



Leadership Connection

February 2011

Volume 5 .No. 1

THE IDEA SOURCE FOR NMF NATIONAL VOLUNTEER NETWORK LEADERS

Published by the National Marfan Foundation
22 Manhasset Avenue, Port Washington, NY 11050
800-8-MARFAN - www.marfan.org

Dear Friends,

Happy New Year! I want to take this opportunity to say thank you for your dedicated service to the NMF. You, as an NMF volunteer leader, drive the effort to build and strengthen the Marfan community in your area, bringing the NMF mission alive for so many who previously had no local point of contact. We now have a National Volunteer Network that has grown to include 9 Chapters, 44 Network Groups and 87 Telephone Support Contacts. All across our country, our volunteers are investing their time, ideas, resources and experiences to lead efforts in bettering the quality of life for all affected individuals and their families. Together, we have created a wide network of connection and communication that was previously very limited. The NMF is grateful for all you do to advance our shared mission, and is proud of where we stand today, with your help!

As one of the country's leading voluntary health organizations, the NMF offers quality training, resources, and networking opportunities that equip you to engage in meaningful service. Core competencies are developed and enhanced through conference call training sessions and individual consultations with NMF staff members. Please take advantage of these rich and varied opportunities, and sign up for your spot today

The NMF staff looks forward to working with you in 2011! Know that we are always here for you. You can call us any time. And, should you be in New York, please stop by Headquarters so we can give you a tour.

Kathy

Kathy Jeffers,
Manager of Volunteer Development

One-hour Conference Call Seminars Open to All Group Leaders and Telephone Support Contacts

**Please make every effort to participate, or appoint a key person
in your group who demonstrates leadership qualities.**

Please note change in registration procedure.

To Register:

Email Barbara Habermann
at bhabermann@marfan.org or call 1-800-8-MARFAN X 36

Volunteer Leadership Training

Winter/Spring Conference Call Seminar Schedule

NOTE: Schedule relates to Eastern Time (E.T.)



Understanding the New Diagnostic Criteria

This session is mandatory for all group leaders and Telephone Support Contacts. If you have not participated yet, please sign up for one of the sessions below.

Since you are representing the NMF at the local level, it is imperative that you understand the new diagnostic criteria and their implications. How are the new criteria different? How do they work? What do they mean for Marfan syndrome and related disorders? How can we be a resource for our doctors? What resources are available? Why it is important for us all to be on the same page? All questions will be answered by the presenters, accompanied by full discussion with participants. **Please choose one day and time that is most convenient for you from the following list. NOTE: You will need phone and computer access for this webinar format.**

**Presenters: Jennifer Buffone, Director of *Support and Volunteer Development*
Josephine Grima, Vice President of Research & Legislative Affairs
Jonathan Martin, Director of Education & Awareness**

1.	Thurs. Feb 16	3:00 pm ET	Jennifer Buffone	Sign up by 2/9
2.	Thurs. March 3	2:00 pm ET	Josephine Grima	Sign up by 2/24
3.	Sat. April 16	2:00 pm ET	Jonathan Martin	Sign up by 3/30

4. Staying Organized as a Network Group Leader

**Presenters: Kathy Jeffers, Manager of Volunteer Development
Cathie Tsuchiya, Administrative Director & Local Fundraising Coordinator**

Date: Thursday, February 24 Time: 1:00 – 2:00 pm ET Sign up by 2/15

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

5. Chapter Leaders Open Forum

Moderator: Kathy Jeffers, NMF Manager of Volunteer Development

Date: Monday, February 28 Time: 8:00 pm ET Sign up by 2/14

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, create solutions and share new ideas from this select group of key NMF leaders. Please submit any specific needs or questions by 3/4 to Kathy Jeffers' e-mail at kjeffers@marfan.org, so we can invite appropriate guest consultants for this session.

6. Ways to Boost Group Participation

Presenter: Kathy Jeffers, Manager of Volunteer Development

Date: Tuesday, March 1 Time: 8:00 – 9:00 pm EST Sign up by 2/22

Description: How to pump up your meetings, create an environment of cooperation, encourage participation, attract new members, and nurture new leadership. You are also encouraged to share ideas on what has worked for you in each of these areas!



