



National Marfan Foundation

**ACTIVITIES PLANNING GUIDE:**

**HOW TO RAISE  
FRIENDS AND FUNDS  
IN YOUR OWN BACK YARD**

**National Marfan Foundation**  
22 Manhasset Avenue, Port Washington, NY 11050  
**800-8-MARFAN** [www.marfan.org](http://www.marfan.org)

# A SAMPLING OF IDEAS FOR PLANNING "PARTIES WITH A PURPOSE"

Art Exhibit	Halloween Party
Auction	Holiday Bazaar
Barbecue	House Sale
Benefit Concert	Masked Ball
Bike-a-thon	Prize Drawing
Birthday Party	Progressive Dinner
Black & White Ball	Raffle
Book Sale	Services for Sale
Bowl-a-thon	Sidewalk Sale
Car Wash	Spaghetti Supper
Carnival	"Sweet-Hearts" Festival
Children's Party	Swim-a-thon
Chocolate Festival	Talent Competition
Craft Fair	Teen Dance
Dance-a-thon	Tennis Tournament
Disco Night	Toy Fair
Fashion Show	Treasure Hunt
Flower Arranging	Valentine Dance
Garage Sale	Walk-a-thon
Garden Tour	Wine & Cheese Reception
Golf Tournament	Yard Sale

The NMF gratefully acknowledges the International Fibrodysplasia Ossificans Progressiva Association for sharing its Fundraising "Bright Ideas." Some of these ideas are reprinted from "50 Ways to Raise \$500 or More," Chardon Press/Grassroots Fundraising Journal (Copyright 1986).

# PLANNING FOR SUCCESS

All successful fundraising is based on one premise:  
**YOU MUST GIVE YOURSELF . . . YOU MUST ASK!**

After that, the possibilities are endless. The ideas and suggestions offered in this booklet are just the starting point for you to build on with your creativity, enthusiasm and sense of fun.

**Always remember that you are planning a "party with a purpose."**

Event Leadership needs to know that each and every dollar raised to benefit the NMF goes toward its life-saving informational services, education and research programs. Let's start with the basics . . .

## START BY ASKING THE RIGHT QUESTIONS

- **How much money do you want to raise from this activity?**  
How much "front" money will be needed before you make money?  
Determining this in advance can help you decide on the type of fundraiser to have.
  
- **How many people can be recruited to help with the work?**  
Special events can be manageable (and a lot more fun) when tasks are shared as a group project. Don't hesitate to recruit family, friends, workmates, Tall Club members and people from your NMF Chapter/Support Group to help as part of a committee.
  
- **What type of event will work in my community?**  
Consider some of the following points: What type of event has worked before? What has worked for other groups in your area or been successful for other Marfan volunteers? What are some of the specific skills and resources my group can contribute to the project?

# MORE PLANNING FOR SUCCESS

## Make a Budget

- Start with a fundraising goal (expected income).
- Estimate costs for the event, including: venue, food, decorations, entertainment, awards, product premiums (for example: tee shirts) printing, postage and publicity.
- NET Proceeds = Total Income minus Expenses

## Select a location, date and time

- Be aware of timing. Pick a date that doesn't conflict with your group's own activities (like National Conference) or other community events such as graduation or major holidays - unless it works for you by capitalizing on it with something like a "Sweets Bake Sale" for Valentine's Day!
- Check with your local authorities: most municipalities require special permits for food handling, raffles and alcohol sales. Make sure you are in compliance with all local safety regulations and insurance requirements.

## Set the timetable

- Develop a checklist for every task that needs to be done in each stage of the project. (For example: location confirmed, deposits due for food, tee shirts ordered.) Establish specific deadlines for each stage and spell out who is responsible for getting it done. This allows you to keep track of the progress being made in each area of responsibility and helps avoid last minute confusion.

## Keep accurate records

- Detailed financial records are essential, but maintaining well-documented files on the timetable of events, names and addresses of sponsors, donors and volunteers and a recap of what worked (and what didn't) can be an invaluable tool in planning any future event.

