteers informed on matters impacting their duties, and volunteers need to reciprocate.

Don't hesitate to ask questions and keep learning more about your responsibilities and the organization as a whole. The more informed you are, the better you can do and stay energetic about your job.

Regular communication with staff can involve the following:

1. Participating in the leadership seminars offered through conference calls from fall through spring. Also, attending the leadership meeting at the NMF National Conference is our annual opportunity to meet in person, build relationships between our key leaders, staff, and board members.
2. Sharing ideas that may help the organization in some way improving member services/relations, streamlining programs, cutting expenses, etc.). We recently had an insightful and very productive discussion with Tony Dodge (Twin Cities Minnesota Chapter board member) about volunteer recognition.
3. Bringing concerns to staff to seek solutions rather than complaining to others or allowing issues to eat at you. There is always a positive track to take in solving problems.
4. Sharing your ideas, challenges, and successes.
5. Discussing how you and the NMF staff can communicate more effectively.

Have a Question? Contact the NMF Staff

Use Central NMF Phone: 800-862-7326 and staff extension listed below

Topic

Who to Contact on the NMF Staff

Network Group Management
Chapter Management
Volunteer Training & Awards
Volunteer Policies & Procedures
Leadership Connection Newsletter

Kathy Jeffers, Mgr. Volunteer Development
kjeffers@marfan.org Ext: 11

Start a Support Group
Telephone Support Contact Liaison
Support Workshops
On-line Support Groups
Insurance Questions
Child & Teen Programs

Jennifer Buffone, Dir. Support Services
jbuffone@marfan.org Ext. 22

Medical Questions
Find a Doctor
Clinic Directory

Amy Kaplan, Manager, Information & Resource Center
akaplan@marfan.org Ext. 26

Education & Awareness
- Programs/Projects
- NMF Exhibits
- Order NMF Materials

Jonathan Martin, Director of Education & Awareness
jmartin@marfan.org Ext. 16

Local Fundraising
- Event Suggestions & Guidance
- Approval of event invitations & programs
- Certificate of Insurance
Camera Ready NMF Logo, Artwork

Cathie Tsuchiya, Administrative Director &
Local Fundraising Coordinator
ctsuchiya@marfan.org Ext. 13

Legislative Advocacy
Research/Clinical Trial

Josephine Grima, PhD, VP Research & Legislative Affairs
jgrima@marfan.org Ext. 17

Budget
Financial Reports
Operating/Event Advances

Judy Gibaldi, Senior VP, Operations & Finance
jgibaldi@marfan.org Ext. 14

Connective Issues Articles
Media Outreach
- Interviews
- Local papers
- Radio/TV
NMF Style Package

Eileen Masciale, Director of Communications
publicity@marfan.org 631-665-2163

NMF Website
Your NMF Web Page
Mailing Lists/Updates

Brian Polk, Director of Information Technology
bpolk@marfan.org Ext. 19

National Conference
Planning

Maggie Hogan, Dir. Foundation Relations & Conference
mhogan@marfan.org Ext. 38

Research

New Diagnostic Criteria for Marfan Syndrome Published in Journal of Medical Genetics

New Guidelines Facilitate Accurate Diagnosis of Life-Threatening – but Treatable – Genetic Disorder

Note: This press release from the NMF will give you important background on the new criteria.

PORT WASHINGTON, NY, July 1, 2010 – An international panel of experts in the diagnosis and management of Marfan syndrome, a potentially fatal genetic disorder, has published new diagnostic criteria for the disorder, thus simplifying the evaluation process for physicians. The new diagnostic process – which continues to be based primarily on a multi-system clinical examination – will provide patients with a more accurate diagnosis and better medical management. The new criteria for Marfan syndrome were published in the Journal of Medical Genetics (*J Med Genet* 2010;47:476-485)

“The diagnostic evaluation for Marfan syndrome is unavoidably complex due to the highly variable presentation of affected individuals, the age-dependent nature of many of its manifestations, absence of gold standards and its extensive differential diagnosis,” said Bart Loeys, MD, Center for Medical Genetics, Ghent University Hospital, Ghent, Belgium, who spearheaded the panel. “While diagnostic criteria should emphasize simplicity of use and the desire for early diagnosis, the highest priority in developing these guidelines was accuracy.” Marfan syndrome and related connective tissue disorders affect approximately 200,000 Americans. Because connective tissue makes up the entire body, the disorder manifests itself in many body systems, including the skeletal system, eyes, lungs, blood vessels and heart. Many people with Marfan syndrome experience an expansion of the aorta. It is essential for affected people to be diagnosed and managed properly. Without proper monitoring and medications to reduce the stress on the aorta, affected people are at high risk for aortic dissection or rupture, which could result in sudden death. With an accurate diagnosis and proper medical treatment, they can live a normal lifespan.

