



Leadership Connection

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THE IDEA SOURCE FOR NMF NATIONAL VOLUNTEER NETWORK LEADERS

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800-8-MARFAN - www.marfan.org

Sign Up for Your Key to Success! Spring Leadership Support Seminars

Seminars Open to All Group Leaders 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 at the local level. 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 as your representative.

At least four participants are required for a session, or it may be cancelled.

Seminars will be offered via one hour conference calls coordinated by the NMF staff.

Time schedules relate to Eastern Time.

How Do I Sign Up?

Please e-mail Kathy Jeffers, Manager of Volunteer Development, at kjeffers@marfan.org, or call her at 1-800-8-MARFAN x 11. You will receive call-in details 2-3 days prior to the seminar date.



Mandatory Session for Chapter Presidents and Treasurers!

1. Using Your New Chapter By-Laws, Guidelines, Strategic Planning/Budget Documents

Presenters: *Judy Gibaldi, NMF Chief Financial Officer
Jennifer Buffone, NMF Director of Support & Volunteer Development
Cathie Tsuchiya, NMF Local Fundraising Coordinator
Kathy Jeffers, Manager of Volunteer Development*

Date: *Tuesday, May 5*

Time: *8:00 pm ET*

Sign up by: *4/30*

The Support and Volunteer Development Committee of the NMF Board of Directors has been editing and updating the NMF Chapter By-Laws and Guidelines. The final version of the documents was recently presented to the Board for approval, and they are now official. This session will introduce Chapter leaders to the new By-Laws and Guidelines and will discuss similarities and differences between the old and new documents. Additionally, a new strategic planning tool that will help Chapter leaders to create their budget will be presented and the current Chapter budget forms will be reviewed. All documents will be emailed to you prior to the session so you have time to review them and there will be plenty of time allotted for questions. We hope both the President and Treasurer of each Chapter will be present. If that is not possible please ensure at least one is able to participate.



2. New and Easy Fundraising Ideas

Presenters: *Jennifer Grignoli, NMF Director of Development*
Cathie Tsuchiya, NMF Local Fundraising Coordinator

Date: *Thursday, May 14*

Time: *2:00 pm ET*

Sign up by: *5/8*

Description: The NMF relies on donations to support our vital programs. Learn how **you** can raise funds for the NMF in your community throughout the year. NEW! Raise more funds with less effort - find out how you can create your own fundraising page online! If you have questions about specific types of fundraising activities, please let us know when you sign up for the call.



3. How to Respond to an Athletic Tragedy in Your Community

Presenter: *Jonathan Martin, NMF Program Director*

Date: *Wednesday, May 20*

Time: *12:00 noon ET*

Sign up by: *5/15*

Description: When news that another young athlete has died on the playing field reaches the media, all of us in the Marfan community can't help but wonder if it was Marfan-related. Regardless of the actual underlying cause of death, these tragedies provide a unique opportunity to raise awareness of the importance of better pre-participation athlete screening and Marfan syndrome. Learn about a new NMF project available as part of the NVN resources available to you to help convert tragedy into positive change.



4. Poster Project

Presenter: *Jennifer Buffone, NMF Dir. Of Support Services and Volunteer Development*
Denise Levino, NMF Social Work Intern (Adelphi University)

Date: *Friday, May 29*

Time: *1:00 pm ET*

Sign up by: *5/22*

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



5. How to Create a Winning Brochure for your Chapter or Network Group

Presenter: *Eileen Masciale, NMF Program Director*

Date: *Thursday, June 4*

Time: *12:00 Noon ET*

Sign up by: *6/1*

Description: A brochure is an effective marketing tool for your group, highlighting who you are, what you do, and where you are located. Using the new NMF Style Guide and a design template, you will leave this session with the knowledge and tools to develop your group's brochure.

