



# Leadership Connection

April 2008

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**THE IDEA SOURCE FOR NMF NATIONAL VOLUNTEER NETWORK LEADERS**

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22 Manhasset Avenue, Port Washington, NY 11050  
800-8-MARFAN - [www.marfan.org](http://www.marfan.org)

## Conference Call Leadership Training - "An easy way to stay informed!" Sign up for the Spring Schedule Today!

*"I found the telephone conference call to be an easy way to stay informed. The conference on "How to Speak About the Clinical Trial" (2/19/08) brought together the diversity of our organization from around the country. I was able to listen in and ask questions about the progress of the Trial for an hour."*

Jerry Bluestein, Los Angeles, CA

### **Seminars Open to All Groups and Telephone Support Contacts**

*The NMF depends on you, our key leaders across the nation, to be the messengers and motivators to move the organization forward. These seminars are offered to enable volunteers and staff to work together in the best way possible to serve our members. **Please make every effort to participate, or appoint a key person in your group as a representative.** At least four participants are required for a session, or it will be cancelled.*

*Seminars will be offered via conference calls coordinated by the NMF staff. Time schedules relate to Eastern Standard Time.*

### **How Do I Sign Up?**

*Please e-mail Kathy Jeffers, Manager of Volunteer Development, at [kjeffers@marfan.org](mailto:kjeffers@marfan.org), or call her at 1-800-8-MARFAN x 11. You will receive call-in details three days prior to the seminar date.*

## **1. Leader's Open Forum**

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

**Date:** Thursday, May 8

**Time:** 12:00 – 1:00 pm

**Sign up by May 5**

**Description:** Share your challenges, solutions and new ideas with other group leaders and members of the NMF staff. Please submit any specific questions by May 5, to Kathy Jeffers by email at [kjeffers@marfan.org](mailto:kjeffers@marfan.org).

## **2. Meet Your Project Coach: Pediatric Sports Initiative**

***Presenter: Jonathan Martin, NMF Program Director***

**Date: Tuesday, May 13**

**Time: 12:00 – 1:00 pm**

**Sign up by 5/3**

**Description:** To ensure continued participation of your members, it is essential to provide meaningful activities. Jonathan Martin will walk you through steps you can take to connect with your local school system, raise awareness about Marfan syndrome with school nurses and athletic directors, and make a real difference for affected children.

## **3. Meet Your Project Coach: Emergency Medicine Campaign**

***Presenter: Jonathan Martin, NMF Program Director***

**Date: Thursday, May 15**

**Time: 12:00 – 1:00 pm**

**Sign up by 5/9**

**Description:** There are various aspects of this project that can be done individually, or in a sequence, addressing hospital preparedness for emergency aortic dissection, as well as personal preparedness. Whether you are a large group or small, Jonathan will assess and explore the best approach to take with this project.

## **4. Providing Effective Telephone Support**

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

**Date: Tuesday, May 20, 2008**

**Time: 7:00 - 8:00 pm**

**Sign up by 5/14**

**Description:** The volunteers listed in Connective Issues and on the NMF website are often the first contact a person has with the Foundation. It is important that you have accurate, up to date information on Marfan syndrome and related disorders and the support services we offer. Therefore, the NMF **Board of Directors has mandated training of all Telephone Support volunteers.** The subject content is also important for **Chapter, Network Group and Support Group leaders**, who are encouraged to register for a training session.

## **5. Using Your Experience to Give Effective Direction**

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

**Date: Tuesday, June 3, 2008**

**Time: 7:00-8:00 pm**

**Sign up by 5/27**

**Description:** Affected individuals and their family members have so much information to share with those who are newly diagnosed, seeking diagnosis, or facing new management issues. At times it can be difficult to determine how much to share, what to share, when to share and the most effective ways to share your experiences. Learn how to use your experiences to provide effective assistance to others.