The new nosology provides a method for evaluating a patient by deriving a systemic score, with various features of Marfan syndrome assigned a numeric value; the diagnosis depends on the total systemic score. This is a change from the previous nosology which relied on evaluation of features as “major” or “minor.” A web-based diagnostic tool for the application of the new criteria is available for physicians at the National Marfan Foundation website, www.marfan.org.

The scoring system reflects three significant changes in the way Marfan syndrome is diagnosed:

- The two cardinal features of Marfan syndrome – aortic root dilatation/dissection and ectopia lentis (dislocated lens of the eye) – are weighted more heavily than other characteristics.
- There is a more precise role for molecular testing.
- Less specific manifestations of Marfan syndrome are either removed or given much less weight in the evaluation process.

The diagnostic criteria have been defined for those with a family history of the condition and for those who may be a sporadic case; that is, they are the first in their family to be affected. Specific guidelines are also given for children (less than 20 years of age), with different scenarios proposed for those with family history and those without family history. For those who do not meet the diagnostic threshold for Marfan syndrome or a related condition, the nosology employs the diagnosis of “non-specific connective tissue disorder,” which fosters ongoing monitoring of aortic size and function, until a specific diagnosis can be made.

The nosology also offers additional diagnostic considerations and recommends more testing if a patient has sufficient findings of Marfan syndrome but, additionally, shows other unexpected features. The differential

diagnosis and management for alternative diagnoses, such as Loeys Dietz syndrome, vascular Ehlers Danlos, mitral valve prolapse syndrome, familial aortic aneurysm and more, are outlined.

“These new diagnostic criteria will be of great benefit to both physicians, particularly those who do not see many cases of Marfan syndrome, and patients,” said Carolyn Levering, President and CEO of the National Marfan Foundation, Port Washington, NY. “It addresses the practical challenges that diagnosing the condition presents to physicians and, at the same time, protects patients by balancing the use of diagnostic categories with a discussion of ongoing risk and the need for follow-up and management.”

Methodology

The revised nosology was based on critical review of clinical characteristics in large published patient cohorts, the experience and opinions of the panel members with extensive experience in applying the former criteria, the differential diagnosis of Marfan syndrome, and the strengths and limitations of molecular genetic testing. The guiding principals for revising the diagnostic criteria were: maximal use of evidence-based decision-making; attention to practical implications; a focus on features and criteria that distinguish Marfan syndrome from other disorders; and definition of purposeful thresholds for diagnosis.

In addition to Dr. Loeys, the panel was comprised of the following Marfan syndrome experts: Harry C. Dietz, MD, and Paul Sponseller, MD, Johns Hopkins University School of Medicine; Alan C. Braverman, MD, Washington University School of Medicine; Bert L. Callewaert, MD, Julie De Backer, MD, and Anne M. De Paepe, MD, Ghent University Hospital; Richard B. Devereux, MD, Weill Cornell Medical College; Yvonne Hilhorst-Hofstee, MD, Leiden University Medical Center (the Netherlands); Guillaume Jondeau, MD, Hopital Bichat (Paris, France); Laurence Faivre, MD, Children’s Hospital, (Dijon, France); Dianna M. Milewicz, MD, PhD, University of Texas Medical School; Reed E. Pyeritz, MD, PhD, University of Pennsylvania; and Paul Wordsworth, MD, Nuffield Orthopaedic Center (Oxford, UK).

Funding for the development of revised nosology for Marfan syndrome was provided by the National Marfan Foundation, March of Dimes, Merck and Solvay Pharma.

Contact: Eileen Masciale, NMF Director of Communications
Tel: 631.665.2163; publicity@marfan.org

Communications

Key Points to Know About the Revised Diagnostic Criteria

Eileen Masciale, Director of Communications

Purpose:

- Simplify the evaluation process for physicians.
- Provide patients with a more accurate diagnosis and better medical management

New: Systemic Score

- Assigns various features of Marfan syndrome a numeric value (no more “major” or “minor” criteria)

Changes in Marfan Syndrome Diagnosis:

- The two cardinal features of Marfan syndrome – aortic root dilatation/dissection and ectopia lentis (dislocated lens of the eye) – are weighted more heavily than other characteristics.
- There is a more precise role for molecular testing.
- Less specific manifestations of Marfan syndrome are either removed or given much less weight in the evaluation process.