6. Network Group Leaders Open Forum

Moderator: *Kathy Jeffers, Manager of Volunteer Development*

Date: *Monday, June 8*

Time: *8:00 pm ET*

Sign up by: *6/3*

Description: Designed as a forum for peer consultation, Network Group leaders come together in this session to discuss what's working and what's not in managing their group. Here is the place to share your challenges, solutions and new ideas with other group leaders. Specific staff members can be invited as needed, with advance notice. Please submit any specific needs or questions by 6/3, to Kathy Jeffers by e-mail at kjeffers@marfan.org.

7. Telephone Support Contact Open Forum

Moderator: Jennifer Buffone, NMF Director of Support and Volunteer Development
Denise Levino, NMF Social Work Intern, Adelphi University

Date: Friday, June 12

Time: 1:00 pm ET

Sign up b: 6/15

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

8. Chapter Leaders Open Forum

Guest Consultant: TBA depending on your needs
Moderator: Kathy Jeffers, NMF Manager of Volunteer Development

Date: Tuesday, June 16

Time: 8:00 pm ET

Sign up b: 6/9

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

Mark Your Calendar - NVN Leadership Meeting 2009

"ENERGIZING THE NMF NATIONAL VOLUNTEER NETWORK"

Friday, August 7 in Rochester, MN

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 and our key leaders across the country. Sessions will focus on meeting new challenges and what Chapters, Network Groups, and Telephone Support Contacts can consider doing to move forward with renewed strength.

There will be a complementary lunch on Friday and a reception with members of the NMF Board of Directors at 4:00 pm. Unlike the past, we regret the NMF is not able to cover a hotel room night for everyone this year, so a one day meeting is planned. Please make every effort to attend.

Registration information will be e-mailed the first week in May.

Who:

- ♥ Chapter Presidents & Officers
- ♥ Network Group Leaders & Co-leaders
- ♥ Support Group Leaders
- ♥ Telephone Support Contacts

WHEN: Friday, August 7, 10:00 am – 4:45 pm



NVN VOLUNTEER SPOTLIGHT:

Susan Meier Chair, Sacramento Network Group President, Northern California Chapter

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

I have been married to my wonderful husband, Eric, for almost 30 years; we have 2 beautiful grown daughters, Stefanie (26) and Michelle (24); and I am especially proud to be called “nana” to 3 adorable grandsons, Jayden (6), Evan (4) and Zachary (2). My husband and I moved to Sacramento, California in 1982 to settle down and start our family after having spent our early married life in the Air Force, living in Alaska for almost 3 years. We now live in Rocklin, California (which is about 20 miles outside of Sacramento). I retired from the State of California in 2006 after 17 years as a senior legal analyst and governmental program analyst for the Department of Social Services, and the Office of the Patient Advocate. Having worked for over 30 years in several private legal offices and in State government, I was able to utilize my legal education, knowledge, experience and analytical skills in helping others, protecting vulnerable populations, and advocating for health care services for others, including myself and my family.

A bit of family history: I am one of seven girls, and the middle child. I am the only one who looked like my mom (who we suspect also had Marfans and passed away in 1999). My youngest daughter, also looks like my mom and me. Thus, the physical and skeletal similarities of Marfans is prominent in our family. However, in 2001, I began experiencing more skeletal pain than in years prior. My pain had begun to interfere with my ability to sit for extended periods of time, walking distances, sleeping, my usual activities, etc. I knew I had scoliosis; however, I never received any treatment for the scoliosis as a child or young adult. So, unsure that the pain might be caused only by the scoliosis, my doctors ordered several CT scans, MRIs, etc. After 4 frustrating months of various tests, I was told I had “cysts on my spine” by a neurologist who could tell me no more! I sought out a second opinion with a neurosurgeon, who did some “measurements” on my arms and legs, reviewed my CT scans, MRIs, and concluded that I have “Marfans.” That neurosurgeon probably saved my life, and the life of my daughter, Michelle, (then 17) as we both later discovered that we had abnormal aortic root measurements. Obtaining medical appointments for a genetic counselor, cardiologists, orthopedists, and ophthalmologists was just the beginning of our Marfan journey. We have been very fortunate to be so close to the Stanford University Medical Center for Marfan Syndrome and Aortic Disorders; however, we have also had to advocate for approvals to see the specialists there, such as Dr. David Liang, Cardiologist; Dr. Craig Miller, heart surgeon, and the wonderful staff at the Clinic, Sunny Pellone and Julie Morris. Shortly after our family’s diagnosis, we were advised that our daughter would need to have her aortic root replaced due to its expanding size. Again, my husband I had to be advocates for our daughter, in seeking out the most expert Marfan care available to us. She had successful aortic root replacement/valve sparing surgery performed by Dr. Craig Miller in 2002. I continue to be monitored by Dr. David Liang at Stanford, and hope to be one of the lucky ones who are spared heart surgery, while living with Marfans. Realistically, I know it may be necessary some day, so I remain optimistic and hopeful that I will continue to enjoy and live a productive life.

