



# Leadership Connection

September 2009

Volume 3 .No. 3

**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](http://www.marfan.org)

***“When we meet for a one hour conference call ...  
we learn... we drive results ...we lead!”***

## **Sign up Now for the Fall/Winter Leadership Seminars!**

The NMF depends on you, our key leaders across the nation, to be the messengers and motivators to move the organization forward at the local level. These seminars are offered to enable volunteers and staff to work together in the best way possible to serve our members. That is why the NMF directs considerable staff time and resources to develop and implement this important volunteer program. Through committing to a one hour conference call, we learn, we drive results – we lead in effectively implementing the NMF mission at the local level. This could not be done without YOU.

Please make every effort to participate, or appoint a key person as your representative.

### **Open to All Group Leaders and Telephone Support Contacts**

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

***Time schedules relate to Eastern Time.***

#### ***How Do I Register?***

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



## **1. Poster Project**

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

**Date:** *Friday, October 9*

**Time:** *1:00 pm ET*

**Sign up by:** *10/5*

**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.

## **2. Network Group Leaders Open Forum**

**Moderator:** *Kathy Jeffers, Manager of Volunteer Development*

**Date:** *Thursday, October 15*

**Time:** *2:00 pm ET*

**Sign up by:** *10/8*

**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 10/8, to Kathy Jeffers by e-mail at [kjeffers@marfan.org](mailto:kjeffers@marfan.org).

## **3. Telephone Support Contact Open Forum**

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

**Date:** *Friday, October 16*

**Time:** *1:00 pm ET*

**Sign up by:** *10/12*

**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. Chapter Leaders Open Forum**

**Guest Consultant:** *TBA depending on your needs*

**Moderator:** *Kathy Jeffers, NMF Manager of Volunteer Development*

**Date:** *Tuesday, October 20*

**Time:** *2:00 pm ET*

**Sign up by:** *10/13*

**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 10/9 to Kathy Jeffers' e-mail at [kjeffers@marfan.org](mailto:kjeffers@marfan.org), so we can invite appropriate guest consultants for this session.



## **5. How to Contribute to the Marfan Memorial Quilt Project**

**Presenter:** *Jonathan Martin, Director of Education & Awareness*

**Date:** *Thursday, October 29*

**Time:** *2:00 pm ET*

**Sign up by:** *10/22*

The Marfan Memorial Quilt is great way to honor those lost to Marfan syndrome and related disorders. Join this call to learn just how easy it can be to make a beautiful and personalized block to remember a friend or family member. We will cover various techniques and options to make a perfect block. NO SEWING SKILL IS REQUIRED. Watch the video highlighting the panels that have been created to date at <http://www.youtube.com/watch?v=i5gBZMyhcDs> before the training to get the creative juices flowing.



## **6. A New and Easy Way to Fundraise On-line**

**Presenter:** *Cathie Tsuchiya, NMF Local Fundraising Coordinator*

**Date:** *Thursday, November 5*

**Time:** *1:00 pm ET*

**Sign up by:** *10/29*

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



## **7. Introduction to the New NMF Style Guide**

**Presenters:** *Eileen Masciale, NMF Communications Director*  
*Jonathan Martin, Director of Education & Awareness*

**Date:** *Thursday, November 12*

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

**Sign up by:** *11/5*

**Description:** Here is the NMF identity tool kit you have been waiting for, with practical tips for using it. Before you design your next meeting invitation, or do your group's flyer or brochure, become familiar with this easy to use tool that will be available on the NMF website. This seminar is a pre-requisite for "How to Create a Winning Brochure/Flyer" on 11/16.



## **8. How to Create a Winning Brochure/Flyer for your Chapter or Network Group**

**Presenter:** *Eileen Masciale, Communications Director*

**Date:** *Monday, November 16*

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

**Sign up by:** *11/9*

**Description:** A brochure or flyer can be an effective marketing tool for your group, highlighting who you are, what you do, and where you are located. You are encouraged to develop a promotional piece to give to doctor's offices and local clinics that deal with Marfan syndrome and related connective tissue disorders. Groups that have done this find it a good way to attract new members. Using the new NMF Style Guide and a design template, you will leave this session with the knowledge and tools to develop your group's brochure or flyer. You must have taken the 11/12 seminar "Introduction to the New NMF Style Guide" to participate in this session.