## **MORE PLANNING FOR SUCCESS**

### **Working with your committee**

- **Remember: people who are involved in the “brainstorming” and planning stages are much more motivated to complete the actual work required to produce a successful event.**
- **Make this a fun experience. Be sensitive to people's capabilities – and respectful of their time constraints.**
- **Be specific about what the job involves when assigning tasks, including setting clear deadlines for when each task needs to be completed.**
- **Train your workers. Let “veteran” workers explain procedures and help new recruits acquire the skills they need.**
- **Check “outside” sources such as youth and senior groups, or church, school and service organizations for volunteers who may be interested in lending their talent, time and expertise to your project.**
- **NEVER turn down a volunteer. Be creative and imaginative about what you ask people to do and convey the attitude that their participation is a valuable part of making the project successful.**

### **Celebrate your success**

- **Don't wait until after the project is over to let committee members know they are appreciated. Be generous with well-deserved praise and recognition all along the way. ALWAYS follow-up with thank you notes to donors, sponsors and volunteers.**

## DINING FOR DOLLARS

### CHOCOLATE LOVERS FANTASY NIGHT



Becky Teenie and Penny Glavis of Levittown, Pennsylvania began this delicious idea in 2000. Sponsored by the Christ United Methodist Women, the evening features a chocolate contest with more than 35 adult bakers and a dozen children bakers. For a \$1 ticket, attendees get to taste every entrée!

According to the late Jeff Goldman, dear NMF friend and member whose mother, Becky, is one of the event's organizers, "This type of fundraiser has tremendous potential to be done throughout the country. It is a fun event that is easy to coordinate - and people have a great time with all that chocolate."

If you would like more information and a step-by-step guide for planning this delectable family event in your community, contact the NMF.

- With 4 or 5 friends, have a spaghetti dinner at a church or union hall or other big room with a large kitchen. Charge \$10 per person and feed more than 50 people. You can charge extra for wine or garlic bread or for dessert.
- Have a fancy dinner at your home or a regular dinner at someone's fancy home. Serve unusual or gourmet food, or have special entertainment. Charge \$25 or more per person, and have 20 or more guests.

## MORE DINING FOR DOLLARS

- Get 3 friends to help you have a progressive dinner. Start at one person's home for cocktails and hors d'oeuvres, progress to the next person's house for soup or salad, the next person's for the main course, and the last person for dessert and coffee. Either charge by course, or for the whole package. To make it extra special (and much more expensive), get a limousine for the evening that carries guests from house to house. (Even better if you know someone who would donate the limo for the evening!)
- Host a wine and cheese party. Do NOT charge admission and invite as many people as you can. During the party, give a short talk about the Marfan syndrome, and ask everyone to consider a gift of \$25, \$50 or \$100 (or more) depending on the crowd. Either pass out envelopes and ask people to give then, or after the party contact everyone individually who came and ask for a donation. Indicate that you have given, and if appropriate, how much you have given.

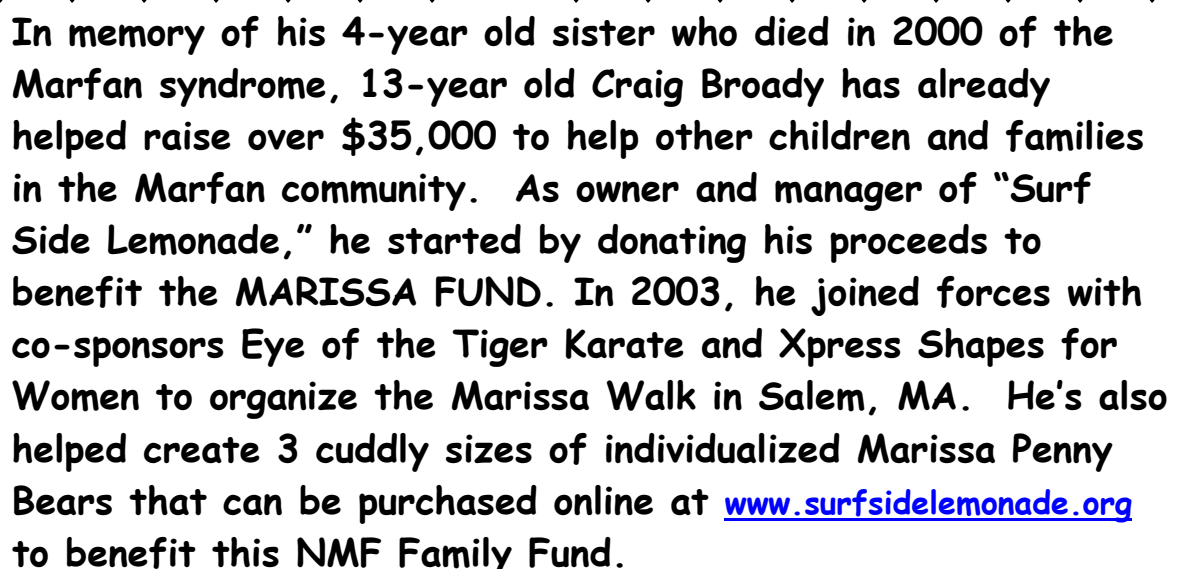
### START A "CHAIN" DINNER FOR CHARITY TO RAISE A TOTAL OF \$500!