Advocating for ourselves, our family, our friends, and our Marfan Community, has been one of the most fulfilling experiences I have enjoyed. Yes, it can be demanding, time-consuming, and even frustrating at times, but in the end, we know that we have to do what is in the best interest of ourselves, the quality of our lives, and the joy and happiness we all deserve in this life.

2. How did you become involved in the NoCal Chapter and the Sacramento Network Group?

I became involved with the Northern California Chapter after our diagnosis in 2001. I began the research on the internet, located the NMF, sought out information, contacts, anything I could read about this diagnosis. I read all the signs, symptoms, what may occur, and how to take care of yourself. I printed out pages of information, read them over and over, and then contacted the Chapter president, Nancy Mateyka, for support and information. It was after that phone call that seemed to last for hours, that I felt relief, that there was support close by, and that I was not alone! It became important to myself and my family that we learn more about the variations of symptoms and signs of Marfan. Through my position at the Office of the Patient Advocate, I was able to share information to the Chapter members about advocating for health care, locating resources for assistance, learning how to communicate with your insurance company, filing appeals to denials, etc. By joining the Chapter early on and participating on the Steering Committee, I have been able to meet new people, make life-long friends, and offer support to others just like I

received upon our diagnosis in 2001. In September 2007, I became President of the Northern California Chapter, and feel very fortunate to be leading a Chapter with experienced Officers and an active Steering Committee that supports the activities of the Chapter.

It was a natural progression of “helping others” when we formed the Sacramento Area Local Network Group in 2006. There appeared to be an unmet need to support others in the Sacramento area, and since I enjoyed participating in the Chapter and meeting new people, I figured, why not set up something near my home. It started out with a core group of 15 and has grown to about 40 members/families. In between the two annual Chapter activities (Spring Symposium and Fall BBQ), the Local Group meets to offer support and education, as well as assists the Chapter in organizing its annual activities. Getting involved and helping others is in my genes too, not just Marfan!

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

The Chapter’s 1st Annual Regional Marfan Educational Symposium, held in May 2008. The Chapter took a “huge” leap of faith after the NMF Annual Conference at Stanford in 2007, and created another opportunity for those who may have missed the Annual Conference for whatever reason, to join us and learn more about Marfan Syndrome. We are especially proud that we succeeded in reaching over 60 parents (some new to the diagnosis) and gained a better understanding of what the educational needs are for our group. We have decided to continue the event on an annual basis, and are currently planning our 2nd Annual to be held on April 25th. I believe in the current economy, regional symposiums are the best way to reach communities, to offer support and education, at a reasonable cost to NMF members.

My first real experience organizing a fundraiser for the NMF was the Heart Mart at the Annual Conference at Stanford in July 2007. For the Chapter, the measure of success that year was not only by the number of tickets sold or the total amount raised for conference scholarships (over \$6,000), but also by the team’s effort in the quantity and quality of donations received, the orderly organization and display of the items, and the Chapter volunteers who stepped up to help throughout the Conference weekend.

The Sacramento Area Local Network Group Meeting/Ice Cream Social in May 2007. The outdoor meeting was attended by 20 members, and then we all enjoyed our delicious ice cream treats while meeting new friends.