### **REMINDERS! DATES & DEADLINES!**

<b>Reminder:</b>	<b>Chapter and Network Group Web Pages</b> 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 <a href="mailto:mhoque@marfan.org">mhoque@marfan.org</a> , or 800-862-7326 x 19.
<b>September</b>	<b>Sign up for conference call workshops</b>
<b>October 15</b>	<b>Network Groups: Quarterly Report Due</b>
<b>30</b>	<b>Chapters: First Quarter Financial Reports Due</b>
<b>November</b>	<b>Family Volunteering Month</b>
<b>January 1</b>	<b>Deadline for Leadership Connection submissions</b>
<b>July 8-11</b>	<b>NMF National Conference in Houston, TX</b>

# KUDOS

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



## **Thank You Minnesota and Iowa Chapters: Volunteer Co-chairs of Conference '09**

Congratulations to Teri Dean, President of the Heart of Iowa Chapter, Heather Hinton, President of the Twin Cities Minnesota Chapter, and all of their members who volunteered to make the conference at the Mayo Clinic in Rochester, MN, a tremendous success. This was the first conference ever hosted by two Chapters, a model that opened both new challenges and opportunities that were met graciously and successfully by all members. There were over 130 outstanding volunteers coordinated by Keith Hardy (MN), including those from both chapters and employees of the Mayo Clinic, who so generously stepped forward to help out in every way. Marsha Jones (IA) and Mary Holland (MN) created a State Fair theme for the family oriented welcome event, complete with festive fair food, pie throwing, petting rabbits, games and prizes for all. Proclamations commemorated the week as Marfan Syndrome Week in the states of Iowa and Minnesota thanks to Jen Holland (MN) and Teri Dean (IA). Tracie Payne (MN) and Kari Dostalik (IA) co-chairs of Heart Mart, set up the largest number of items (350) ever donated by members for this auction that raised an astounding \$6,000 for the NMF Scholarship Program. This will assist conference attendees at the Houston conference (July 8-11, 2010). Heart Mart is a tremendously popular, member driven event that continues to grow and provide more scholarships every year.

The following Committee Chairs worked prior to the conference as well as on site to make this event welcoming and fun for everyone: Tony Dodge (MN), Public Relations; Laura Biggart (IA), Welcome Bags and Conference Notebooks; Lori Bates (MN), Children's Program; Ben Weisman (MA) and Maya Zimmerman (CA), Teen Program; Shelly Harren (MN) 20-30's Group Program.



## **Congratulations to Jon Rodis, newly elected President of the Massachusetts Chapter**

The Board of Directors of the Massachusetts Chapter elected Jon Rodis as interim President, replacing Inez Steele, who resigned that position, but is remaining on the board. A formal election of officers will be held at their next Annual Meeting in 2010.

## **Welcome New Network Groups**



### **North Dakota**

Selma Kerzman; 701-221-2063; [selmading@hotmail.com](mailto:selmading@hotmail.com)  
Dena Kemmet; 701-873-5993; [dkemmet@ndsu.edu](mailto:dkemmet@ndsu.edu)

### **Phoenix, Arizona**

Steve & Amy Jerome; 602-843-0908;  
[sjerome@swlaw.com](mailto:sjerome@swlaw.com)

### **Kingsport, Tennessee**

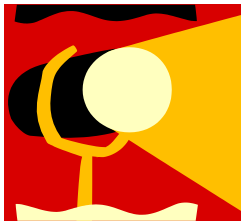
Deborah Peters; 423-239-6650;  
[seymoretowns@yahoo.com](mailto:seymoretowns@yahoo.com)

### **Fort Lauderdale, Florida**

MJ and Max Freeman; 954-262-1518;  
[freemanmj@bellsouth.net](mailto:freemanmj@bellsouth.net)

*“ ... the work goes on, the cause endures, the hope still lives, and the dream shall never die.”*

