



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

Leadership Support Seminars

An essential resource for NVN leaders!

Support for the expertise of engaged leaders strengthens the National Volunteer Network and the NMF

Winter-Spring Schedule

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. Fundraising Basics

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

Date: Wednesday, February 4

Time: 2:00 pm ET

Sign up by: 2/2

Description: The NMF relies on donations to support our vital programs. Learn how **you** can raise funds for the NMF in your community during Marfan Awareness Month - and throughout the year. NEW! 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.



2. Poster Project

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

Date: *Friday, February 6*

Time: *1:00 pm ET*

Sign up by: *2/3*

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.

3. 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, February 20*

Time: *12:00 noon ET*

Sign up by: *2/16*

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.



4. RENT: How to Raise Awareness and Funds When this Popular Musical is in Your City

Presenter: *Jonathan Martin, NMF Program Director*

Date: *Tuesday, February 24*

Time: *12:00 noon ET*

Sign up b: *2/17*

Description: Learn about this exciting opportunity to join forces with touring or local productions of RENT to make a difference for the Marfan community. Find out what other groups have done, and brainstorm ideas for your own RENT activity.

Note: Visit the NMF website (click the RENT link) to find out if the show will be playing in your community.

5. Network Group Leaders Open Forum

Moderator: *Kathy Jeffers, Manager of Volunteer Development*

Date: *Monday, March 2*

Time: *8:00 pm ET*

Sign up by 2/16

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 2/16, to Kathy Jeffers by e-mail at kjeffers@marfan.org,

6. Chapter Leaders Open Forum

Guest Consultant: *Suzanne Kouri, Immediate Past President, Massachusetts Chapter*
Moderator: *Kathy Jeffers, NMF Manager of Volunteer Development*

Date: *Monday, March 16*

Time: *8:00 pm ET*

Sign up by 3/9

Description: This is a forum for peer consultation, where chapter presidents come together to discuss what's working and what's not. Suzanne is eager to share the golden nuggets of her experience as Chapter President for five years. 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 3/9 to Kathy Jeffers' e-mail at kjeffers@marfan.org.

7. Telephone Support Contact Open Forum

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

Date: Friday, March 13

Time: 1:00 pm ET

Sign up by 3/6

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.



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

Presenter: Jonathan Martin, NMF Program Director

Date: Wednesday, March 25

Time: 12:00 noon ET

Sign up by 3/18

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.

9. Legislative Advocacy: Creating a Strong Voice for Marfan Syndrome

Gavin Lindberg, NMF Board Member

Date: Thursday, April 2

Time: 7:00 – 8:00 pm EST

Sign up by 3/26

Learn how your 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. A copy of the NMF Legislative Agenda will be sent to you prior to this session, along with other pertinent materials to share with your group members.

Education & Awareness

Get Involved for National Marfan Awareness Month

National Marfan Awareness Month – February – is an ideal time to spread awareness of Marfan syndrome and raise money for the NMF.

In conjunction with National Marfan Awareness Month, the NMF launches its **haveheart campaign** every February. Through this campaign, NMF members can organize local events to raise awareness and funds for Marfan syndrome and contact the local media to generate local market coverage of Marfan syndrome.

Letter-writing campaigns, local health fairs and getting donations for the Hang Heart campaign, which debuted last year, are among the projects you can consider.

ACTION: If you would like to work with the local media, contact Eileen Masciale at 631.665.2163 or publicity@marfan.org. She can provide the NMF guidelines, How To Work with the Local Media, as well as a local media list for you (including daily and weekly newspapers, radio, television contacts).

ACTION: If you would like to conduct a local event, contact Cathie Tsuchiya at 800-8-MARFAN, ext. 13, or ctsuchiya@marfan.org, to get more information and helpful materials.

RENT Taking on a New Life in Communities Nationwide

When one door closes, another door opens. So it is for the Broadway show, *RENT*, the multi-award winning hit musical, which finished its run on Broadway on September 7, 2008.

Now, school, community and regional theater productions of *RENT* will bring the words and music of playwright Jonathan Larson to an even greater audience. There will also be an increased number of opportunities for Marfan syndrome awareness.