4. What motivates you to stay involved with the Chapter, the local Network Group, and the NMF?

If there were no volunteers interested in this organization, I believe that we all probably would be “floundering” in the real world, trying to make sense of our condition, fighting for health care, feeling frustrated and alone. To me, that would be devastating! I remember how I felt upon receiving the diagnosis, (although somewhat relieved that “it” had a name) and then researching Marfan Syndrome on the internet. I remember speaking to someone for the first time, who also had some of the same Marfan symptoms that I had. To speak to someone who had already had heart surgery, who could offer advice on what to expect, what to pack, etc. Whew – I was not the only one, and neither was my teenage daughter! It was all making so much more sense now. Knowing that others have the same feelings, same questions, same concerns as I once had, I am able to share our family’s Marfan story with others and offer support and hope. It was only natural to want to volunteer for an organization that meant so much to me and to my family, and to help raise awareness and funds for research so that future generations may live long and productive lives!

More knowledge is power. Networking is vital to feeling a part of a group. Helping others and giving back to the Marfan Community is the least I can do at this time in my life. So as long as I am able (and as long as my family supports me), I intend on being involved in the Chapter, whether it be as an Officer or on the Steering Committee, and continue leading the Local Network Group in the Sacramento Area, and supporting the NMF.

5. What is your advice for other group leaders?

- To be patient when forming a new group. Attendance will fluctuate throughout the year, at meetings, activities, etc., so don’t be discouraged. Helping just one person makes a huge difference in not only their life, but yours too!
- Encourage members to “tell their Marfan stories” at the meetings. It’s amazing how little we really know about each other, until we hear their “story” and their challenges.
- Encourage members to be active in the Chapter/Group, fundraising activities, locating speakers, providing a snack, etc. Make everyone feel needed and important to the success of the group.
- Delegate – something that I am still learning how to do as the “President”!
- Have fun activities too, especially for the children and teens!

Fundraising



NEW!! Create Your Own Personal Fundraising Page - Raise More Money with Less Effort!

You too can raise much-needed funds to support the National Marfan Foundation's vital programs – without locating a venue, selling tickets, ordering food, etc. Fundraising online is a very effective way to create awareness about Marfan syndrome and related disorders and raise funds to sustain your #1 organization – the NMF! Use your custom page as its own fundraiser or in conjunction with other fundraising efforts. You can use any event – or non-event – to raise funds for the NMF! It's fun and easy as 1..2..3!

1. **Visit www.firstgiving.com/Marfan**
 - Easily create fundraising pages
2. **Personalize your online fundraising page**
 - Set your goal
 - Write your message
 - Add pictures and/or videos
3. **Email your page link to everyone you know**
 - Email asking is easy
 - Giving online is simple and secure
 - Send more emails, get more donations
 - Donors receive automatic thank-you emails
 - Donors receive automatic thank-you emails

Fundraise with bike rides, birthdays, walkathons, weddings, marathons, anniversaries, tributes whatever you can think of! Creating your page is quick and easy!

Interested? Have questions before you get started? Contact Cathie Tsuchiya, NMF Local Fundraising Coordinator, at ctsuchiya@marfan.org

Who's fundraising for the NMF on Firstgiving.com now?

Jon Gould of Verona, WI, an avid runner, decided to tie in fundraising for the NMF with his participation in marathons. He and his wife, Beth, set up the first active personal fundraising page in support of Jon's participation in four marathons this year to raise funds for the NMF! The first was the Boston Marathon on April 20th.

As of mid-April, nearly \$6,000 has been raised, with more coming in every day!

*You have to accept whatever comes, and the only important thing is
that you meet it with the best you have to give.*

- Eleanor Roosevelt

Group Management

Foundations for Building Group Participation

One common challenge group leaders share – whether they are in charge of a Chapter or a Local Network Group – is how to build participation. It helps to realize what draws people to become part of a meeting or activity, so you can focus on doing the things that motivate them. There are three reasons why people join a group:

- To find support for and education on common concerns
- To do something productive about those concerns, and
- To affiliate with a social group of interest.

Let's take a look at how your group can fulfill these motivations.