*- Senator Teddy Kennedy*



## **NVN VOLUNTEER SPOTLIGHT:**

**Rene Jones**

**Chair, Vermont/New Hampshire Network**

**(603) 769-1263 or (603) 628-5811 Email: [coordinator@nhvtmarfan.org](mailto:coordinator@nhvtmarfan.org)**

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

I am the mother of three children, with one affected by Marfan syndrome. My son Drew was diagnosed at the age of 12 in 2004, and the doctors informed us it was a new gene mutation. Drew has built awareness by sharing his background with peers at school. Drew is a senior this year and is currently looking at colleges he would like to attend to study Veterinary Medicine. He lives a very active life and enjoys snowboarding at Sunday River, paintball and skateboarding. My daughter, Lauren Barletta, attends Massachusetts College of Pharmacy and Health Sciences in Boston and will graduate in 2012 with her Masters of Physician Assistant Studies. Lauren is also very active within the NMF and currently is serving on the Board of Directors for the Massachusetts Chapter. My son, Matthew, is an eighth grader and attends Merrimack Middle School. Matt is active in cross country running, snowboarding and skateboarding. I work as a Project Manager and Quotes Coordinator for Square D/Schneider Electric.

### **2. How did you become involved in the Massachusetts Chapter and the Network Groups?**

I became involved with the Massachusetts Chapter after meeting Heather Holmes-Floyd at the National Conference in 2004. Once Drew was diagnosed, I started attending the Chapter meetings and volunteered at many of the events the Chapter was hosting. I started the NH/VT Network Group in fall 2008, after moving to Merrimack, NH from Andover, Maine. When Drew was diagnosed in 2004 we lived 4 hours away from Children's Hospital and drove 3 1/2 hours to attend a "local" meeting. I decided at that time that once Drew was fully recovered from his spinal fusions, that it would be my goal to start a support group that truly was local for families that lived in rural communities and in the states of New Hampshire and Vermont.

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

The most successful fund-raiser was when I filled out the Grant Application forms with my employer and requested that our Network Group receive the \$10,000 that was available for a non-profit organization. Our group decided that the funds were to be used for the Teen Programs at the 24th Annual Conference in Boston last year.

The most satisfying meetings are those that connect families who are affected with Marfan syndrome with another family affected with Marfan syndrome. On several occasions we have received phone calls from individuals and families that their only request is to meet another person who knows exactly what they are dealing with living with Marfan syndrome on a daily basis. So far we have welcomed three families into our group that had never met another affected person, although their families have been living with Marfan syndrome for over 10 years.

It is a great feeling to watch that connection and the overwhelming realization that they are truly not alone in dealing with the challenges presented by Marfan syndrome.

### **4. How have you enjoyed your experience as a member of Chapter and Network Groups?**

The past five years has been an incredible roller coaster ride for Drew and our family. Since becoming a member of the NMF in 2004, we have attended five conferences, and now plan our vacations around the annual conference. The conference allows every one in our family (Drew, Lauren, Matt and myself) to speak with physicians we would not have access to otherwise, to build relationships with other families and to share our experiences and knowledge with each other. The friendships we have made over the course of the last five years have meant so much to our family. The first person Drew met at our first conference was Dylan Rohrer, and they formed an immediate bond. From that July day in 2004, until October 2008 when Dylan passed away, Drew and Dylan stayed in close contact and shared many of their life experiences together. Drew credits his living successfully with Marfan syndrome to Dylan. Dylan always was positive, never complained about the pain he dealt with daily, and always showed Drew and me the positive side of life.

It is our commitment to share with others who are recently diagnosed, the concept that having Marfan syndrome doesn't just mean the end of your life as you once knew it. It also means change, and change often brings us new opportunities and many wonderful experiences. Our family has met so many amazing people volunteering for the MA Chapter, the NMF and our Network Groups. Although planning the 2008 Conference in Boston was very time consuming, we would all do it again. To know how many lives were impacted and perhaps saved by clinic, makes all the long hours and hard work well worthwhile.

