



Leadership Connection

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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

Leadership Support Seminars

Many  one hour conference calls make your job easy

Sign Up Now for Fall Schedule Offerings!

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 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 three days prior to the seminar date.

1. Meet Your Project Coach: Emergency Medicine Campaign

Presenter: Jonathan Martin, NMF Program Director

Date: Thursday, September 25

Time: 4:00 pm ET

Sign up by 9/19

Description: This session will enable you to inform your group about one of the most important outreach activities you can do. There are various aspects of this project that can be done individually, or in a sequence, addressing both hospital preparedness for emergency aortic dissection, as well as personal preparedness. Become familiar with the NMF's new Emergency Planning Packet, available to all members. Whether you are a large group or small, Jonathan will assess your situation and human resources, while exploring the best approach to take with this multidimensional project.

*“Alone we can do so little; together we can do so much.”
~ Helen Keller*



2. Using Lessons from the "Mafia" to Deal with Dwindling Group Participation

Presenter: *Bruce Klein, President, Northern Illinois Chapter*

Date: *Thursday, October 2*

Time: *9:00 ET*

Sign up by: *9/22*

Description: Do you find attendance dwindling and you, with perhaps a few others, taking all of the responsibility for making the group function? Learn from a master of delegation and strong arm techniques that effectively draw members in to accept jobs they cannot refuse, "Mafia" style! They will end up loving you for it, and your group will reap the benefits.



3. Planning for NMF National Fundraising Initiatives for Marfan Awareness Month

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

Date: *Monday, October 6*

Time: *7:00 pm ET*

Sign up by: *10/2*

Faced with the challenge of raising enough money to sustain and build member programs for the coming year, the NMF has asked for full participation of Chapters, Network Groups and Telephone Support Contacts in two easy-to-do fundraisers that are adaptable to any community. Learn about the Hang a Heart mobile campaign and the Have Heart Challenge. Find out how you and your group can get involved this year! There will be time for you to present your general fundraising questions as well.

4. Providing Effective Telephone Support

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

Date: *Friday, October 10*

Time: *1:00 pm ET*

Sign up by: *10/6*

Description: The volunteers on our Get in Touch List 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.

5. Using Your Experience to Give Effective Direction

Presenters: *Jennifer Buffone, LCSW, NMF Director of Support Services and Volunteer Dev.*
Denise Levino, NMF Social Work Intern (Adelphi University)

Date: *Friday, October 17*

Time: *1:00 pm ET*

Sign up by: *10/10*

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. How to Organize a Regional Conference

Presenter: *Susan Meier, President, Northern California Chapter*

Date: *Tuesday, October 21*

Time: *8:30 pm ET*

Sign up by: *10/14*

Description: The Northern California Chapter's outstanding success with their First Annual Symposium in May, 2008, has stirred interest among other Chapters and Network Groups. In this session Susan will explain the planning process, share her recommendations, and supply you with an outline, sample budget, timeline and other helpful handouts. If you are curious, or if you think this exciting project is a viable possibility for your group, please plan to join us.



7. Chapter Leaders Open Forum

Moderator: Kathy Jeffers, NMF Manager of Volunteer Development

Date: Thursday, November 6

Time: 8:00 pm ET

Sign up by 10/22

Description: This is a forum for peer consultation, where chapter presidents and officers come together to discuss what's working and what's not. Share your challenges, solutions and new ideas with other group leaders. Staff members can be invited to join in the discussion as needed, with advance notice. Please submit any specific needs or questions by 10/30 to Kathy Jeffers' e-mail at kjeffers@marfan.org.



8. Telephone Support Contact Open Forum

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

Date: Friday, November 7

Time: 1:00 pm ET

Sign up by: 11/3

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 for Telephone Support Contacts to share thoughts and ideas, support each other and learn from each other.



9. Network Group Leaders Open Forum

Moderator: Kathy Jeffers, Manager of Volunteer Development

Date: Monday, November 10

Time: 8:00 pm ET

Sign up by 10/29

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. 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 10/29, to Kathy Jeffers by e-mail at kjeffers@marfan.org.



