



Leadership Connection

January 2010

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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

Register Now for Winter Conference Call Workshops

Open to All Group Leaders and Telephone Support Contacts

Seminars will be offered via one hour conference calls coordinated by the NMF staff. Please make every effort to participate, or appoint a key person as your representative.

Time schedules relate to Eastern Time.

How Do I Register?

Please e-mail Kathy Jeffers, Manager of Volunteer Development, at kjeffers@marfan.org, or call 1-800-8-MARFAN X 11. Dial-in details will be sent two days prior to the seminar.



1. Creating a Personal Fundraising Page

Presenter: Cathie Tsuchiya, NMF Local Fundraising Coordinator

Date: Thursday, February 11

Time: 1:00 pm ET

Sign up by: 2/5

Description: You or your group can raise funds for the NMF easily by creating your own fundraising page and sending it to everyone you know. No venue, tickets etc. required! For this workshop, we ask you to sit at your computer and learn just how easy and fun it is to create a fundraising page.



2. Doctors Office Outreach Project

Presenter: Jennifer Buffone, NMF Director of Support Services and Volunteer Development
Colleen Hayden, NMF Socical Work Intern

Date: Thursday, February 18

Time: 1:00 pm ET

Sign up by: 2/11

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. Our new awareness poster, along with NMF brochures and pens are packaged for you to take to your next doctor's appointment.

3. Telephone Support Contact Open Forum

Moderator: Jennifer Buffone, NMF Director of Support and Volunteer Development

Date: Thursday, February 25

Time: 3:00 pm ET

Sign up by: 2/18

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.

4. Creating and Updating Your Group's NMF Web Page

Presenters: Mahab Hoque, NMF Systems Administrator
Kathy Jeffers, NMF Manager of Volunteer Development

Date: Tuesday, March 2

Time: 1:00 pm ET

Sign up by: February 2/23

Description: To draw new people to your group and keep members updated, Chapters, Network Groups and Support Groups have the opportunity to create their individual web page on the NMF website. Group leaders, or their representatives, will learn about what information and types of photographs to use, and how to submit updates to keep your page current. It's easy to do, and is maintained by the NMF at no cost to the local group.

5. Chapter Leaders Open Forum

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

Date: Tuesday, March 9

Time: 2:00 pm ET

Sign up by: 3/2

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 3/2 to Kathy Jeffers' e-mail at kjeffers@marfan.org, so we can invite appropriate guest consultants for this session.

6. Network Group Leaders Open Forum

Moderator: Kathy Jeffers, NMF Manager of Volunteer Development

Date: Thursday, March 11

Time: 2:00 pm ET

Sign up by: 3/8

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 3/8, to Kathy Jeffers by e-mail at kjeffers@marfan.org.

Research

Mandatory Workshops on New Diagnostic Criteria this Spring By Josephine Grima, PhD, NMF Vice President of Research & Legislative Affairs

The diagnostic criteria for Marfan syndrome have been re-evaluated and revised. The new criteria will be published in the Journal of Medical Genetics in a few months. Network Group and Chapter leaders and Telephone Support Contacts will be required to attend a telephone training session to learn about these new criteria. An e-mail will be sent indicating the time and dates of these training sessions in the near future. Multiple opportunities will exist to participate in one of these trainings since it will be mandatory for all Network Group Leaders, Chapter Leaders and Telephone Support Contacts to attend. Please look for important updates on the diagnostic criteria in the near future

KUDOS

Kudos: n 1. syn see EMINENCE; 2. syn see HONOR



Baltimore/Washington /N.VA Network Group To Become Mid-Atlantic Chapter

The NMF will soon have eight chapters! The emerging Mid-Atlantic Chapter has acting officers and a board of directors prepared to support them through the steps to becoming a full fledged chapter when the NMF Board considers their approval at their July board meeting in Houston. Congratulations to Mary Ahearn (MD), President, and her board: Lisa Riiber (VA), Vice President; Clare Whittaker (MD), Secretary; Caryn Kauffman (VA) Treasurer; Directors at Large: Kelly Berklite (VA), Rob Berklite (VA), Jen Ledroot (MD), Gretchen Oswald (MD), Amy Speck (MD). Medical Advisor: Dr. Hal Dietz (MD).

A Warm Welcome to Silicon Valley Network Group!