## 5. What motivates you to stay involved with the Chapter, Network Groups and the NMF?

I am deeply motivated by my son, Drew, and all the amazing people we have been fortunate enough to meet and become very close to over the last 5 1/2 years. It is my goal and our group goal, to continue to spread awareness until one day when we say Marfan syndrome, that the next words we hear are not, "What is that?" We want to reach out to schools, hospitals and the community to raise awareness of Marfan syndrome and its characteristics..

## 6. What is your advice for other group leaders?

**Try not to become discouraged.** The first six months to a year is very difficult in getting a regular amount of folks to attend the gatherings. Stay consistent. We hold our meetings whether one person confirms they are coming or 20 confirm. Had we chosen to not meet because only one family was attending, we would missed helping two families that finally took the step to reach out and attend one of our events. From that meeting we were able to tell them about conference and they attended the conference this year on scholarship.

**Ask for help from others** and let them help you in what they are strong in. When I first started the Maine support group I tried doing it all myself. BIG MISTAKE! Now, when someone tells me they enjoy doing something, I let them tell me how much they want to be involved and let them run with it. We are in the middle of planning a Marfan Health Symposium in late spring (May or June) of 2010 at the Dartmouth Hitchcock Medical Center. We all are working together to make this event a success.

**Use the resource tools that are made available through the NMF.** There are many Chapters and Network Groups that have held very successful events and projects, and Kathy Jeffers or Cathie Tsuchiya can put you in touch with them for consultation. Having an NMF web page, and participating on NMF Connect helps bring in new people who are not yet connected to the NMF community, and allows you to keep your group updated on group happenings.

Finally, **realize you are doing something very important** when you bring people with a common concern together. You are giving them the gift of increasing their knowledge and understanding of their disorder, support for common concerns, and the opportunity to actively do something about it together, for the common good. Here is how the Fuller family from New Hampshire described their Network Group experience.

*"The NH/VT network group has been helpful for me, just getting a chance to talk with people who are similarly afflicted, but it has also been wonderful for my mom. Just recently she had a serious heart valve replacement operation. She was in ICU for nearly a week before heading home. Immediately after she returned, members of the NH/VT group came to the house laden with food and the intention of lifting her spirits. It worked, and I'll always be grateful. Mom wouldn't let anyone leave until they all signed the "heart pillow" the hospital gave her, and she talked about the visit for weeks. That kind of caring and support is like having a second family!"*

# Public Relations

## Reaching Out to Local Media: – What the NMF Can Do & What You Can Do By Eileen Masciale, Communications Director

### Local Publicity: More Ways the NMF Can Help

There are many reasons for chapters and network groups to try to generate media coverage:

- To publicize meetings (as a way to attract more participants)
- To let the public know about fundraisers and educational events so they will support your endeavors
- To arrange articles about Marfan syndrome to increase public awareness

In the past, the NMF has provided information to teach chapters and network groups the basics of contacting the media, from developing press releases to conducting media follow-up. Now, the NMF has a new tool that will help us contact the media for you.

Through Vocus, an on-line media database to which the NMF subscribes, we can easily and efficiently do the following for our members of our National Volunteer Network:

- Develop a local market media list, consisting of health reporters at daily newspapers, editors at weekly papers, health producers at television stations and public service contacts at radio stations (which of these is included depends on what you are publicizing and your goals).
- Distribute your press release for you with just a few keystrokes.
- Provide you with the list of media contacts so that you can follow up by phone and/or by email.

**All you need to do is contact Eileen Masciale, NMF Director of Communications, about your needs and provide her with your press release (she can review your draft and make suggestions). She can be reached at 631-665-2163 or [publicity@marfan.org](mailto:publicity@marfan.org).**

Please note that media requires lead time when covering a story.

- Calendars, in daily or weekly newspapers, often require three weeks or more.
- Health reporters at daily newspapers need less time, but it might take you a couple of weeks to get them on the phone and really encourage them to do your story.
- Television requires the least amount of lead time, with decisions to cover a story often made on that day (although you don't want to wait till that day to get them your information!).

The NVN is extremely vital in conducting grass roots awareness for the NMF. We are here to support your efforts and hope that many of you take advantage of this new technology. We encourage you to work with Eileen and learn from her 25 years of public relations experience to bolster your group and raise Marfan syndrome awareness in your area.