10. Incorporating the NMF's Expanded Mission in Your Group Activities

**Presenters: Jennifer Buffone, LCSW, NMF Director of Support Services and Volunteer Dev.
Denise Levino, NMF Social Work Intern (Adelphi University)**

Date: Friday, November 21

Time: 1:00 pm ET

Sign up by: 11/14

In 1996, the NMF expanded its mission to include related disorders. Learn more about the related disorders that are part of the mission and how to incorporate the expanded mission in your group activities.

I have learned two lessons in my life: first, there are no sufficient literary, psychological, or historical answers to human tragedy, only moral ones. Second, just as despair can come to one another only from other human beings, hope, too, can be given to one only by other human beings."

~ Elie Wiesel



NVN VOLUNTEER SPOTLIGHT:

Sheila Shawen Chair, Dayton Network Group

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

My husband Gregg is from Dayton, Ohio; I am from Juliette, Georgia. We met and married in Memphis, Tennessee, living there 19 years before moving back to Gregg's hometown 4 years ago. We have two sons: Dayton, who is almost 18, and Oliver, who is almost 17. We first learned about Marfan syndrome with Dayton's diagnosis at age three. I noticed that when he watched TV he would sit right in front of it, and when I tried to get him to move back, he would lose all interest in it. So I took him to a pediatric ophthalmologist for an examination that revealed he had subluxated lenses and was extremely nearsighted, with a high degree of astigmatism and a lazy eye. The ophthalmologist sent us back to our pediatrician with a letter explaining that without a trauma to explain Dayton's subluxated lenses, he needed to be checked for a genetic cause. Fifteen different genetic conditions were listed, including Marfan syndrome. Since we lived in Memphis at the time, we brought Dayton to University of Tennessee Genetics, where he was diagnosed with Marfan syndrome. He had characteristics in every category of the Marfan checklist. After researching the condition at the UT Library we found an article recommending that siblings of affected patients be checked, and we asked that Oliver, at two years old – our younger son, be evaluated. He exhibited characteristics in several categories, but not enough for a formal diagnosis; however, since his aorta was dilated at the time, he was given a "probable Marfan" diagnosis. He joined Dayton on beta blockers and all the physical restrictions that go with the diagnosis. Gregg and I were also evaluated, but neither of us exhibited any of the characteristics (our aortic root diameters were smaller than our sons'), so we were cleared of suspicion. Because of its dominant inheritance, there are very few reports of affected siblings of unaffected parents. So, we were doubly interested to find out as much as we could about the disorder. However, as Oliver grew up, his aortic root diameter dimensions became increasingly normalized and then remained stable, so his doctors began to suspect he did not have Marfan syndrome about three years ago. Genetic testing of the two boys two years ago confirmed Dayton's diagnosis and found his mutation, but did not find a mutation for Marfan syndrome for Oliver. Dayton had lens replacement surgeries with Morcher Rings in both eyes at ages 7 and 8, which restored his sight. He still calls this the greatest miracle of his life. Over the past year and a half, he has been hospitalized for 61 days with 4 brain surgeries related to an arachnoid cyst and the accompanying high and low CSF pressure headaches, but he is still the most upbeat kid I know. He thinks that all he has gone through has given him such a better perspective on life than many teenagers can have. He appreciates every day.

2. How did you get involved in the Dayton Network Group?

Right after Dayton was diagnosed in Memphis, we joined the NMF and I became a local telephone contact and support group leader. We got involved as a family and really enjoyed meeting others who could empathize with our concerns and interests. When we moved to the Dayton, Ohio, area in 2004, I got in touch with Lynn Smith, who had been a telephone contact for this area, and who was interested in working with me to start a network group here. While we don't have a set meeting schedule, we try to meet at least three times a year, and we keep in touch e-mail and telephone in between.