7. Celebrating the NMF's 30th Anniversary: How the NVN Can be Involved

Presenter: Eileen Masciale, Communications Director

**Date: Monday, March 7
Thursday, March 10**

**Time: 6:30 pm E.T.
1:00 pm E.T.**

**Sign up by 3/1
Sign up by 3/3**

Description: As the NMF's 30th Anniversary approaches in 2011, we are preparing for extensive media coverage across the nation. Find out how to become a part of this special opportunity to support your group and your organization!



8. "TOWN MEETING" With Carolyn Levering, NMF President and CEO

Presenter: Carolyn Levering, President & CEO

Date: Wednesday, March 9

Time: 2:00 pm

Sign up by 2/24

Description: The focus of this second Town Meeting will be new program and service initiatives for the NMF. All group leaders and chapter board members are invited to meet with Carolyn to hear the latest NMF news and trends, to ask your questions, and to brainstorm with Carolyn on how to make these initiatives most meaningful to you and the people in your area.



9. Providing Support Throughout the Grief Process

Presenter: Jennifer Buffone, Director of Support and Volunteer Development

Date: Friday, March 11

Time: 1:00 pm ET

Sign up by 3/3

Description: Participants will learn how to support individuals that contact them as group leaders or phone contacts who are grieving. Grief/loss is will be addressed in terms of supporting people who have lost a family member or friend to Marfan syndrome or a related disorder as well in relation to loss of the idealized self which many people experience upon learning they have Marfan syndrome/a related disorder. Participants will learn about the grief process as well as how they can provide support throughout the process.

10. Telephone Support Contact Open Forum

Moderator: Jennifer Buffone, Director of Support and Volunteer Development

Date: Wednesday, March 16

Time: 3:00 pm ET

Sign up by 3/8

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.



11. Using Online Resources To Enhance Your Group

Presenter: Jennifer Buffone, NMF Director of Support Services and Volunteer Development

Date: Wednesday, March 30

Time: 1:00 pm ET

Sign up by 3/23

Description: NMFconnect. Facebook. Youtube. The possibilities are endless. Learn how to use online resources/services to promote your group and enhance your groups' activities.



12. Becoming a Chapter – Is Your Group Ready?

Presenters: Kathy Jeffers, Manager of Volunteer Development

Date: Tuesday, April 5

Time: 8:00 pm ET

Sign up by 3/29

Description: Are you wondering what it takes to become an official NMF Chapter? Whether you think your group may be ready now, or you want to know what to work toward, please join in this discussion. We will explore the elements that need to be in place to apply for official chapter status, and what is required of chapters once they are in place.

13. Network Group Leaders Open Forum

Moderator: Kathy Jeffers, Manager of Volunteer Development

Date: Monday, May 9

Time: 8:00 pm ET

Sign up by 5/1

Description: Designed as a forum for peer consultation, Network Group leaders come together to discuss what's working and what's not in managing their groups. Here is the place to share your prized successes, challenges, solutions and new ideas with other group leaders. Specific staff members can be invited as needed, with advance notice. Please submit topics or questions by 4/25, to Kathy Jeffers at kjeffers@marfan.org.

14. Consultation on Education and Awareness Group Projects

Staff Consultant: Jonathan Martin, Director of Education & Awareness

Call for an Appointment: 800-862-7326 x 16

Description: To ensure continued participation of your members, it is essential to plan meaningful activities. Jonathan Martin is available to group leaders for individual consultation to explore how NMF designed projects can best be implemented in your community.

KUDOS

Kudos: *n* 1. *syn* see EMMINENCE; 2. *syn* see HONOR

North Dakota Chapter Status Approved

At the October 30 meeting of the NMF Board of Directors, the North Dakota Network Group, chaired by Selma Kerzman, was awarded full chapter status. Congratulations to Selma Kerzman, President and her board: Dena Kemmet, Vice President; Kent Vernon, Treasurer; Ken Stockert, Secretary.

New Network Group Leaders

Laura Amarys – Eugene, OR
Betty Carr – Naples, FL
Carole and Joe Nowak – Phoenix, AZ
Karen Singley Collins – Denver, CO
Barbara Shields – Latham, NY

New Telephone Support Contacts

Anthony Trapp – Old Bridge, NJ



NVN VOLUNTEER SPOTLIGHT: Oregon Network Group Chairs!

**Rebecca Stroda, Portland Network Group
Laura Amarys, Eugene Network Group**

With the NMF National Conference in Oregon this July, we thought you would enjoy getting to know your colleagues in Portland, our host city, and Eugene. Remember, your group can support the conference scholarship program by donating a gift basket, representing your city or state, to Heart Mart!



