

heart happenings

Heart of Iowa Chapter - National Marfan Foundation

Join Us at the Have Heart Walk-Fun Run & Moonlight Stroll for Marfan

Everyone is encouraged to participate in the Heart of Iowa Chapter's annual fundraiser – the Scott Keifer "Have Heart for Marfan" Walk-Fun Run – Labor Day weekend.

Walk-Fun Run

The 7th annual walk-fun run will take place **Saturday, September 1st** in conjunction with the Pleasant Hill Labor Day Festival. This family-friendly event features a 2K walk, 6K and 10K runs and a youth fun run, in addition to several kids' activities. Participants will also have the opportunity to bid on over 20 themed baskets during the silent auction. Following the Saturday morning event, individuals are welcome to join the Chapter on its float during the Labor Day parade.

Moonlight Stroll for Marfan

This year, the Chapter is introducing another new event – the Moonlight Stroll for Marfan. This fun event will help kick-off the festivities on **Friday, August 31** at 9:00 p.m. Each participant will receive a goody bag and refreshments will be served following the leisurely stroll around Copper Creek. Silent auction baskets just for this event will be up for bids as well. In addition, free childcare for children 10 and under will also be available.

Proceeds

Proceeds from both events will support Marfan research, in addition to the National Marfan Foundation's Emergency Room and Pediatric Awareness campaigns. Individual donations may also be designated toward the 2009 NMF Conference, to be held in Rochester, Minnesota.

Get Involved

If you are unable to attend, there are still plenty of ways to get involved, such as donating items for silent auction baskets or raising additional funds for the event. Every little bit helps. For tips on an easy way to raise \$250, turn to page 2.

Registration

Additional information and the registration form for both events is included in this newsletter.

Accommodations

Discounted rooms are available at the Pleasant Hill Sleep Inn. Call 1-515-299-9922 for reservations.♥



2007
Summer

Volume 4, Issue 2

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Dates to Remember

- **August 31**
"Moonlight Stroll for Marfan" around Copper Creek Lake
- **September 1**
Scott Keifer "Have a Heart for Marfan" Walk-Fun Run
- **October 13-14**
Maze for Marfan



Teri Dean

Teri's Tidbits

the diagnosis to "Wow! There is concrete hope because of the research that the Foundation helped pioneer."

In addition, we've gone from absolutely no recognition in the national media to segments on NBC's "TODAY" show, the movie "MO," a documentary filmed at this year's conference that hopefully will be aired on the Discovery Channel, as well as coverage in several national print publications, including *The Wall Street Journal*.

The research surrounding Marfan syndrome has helped so many individuals, including those with other disorders, such as Duchenne muscular dystrophy. Any type of aortic aneurysm disease now seeks knowledge from our research and, just recently, research has discovered that a condition frequently diagnosed as Marfan syndrome – Ehlers Danlos Vascular Type IV – is really Loey's Dietz. Look for additional information on this subject in the next newsletter.

All of the education, extended family connections, laughter and most importantly, HOPE we currently have would not be possible without the National Marfan Foundation (NMF).

The NMF currently serves over 28,000 households in its database. However, only about 2,300 of these households actually support the NMF. During the past two years, the foundation has steered all of their large donors toward the Losartan clinical trial to ensure that this research happens, leaving very little funding to maintain all of the

programs that they currently have in place. This organization has the least amount of administrative costs for the programs they administer in the not-for-profit world. That says something about the commitment the NMF staff makes to each and every one of us, as well as our families.

My message is this...please, in any way you can, support the National Marfan Foundation so their work may continue. Become a paid member, make a small donation, use your United Way dollars (you can designate the National Marfan Foundation to be your recipient of those funds), or use your employer matching dollars.

Provide me with contacts at your place of employment so we can request that America's Charities be added to the options for donating funds. Use the Internet search options goodsearch.com and igive.com. Goodsearch gives the NMF \$.01 for each legitimate use. At igive.com, retailers donate a percentage of your purchase to your designated charity. This week alone, the merchants I purchased from online donated \$11.86 to the NMF.