Other Considerations:

- Diagnostic criteria have been defined for those with a family history of the condition and for those who may be a sporadic case

- There are specific guidelines for children (under 20) – with and without family history.
- New category of “non-specific connective tissue disorder” for those who do not meet the diagnostic threshold for Marfan syndrome or a related condition; emphasizes continued follow-up, especially of the aorta.
- Additional diagnostic considerations and recommends more testing if a patient has sufficient findings of Marfan syndrome but, additionally, shows other unexpected features.
- Outlines differential diagnosis and management for alternative diagnoses, such as Loeys Dietz syndrome, vascular Ehlers Danlos, mitral valve prolapse syndrome, familial aortic aneurysm and more.

A question you may hear is: If I or a family member has a Marfan syndrome diagnosis, what do the revised criteria mean to me?

We asked Dr. Hal Dietz and this is what he told us:

The revisions to the diagnostic criteria focus on improving the efficiency of the diagnostic process, assuring accurate diagnosis, and suggesting follow-up procedures for people who do not meet diagnostic criteria. Importantly, the diagnostic criteria largely formalize existing diagnostic philosophies and practices. We do not anticipate that the diagnosis will change for the majority of individuals, and we anticipate that most diagnostic changes will not alter management. On this basis, we do not believe that individuals with an established diagnosis of Marfan syndrome should schedule an immediate appointment for consideration of these revisions. Rather, this should be a topic for discussion at the time of the next routine follow-up visit.

Education & Awareness

Raise Awareness and Funds Using NMF Youtube Videos **Jennifer Buffone, LCSW, Director of Support and Volunteer Development**

Did you know the NMF has a Youtube page? The NMF often creates short videos, 5 minutes or less, for a variety of purposes to honor individuals who receive awards at the Annual Conference and Heartworks Galas, to educate, to raise awareness and to raise funds. Most of these videos are on the NMF's Youtube page and can be easily accessed by NMF volunteers. Video is a great way to add something different and special to group meetings, awareness events and fundraisers. Video provides a visual and makes presentations more dynamic. The NMF recently created three videos on the Annual Conference, a 2010 Conference video recap, a kid and teen program video and a patient assessment video. These videos could be used to show local group members who have never attended a Conference what it's like and to raise funds for the Conference scholarship program and kid and teen programs. The NMF also recently created a Faces of MFS video which features close ups of children living with Marfan syndrome. This video can be used to raise awareness, to educate and to raise funds. You could have it playing in the background at any event or highlight it during an educational activity. The uses are endless. These are examples of just 4 of the many videos on the NMF's Youtube page. The next time you organize a meeting or event consider using video to enhance your presentation. To view NMF videos go to www.marfan.org and click the Youtube icon on the homepage. The NMF is also happy to email volunteers specific videos. Reminder: If you are looking for something longer to show at event or meeting the NMF also has several DVDs such as the Heart of the Matter DVD. These DVDs are in your lending library.

*Look to this day, for it is life, the very life of life
... the glory of power for yesterday is but a dream
and tomorrow is only a vision.
But today, well lived
makes every yesterday a dream of happiness
and every tomorrow a vision of hope.*

~ Mahakavi Kalidasa

Support

Connect With Local Doctors to Raise Awareness of NMF Services and Local NMF Groups

Jennifer Buffone, LCSW, Director of Support and Volunteer Development

Here's a simple awareness project for individual volunteers or groups, and it doesn't require you doing anything you don't already do. The NMF has posters and postcards detailing services the NMF provides, such as the Information Resource Center, NMF website, Annual Conference, Connective Issues Newsletter, and our local Chapters and Network Groups. Simply request a supply of posters and postcards from the NMF, and bring them to your individual doctors. Ask them if they will hang the poster up or keep a supply of postcards on hand to give to patients who may have Marfan syndrome or have Marfan syndrome. Bring them to your cardiologist, ophthalmologist, orthopedist, geneticist, pediatrician and general practitioner. If you are part of a local Chapter of Network Group, you can also bring information on your group. This doesn't require a special trip. Bring them the next time you or your family member have an appointment. It's a simple way to raise awareness of Marfan syndrome, the NMF and its services. To obtain a supply of the posters and postcards contact Jennifer Buffone, Director of Support Services and Volunteer Development at jbuffone@marfan.org.

Support Q & A

Stenting and Marfan Patients

Amy Kaplan, RN, BSN, Manager, Information and Resource Center

1-800-8-MARFAN ext. 26; akaplan@marfan.org

In this column we showcase sample questions and answers on topics that you may encounter. Amy is available for consultation five days a week at akaplan@marfan.org or 800-862-7326 x 26.

