



# Leadership Connection

January 2008

Volume 2, No.1.

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THE IDEA SOURCE FOR NATIONAL VOLUNTEER NETWORK LEADERS

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Published by the National Marfan Foundation  
22 Manhasset Avenue, Port Washington, NY 11050  
800-8-MARFAN - [www.marfan.org](http://www.marfan.org)

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## Announcing . . .

### VOLUNTEER LEADERSHIP TRAINING WINTER SCHEDULE

## . . . Your Way to Shine!

#### **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.** 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. Overview of Educational Initiatives for Groups**

*Jonathan Martin, NMF Program Director*

Date: Tuesday, January 22

Time: 1:00 – 2:00 pm

Sign up by 1/15

Date: Tuesday, January 22

Time: 8:00 – 9:00 pm

Sign up by 1/15

To ensure continued participation of your members, it is essential to provide meaningful activities. Jonathan Martin will explain projects the NMF has designed for local implementation and the important service each provides.

#### **2. Sharing Positive Messages through Experience, Strength and Hope**

*Joe Gagliano, President, NMF Board; Bruce Klein, President, Northern Illinois Chapter*

*Ben Weisman, NMF Youth Conference Advisor*

Date: Thursday, February 7

Time: 7:30 – 8:30 pm

Sign up by 1/28

Date: Saturday, February 9

Time: 3:00 – 4:00 pm

Sign up by 1/28

Your own attitude is a key element in how you deal with the challenges Marfan syndrome presents, and in how people react to you, as well. If you are leading a Chapter of Local Network Group, or are sharing your experience as a Telephone Support Contact, it is important to give productive messages and help

people move in a positive direction. How do you get past denial, anger and fear, to acceptance and loving your life WITH Marfan syndrome? Join this inspiring group of NMF members as they reveal their own journeys to living successfully with Marfan syndrome and related disorders.

### **3. Using New NMF Key Messages: Speaking Accurately and Effectively about Marfan Syndrome & the NMF**

*Eileen Masciale, NMF Communications Director*

**Date: Monday, February 11**

**Time: 12:00 noon – 1:00 pm**

**Sign up by 2/6**

**Date: Monday, February 11**

**Time: 8:00 – 9:00 pm**

**Sign up by 2/6**

As representatives of the NMF, be sure you are up to date on the latest information and terminology for speaking about Marfan syndrome and the NMF. A Power Point presentation will be sent by email to use in tandem with this conference call, or a handout can be sent prior to the session, if you prefer.

### **4. How to Speak About the Clinical Trial**

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

**Date: Tuesday, Feb. 19, 2008**

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

**Sign up by 2/13**

Telephone Support Contacts and Group Leaders should be able to speak about and appropriately assist potential participants of the Clinical Trial: Atenolol vs. Losartan in People with Marfan syndrome. You will be briefed on the most current news and developments on this hot topic, the leading issue in Marfan syndrome today.

### **5. Creating and Updating Your Group's Web Page**

*David Morris, NMF Information Technology Manager*

**Date: Thursday, February 28**

**Time: 12:00 – 1:00 pm EST**

**Sign up by 2/21**

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. Leaders, or their representatives, will learn about what information and photographs to use, and how to submit updates to keep your page current. It's easy to do, and is maintained by the NMF, at no cost to the local group.

### **6. Staying Organized as a Network Group Leader**

*Kathy Jeffers, Manager of Volunteer Development*

*Cathie Tsuchiya, Administrative Director & Local Fundraising Coordinator*

**Date: Thursday, March 13**

**Time: 1:00 – 2:00 pm EST**

**Sign up by 2/29**

This review of leader responsibilities will cover timelines and efficient use of reporting forms for meetings, fundraising, reimbursement, and finances for Network Groups. This will include a review of the contents of your Resource Notebook. If you have specific questions, please e-mail Kathy Jeffers prior to the workshop.

### **7. Ways to Create Interest and New Participation in Your Meetings and Events**

*Kathy Jeffers, Manager of Volunteer Development; Suzanne Kouri, President, Massachusetts Chapter; Cindy Strupp, Chair, Network Group of Central Pennsylvania*

**Date: Thursday, March 20**

**Time: 8:00 – 9:00 pm EST**

**Sign up by 3/14**

How to pump up your meetings, create an environment of willingness and cooperation, and encourage new leadership among group members.