Stay on top of your legislators to ensure that funding is made available through the National Institute of Health (NIH), Center for Disease Control (CDC), and the National Heart, Lung, and Blood Institute (NHLBI). There are many ways to provide financial support to the NMF. Every dollar is important. Any amount can make a difference. ♥

Many moons have passed since our last newsletter. We try really hard to put out a newsletter and keep in touch with everyone on a consistent basis, but sometimes life just gets in the way. We all have jobs, families, volunteer for other organizations and have other influences in our lives, and aren't always able to keep up. But we will continue to do our best and work on more frequent communication. We welcome any help!

In mid-July, I had the pleasure to attend the 23rd Annual National Marfan Foundation Conference in San Francisco, California. Talk about an emotional roller coaster! I remember when the Foundation was run by two volunteers in the bedroom of Priscilla Ciccariello – one of the most influential individuals in the layman's medical world.

The amount of work and advances the NMF has accomplished during that time is mind-boggling. We have gone from most people not recognizing the word "Marfan" to, "I know I've heard that term, but don't remember exactly what it is." We have gone from feeling like we received a "death sentence" with

How to Raise \$250 in One Week!

Day 1:	Start by sponsoring yourself for \$25	\$ 25.00
Day 2:	Ask one family member to sponsor you for \$25	\$ 50.00
Day 3:	Ask five friends to contribute \$20 each	\$150.00
Day 4:	Ask five co-workers to contribute \$10 each	\$200.00
Day 5:	Ask five neighbors to contribute \$5 each	\$225.00
Day 6:	Ask your boss for a company contribution of \$25	\$250.00
Day 7:	Check to see if your company offers matching gifts	\$BONUS



Join Us at the Maze for Marfan

Iowa Corn Maze Raises Awareness & Funds for Marfan Syndrome

Come join us October 13 at the Maze for Marfan syndrome at Geisler Farms!

"Geisler Farm's mission is to provide families with a fun, affordable experience at the farm," stressed Malinda Geisler, executive vice president, Geisler Farms Inc. "We are thrilled to once again team up with the Heart of Iowa Chapter-NMF for this fun family event!"

How does it work?

Geisler Farms is offering the Heart of Iowa Chapter-NMF two ways to raise funds. First, members can volunteer their time at the maze in exchange for \$8 per hour for the chapter. "When you volunteer, you also have the chance to experience the maze free of

charge," added Geisler.

She predicts the busiest dates will be October 6-7; 13-14; and 20-21. Members may work a two-, four-, or six-hour shift. Positions available include selling tickets, concessions, pumpkin sales and distributing maze maps.

Geisler added, "To say 'thanks' for your tremendous support, Geisler Farms will also donate \$1 per admission on Saturday, October 13 to the Heart of Iowa Chapter-NMF. Last year, we had more than 500 visitors on that comparable Saturday."

Last season, Geisler Farms paid the Heart of Iowa Chapter-NMF over \$1,200. This year, the chapter plans to earmark the funds toward the 2009 NMF Conference, which



The NMF's Jonathan Martin & Haley Dostalik peer through the corn maze at Geisler Farms.

will be held just north of Iowa, in Rochester, Minnesota.

How do I sign up?

Complete the form below and fax it to 515-254-1125. Contact Kari at kdostalik@msn.com or 515-252-1892 if you need additional information or are interested in volunteering at the maze. ♥

Volunteer to Work at the Maze!

Name(s) _____

Address _____

City _____ State _____ Zip _____

E-Mail _____

Phone _____

Please Check All That Apply:

I can work the following date(s):

- October 6-7 October 13-14 October 20-21

I prefer to work the following shift length:

- 2-hour 4-hour 6-hour

Please mail this form by Sept. 24, 2007 to:
Kari Dostalik; 8211 Goodman Drive, Urbandale, Iowa 50322
Fax to: 515-254-1125
Questions? E-mail Kari at kdostalik@msn.com



What are the benefits?

This fundraiser offers the Heart of Iowa Chapter-NMF several benefits, such as:

- Easy fundraising that does not require any setup. Just travel to the farm and volunteer your time and enthusiasm!
- Only maze-related event like this in Central Iowa, making it a unique, fun event to draw people.
- Opportunity to interact with the public and to teach them about Marfan syndrome.