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

Our most satisfying experiences have come from witnessing the benefits of community that come from sharing our experiences with others on this journey. We comfort each other, share our stories with each other, help each other in practical ways and laugh together. We've had several successful projects – our emergency planning brochure, our local medical directory, our shared experiences resource list and newsletter. Our most enjoyable meeting was the last one, as we focused on humor and creativity as wellsprings for joy in our lives. We try to engage everyone who comes to the meetings, and we always have something yummy to eat.

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

I stay involved in our local group because I enjoy the fellowship, and I want to make sure that any new members have a group to turn to. We do this for our son, but also for ourselves and for all the others affected in our community. I am motivated to stay involved with the NMF because it is the lifeline of hope for curing this disorder and for managing to cope with it in the meantime. I am so encouraged by the many wonderful resources available to us through the NMF.

5. What is your advice for others in the National Volunteer Network?

My advice to others in the volunteer network is to focus on being there for each individual who reaches out to you, to keep updated on the information and resources available from the NMF, and to always find a way to reach your own sense of humor and share it with others. As Julie Kurnitz liked to say, "You cannot keep the birds of suffering from flying overhead, but you can keep them from building nests in your hair."

Group Management

November is Family Volunteering Month

November is National Family Volunteer Month, the perfect time to kick off plans for a family project for the NMF. Many families who volunteer on our programs say that it is a unique opportunity to bond together in an experience that combines supporting our common cause with teaching about dignity, compassion and integrity and instilling a sense of community. This charitable spirit typifies a growing movement across the country in which entire families are volunteering together. Calling family volunteerism an “emerging trend”, Sheryl Nefstead, an associate professor at the University of Minnesota Cooperative Extension Service in St. Paul, MN, says, “People are trying to put more emphasis on family cohesiveness, and they’re searching for ways to help young people have a sense of hope and satisfaction.” Working side by side can be life changing for all who experience it. Perhaps this is even truer for volunteer families with young children who are just starting to form their views of the world.

Family volunteering strengthens families and strengthens our Marfan community. When you decide to volunteer for the NMF as a family, you are not only contributing to an important cause, but you are also helping your family and children in ways you never thought possible. Here is a sampling of benefits your family and your community can achieve through family volunteering.

- **Children** are able to develop compassion and an understanding for others. Not only will involving children in the decision-making process and volunteer activity help them feel appreciated and respected, but the volunteer activity will also enable them to discover talents, acquire new skills and learn about cooperation and problem solving. It also fosters intellectual and spiritual qualities (as opposed to materialism), as it is process, rather than product oriented.
- **Parents** can help others while spending more time with their kids, passing on important values, and sharing meaningful conversations in a positive environment.
- **The NMF** needs your help. Family volunteering helps broaden our outreach to the community, increasing our education and awareness efforts, while improving corporate image and public relations.
- **Society** benefits from family volunteering, as it is a natural multiplier of volunteers. Studies show that children who volunteer are much more likely to continue as adults and carry on the tradition with their own children.

Here are some projects that would be fun and exciting for families to do to raise awareness of Marfan syndrome and related disorders and raise much needed support for NMF programs. Expand your corps of volunteers by inviting friends and extended family to join you.

- ♥ Work with your school to do an awareness event, or introduce the NMF Hang a Heart project.
- ♥ Coordinate a Special Event for Families for your neighborhood or your community: a Treasure Hunt, Spaghetti Dinner, Tennis Tournament, Bowl-a-thon, or benefit concert.
- ♥ Offer Services for sale (yard clean-ups, car wash, painting, providing a meal you cook together)
- ♥ Have a toy sale, yard sale, bake sale.

Please share an experience you and your family have had volunteering together, and send pictures! (Please email Cathie Tsuchiya, NMF Local Fundraising Coordinator at ctsuchiya@marfan.org). Outstanding volunteer efforts are recognized annually at the Awards Lunch at the National Conference. Not only will families be recognized, but a new “Grammy Award” will be given to honor the special efforts of Grandmas and Grandpas.