Serve members' needs for EDUCATION

Focus educational meetings around topics of interest expressed by your group members. Use video tapes and DVDs from the NMF Lending Library as a source of information, as well as a springboard for discussion. A meeting can become a forum for designated members to share their experience as speakers on a panel relating to a specific topic (e.g. from Marin County Network Group: "Unraveling the Mysteries of Open Heart Surgery", or from the Detroit Network Group: "What We Can Learn from Sharing Emergency Room Experiences").

Invite guest speakers from the local community. Or, with adequate planning time and a speaker phone at the meeting place, it is possible to arrange for a doctor to consult with the group on a specific topic. Questions can be sent to the specialist ahead of time, and the session can be interactive, as well. Some members of our PAB may be willing to do this. You should also inquire with local doctors. We suggest planning three months ahead.

Serving members' needs for SUPPORT

Support happens naturally through connecting with others who are dealing with similar challenges of Marfan syndrome and related disorders. Commitments, agreed upon by a group can allow it to bond and grow and help to create a caring community.

- **Practice confidentiality.** Explain that nothing that is shared (experiences, contact information, etc.) goes outside of the group or NMF. The local contact list is shared only among group members and the NMF, and is used solely for group communications.
- Implement NMF project for compiling a **Local Medical Resource List**.
- Do a similar list for **Local Peer Support**. Create a list of members who are willing to talk to others in a constructive way about their health experiences (operations, emergencies, how to prepare, what to expect, how to deal with, etc.). See sample developed by the Dayton Network Group on the Leaders Forum web page on the NMF website.
- Make a commitment to come together to **welcome a new member to the group**. Call a few members together if your meeting is not for a while. This means a great deal to anyone who is newly diagnosed, or has never met anyone with Marfan syndrome.
- **Respond to expressed needs** through phone calls, notes or putting people in touch with someone who can help (peers, NMF Support Services, local resources). You are not expected to be an expert on Marfan syndrome, or to have the answers to all questions. You can refer inquiries to the NMF Director of Support Services, Jennifer Buffone (800-8-MARFAN x 22) or Manager of Information and Resource Center, Amy Kaplan, (x 26).
- If questions reach beyond the knowledge or scope of the group, or if you suspect incorrect information is being given by a group member, you can state, "This meeting is not meant to answer those questions. It would be more appropriate for you to ask your primary physician."
- In between regularly scheduled Network Group meetings, **encourage smaller gatherings of members with common special interests** (e.g. children, teen or young adult group, parents' group, unaffected spouse group).

- If enough members are interested, a Network Group or Chapter may **start a Support Group** for in-depth emotional support. Inevitably, some will not be interested. Consult with the NMF Support Services Director about how to start this support activity and how to find a professional, volunteer facilitator. It is suggested to hold support meetings at least quarterly.

NOTE: Resources for a volunteer professional facilitator include: psychologist, social worker (or graduate student in social work), or inquire with major medical institutions. In some cases a group member may have the skills to facilitate support sessions, but doing so would, more or less, preclude his/her participation as a recipient of support.

Serving members' needs for AFFILIATING WITH A SOCIAL GROUP

Sharing common interest can provide a strong foundation for group gatherings. Here are some suggestions to increase member affiliation with your group.

- **Plan gatherings just for fun** – a picnic, barbeque, brunch, play or movie, girls night out, men's night out, a family outing (trip to the zoo, or museum)
- **Celebrate your successes** and individuals who contribute to them.
- **Don't let meetings become "Pity Parties"**, where members share lists of complaints or regrets. Keep the party line positive by:
 - Concentrating on what individuals learned from their experience, or advice they can share that would benefit others.
 - Setting aside time during the meeting for sharing.
 - Setting up presentation panels of members who can share their experience focused on a particular issue (open heart surgery, managing pain, alternative therapies, etc.).
 - Setting up a local peer support network (polling members on experiences they are willing to share).

Serving members' needs for DOING SOMETHING MEANINGFUL

Focus action around a common concern. Some people will not talk, but will DO things that make a difference to the greater cause, as a way of healing themselves psychologically.

