



Leadership Connection

September 2011

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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 Seminars and Individual Consultation Schedule

One-hour Conference Call Seminars

open to Chapter and Network Group leaders, Telephone Support
Contacts, and all group members with leadership potential.

To Register:

Contact Barbara Habermann

bhabermann@marfan.org or call 1-800-8-MARFAN X 36



Individual Consultations with NMF Staff Members
available by appointment.

FALL/WINTER CONFERENCE CALL SEMINAR SCHEDULE

1. Chapter Leaders Open Forum

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 interests or questions by 10/4 to Kathy Jeffers' e-mail at kjeffers@marfan.org.

Moderator: Kathy Jeffers, NMF Manager of Volunteer Development

Date: Tuesday, October 18

Time: 7:30 pm ET

Sign up by: 10/11

2. Network Group Leaders Open Forum

Designed as a forum for peer consultation, Network Group leaders will discuss what's working and what's not. Share your prized successes, challenges, solutions and new ideas with other group leaders. Specific staff members can be invited as needed, with advance notice. Submit topics or questions by 10/5 to Kathy Jeffers at kjeffers@marfan.org.

Moderator: Kathy Jeffers, Manager of Volunteer Development

Date: Thursday, October 20

Time: 7:30 pm ET

Sign up by: 10/12

3. Telephone Support Contact Open Forum

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.

Moderator: Jennifer Buffone, Director of Support and Volunteer Development

Date: Friday, October 21

Time: 1:00 pm ET

Sign up by: 10/13

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

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.

Presenter: Carolyn Levering, President & CEO

Date: Tuesday, November 8

Time: 1:00 pm

Sign up by: 11/1

5. Using Online Resources To Enhance Your Group

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

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

Date: Friday, November 18

Time: 1:00 pm ET

Sign up by: 11/10

6. Reaching Out to Your Local School Nurses

School nurses play a vital role in the health of our nation's children and teens. They are in a unique position to help identify students who are in need of an evaluation for Marfan syndrome or related disorders, and, equally important, they are key members of the healthcare team for those who have been diagnosed. Find out how you and your group can reach out to school nurses in your area with valuable NMF resources.

Presenter: Jonathan Martin, Director of Education and Awareness

Date: Wednesday, November 30

Time: 7:00 pm ET

Sign up by: 11/16

7. Incorporating and Enhancing Support Services for Your NVN Group

Often one of the main reasons volunteers decide to start a local group is to provide and receive support. However, group leaders don't always know how to incorporate and enhance support services for members of their group. While simply providing a time and place for group members to get together, talk and share experiences can be a very powerful support service you can offer group members, there are many other things you can do to provide support for your group members. This training will provide you with concrete projects and ideas you can implement to provide and enhance support services for your group members.

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

Date: Friday, December 2

Time: 1:00 pm ET

Sign up by: 11/17

8. Organizing Your Marfan Story

The most valuable asset the NMF has is its vast network of volunteers with real stories to share. These stories can be used to increase public awareness, provide support to other affected individuals and families, and to help healthcare professionals understand the realities faced by people living with Marfan syndrome and related disorders. Being able to tell your story in an audience-specific way with strict time constraints can be a challenge. Find out how you can organize the key points of your story, consider what parts are appropriate for different audiences, and speak with confidence.

Presenter: Jonathan Martin, Director of Education and Awareness

Date: Monday, December 5

Time: 7:00 pm ET

Sign up by: 11/28

9. Using Online Resources To Enhance Your Group

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

Presenter: Jonathan Martin, Director of Education and Awareness

Date: Monday, December 12

Time: 7:00 pm ET

Sign up by: 11/10

INDIVIDUAL CONSULTATIONS and PROJECT COACHING BY APPOINTMENT

Please contact the staff member who can best help you accomplish what you want to do. Otherwise, call Kathy Jeffers, who can help guide you to the appropriate person.