Information & Technology

Examples Speak Volumes: Leader's Forum Web Page at Your Service!

The new Leaders' Forum page is now up on the NMF website. Have you checked it out? 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. Chapters, Network Groups, Support Groups and Telephone Contacts can post their good ideas, problems, or questions for feedback. Sections include Challenges & Solutions, Successful Meetings, Simply Social, Winning Projects, Special Events, Sample Newsletters, Media Happenings, and Fund with Fundraising. Send your submissions to David Morris, I.T. Manager, at dmorris@marfan.org.

New Design for NMF Website to be Launched January 2009

The new NMF website will be launched before the end of calendar year 2008 and will feature a new, exciting, interactive design scheme, including improved navigation, a new fundraising system, Web 2.0 features (RSS, Online Calendar, embedded HTML code), and a "social network" component. Users will have the ability to create profiles, message each other, post pictures and videos, and post to a message board. These revisions are happening to meet the needs of members for more user friendly functions and to enable increased connection and interaction between our nationwide community. Mark your calendar, and make a New Year's resolution to visit the NMF website on January 1, 2009, at www.marfan.org.

Fundraising

Grant Writing Basics - Part I

A grant proposal is part of a grant application process that reflects a well thought out plan. If you have a project or a program that requires financial assistance, it is important to have the knowledge and skill to make a competitive proposal presentation.

Preparation

Preliminary grant writing steps are the most time consuming, but the most important.

Define your project

- Clarify the purpose of your project.
- Define the scope of the work that is to be performed (this will focus your funding search).
- Determine broad project goals, then draft expected project outcomes in specific measurable terms (specific objectives) that define how you will focus the work to accomplish those goals. (Remember a goal is a general direction and an objective is specific and measurable ("our objective is to deliver X results by Y date at a cost of Z dollars").
- Decide who will benefit – who are your direct beneficiaries and indirect beneficiaries?
- Draft a timeline that includes the planning phase, period of searching for funds, proposal writing and the intended project start date.
- Determine project expenses. What are the costs associated with the project?
- Check for duplication of services to be sure that there are no similar programs/projects being offered in the same geographic area. If similar services/projects are being offered, consider a collaborative effort with others in your community to increase the effectiveness of the project.

After **Project Planning**, (refining concept and budget details) the first step in the grant application process is **Prospect Research** in which you:

Identify the Right Funding Sources

- Develop a list of funders and contact person(s) for each funder to discuss upcoming projects and get feedback as to whether the project has the potential to receive funding. Foundation centers (The Foundation Center, NYC has print directories of funders), computerized databases, foundation web sites, public libraries are good resources to assist in your funding search.
- A tool used often in evaluating funding sources is a foundation's IRS Form 990-PF.
- Check the funding priorities and annual reports to be sure that your project falls within the kind of activities being funded.
- Acquire Proposal Guidelines. Read the funding guidelines and application instructions carefully, as they can and do change from year to year. These will tell you about submission deadlines, eligibility requirements, proposal format, review timetable, budgets, funding goals and priorities, award levels, evaluation process and criteria, whom to contact, other submission requirements. Note deadlines of each application – some funders offer a rolling deadline, some do not. A useful grant management tool at this stage is a monthly calendar to jot down deadlines.
- Plan to submit your proposal before the deadline; log in your calendar how the funder will notify you about the receipt and status of your proposal
- Contact the funder. The funder is sometimes your best resource: identify a project officer who can address questions. Ask about how proposals are reviewed and how decisions are made. Inquire about budgetary requirements – some questions to ask: are matching funds available? Is in-kind (non-cash contribution) acceptable as a portion of the applicant's share? What may be counted as in-kind and how might it be applied?
- Do not limit your funding search to one source

Writing the Proposal

You may need to send a **letter of inquiry** before an application or full proposal is submitted or invited to be submitted.

