

# heart happenings

Heart of Iowa Chapter - National Marfan Foundation

## Heart of Iowa Chapter-NMF Co-Hosts 25th NMF Conference

*Help Us Welcome Marfan Community to the Midwest*

The Heart of Iowa Chapter-NMF is excited to co-host the 25<sup>th</sup> Annual Conference on Marfan Syndrome and Related Disorders with the Twin Cities NMF Chapter and Mayo Clinic in Rochester, Minnesota, August 6-9, 2009. People with Marfan syndrome and related disorders, their family members and friends will have the opportunity to learn about new developments in research, treatment options, and issues in health management throughout this conference.

The four day conference will offer participants the opportunity to take advantage of a free Marfan clinic at Mayo, and to attend more than 70 workshops, educational sessions and quality of life support groups designed to help them become educated consumers and advocates of their own health care. Members of the NMF professional advisory board, physicians from Mayo Clinic, and invited guest specialists - the world's leading experts in the field - will staff the clinic and lead educational sessions.

The conference will also offer special programming for affected children, teens, and their siblings. Each year more than 150 youngsters are provided with the opportunity to learn about Marfan syndrome and its related disorders while building awareness, acceptance, and positive self-image through activities designed to encourage team-building and self-expression.

There's still a lot of work to do in order to make this conference a success. This newsletter is full of fun ways you can get involved. ♥

### Help Support the NMF Conference!

Participate in one or more of these upcoming events to help raise funds for the NMF Conference...

- Tastefully Simple Fundraiser (February 14-April 30)
- Pampered Chef Fundraiser (April 1-30)
- Drink for a Cure (May 16)
- Moonlight Stroll for Marfan (July 17)
- Have Heart for Marfan Walk/Fun Run (July 18)
- Purchase a *Recipes from the Heart* Cookbook



February 2009



### What's Inside

Teri's Tidbits 2

Volunteer for 2009 NMF Conference 3

Drink for a Cure 4

NMF Conference Scholarship Application 5

Recipes from the Heart 7

Omaha Network Group Update 9

#### Dates to Remember

- May 16 - Drink for a Cure
- July 17 - Moonlight Stroll for Marfan
- July 18 - Have Heart for Marfan Walk/Fun Run
- Aug. 6-9 - NMF Conference, Rochester, MN



Teri Dean

It's beginning to feel like spring will never arrive. Winter weather hit us after Thanksgiving and it continues to go full bore. While we've had a few nice days recently, it just isn't enough to keep my spirits high!

This last week found me in Rochester, Minnesota, at the Mayo Clinic making a pitch for volunteers to help with the 25<sup>th</sup> Annual National Marfan Conference. There is so much to do and so little time to get everything accomplished. Not only do we need help *during* the conference, we also need help *before* the conference soliciting items for Heart Mart, and raising funds to cover conference expenses.

### **Heart Mart**

Heart Mart remains a staple at the NMF Conference year after year. This raffle features a wide variety of heart-themed items donated by members of the Marfan community. All money raised at Heart Mart goes toward the NMF Conference Scholarship Fund. Without this fundraiser, many people (including some of you who have received scholarships in the past), would not be able to attend the conference and experience its wonderful benefits first-hand. The Boston NMF Chapter has challenged us to raise more than \$12,000 this year, so we have our work cut out for us. For further informa-

## Teri's Tidbits

tion on Heart Mart donations, refer to page 8.

### **What's Your Passion?**

My passion is, and will continue to be, helping the Marfan community any way I can. It takes more than \$200,000 to put on the NMF Conference. Very few foundations provide such an educational, psychosocial, and hands-on opportunity for its members. How many other foundations have world-renowned researchers and treating physicians available for its constituency on a one-on-one basis? How many run such a lean organization, where more than 75 percent of funds raised goes directly toward research opportunities, care, and service for their constituency?

If you don't know the answers to these questions, I challenge you to do a little homework. I think you will discover the answer is, "none!" The NMF has a phenomenal track record for its cutting edge research for Marfan syndrome and related disorders. Just think, without this research there wouldn't be a clinical trial, the life expectancy for someone with Marfan syndrome wouldn't be in the 70's, and so many life-saving techniques would be undiscovered. So many positive things continue to happen in the Marfan syndrome field.