Group Management, Growth & Resources

Meeting invitations, agendas, reports, materials
Strengthening your group
Leaders Resource Book
Business expense reimbursement
NVN Policies, Procedures

Kathy Jeffers (800-862-7326 x 11; kjeffers@marfan.org)

Communications & Media Connections

Promote group through local media
Create a newsletter
Create a group flyer/brochure
NMF Style Guidelines

Eileen Masciale (631-665-2163; publicity@marfan.org)

Education & Awareness Projects & Events

Implement an education or awareness project
Outreach to schools, medical community, public
Memorial Quilt Project

Jonathan Martin (800-8-MARFAN x 16; jmartin@marfan.org)

Local Fundraising

Successful fundraising ideas
How to develop a local fundraiser

Cathie Tsuchiya (800-8-MARFAN x 13; ctsuchiya@marfan.org)

Support

Medical Office Outreach Project
Develop a support function for your group

Jennifer Buffone 800-8-MARFAN x 22; jbuffone@marfan.org

Research & Legislative Affairs

Request speakers from our medical community
Guidance on Legislative Affairs

Josephine Grima 800-8-MARFAN x 17; jgrima@marfan.org

REMEMEMBER FAMILY VOLUNTEER DAY

Saturday, November 19!

The Saturday before Thanksgiving, November 19, 2011, is "National Family Volunteer Day", demonstrating the power of families who choose to volunteer together to support their favorite cause in the communities in which they live and serve. The NMF provides many opportunities for family members to be role models, while making significant contributions to the Foundation's programs in education, awareness, and support and fundraising.

Volunteering as a family provides many benefits:

- quality family time for busy families
- strengthens communication and bonds
- positively impacts our local Marfan and related disorders communities
- teaches positive values to children
- creates life-long volunteers and a legacy of volunteering for the next generation to carry into the future.

Need some ideas? Set up an **awareness display** on the NMF and Marfan syndrome at a local community event (health fair, craft fair), at your hospital, clinic, school, business, grocery store or mall. Get the whole family involved in a **garage sale**, while doing a fall cleanup. **Offer services for sale:** childcare, painting, yard work, house cleaning, gift wrapping, shopping for holiday gifts, etc.

The NMF will highlight families who volunteer together in November, or any time of year! Please send a photo and description of your volunteer project to Kathy Jeffers, NMF Manager of Volunteer Development, at kjeffers@marfan.org.

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 or update your page, contact Kathy Jeffers at kjeffers@marfan.org .
October	Sign up for conference call workshops and individual consultations
October 30	Chapters: First Quarter Financial Reports Due
November 19	Family Volunteer Day
January 1, 2012	Deadline for Connective Issues: send your meeting/event dates & photos to Kathy Jeffers at kjeffers@marfan.org; Fundraising dates and photos to Cathie Tsuchiya at ctsuchiya@marfan.org (Photos must be in high resolution jpeg format).
February	National Marfan Awareness Month NMF Have Heart Campaign Hang a Heart Fundraisers across the country
April 15-21	National Volunteer Week
August 2-5	NMF National Conference in Chicago, Illinois

KUDOS

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

Thank You Portland Network Group and Volunteers for NMF Conference 2011!

Invaluable support for the NMF National Conference in Portland came through Rebecca Stroda, Chair of the Portland Network Group and Local Volunteer Coordinator, who, along with Jennifer Powers, coordinated a dynamic volunteer team from all over the city. Kathryn Thompson and her team created a fabulous Heart Mart that raised over \$4,000 for conference scholarships.

A Grateful Bow to the Portland Skyliners of Tall Clubs International for your volunteer support of the NMF National Conference. Megan Lukens, Sue Layton, Will Werner, President - it was great to meet you all, and heartwarming to have your participation. Thank you for joining the NMF in this life-saving partnership.

Congratulations New Group Leaders!

New Chapter President

Amy Speck, President Mid-Atlantic Chapter – 301-371-5660; siberianspring@hughes.net

New Network Group Chairs

Barbara Krueger, Co-chair San Diego Network Group - 858-792-6061; bkrue@earthlink.net

Phyllis Weiss, Co-chair San Diego Network Group – 858-282-8466; pweiss1@san.rr.com

Renita Salzillo, Co-chair Eugene Network Group – 541-603-5617; renitann17@yahoo.com

Welcome New Network Groups!