Invite 10 people to your home for dinner and charge \$10 per person. Ask 2 of the 10 people who were guests in your home to host a dinner party of their own and also invite 10 people at \$10 each. Each host must then ask one of their guests to continue the chain and also invite 10 guests at \$10 each. See how quickly it adds up:

Original Dinner Party Income (10 x 10)	\$100
<u>ASK 2 GUESTS TO HOST</u>	
Party Host #1 (10 x 10)	\$100
Party Host #2 (10 x 10)	\$100
<u>PARTY HOSTS #1 + #2 EACH ASK 1 GUEST TO HOST</u>	
Party Host #3 (10 x 10)	\$100
Party Host #4 (10 x 10)	\$100
TOTAL DONATION TO NMF	\$500

## **SELL STUFF TO SUPPORT THE NMF**

- Ask 2-5 friends to help with a **BAKE SALE, BOOK SALE** or **GARAGE SALE**. You and your friends bake the goodies, or get the books or other stuff required for the sale, staff it, and help clean up afterwards. This is an excellent way to get people involved in fundraising without ever actually asking them for money.
- Another idea: have a sidewalk or garage sale for your whole neighborhood or building. Go around to your neighbors and tell them you will take their stuff outside and sit with it all day to sell it if they will donate half (or all!) of the proceeds to support the NMF. Since this is stuff people want to get rid of anyway, it is a good deal for them. With a few high-tickets items, such as a washer/dryer or some nice lamps, you can make good money. (Three volunteers netted \$3,000 in one day by getting neighbors from all ten apartments in their building to donate their unwanted stuff -- proving "one man's trash is another man's treasure!")
- Are you and your friends crafty? You'll have fun creating an assortment of "themed" items to offer for sale to benefit the NMF. (Baby and children's gifts are always a good choice as are handmade holiday items for Christmas and Chanukah.)



In memory of his 4-year old sister who died in 2000 of the Marfan syndrome, 13-year old Craig Broady has already helped raise over \$35,000 to help other children and families in the Marfan community. As owner and manager of "Surf Side Lemonade," he started by donating his proceeds to benefit the **MARISSA FUND**. In 2003, he joined forces with co-sponsors Eye of the Tiger Karate and Xpress Shapes for Women to organize the Marissa Walk in Salem, MA. He's also helped create 3 cuddly sizes of individualized Marissa Penny Bears that can be purchased online at [www.surfsidelemonade.org](http://www.surfsidelemonade.org) to benefit this NMF Family Fund.

## SERVICES FOR SALE

- If you have an artistic bent, offer to design greeting cards to specification for organizations or individuals for a fee. Talented artist, Malki Loewenstein, raised money for the NMF this way by creating and selling distinctive hand-made note cards featuring heart motifs in fabric and novelty papers.
- Good at calligraphy? Promote your skills to schools for graduation announcements, to friends for classy but low-cost wedding invitations or sell fun certificates for special occasions such as "World's Greatest Dad" for Father's Day. Create unique Halloween costumes and masks, personalized Holiday decorations or individually designed home items. Donate the proceeds from your artistry to the NMF.
- Teach a seminar on a topic you know like knitting, gardening, gourmet cooking, dog grooming, crafts or lead a nature walk, architectural or historic tour, sailing or rafting trip. Charge a competitive rate (usually \$20-50 per person) with a goal of 25 people.
- Organize a "Top 10 Things To Make My Life Easier" prize drawing. Get 10 people (including yourself!) to donate services. Things like a full day of housecleaning, childcare for two weekend nights, yard work, house painting (interior or exterior), cleaning out the garage, gift wrapping, or shopping for holiday gifts. (Complete the list by asking yourself and a few friends for suggestions of what would make life easier for them!) Sell tickets at \$5 each to neighbors, work mates, friends and family. Encourage multiple sales by offering tickets at \$5 each or 6/\$25. Just remember \$25 is a real bargain for a full day of house cleaning. By keeping the price a little high you don't have to sell so many - and buyers have a higher chance of winning.