## **6. Have Some Fun with Fundraising**

***Presenters: Jennifer Grignoli, Director of Annual Initiatives***

***Cathie Tsuchiya, Administrative Director, Coordinator of Local Fundraising***

**Date: Tuesday, June 10**

**Time: A - 12:00 – 1:00 pm OR**

**Sign up by 6/5**

**B - 7:30 – 8:30 pm**

**Description:** Our resident local fundraising experts explain some easy to do activities that will be fun as a group (or individual) effort, and will add your name to the important list of contributors supporting NMF member programs. Also remember – the NMF encourages you to raise money to help two people from your group to attend the National Conference and report back to your members.

## **7. Leader's Open Forum**

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

**Date: Saturday, June 28**

**Time: 3:00 – 4:00 pm**

**Sign up by June 25**

**Description:** Share your challenges, solutions and new ideas with other group leaders and members of the NMF staff. Please submit any specific questions by June 25, to Kathy Jeffers by e-mail at [kjeffers@marfan.org](mailto:kjeffers@marfan.org).

## Welcome New Network Groups!

We are delighted to announce the initiation of two new Local Network Groups initiated by some of our long standing NMF members! Ellen England (Auburn, IN) and Steve Marpman (Queens Village, NY) are past and current NMF board members, respectively. Lisa Ritell (Briarcliff Manor, NY) is an artist who contributes her work annually to the Heartworks Gala fundraiser in New York City.

Add these new groups to your National Volunteer Network contact list, and call to congratulate the leaders and offer your encouragement and wishes for success!

<b><u>Fort Wayne, Indiana</u></b>	<b><u>New York, New York</u></b>	
<b>Chair:</b>	<b>Co-chairs:</b>	
Ellen England	Steve Marpman	Lisa Ritell
260-925-4041	718-464-5892	914-941-5998
<a href="mailto:eeengland@gmail.com">eeengland@gmail.com</a>	<a href="mailto:srm2@verizon.net">srm2@verizon.net</a>	<a href="mailto:lisarit2@aol.com">lisarit2@aol.com</a>

## Information & Technology

**David Morris**  
Manager of Information and Technology

### **New Leader's Forum Web Page To Begin May 15**

An excellent idea presented by Maya Zimmerman, Chair of the Columbus, Ohio Network Group prompted the initiation of a new page on the NMF website, where Chapters, Network Groups, Support Groups and Telephone Contacts can post their good ideas, questions for feedback, successful events and meetings, etc. Send your submissions to David Morris, I.T. Manager, at [dmorris@marfan.org](mailto:dmorris@marfan.org). Along with the new "Open Forum" conference call workshops, this is expected to provide a rich exchange of thoughts and experiences to support all volunteer leaders in their respective jobs serving the Marfan and related disorders community.

*Wheresoever you go,  
go with all your heart,  
- Confucius*

### **Network Group Web Pages Due by June 1**

To draw new people to your group and keep members updated, Chapter, Network Groups and Support Groups have the opportunity to create their individual web page on the NMF website. This is an important point of connection, not only with your members, but with the general public. Often this will be the first contact made by a new person needing information about Marfan syndrome and how to join a local group and the NMF.

It's easy to do, with no cost to your group, and is maintained by the NMF Information Technology Manager, David Morris. All you have to do is provide the pertinent information and updates to David, so your page remains current. You may appoint someone in your group to be in charge of updating information, meeting dates, photos, etc. If you have not created your page yet, you will be hearing from Kathy Jeffers and David Morris for support to complete this task. **It is requested that all groups have their page done – or updated - by June 1.**



## **NVN VOLUNTEER SPOTLIGHT: Dr. Li Li, PhD Chair of Detroit Network Group**

Dr. Li Li, of Detroit Michigan has been an active NMF member since 1996, and in 2007 became a Lifetime Member. Li Li, as everyone calls her, does research and education in cardiovascular medicine at Wayne State University. She started the Detroit Network Group in 2007, which has focused on educational forums and activities that serve members' needs, so they can be excellent advocates for their health care. She has consistently planned focused, well attended meetings, and members enjoy getting together at their gatherings every other month.