Nashville, Tennessee

Barry Martin, Chair – 615-758-5005; nccbmartin@hotmail.com

Northeast Florida

Marybeth Geronimo, Chair – 904-825-0710; mgero67@aol.com

Orlando, Florida

Nadine Spain, Chair – 404-275-7760; nadinespain64@gmail.com

Southwest Florida

Betty Carr, Co-Chair – 239-395-3410; ewcarr39@aol.com

Nadine Sarlin, Co-chair – 239-390-1487; nadinesarlin@gmail.com

Southeast Florida: Continuing with new co-leadership

Stacey Tabacco, Co-Chair - 954-707-2293; jacobmommy2002@yahoo.com

Betty Hiraga, Co-Chair – 954-265-5823; bhiraga@mhs.net

Tampa, Florida

Michele Perlotto, Chair - 813-395-8323; mfernmfern@yahoo.com

Sarasota, Florida

Candy Labovites – 303-570-2216; candylee55@gmail.com

Tidewater Area Virginia

J.D. Oliver & Jean MacLeay, Co-chairs; oliverva@aol.com or 757-962-4823



NMN VOLUNTEER SPOTLIGHT:

**Jon Rodis, President
Massachusetts Chapter
617-846-4975; jrmarfan58@aol.com**

Brief Bio: *Jon has a B.S. in Management at Northeastern University, M.B.A. in Executive Management at Suffolk University. Jon had over 20 years experience in business management/consulting with eight years in senior management positions. He worked as a Business Development Manager for MyKroWaters, a family run environmental firm until becoming permanently disabled in the Fall of 2001. Since that time, Jon has been involved with several Marfan and related connective tissue awareness initiatives. Among them, Jon created a website on his experiences with Marfans and wrote a Disability Checklist that was featured in a Winter 2005 issue of the NMF's Connective Issues. Jon has helped many people get approved for SSI and SSDI in the early stages of the process. He is currently the President of the NMF Massachusetts Chapter and Chair of the Chapter's Physicians Awareness Committee. Jon has dedicated his life to spreading the word on Marfan and other related connective tissue disorders, doing whatever he can to improve the lives of those who are affected.*

1. Tell us about yourself, your career, family and your connection to Marfan syndrome.

I was diagnosed in 1966, when I was just 8 years old. Our family doctor, who also delivered me and my sisters, suspected some form of condition when he saw my long legs, fingers and slightly indented chest bone. He sent me to see an orthopedist and ophthalmologist at Children's Hospital in Boston and that is when my mother and I received the news.

Through the years, not much was known about Marfan so my doctors didn't have much to tell me other than to check my heart every so often. I, like many others with Marfan, went about with life and probably did a lot of activities that weren't beneficial to my health. (lifting weights, active in sports, skydived, etc.) As time went by and my health went from a back seat to the front seat, I somehow was able to get my undergraduate and graduate degrees and build a successful career in business management. I think a lot of my strength to achieve what I did, despite my health issues, was due to my mother, who taught us to work hard for what we want and to do it with honor, respect, and heart.

2. How did you become involved in the NMF? The Massachusetts Chapter?

After becoming disabled in 2001 and having my life turned upside down, I made a promise to myself to learn as much about Marfan syndrome as I possibly could. The National Marfan Foundation was a wonderful resource for information and support through what was one of the darkest periods of my life. Once I got back on my feet, I made another promise to help the NMF in any way I possibly could both locally and nationally.

It's pretty amazing to think that the first time I met another person with Marfan syndrome was in 2003 at my first Massachusetts Chapter Support Group meeting at the home of Richard Saltus. (who was President at the time.) From the moment I walked in the door, I was so excited. I saw people who looked like me, have experienced many things I had and didn't stare at me or tell me how tall I am. On the ride home, I was so happy and excited that I was like a little kid at Christmas, as my wife Kathleen described it.

