



National
Marfan
Foundation

26TH ANNUAL CONFERENCE

July 8–11, 2010 ★ Houston, Texas

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

THE NATIONAL MARFAN FOUNDATION ANNUAL CONFERENCE HEADS FOR THE LONE STAR STATE

The NMF is pleased to present its 26th Annual Conference on Marfan Syndrome and Related Disorders with co-sponsors Baylor College of Medicine and the University of Texas Health Science Center.

Join us in Houston, July 8–11, 2010!



CONFERENCE PROGRAM AT-A-GLANCE

Thursday, July 8

By appointment* Medical Testing at Baylor College of Medicine

Friday, July 9

By appointment* Patient Assessments at Baylor College of Medicine

9:00 AM HeartMart and Exhibits open
1:00 – 7:00 PM Registration
4:00 – 5:00 PM Orientation for First-Time Attendees
5:30 – 7:00 PM Welcome Reception
7:00 – 8:30 PM Special Screening of Marfan documentary, *In My Hands*

Saturday, July 10

7:00 – 8:30 AM Continental Breakfast
7:00 AM HeartMart and Exhibits open
7:00 – 10:00 AM Registration
8:30 AM – 12:15 PM General Session
12:30 – 2:15 PM Awards Lunch
2:30 – 6:00 PM Afternoon Workshops
After 6:00 PM Dinner on Your Own
Optional Evening Activities

Sunday, July 11

7:00 – 8:30 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

Assessments provide an opportunity for patients of all ages to receive a consultation and/or evaluation by Marfan and related disorders experts in all pertinent body systems. Physicians and specialists from Baylor College of Medicine and the University of Texas Health Science Center will join NMF Professional Advisory Board members in bringing this extraordinary opportunity to registered conference attendees. Priority will be given to first-time attendees who need assistance with diagnosis or ongoing management and lack access to specialty care at home.

To make an appointment for a patient assessment go to:
<http://www.bcm.edu/study/marfan/>

For questions about patient assessments, contact:
marfan2010@bcm.edu or 832-355-9919

Deadline: May 17, 2010

Conference programs will take place at the Houston InterContinental. Transportation between Baylor College of Medicine and the Houston InterContinental will be available during medical testing and patient assessment hours.

REGISTER ONLINE AT WWW.MARFAN.ORG

To request a mail-in copy of the registration form, contact the NMF at 800-8-Marfan, Ext. 36, or bhabermann@marfan.org.

GENERAL SESSION: SATURDAY, JULY 10

Part 1

Moderator	Dianna Milewicz, MD, PhD <i>Univ. of Texas Health Science Center, Houston</i>
8:30 – 8:45 AM	Welcome/Opening Remarks <i>Josephine Grima, NMF</i>
8:45 – 9:10 AM	Session 1: What Is Marfan Syndrome? What Is Not Marfan Syndrome? Dianna Milewicz, MD, PhD,
9:10 – 9:35 AM	Session 2: Cardiology Update Heidi Connolly, MD <i>Mayo Clinic, Rochester, MN</i>
9:35 – 10:00 AM	Session 3: Ophthalmological Concerns Irene Maumenee, MD <i>Univ. of Illinois Eye and Ear Infirmary, Chicago</i>
10:00 – 10:25 AM	Q & A
10:25 – 10:45 AM	Break

Part 2

Moderator	Scott A. LeMaire, MD <i>Baylor College of Medicine, Houston</i>
10:45 – 11:10 AM	Session 4: Pediatric Complications Ronald V. Lacro, MD <i>Children's Hospital Boston</i>
11:10 – 11:35 AM	Session 5: Marfan Syndrome and Cardiothoracic Surgery Joseph S. Coselli, MD <i>Baylor College of Medicine, Houston</i>
11:35 – 12:00 noon	Research Update Hal Dietz, MD <i>Johns Hopkins University, Baltimore, MD</i>
12:00 – 12:15 PM	Q & A



CONFERENCE EXHIBITS

Informative exhibits will be open during the conference including:

GenTAC – National Registry of Genetically Triggered Thoracic Aortic Aneurysms and Cardiovascular Conditions

Members of the GenTAC project team will be available at the conference to share information about the GenTAC Registry and how you can participate. If you are interested in learning more about the Registry and how to enroll please call the Data Coordinating Center (RTI) at 1-800-334-8571, ext. 24640, or visit the study website at <http://gentac.rti.org>. Interested parties are encouraged to enroll at a participating Regional Coordinating Center prior to the conference. Participation involves providing a blood or saliva sample, completion of two questionnaires, and release of pertinent medical records related to your genetic disorder.