### **You Can Help**

Throughout this newsletter you will find several ways you can help. One simple thing you can do is to pay your NMF annual dues. The NMF relies on these funds to support the many programs available to its membership and physicians. All of us have felt the economic impact and the NMF and chapter are no different. A long time ago, someone told me, "If you really want to do something you will find a way regardless of the cost." I

plead with you to check your heart and see how you can help us reach our goals.

The newly formed Twin Cities NMF Chapter and the Heart of Iowa Chapter are co-hosts of the 2009 NMF Conference and it is our responsibility to help the NMF secure money for this event. We are busy writing grants; holding fundraisers (several are mentioned throughout this newsletter); contacting companies for funds, items to raffle, and items to be given to the conference participants; as well as planning a memorable conference. Remember, this is the Midwest and our hospitality needs to shine through.

Please fill out the survey on the next page to let us know how you can help or support our fundraising efforts. Two simple ways include: 1) placing an online order with Tastefully Simple or Pampered Chef, or 2) recruiting friends and family members to attend fundraising events and/or to help at the conference.

As in years past, the Heart of Iowa Chapter-NMF will have a scholarship fund that we will use in conjunction with the NMF to ensure that as many of our chapter members as possible have the opportunity to attend the conference. The application form can be found on pages 5-6.

### **Help Us Go Green**

Help us save paper and postage by providing us with your e-mail address. E-mail me at [tkdean11@mchsi.com](mailto:tkdean11@mchsi.com), and put "Heart of Iowa-NMF" in the subject line to add your name to the database. I'm looking forward to seeing all of you at conference. Till we meet again! ♥

# Volunteers are needed to help at the 25<sup>th</sup> Annual NMF Conference Co-hosted by Mayo Clinic on August 6-9, 2009



NAME \_\_\_\_\_

E-MAIL \_\_\_\_\_

PHONE \_\_\_\_\_

ADDRESS \_\_\_\_\_

1.) I would be interested in **servicing on a conference volunteer committee:**

\_\_\_\_\_ **Fundraising** Are you willing to work on a fundraiser in your community? Do you work for or know of a company or grant program that might be interested in funding this conference?

\_\_\_\_\_ **Welcome Event** The welcome event will feature a State Fair theme. Do you know a vendor that could help support this event with donations of food, fun and a warm welcome for attendees? Can you provide small trinkets to use as prizes for the children's games?

\_\_\_\_\_ **Heart Mart** Are you able to solicit and/or make items for the "heart" themed raffle that supports the conference scholarship program?

\_\_\_\_\_ **Welcome Bags** Are you able to solicit items from Iowa-based businesses for the conference "Welcome Bags," a tote bag given to conference attendees?

\_\_\_\_\_ **Children's Program** Can you identify leaders for (60) 6-12 year olds (teachers, camp leaders, professional agency, nursing programs, educational programs at colleges, etc.) or help chaperone during conference?

\_\_\_\_\_ **Teen Program** Can you help chaperone during conference?

2.) I would be interested in **helping on-site staff at the conference** on Thursday and/or Friday with set-up, registration, directing attendees to clinic appointments and/or educational sessions.

\_\_\_\_\_ YES \_\_\_\_\_ NO

### Please return survey to:

Teri Dean, 435 Schaffer Blvd., Pleasant Hill, IA 50327  
[tkdean11@mchsi.com](mailto:tkdean11@mchsi.com) ♥ 515-254-1125 (fax)

# Drink for a Cure

## Chapter Introduces Fun, New Event to Raise Funds for NMF Conference

The Heart of Iowa Chapter-NMF is branching out its fundraising efforts with a fun, new event designed to broaden the group's target audience. Drink for a Cure, designed after the successful Drink for a Cure events held in Colorado and Illinois, will take place Saturday, May 16, at the Rock Bottom Restaurant & Brewery, in West Des Moines, Iowa.

"This event has been a successful fundraiser for other chapters, so we thought we'd give it a try," explained Teri Dean, chapter president. "Several of our members expressed an interest in an event of this sort and we are hopeful that it will not only attract a wide variety of participants, but raise awareness and funds for Marfan syndrome as well."

