



THE NATIONAL MARFAN FOUNDATION CONFERENCE TURNS 25!

The National Marfan Foundation is pleased to present its 25th Annual Conference on Marfan Syndrome and Related Disorders at Mayo Clinic in Rochester, MN, August 6-9, 2009.

This is a very special year for the conference—it's our 25th and we're partnering with Mayo Clinic for the first time. Join the Marfan syndrome and related disorders community for four days of exceptional activities including a comprehensive clinic for patient assessment sponsored by Mayo Clinic, medical workshops presented by world-renowned experts, and special programs for your children and teens. You will also have the opportunity to make new friends and share your experiences with each other at the Friday evening state fair-themed Welcome Reception and other informal social gatherings.

The NMF is grateful to our members in the Twin Cities Minnesota Chapter and the Heart of Iowa Chapter for their support and hard work in making the conference possible this year.

Join us in Rochester, August 6-9!

CONFERENCE CO-HOST: Marfan and Thoracic Aortic Clinic at Mayo Clinic Rochester

Since 1959, more than 3,600 patients from all walks of life have found answers to Marfan syndrome-related questions at Mayo Clinic in Rochester, Minnesota. The Marfan Clinic, established in 2002, offers an integrated medical, genetic and surgical approach to the diagnosis and treatment of Marfan syndrome and related disorders. Heidi Connolly, MD, member of the NMF's distinguished Professional Advisory Board and co-director of Mayo Clinic's Marfan Clinic with Thoralf M. Sundt, III, MD, looks forward to welcoming you to Rochester.

CONFERENCE PROGRAM AT-A-GLANCE

Thursday, August 6

By appointment* Medical Testing at Mayo Clinic

Friday, August 7

By appointment* Patient Assessments at Mayo Clinic

1:00 – 5:00 PM Registration

4:00 – 5:00 PM Orientation for First-Time Attendees

5:30 – 7:00 PM Welcome Reception, Rochester Art Center

Saturday, August 8

8:00 – 10:00 AM Registration

8:30 – 12:30 PM General Session

12:45 – 1:45 PM Lunch

2:00 – 5:30 PM Afternoon Workshops

7:00 – 9:30 PM Awards Dinner

Sunday, August 9

8:00 – 9:00 AM Registration

8:30 AM – 12:45 PM Workshops

1:00 – 3:00 PM Farewell Lunch, Living Successfully Program

**for registered conference attendees only.*

Final program subject to change.



PATIENT ASSESSMENTS

Patient assessments are sponsored by the Marfan and Thoracic Aortic Clinic at Mayo Clinic Rochester. The clinic provides comprehensive, multidisciplinary care to people of all ages living with Marfan syndrome and related conditions. In addition to physicians and specialists from Mayo Clinic, medical practitioners from the NMF Professional Advisory Board will participate. Appointments are limited and priority will be given to first-time conference attendees who need assistance with diagnosis or ongoing management and lack access to specialty care at home. *You must be a registered conference attendee to qualify for a patient assessment.*

Echocardiograms & Ophthalmology exams: Thursday, August 6
Consultations & Evaluations: Friday, August 7

Request an appointment packet:

E-mail: marfan2009@mayo.edu
Telephone: 507-284-3518
(leave a message with name, address & phone)
Fax: 507-538-4749

Contacts:

Susan M. Nelson
Site Coordinator, NMF 2009 Conference

Caroline A. Arpin, R.N.
Clinic Coordinator, NMF 2009 Conference

Deadline for appointments: June 1, 2009
(Participants will be notified of appointments by June 15, 2009)

CHILDREN'S PROGRAM (ages 5–12)

Friday, August 7

Meet other children ages 5–12 at the official conference Welcome Reception.

Saturday, August 8

Have fun visiting the Quarry Hill Nature Preserve, enjoying a magic show, watching movies, playing games and doing art projects together.

Sunday, August 9

Dr. Jessica Davis, geneticist from New York-Presbyterian/Weill Cornell Medical Center, will answer your questions about Marfan syndrome and related disorders.

Children's registration closes Monday, July 15
(sorry, no on-site registration)



GENERAL SESSION—SATURDAY, AUGUST 8

Something new at Mayo! This year, medical professionals participating in Mayo Clinic's Continuing Medical Education (CME) program will join you at the general session. CME information is available online at mayo.edu/cme or email cme-jax@mayo.edu.

Topics:

Is It Marfan Syndrome or Something Else?

Presenter: Dianna Milewicz, MD, PhD, University of Texas Medical School, Houston

Genetic Testing: Is It Right for Me?