## **ORGANIZE A GOLF TOURNAMENT, SPORTING EVENT OR MARFAN "MARATHON"**

Consider hosting a Golf or Tennis Tournament or holding a Walk-a-thon, Bike-a-thon, Bowl-a-thon, Swim-a-thon, Exercise-a-thon or Dance-a-thon (or make up your own!) event at a local country club, public park, school or even a mall. People can participate individually or form teams and collect pledges for completing the entire activity or specifically for how far they walk, how many laps they swim, how many strikes or points they get, etc.

Keep in mind that these types of events can produce a big pay-off -- but they do require a much longer planning lead time and a lot of manpower.



Just ask Bruce Klein: "Our Chicago NMF Chapter organized its first Walk-a-thon in 1996. Thanks to the on-going support we've also received from Chicago's Paramount Tall Club, it has now become an annual event that's raised almost \$65,000 to date!"

The NMF can put you in touch with Bruce or several other groups who have had great success with these types of fundraising events to provide more extensive planning tips and "templates" to write letters soliciting community sponsorship.

## MORE SPORTS SUCCESS STORIES



Glenn Stidham, from Nesconset, Long Island in New York, organized his first "JAFGO" event (Just Another Family Golf Outing) in 1999 because his grandson Michael is affected by the Marfan syndrome. This annual event has raised over \$70,000 since it began. His secret for success?

"Start out slowly, learn from your mistakes, and get as many people as possible involved to help." In addition to planning the logistics, Glenn's large extended family works together as a team to solicit great raffle prizes from local merchants, get golf shirts donated for participants and plaques engraved for sponsors.

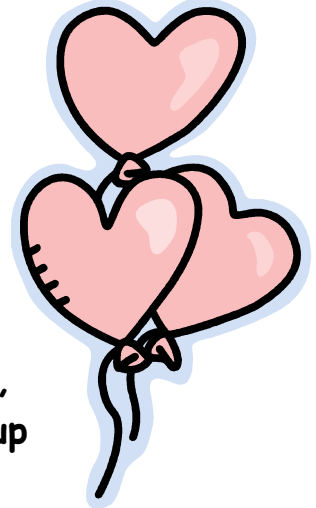


Organized by Teri Dean, leader of the Heart of Iowa Chapter, this year's "thon" held in Pleasant Hill in memory of former NMF Board member Bev Kiefer's son Scott, was expanded to include Walking - Running - and Biking. By coordinating this event with the community's annual "Summerfest," The Scott Kiefer Have-A-Heart for Marfan "multi"-thon has not only raised over \$6,100 in two years, it has also been very successful in generating significant local media coverage.

### HERE'S A PLAN TO HELP EACH PARTICIPANT RAISE \$250 IN JUST ONE WEEK!

Day 1:	Start by sponsoring yourself for \$25	\$ 25
Day 2:	Ask 1 family member to sponsor you for \$25	\$ 50
Day 3:	Ask 5 friends to contribute \$20 each	\$150
Day 4:	Ask 5 co-workers to sponsor you for \$10 each	\$200
Day 5:	Ask 5 neighbors to contribute \$5 each	\$225
Day 6:	Ask your boss for a company contribution of \$25	\$250
Day 7:	Check to see if your company offers matching gifts	\$BONUS

# Great FUNdraising Ideas To Add To Your NMF Event

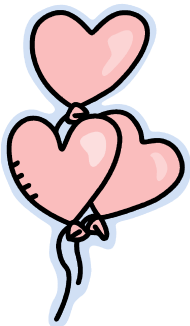


## YOU GOTTA HAVE HEART (BALLOONS)!

Ask local merchants to donate prizes. (Gift certificates, books, videos and CD's are easy take-home items.) Group the prizes at price points of \$5, \$10, \$25 or \$50 and value them so guests feel like they're getting a bargain. List prize descriptions on display board (for example: Gift Certificate for Lunch for 2 at Joe's Café). Inflate balloons and tie a ribbon with a gift card stating the prize. Guests purchase a balloon and get the designated prize.