In this interview, Li Li reveals some highlights of her success. She says, *"It is because of the efforts of the whole group that we continue to gather regularly. There is some highlight at every meeting. We enjoy each other's company, updating our life happenings, and value the rich opportunities the group offers for education and support."*

### **1. How did you get involved in the Detroit Network Group?**

A: When I was first diagnosed, I started a support group in Houston. I really benefited from the support group. When I moved to Detroit, I joined in the Detroit support group led by Judith Ligosky. Our group was not active for a couple of years due to lack of attendance. In 2006, Kathy called to ask me to lead the Detroit Network Group. NMF support made it so simple, as always. I told her that since I have learned a great deal from attending Marfan support group meetings, I thought it a great idea to have local group meetings where we can share our Marfan experience. We had a great first meeting. Several people and their families have been active participants since then.

### **2. What have been your most successful and satisfying activities, meetings, or events?**

A: We are learning something special at every meeting. The most important project we have done was to compile a Local Resource List of doctors for Marfan care from our members. The most successful activity was developed as part of our involvement in the NMF Emergency Medicine Campaign project. We gave a mini conference for health professionals at Wayne State University. Three members, Liz Underwood (ER nurse) and Michelle Petry (NR) and I, presented to the residents and doctors of the department of emergency medicine and internal medicine. That was in response to NMF emergency room campaign upon the premiere of the Rent movie. We also enjoy the birthday party for Ken Robins to celebrate another year of good life after his total aorta replacement.

### **3. What motivates you to stay involved with the local Network Group and the NMF?**

A: Several members and their families make real efforts to attend meetings whenever possible. We actually look forward to meetings. It is a great opportunity for us to share and learn Marfan experience. We also build our friendship over time.

### **4. What is your advice for others in the National Volunteer Network?**

A: Get more people involved in planning and organizing group meetings. We are fortunate to have several enthusiastic members who support and attend meetings. I think a secretary is the most important and hardest job for the group. We are grateful to have Kym Natzke who takes all the minutes and sends out mass mail for the group.

# Communications

## Local Market Publicity: How the NMF Can Help

Eileen Masciale

Director of Communications

The media is an important partner for the Marfan community. Our volunteers nationwide have increasingly turned to their local newspapers and television stations to help promote their events and increase awareness of Marfan syndrome and related connective tissue disorders. It is heart-warming that so many volunteers are willing to share their Marfan journey with the public for the purpose of helping others.

The NMF has a number of resources for our volunteers who are working with the local media:

- Our on-line press room (at [www.marfan.org](http://www.marfan.org)) contains **press materials** that can be given to reporters. You can email them or print them out. These materials have been approved by the NMF and its Professional Advisory Board.
- **Interview tips** are available from NMF Director of Communications Eileen Masciale ([publicity@marfan.org](mailto:publicity@marfan.org), 631-665-2163). She can email them to you and review them with you by phone.
- Volunteers who are speaking to the media should be aware of the **NMF key messages**, developed by the Foundation to ensure that we are accurate and consistent when we talk about our organization and Marfan syndrome. These can also be obtained from Eileen Masciale.
- As background, volunteers should also be familiar with additional information about Marfan syndrome – you can simply refer to the **Heart of the Matter Fact Sheets** on our website for easy-to-understand explanations about the disorder. Although you are not a medical expert, you should be able to communicate some basic information to a reporter. For tough questions, refer reporters to Eileen, who can answer their questions or arrange for them to interview a Professional Advisory Board member.

**Are you going to be interviewed by a reporter and need some guidance? Not sure how to handle an interview? Need to provide a press release to local media about your event and not sure where to start?** Please contact Eileen and she can provide direction, review your materials and conduct media training with you (very informal) over the telephone. She can also be a great resource for reporters. If you know you have an interview coming up, please do not wait until the last minute to contact her. As soon as you have some information about the interview, call or email her so you can arrange a mutual time to talk.

By generating more awareness of Marfan syndrome and related connective tissue disorders, we can increase early diagnosis and connect more people to the NMF for its full array of education and support services. Working with the media is a great way to achieve these goals!