Rebecca Stroda

I am a wife and mother of three children. One of our daughters has Marfan syndrome, the first incidence in our family. I first heard of Marfan syndrome back in 2004. It has been a journey with many specialty appointments and back surgery a year ago. My husband and I are extremely thankful to the NMF for their support and the resources they so generously share. My hope is to continue to connect with others and spread awareness and education. I have found the Marfan community to be supportive and educational, and I have met the most amazing individuals who always shine even in difficult times.

I was involved in a previous Oregon group and still remember the day I received the meeting notice, and how excited I was to be invited to connect with others. When the group leader had to step down, I considered starting the local Portland Network Group. With great support and resources from the NMF our partnership began. My hopes are for this group to continue to flourish and grow.

My motivation to be involved with this group stems from my daughter, her love and her beautiful, generous heart that never ceases to amaze me. She puts herself out there to spread awareness and give support to others affected with Marfan Syndrome. I am also grateful for those who are involved in our group and who have encouraged me with their thoughtful words and notes. Volunteering can be quite the juggling act at times with my other commitments and passions in life, but I have found it to be extremely rewarding as well. When you help others it truly can be a blessing to yourself, as well.

Contact Information: Rebecca Stroda - (503) 397-0462; kk4ra@hotmail.com



Laura Amarys

My mother recorded her first impressions of me in my baby book..."Long fingers and toes". This was probably the first indication that I was different than my siblings. Growing up in school others noticed the difference too, "Sasquatch" and "Cranefingers" were the nicknames that I heard as I traveled the halls of grade school and Jr. High. It wasn't until I was a teenager that I was first told I might have Marfan syndrome, but I wasn't actually diagnosed till the age of 29 when my partner and I decided to start a family. After considering the risk of possibly passing Marfan Syndrome on to our child, and the risk to my own health (the doctor said I had a about a 50% chance of dissecting during pregnancy or childbirth), we ultimately decided to adopt and I now am the mother of a son, 13 years old and a daughter, 11 years old.

I was a registered nurse for 20 years working in hospice until 2005, when I had to quit due to my health. Since then I have looked for ways to continue to contribute to my community despite my disability. I volunteer at my son's school and have led an after school knitting group at my daughter's school for the past 3 years. A call from Rebecca last fall inviting me to the NMF meeting in Portland led me to consider chairing a network group in Eugene. This seemed like just the opportunity I had been looking for and there was definitely a need for a group outside the Portland area. I believe it is important to connect with others who are on a similar journey, and believe that working together we can make a difference. Having come from a nursing background, I am excited about the potential for educational outreach in our local community. I have found that meeting with others in the group energizes me and motivates me to stay involved. I think one of the most important things we can each do is to connect with each other, because as a group we are powerful.

Contact Information: Laura Amarys – (541)344-5847; amarys4@gmail.com

Research

Clinical Trial Enrollment Closing

Josephine Grima, PhD, Director of Research & Legislative Affairs

On behalf of the National Heart, Lung, and Blood Institute, the Pediatric Heart Network, all the clinical trial enrollment sites and the National Marfan Foundation, we would like to extend our sincere thanks to all those in the Marfan community who have enrolled in the clinical trial. We are pleased to announce that enrollment will close early in 2011. We currently have only 6 more patients to enroll and those patients are currently being screened. Once they are randomized in the trial, enrollment will officially be closed.

We are indebted to all those who have selflessly agreed to participate in the study to help the medical community investigate new therapies that have the potential to change the traditional medical management for individuals affected with this syndrome. We deeply appreciate the efforts of those who have traveled long distances to participate. Marfan syndrome is now being hailed as a model for rare disease research and a prime example of successful translational research. It is only with the help of all those committed to this disease that we were able to help make this happen.

The end of the enrollment period indicates that we now have a firm time frame for results of this trial to be released; this will happen in 2014. Those patients who enrolled during the first year are already ending their time in the study. However, those who have just been enrolled need to be followed three years before all the data can be analyzed.