Letter of Inquiry

A letter of inquiry is a preliminary proposal - a 1-2 page overview of the project - in the form of a letter. Its purpose is to convince the funder to consider your request. It provides you the opportunity to introduce your organization and proposal to the funder.

If the funder's preferred initial approach is to receive a **letter of inquiry**, the letter should include the following information:

Organization mission statement

Reason for and amount of funding request

Needs or problem (include who will benefit)

Project description

Other funders, either prospective or committed

How will the project be sustained after the grant?

The Proposal - Standard Proposal Elements:

Project Narrative

Project Budget

Budget Narrative

Appendix of supporting documentation

When writing a proposal, these are the typical questions that must be answered:

What do we want?

What concern will be addressed and why is it important?

Who will benefit and how?

What specific objectives can be accomplished and how?

How will results be measured?

How does this funding request relate to the funder's purpose, objectives and priorities?

Who are we (organization) and how do we qualify to meet this need?

Project Narrative

When writing the narrative, the first sentence is the most important – state how much money is requested and what the money will be used for. The Project Narrative consists of several descriptive sections:

Statement of Need – this section describes the purpose, goals, measurable objectives and a reason why the proposal should be supported. Background is also a desirable component.

Approach – this section states the methodology or process of accomplishing the goals and objectives. It includes a description of the intended scope of work with expected outcomes, outline of activities, description of personnel functions with names of key staff and consultants.

Project Timeline – here you paint a picture of the project flow that includes start and end dates, schedule of activities and projected outcomes.

Organizational Background and Staffing – this section includes information about the applicant that certifies your ability to successfully undertake the proposed project. The organization track record and staff bios are included here.

Evaluation – This section describes how results will be measured and reported on. Funders want to know how their money is being used and if the projects they support are successfully accomplishing their goals and objectives proposed.

NOTE: This is the first of a two part series offered by Sue Amsterdam, NMF Grants Manager. If you have any questions, please e-mail Sue at samsterdam@marfan.org. Applying for grants from local government, corporate, or foundation resources can be a new source of income to support your education and awareness projects.

February is National Marfan Awareness Month - Now is the time to start planning activities to raise funds and awareness!



This Valentine's Day, Hang a Heart for Marfan syndrome!

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!

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: 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: Collect donations

Last year, 15 volunteers from across the country participated in the Hang-a-Heart project and raised nearly \$10,000. **We’d like to double that amount this year and we need your help!** 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!

As Sharon Nasutovicz, from Utica, NY, who raised nearly \$3,000, said: “I’m honored to be able to raise awareness about Marfan syndrome and will continue to do so.”

We hope you’ll get involved this year! Contact Cathie Tsuchiya, NMF Local Fundraising Coordinator, at 800-8-MARFAN, ext. 13 or ctsuchiya@marfan.org. She can see that you get all the necessary materials. Let’s hang those hearts from coast to coast!

A few of the volunteers from the first Hang-a-Heart campaign:



Sharon Nasutovicz with hearts hung at her workplace



The Ross Family with hearts hung in Houghton, MI



The Bates Family with hearts hung in Staples, MN

Hope to see your photo here next year!!

Communications

**NMF MEDIA CONTACT:
EILEEN MASCIALE, DIRECTOR OF COMMUNICATIONS
631-665-2163, PUBLCITY@MARFAN.ORG**

Bring Your Newsletter to Life

Communicating with your group members through a regular newsletter provides a great value to your local community. For the people who attend your meeting and events, it offers a way for them to stay connected between get-togethers. For others, it provides assurance that the group is active should they need to make a local connection. Groups can also use their newsletter to reinforce connections with local doctors and businesses.

The January 2008 issue of *Leadership Connection* included some helpful hints for starting your newsletter. The newsletter is where you need to promote your upcoming events and meetings and remind your members of key NMF happenings. But your newsletter can do so much more. Here are some ways to take your newsletter to the next level -- to really bring it to life and to use it as a tool to generate more excitement among group members and in the local community.