**NMF MEDIA CONTACT:  
EILEEN MASCIALE, DIRECTOR OF COMMUNICATIONS  
631-665-2163, [PUBLICITY@MARFAN.ORG](mailto:PUBLICITY@MARFAN.ORG)**

# Exemplary Leadership Skills

## Connection Leads to Cooperation

Compiled by Kathy Jeffers  
Manager of Volunteer Development

As a group matures, individual members bond with their leader and each other. A sense of connection develops, caring about the well being of fellow members and the group as a whole. Connection and caring lead to cooperation, a willingness to make the most of one's group experience. This progression can be fostered by the group leader in various ways. Actions that provide the foundation for connection and cooperation include:

**Set a standard of respect for and caring** about each other. Hold group members to that practice.

**Show inner conviction** – belief in the members and the objectives of this group creates enthusiasm, courage, hope and cooperation.

**Show a genuine interest in your members** and how they are doing. Remember their names. Call or write to them when appropriate.

**Show personal integrity** and your members will “keep the faith”.

**Communicate effectively.** Talk and write simply, clearly (and persuasively when necessary). It will be easier for them to listen and digest your message.

**Allow everyone to speak** and share experiences or ideas, without dominating a discussion.

**Be decisive.** Consensus is best. That means coming to agreement through group discussion and acting on the greater good of the whole group or organization. If when the group remains indecisive, suggest a path from your best judgment of the discussion and ask for their support to move forward.

**Don't do everything yourself.** Ask others to take responsibility, and they will be flattered!

If **child care assistance** is needed, consider group babysitting or have friends or family members of the group take turns looking after the children at the meeting.

**Recognize significant life events** (like birthdays, anniversaries, births, graduations, honors) at meetings or send a card or flowers (if everyone wants to contribute).

Losing a member through death should be handled as the group sees appropriate. At a meeting the individual should be recognized and thoughts shared. A phone call to the family, or card from the group, is appropriate, as is attending services.

The NMF should be notified (Kathy Jeffers or Cathie Tsuchiya), and has a dignified memorial process, if the family is interested in having donations made to the Foundation.

**Relax!** Use your sense of humor, bringing in light remarks and opportunity for laughter.

# Group Management

## Staying Organized as a Group Leader

Part of your ability to stay organized as a group leader or Telephone Support Contact is to know how and when to report on your activities. We hope the following charts will help!

## Reporting Forms & Timelines

<u>Form</u>	<u>Purpose</u>	<u>Due Date</u>
<b><u>Meetings, Projects, Events</u></b>		
Meeting Recap Form	Summaries for first three meetings	Week after meeting
Quarterly Report	Summary of activity for quarter	January 15 May 15 September 15
Reimbursement	Business Expenses (with receipts) (Xeroxing, envelopes, paper, stamps)	Within 60 days
<b><u>Mailing List Maintenance</u></b> (no form)		
Notify David Morris <a href="mailto:dmorris@marfan.org">dmorris@marfan.org</a>	Adding new people not on NMF data base. Include: <ul style="list-style-type: none"><li>• Name</li><li>• Address</li><li>• Phone #</li><li>• E-mail</li><li>• Who is affected</li><li>• Specify diagnosis</li></ul>	Ongoing
Mailing List Updates	NMF sends you list updates Including: <ul style="list-style-type: none"><li>• Lost addresses</li><li>• Deceased</li><li>• Added names</li><li>• Updated addresses</li><li>• Complete updated list</li></ul>	February August
<b><u>Awareness Events</u></b> (no form)		
Request for NMF Materials From Jonathan Martin <a href="mailto:jmartin@marfan.org">jmartin@marfan.org</a>	Health Fairs, Presentations, Events	One month prior

## **Fundraising**

See “NMF Procedures for Local Fundraising Events”

NMF policies to refer to prior to planning your event

### Forms:

Local Fundraiser Proposal Form

NMF needs all the event details in order to approve the event and also to offer assistance in the form of awareness materials etc.