Although enrollment will close soon, we are still striving to make the most of this trial. Therefore, with the financial support of the NMF Research Program, we are proud to announce two new ancillary studies that will be available to trial participants at their next visit. The first of the two studies will evaluate quality of life for children and young adults with Marfan syndrome. A better understanding of the influences of medical severity, medical intervention and family dynamics on quality of life will lead to more effective clinical management and improved outcomes for patients. The second ancillary study will determine if circulating TGF- β levels can be linked with clinical outcomes such as a change in aortic root Z-score, final aortic root dimension or final aortic root Z-score. Circulating TGF- β levels could, in theory, allow for more precise tailoring of therapeutic procedures to the individual. Therefore, positive results of this study could ultimately translate to clinical care. We hope that we can count on the trial participants to enroll in these studies during their next visit.

We look forward to completing the last three years of follow-up in this trial and to the answers to important questions that it will provide. We approach this ongoing effort to identify new and perhaps even better treatment options for Marfan syndrome with pride in our community and confidence that our shared goals are within reach.

Legislative Affairs

HELP ADVANCE THE NMF'S ADVOCACY MISSION IN 2011!

**Gavin Lindberg, NMF Board of Directors
Chair, Research and Government Relations Committee**

Thanks to the support of grassroots patient advocates, the NMF advocacy program has enjoyed a number of success in recent years. Examples include;

- Directed federal funding to the NMF for a Marfan syndrome awareness program.
- Significant and consistent support for basic and clinical research on Marfan syndrome and related connective tissue disorders through the National Institutes of Health.
- Passage of legislation enhancing the ability of patients with rare diseases to participate in clinical trials.

- Ongoing collaboration with the Social Security Administration to streamline the disability application process for NMF patients.
- Support for consumer protections in the new health reform law including; prohibition on pre-existing condition exclusions, prohibition on lifetime and benefit caps, and expanded eligibility for children to remain on their parent's policy (up to age 26).

We need your help to continue to successfully advocate for research, awareness and support for the Marfan syndrome community. This is particularly true this year with 96 new members of the House of Representatives and 16 new senators recently sworn-in on Capitol Hill. These freshman lawmakers need to be educated about Marfan syndrome, how it affects families in their communities, and how they can help support our efforts to discover better treatments and eventually, a cure.

Unfortunately, many of the federal agencies that support MFS research and awareness activities, including the National Institutes of Health and Centers for Disease Control and Prevention, are currently facing significant budget cuts. If these important programs are to be spared this year, it will be because constituents impress upon their local legislators how important they are to patients living with chronic, life-altering diseases.

We hope you will get involved and make a difference! Congressional letter writing campaigns, meetings with lawmakers in their Washington or local office, participation in legislative town hall meetings, or hosting Members of Congress at a Chapter or Support Group meeting are great examples of how to become engaged.

To learn more please contact Gavin Lindberg, Chairman of the NMF Research and Government Relations Committee at (202) 544-7499 or lindberg@hmcw.org

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”

Margaret Mead

Support

NMF Offers Phone Support Groups

Jennifer Buffone, Director of Support and Volunteer Development

Did you know the NMF now offers phone support groups on six different topics? These are valuable resources where you can refer individuals and families who contact you. The NMF is currently offering phone support groups on the following topics: Coping with Marfan Syndrome and Related Disorders, Parent Support, 50+ Support, Young Adult Support (for people in their 20's and 30's), Undiagnosed Support (for those in the evaluation process or who don't have a clear diagnosis) and The Other Half (for unaffected spouses and care givers). While in-person support groups are ideal, these phone support groups provide an opportunity for people to connect who don't have access to in-person groups, for people who can't find others to connect with on their specific issue, and for people to supplement their in-person support meetings. All phone support groups are offered free of charge. If you or someone you know would be interested in joining any of these phone support groups contact Jennifer Buffone, Dir. of Support Services and Volunteer Development, at jbuffone@marfan.org for more information.

New for Telephone Support Volunteers: Orientation Manual and Questionnaire

ATTENTION TELEPHONE SUPPORT CONTACTS! The NMF recently updated the packet all Telephone Support Contacts received upon becoming volunteers. There is a brand new orientation manual which includes information on the revised diagnostic criteria, suicidal ideation, the grief process, how to assist with parent/child relationship issues and much more. This new manual will be posted on the NMF website in the volunteer tool kit and will be emailed to all current phone contacts. Additionally, all phone contacts will be receiving the new Telephone Support Contact Questionnaire to complete. This new questionnaire asks more targeted questions that help the NMF to better connect people who contact the Information Resource Center to phone contacts who have experienced their specific issues. We hope the new manual addresses concerns that phone contacts have expressed to the NMF. Look for it in your email box in the next few weeks!