The event will feature an appetizer buffet and a beer sampling buffet, complete with a detailed explanation of each beer by the Brewmaster and a tour of the brewing facilities. In addition, the Brewmaster will prepare a special beer just for the event. Participants will also enjoy live music, fun games, a silent auction, and raffle.

Advance admission to the event is \$40/person, and \$50/person at the door. Admission includes the food, beer sampling, a T-shirt and ad booklet.

Hours of the event are 6:00 to 9:00 p.m. Rock Bottom Restaurant & Brewery is located at 4508 University Avenue in West Des Moines, Iowa.

More detailed information will be sent out closer to the event. ♥



### Drink for a Cure

Saturday, May 16  
6:00 to 9:00 p.m.

Rock Bottom Restaurant & Brewery  
4508 University Avenue  
West Des Moines, Iowa

Advance: \$40/person  
At the Door: \$50/person

**Great Food  
& A GREAT CAUSE**

Heart of Iowa Chapter  
of the National Marfan Foundation

You're invited to participate in a  
very special fundraising event!

Orders placed Feb 14 - April 30, 2009  
through the website below by selecting  
"Iowa Marfan Foundation" as the host to  
guarantee credit to the fundraiser.

Contact me for more information.

**TASTEFULLY  
SIMPLE**

Laura Biggart #23853  
515.971.2393 \* [laurabiggart@gmail.com](mailto:laurabiggart@gmail.com)  
[www.tastefullysimple.com/web/biggart](http://www.tastefullysimple.com/web/biggart)

## Note Date Change!



**Moonlight Stroll for Marfan**  
July 17



**Have Heart for Marfan  
Walk-Fun Run**  
July 18

## Join Us!

The Heart of Iowa Chapter-NMF is looking for volunteers to help with our booth at the Iowa School Nurse Organization (ISNO) Annual Spring Conference on April 16, 2009, at Ankeny, Iowa.

### Interested?

Contact Marsha Jones at [iowamarf@hotmail.com](mailto:iowamarf@hotmail.com)

# Heart of Iowa Chapter-NMF Conference Scholarship Application

**Deadline:**  
**April 30, 2009**

**Who is eligible?** The intent of the NMF and Iowa scholarship programs are to sponsor people who, due to financial hardship, would not otherwise be able to attend the NMF conference. In an effort to assist as many people as possible, it is highly unlikely that those who have attended a previous conference or received a scholarship in the past will be awarded a scholarship from the NMF this year. However, these individuals may be eligible for a scholarship from the Heart of Iowa Chapter-NMF. Anyone in need of financial assistance is encouraged to apply for scholarships from *both* organizations.



## How to apply for a scholarship?

1. Complete the NMF application form at [www.marfan.org](http://www.marfan.org). E-mail, fax or mail the completed form to the NMF by **April 30, 2009**.
2. Complete the Heart of Iowa application form. Fax or mail the completed form to the Chapter by **April 30, 2009**.



Name \_\_\_\_\_

Street \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Telephone day \_\_\_\_\_ Telephone evening \_\_\_\_\_

E-mail \_\_\_\_\_



List the persons in your family (for example: myself, my mother, my father, my niece, my daughter etc.) who have already been diagnosed with MFS. Include those not coming to Conference.

List the persons in your family who are suspected of having Marfan syndrome.

So we can best understand your situation, please check off below as many reasons as you wish. I would like to attend the NMF conference so I can:

- See a Marfan doctor at the Conference Marfan Clinic
- Have my child see a doctor in the Conference Marfan Clinic
- Find out the latest in Marfan research and medical management
- Find out how to take care of myself or a family member
- Meet other people who have Marfan syndrome
- Help my child better understand Marfan syndrome
- Have my child meet others with Marfan syndrome

Please check the item below that best describes your situation:

- The doctors in my area understand MFS and I have good medical care.
- I am worried that my doctors may not know enough about MFS to properly take care of me.
- I have some medical problems that no local doctor has been able to help me with.

# Heart of Iowa Chapter-NMF Conference Scholarship Application

If you wish, include a short statement to tell us more about why you want to come to the Conference and/or how you think the Conference can help you.