The NMF has worked closely with the licensing group, Music Theater International, to ensure that information about Marfan syndrome is included in the packet that local theatre groups receive when they are going to stage the performance. We encourage our local volunteers to partner with these regional groups and maximize the opportunity for Marfan awareness in their area. For a complete list of productions that are being staged across the U.S., log on to the NMF website (www.marfan.org) and click on the link for the *RENT* tie-ins.

Also, original Broadway cast stars Rapp and Adam Pascal will be joining the national tour of *RENT* from January through August. If *RENT* is going to be in your area, please contact NMF Program Assistant Barbara Habermann (bhabermann@marfan.org) to find out how you might be able to coordinate a public awareness or local fundraising event in your town. Be sure to give us at least 4-6 weeks notice. The tour schedule can be found at www.siteforrent.com.

It is the hope of Al Larson (Jonathan Larson's father) that, although *RENT* has said goodbye to Broadway, thousands of new people will be exposed to Jonathan's story through touring, school, community and regional theatrical productions.

Research

What is GENTAC and Why Should I Join?

What is GENTAC?

GenTAC stands for the National Registry of **Genetically Triggered Thoracic Aortic Aneurysms and Cardiovascular Conditions**. This is a database (also known as a registry) which will record the medical histories of each and every patient with a history of genetic aortic aneurysms (enlargement of the large vessel in the heart).

Who is in charge of GENTAC?

GENTAC was developed by the National Heart Lung and Blood Institute in partnership with the NMF.

Why was GENTAC developed?

GENTAC was developed in order to obtain the following information:

- Document the medical history of patients with genetic disorders that lead to enlargement of the aorta.
- Collect blood or saliva samples from patients so that researchers can use these to investigate the causes of these disorders.
- To establish a database where researchers could use the medical history information to

track treatment patterns and develop better methods for patient care

Who can be in GENTAC?

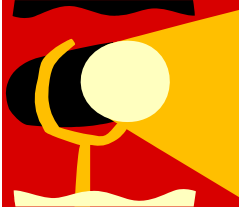
Anyone with the following conditions should consider joining GENTAC

- Marfan syndrome
- Turner syndrome
- Ehlers-Danlos syndrome
- Loeys-Dietz syndrome
- Shprintzen-Goldberg syndrome
- Bicuspid Aortic Valve
- Family history of aortic aneurysms and dissections

What do I have to do to join GENTAC?

Step 1: CALL US! Call a participating clinical center to join.

Step 2: COME IN OR SEND US YOUR MEDICAL RECORDS. Joining GENTAC will only require a small amount of time. You will be for the following information.



NVN VOLUNTEER SPOTLIGHT:

Sherry Heldt Chair, Network Group of Omaha

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

I have been married to my wonderful husband Roger for 37 years, we had one son together Shawn who died from an aortic dissection due to Marfan syndrome. I have two step-sons Roger Jr. and Tod with 2 grandchildren from Tod TJ and Dylan. who live in Wisconsin. I worked for the Omaha Public Schools for 17 years with Special Needs children at the Middle School. I recently retired in June 2008. I am also involved in West Hills Church in Omaha, as a Deacon of Stephen Ministry since 1994.

On Dec 11, 2000 we lost our beautiful 22 yr. old son Shawn due to a misdiagnosis in the emergency room at our local hospital. A year later I got a diagnosis of Marfan syndrome after seeing a Genetic doctor. After that, I became involved in raising awareness about Marfan syndrome in Omaha and surrounding areas. My first attempt was a Garden Walk. Then I became involved in the Heart of Iowa Chapter of NMF, volunteering with their Walk/Fun/Run held annually on Labor Day weekend, and talking to first and second year medical students about our story. It is compelling, and they learn more than reading a paragraph in their text book, which is all that is generally offered on the subject!

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

In 2006, I decided it was time to start a group in our local area, along with the help of NMF and Kathy Jeffers. On October 21, 2006, the Network Group of Omaha held its first meeting at Denney's Restaurant. In 2007, we grew in numbers and thanks to Dr. Schaefer a Genetic Specialist at UNMC, we were given a Conference Room to hold regular meetings. We are going on our third year now, and are still growing. It is gratifying to know that due to our efforts, more people in the Omaha area are becoming aware of Marfan syndrome.