- **Encourage the group to commit to doing meaningful activities** related to members' concerns and interests, and serving the larger Marfan cause. We suggest implementing projects the NMF has developed for this purpose (see section 10 of your Resource Notebook). In addition, responding to Legislative Alerts (calls to action), or **fundraising** for NMF programs can provide bonding experiences that are important to the greater Marfan community (refer to Activities Guide in section 10 of your leader's Resource Book).
- **Find a role for everyone** who wants to help. Suggestion for roles to fill: Member Contact List Manager, Librarian (keep track of Lending Library), Secretary, Web Page Manager (for your space on the NMF website), Project/Event Manager, Newsletter Editor, Telephone Support Contact, Telephone Tree Initiators, Meeting Host, Photographer.
- **Start a newsletter** to keep members updated on group activities, show pride and appreciation in what you have accomplished, highlight members with brief bios, share recipes, meeting summaries, future plans, and use photos. This valued communication can be emailed to reduce, or eliminate mailing costs!
- **Recognize volunteer efforts** of the group members to provide reinforcement and nurture new leadership. Highlight members at meetings, on your NMF web page, or in your newsletter. Occasionally, it may be appropriate to contact the local newspaper for a special accomplishment.

*What is behind us and what is before us
are small matters compared to what is within us.*
Unknown

Support Q & A

In this new column we will provide sample questions that have been addressed by either Amy Kaplan, RN, Manager of the NMF Information and Resource Center, who staffs the NMF Hotline, or by one of our Telephone Support Contacts or Chapter or Network Leaders. We think those that follow are representative of some that you would encounter, and that need some expertise and finesse to answer well. Amy is available for consultation five days a week at akaplan@marfan.org or 800-862-7326 x 26.

Q: I was wondering if I might be mildly affected (I was only 5'8" at my tallest, before my lower back started deteriorating, but with a 6 foot arm span. I have scoliosis and am extremely myopic.). My doctor said it was highly unlikely and didn't really matter anyway, as all they can do is treat the symptoms as they show up.

A: There are many medical professionals who are not very familiar with Marfan syndrome, and will not recommend an evaluation, unless an individual presents with practically all the physical features (and sometimes not even then).

We explain to callers who have these physical features that there is variable expression with Marfan syndrome and the disorder can vary in severity from mild to severe, and that the features and symptoms can also vary, even within members of the same family. We basically recommend that they consider having an evaluation, at the very least having an echocardiogram, to evaluate the current status of the aortic root and heart valve. We explain that as Marfan syndrome is a relatively uncommon disorder, there are only a select number of providers who have expertise in diagnosing and managing Marfan syndrome. We explain the process: that a medical geneticist is best positioned to coordinate the diagnosis among the specialties involved. As part of the work-up, a cardiologist performs an echocardiogram to evaluate the current status of the aorta closest to the heart and the heart valves, and an ophthalmologist does a slit lamp exam with the eyes fully dilated to assess for a lens dislocation. The geneticist should also be evaluating for certain related disorders of the connective tissue that share certain overlapping characteristics with Marfan syndrome, such as Loeys Dietz syndrome. There are also individuals who can have certain of the physical features that are often associated with Marfan syndrome without having any distinct disorder.

Amy Kaplan, RN

Manager, NMF Information & Resource Center

Q: I wanted to let the group know that my husband had his surgery, and passed away last month – only a year later. It has been a long road and it is going to continue that way for us. He had a lot of complications with this surgery and was not getting better. I am sorry I have to tell you in an email. I would love to still come to the Marfan meetings, but I will have to let you know when, since a lot is happening right now.

A: I am so very sorry for your loss . . . words cannot express the sorrow in my heart for you and your family. What can we do to help - even if it is just little things, like help baby-sitting, mowing your yard, bringing you food, or anything at all. We are here to help you through this difficult time. Please remember that the NMF Central Ohio Network Group is more than just a group of people who get together once in a while - I view us as a support group for each other and this being the greatest time of support that I can imagine. Please remember that we are here even if you just need someone to vent or talk with - most of us are all dealing with similar medicine scenarios and somewhat know the battles that you have been facing and would be happy to "lend an ear" and a "shoulder to cry on".