## **8. Legislative Advocacy: Creating a Strong Voice for Marfan Syndrome**

***Gavin Lindberg, NMF Board Member***

**Date: Thursday, April 3**

**Time: 7:00 – 8:00 pm EST**

**Sign up by 3/27**

Learn how you and NMF members in your area can impact legislative issues at the local and national levels. Help organize your group to be part of our grassroots advocacy network and to speak with a national voice on issues that will make a lasting difference for everyone in the Marfan community.

## **9. Working With Challenging Group Members**

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

**Date: Tuesday, April 8, 2008**

**Time: 7:00 – 8:00 pm EST**

**Sign up by 4/1**

Does your group have a monopolizer, a complainer, an individual you just can't seem to engage? If you are unsure how to handle the situation and incorporate them into the group, then this session is for you. Learn how to identify and manage challenging members and ultimately utilize their strengths to strengthen your group.

## **10. Providing Effective Telephone Support**

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

**Date: Tuesday, May 6, 2008**

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

**Sign up by 4/29**

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.

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

***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**

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.

### **Note on Spring Workshop Schedule & Topic Suggestions**

Additional workshops will be scheduled for publication in the spring issue of *Leadership Connection*. If you have suggestions for workshop topics, please contact Kathy Jeffers, Manager of Volunteer Development.

## Research & Legislative Affairs

### MAKE YOUR VOICE HEARD IN WASHINGTON HELP SUPPORT THE NMF ADVOCACY AGENDA

*“Politics is like a wheel barrel, nothing happens until you start pushing.”*

**Gavin Lindbergh, NMF Board of Directors –  
Advocacy Committee Chair**

Did you know that Congress is currently in the process of deciding how much funding to provide to the National Institutes of Health in 2008 for biomedical research on Marfan syndrome and other life-threatening diseases? Or, that lawmakers are negotiating legislation to reauthorize the State Children’s Health Insurance Program that provides health care coverage to over 6 million kids? Are you aware that the House of Representatives has overwhelmingly passed a bill that would ban genetic discrimination in the workplace and in the health insurance market, but it has stalled in the Senate?

The National Marfan Foundation is working to advance these and other public policy priorities of interest to our patients and families – but we need your help. Iowans are in a unique position to further the interests of NMF in the nation’s capital because Senator Tom Harkin (D-IA) is the chairman of the Senate appropriations subcommittee that funds the NIH, Centers for Disease Control and Prevention, and other federal health care agencies. Senator Harkin has a strong record of supporting the Marfan syndrome community thanks to his interaction with NMF members from Iowa many years ago.

Expressing our gratitude to Senator Harkin for his leadership and introducing him to new patients and family members from his home state is a priority for NMF as we seek to expand federal health care programs focused on Marfan syndrome and related connective tissue disorders.

To learn more about NMF’s public policy agenda and how you can get involved please contact Gavin Lindbergh, NMF Washington Representative, at (202) 544-7499 or [lindbergh@hmcw.org](mailto:lindbergh@hmcw.org). In addition, contact David Morris, NMF Information Technology Manager at [dmorris@marfan.org](mailto:dmorris@marfan.org), or 1-800-8-MARFAN x 19, and ask to be added to the Foundation’s e-mail network. Legislative advocacy alerts are distributed to NMF members and friends through the e-mail network.

Finally, take advantage of the political climate in Iowa surrounding the upcoming presidential caucuses to raise awareness of Marfan syndrome with candidates, members of Congress, and the media. The ability of one committed public official to make a difference on our behalf cannot be overstated. However, they have to be asked (or gently pushed).

### **RESEARCH UPDATE**

**Josephine Grima  
V.P. Research and Legislative Affairs**

The NMF Research Program is proud to announce that three grants for research in the area of Marfan syndrome have been awarded, in addition to a new fellowship grant for a young investigator at Yale University. Details of these grants will be available in the next issue of Connective Issues.

The clinical trial has been enrolling patients for the past 9.5 months and 155 people are currently enrolled. We are currently trying to finalize contracts for an additional three studies to take advantage of the clinical trial to find out more about how atenolol and losartan affect the other parts of the body. The clinical trial is an important opportunity that the NMF is anxious to leverage to its fullest.

# Communications

## Making Local Connections with Connective Issues

**Eileen Masciale**  
**Director of Communications**

Chapter News... Network Group News... People and Events... Dates and Deadlines. These columns, which appear in every issue of the NMF's newsletter, *Connective Issues*, focus on the grassroots efforts conducted by you, our volunteers.

They give you an opportunity to promote your events, so that people in your area can learn about your activities ahead of time, and showcase your successes. This is vital to our organization and its members for so many reasons.