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

I believe the most satisfying activity where we get to see the growth and success of our group is at our annual picnic. This brings people together on a bigger scale and allows them to get to know one another on a casual basis and share stories with each other. It might be the only time people come together with someone they can identify with.

Our most successful meeting was this September, when 17 members gathered to watch the DVD "How Do Your Genes Fit". We had a question and answer session afterward that turned into a round-table discussion on genetics. It was really cool! We had a Pizza/Pop/Dessert Party afterward, adding some fun and sociability.

We've had several doctors present on topics dealing with Marfan syndrome: dealing with joint, heart and dental problems, as well as genetics.

We hold two fundraising events a year. For the Younkers Community Day Event we sell coupon booklets for \$5. We are allowed to keep the entire \$5, and in 2008 we sold over \$1,600 dollars worth of coupon books between the spring and fall events. We donated proceeds to the 2009 NMF Conference Scholarship Fund. For a small group, I am delighted that we've been pretty successful with fundraising and getting the word out about Marfan syndrome.

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

I believe the biggest thing that keeps me motivated is the fact that I realize how important Marfan awareness is and helping people get the help they need to take care of themselves medically, while keeping them updated with the most current information on Marfan syndrome. It is also important to me that my efforts will prevent another parent from having to go through the journey Roger and I went through losing Shawn.

The Network Group could not have gotten this far without the help of NMF. The wonderful feedback and praise they offer us is the fuel that keeps me going. We also have two wonderful Co-Chairman Debra Fearl and Jeni Guzinski, who show up for every meeting, make suggestions, and help with whatever needs to be done. They make a difference to our group and in our community.

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

You're going to get discouraged at times especially when at every meeting people are not showing up like you wish they would, hang in there. Remember no one likes to go to a boring meeting, find new ways to draw people in, make it interesting and fun to come to a meeting. Ask them what they would like, involve them in by getting their input, listen to their needs, bring in speakers, do whatever it takes to get people involved. The biggest help I've found is the Conference Call Leadership Training Seminars that the NMF offer, this gives you idea's, allows you to talk with other Chapter and Network group leaders and get their thoughts and idea's to use in your group. Also, do a Chapter or Network Newsletter, this shows people you are sending it to that you are real. Also do a webpage on the NMF website, this allows people who are in your area to know what is happening in their area.

Exemplary Leadership Skills

Establishing Meeting Ground Rules

Ground rules, or norms, provide guidelines for helping a group work together in an agreed upon manner. These norms are intended to facilitate a healthier interaction and limit wasted time and effort. Using this technique will virtually eliminate behavior problems before they begin. Be certain to discuss, and agree upon, all ground rules before the meeting begins. It is also important for the group to determine what measures it should take if the ground rules are not followed. Once the meeting begins, anyone, at any time, can remind the group that the ground rules aren't being respected.

Ground rules support meeting productivity, creativity and participation, and help keep the meeting on track. Some examples of ground rules are:

- ♥ Follow our standard of confidentiality.
- ♥ Listen to, and honor all opinions.
- ♥ One conversation at a time.
- ♥ We allow everyone to speak and share experiences or ideas, without dominating a discussion.
- ♥ Focus on the subject/task at hand.
- ♥ Fun is allowed.
- ♥ Help us stay on track and on schedule.
- ♥ Avoid detail overload.
- ♥ Offer solutions, not complaints.
- ♥ Avoid personal agendas.
- ♥ No lectures.
- ♥ No phone or page interruptions.

Once norms are established, it is imperative that everyone follows them. Many groups have been proactive about establishing norms. Unfortunately, some fail to hold everyone accountable to the norms. This can be more damaging than no norms at all. The meeting leader must respectfully remind participants of the norms when they start to stray. Keep ground rules posted at every meeting as a reminder.

Communications

Creating a Brochure for Your Local Chapter or Network Group

Promoting your local group goes hand-in-hand with the various activities that you do as a chapter or network group leader. Expanding your group membership, along with NMF membership, is an important goal of the work you do in your town, city or state. The growth of your local group enables you to help more people who are part of the Marfan and related disorders community. It also provides more people to connect with and share experiences, as well as more support for the activities your group is doing.