Presenter: Peter Byers, MD, University of Washington School of Medicine, Seattle

Orthopedic Challenges in Marfan Syndrome and Related Disorders

Presenter: Paul Sponseller, MD, Johns Hopkins Hospital

Echos, CTs and MRIs—What's the Difference?

Aortic Imaging in Marfan Syndrome and Related Disorders

Presenter: Heidi Connolly, MD, Mayo Clinic Rochester

Medical Treatment Options for Marfan Syndrome and Related Disorders: A Research Update

Presenter: Hal Dietz, MD, Johns Hopkins University School of Medicine

What are the Options for Aortic Surgery in Marfan Syndrome and Related Disorders? What are the Results?

Presenter: Thoralf M. Sundt, III, MD, Mayo Clinic Rochester

TEEN PROGRAM (ages 13–19)

Friday, August 7

Following a teen welcome session, learn about self-image and photography from acclaimed photographer Rick Guidotti and get your weekend photo project. Attend the official conference Welcome Reception, then spend the evening sharing experiences in a *Living Successfully* program.

Saturday, August 8

Start the day with breakfast with Dr. Hal Dietz, the renowned Johns Hopkins Marfan syndrome researcher, followed by a session focusing on *Coping with Loss*. Enjoy an afternoon boat ride on the Mississippi River, have dinner together at a local restaurant, and spend the evening playing games and dancing.

Sunday, August 9

Learn *How to be Your Own Advocate* from NMF board member Chris Heaney, enjoy game time and take part in art projects. Wrap it all up at the adult *Living Successfully* session and luncheon.

Teen registration closes Monday, July 15

(sorry, no on-site registration)

YOUNG ADULTS (20 & 30-SOMETHINGS)

If you are in your 20s or 30s, meet your peers at the Friday evening Welcome Reception. Join in activities for this age group and take part in the Young Adults support group on Sunday.

DO YOU HAVE A RELATED DISORDER?

The NMF conference is for you, too! Providing support for those affected by Familial Aortic Aneurysm (FAA), Loeys-Dietz syndrome (LDS), and other related disorders is an important part of the NMF mission. Related disorders will be addressed in special workshops as well as in workshops addressing specific body systems.

CONFERENCE SCHOLARSHIPS

The NMF Conference Scholarship Program provides registration fee waivers and assistance with hotel accommodations for individuals and families with financial need. Priority is given to first-time conference attendees. **Applications must be received at the NMF office no later than May 15.**

Request an application by email at conference@marfan.org or call 800-8-MARFAN, ext.36 (leave a message).

Workshops: Saturday, August 8		
2:00–3:00	3:15–4:15	4:30–5:30
A1 Cardiac Concerns	A2 Post Dissection Cardiac Concerns	A3 Cardiac Concerns
B1 Aortic Surgery Options	B2 Vascular Surgery: Aneurysms Affecting Vessels other than the Ascending Aorta	B3 Aortic Surgery in Children and Teens
C1 Pediatric Issues	C2 Dental Issues	C3 Pediatric Cardiac Issues
D1 Pectus Management	D2 Orthopedic Issues	D3 Pediatric Orthopedic Issues
E1 Podiatric Issues	E2 Pre-conception, Pregnancy and Post-partum Cardiovascular Management and Related Issues	E3 Non-surgical Approaches to Dural Ectasia and Back Pain
F1 Ocular Issues, General	F2 Ocular Corrections and Visual Rehabilitations	F3 Open
G1 Genetic Testing Limits/Benefits	G2 Pulmonary Issues	G3 Planning a Family: Preimplantation Genetics, Genetic Diagnosis, Adoption
H1 Loeys-Dietz Syndrome Introduction	H2 Loeys-Dietz Syndrome: Vascular Surgery in LDS	H3 Open
I1 Pain Management Adults/Pediatrics	I2 Growing Older with Marfan Syndrome	I3 Cardiac Imaging: Understanding Your Imaging Studies & Z-score
J1 Marfan 101	J2 Radiology	J3 Complementary Medicine
K1 Exercise and Staying Fit	K2 Related Disorders (other than LDS)	K3 Sleep Apnea

PARTICIPATE IN MARFAN SYNDROME CLINICAL TRIAL

Your child can be part of a critical clinical trial studying the effects of the drugs atenolol and losartan on the aorta in Marfan syndrome. Designed for people between the ages of six months and 25 years, the trial is currently underway at sites in the U.S. and Canada. Visit the clinical trial exhibit at the conference for additional information. Details are also always available by calling the NMF at 800-8-MARFAN, Ext. 22, or logging on to www.marfan.org.



