



Invitation to NVN Leadership Meeting 2009

ENERGIZING Our National Volunteer Network!

The National Marfan Foundation Board of Directors and staff invite you to our *National Volunteer Network Volunteer Leadership Meeting 2009: Energizing Our Volunteer Network*, on Friday, August 7, 9:30 am – 5:00 pm. It will be held at the Marriott Hotel, Ballroom II, in Rochester, MN, just before the official opening of the NMF Annual Conference.

Why?

To support you in your volunteer job and to nurture an effective working relationship, we have created this opportunity for learning and communication between the NMF staff, board and our key leaders across the country. You are our most important partners in accomplishing our shared mission at the local level. We count on you to be connected and well informed in order to keep your local constituents up to date.

Who is invited?

This meeting is open to Telephone Support Contacts, Chapter Presidents and Officers, Network and Support Group Leaders, and any members of your group who will provide future leadership. We encourage each group to send at least two representatives. Please send this meeting information on to the representatives you select to invite.

What is on the Schedule?

This one-day meeting will include presentations and discussions on new information and emerging issues that affect the dynamics of the Foundation and our National Volunteer Network. Attendees will enjoy coffee and muffins on Friday morning and a complementary lunch where you can network with colleagues. There is also a special reception with the NMF Board of Directors at 4 pm. Board members want to meet you, so come and mingle with these exemplary volunteers who lead the NMF. Then, head off for the Conference Welcome Reception. Remember to wear your new volunteer pin!

All Groups Can Participate in the NVN Poster Exhibit!

All Chapters and Network groups are invited to have a poster representing the highlights of their year displayed in the NMF exhibit space at the Marriott Hotel.

Poster Instructions: Please use black foam board, measuring 20" x 30" (we will have a few extra boards on hand if you choose to make it on site). To identify your poster, use your group's logo, or the NMF logo attached on the last page of this email, and add your group's name below. Center it at the top of your poster, with your photos and other information arranged attractively. Each poster will be displayed on a standing easel (provided). Please bring posters to the NMF exhibit area at the Marriott Hotel on Thursday or Friday (August 6-7) before 1 pm. If you are not attending the conference, you may send your poster **by July 17** to Kathy Jeffers at the NMF, 22 Manhasset Ave., Port Washington, NY 11050, and we will be sure it is displayed.

How do I Register?

Please return your registration form to Kathy Jeffers **by May 30** by email, fax or regular mail (kjeffers@marfan.org, 516-883-8040, 22 Manhasset Ave., Port Washington, NY 11050). If you have any questions or concerns, please contact Kathy at 800-862-7326 x 11.



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Friday, August 7, 9:30 am – 5:00 pm
Marriott Hotel – Ballroom II, Rochester, MN

Agenda

- 9:30 – 10:00** **Coffee, Muffins & Networking**
- 10:00 – 11:00** **Introducing the NMF Style Package**
Eileen Masciale, Director of Communications
Here is the NMF identity tool kit you have been waiting for, with practical tips for using it.
- 11:00 – 11:45** **Showcase: Group Activity Highlights**
(explanation and sign up on registration page)
- 11:45 – 12:00** **Break**
- 11:45 - 12:30** **Making the Clinic Connection**
Bruce Klein, President, Northern Illinois Chapter
Creating a relationship with your local clinic is an important and fortifying effort for your group. No clinic in your area? You can help create one! Bruce initiated four clinics in the Chicago area, with benefits to his chapter. Through sharing his success stories, you'll see how to make the most of your clinic connection.
- 1:00 – 2:00** **Lunch and Networking**
- 2:00 – 3:00** **The Online Advantage: Using NMF Website & Other Services**
Jonathan Martin, Program Director
Jennifer Buffone, Director of Support & Volunteer Development
Become familiar with the new NMF website and tools it offers local groups and Telephone Contacts. Learn how to use NMFconnect, Facebook, Twitter and your group/personal web page to build the Marfan community in your area, and raise awareness.
- 3:00 – 4:00** **New Horizons in Fundraising**
Jennifer Grignoli, Director of Development
Cathie Tsuchiya, Administrative Director, Local Fundraising Coordinator
In this challenging economic climate, the NMF, its Chapters and Network Groups are faced with thinking creatively about fund development. We will discuss new strategies to help all local groups and programs flourish, despite the current environment.
- 3:45 – 4:00** **Wrap Up**
- 4:00 – 5:00** **Reception with NMF Board of Directors and Staff**

Registration Form Submission Instructions

Registration forms are due May 30th.

You may either complete the form using WORD and email the completed form back to us (see instructions below); or you may print the form, handwrite the information, then mail or fax the completed form (address and fax # appear below)

If you choose to email, use WORD:

1. Open the attached file.
2. Save to WORD using the "Save As" command and give the file the following name: Leadership Meeting 09 Registration
3. Use **Tab** to move **forward**
4. Use **Shift-Tab** to move **backward** from box to box.
5. Save the file using the naming convention in #2 above.
6. Attach the **new** file to an Email and send to: kjeffers@marfan.org

If you choose to mail the completed form, send to:

Kathy Jeffers
National Marfan Foundation
22 Manhasset Ave.
Port Washington, New York 11050

Fax #: (516) 883-8040 Att: Kathy



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REGISTRATION FORM – DUE MAY 30

Please return to Kathy Jeffers, Manager of Volunteer Development
NMF, 22 Manhasset Avenue, Port Washington, NY 11050
Fax: 516-883-8040 E-mail: kjeffers@marfan.org Phone: 800-862-7326- x 11

Name: **Chapter/Group Name:**
Address: **Phone:**
City/State: **E-mail:**

Please check the appropriate spaces.

- I will attend the training on Friday, August 7, from 10:00 am to 4:45.
- I will attend the 4:00 Reception & Networking Session with the Board of Directors.
- I will not be able to attend the volunteer leadership meeting session this year.
- I have registered to attend the NMF National Conference.

Chapter/Network Group Poster Exhibit

Each Chapter and Network Group will have the opportunity to showcase their activities by having a poster in the NMF exhibit area. See instructions on letter of invitation.

- My Chapter/Network Group will have a poster for the NMF exhibit area
- I will bring the poster with me.
- I will send the poster to the NMF by July 17.

Group Activity Showcase

This is not mandatory, but we hope you will sign up to present your best ideas and successes of the past year. Five to ten minutes are allotted for each presentation. Bring samples of anything you would like to share – a point of pride that worked particularly well (photos, invitation, newsletter, brochure, etc.). Possible topics are listed below. Please check the appropriate box and give a brief explanation.

- Outstanding Meeting** (sample agenda, explanation, outcome)
- Education or Awareness Project** (your work with schools, medical community or general public; what was the outcome?)
- Local Medical Resource List** (sample of finished product, how did you organize it?)

- Local Peer Support Contact List** (sample of finished product, how did you do it?)
- Newsletter, brochure or other publication** (bring samples, helpful hints)
- Media Outreach** (Local/regional newspaper or television station: What did you do? How? Outcome?)
- Collaboration with local clinic or hospital** (What did you do – and how? Outcome?)
- Local Fundraiser** (What did you do? How? Outcome?)
- Social Event** (What did you do? How? Outcome?)
- Something else that you are proud of?** (please explain below)

Please share your comments or questions here!