## Exemplary Leadership Skills

### **Steps to Boost Your Happiness Factor** **Compiled by Kathy Jeffers, Manager of Volunteer Development**

Find yourself complaining? Overwhelmed with too much work and too few committed volunteers? It might be a good time to evaluate just how happy you are – and then do something about it.

Happiness isn't something you're born with. It's a choice. You can choose to be happy, no matter what.

Your positive outlook – or lack of it – can directly impact your ability to effectively relate to and manage group members and other volunteers. Volunteers are drawn to positive people. You set yourself apart if you're positive.

So what choices can you make to be happy? Try these three steps to help foster a sunny disposition, no matter the weather:

1. Wear a smile, even when you're alone. It tricks the brain into being more upbeat and confident.
2. Choose not to complain. If you find yourself sinking to a complaining mode, take stock of all you have to be thankful for. Recognize that problems are temporary.
3. Be persistent about choosing to be positive. Begin each day knowing you can and will accomplish big goals, even if you do it in small steps. Don't get bogged down by others' negativity.

"Optimism is the cheerful frame of mind  
that enables a teakettle to sing,  
though in hot water up to its nose."

~ Author Unknown

# Support Q & A

**By Amy Kaplan, RN, Manager of the Information and Resource Center**

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](mailto:akaplan@marfan.org) or 800-862-7326 x 26.

**Q:** *I've been getting a lot of headaches lately. I also have been having a lot of leg pain, and have difficulty staying in any one position for very long. Do you think it could be related my having Marfan syndrome?*

**A:** From the symptoms you describe it is possible that you have dural ectasia. Many individuals affected with Marfan syndrome and Loeys Dietz syndrome have this condition. We would suggest that you discuss your complaints further with your doctor so that the cause of your symptoms can be investigated. The enlargement of the membrane around the brain and spinal cord is referred to as dural ectasia. Arachnoid, perineural and meningocele cysts also come under the umbrella of dural ectasia. Dural ectasia is usually diagnosed by MRI. Symptoms of dural ectasia can include, but are not limited to, back, leg, abdominal pain and headaches. One of our experts has indicated that generally a neurosurgeon or neurologist would be the best person to see for dural ectasia (who hopefully has connective tissue expertise). The mainstay for treating dural ectasia is pain management (generally speaking, consideration for surgery should be entered into extremely cautiously only after all conservative measures have been exhausted and have been ineffective).

**Q:** *My mother has Marfan syndrome, and I have a few of the features, but I am very overweight. Could I still have Marfan syndrome?*

**A:** Yes, it is possible to have Marfan syndrome and to be overweight. There is variable expression with Marfan syndrome and the disorder can vary in severity from mild to severe, and the features and symptoms can also vary, even within members of the same family. Although being thin is often associated with Marfan syndrome, not all affected individuals are thin. In fact on a few occasions the hotline has received a call from an affected individual who is morbidly obese, and has had, or is planning to have a gastric bypass procedure.

## Communications

### Communicate with NMF Staff

**By Kathy Jeffers, Manager of Volunteer Development**

Teamwork requires regular two-way communication. Paid staff members need to keep volunteers informed on matters impacting their duties, and volunteers need to reciprocate.

Don't hesitate to ask questions and keep learning more about your responsibilities and the organization as a whole. The more informed you are, the better you can do and stay energetic about your job.

Regular communication with staff can involve the following:

1. Participating in the leadership seminars offered through conference calls from fall through spring. Also, attending the leadership meeting at the NMF National Conference is our annual opportunity to meet in person, build relationships between our key leaders, staff, and board members.
2. Sharing ideas that may help the organization in some way improving member services/relations, streamlining programs, cutting expenses, etc.). We recently had an insightful and very productive discussion with Tony Dodge (Twin Cities Minnesota Chapter board member) about volunteer recognition.
3. Bringing concerns to staff to seek solutions rather than complaining to others or allowing issues to eat at you.
4. Discussing how to be more effective in your volunteer job.