Workshops: Sunday, August 9		
8:30–9:45	10–11:15	11:30–12:45
A4 Coping with Marfan Syndrome	A5 Coping with Marfan Syndrome	A6 Coping with Related Disorders
B4 Communicating with Your Doctors	B5 Coping with Loeys-Dietz Syndrome	B6 Developing your Emergency Plan
C4 Communicating with Your Child's School	C5 Facing Cardiovascular Surgery (guided imagery)	C6 Transitioning to Adult Care
D4 Preparing Your Child for Surgery	D5 Support Group for Parents of Teens	D6 Support Group for Mothers
E4 Support Group for Couples	E5 Support Group for Unaffected Spouses and Significant Others	E6 Support Group for Fathers
F4 Non-Operative Management for Musculoskeletal Issues	F5 Facing Orthopedic Surgery	F6 Support Group for Young Adults (20s and 30s)
G4 Becoming an NMF Volunteer	G5 Fundraising for the NMF	G6 Should You Participate in a Research Study?
H4 Medical Insurance/Disability Issues?	H5 Options for Home INR Monitoring	H6 Pilates and Connective Tissue Disorders
I4 Positive Effects of Massage and Physical Therapy for Marfan Syndrome	I5 Gentle Chair Yoga	I6 Open

REGISTER ONLINE AT WWW.MARFAN.ORG

CONFERENCE REGISTRATION FORM

please complete both sides

SUMMARY OF ATTENDEES		Prefix	First Name (as will appear on badge)	Last Name	Email Address
Adults (19+) in Party	Adult #1				
	Adult #2				
Child 5-12 or Teen 13-19 in Party	Child/Teen #1				
	Child/Teen #2				
	Child/Teen #3				

Children and teens must be accompanied by a registered adult.

Please provide the information requested below and on the reverse for each person in your party. Please circle selections where applicable.

Adult # 1 (as listed above)	Address 1:	Address 2:	City:	State:	Zip:
	Country:	Home Phone:	Work Phone:	Is this your first conference?	YES NO
	Affected with Marfan:	YES NO Maybe	List any Related Disorders:	Do you use a wheelchair?	YES NO
Adult # 2 (as listed above)	Include my contact info on network list to be distributed at conference YES NO				
	Workshop Choices				
	Meal preferences:	Regular	Vegetarian	Saturday Session 1:	Sunday Session 4:
	Will attend:	Friday Reception:	YES NO	Saturday Awards Dinner:	YES NO
		20-30 Something Activities:	YES NO	Saturday Session 2:	Sunday Session 5:
	Address 1:	Address 2:	City/State:	State:	Zip:
		Country:	Home Phone:	Work Phone:	Is this your first conference?
	Affected with Marfan:	YES NO Maybe	List any Related Disorders:	Do you use a wheelchair?	YES NO
	Include my contact info on network list to be distributed at conference YES NO				
	Meal preferences:	Regular	Vegetarian	Saturday Session 1:	Sunday Session 4:
Will attend:	Friday Reception:	YES NO	Saturday Awards Dinner:	YES NO	
	20-30 Something Activities:	YES NO	Saturday Session 2:	Sunday Session 5:	
Saturday Session 3:					
Saturday Session 6:					
form continues on reverse					

CONFERENCE REGISTRATION FORM

please complete both sides

Child/Teen #1 <small>(as listed on reverse)</small>	Age: _____	Is this your first conference? YES NO	Include my contact info on network list to be distributed at conference: YES NO
	Affected with Marfan: YES NO Maybe	List any Related Disorders: _____	Do you use a wheelchair? YES NO
	Will attend : Friday reception: YES NO Saturday program: YES NO Sunday program: YES NO		Meal preferences: Regular, Vegetarian
Child/Teen #2 <small>(as listed on reverse)</small>	Age: _____	Is this your first conference? YES NO	Include my contact info on network list to be distributed at conference: YES NO
	Affected with Marfan: YES NO Maybe	List any Related Disorders: _____	Do you use a wheelchair? YES NO
	Will attend : Friday reception: YES NO Saturday program: YES NO Sunday program: YES NO		Meal preferences: Regular, Vegetarian
Child/Teen #3 <small>(as listed on reverse)</small>	Age: _____	Is this your first conference? YES NO	Include my contact info on network list to be distributed at conference: YES NO
	Affected with Marfan: YES NO Maybe	List any Related Disorders: _____	Do you use a wheelchair? YES NO
	Will attend : Friday reception: YES NO Saturday program: YES NO Sunday program: YES NO		Meal preferences: Regular, Vegetarian