## HOLD A "CHINESE AUCTION"

This fun hybrid between an auction and a raffle is an easy way to add excitement to your event - and significantly boost your fundraising efforts. Choose a "theme" and ask guests to bring an appropriate item to be donated and displayed on a table the night of the event. Guests can purchase 2-part numbered tickets (these are readily available at office supply stores) - and "bid" on a specific selection by dropping one part of their ticket in a separate container placed next to each item. At the end of the evening, a "winning ticket" is drawn and posted for each item. Winners collect their prize by presenting the matching ticket stub. At the 2003 Annual Marfan Conference held in Chicago, tickets were sold for \$1 each or 6/\$5 and participants donated over 60 heart-themed items, helping the NMF raise \$1,261 to support the Scholarship Fund.



## ADD A PRIZE DRAWING

Solicit local restaurants, movie theaters, wine stores and gourmet shops to donate items for a prize drawing. Price tickets based on how many prizes are available to win! Even people who can't attend the event can participate.

## **NO TIME TO PLAN AN EVENT ... BUT STILL WANT TO HELP?**

### **"INDIVIDUAL" IDEAS THAT MAKE A DIFFERENCE**

#### **RESOLVE TO QUIT A BAD HABIT FOR A GOOD CAUSE**

- Offer to do something your friends and family have been nagging you to do anyway, and attach a price to it. For example, quit smoking on the condition that your friends donate a certain amount to the NMF for every day you don't smoke up to 30 days. Agree to match their gift at the end of 30 days if you didn't smoke. Give them back their money if you did. (This method can be applied to other healthy habits, such as exercising or not eating sugar.)

#### **CHILDHOOD COLLECTIONS**

- Consider selling something you collected avidly as a child if it's been stored in your basement for over 5 years. Coins and stamps, in particular, have usually increased in value over the years. But your collection of rocks, toy ships, rockets, arrowheads or dolls can also be valuable. Since you probably paid little or nothing as a child to acquire these items, you get the added bonus of a tax deduction when you donate the income from the sale of the collection.

#### **HAPPY BIRTHDAY**

- Celebrate your birthday each year by holding a big bash and selling tickets to attend - with proceeds donated to the NMF. You can also just invite people to your birthday party and ask that in lieu of gifts they make a contribution to support the NMF.

**NO TIME TO PLAN AN EVENT ... BUT STILL WANT TO HELP?**

## **KEY STEPS TO PLANNING A SUCCESSFUL LETTER WRITING CAMPAIGN**

Raising money through a letter writing campaign can be a great way for individuals to participate in a specific event (like a golf tournament or bike-walk-bowl-a-"thon") ... or may be your personal way of supporting our Annual Have-a-Heart campaign. Here's some ideas to help get you started:

### **CREATE A LIST**

- Include friends, family and co-workers (both past and present)!

### **WRITE A PERSONAL AND INFORMATIVE LETTER**

- Begin by telling your own personal reason for writing the letter.
- Educate the reader about the Marfan Syndrome. (For example, include that it is a genetic/heritable disorder, describe its complexity and the number of body systems affected, and explain that approximately 200,000 men, women and children in the US are affected by the Marfan Syndrome and related connective tissue disorders.)
- Tell the reader about the NMF and the services it provides. It is particularly powerful to relate a personal experience and specific benefit you have received from the foundation. (The NMF provides funding for cutting-edge research, awareness and education programs for healthcare professionals and support services for affected individuals and families.) Over 93% of all donations directly support these programs and services.