# Have a Question? Here's Who to Contact

Use Central NMF Phone: 800-862-7326 and staff extension listed below

## Topic

## Who to Contact on the NMF Staff

**Network Group Management**

**Chapter Management**

**Volunteer Training & Awards**

**Volunteer Policies & Procedures**

**Leadership Connection Newsletter**

**Kathy Jeffers**, Mgr. Volunteer Development

[kjeffers@marfan.org](mailto:kjeffers@marfan.org) Ext: 11

**Start a Support Group**

**Telephone Support Contact Liaison**

**Support Workshops**

**On-line Support Groups**

**Insurance Questions**

**Child & Teen Programs**

**Jennifer Buffone**, Dir. Support Services

[jbuffone@marfan.org](mailto:jbuffone@marfan.org) Ext. 22

**Medical Questions**

**Find a Doctor**

**Clinic Directory**

**Amy Kaplan**, Manager, Information & Resource Center

[akaplan@marfan.org](mailto:akaplan@marfan.org) Ext. 26

**Education & Awareness**

- Programs/Projects

- NMF Exhibits

- Order NMF Materials

**Jonathan Martin**, Program Director

[jmartin@marfan.org](mailto:jmartin@marfan.org) Ext. 16

**Local Fundraising**

- Event Suggestions & Guidance

- Approval of event invitations & programs

- Certificate of Insurance

**Camera Ready NMF Logo, Artwork**

**Cathie Tsuchiya**, Administrative Director &

Local Fundraising Coordinator

[ctsuchiya@marfan.org](mailto:ctsuchiya@marfan.org) Ext. 13

**Legislative Advocacy**

**Research/Clinical Trial**

**Josephine Grima**, PhD, VP Research & Legislative Affairs

[jgrima@marfan.org](mailto:jgrima@marfan.org) Ext. 17

**Budget**

**Financial Reports**

**Operating/Event Advances**

**Judy Gibaldi**, Senior VP, Operations & Finance

[jgibaldi@marfan.org](mailto:jgibaldi@marfan.org) Ext. 14

**Connective Issues Articles**

**Media Outreach**

- Interviews

- Local papers

- Radio/TV

**Eileen Masciale**, Director of Communications

[publicity@marfan.org](mailto:publicity@marfan.org) 631-665-2163

**NMF Style Package**

**NMF Website**

**Your NMF Web Page**

**Mailing Lists/Updates**

**Mahab Hoque**, Systems Administrator

[mhoque@marfan.org](mailto:mhoque@marfan.org) Ext. 19

**National Conference**

**Maggie Hogan**, Dir. Foundation Relations & Conference Planning

[mhogan@marfan.org](mailto:mhogan@marfan.org) Ext. 38

# Group Management

## Tools and Resources for Volunteers on the NMF Website

By Jennifer Buffone, Director of Support and Volunteer Development

Did you know there are lots of new tools and resources on the NMF website for individual volunteers and group leaders?

**-NMFconnect:** The NMF's new online community, offers volunteers several new tools. There's an events section where individual volunteers and groups can post social gatherings, fundraisers, education and awareness events. Several Network Groups and Chapters have taken advantage of the "group" feature, which allows members of your local group to keep in touch online in between in person meetings in a way that's more dynamic than regular email. Some individual volunteers have utilized the "group" feature to spark interest in or assess interest in starting a local Network Group where there isn't one already. You can also post photos and videos of local events to NMFconnect. Go to: [www.marfan.org/NMFconnect](http://www.marfan.org/NMFconnect) (online community)

**-Volunteer Toolkit:** This is a new section of the NMF website. The Volunteer Toolkit features project templates for individual volunteers as well as group leaders. It includes templates for projects such as the Marfan Syndrome Public Awareness Flyer project and the Marfan Memorial Quilt project. New projects are being added all the time so check the Volunteer Toolkit often for new ideas. Go to: [www.marfan.org/Get Involved / Volunteer Toolkit](http://www.marfan.org/GetInvolved/VolunteerToolkit)