First and foremost, being included in the newsletter enables your group to shine. It gives attention to the activities in your geographic area, empowers your group members and provides an opportunity for growth as people in your area who might not know about your group read about it in the national publication. Your next event may be even bigger or more successful as excitement builds locally.

Coverage of your event in *Connective Issues* can also give ideas to chapters, network groups and individual volunteers in other parts of the country. If an event was successful where you live, it could work elsewhere. By sharing news of your winning fundraising and awareness events, others in the Marfan community can start their event planning with confidence in their goals for the activity.

While Chapter News, Network Group News and People and Events usually feature highlights of events that already happened, Dates and Deadlines, always on the second page of the newsletter, promotes upcoming events. Each entry has the date, place and contact information for the activity. This gives you another way to reach your local Marfan community. As the Marfan community expands daily, it also enables you to reach new NMF members in your geographic area who may not be on your local mailing list.

On a national level, it is also important that our grassroots efforts around the country are featured in our newsletter. In addition to reaching people affected with Marfan syndrome and their families, *Connective Issues* is disseminated to hospitals and other medical institutions, government bodies, members of various medical associations, healthcare providers in many disciplines, and potential donors. We want them to read about the enthusiasm of our volunteers, the breadth of our grassroots network and the dedication of our members to the NMF mission. As a result, they will want to partner with us, support us and donate to our cause.

### **What kind of information do we need?**

For upcoming events, we need to know when and where it is taking place, what is happening there, featured speakers and any other key facts about the activity. We also need a name, phone number and email address so that people reading the newsletter can get more information.

For events that have already taken place, please tell us the name of the event, when and where it took place, how many people attended, how much money was raised (if it was a fundraiser), who it reached (if it was an awareness activity), and any feedback. Tell us as much as you want! We may only be able to include a short paragraph in the newsletter, but you never know where else we may want to feature your activity.

We would also love pictures! Group shots are ok, close-ups are better, action shots are the best. Please send us more than one photo to choose from and include the names of people who are in the pictures. If there are doctors or local VIPs (e.g., celebrities, politicians), please include their title and affiliation too.

We like to receive photos via e-mail (jpg format), but you can also send regular pictures if you do not have access to a computer. If you need the photo back, be sure to write that on the back of the picture.

**We cannot use photos from cell phones, photos sent to us through photo-sharing websites or photos that are poor quality.**

**When do we need the information?**

*Connective Issues* is published three times each year: winter, spring and fall. The deadlines are:

Spring issue: March 15  
Fall issue: July 15  
Winter issue: November 15

Please make sure to submit your information in a timely matter so that we can highlight your efforts! If you send your details after the deadline, we might not be able to include your event in a future issue.

**Where do we send our information?**

Network Group news should be sent to Kathy Jeffers, [kjeffers@marfan.org](mailto:kjeffers@marfan.org).

Chapter news, details about the efforts of individual volunteers and for Dates and Deadlines should be sent to Cathie Tsuchiya, [ctsuchiya@marfan.org](mailto:ctsuchiya@marfan.org).

We try to include as many local events and activities in the newsletter as possible. We are limited by the number of pages and other news that is happening in the Marfan community.

Get your information in early for the best chances of being included! If you have any questions, you can contact Cathie or Kathy, or contact the NMF newsletter editor, Eileen Masciale, [publicity@marfan.org](mailto:publicity@marfan.org) or 631.665.2163.

*Connective Issues* is **your** newsletter. Make it work for you!

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

**In February you will receive updates to your entire mailing list** of all members in your area. This will include new names since the last update, lost, deceased and updated addresses, plus your group's complete, up to date mailing list. If you are planning a meeting or event, and would like the NMF to do a mailing to your entire list, please schedule a mailing date with Kathy Jeffers, Manager of Volunteer Development ([kjeffers@marfan.org](mailto:kjeffers@marfan.org) or 800-862-7326 x 11).

**Web pages for all groups are available** on the NMF website. Create or update yours by contacting David Morris, Information Technology Manager at [dmorris@marfan.org](mailto:dmorris@marfan.org) or 800-862-7326 x 19.

**Deadline for the spring *Connective Issues*** is March 15. Send your news and photos to Eileen Masciale at [ejm@ejmpr.net](mailto:ejm@ejmpr.net).

**Fundraising** to support all NMF mission areas is getting into full swing, with the new **Hang a Heart** project kicking off in February. Also, watch your mail box for the **Have Heart** campaign, on its way to you in the next few weeks. Remember - you can do a fundraiser any time of year!