Some of our groups have expressed interest in a chapter or network group brochure. When developing this, it is important to understand the purpose of the brochure and the target audience. The group member creating the brochure should have a firm grasp of the goals of the brochure – what the content should include and what can be left out (because the NMF has other resources to cover some of it for you!).

The goal of the brochure is to generate awareness of the local group – what it can offer, its activities, how to get involved, how it is part of the national organization.

Target audiences include doctors (and other medical professionals), the general public, people who contact you after finding you on the NMF website or in *Connective Issues*. It is your tool to showcase your group when you do health fairs and fundraisers, when you hold awareness events, when you give presentations at schools or hospitals.

Based on our work with chapters, the NMF now provides specific parameters for your brochure content. This will help create a unified identity while providing recognition for your specific group.

Cover

- NMF logo (read more about this in the section below on photos and graphics)
- Name of the chapter or network group
- NMF tagline: *Serving the needs of people with Marfan syndrome and related disorders*. Additionally, you may want to include the slogan: *Marfan Syndrome: Learn about it, Recognize it, Save a Life*

Inside

- Who we are: a description of the chapter; include that the chapter implements the mission of the NMF locally, and then include the NMF's mission statement.
- Services and activities: an overview of the activities that the chapter or network group is involved with
- Getting connected: How to become part of the Marfan community through the NMF and your local group; include contact information for the Foundation and for your group. Make sure that you don't limit the usefulness of your brochure by printing the name and contact information of a group leader who may not be in the position for long.
- Marfan syndrome overview: A very brief, easy-to-understand description of Marfan syndrome. You do not need to go in-depth because the NMF has approved materials on Marfan syndrome that you can disseminate with your brochure.

In general, keep the information simple. Use bullets whenever you can so the copy is easy to read. Focus on the highlights; you do not have to include every detail about your chapter. Let the reader come to your meeting or event to find out more!

Use of Photos and Graphics

Photos and graphics add to the attractiveness of your brochure. Even if your brochure will be printed in black and white, photos will bring your information to life. Consider shots of your members in action at events, close-ups of members of various ages and ethnicities, and photos that include a doctor who may be very close to your chapter. Make sure you get

permission from people in the photos to use them in your brochure. (The NMF can provide you with a permission form so you have a written record of their approval.) Only use high quality photos, otherwise they will not have the effect that you want.

The NMF logo should be used in accordance with the NMF Style Guide, which will be available to NVN members during the first quarter of 2009. The Style Guide will include the guidelines for use of color with the NMF logo in different media, as well directions about the use of fonts.

NMF Approval

All chapter and network group brochures need to be approved by the NMF prior to printing. Feel free to involve us in the process by submitting a draft for review in your early stages of development. We are glad to provide feedback and help facilitate the process so you can create a brochure that meets your needs and fits within the NMF guidelines.

Eileen Masciale, NMF Director of Communications, is your point person for brochure development. She can answer your questions and provide guidance as you create the piece. She will also ensure that you get the approval you need in a timely way to proceed with printing.

If you are creating a chapter or network group brochure, please contact Eileen at 631.665.2163 or publicity@marfan.org.

Support

Coming Soon: NMFconnect

A New Exciting Way to Connect with the NMF and Related Disorders Community

The new NMF Website will be making its debut early in 2009. One very exciting new feature of the website is the online community, NMFconnect. NMFconnect will be very similar to Facebook and MySpace but exclusively for the Marfan and related disorders community. With NMFconnect you will be able to create a profile, blog, share photos, videos, and music, create forums and join and create online support groups. Parents Place, Growing Older with Marfan Syndrome, Teen Spot, and Loeys-Dietz Support are just a few of the many online support groups you'll have the opportunity to join. Additionally, NMFconnect will be a place for you to promote your local group. You will have the ability to create an online group just for your local members, share photos and videos of group events, and promote your events all on NMFconnect. You'll access NMFconnect on the new website by simply clicking "Online Community" on the homepage. Be sure to check it out.

New Medical Office Poster Project

Would you like to attract new people to your group while building relationships with local Marfan and related

disorders medical offices? Then this project is for you. The NMF has created a new poster specifically to hang in medical office waiting areas and exam rooms. The poster details the NMF services and how to access them including the Information Resource Center, the Annual Conference, the NMF newsletter: Connective Issues, the NMF website and the National Volunteer Network. The goal of this project is for volunteers to hand deliver this new poster to any and every medical office that works with Marfan and related disorders patients and ask them to hang it in their waiting area and/or exam rooms.