Support Q & A

Amy Kaplan, RN, BSN, Manager, Information and Resource Center

1-800-8-MARFAN ext. 26; akaplan@marfan.org

In this column we showcase sample questions and answers on topics that you may encounter. Amy is available for consultation five days a week at akaplan@marfan.org or 800-862-7326 x 26.

Q: My daughter was tested for Loeys Dietz and the tgfbeta genetic mutation was not identified. Is this conclusive that she does not have Loeys Dietz?

A: While genetic testing for Loeys Dietz is considered to be very highly accurate it is not 100% percent conclusive. Genetic testing for the fibrillin one gene mutation that causes Marfan syndrome is also not 100% accurate. It is considered to be approximately 90-95 percent accurate. We recommend discussing your daughter's genetic testing results with the specialist who is coordinating your daughter's evaluation, who is most often a geneticist or cardiologist.

Q: I have read that with proper diagnosis, medical management and following life style modifications it is possible for an individual with Marfan syndrome to have a normal life span. Does the same hold true for those affected with Loeys Dietz?

A: We hope so, but our experts say it is too early to tell, as Loeys Dietz was only discovered several years ago. Our experts however are confident that the outlook looks much brighter than it did just a few years ago.

Q: I had a CT scan and an incidental finding was a cyst found on both my liver and kidney. Can there be any connection to Marfan syndrome?

A: There are many possible causes for cysts which should be explored with your doctor. It is possible that it can be connected to having Marfan syndrome. A research study was conducted a few years ago; a finding was that Marfan syndrome patients have liver and renal cysts more often, in increased number, and at an earlier age than controls. Another finding was that there was an increased prevalence of cholelithiasis (gall stones) in Marfan patients.

Disclaimer: *The National Marfan Foundation (NMF) is a health advocacy organization. The NMF does not provide medical advice or treatment. We are not a health care provider. It is important to realize that information provided by the NMF is not meant as a replacement for proper care from a doctor, therapist, etc. Information provided by the NMF is not a substitute for medical treatment or psychological care. It is vital that you talk with your health care providers regarding the diagnosis and treatment of Marfan syndrome and related disorders and your symptoms/features. Minors should consult with a parent/legal guardian when considering treatment and providers.*

Health care provider information is supplied solely by the providers themselves and is not checked or warranted by the National Marfan Foundation. The NMF provides contact information for health care providers who are known to have seen patients with Marfan syndrome and related disorders. The NMF does not endorse or recommend individual health care providers. You are responsible for interviewing and selecting the practitioner. By requesting health care provider resources you understand and agree that the NMF and its affiliates are not responsible for any providers' services or lack thereof.

There are four questions of value in life... What is sacred? Of what is the spirit made? What is worth living for, and what is worth dying for? The answer to each is the same. Only love.

~ Johnny Depp

Information Technology

News About Your Web Page

Brian Polk, Director of Information Technology

516-883-8712 x 19; bpolk@marfan.org

If you haven't visited the "Find a Local Contact" page on the NMF web site recently, check it out at www.marfan.org/marfan/2507/Find-a-Local-Contact. Over the past month, I've streamlined this page including adding a clickable map of the United States at the bottom. If you click on a state of interest, you will be redirected to a page with the NMF volunteer contact information for that state. For all of the Chapters and Network Groups with web pages, the clickable words "Visit Web Page" will appear next to the group name.

If your group doesn't currently have a web page, but you would like to see what is possible, check out the recently updated web page for the Mid-Atlantic Chapter at <http://marfan.org/marfan/4337/Mid-Atlantic-Provisional-Chapter>. They've made use of head-shot pictures and bios for their officers, board of directors, advisors and committee members. On this page you will also find links to a downloadable flyer (see the February 27th "Heart and Soul" event) as well as a slideshow of pictures (see the August 13, 2010 golf event).

Contact Kathy or me if you want more information on how to set up or make changes to your existing web page. No technical knowledge on your part is required to implement any of the features mentioned above. All you need to provide are the pictures and information, and we will do the rest.

Exemplary Leadership Skills

New Year's Resolution:

Establish System to Record Volunteer Tax Deductions

From *Volunteer Insider*, by Stevenson, Inc.