We applaud our new Network Group leader, Maya Zimmerman, and her growing membership! Contact Maya at: 614-551-0609; maya.zimmerman@gmail.com .

Exemplary Leadership Skills

The Advantage of Being a Giver

By Priscilla Ciccariello, NMF Chair Emeritus
cilla71@aol.com

I have always said that the support the NMF provides is at least as important as the good feeling that people get from being a "giver" rather than a "taker." People with health challenges can easily feel victimized. I know myself that I couldn't stand pity, although I often pitied myself, and still do, but I could not stand being in the pitied category. Through the empowering support and education we find through the NMF and our peers, we are able to take a leap beyond self pity and start becoming part of a solution and our own self healing. In this state of mind we can become leaders, identify with our empowering cause, and inspire others to do the same.

Of course we have to learn to be the recipient . . . gracefully. It doesn't come easily. But we do learn, and having the opportunity to be the giver makes for longer and more productive living. As with any kind of loss or demanding condition, having the fortune to be the giver turns sadness into wonderful opportunity and friendships - life-long, as we all know from experiencing our NMF family!

Group Management

Helpful Hints

By Kathy Jeffers, NMF Manager of Volunteer Development
kjeffers@marfan.org; 800-862-7326 x 11

Retention Advice

The odds of retaining group members over time improve if you can diversify their experience. While some people like routine, most prefer variety to stay energized. Vary educational, social, outreach and fundraising activities. Direct your group toward NMF projects focusing on different interest areas and causes that can motivate member participation.

Leadership Recruitment Tip

Don't assume that a "no" response from a would-be volunteer means never. Timing may be a factor. Keep a list of those who reject your offer to lead a task or event, and re-approach them at a later date.

Introduction Etiquette

When making introductions, remember guests have precedence over fellow colleagues. Women have precedence over men; older people over younger (as long as they are the same gender).



NVN VOLUNTEER SPOTLIGHT:

Kathy Magee

Chair, San Antonio Network Group

katachat@hotmail.com; 210-442-8265

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

I am hopelessly optimistic and find it difficult to take life very seriously. My humor sustains me and evidently it works wonders for others as well. Even the "victims" of some of my pranks (motivated by my "evil twin") seem to take life a little less seriously. I have worked as a counselor, in a bank, as a 911 police/fire dispatcher and a high school teacher. All of these have prepared me for my most important job title--Mom.

Both my son, Aiden, and I are affected by Marfan syndrome.

2. How did you become involved in the San Antonio Network Group?

My husband, Mac, and I started a network group here in San Antonio after returning from a four year deployment to Germany. Our son was the driving force behind getting involved and allowing others the same opportunity. While I had never sought out a group for myself, we felt it imperative that everyone around us be educated about Marfan syndrome, especially other parents.

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

The most satisfying event for me would be my first quilt fundraiser. It forced me to come out of the shadows about Marfan syndrome and be vocal. We spend the better part of our lives trying to "not be different" - well, we ARE different and I am finally able to stand in front of people and talk freely about "being Marfan." I was overwhelmed by the support of family, friends, and acquaintances that had no idea that I was different, and they were floored by my ability to be so candid and open. They also have tried to educate others about Marfan syndrome, and to me this is fantastic!!

4. How have you enjoyed your experience as a member of the Network Group?

It is wonderful getting to know other families and supporting one another through all of life's ups and downs. We have a real group of upbeat people who want to make a difference.

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

Insanity.....(ok, evil twin at it again) and, truly, being able to give back to others. This opportunity does wonders for me and empowers my whole family.

6. What is your advice for other group leaders?

Be the kind of leader you would like to have as a leader. When you are exasperated, tired and feel like you have no more to give, dig down and give more. It may be life changing for the person you are helping. Also, keep a positive attitude in all you do. If you hold upbeat meetings, people will be upbeat and want to continue coming to the meetings. Additionally, when you need help - ask for it. I've learned that calling my people one on one and asking for help on a project BEFORE the meeting works wonders. That way you are not asking for help in a meeting and getting no response which is disheartening. Set high expectations and hopefully they will rise to the occasion--set no expectations, and well, that's what you'll get--zero.

"Giving frees us from the familiar territory of our own needs by opening our mind to the unexplained worlds occupied by the needs of others."