## **MAKE IT EASY FOR PEOPLE TO DONATE**

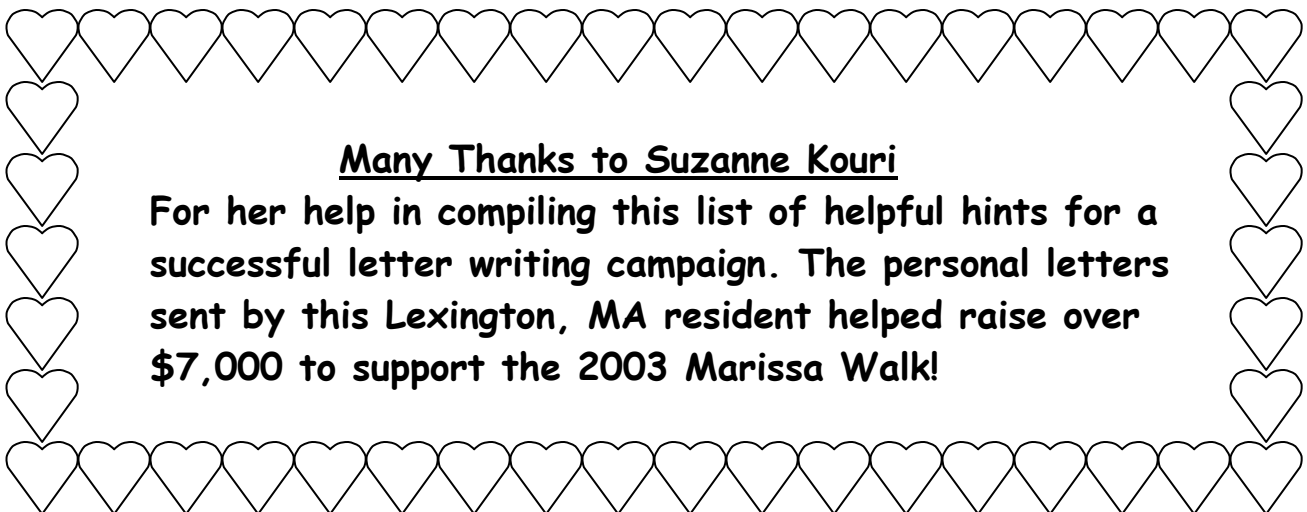
- Ask the reader to help you make a difference by making a donation. If your letter writing campaign is supporting a specific event, be sure to include the name, date, organizer's name and overall financial goal. Be sure to also tell the reader what you have set as your personal fundraising goal.
- Clearly state directions to make all checks payable to the NMF, create a form to accommodate credit card donations, include a self-addressed envelope and let them know their donation is tax-deductible.

## **KEEP GOOD RECORDS**

- Maintain an updated record of your complete mailing list and copies of all letters you send. Keep an accurate log of all donations, including the name, address, amount and gift method.

## **ALWAYS FOLLOW-UP WITH A THANK YOU LETTER**

- Tell your donor how much you appreciate their generosity and how their help has made a difference to you personally -- and the Marfan community in general.
- Recap any specifics about the event (including the spirit/energy, number of participants, and acknowledgment of any special attendees like local celebrities or physicians). Tell the reader how much was raised by the event and by your own personal efforts -- and include comparisons to the original goals for each.



### **Many Thanks to Suzanne Kouri**

**For her help in compiling this list of helpful hints for a successful letter writing campaign. The personal letters sent by this Lexington, MA resident helped raise over \$7,000 to support the 2003 Marissa Walk!**

# PROMOTE AWARENESS IN THE WORKPLACE

## FIND OUT HOW YOUR EMPLOYER SUPPORTS NON-PROFIT ORGANIZATIONS

Does your company provide grants through a philanthropic foundation? Offer sponsorship for community events? Participate in a matching gift program? Does it support volunteerism and provide ways for associates to get involved?

- Ask if you can set-up and staff a workplace table display during National Marfan Awareness Month.
- Request the company's charity / grant guidelines and send the information to the NMF
- If available, **ALWAYS** submit a matching gift form to increase your NMF donations.



### THIS COMPANY HAS HEART

The Bell Oaks Company of Atlanta, Georgia, employer of the late Eric Eshleman, established the Bell Oaks Foundation after Eric died from an aortic dissection that resulted from undiagnosed Marfan syndrome. The foundation is committed to serving its local community by sponsoring quarterly volunteer projects for their employees. The foundation continues to honor Eric's memory by promoting Marfan awareness and recently underwrote a Bowl-a-thon with all proceeds benefiting the NMF.

## **PROMOTE AWARENESS IN YOUR COMMUNITY**

### **SERVICE ORGANIZATIONS, SOCIAL CLUBS AND SMALL BUSINESSES**

- Ask friends who belong to local business associations, service clubs, sororities, antique collecting groups, support groups, bridge clubs, etc. to discuss the NMF in their group and pass the hat for donations. This is a great opportunity to spread awareness - and a once-a-year sweep of even small organizations can yield \$100 from each.
- Research the giving policies of service clubs in your own community. They usually have formal guidelines for grant amounts above \$1,000, but you can often raise \$200-500 with a simple proposal and oral presentation. This can be especially effective if you are a member or actively involved in any of these organizations.