Posters can be brought to cardiologists, orthopedists, to your group as the poster makes people going to that office aware that there is a foundation that serves the Marfan and related disorders community and there are local groups they can participate in and tells them how to find a group in their area. This is also a great opportunity for you to network with doctors, nurses, and genetic counselors in your area, make them aware of your group and open the door to them doing a presentation for your group. If you are interested in getting involved in this project please contact Jennifer Buffone, Director of Support Services and Volunteer development at 1-800-8-MARFAN ext. 22 or jbuffone@marfan.org.

Fundraising

Grant Writing Basics - Part II

To summarize from our last article, a grant proposal reflects a well thought out plan. Now that we have had an overview of the project planning process and proposal basics, we can concentrate a bit more on the actual proposal itself.

The basic components of a proposal are:

- Proposal Summary (also called Introduction, Executive Summary or Abstract)
- Introduction of Organization
- Problem Statement (or Needs Assessment)
- Project Objectives
- Project Methods and Workplan/Timeline
- Project Evaluation
- Future Funding (Sustainability) and
- Project Budget

The complete proposal package includes:

- Cover letter
- Proposal
- Budget
- Supporting Documentation (Appendices)

Critical elements during the grant writing stage are structure, reasonable budget, attention to funder's specifications and a concise but persuasive writing style.

Cover Letter

The cover letter's purpose is to introduce the organization to the funder. The following criteria should be met in a cover letter:

- Provide a brief overview of the organization and its purpose
- The reason for the funding request
- The amount requested
- Length is one-page
- Includes the funder's name, title and address
- Includes the name and phone number of contact for the organization
- Is signed by a person who can speak with authority on behalf of the organization

Proposal Summary

As the name implies, the summary is a concise and clear synopsis of the request. About a page in length, it provides the reader with a basic idea of the rest of the proposal. The summary should meet the following criteria:

- Include one sentence describing the problem
- Include one sentence on the objectives of the request
- Describe methods for carrying out the project in about a sentence
- Include the total costs, any funding already obtained and the amount requested of the funder

Organization Introduction

In this section, you describe the applicant organization and its qualifications for carrying out the project. Here you describe the organization's credibility and standing on solving the issue. The programs and accomplishments are included in this section also. Overall, this section's purpose is to demonstrate to the funder that the organization is the appropriate agency to conduct the project. By the time the reader has finished with this section he/she should understand that the organization has the means and creativity as well as the personnel to solve the particular problem or meet the need. It is more important to focus on the special attributes of the organization to carry out the project successfully, not

over emphasize accomplishments. (A funder can and often does request an Annual Report, where accomplishments are readily available).

This section should:

- Clearly establish the organization's purpose and long-range goals
- Describe current programs and activities
- Describe organization's constituency
- Provide evidence of applicant's accomplishments
- Present qualifications in the area of activity in which funds are being sought
- Describe qualifications of key personnel involved in the project
- Be brief

Problem Statement/Needs Assessment

A well-supported statement of the problem that the project will address is described here. Rely on facts, and document the following:

- The nature of the problem – present hard evidence as much as possible
- What is currently being done about the problem
- Who is affected by the problem – how will they benefit from the project
- The specific way in which the project will solve the problem

Remember, objective research help to make a compelling case for support because it justifies the need or problem. It is important that it be sufficient to demonstrate that a problem or need exists. Some additional information for inclusion in this section:

- A description of the target population to be served by the project
- Define the need in the geographic area served by the project
- Relate the problem to the overall purposes and goals of the organization
- Use statistical evidence if available
- Use input from beneficiaries already being served
- Be brief

Program Goals and Objectives

Specific activities and outcomes of the project are discussed here. Identify all objectives related to the goals to be reached. Be sure to include methods to achieve the stated objectives. Should funding be awarded, the stated objectives will be used to evaluate program progress. Be realistic about goals and objectives.