- Barbara Bush

Communications

Various Ways to Meet and Communicate to Enhance Local Connections

By Eileen Masciale, NMF Communications Director

President, EJM Public Relations

631.665.2163 ejm@ejmpr.net

We hear from Network Group leaders that they are often not satisfied with meeting attendance. There is no doubt that in-person participation is important and meaningful, but it can fluctuate depending on geography, weather, work and family issues and the simple fact that Marfan syndrome may not be a primary concern in the member's life at a particular time.

It is important for Network Group leaders to realize that the end all goal of the local group is *not* the meeting alone. The goal is *local connectedness*. No one wants to feel that they are the only one in their region who has Marfan syndrome or a related disorder. The Network Group serves the purpose of being the local connection to the Marfan community. The reasons that people want a local connection vary. They may want to:

- Learn about local resources
- Talk to other people who are facing the same challenges
- Know that someone is there to talk to *in case* they need them
- Band together with others to educate the local community about Marfan syndrome
- Find other people to work with to raise funds for the NMF
- Develop a social network of people with a similar interest in Marfan syndrome

As you can tell, some of these individual goals would be satisfied by being connected once, others would be satisfied by connecting frequently for a particular project and others would only be satisfied by meeting, either in person or virtually (online), on a regular basis. As well, some people will be satisfied just knowing the local group is there if and when they need them.

As the Network Group leader, realize that everyone has different needs. By diversifying your means of communications, you can reach new people in your target audience (the people in your area who have Marfan syndrome and who are on your mailing list). Meetings are valuable, but may not be the only answer. Try using some of the following ways of connecting with members in your area, and see if new people respond :

- Creating a group on NMFconnect for your Network Group (see sample at <http://nmfconnect.marfan.org/group/southeastlouisiananetworkgroup>). Contact Kathy Jeffers (800-862-7326 x 11) to find out how to do this if you are unfamiliar with NMFconnect.
- Having an online chat through NMFconnect by setting up a particular time for your Network Group members to go online and "meet" virtually. They don't have to worry about the weather, the travel time or even what to wear!
- Setting up a Facebook group, which will be comfortable for your members who are already on Facebook. It will be part of their life, not just their Marfan life. (See sample at <http://www.facebook.com/?ref=home#/group.php?gid=22369587762>).
- Arranging a phone meeting – a conference call – so that everyone can meet and chat by phone. The NMF can facilitate this. Just call Kathy Jeffers (extension 11) at the NMF office to help you. Please note that the cost of this will be billed back to your group if you are a chapter. The NMF will absorb the cost for Network Groups, as they do not have bank accounts.
- Setting up an email list for your Network Group members, sharing it with them, and sending them NMF news and announcements that would be of interest to them. Stay connected!

Communications has changed significantly over the past several years. Hard copy newsletters, in-person meetings and even phone calls have been replaced in our virtual, online world. However, regular communications, whether or not they are in-person, can lead to success for your Network Group. It is even likely that people who "talk" online frequently will eventually want to get together, meet face to face, socialize, initiate education projects and fundraise for the NMF. The first step is to get people connected, and it's easier if it is done in a way that is comfortable to them. Use variety, learn new technology, call on the NMF for assistance. We are here for you.

Research & Legislative Affairs

Help Advance the NMF's Advocacy Mission in 2010!

By Gavin Lindberg, Chair, NMF Research and Government Relations Committee

Did you know that Congress appropriated \$250,000 to the National Marfan Foundation in 2009 to support an awareness campaign on Marfan syndrome and aortic dissection?

Did you know that Congress consistently directs the National Heart, Lung and Blood Institute, and the National Institute of Arthritis and Musculoskeletal and Skin Diseases to expand their Marfan syndrome research portfolios as part of the annual appropriations bill for the National Institutes of Health?

Did you know that NMF was the only patient organization to testify before a committee of prominent cardiologists charged with rewriting the Social Security disability criteria for cardiovascular diseases in Washington last month?

Do you know what all of these facts have in common? They are the result of the Foundation's robust government affairs program and would not have been possible without the involvement of NMF grassroots advocates.

With the New Year upon us, we encourage all Foundation members to get involved in our advocacy program in 2010. Some of our key priorities include:

- 1) Increase federal funding for research, prevention and awareness programs focused on Marfan syndrome and related connective tissue disorders.
- 2) Ensure inclusion of important protections for chronic disease patients in healthcare reform legislation (e.g., prohibition of pre-existing condition coverage exclusions, elimination of lifetime and annual benefit caps, expanded coverage of clinical trials).
- 3) Educate policymakers on Marfan syndrome and related disorders and the challenges patients and families face.