Every quarter, take stock of the volunteer efforts that you have accomplished to date and review your recorded expenses to ensure nothing is forgotten at tax time. According to the U.S. Department of the Treasury in Washington, D.C., expenses incurred by volunteers in connection with their volunteer services can be deducted for those expenses a charity would otherwise have to incur.

For example, volunteers may deduct the cost of materials they donate for use in supplies for leading activities or uniforms they wear while serving the nonprofit. Additionally, volunteers may typically deduct mileage, overnight travel expenses, related phone call expenses, postage and so on.

Maintain tax records by recording the following:

- Date of service
- Name of the organization for which you are volunteering on that date
- Number of miles driven to and from volunteer effort by recording odometer readings
- Expense incurred. Collect and save receipts for out-of-pocket expenses.

Meticulous record keeping can be a fail-safe way to record potential deductions for the upcoming tax season. If you do not already do so, begin now to keep a tax notebook in your vehicle to record mileage and all other eligible expenses each day that you volunteer. Review these items with your tax preparer when you file to determine which expenses can be deducted. Then, when tax filing time comes around, you'll be pleased with how easy the filing process is.

Education & Awareness

Rare Disease Day 2011

Support Rare Disease Day on February 28, 2011 and visit www.rarediseaseday.us to learn about ways to support this effort.

Rare Disease Day is an international advocacy day to bring widespread recognition of rare diseases as a global health challenge. The day is celebrated on the last day of February every year and this year will be observed February 28, 2011. Learn more about the [History of Rare Disease Day](#), [Past Successes](#) or the [Goals and Plans](#) for this year.

Anyone can be involved in Rare Disease Day and there are many [suggested activities](#). The day has been established as a grassroots advocacy day and we encourage everyone to participate in some way.

Goals and Plans for 2011

This is the third annual observance of Rare Disease Day US. The growth in just a few short years has been remarkable, but we look to everyone to continue that momentum to make this year's celebration the most successful yet. Throughout the rare disease website, you will find many ways you can get involved. Big picture goals this year include:

- Creating a video encyclopedia of rare diseases
- Extensive media coverage
- Social networking blitz
- Creating a Rare Disease Physician Database
- Sharing patient stories, videos, photos, and blogs
- Joining hands with others worldwide

Theme of the Day

Every year, Rare Disease Day has a specific theme worldwide. This year's theme is "Rare but Equal" which will highlight "Rare Diseases and Health Inequalities." You can read more about this theme on the global [Rare Disease Day website](#).

Take Action Now

The purpose of World Rare Disease Day is to harness the creative energy of the millions of people around the world with rare diseases — as well as that of all the people who care about and assist them — to help others understand certain fundamental issues that need to be addressed.

Rare Disease Day is a grassroots activity. This means you can help us achieve the goals of the day from wherever you happen to be. You don't have to travel to Washington DC. You don't have to have special skills or spend a lot of money. And you can start right now.

Make sure your state is supporting Rare Disease Day. You can [Write Your Representatives](#) to obtain a proclamation. Not sure if your state is already a supporter? Find out by checking [What's Happening In Your State](#).

One way almost anyone can help raise awareness for Rare Disease Day, is to [Write Your Reps](#) in Congress to encourage them to become members of the Rare Disease Caucus. You can learn more about how this would help the rare disease community and how you can encourage your representatives to get involved.

[Become a Rare Disease Day Partner](#) (for organizations, agencies, societies, and companies) or Become a Rare Disease Day Ambassador (for individuals). By signing up and showing your support, you can share why Rare Disease Day is important for you and get updates about the day.

[Tell Your Story](#). Sharing experiences helps people understand what it is like to live with a rare disease.

This year, one of the ways we are asking people to raise awareness is through a video. We hope these short videos from individuals will become a library, telling the story of the millions of people affected by rare diseases. Add your voice to the [Video Library Project](#).

The National Organization for Rare Diseases (NORD) is also looking to compile a physician database identifying rare disease experts throughout the country. To learn more about this initiative, see if your doctor qualifies, or add someone's name, visit [Help Us Find the Experts](#).

Still unsure what you can do to take action for Rare Disease Day? Whether you are an individual, organization, company, or student, we have tools and suggestions for you in [Suggested Actions](#).