CONFERENCE FEES

Full Conference	No. Attending	Cost per Person	Total Cost
Members (19+) (Register by June 15)		\$ 300	\$
Members (19+) (Register after June 15)		\$ 400	\$
Non-Members		\$ 425	\$
Teens (13-19)		0	NA
Children (5-12)		0	NA

One Day Only

Members (19+)	\$ 175	\$	\$
Non-Members	\$ 225	\$	\$
Teens (13-19)	0	NA	NA
Children (5-12)	0	NA	NA

Optional

Scholarship Fund Donation	\$	\$	\$
Membership Dues (Individual)	\$ 35	\$	\$
Membership Dues (Family)	\$ 50	\$	\$
Membership Dues (Professional)	\$ 50	\$	\$
Additional Welcome Reception tickets	\$ 20	\$	\$
Additional Awards Dinner tickets	\$ 35	\$	\$
Total Amount Due		\$	\$

PAYMENT METHOD

I am applying for a conference scholarship. Attach this registration form to your scholarship application form.

My check or money order in the amount of \$ _____, payable in U.S. funds to the National Marfan Foundation, is enclosed.

Please charge my credit card in the amount of \$ _____:

Visa Master AmEx Discover

Card No.: _____

Exp. Date: _____

Full Name on Card: _____

Billing Address (if different from primary contact): _____

Cardholder Signature: _____

Please complete this form and return it with your payment to:
 National Marfan Foundation – 2009 Conference
 22 Manhasset Avenue
 Port Washington, NY 11050 or

REGISTER ONLINE AT WWW.MARFAN.ORG

form continued from reverse



National Marfan Foundation
22 Manhasset Avenue
Port Washington, NY 11050

Non-Profit Org.
U.S. Postage
PAID
Permit No. 262
Port Washington
New York 11050

IMPORTANT DEADLINES

- May 15** **Scholarship Applications Due**
- Clinic Appointments for Scholarship Applicants**
- June 1** **Schedule Clinic Appointments**
- June 15** **Early Bird Discount Registration**
- Children/Teens Registration Closes**
- July 8** **Hotel Reservations at Group Rate**

**25TH ANNUAL CONFERENCE —
JOIN US, IT WILL CHANGE YOUR LIFE!**

♥♥♥♥♥ **HEART MART** ♥♥♥♥♥

Heart Mart, a heart-themed raffle at the conference, raises funds to support the NMF Conference Scholarship Program. Donations of heart-themed gifts, jewelry, works of art, handicrafts and other items are being accepted for the 2009 Heart Mart. Donations for grand prizes (not necessarily heart-themed) are also welcome. Donations can be brought to the conference or sent (by July 1) to:

Tracie Payne	or	Kari Dostalik
1596 Saint Albans St. N.		8211 Goodman Drive
St. Paul, MN 55117		Urbandale, IA 50322
(tapayne@comcast.net)		(kdostalik@msn.com)

HOTEL INFORMATION

The following Rochester hotels are offering special rates for conference attendees. Rooms at these rates are subject to availability so make your reservations early. All hotels are within easy walking distance of Mayo Clinic and linked by pedestrian subway. **Reservations must be made by July 8.**

Rochester Marriott: www.marriott.com; 877-623-7775
Single/Double/Triple \$139

Residence Inn by Marriott: www.residenceinn.com; 877-623-7775
Single/Double/Triple/Quad: \$149

Kahler Inn and Suites: www.kahlerinnsuites.com; 800-533-1655
Single/Double/Triple/Quad \$95

For additional details, please check the NMF website.

TRAVEL INFORMATION

Rochester International Airport (RST)
located 8 miles from Rochester

Complimentary shuttle service is available to the hotels. Request service using telephones in baggage claim area or stop at the Visitor Information desk for assistance. Taxis are also available.

Minneapolis-St. Paul International Airport (MSP)
located 80 miles from Rochester

Van service to/from Rochester is available through GO Rochester Direct. Travel time one-way is approximately 90 minutes. Schedule and reservations: 800-280-9270; www.gorochesterdirect.com.

REGISTRATION FEES

	BY JUNE 15	AFTER JUNE 15
MEMBERS	\$300	\$400
NON-MEMBERS	\$425	\$425

There is no charge for children and teens, but they must be accompanied by a registered adult. Conference registration includes all sessions and materials, the Welcome Reception, lunch on Saturday and Sunday, and the Saturday Awards Dinner.

REGISTER ONLINE AT WWW.MARFAN.ORG