### **TALL CLUBS INTERNATIONAL**

The NMF is proud to be the official charity of Tall Clubs International (TCI), and the beneficiary of many of TCI's own fundraising events in addition to partnerships with local NMF volunteer groups. This social club for tall men (over 6'2") and women (over 5'10") has chapters worldwide, including 66 in the United States.

Jan Palmer, NMF liaison for the TCI, invites all NMF members who meet the TCI height requirements to get involved - and have a great time by joining their local chapter. To find the nearest Tall Club in your area, contact 888-I-M-TALL-2 or visit [www.tall.org](http://www.tall.org).

## **START SPREADING THE WORD**

### **TIPS ON HOW TO GENERATE LOCAL MEDIA COVERAGE AND RAISE AWARENESS ABOUT THE MARFAN SYNDROME**

Get placement for news articles or broadcast health segments by developing a list of local media outlets, including health reporters at newspapers, television news programs and radio shows in your community. (Public access and cable stations can be a good choice because they often devote longer segments to a single subject.)

- Write a brief letter stating why it is important to feature the Marfan syndrome. Be sure to include information about your local chapter or support group and/or some information about local families who are affected and willing to be interviewed.
- Contact the NMF for fact sheets and other press materials to include with your letters.
- Follow up your letters with a phone call offering to help arrange interviews with the local families. Inform the media that the NMF can also arrange for them to speak with physicians who are experts on the disorder.

### **ADDITIONAL IDEAS TO RAISE AWARENESS**

- Contact local government officials for a proclamation stating that February is National Marfan Syndrome Awareness Month. (This can be a useful tool in generating media coverage.)
- Place ads in local publications. Call the NMF for camera-ready ad slicks that promote early diagnosis and feature our toll-free number.
- Write letters to the Op Ed section of your local newspaper.

## HOW THE NMF CAN HELP YOU

- Once your event has been scheduled, contact the NMF at 800-8-MARFAN to receive your complimentary Event Promotion Kit. We can also provide informative fact sheets, videos and other educational materials that you can display to raise awareness about the Marfan syndrome.
- Check out our website at [www.marfan.org](http://www.marfan.org) for details on new HAVE-a-HEART campaign items specially created to promote National Marfan Awareness Month every February. These include colorful and fun products for sale such as the NMF Awareness Pin, HEARTWORKS Note Card Set, and the HAVE-a-HEART tee shirt designed annually.
- Get in touch with the NMF to provide fact sheets, press kits, ad slicks and other materials you need to generate media coverage about the Marfan syndrome in your own community.
- Need a helping hand? Call the NMF to discuss your questions and concerns. We can put you in touch with the real pros -- other NMF volunteers across the country who have successfully raised friends and funds in their own back yards!
- Please let us know about the event you're planning so we can share it with other volunteers from the Marfan community. Send us photos and a recap of the day's activities so we can feature it in our quarterly newsletter, *Connective Issues*.

# FEBRUARY IS NATIONAL MARFAN AWARENESS MONTH

## FIVE FUN WAYS TO SUPPORT THE NMF HAVE-a-HEART CAMPAIGN

(in February and all year long!)

### SEND YOUR HEARTFELT WISHES

- ♥ Order a set of beautiful HEARTWORKS Note Cards from the NMF and use them all through the year to celebrate birthdays, say thank you, send get well wishes or let your Valentine know they're in your heart.

### A THANK YOU FROM THE HEART

- ♥ One NMF member thanks the heart surgeon who saved her life by sending a donation in his honor every year to support the NMF HAVE-a-HEART campaign.

### HEARTS AND KISSES

- ♥ Keep a bowl of candy (wrapped heart lollipops or chocolate kisses are both good choices) on your desk with information about the Marfan syndrome. Raise awareness and collect donations in a heart shaped bank to support the work of the NMF.

### A "CHANGE" OF HEART

- ♥ Ask 5 friends to help you change the world. Save all the coins each of you accumulate every day for the month of February. You'll be surprised how quickly your tax-deductible donation to the NMF adds up.

### PLAN A "SWEET-HEARTS" FESTIVAL

- ♥ Gather friends, family and neighbors to enjoy heart themed baked goods, candies and other sweet delights. (Provide coffee, tea and soft drinks and solicit donations of goodies from your favorite gourmet cook, restaurant, bakery or candy store.) Charge \$5 per person for sampling to their heart's content.