3. What have been your most successful and satisfying activities, meetings or events?

I have enjoyed all the meetings and events through the years. One of my greatest experiences was attending my first National Marfan Foundation Conference which was in Philadelphia in 2006. At the conference, while reading one of the exhibits, a woman next to me said, 'Jon Rodis' and I turned to her not recognizing her read her name tag which read, Priscilla Ciccariello. We were both very happy to see one another and especially how we met, after having been friends through e-mail for many years. She had been a major influence in my life and work to that date and till the present day.

4. How have you enjoyed your experience with the Massachusetts Chapter?

Ever since I walked through that door in 2003, the Massachusetts Chapter has become an important part of my life. Along with the strength, love and support I get from my wife Kathleen and my family, I am extremely lucky to have so many who I now call friends in my home state. Indeed, I now have a much larger family not just here in Massachusetts but around the world.

5. What motivates you to stay involved with the Chapter and the NMF?

My main motivation in staying involved with the Chapter is the members and what we have shared and accomplished together through the years. Although our lives can take us in different directions at times, we are always there to lend each other support. It is this bond that makes what we go through on a daily basis that much better.

6. What is your best advice for other group leaders?

One of the best things I can say to all the group leaders around the country is that you are not alone in your efforts to help one another. The key, no matter how small or large your group is, is to meet regularly, foster communication and awareness, utilize all the tools and tips the NMF has to offer and network both locally and nationally with other group leaders to maximize support for your membership.

Exemplary Leadership Skills

Who Are Your Heroes? Ways to Recognize Your Volunteers!

Kathy Jeffers, Manager of Volunteer Development
516-800-8-MARFAN x 11; kjeffers@marfan.org

One of the best practices you can develop as a group leader is thanking your volunteers, who are often our unsung heroes. As a volunteer leader, express appreciation to those who step up and help the group accomplish your goals. Thank those who take higher positions of responsibility, as well as those who are the helpers. Thank them in seven different ways! Here are some ideas you can use to recognize volunteers for various levels of contribution.

1. Always thank your volunteer in person.
2. Write a special note, or make a phone call in addition to solidify your appreciation.
3. Also thank their spouse and family, who may have helped, but who always sacrifice time together while your volunteer is working.
4. Highlight their names and their contribution at a meeting or in your newsletter. Add photos for extra impact.
5. Celebrate their accomplishments with a special cake or homemade cookies at your next meeting.
6. Host an appreciation event: breakfast, lunch, dinner, or tea to honor volunteers and the group's accomplishment. Consider the possibility of asking those who were not able to volunteer for a specific event to host this gathering.
7. **New Ideas: Contact Kathy Jeffers, Manager of Volunteer Development at the NMF to report your outstanding volunteers.** Use the NMF Meeting Report (see a copy on "Attachment A" on the last page of this Leadership Connection), which provides a space to highlight your deserving volunteers. You can also call at any time to request one of the following tokens of appreciation for your special volunteer.
 - **An NMF Certificate of Appreciation in a presentation folder**
 - **A heart pin/tie tack (red enamel with silver signature heart)**
 - **An NMF volunteer pin for those who have given 100 hours or more**

The Wisdom of Flying Geese

Retold by Kathy Jeffers, Manager of Volunteer Development

The following parable highlights the importance of cooperation and supportive teamwork that can be inspired by group leadership. Tell this story to your group members to deliver a strong, but compassionate message that everyone must do their part. Then delegate jobs you need to have done!

In the Fall, when you see geese heading south, or in the spring, when you see them heading north for the summer, flying along in the V formation, you might be interested in knowing what scientists have discovered about why they fly that way. It has been learned that as each bird flaps its wings, it creates an uplift for the bird immediately following.

By flying in "V" formation, the whole flock adds at least 71 percent greater flying range than if each bird flew on its own.

Basic Truth No. 1: *People who share a common direction and sense of community can get where they are going quicker and easier because they are traveling on the thrust of one another.*

Whenever a goose falls out of formation, it suddenly feels the drag and resistance of trying to go it alone and quickly gets back into formation to take advantage of the lifting power of the bird immediately in front.

Basic Truth No. 2: *If we have as much sense as a goose, we will stay in formation with those who are heading in the same direction as we are.*

When the lead goose gets tired, he rotates back in the wing and another goose flies point.