Please let me know your phone number, and I would like to give you a call to see what we can do to help. Also, to increase the support for you, is it ok to share this information with others in the group who have met you two? I am certain that others will want to reach out and do whatever possible to help you as well. I will provide all our phone #'s below -- please feel free to call us ANYTIME you need anything.

Again, our deepest sympathies –

Scott Osterholt

Chair, Central Ohio Network Group

Education & Awareness

Appropriate Screening of Athletes

As you know, it is very important that young athletes be properly screened before playing competitive sports in junior high and high school to assure that those with potentially life-threatening conditions such as Marfan syndrome (MFS) are caught and referred for proper management. It is also important to make sure that those students who have been diagnosed with Marfan syndrome, or a related connective disorder, get modified programming so they can safely participate in gym class.

There are a number of things you can do to help us reach schools about this important issue.

- **Contact your school's athletic director and ask to see a copy of your district's pre-participation athlete screening physical examination forms.** Many states have specific questions about Marfan syndrome and family history of sudden cardiac death. The more direct the questions the better. For instance, examinations that look for the physical characteristics that could indicate Marfan syndrome, such as arms and legs that are too long compared to the length of the body, indented or protruding chest bone, and loose joints are important because these outward signs should alert the physician that further evaluation for a connective tissue disorder may be necessary.
- **If language about Marfan syndrome is vague or is not included, find out who the appropriate person is at the district and present him/her with material about Marfan syndrome and ask that they consider revising the forms.** If necessary, you may need to pursue this with the school board.
- **Ask your school board how to get on its agenda to address this issue to protect the health of young athletes.** Most school boards have a process through which concerned parents can address the board and community at official meetings. The NMF can help to provide you with information and talking points to make your case.
- **Provide your school nurse with materials from the NMF -- including attractive, attention-grabbing posters -- to help them in identifying students who may have Marfan syndrome and to provide a resource to parents of children who may require evaluation.** The NMF has materials that were developed for school nurses and parents. We would be happy to send them to your school nurse on your behalf. Please provide the nurse's name, school name, address, and phone number.

Please let me know if there is any way I can help you as you prepare to approach your schools. If you have questions or need more copies, please contact me at jmartin@marfan.org or (800)8-MARFAN, x16.

THE NMF NATIONAL CONFERENCE TURNS 25!

This is a very special year for the conference -- we're celebrating our 25th anniversary and partnering with Mayo Clinic for the first time. Join the Marfan syndrome and related disorders community in Rochester, MN, August 6 – 9 for four days of exceptional activities including :

- a comprehensive clinic for patient assessment sponsored by Mayo Clinic
- medical workshops presented by world-renowned experts
- special programs for your children and teens
- You will also have the opportunity to make new friends and share your experiences with each other at the Friday evening state-fair themed welcome reception and other informal social gatherings.

Visit the NMF web site at www.marfan.org for conference details and registration information. Also, look for an email announcement in the next couple of weeks about the Leadership Meeting at the conference, for Chapter, Network, and Support Group leaders and Telephone Support Contacts.

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. To create yours, contact Mahab Hoque, Information Technology Manager, at mhoque@marfan.org, or 800-862-7326 x 19. |
| April 30 | Deadline for Chapter Third Quarter Financial Form Heartworks – New York City |
| May 9 | Heartworks Westchester – White Plains, NY |
| May 15 | Conference Scholarship Application Deadline |
| June | NMF Membership Appeal |
| June 1 | Conference Clinic Appointment Deadline |
| June 15 | Conference Early Registration Discount Deadline |
| July 15 | Network Group Quarterly Report Due |
| July 30 | Deadline for Chapter Fourth Quarter Financial Form |
| August 5 | Deadline for Fall <i>Connective Issues</i> submissions |
| August 6-9 | NMF 25th Annual National Conference: August 6-9 in Rochester, MN |
| August 7 | NVN Leadership Meeting at National Conference 10:00 AM – 4:00 PM |
| October 15 | Network Group Quarterly Report Due |