**-Plan a Fundraiser:** This section of the website provides volunteers with ideas for planning a local fundraiser and also offers volunteers a way to fundraise without leaving the comfort of their own homes through Firstgiving. First Giving allows volunteers to create an online fundraising page and email it to their friends and family. The goal is for those people to send it to their friends and family and so on. It's viral fundraising. [www.marfan.org/Get Involved / Plan a Fundraiser](http://www.marfan.org/GetInvolved/PlanFundraiser)

**-Chapter and Network Group Web Pages:** Every Chapter and Network Group has the opportunity to create their own page on the NMF website. If you are a group leader and your group doesn't have their own page on the NMF website you should create one as soon as possible. This is your place to highlight your group and its activities. [www.marfan.org/Get Involved / Chapter and Network Group Web Pages](http://www.marfan.org/GetInvolved/ChapterNetworkGroupWebPages)

Visit the NMF website often. In addition to the volunteer tools and resources listed above, there is new information being added to the website all the time. As an NMF volunteer you should be aware of the latest research and facts about Marfan syndrome and related disorders. Be familiar with Atenolol vs. Losartan Clinical trial sites in your area. Check to make sure you have copies of the newest Fact Sheets to give to new members of your group. Don't forget to update your clinic directory regularly by going to [www.marfan.org / Find a Doctor](http://www.marfan.org/FindADoctor). Contact information and clinic coordinators change regularly. The NMF values your ideas and suggestions. If you can't find something on the website that you think would be valuable, let us know.

*Your true character is revealed  
by the clarity of your convictions.  
Hold strongly to your principles and  
refuse to follow the currents of convenience.  
~ Unknown*

# Fundraising



## It's time to start planning for the holidays!

The holidays are a time for giving – and a time when it's more important than ever to show how meaningful it is to **give back** -

This holiday season, instead of giving store-bought gifts, ask your family, friends and colleagues to make a donation to the National Marfan Foundation. Let them know that all donations will support the NMF's lifesaving mission of research, education and support for people living with Marfan syndrome and related disorders. Tell them how much your support will mean to you and your family, and to all those in the Marfan community.

A very easy way to encourage friends to donate to the NMF is by creating a personal fundraising page through Firstgiving – it's quick, easy and secure. You can personalize your page with a message and photos and/or video to encourage friends and family to donate to the NMF.

Go to [www.firstgiving.com/marfan](http://www.firstgiving.com/marfan) to get started.

Send your holiday greetings to everyone you know – and enclose the link to your personal fundraising page. Spread the word through **Facebook** and **Twitter** too!

Creating a personal fundraising page is fun and easy as 1..2..3!

1. **Visit [www.firstgiving.com/Marfan](http://www.firstgiving.com/Marfan)**
  - Click on Get Started to easily create your fundraising page
2. **Personalize your online fundraising page**
  - Set your goal
  - Write your message
  - Add pictures and/or videos
3. **Email your page link to everyone you know**
  - Email asking is easy
  - Giving online is simple and secure
  - Donors receive automatic thank-you emails

Interested? Have questions before you get started? Contact Cathie Tsuchiya, NMF Local Fundraising Coordinator, at [ctsuchiya@marfan.org](mailto:ctsuchiya@marfan.org) or 800-8-MARFAN, ext. 13.



# Research & Legislative Affairs

## The Real Truths about Health Care Reform Proposals before Congress

Contributed by Josephine Grima, Vice President of Research and Legislative Affairs

The lack of effective health care coverage is one of the most important issues facing our nation. Nearly 50 million Americans have no coverage at all, and many more have coverage that does not provide for their basic health and long-term care needs. The problem is especially acute for Americans with a chronic disease or disability—the people we represent.

Failure to reform the health care system will result in health care spending consuming an estimated 20% of our gross domestic product by 2017, at which time the U.S. will spend nearly \$4.3 trillion on health care. This increase in health care costs is unsustainable, will strain the U.S. economy and will result in increasing numbers of uninsured and underinsured if we fail to act now.

Along with the National Health Council, we seek to shift the debate on health care in favor of rational discourse. Misleading and distorted claims that lack any basis in the health reform proposals currently before Congress threaten to derail efforts to improve our nation's health care system. Here is the real truth about several widespread misperceptions.