Basic Truth No. 3: *It pays to take turns doing hard jobs, with people or with flying geese. These geese honk from behind to encourage those up front to keep up their speed.*

Basic Truth No. 4: *We need to be careful what we say when we honk from behind.*

Finally, when a goose gets sick or is wounded by gunshot and falls out, two geese fall out of formation and follow him down to help and protect him. They stay with him until he is either able to fly or until he is dead, and then they launch out on their own, or with another formation, until they catch up with their group.

Final Truth: *If we have the sense of a goose, we will stand by each other, protect one another and sometimes make new friends who seem to be going in our direction.*

National Conference News

Leadership Meeting Report: Conference 2011 in Portland, OR

Kathy Jeffers, Manager of Volunteer Development

The format of our Leadership Meeting schedule at conference was reconfigured this year to accommodate travel to the west coast. Friday afternoon showcased successful projects and events implemented by various groups that could be duplicated by others: Jon Rodis (, followed by a reception with the NMF Board of Directors. You can discuss project ideas with their creators

On Sunday, a workshop track for NVN leaders focused on three topics, "Using the NMF Website and Social Networking Sites to Enhance Your Group", "Fundraising", and a "Town Meeting" with Carolyn Levering, NMF President and CEO. Although there were no handouts for these sessions, you may take advantage of upcoming conference call seminars on the same subjects.

Feedback from all attendees was very positive. The consensus for next year was to add more time to Friday afternoon for sharing projects and discussing issues pertinent to group development. All agreed that it was beneficial that we opened registration for the Leadership Meeting and Sunday NVN workshops to those who showed leadership potential, without having to register for the conference. This enabled local members, especially, to participate in a productive way and bring back ideas to strengthen their group.

Conference 2012

Mark your calendars for next year's conference hosted by Northwestern Memorial Hospital in Chicago, August 2-5, 2012. We have secured the Allerton Hotel and will have extra accommodations at the Inn of Chicago. Check the NMF website in February for conference details.

2012 will also mark the 20th anniversary of the Northern Illinois Chapter. Time to celebrate!

Local Conference Scholarship Fundraising

Remember, the NMF encourages Chapters and Network Groups to fundraise to help two members attend the conference. It is strongly suggested that the primary leader or co-leader of the group attend. In addition, another person who is active in group activities should be selected. Selection of those who receive the group's assistance should be based on values similar to those the NMF uses for scholarships: financial need, need for diagnosis, lack of access to experienced medical care, has not attended conference in the past, is a participating group member, is capable and willing to report back to the entire group on their conference experience and what they learned. If your group raises funds for conference scholarships and nobody from your group is able to attend, consider donating to the NMF Conference Scholarship Program, where it will always go to good use!

Education & Awareness

Información en Español Sobre el Síndrome de Marfan

Jonathan Martin, MS, Director of Education and Public Awareness
(516) 883-8712, ext. 16; jmartin@marfan.org

The NMF is pleased to announce that the entire series of Heart of the Matter fact sheets is now available in Spanish, thanks to the educational grant from the Centers for Disease Control. It has long been a goal of the NMF in our strategic plan to provide information to underserved populations, and reaching monolingual Spanish speakers is an important part of this goal. The entire series is available for download for free on the NMF website at <http://marfan.org/marfan/2326/Fact-Sheets/>. A limited number have been printed and are available for targeted outreach activities.

Also, our children's book, *Marfan Syndrome A to Z*, is also available in Spanish at <http://marfan.org/marfan/2493/Children-and-Teens> (scroll to the bottom). Until we identify a source of funding for this, this one is only available as a PDF.

Contact Jonathan Martin, Director of Education and Public Awareness at jmartin@marfan.org if you are planning an event or activity and would like to obtain educational resources for free.

Marfan Memorial Quilt

The Marfan Memorial Quilt project was started in 2003, and consists of individually crafted quilt blocks lovingly created to memorialize family and friends lost to Marfan syndrome and related disorders. In addition to being a touching tribute, it is an important symbol of the importance of public awareness that encourages early and correct diagnosis. Many people have reported that creating a block has helped them to grieve and to pay tribute to their loved one.