Q: *I'm under the impression that the NMF doesn't endorse stenting as a recommended option for Marfan patients, but I thought I'd check to see if the NMF has an official position on the topic.*

A: You are correct. The use of stents in patients with Marfan syndrome remains controversial and is generally not recommended for individuals with Marfan syndrome or related disorders of the connective tissue. Minimally invasive cardiac procedures in lieu of open heart surgery are generally not recommended for affected individuals. A number of our experts have serious concerns regarding the use of stents and stent-like implants with Marfan patients. Because data on use of stent-grafts in people with Marfan syndrome are very limited, there is insufficient information to guide decisions regarding their safety and efficacy.

According to our understanding there are very limited situations in which stenting is considered, and we would suggest that you consult with one or more of the Marfan experts concerning whether stenting would be a viable option to consider in your case. The NMF IRC can provide a clinic directory and partial list of surgeons (by no means complete) known to the National Marfan Foundation as having Marfan expertise.

Disclaimer: The National Marfan Foundation (NMF) is a health advocacy organization. The NMF does not provide medical advice or treatment. We are not a health care provider. It is important to realize that information provided by the NMF is not meant as a replacement for proper care from a doctor, therapist, etc. Information provided by the NMF is not a substitute for medical treatment or psychological care. It is vital that you talk with your health care providers regarding the diagnosis and treatment of Marfan syndrome and related disorders and your symptoms/features. Minors should consult with a parent/legal guardian when considering treatment and providers.

Health care provider information is supplied solely by the providers themselves and is not checked or warranted by the National Marfan Foundation. The NMF provides contact information for health care providers who are known to have seen patients with Marfan syndrome and related disorders. The NMF does not endorse or recommend individual health care providers. You are responsible for interviewing and selecting the practitioner. By requesting health care provider resources you understand and agree that the NMF and its affiliates are not responsible for any providers' services or lack thereof.

Fundraising

Fall - the Perfect Time to Plan Fundraising Activities!

For ideas and to find out how to get started, contact Cathie Tsuchiya, NMF Local Fundraising Coordinator, at ctsuchiya@marfan.org or 800-862-7326, ext. 13.



- **Get ready to Hang Hearts for Valentine's Day!**

Help raise awareness and funds for the NMF by asking local businesses, schools etc. to "sell" our red paper hearts and hang them prominently for all to see. Although this can be done any time of year, they add a really special look around Valentine's Day – a great way for businesses to "decorate" for the holiday while showing they have a heart for Marfan syndrome! Now's the time to get started – so contact the NMF to find out how!

- **Get your families involved!**

The Saturday before Thanksgiving, November 20th, is National Family Volunteer Day. There are many opportunities for family members to volunteer in ways that result in significant contributions to the Foundation mission areas of education, support and research. Family volunteering is not new to the Marfan community. From getting local businesses to participate in Hang-a-Heart -- to organizing a fundraising event, large or small -- there are many ways that families can participate in volunteer activities to benefit the NMF.

- **Start planning for the holidays!**

The holidays are a time for giving – and a time when it's more important than ever to show how meaningful it is to **give back** – so, this holiday season, instead of giving store-bought gifts, ask your family, friends and colleagues to make a donation to the National Marfan Foundation. Let them know that all donations will support the NMF's lifesaving mission of research, education and support for people living with Marfan syndrome and related disorders. Tell them how much your support will mean to you and your family, and to all those in the Marfan community. Mention the benefit of their tax-deductible donations that are made by December 31st.

National Conference News

Conference 2011 in Portland, Oregon

The 27th Annual Conference on Marfan Syndrome and Related Disorders will be held July 14-17 in Portland, Oregon at the Portland Marriott Downtown Waterfront hotel. We will be on the riverfront, near Shriners Hospital and many of the top attractions in the downtown area. Look for details on the NMF web site in February!

On the last page of this newsletter, is a flyer to share with members in your area.

Conference 2012 in Chicago, Illinois

We are pleased to announce that the 28th NMF Annual National Conference will take place in Chicago, August 2-5 2012, in conjunction with Northwestern Memorial Hospital. We will be located at the Allerton Hotel, across the street from the hospital.



NMF Annual National Conference 2011 SAVE THE DATE!

**Co-sponsored by Shriners Hospitals for Children and
Oregon Health & Science University**

- ★ Attend workshops and medical presentations by world-renowned doctors and researchers
- ★ Make an appointment for a medical assessment at the Marfan Clinic when registration opens in the Spring of 20-11 (limited availability)
- ★ New Young Adults Program
- ★ Bring your children and teens for a special fun-filled and educational weekend
- ★ Share experiences with others in the supportive environment that is unique to NMF conferences

**Look for details on the NMF web site in January 2011
at www.marfan.org**