Energize Your Marfan Community

Nothing creates excitement in a group more than celebrating a success. No matter how big or small, people band together when they can rejoice over an individual or group achievement. Find ways to highlight what is going on locally in your Marfan community. Here are some examples:

- A fundraiser or awareness event that the group or an individual organized. *Marie Jones raised \$500 for the NMF through a garage sale on Saturday!*
- A singular outreach conducted by one group member that resulted in positive feedback. *John Smith talked to the school nurses in our community and they were very interested in learning what to look for when they do scoliosis exams with the students.*
- The accomplishments of one of your members in a non-Marfan activity. *Congratulations to Adam Cole, 14, who became the editor of his middle school newspaper.*

Celebrate your successes together and become a "family." People will then want to socialize together; this can also encourage teamwork and collaboration with projects you may plan for the future.

Highlight Your Members

The basis for connections between NMF members is that everyone can learn from each other. We can learn from each other's experiences with Marfan syndrome, we can learn how to deal with schools and employers, we can learn how to navigate the healthcare system, we can learn how to find a new outlook on life after Marfan syndrome deals some challenges.

Each year, the NMF Annual Conference closes with a panel called *Living Successfully with Marfan Syndrome*. Panel members talk about their journey with Marfan syndrome and offer advice. Find members of your group who are willing to write about themselves and share their coping tips. This provides a great service to your members. It also gives a feeling of satisfaction to those who are willing to be highlighted. Perhaps it will also generate some feelings of leadership.

Profile Local Healthcare Providers

Has your pediatrician gone out of his way to learn about Marfan syndrome? Has the nurse at your local Marfan clinic taken extra time with you to discuss a problem you may be having? Has your geneticist given a talk to medical students about Marfan syndrome?

You can use your newsletter to profile these local healthcare professionals. Include basic information about the individual and how they have helped the Marfan community. Definitely ask the doctor for a photo. This is a thank-you they will really appreciate as it highlights their efforts to potential patients.

Make sure you send a copy of the newsletter to the individual highlighted. Include a note thanking them again. This will certainly reinforce the doctor or nurse's interest and commitment to the Marfan community.

Feature Local Businesses and Retail Establishments

Did the local bookstore allow you to wrap books for donations to the Did a local restaurant open their doors to you for a fundraiser? Did the theater let you staff an awareness table when RENT came to town? local library provide you with a meeting room for your group?

Use your newsletter to thank the local businesses. Even highlight the the specific individual who helped you. Include a photo. Definitely send newsletter with a handwritten note to the person to make sure they see will certainly appreciate the good publicity. In addition, this relationship-can pay dividends in the future, when you are planning another activity or

General Tips

As you are creating these feature stories, there are some rules of thumb.

- Make sure all names are spelled correctly and that you write the titles of people accurately.
- Use photos – preferably action photos – to keep your newsletter looking attractive.
- Bullets make it easy for people to read your articles.
- Incorporate quotes from your members to add “color” to a story.

Need more ideas about how to plan your newsletter or what kind of articles to include? Feel free to contact NMF Director of Communications Eileen Masciale (publicity@marfan.org, 631-665-2163). She has been writing *Connective Issues* since 1995!



Christie Wilson, of the Reno Network Group, received a \$1,000 community grant from the Sparks, NV, Wal-Mart. The grant brought the group's Hang-a-Heart total to \$2913.

NMF?
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Exemplary Leadership Skills

Support Members in Their Time of Grief

Living with Marfan syndrome presents the risk of living with loss. What can you and your group members do to support a member who has just lost a loved one? Here are some suggestions of ways to show you care and offer support during this difficult time in a member's life. Expressing these basic acts of kindness will support the standard of caring you want to maintain among group members.

- ♥ Inform the NMF Manager of Volunteer Development at 800-862-7326 x 11. The NMF will follow up by sending a card/note to the family. If the family wants NMF donation envelopes or brochures, please mention this at the same time.
- ♥ Express sympathy on behalf of the group by phone or visit.
- ♥ Send a sympathy card, flowers or fruit basket.
- ♥ If possible, attend the services with group members.