Communications

30th Anniversary Ideas for Chapters

Eileen Masciale, Director of Communications



National Marfan Foundation • 1981-2011

This year, the NMF is celebrating its 30th anniversary! There are a lot of activities the NVN can do to generate excitement within each group and in the local community. Here are some ideas for you:

- Use the NMF's 30th anniversary as a theme for a group social event. Share stories about how the NMF has made a difference in your life and celebrate with an anniversary cake!
- Create a group scrapbook showing what the NMF means to group members. Traditional scrapbooks can be sent to the NMF by July 1 for showcasing at the annual conference in Portland, OR (July 14-17). Digital scrapbooks can be emailed to the NMF (publicity@marfan.org) and we will post on our website.
- Incorporate the milestone into any flyers, newsletters or press releases you send out. When you request an NMF logo for your materials, ask for our 30th anniversary logo. You can also feature the 30th anniversary at your education events and fundraisers.
- Suggest that group members think of the NMF's anniversary on their birthday and direct donations, in their honor, to the NMF. "It's my birthday and the NMF is celebrating its 30th anniversary too! To honor my birthday, please donate to the NMF by clicking [here](#)."

In addition, the NMF is collecting Marfan stories from our members – we want to hear about how the NMF has impacted your Marfan journey. You can email your story – 500 words maximum – to publicity@marfan.org. Please include the year you were diagnosed, how old you were at the time, and contact information in case we want to find out more. We will be using these stories in the newsletter, on the website and, potentially, in media outreach.

Eileen Masciale, NMF's Consulting Director of Communications, will be leading trainings related to the NMF's 30th Anniversary in March. Please check the training calendar and join us to discuss ways to leverage this milestone in your local area.

National Conference News

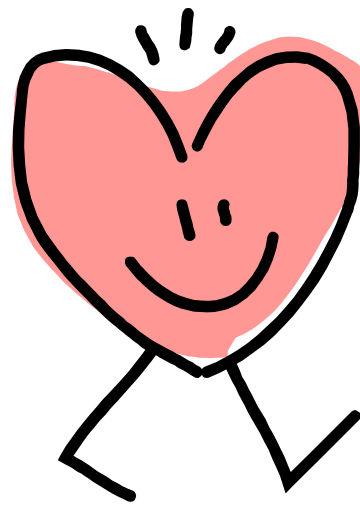
Leadership Meeting at NMF National Conference Friday, July 15, 2011 in Portland, Oregon Kathy Jeffers, Manager of Volunteer Development

Where is the most exciting place to learn the newest about Marfan syndrome, the NMF and to hone your leadership skills as well? The NMF National Conference, July 14-17, in Portland, Oregon! We would love to see you there. One of the conference highlights for NMF group leaders and Telephone Support Contacts is the annual Leadership Meeting, which will be held this year on Friday, July 15, from 9:00 am – 4:00 pm, followed by a reception with the Board of Directors from 4:00 – 5:00 pm. This is a great opportunity to meet your colleagues in volunteer leadership from across the country. The meeting provides opportunities for a rich exchange of ideas, education on news from each department, and, training on new projects and procedures at the NMF. If you are not able to come, yourself, encourage someone with leadership potential to attend and report back to your group about what they learned at the conference. The NMF supports groups fundraising to help two people attend the conference from your group. It is strongly suggested that the primary leader of the group attend, or another person who offers leadership in group activities. Selection of others who receive the group's assistance should be based on values similar to those the NMF uses for scholarships: financial need, lack of access to experienced medical care, has not attended conference in the past, is a participating group member, is capable and willing to report back to the entire group on their conference experience and what they learned.

More information about the Leadership Meeting agenda and registration will be sent to group leaders and Telephone Support Contacts by May 1. Questions? Please, contact Kathy Jeffers, Mgr. of Volunteer Development: kjeffers@marfan.org; 800-862-7326 x 11.



Your help Needed for HeartMart!!



HeartMart is an integral part of the NMF Annual Conference on Marfan Syndrome and Related Disorders each year. HeartMart has traditionally been conducted as a "Your Choice" Raffle where attendees purchase tickets and place them in the drawing for the item they wish to win. Items featured have included heart-themed art and jewelry, excursion trips local to the Conference location, packages with craft supplies, toys and games for children, and electronics.

Donations needed!

- Items for gift baskets
 - Jewelry, Fashion, Beauty items
 - Items for the Home
 - Children's Items
- Electronic items
- A fun package could include several items from your own state - last year, we had a North Dakota Basket!
- Gift cards (can be used to purchase additional items or be one of the prizes)
- Etc.