Clinical Trial Update

By Priscilla Ciccariello

This year marks the beginning of the most promising research undertaken on behalf of people with Marfan syndrome. Up to this point, the use of Beta Blockers and ultimately surgery has remained the primary response to cardiovascular complications. We are now looking at the possibility of arresting these cardiovascular complications and perhaps even reversing them in some cases.

Although we know that Losartan has been safe and effective over many years in reducing high blood pressure in the general population, we will not know for sure how this drug works with people with Marfan syndrome in reducing the deterioration and/or enlargement of the aorta, versus the use of a Beta Blocker, until we complete this three year study. This is what the clinical trials will demonstrate.

We in the Marfan community have never had such a promising opportunity. We are thankful to our NMF Professional Advisory board member and researcher, Dr. Hal Dietz, of Johns Hopkins, for his steadfast and brilliant research for over 20 years, which has brought us to this point.

It is not often that we, as individuals, can participate and contribute to the effort to better the lives of people. Now is our opportunity to 1) support the current research trials financially by our membership to the NMF, and 2) participate in these trials. If each of us sends

in our NMF membership dues we will be able to meet the added financial demands of additional studies called "Ancillary Studies" to these trials, which will benefit all with Marfan syndrome beyond the scope of the initial drug therapy. I also encourage you to find out if you qualify for the trials and receive the benefit of this community undertaking.

This research and the interest of the National Heart, Lung, and Blood Institute (NHLBI) represent many millions of dollars invested by the National Institutes of Health – more research money than the NMF could have undertaken itself. Also, these trials would not have been accomplished without the dedication of and impressive research on the part of Dr. Dietz and his colleagues.

Yet, the National Marfan Foundation, by its impressive membership and support of research over the past 25 years, has played a major role in this effort by throwing the spotlight on the lives of people who have this condition and who must individually deal with its complications and sometimes tragic results. As we gather together, we gain the support of one another. We must continue to work together to bring the promise of this research to everyone with Marfan syndrome.

The Clinical Trial

The trial is funded by the National

Institutes of Health (NIH), National Heart, Lung and Blood Institute and will be conducted by the Pediatric Heart Network. The trial will study the growth of the aorta in two different groups of people. One group will take Losartan and the other will take Atenolol (a Beta Blocker). Everyone in the trial will take one medication or the other.

This core trial is only studying the possible effect of Losartan versus Atenolol on the growth of the aorta. The NMF is working with NIH and private donors to find funding for trials that can study possible effects of Losartan on other body systems including the lungs, bones, muscles and eyes.

This NMF Clinical Trial Initiative hopes to raise enough money to fund ancillary trials, which can include the same people who participate in the core trial. Conducting the core and ancillary studies at the same time offers a unique opportunity for comprehensive study of the effects of Losartan on Marfan syndrome features.

For additional information on the clinical trial, visit www.marfan.org or contact the St. Louis clinical trial site at:

Washington University
Dr. Angela Sharkey
& Dr. Alan Braverman
Coordinator: Cheryl Rainey
314-747-6794
cherylr@twins.wustl.edu

Chapter Member Represents Iowa at National Spelling Bee

Congratulations to Taryn Shaw, a fifth-grade student at Eddyville Elementary School in Oskaloosa, Iowa. Taryn represented Iowa at the national Spelling Bee contest, sponsored by Scripps Howard, in Washington, DC, at the end of May. Taryn and her family, regular participants in the Have Heart Walk-Fun Run, are members of the Heart of Iowa Chapter. Way to go, Taryn!!! ♥



Taryn & family at the Walk-Fun Run.

Omaha Network Group Nears One Year Mark

By Sherry Heldt, Omaha Network Group Leader

In July, the NMF Network Group of Omaha held a meeting at the Denny's Restaurant in Omaha. Dr. G. Bradley Schaefer, director of the Genetic Department at the University of Nebraska Medical Center, served as our guest speaker.