You can view a video slideshow of the quilt here:

<http://www.youtube.com/user/NationalMarfanFndtn#p/u/25/i5gBZMyhcDs>.

SEWING SKILL IS NOT NECESSARY. Many people have made blocks out of iron-on transfers or patches, fabric paints, a loved one's favorite t-shirt. The possibilities are endless. You can get the guidelines for creating a block on the NMF website at <http://marfan.org/marfan/2615/Marfan-Memorial-Quilt>.

Contact Jonathan Martin, Director of Education and Public Awareness, at jmartin@marfan.org for more information of if you would like to brainstorm ideas for creating a quilt block.

Information Technology

NMF Integrity: Dealing with Risk

Brian Polk, Director of IT

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

Risk is an area which we all need to be constantly vigil about. For an organization like NMF, risk is something which is of paramount importance. Risk covers a wide variety of topics, including making sure that the information we keep about our constituents is adequately secured.

Many of you regularly request a copy of the NMF's constituent database for people within your support region. We are responsible to our constituent base to make sure that this data is handled in a way which is secure and without risk. Using email to send any information is inherently insecure, meaning that there are ways in which others may be able to gain access to the information.

Some of you have seen that we have started using third-party services in order to transmit these database files to you. We are now using TransferBigFiles. These services work by sending you a secure link to the file, rather than emailing you the file directly. This allows us to reduce the risk that the NMF's constituent information may be viewable by outsiders.

The email you receive will look like it came from me, and will contain an embedded link to a secure web page where you can download the file. You just need to click on the link and then select "Download".

You may ask for an updated constituent list at any time. The NMF no longer sends them out automatically twice a year.

A big "thank you" to everyone for their partnership and assistance in preserving the integrity of the organization.

Support

Using NMFconnect and Facebook to Provide Support and Find New Group Members

Jennifer Buffone, LCSW, Director of Support and Volunteer Development

516-883-8712 x 22; jbuffone@marfan.org

Are you a member of NMFconnect? The NMF Facebook page? If you answered no to either of these questions the next thing you should do after finishing reading this newsletter is to sign up for both. NMFconnect and the NMF Facebook page both provide great ways for you to connect with your group members in between in-person meetings. They also provide a place for you to announce group events and are a great way to find new potential members for your group.

Even if you've already signed up for NMFconnect and are a member of the NMF Facebook page, you may not be taking advantage of all of the ways you could be using them to enhance your group. For example, do you post all of your group's meetings and events on both NMFconnect and Facebook? If not, you should. While some people are members of both not everyone is and there are constantly new people joining both NMFconnect and the NMF Facebook Page. There are a good number of people that participate in NMFconnect and/or the NMF Facebook page that haven't ever contacted the NMF any other way. Due to this, these people aren't in the NMF's database and therefore aren't part of your group's mailing list. If the only way you promote your group's meetings and events is by sending out a flyer or email you probably aren't reaching all of the potential people who could be participating in your group's activities. The National office now routinely posts everything we send out in the mail or by email on NMFconnect and the NMF Facebook page to ensure that we are reaching the widest audience. You can also find new families in your local area living with Marfan

syndrome and related disorders by posting your events on NMFconnect and Facebook every time you send a mailing or email to your members.

Some group leaders also make a point to introduce themselves to anyone from their state who is new to NMFconnect or Facebook. They will check both forums on a regular basis - weekly/bi-weekly/monthly - for new people from their state and when there is a new person, they will introduce themselves and let the person know about the local group. This is a great job for a member of your group who enjoys participating in social networks and participates often on their own. Remember, the group leader doesn't always have to be the person to take on every task. Don't be afraid to find members of your group who are happy to do tasks like this and give them the assignment.

Does your group have an online group in NMFconnect in addition to your in-person group? Creating an online group is a great way to stay in touch between meetings. Once you've joined NMFconnect, you can create an online group in five minutes or less. It's as easy as clicking on "groups", clicking "add a group" and then writing your group name and a brief description. An online group is a great way to provide support 365 days per year.