At least 6 weeks prior

Proposed Budget/Financial Summary for Local Fundraiser

Provide expected income and expenses prior to the event

One month prior

Provide actual income and expenses once the event is over

Within 30 days of the event

See “Guidelines for Remitting Funds to the NMF”

Refer to these guidelines to submit funds raised to the NMF, along with Financial Summary

Within 30 days of the event

## **REMINDERS! DATES & DEADLINES!**

- |                   |   |
|-------------------|---|
| <b>April 30</b>   | <b>Chapter Financial Reports</b> for the fourth quarter due   |
| <b>May 5</b>      | <b>Deadline for Conference Scholarship Applications</b>   |
| <b>May 15</b>     | <b>Leader’s Forum web page opens</b> on NMF website<br><b>Deadline for Clinic Appointments</b> at National Conference   |
| <b>June 1</b>     | <b>Material due for all Network Group Web Pages; also updates for current web pages are due.</b> Contact David Morris, Information Technology Manager at <a href="mailto:dmorris@marfan.org">dmorris@marfan.org</a> or 800-862-7326 x 19. |
| <b>June 10</b>    | <b>Discount Hotel Reservation Deadline</b>  |
| <b>July 10-11</b> | <b>Leadership Training at National Conference</b>   |
| <b>July 10-13</b> | <b>NMF Annual Conference</b> at the Copley Place Hotel in Boston, MA. On-line registration is available this year on the NMF website <a href="http://www.marfan.org">www.marfan.org</a> .   |
| <b>July 25</b>    | <b>Deadline for the fall <i>Connective Issues</i>.</b> Send your news and photos to Eileen Masciale at <a href="mailto:ejm@ejmpr.net">ejm@ejmpr.net</a> .   |
| <b>August 6-9</b> | <b>NMF Annual Conference 2009</b> in Rochester, MN, co-hosted by the Mayo Clinic  |

## Have a Question? Here's Who to Contact

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

### Topic

### Who to Contact

Group management  
Volunteer Training & Awards  
Volunteer Policies & Procedures  
Leadership Connection

**Kathy Jeffers**, Mgr. Volunteer Development  
[kjeffers@marfan.org](mailto:kjeffers@marfan.org) Ext: 11

Start a Support Group  
Insurance Questions  
Telephone Support Contact Liaison  
Children's Programs  
Support Workshops

**Jennifer Buffone**, Dir. Support Services  
[jbuffone@marfan.org](mailto:jbuffone@marfan.org) Ext. 22

Medical Questions  
Find a Doctor  
Clinic Directory

**Amy Kaplan**, Manager, Information & Resource Center  
[akaplan@marfan.org](mailto:akaplan@marfan.org) Ext. 26

Education & Awareness  
Programs/Projects  
NMF Exhibits  
NMF Materials

**Jonathan Martin**, Program Director  
[jmartin@marfan.org](mailto: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](mailto:ctsuchiya@marfan.org) Ext. 13

Legislative Advocacy  
Research/Clinical Trial

**Josephine Grima**, VP Research & Legislative Affairs  
[jgrima@marfan.org](mailto:jgrima@marfan.org) Ext. 17

Budget  
Financial Reports  
Operating/Event Advances

**Judy Gibaldi**, Senior VP, Operations & Finance  
[jgibaldi@marfan.org](mailto:jgibaldi@marfan.org) Ext. 14

Connective Issues Articles  
Media outreach  
- Interviews  
- Local papers  
- Radio/TV

**Eileen Masciale**, Director of Communications  
[ejm@ejmpr.net](mailto:ejm@ejmpr.net) 631-665-2163

Your Web Page or  
NMF Website  
Mailing Lists

**David Morris**, Manager, Information Technology  
[dmorris@marfan.org](mailto:dmorris@marfan.org) Ext. 19

National Conference

**Maggie Hogan**, Director of Foundation Relations  
& Conference Planning  
[mhogan@marfan.org](mailto:mhogan@marfan.org) Ext. 38