Dr. Schaefer opened with a round table discussion about the genetic factors of Marfan syndrome; the two drugs currently being studied (Losartan and Doxycycline); as well as the Losartan clinical trial.

He also spoke about diagnosing Marfan syndrome and the current blood test used to determine Marfan syndrome - the effectiveness of the test, how it is done, the cost, insurance issues, etc..

In addition, he shared the exciting news that the University of Nebraska Medical Center plans to open a Marfan clinic in the next year or so. They are currently putting together a team of experts.

Dr. Schaefer also addressed some of our concerns, and provided information on doctors and surgeons who treat patients with Marfan syndrome in the area.

Heart of Iowa Chapter Update

Teri Dean, president of Heart of Iowa Chapter-NMF and current NMF board member, made a special trip to Omaha to attend our meeting with Dr. Schaefer. Teri shared information about upcoming chapter events, including the Walk-Fun Run and corn maze. She also updated the group on the latest news from the National Marfan Conference held in Palo Alto, Calif.

Future Meetings

Our next meeting will be a barbecue at a local park in Omaha on Saturday, Sept. 22. It will be a potluck with the Omaha Network Group providing the meat. This will give us a chance to relax and get



Dr. G. Bradley Schaefer & Dr. Mary Lou Flearl attend the July meeting.

to know each other better. We will also celebrate our one year anniversary since our Network group formed, Yeah! We did it!!

On Saturday, Nov. 17, we will meet at Hattie B. Munroe Center across from UNMC. Dr. Schaefer has graciously offered us a room at Munroe to hold our meetings. We will discuss our fund raiser at Barnes and Noble for December to raise funds for the NMF.

For additional information, contact Sherry Heldt at roshawco@hotmail.com ♥

Eastern Iowa Network Update

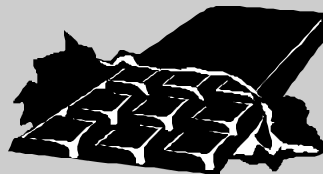
By Marsha Jones, Eastern Iowa Network Group Leader

In February, the Eastern Iowa NMF Network Group joined the Northern Illinois Chapter in selling candy bars. The group sold 400 candy bars in area businesses, doctors' offices and waiting rooms - even a hospital room!

In March, several members from Illinois and Iowa joined the Heart of Iowa Chapter to listen to a presentation by Dr. Hal Dietz on the latest advances in Marfan research and the Losartan clinical trial.

November will bring an informative get-together covering "Must-Have Medical Awareness." The group discussion will include emergency awareness for individuals and area hospitals, doctor choices, the hospital interview, as well as the NMF Emergency Room Awareness Campaign.

For additional information on the Eastern Iowa Network Group, contact Marsha at iowamarf@hotmail.com. ♥



Stay Informed!

Join the Heart of Iowa Chapter E-Mail Database

- Receive timely e-mail updates and notices
- Help the Chapter save mailing costs



E-mail Teri at tkdean11@mchsi.com to get added to the list!



435 Schaffer Boulevard
Pleasant Hill, Iowa 50327

Phone: 515-263-1948
Fax: 515-254-1125
tkdean11@mchsi.com



We're on the Web!
www.heartofiowa.org

If you would like to be removed from our mailing list or change your address e-mail tkdean11@mchsi.com.

Dietz Brings Message of Hope to Iowa

In March, the Heart of Iowa Chapter arranged for Dr. Hal Dietz to visit Des Moines for a medical education program on March 30 and a session for the general public on March 31. Over a dozen medical physicians attended the medical presentation, while 50 people attended the consumer discussion. For many, it was their first time attending a chapter event.

Dietz shared his research with Marfan mice and the hope Losartan that holds for the Marfan community. The Chapter is grateful to Dr. Dietz for all he has accomplished and for taking time to share his message in Iowa. ♥



Dr. Hal Dietz shared his Marfan research advances with the group in March.



Left: Hal Dietz, MD, and Teri Dean.

Lower Left: Pam Austin and Bev Kiefer reconnect.

Lower Right: Hal Dietz, MD, and Haley Dostalik.