**THE REAL TRUTH: Health care reform will put more decision making in the hands of patients and doctors. It will NOT enable the government to make individual treatment decisions.**

The health reform legislation before Congress preserves choice and decision-making for patients and would improve the coordination of care for patients. Every proposal being considered would allow individuals to choose their own health plans, providers, and hospitals; none of the proposals would prevent patients and their doctors from choosing the best possible care.

**THE REAL TRUTH: Health care reform will expand our insurance choices. It will NOT result in socialized medicine.**

None of the major health reform proposals under consideration propose a government-run health care system in which the federal government is the single payer or provider of health insurance. Proposed legislation preserves coverage through private insurance companies with incentives for individuals and employers to participate. Americans will have the choice to keep their employer-sponsored plan or buy a plan from a new health insurance marketplace.

**THE REAL TRUTH: Health reform will prevent discrimination against people with chronic conditions. It will NOT put insurance companies out of business.**

Today, insurance companies determine what care will be provided and, often, to whom. Health reform legislation proposes to build protections for people with pre-existing conditions and prohibit insurance companies from retroactively denying coverage. Health reform legislation would not force private insurers out of business or force people into public plans.

**THE REAL TRUTH: Health care reform will expand coverage to more American citizens. It will NOT provide coverage to illegal immigrants.**

None of the health care reform bills would provide any health coverage to illegal immigrants. In fact, the House health care reform bill contains explicit language stating that federal payments are prohibited for undocumented aliens.

**THE REAL TRUTH: Health care reform will expand Medicare benefits. It will NOT lead to euthanasia for senior citizens.**

Health reform proposals look to expand Medicare benefits and reduce out-of-pocket costs for certain Medicare services. In fact, the House bill proposes to enhance Medicare benefits by closing the coverage gap for prescription drugs in the Medicare Part D program. The bills before Congress also would create a way to pay physicians for talking to patients

about advanced care planning. Patients regularly consult now with their health providers to plan for end-of-life needs, such as advance directives and palliative care. Under the proposals before Congress, these consultations would continue to be voluntary, would not promote euthanasia (which is illegal in 48 states), and would allow physicians to get paid for the helpful information they already provide to patients.

**THE REAL TRUTH: Health reform would establish an essential health benefits package that all plans must provide. It will NOT mandate use of taxpayer money to fund abortions.**

All qualified health plans would be required to offer an essential health care benefits package that provides a comprehensive array of services. These required benefits must include hospitalizations, emergency services, prescriptions drugs, rehabilitative services, mental health and substance abuse services, preventive services, maternity and newborn care, and pediatric services. None of the proposals before Congress would mandate coverage of abortion services.

**THE REAL TRUTH: Health care reform will reduce out-of-pocket payments for patients. It will NOT make health care more expensive.**

With health care costs soaring, individuals have been forced to bear greater financial burdens as they spend more out of their own pockets on their medical care. Plans that participate in the proposed national insurance marketplace must abide by out-of-pocket caps or cost-sharing limits on benefits that would make health care – especially preventive care – easier for patients to afford.

## **Health Care Reform Comparison**

Congress is currently considering legislation to reform the nation's health insurance system. **Attached is a detailed side-by-side summary comparing the major reform bills in the House and Senate.** The three committees of jurisdiction over health care in the House have all reported a bill. House leaders are expected to bring that legislation to the floor in the Fall. In the Senate, one of two committees with jurisdiction have reported legislation (Committee on Health, Education, Labor and Pensions). The other panel, Committee on Finance, has yet to finalize its proposal.

# SAVE THE DATE!



**Co-sponsored by Baylor College of Medicine and  
the University of Texas Health Science Center  
at Houston**

- ★ Attend workshops and medical presentations by world-renowned doctors and researchers
- ★ Make an appointment for a medical assessment at the Marfan Clinic (limited availability)
- ★ Bring your children and teens for a special fun-filled and educational weekend
- ★ Share experiences with others in the supportive environment that is unique to NMF conferences

**Look for details on the NMF web site in 2010  
at [www.marfan.org](http://www.marfan.org)**