**Chapter Financial Reports** for the second quarter are due by January 31; fourth quarter due April 30.

**NMF Annual Conference** is scheduled for July 10-13, 2008 at the Copley Place Hotel in Boston, MA. The 2009 conference will be held at the Mayo Clinic in Rochester, MN, August 6-9.

# Group Management

## Starting a Newsletter? Helpful Hints to Make it Great!

A local newsletter for your group can do wonders to keep members informed and connected between meetings. It can be effectively done whether it is one page with simple black and white graphics, or a multi-page edition with color graphics and photographs. Groups use primarily e-mail for distribution.

### **Signatures of a well done newsletter include**

- ♥ A masthead with full group name and date
- ♥ Two or more issues published annually
- ♥ Articles contributed from members
- ♥ Complete and accurate information
- ♥ Photos if possible
- ♥ In each issue, include:
  - Letter from editor or president
  - NMF news (from periodic NMF News Briefs)
  - Information about local resources
  
  - Upcoming events/meetings
  - Recognition of volunteers
  - Updates to your local contact list

You may contact groups that currently have newsletters, and consult with the editors on how to get started. Use your NMF National Volunteer Network Leaders Contact List for e-mail and phone numbers.

### **Network Group Newsletters**

Shelley Harren, St. Cloud, Minnesota  
Heather Hinton/Judy Reiner, Minneapolis, MN  
Li Li, Detroit, MI  
Maya Zimmerman, Columbus, OH

### **Chapter Newsletters**

Annette & Dan Makanoff, Penn-Jersey  
Teri Dean, Heart of Iowa  
Bruce Klein, Northern Illinois

## Tips on Finding Speakers

Inviting a guest speaker can be the highlight of a meeting and draw more members to attend. Where do you find an effective speaker – especially in rural areas? Here are some options to try.

1. Contact your local clinic or hospital to see if you could meet there and have a speaker from the staff (specialty doctor, surgeon, geneticist, emergency medical technician), or invite the speaker to come to you. They have been known to be very generous reaching out to the Marfan community.
2. Use your local medical resource list of professionals serving the members in your area to invite the individuals members of your group use for care as speakers.
3. Create a panel of group members to speak about their experience on a focused subject. Members have a first hand expertise and a wealth of insight and advice to share. Topics could include
  - Unraveling the Mysteries of Open Heart Surgery (Marin County Network Group sample attached, with summary notes).
  - Preparing for Surgery; What to Expect After Surgery
  - Being a Teen with Marfan
  - Sharing your Marfan Story – or an aspect of Living with Marfan syndrome

- How to be Prepared with and Emergency Plan (the article written by Chris Heaney in your Emergency Medicine Campaign project materials is helpful for this topic).
  - What Supports Your Spirit, Strength and Hope in dealing successfully with Marfan?
4. For speakers on health and disability insurance, contact your local hospital's social worker in the Patient Services department, the local Legal Aid Society, Bar Association, or Social Security office (1-800-772-1213).

## **Exemplary Leadership Skills**

### **Three Rules for Delegating Effectively**

When you are in charge, these three delegation rules will help put you at ease when turning over jobs to colleagues in your group:

1. Put it in writing. Provide an outline of what is to be done that includes a description of expected outcomes.
2. Confirm the assigned project is fully understood. Ask the volunteer to describe, in detail, what it is she/he will be doing from beginning to end.
3. Ask for update reports. Instruct the person completing the task to submit regular reports (e-mails of phone calls) stating what has been accomplished to date.

### **What Matters Most in Your Life?**

Many who volunteer over a period of time come to realize that their gift of service is also a gift to themselves. For the more we give of ourselves, the more we are rewarded and fulfilled in our own lives. To give is to receive.

To achieve greater fulfillment in your everyday life, ask yourself these three questions:

1. What would I want to do if I had only a few months to live?
2. What would I want to have or do if I could have any one wish fulfilled instantly?
3. Would I be truly happy if I got whatever I thought I most deeply wanted? And what would I do with it?

After answering these questions, think about your work as a volunteer. Chances are, you'll find that the kindness you share with others is key to your ultimate happiness.

*There is a destiny That makes us brothers:  
None goes his way alone.  
All that we send into the lives of others  
Comes back into our own.*

*- Edwin Markham*

# 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**, Dir. Foundation Relations  
& Conference Planning  
[mhogan@marfan.org](mailto:mhogan@marfan.org) Ext. 38