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, Chair 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 Q & A

By Amy Kaplan, RN, Manager of the Information and Resource Center
akaplan@marfan.org; 800-862-7326 x 26

QUESTION: *As I am getting older, it's becoming more difficult for me to work due to issues related to my Marfan syndrome. Do I qualify for social security disability?*

ANSWER: Marfan syndrome is not considered in and of itself a disability. In applying for disability, one needs to establish that they have functional limitations that prevent them from working a normal seven hour work day. Keeping a log of your daily activities and obtaining letters of support from your doctors is often helpful in getting a case approved. Remember, getting approved for social security disability is often difficult, and many times approval is granted on some level of appeal. The National Marfan Foundation provides the service of writing a letter of support for those appealing a social security disability claim denial. Remember, any type of work that involves strenuous physical activity is not recommended for individuals affected with Marfan syndrome.

Q: *I have a troublesome recurring hernia. Could this be related to my Marfan syndrome?*

A: A recurrent or incisional hernia is considered a minor criterion in diagnosing Marfan syndrome. Individuals with Marfan syndrome are more prone to the development of recurrent/ incisional hernias. We know of no studies comparing the various techniques for hernia repair in Marfan syndrome. Some well respected general surgeons have recommended the use of a Mesh repair in hernia surgery for those with connective tissue problems.

Q: *I am thinking of pursuing a path in the military. Although I have not been formally diagnosed, there is a concern that I might have Marfan syndrome. Is this a suitable avocation if am affected?*

A: A career in the military is not a recommended career choice for affected individuals. The rigors of boot camp and having to be combat ready are serious concerns for affected individuals. There are general physical activity guidelines for affected individuals which include not participating in strenuous physical activity such as competitive and contact sports, isometric exercises such as sit ups and pushups, and heavy lifting.

Q: *I have been diagnosed with a recurrent corneal erosion. Is this type of eye problem connected to my having Marfan syndrome?*

A: A recurrent corneal erosion is considered a common problem and is not considered to be associated with Marfan syndrome. Generally speaking, the medical management is the same as in the population at large.

"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

Fundraising

Reminder – February is National Marfan Awareness Month!

By Cathie Tsuchiya, Local Fundraising Coordinator

ctsuchiya@marfan.org; 800-862-7326 x 13

You and your group can show your support in one of several ways:

- **Have Heart Campaign Mailing**

Watch your mailbox for this important annual fundraising campaign mailing and make an individual donation.

- **Have Heart Challenge**

Write a letter or email to ask friends, relatives, colleagues to also make a donation; contributions to Have Heart Challenge will be matched, dollar-for-dollar up to \$10,000, by a challenge grant from Neuco, Inc. and the Neustadt Family. See your Have Heart mailing for instructions and a donation log – **OR** – you or your group can join the Have Heart Challenge online and create your own fundraising page through Firstgiving! See the instructions attached to find out how to create your page (**for step 3, be sure to select “Have Heart Challenge” as the event!**)

- **Hang-a-Heart**

Ask local businesses, schools, etc. to “sell” red paper hearts for a donation of \$1 or more. Hearts are then hung around the store, school etc. – raising awareness about Marfan syndrome and funds for the NMF. It’s a great way for businesses to “decorate” for Valentine’s Day too! All materials are provided free of charge from the NMF.

- **Organize a Local Fundraising Event**

Now is a perfect time for your group to plan a fundraising event to take place during February or anytime this year. Some great fundraising events that took place last year include:

- Kelly Berklite and her 10 year old daughter, Jessica, held a fundraising evening at Foster’s Grille in Chantilly, VA; the restaurant donated 10% of sales and the mom and daughter team collected donations, resulting in more than \$1,300 in total raised for the NMF.
- Laurel Giacone and members of the Eighth Grade Service Learning Club made chocolate roses and sold them at school to raise \$1,000 for the NMF.
- Andrew Melin, age 12, organized a “Change” of Heart Fundraiser; he and his younger brother, Stephen, distributed specially designed (by Andrew) paper bags to neighborhood homes, asking people to put their change in the bags for the next two weeks, as a donation to the NMF. \$400 was raised for the NMF.
- The Twin Cities Minnesota Chapter participated twice in the Community Day coupon book fundraiser through the Bon-Ton family of stores and sold coupon books for \$5 each. The chapter was able to keep 100% of the proceeds and raised over \$1,500 from both events. *The next Community Day is February 27th. This is a great way for chapters and network groups to raise funds. If there is a store in your area that participates (such as Bon-Ton, Elder-Beerman, Bernger’s, Boston Store, Carson’s, Herberger’s, Hounkers and Parisian), contact Cathie Tsuchiya at ctsuchiya@marfan.org or 800-862-7326, ext. 13*

Virtual Fundraising for National Marfan Awareness Month and Beyond

**By Eileen Masciale, NMF Communications Director with
Cathie Tsuchiya, NMF Local Fundraising Coordinator**

For several months, we have been telling NMF members about Firstgiving, the easy-to-set up, easy-to-use online fundraising tool. As evidenced in the winter issue of Connective Issues, many members – particularly those who are involved in walk-a-thons or marathons in honor of a family member with Marfan syndrome – have taken advantage of this tool to raise money for the NMF.

“But”, you are saying, “I can’t get my Network Group to do fundraising. I can’t get them to get together to even plan it. We don’t know what to say and we are not comfortable asking people for money.”

We are here with the solution: Firstgiving.

Why is Firstgiving the solution?

- It’s an easy way to get your group to do fundraising
- It’s not necessary for the group to get together to plan an event
- If you don’t know what to say, we are here to help you
- If you are not comfortable asking for money, it’s very easy to request a donation by e-mail
- Firstgiving has made it simple to set up a page, even for computer novices

“Yes”, you say, “I’ve heard about Firstgiving. But if I’m not comfortable on the computer, it seems so hard to set it up. It’s intimidating. What do I write? How do I get my Network Group to participate?”

Here’s how your Network Group can easily launch a Firstgiving Have Heart Campaign.

- A group leader or member create the Network Group’s Firstgiving page (step-by-step directions are attached).
- When you customize your page, talk briefly about your Network Group – how many people in your geographic area, special projects you take on, how you support each other. Perhaps you can mention some of your members and some of the challenges they have faced on their Marfan journey, and how the NMF and the Network Group has helped. If you would like assistance with this write-up, feel free to contact Eileen Masciale, NMF Director of Communications (631-665-2163 or publicity@marfan.org).
- Tie in your Firstgiving page to the NMF’s Have Heart campaign. Describe the campaign and how the funds raised support the NMF mission areas. Mention that the campaign kicks off in February, **National Marfan Awareness Month**, and continues throughout the year (so that people feel like they are part of the effort even if they go to your page after February). Ask people to consider making a donation to support this important campaign. Stress that each and every dollar will help you reach your goal.
- Talk to your Network Group members (in person, by phone or by email) about inviting the people in their email address book to visit the Network Group Firstgiving page. They can further customize an email message about how the NMF has personally supported them and how they have benefited from NMF programs and services in order to get their contacts to contribute to the Firstgiving page.
- After February is over, you can send another email telling people how successful your efforts were in February and reminding them that this is a year-long campaign.

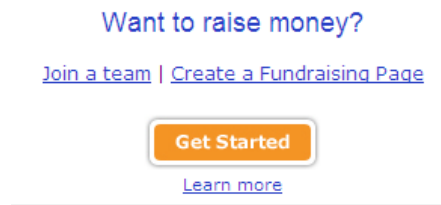
If you have any questions about setting up your Firstgiving page, please contact Cathie Tsuchiya at 800-8-MARFAN, ext. 13, or ctsuchiya@marfan.org.