I have been to Conference in the past.  YES  NO

I have received a Conference scholarship in the past  YES  NO

Number of adults you would like to come to conference with you \_\_\_\_\_

Number of children \_\_\_\_\_

I need help with:

registration (\$300 per adult)

hotel

other

The majority of our scholarships are partial. If you receive a partial scholarship, would you still be able to attend the Conference?

YES  NO  MAYBE

We may call you to get additional information. All information in this application is strictly confidential. You should make your hotel reservations when you send in your registration form. You may cancel the hotel if we are not able to help with expenses in the amount you require. Just be sure and cancel the hotel at least 24 hours before the day of your arrival.

Return this form to **Heart of Iowa Chapter-NMF by April 30, 2009**. Send to: Heart of Iowa Chapter-NMF, 435 Schaffer Boulevard, Pleasant Hill, Iowa 50327 or fax to 515-254-1125. You will be notified of Iowa scholarship assistance by July 1, 2009.



**Plan to Attend 25th Annual NMF Conference**  
**August 6-9, 2009 ♥ Mayo Clinic, Rochester, Minnesota**  
***Join or Renew Your NMF Membership and Save!***

**T**ake advantage of the special conference member registration fee. Become a NMF member or renew your membership and save up to \$125 off the individual conference registration fee! Join or renew online at [www.marfan.org](http://www.marfan.org) or mail your check (\$35 individual; \$50 family) to NMF, 22 Manhasset Ave., Port Washington, NY 11050.

If you are unable to afford the basic membership fee due to financial hardship, please contact Amy Kaplan at 800-8-MARFAN, ext. 26.♥

# Support American Heart Association & NMF



Purchase a Swarovski Crystal Red Dress Pin (1.25 inches high) to help underwrite the expense for a child with Marfan syndrome to attend the National Marfan Foundation's 25th Annual Conference at Mayo Clinic in Rochester, Minnesota, August 6-9, 2009.

only **\$15.00**

If you would like to order a pin(s), contact Teri Dean:  
515-263-1948 ♥ [tkdean11@mchsi.com](mailto:tkdean11@mchsi.com)

## Recipes from the Heart

### *Member Creates Recipe Book to Raise Funds for NMF Conference*

**M**arsha Jones has spent the last few months feverishly working on a large project to support a cause close to her heart - Marfan syndrome. Jones, leader of the Eastern Iowa NMF Network and a Heart of Iowa Chapter board member, came up with the idea to create a personalized cookbook last fall. Since that time, she single-handedly coordinated the project from inception to completion.

The recipe book features nearly 700 mouth-watering recipes from around the world. Most of the recipes came from Jones' family, friends, and people she's met in the Marfan community.

"I'd like to extend a special thanks to those who helped me compile this collection of recipes," said Jones. "Each person who contributed has had a direct impact on my life and for that I'm eternally grateful."

The book also includes valuable information about Marfan syndrome. All proceeds will go toward the 2009 NMF Conference or Iowa Conference Scholarship Fund. "I hope this book will be enjoyed by many and will be passed along for generations to come," added Jones.

Order your copy of *Recipes from the Heart* for just \$20, plus \$2.50 s & h. ♥


### ***Recipes from the Heart* ♥ Order Form**

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

	X	\$20 =		
_____			_____	
# Books				
_____	X	\$2.50 =	_____	
# Books		s & h		
<b>GRAND TOTAL</b>			_____	



My check is enclosed. *Payable to Heart of Iowa Chapter-NMF.*

Bill my credit card.     Visa     MC     AMEX     Disc

Card # \_\_\_\_\_ Exp. Date \_\_\_\_\_

Signature \_\_\_\_\_

*Mail to: Marsha Jones, 1779 Larch Avenue, Wellman, IA 52356*

# Help Support Heart Mart

## *Raffle Supports NMF Conference Scholarship Fund*

**H**earth Mart, a raffle featuring heart-themed items, is an annual conference tradition that allows members and friends to express their creativity while raising funds to support the NMF conference Scholarship Program.