NMFconnect and Facebook can also be a great way to raise funds for your group and the NMF. The Iowa Chapter recently had an auction as part of a larger event. To increase auction bids the Chapter posted photos of the auction items on Facebook to provide people who weren't able to attend the event in person with a way to bid. This is just one way these online resources can be used to enhance your group's fundraisers.

To learn more about using online resources to enhance your group, sign up for the teleconference training, "Using On-line Resources to Enhance Your Group", given on November 18 and December 12.

Support Q & A

Nutrition: Diets and Supplements

Amy Kaplan, RN, BSN, Manager, Information and Resource Center
1-800-8-MARFAN ext. 26; akaplan@marfan.org

In this column we showcase questions and answers on topics that you may encounter. Amy is available for consultation five days a week from 8:00 am to 4:00 pm Eastern Time.

Q: Is there any specific diet or supplement that is beneficial for individuals with Marfan syndrome?

A: The National Marfan Foundation supports the national nutritional guidelines that advocate a low fat and low salt diet, with appropriate portions of vegetables, fruits and grains related to age and overall body weight, and nutritional snacks. Our literature indicates that there is no evidence of any specific deficiencies in Marfan syndrome or evidence that any particular food or supplementation provides any benefit. Prior to trying any supplement, we would suggest discussing with it with your doctor. Difficulty gaining weight and building muscle is a common problem among many individuals affected with Marfan syndrome. Please note that body building is not a recommended activity for individuals with Marfan syndrome

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.

Communications

Press Releases 101

Eileen Masciale, Consulting Director of Communications
631.665.2163; publicity@marfan.org

Note: Eileen cannot be reached through the NMF toll free number.

Awareness of Marfan syndrome and related disorders is an important goal of the National Marfan Foundation. Many of our members want to help the NMF increase awareness and raise the profile of Marfan syndrome. On both a national and local level, the media is an important partner to the NMF as we work to achieve our awareness goals. But how can a volunteer effectively secure local media coverage to generate publicity about Marfan syndrome, related disorders and the NMF?

When To Use a Press Release

A press release is an announcement about news that is sent to members of the media. It states that there is something important (“newsworthy”) that you want to communicate.

What are some situations in which a news release is appropriate? What may you be announcing? Chapter, network groups and even individual volunteers can issue a press release for:

- An upcoming fundraising event (XX Chapter is Holding a Garage Sale to Benefit the NMF)
- An upcoming meeting (The XXX Network Group is Holding a Meeting...)
- A new network group (The NMF’s Newest Network Group Launches in City)
- A special speaker at a meeting (Dr. XXX Will be Addressing the City Network Group)
- Individual volunteer’s efforts (John James is Holding a XXX Fundraiser to Benefit the NMF)

If you do not have news or you are not making an announcement, then a press release is not the correct tool for you to be using to contact the media. You can contact NMF Consulting Director of Communications Eileen Masciale (publicity@marfan.org) to discuss your goals and she can help you determine the best plan of action.

Writing Your Press Release

Every press release should contain the following elements:

Contact information for the media. This is the name/telephone number/email that media can contact for additional details. It is usually found on top of the press release and is not included in any article that is published.

Headline. This is a strong statement describing what you are announcing.

Dateline. At the beginning of the release, include the date of the announcement and the city/state where the announcement is originating.

Lead paragraph. This should contain the most important information – who, what, when, where.

Body. Include additional supporting details. Describe to the reader why your announcement is important. Think about localizing the reason; why is it important to your local community. Include a quote from a local person (group member).

Call to action. What do you want the reader to do? Come to an event? Go to the NMF website? Make a donation? Be clear.

Boilerplate. This is the basic information that is included in every press release, describing the NMF and Marfan syndrome and related disorders. The NMF’s toll-free number and website should be included, along with the contact information for the local group.

Eileen Masciale, the NMF's Consulting Director of Communications is available to assist you with your press release needs. She can:

- Provide you with guidance for developing your release and provide samples.
- Edit and make suggestions to your copy.
- Provide you with a media list for your geographic area.
- Distribute your press release to your local media via email (in some situations)

Securing Media Coverage: Using Your Press Release

Writing and distributing a press release is only the first step in generating local media coverage. Securing articles usually requires phone follow up, re-sending information and more. And, sometimes a press release is not the right vehicle for reaching out to your local media. Eileen can help you determine if a press release is needed or if there is another public relations tool that is more appropriate.