Firstgiving: Create a Personal Fundraising Page Step-by-Step Guide

1. Go to our Firstgiving start page: <http://www.firstgiving.com/marfan>



2. Click on where it says **Create a Fundraising Page**



3. To create your own page, go to the choices under **Doing something we haven't listed?**



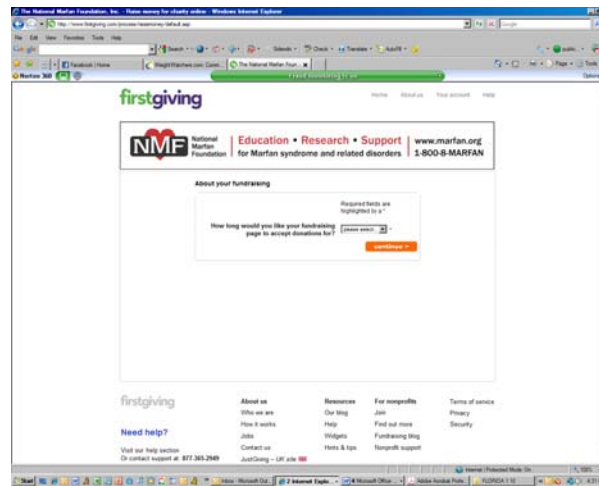
3. Choose from the drop down list and then click on **continue**.

Doing something we haven't listed?

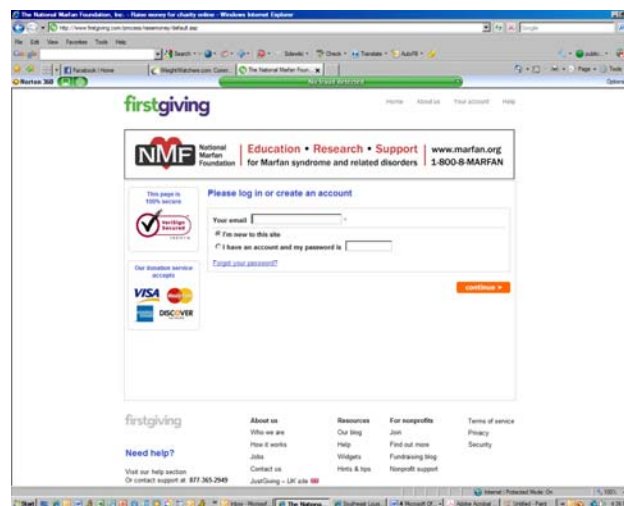
Let us know how you're raising money:

Other

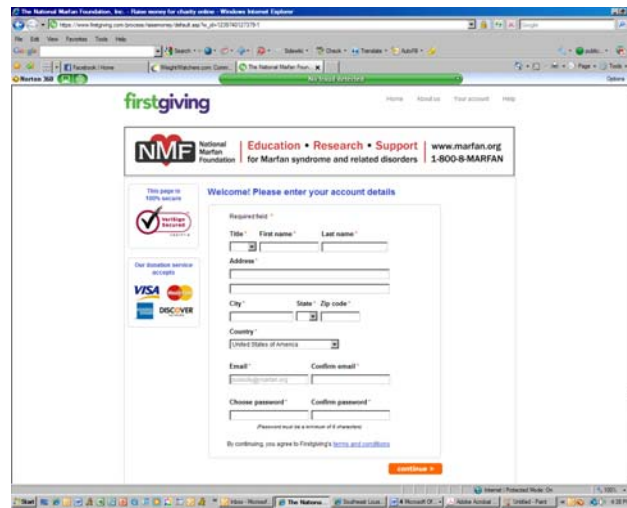
4. The next page asks about how long you would like to fundraise. Choose from the drop-down menu.



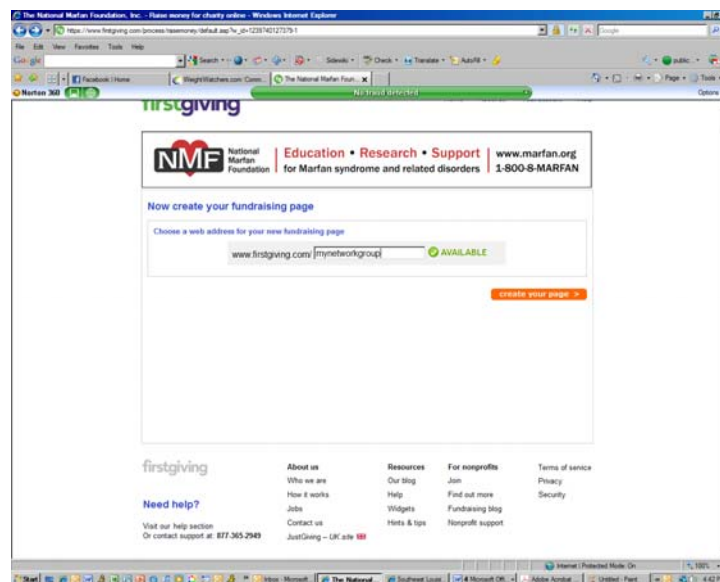
5. On the next screen, enter your e-mail address. In addition, you need to answer here if you are new to this site or, if you are not new, enter your password. Then click **Continue**.