### ***What is Heart Mart?***

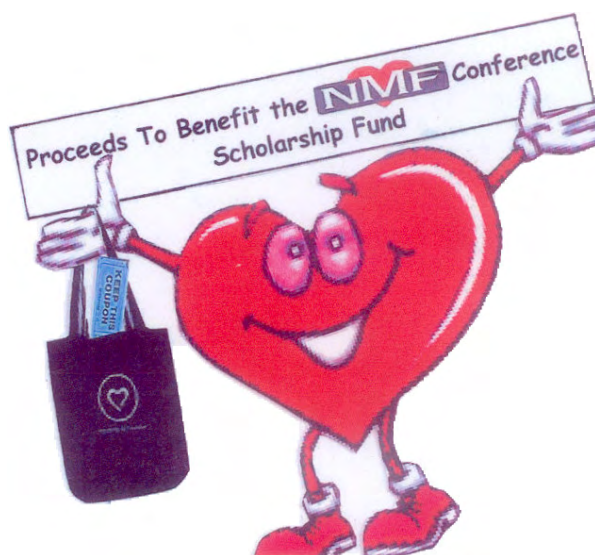
Heart Mart is a "Chinese Auction." Throughout the conference, attendees have the opportunity to view the donated items and purchase raffle tickets. They "bid" by placing a ticket in the container that is numbered the same as the item(s) they wish to win. They can enter each drawing as many times as they'd like. Winners are drawn at 5:00 p.m. on Saturday, August

8, and prizes are claimed that evening or on Sunday, August 9.

This year, our goal is to raise \$12,000. With the support of the Iowa and Minnesota Marfan communities, we remain hopeful that this goal can be reached.

### ***How to Help***

In order to reach our goal, we are asking you to consider donating items to be included in the Heart Mart. Donated items should be new, and possibly have a heart theme or be red in color. Creativity is always welcome!



Consider asking someone creative you know to make jewelry, cards, quilts, etc. for Heart Mart. Gift cards to national chains are also great.

In addition, we are looking for several "larger" prizes for the raffle. Ideas include: IPODs, digital cameras, GPS navigation systems, video game systems, and computers. Autographed sports memorabilia and tickets to sporting events also remain popular. Iowa-themed items would also be fun to include at Heart Mart. Use your imagination!

### ***Where to Send Items***

Send Heart Mart items to Kari Dostalick by July 15, 2009.

Kari Dostalick  
8211 Goodman Drive  
Urbandale, IA 50322  
[kdostalick@msn.com](mailto:kdostalick@msn.com)

Donations will also be accepted on-site during the NMF conference August 6-7. ♥

### **How would you like to help raise money to go toward the Annual NMF Conference without having to wash cars or sign up for a magazine subscription?**

In April, the Heart of Iowa Chapter-NMF is hosting a Pampered Chef fundraiser! It's so easy! First, check out the catalog online at [www.pamperedchef.biz/hjhoug](http://www.pamperedchef.biz/hjhoug) and do your shopping starting April 1st. You can have your order shipped directly to your door or have it sent to Teri Dean, the fundraiser coordinator (if you live in the Des Moines area).

In addition to purchasing something for yourself, Pampered Chef items make great gifts for weddings, bridal showers, Mother's Day, graduation, and more! Spread the word to your friends, family, co-workers, etc. about this fundraiser by sending them an e-mail that tells them about our cause! Let Teri Dean know if you'd like a catalog to pass around as well.



Place your orders April 1-30

[www.pamperedchef.biz/hjhoug](http://www.pamperedchef.biz/hjhoug)

# NMF Network Group of Omaha Update

The Network Group of Omaha continues to grow. The group met in January to discuss the Emergency Room Information Packet created by the National Marfan Foundation, to plan events for the upcoming year, and to enjoy one another's company.

The group's next meeting will feature Dr. Shushma Rai, an eye specialist at the University of Nebraska Medical Center. Dr. Rai will discuss eye concerns as they relate to Marfan syndrome. The meeting will take place on Saturday, March 21, at 1:00 p.m. in the Monroe-Meyer Institute,

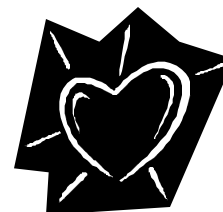
4420 Dewey Ave., Conference Room 1027.

On May 16, Dr. Ali Khoynzhad, a board certified University of Nebraska Medical Center cardiovascular surgeon, will meet to collaborate with the group on how to improve the outcome of patients with Marfan syndrome. Dr. Khoynzhad specializes in open and endovascular repair of various aortic diseases.