- ♥ Occasionally send a note or email, or call and let them know you miss them and hope they will return to the group soon.

- ♥ Coordinate meals during the time following death.
- ♥ Create a quilt square in memory of your lost colleague to be included in the NMF memorial quilt.

Marfan Memorial Quilt Project

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. Each block is unique in its design and expression. We are continually receiving additions, and are almost ready to put together another panel. If you do not sew yourself, perhaps you could ask a friend to help execute the square. Jonathan Martin, NMF Program Director, oversees quilt production, and will be happy to consult with you. Please refer to more details on the NMF website, www.marfan.org, where you will see the link on the home page. Below is one of the first two panels completed in 2005.



Research

Help Recruit for the Atenolol vs Losartan in Marfan Syndrome Clinical Trial

As of August 2008, 276 young people, of the 604 that are needed, have enrolled in the trial. This means we still need 328 individuals to enroll who are between the age of 6 months and 25 years. How can you help? By spreading the word. Make sure every member of your group knows about the trial and its importance. Tell even those people you know who aren't affected or don't have affected children. They may know someone who is affected, or who has an affected child. The more people who know about the trial and its importance, the more likely the Pediatric Heart Network is to enroll the number of needed participants sooner. The sooner all 604 participants are enrolled, the sooner we will know the effects of Losartan in people with Marfan syndrome. In addition to telling your friends and families, make sure you tell your doctors, and ask them to tell their patients about the trial. Each one. Reach one. Thank you for your help with this very important research initiative. You can print information about the trial from the NMF website to share with your doctors at http://www.marfan.org/nmf/files/FactSheet_ClinicalTrial.pdf



SAVE THE DATE: August 6-9th, 2009

NMF 25th Annual Conference on Marfan Syndrome and Related Disorders

The new Twin Cities Minnesota Chapter and the Heart of Iowa Chapter, under the leadership of presidents Heather Hinton and Teri Dean respectively, have joined forces to become our first partnership as volunteer co-hosts of the 2009 conference at the Mayo Clinic in Rochester, Minnesota. At a recent conference organizing meeting in St. Cloud, Minnesota, Iowa and Minnesota members met with Kathy Jeffers, NMF Manager of Volunteer Development and Sue Nelson, Mayo Clinic Coordinator, to discuss plans and set up committees. "We are excited about the opportunity to focus our chapter members on the things we can do to put our Midwest signature on this major event", said Heather. "Since Minnesota is so close to Iowa, we looking forward to working together to make this the

most welcoming, family friendly conference ever!", said Teri.

The Mayo Clinic serves patients both close to home and worldwide. The Mayo Health System is a family of clinics, hospitals and health care facilities serving 70 communities in Minnesota, Iowa and Wisconsin. In addition, Mayo services patients nationwide and internationally. Since its inception in 1992, Mayo Health System has grown from a new idea to one of the most successful regional health care systems in America. The NMF is proud to have the prestigious Mayo Clinic as its national conference co-sponsor in 2009, and is delighted to be working closely with the volunteers in the Minnesota and Iowa Chapters on this exciting event.

REMINDERS! DATES & DEADLINES!

Reminder:	Web Pages on the NMF web site are available for all Chapters, Network Groups and Support Groups. To create yours, contact David Morris, Information Technology Manager at dmorris@marfan.org or 800-862-7326 x 19.
September 12	Sign up deadline for first Conference Call Training session
October 31	Deadline for Chapter Quarterly Financial Form
November 1	Deadline for Winter '08 Connective Issues submissions Family Volunteering Kick off Month
January 15	Next Leadership Connection published (copy deadline 1/2) Quarterly Activity Reports Due
February	Marfan Awareness Month (Have Heart & Hang a Heart Campaigns)
August 6-9	NMF Annual National Conference 2009 in Rochester, MN