The NMF has a guide for volunteers, "How to Generate Local Media Coverage" to help you in this process. Eileen can review the steps with you and counsel you about how to best pique the interest of your local media, based on your local news.

Resources for you:

- Press Room on the NMF website (www.marfan.org)
- *How to Generate Local Media Coverage* (submit request to publicity@marfan.org)
- One-on-one counseling in support of your local media efforts, including guidance on writing your press release (contact publicity@marfan.org)

Fundraising

Fundraising for the NMF

Cathie Tsuchiya, Administrative Director, Local Fundraising Coordinator
516-883-8712 x 13; ctsuchiya@marfan.org

Here are some great ways to partner with businesses in your own community to raise funds for the NMF – and awareness about Marfan syndrome and related disorders!

Hang-a-Heart

What: 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! And we supply all materials they'll need.

How:

- Ask the retailer or other business to have the paper hearts near the cash register and ask customers to:
 - Donate \$1.00
 - Write their name on the heart
- Then the retailer can hang the heart on the counter, wall etc. – the red hearts add a fun look during January and February!

When:

- *September/October:* Obtain agreement forms, etc., from NMF*
- *September - November:* Ask businesses/schools to commit
- *December/January:* NMF will send hearts to you
- *January:* You will deliver hearts to businesses
- *March:* Businesses will send checks to the NMF

Do you have a favorite store, hairdresser, bank, pizza shop, deli or restaurant? How about your workplace or doctor's office? Do you work in a school or have kids in school? The hearts can play a great part in a Valentine's Day event at school!



Restaurant Events

Many restaurants offer fundraising opportunities for local groups – including Foster's Grille, Jamba Juice, Coldstone Creamery, Applebee's and Chick-fil-A, just to name a few.

What:

- Restaurant sets aside certain hours on a particular date
- Customers usually have to present a flier when they pay their bill during those hours and restaurant donates a percentage of the bill to the NMF

How:

- Contact restaurants in your community to find out if they offer such fundraising opportunities
- Set up the date and let us know when it will be taking place so that we can be sure to send some NMF awareness materials etc. for you to have on hand*
- If fliers are required to be presented at the restaurant, make sure that plenty of copies are provided to everyone in the community!

Quotable Quotes

Leadership is not so much about technique and methods as it is about opening the heart. Leadership is about inspiration - of oneself and of others. Great leadership is about human experiences, not processes. Leadership is not a formula or a program, it is a human activity that comes from the heart and considers the hearts of others.

~ Lance Secretan, Industry Week, October 1998

Every man must decide whether he will walk in the creative light of altruism or the darkness of destructive selfishness. This is the judgment. Life's persistent and most urgent question is "What are you doing for others?"

~ Dr. Martin Luther King, Jr.

Attachment A

NMF Meeting Report
For Chapters, Network Groups, Support Groups

Please use this form to report on each meeting you hold, and to highlight individuals who show outstanding performance and leadership.

Group Name: _____

Meeting Date: _____ # In Attendance _____

Chairperson: _____

Meeting Location: (city) _____ (state) _____

Meeting Purpose:

General Membership

Social

Event/Activity Planning

Support Group

Marfan Education (specify topic)

Speaker (who)

Other (please specify)

Summary of Meeting Activities:

Next Steps/Action Required:

Are there any group members you would highlight for outstanding performance or future group leadership? Indicate if you would like us to send them/you a certificate, heart pin or NMF volunteer pin (pin is for 100 hours or more).

Attach a list of new members to be added to the NMF database.

Next Meeting Date/s: _____

Please send a copy of this report within one week of the meeting date to Kathy Jeffers, Manager of Volunteer Development, at kjeffers@marfan.org; or fax: 516-883-8040; or mail to:

National Marfan Foundation
22 Manhasset Avenue
Port Washington, NY 11050