Describe what you hope to accomplish and what the project's outcomes are. Elaborate on one objective for each problem or need in the problem statement (above). Remember that a goal is a general direction, and objectives are measurable and quantifiable. (*Our objective is to deliver X results by Y date at a cost of Z dollars*).

Project Methods and Workplan/Timeline

Here you describe the actual activities that will achieve the desired objectives. Describe the rationale for choosing a particular approach, be chronological in your description in describing the operations, logistics or sequence of events of the proposed project. You should include a timeline to describe a work flow that includes start and end dates, schedule of activities, who is assigned to carry them out and why and projected outcomes. Be detailed and include reasons for the selection of the specific activities.

Evaluation

This is your plan for determining the degree to which your objectives are met. For many funders, this section represents an intelligent investment for them. Be sure to include:

- A plan for evaluating accomplishment of objectives
- A plan for modifying methods (a "course correction") during the project
- The evaluation criteria
- How data will be gathered
- Any test instruments or questionnaires to be used (attach a sample in the appendix)
- How evaluation will be used for program improvements (I think of this section as the basis for formulating a needs statement).
- Describe any evaluation reports that will be produced

Future Funding (Sustainability)

Sustainability is all about planning for continuation beyond the grant. Here you describe the availability of other resources necessary to implement the grant:

- Present a specific plan to obtain funding if program continues
- Describe how future costs incurred will be covered
- Describe how additional funding will be garnered to implement the project
- Include a list of funders being approached on behalf of the project (funder's name, date of submission, amount requested, current status – pending or committed)

Project Budget

Budgets are cost projections. They provide the funder with a window into how the project will be implemented and managed. Budgets should show expenses and income and structured in columnar form. Budgets should be:

- Detailed
- Include project costs incurred at the time of project's implementation
- Explain miscellaneous expense amounts
- Include items asked of by the funding source
- Include items paid for by other sources
- Include all volunteers and consultants
- Details fringe benefits, separate from salaries
- Include separate non-personnel costs

Be flexible about your budget, as the funder may choose to negotiate costs. A well-prepared budget justifies all expenses and income and relates back to the narrative sections. Be sure when drafting the budget that you are telling the funder that the job can be accomplished with the expenses proposed; that the costs are reasonable; that they are consistent with the proposed activities and that you provide sufficient detail and explanation of all budget items.

Appendices

Funders ask for supporting documentation and it is organized in a section entitled Appendices. These are the materials that endorse the organization and the project. Every funder has different requirements for the supporting documents that need to be enclosed in the proposal package. Each funder's guidelines will specify. DO NOT submit any materials not asked for.

Appendices can include:

- Annual Report
- IRS 990 Tax Form
- Verification of tax-exempt status (the 501 (c)(3) letter)
- Names and affiliations of officers and Board of Directors
- Financial statements for last completed fiscal year
- Current organization operating budget
- Project budget
- List of other funding sources
- Biographies of key personnel

Conclusion

Ask yourself these questions when assessing your narrative:

- Who are we and how do we qualify to meet this need
- What concern are we addressing and why
- Who will benefit and how
- What specific objectives can be accomplished and how
- How will results be measured
- How does this project relate to the funder's purpose, objectives and priorities

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 Judy Gibaldi, at jgibaldi@marfan.org , or 800-862-7326 x 14.
January 30	Deadline for Chapter Second Quarter Financial Form Quarterly Activity Reports Due
February	Marfan Awareness Month (Have Heart & Hang a Heart Campaigns)
February 2	Sign up deadline for first winter Conference Call Training session
February 27	Deadline for Spring <i>Connective Issues</i> submissions
March 7	Heartworks – The Marfan Gala - St. Louis
April 15	Next Leadership Connection published Quarterly Activity Reports Due
April 30	Deadline for Chapter Third Quarter Financial Form Heartworks – New York City
May 9	Heartworks Westchester – White Plains
June	NMF Membership Appeal
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

Life is a storm, my young friend. You will bask in the sunlight one moment, be shattered on the rocks the next. What makes you a man is what you do when that storm comes. You must look into that storm and shout ... Do your worst, for I will do mine! Then the fates will know you ...

*Alexander Dumas, from The Count of Monte Cristo
Submitted by Kati Robertson of Santa Barbara, CA
on behalf of her brother, Aaron Robertson*