Please send items to the 2011 HeartMart Chair:

Kathryn Thompson

Heart Mart Donations for NMF


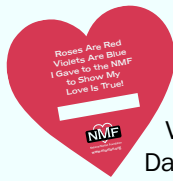
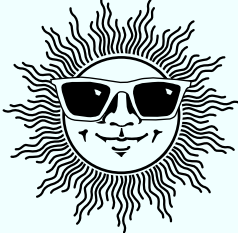









P.O. Box 760

Brush Prairie, WA 98604



have heart

You can make a difference all year long!

January	February	March	April
<p>Start planning a HaveHeart event at home, at work or at school! See the NMF "Activities Planning Guide" for fun ideas and easy-to-follow tips for planning successful local events all through the year.</p> 	<p>It's National Marfan Awareness Month—and the kick-off of our annual HaveHeart Campaign! Ask local businesses to participate in the NMF Hang-a-Heart program, a great project for Valentine's Day!</p> 	<p>Think summer! Now is the time to start planning a fun summer event. Contact the NMF for ideas and help getting organized.</p> 	<p>April showers keeping you indoors? Create a personal fundraising page online to raise funds for the NMF. Send the link to your page to everyone you know and share it on Facebook too! See www.firstgiving.com/marfan to get started.</p> 
May	June	July	August
<p>Hold a garage sale! Do your spring cleaning and hold a garage/yard sale to raise funds for the NMF. Ask your friends and neighbors to join you and plan a mega-sale!</p> 	<p>Organize a car wash! Ask local students, a scout troop or another community group to set up a car wash and donate the proceeds to the NMF. Prefer fur to chrome? Make it a dog wash!</p> 	<p>Ask 5 friends to help you "change" the world! Save all the coins each of you accumulates every day for the entire month and donate the final amount to the NMF. You'll be surprised how quickly that change adds up!</p> 	<p>Going on vacation? Pack NMF awareness materials along with your swim suit and help spread the word about Marfan syndrome wherever you go. Visit our store at www.marfan.org and stock up on NMF pens, Have Heart wristbands, and At-a-Glance bookmarks.</p> 
September	October	November	December
<p>Heading back to school? Start a Marfan awareness club on campus, sell Have Heart wristbands, or reach out to school health care staff with information about Marfan syndrome.</p> 	<p>Put your job to work for the NMF! Contact the NMF to find out how your employer can be part of America's Charities Health1st workplace giving campaign. Ask your employer to let you set up a display in the workplace to raise awareness about Marfan syndrome.</p> 	<p>Start your holiday shopping at the NMF store! Shop the NMF store at www.marfan.org for unique holiday gifts, like the cuddly Have Heart Bear, beautiful HeARTworks note cards, Marfan heart T-shirts and more.</p> 	<p>Wrap gifts for the NMF! Barnes & Noble stores have a program for volunteers to wrap gifts and raise money for their favorite charity. Contact your local store for details, or ask another store if you can set up a charity gift wrapping table.</p> 

Please contact Cathie Tsuchiya, NMF Local Fundraising Coordinator, at 800-8-MARFAN (x13) or ctsuchiya@marfan.org with your questions and ideas.

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. Remember to update your page as necessary. To create/update your page, contact Kathy Jeffers.
January 31	Chapters: Second Quarter Financial Reports Due
February	Marfan Awareness Month Have Heart Fundraising Month
February 2	National Women in Sports Day to honor Flo Hyman
February 15	NMF Conference 2011 information available on-line
February 21	NMF piece airs on National Geographic Channel about Lincoln
February 26	Heartworks St. Louis
March 1	Deadline for articles in Spring Connective Issues
April 7	Heartworks New York Gala
April 10-16	National Volunteer Week
May	NMF Membership Drive
May 14	Heartworks Westchester, NY
July 14-17, 2011	NMF National Conference in Portland, OR at the Marriott Waterfront Hotel
July 15	NVN Leadership Meeting 9:00 am – 5:00 pm at NMF Conference
July 30	Chapters: fourth Quarter Report Due
August 1	Deadline for Fall Connective Issues submissions
August 2-5, 2012	NMF National Conference in Chicago, IL

*If we hope to overcome the ocean of darkness in the world,
we must first light a candle in our own hearts...
Committing oneself to the path of love
can be the most revolutionary way to change the world.
~ Robert Lawrence Smith*