Future group plans include presentations by an emergency room technician or doctor and a registered dietician, as well as a picnic

and the Younkers Community Day fundraiser in the fall.

For additional information on the Omaha Network Group, contact Sherry Heldt at [roshawco@hotmail.com](mailto:roshawco@hotmail.com). ♥



---

## Welcome Stephanie DeJong

### *Newest Board Member Brings Enthusiasm to Position*

Stephanie DeJong got involved with the Heart of Iowa Chapter-NMF shortly after her son, Matthew, was diagnosed with Marfan syndrome in January 2008. "We knew something was different with Matthew because his skin was so soft and he was able to bend his fingers every which way at a very young age," explained DeJong. "Matthew also had a stroke either right at birth or shortly after, so our local Area Education Association followed him for a year to make sure he was hitting all of his milestones." A physical therapist suggested they follow up with an Orthopedist to evaluate Matthew for scoliosis.

"Two years ago, we were at our yearly checkup with the Orthopedist when I finally asked about his flexible fingers," reflected DeJong. "He referred us to the Genetics Clinic at Iowa City." Matthew wasn't evaluated for Marfan syndrome until his second appointment one year later.

"I am so grateful that the National Marfan Foundation has such an informative website and that there was a

local chapter for my family to join," stressed DeJong. "I want to make sure Matthew understands that he is not the only one who can't do all of the things (such as contact sports) that he really loves to do."

DeJong decided to join the board of directors to get more involved in the Marfan community and to help "get the word out" about Marfan syndrome. She and her husband, Michael, also have an 8-year old son, Nicholas. DeJong works at Pella Corporation in the Corporate Accounts division. Outside of work, she enjoys scrapbooking, walking, riding bikes, going to movies, shopping with friends, baking, and spending time with family.

"I am so glad that I decided to get involved in the Heart of Iowa Chapter-NMF," concluded DeJong. "I have learned so much about my son's disorder thanks to this group. Meeting others affected with Marfan syndrome or those



*Stephanie DeJong*

with affected family members has also been very helpful. It lets me know that we aren't the only family going through this." ♥

### Want to stay informed?

Join the Heart of Iowa Chapter-NMF e-mail database!

Receive timely updates, volunteer opportunities and more!

**E-mail:**

**[tkdean11@mchsi.com](mailto:tkdean11@mchsi.com)**

Type "Heart of Iowa Chapter-NMF" in the subject line.



435 Schaffer Boulevard  
Pleasant Hill, Iowa 50327  
Phone: 515-263-1948  
Fax: 515-254-1125



We're on the Web!

[www.heartofiowa.org](http://www.heartofiowa.org)

If you would like to be removed from our mailing list or change your address e-mail [tkdean11@mchsi.com](mailto:tkdean11@mchsi.com).

## Heart of Iowa Chapter-NMF Membership Form

Annual membership dues help cover printing and mailing costs associated with the *heart happenings* newsletter, published quarterly. Dues are just \$10 for a single and \$15 for a family membership. Thank you for your support!

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

E-Mail \_\_\_\_\_

### Mail Form & Payment to:

Heart of Iowa Chapter - NMF  
c/o Teri Dean  
435 Schaffer Boulevard  
Pleasant Hill, Iowa 50327

### BOARD of DIRECTORS

Our board members represent central, eastern and western Iowa. Feel free to contact us with any questions, suggestions, or to volunteer for any of our activities. We'd love to hear from you!

**Teri Dean, President**  
515-263-1948  
[tkdean11@mchsi.com](mailto:tkdean11@mchsi.com)

**Stella Lane, Treasurer**  
515-371-0082  
[stella44446@yahoo.com](mailto:stella44446@yahoo.com)

**Kari Dostalick, Secretary**  
515-252-1892  
[kdostalick@msn.com](mailto:kdostalick@msn.com)

**Sherry Heldt, Member at Large**  
402-932-4504  
[roshawco@hotmail.com](mailto:roshawco@hotmail.com)

**Marsha Jones, Member at Large**  
319-461-4228  
[iowamarf@hotmail.com](mailto:iowamarf@hotmail.com)

**Stephanie DeJong, Member at Large**  
641-628-8438  
[dejongSK@Pella.com](mailto:dejongSK@Pella.com)