6. Enter your contact information and choose a password, check that you have read the terms of services and click **Continue**. Once you complete this page, an email will be sent to you confirming your account and providing a record of your password.



7. Choose your fundraising page address and press **Create your page**.



8. Click Personalize and share your page
9. Give your page a title and set a fundraising goal. Then upload a photo and customize the text to tell your fundraising story and thank your donors. When you are finished, click **Save and Continue**.
10. Click the **Email your friends** link to send your page to friends, family and co-workers.

Remember -- **the more personalized the fundraising page text, the more effective it will be.**

Education & Awareness

Global Rare Disease Day is February 28, 2010

Jonathan Martin, NMF Director of Education & Awareness

jmartin@marfan.org; 800-862-7326 x 16

The National Organization for Rare Disorders (NORD), in partnership with 200+ organizations representing different rare conditions, is the U.S. sponsor of Rare Disease Day 2010. The purpose of this day is to raise awareness of rare diseases as a public health issue.

You can be part of an international effort to raise awareness of rare diseases by participating in Rare Disease Day activities! It's a great way to cap off Marfan Awareness Month with a sound statement that we are part of a larger community of people affected by rare diseases and conditions.

We ask members of the Marfan Community to visit the Rare Disease Day website at <http://rarediseaseday.us/> and check out the various ways to get involved. Goals and plans for 2010 include the following:

- Extensive media coverage
- Social networking blitz
- Creating a Rare Disease Physician Database
- Sharing patient stories, videos, photos, and blogs
- Honoring researchers through the Hall of Fame
- Joining hands with others worldwide

The best awareness is that which happens in your own community! Share your stories! Spread the word on Facebook, Twitter, NMFconnect, email and more! Write your elected officials! Sing out from the mountaintops to all who will listen that rare diseases and conditions are an important public health issue!

Please make sure you contact Jonathan at the NMF and let him know about your activities:

jmartin@marfan.org.

Conference News



Conference 2010

The NMF 26th Annual conference will take place in Houston, TX, July 8-11, 2010 in collaboration with co-hosts Baylor College of Medicine and the University of Texas Health Science Center at Houston. All conference activities will be held at the InterContinental Houston in the heart of "uptown" Houston near shopping, restaurants and a vibrant local entertainment scene. Look for details about educational programs, clinic

appointments, instructions on applying for a conference scholarship, travel and other information on the NMF web site in March. In the meantime, if you have any questions, email Maggie Hogan, NMF Director of Conference Planning at mhogan@marfan.org.

Conference 2011

We're pleased to announce that the conference is confirmed to take place in Portland, Oregon, July 14-17, 2011. Our co-host is Shriners Hospital and we will be working closely with Lynn Sakai, Ph.D., NMF Professional Advisory Board member and Senior Investigator, Portland Shriners Research Center, to organize an exceptional conference in the midst of this beautiful Pacific Northwest city.

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 your page or update it, contact Mahab Hoque, Systems Administrator, at mhoque@marfan.org , or 800-862-7326 x 19. Copy Kathy Jeffers on your request: kjeffers@marfan.org
January	Sign up for conference call workshops
January 30	Chapters: Second Quarter Financial Reports Due
February	Marfan Awareness Month
February 1	Network Groups: Five Year Assessment Due
February 28	Rare Disease Day
March 1	Deadline for Spring Connective Issues submissions Conference Registration opens on NMF website
March 6	Heartworks Saint Louis
April 20-27	National Volunteer Week
April 22	Heartworks New York
April 30	Chapters: Third Quarter Report Due
May 6	Heartworks Atlanta
May 22	Heartworks Westchester (NY)
June 1	Conference Clinic Appointment Deadline
June 15	Conference Early Registration Discount Deadline
July 8-11	NMF National Conference in Houston, TX
July 9	All Day Leadership Meeting at Houston Conference 9:30 am – 4:00 pm
July 30	Chapters: Fourth Quarter Report Due
August 1	Deadline for Fall Connective Issues Submissions
July 14-17, 2011	NMF National Conference in Portland, OR