Losartan vs. Atenolol Clinical Trial

Learn more about the clinical trial studying the effects of the drugs atenolol and losartan on the aorta in Marfan syndrome.

CHILDREN'S PROGRAM (ages 5–12)

Friday, July 9

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

Saturday, July 10

Have fun and learn at Houston's Downtown Aquarium in the morning and the Museum of Health and Science in the afternoon. Games and other activities will be scheduled after dinner with your family.

Sunday, July 11

After morning games and activities. Ask Dr. Jessica Davis and Dr. Dianna Milewicz your questions about Marfan syndrome and related disorders. Spend the afternoon making a t-shirt to take home.

TEEN PROGRAM (ages 13–19)

Friday, July 9

Arrive by 4:00 PM for a special welcome session. A Living Successfully with Marfan Syndrome and Related Disorders program will take place in the evening.

Saturday, July 10

Start the day with a breakfast session with Dr. Hal Dietz. Learn about the latest research in Marfan syndrome and related disorders. You then get to choose from a line-up of great workshops presented by docs and special friends. After an afternoon field trip to Houston's largest guest ranch have dinner on your own with your family followed by an evening of dancing and games.

Sunday, July 11

Learn how you can become involved by volunteering for the NMF, attend a session on How to talk with Your Doctors and join your parents at lunch and the conference closing session.

Teen Workshops: Saturday, July 10

SESSION 1	SESSION 2
#1 Coping Skills	#4 Cardiac Issues
#2 Transitioning to Adult Care	#5 Orthopedic Issues
#3 Marfriends	#6 Ask Your Questions

Registration for Children's and Teen Programs closes May 31. (sorry, no on-site registration)



Attending this conference is the best way I have found to understand my medical condition and risks for my children. I am grateful that so many specialists give their time and expertise for us.



YOUNG ADULTS (20 & 30-SOMETHINGS)

If you are in your 20s or 30s, meet your peers at the Friday welcome reception. Then explore Houston Friday and Saturday nights with your peers and take part in special workshops offerings on Sunday

CONFERENCE SCHOLARSHIP PROGRAM

The annual Conference Scholarship Program provides help with registration fees and hotel accommodations. Because funding is limited and a great number of people apply each year we are unable to provide travel assistance.

Complete the online application form at www.marfan.org or contact the NMF at 800-8-MARFAN, ext. 36, or bhabermann@marfan.org to request a copy.

I really enjoyed being able to talk with some of the doctors and speakers on an individual basis. They are open and genuinely interested in researching and trying to find answers for the condition.



Workshops: Saturday, July 10

SESSION 1 2:30–3:30	SESSION 1 3:45–4:45	SESSION 3 5:00–6:00
A1 Marfan 101	A2 Related Disorders (not LDS)	A3 Genetic Testing limits/benefits in Diagnosis
B1 Orthopedic Issues	B2 Pediatric Orthopedic Issues	B3 Non-surgical Approaches to Dural Ectasia and Back Pain
C1 Pediatric Cardiac Issues	C2 Pediatric Cardiac Issues	C3 Aortic Surgery in Children/Teens
D1 Pediatric Issues in Marfan Syndrome	D2 Cardiac Imaging and Radiology: Understanding Your Imaging Studies & Z-score	D3 Vascular Surgery Aneurysms Affecting Vessels other than the Ascending Aorta
E1 Adult Cardiac Issues	E2 Post Dissection Cardiac Concerns	E3 Adult Cardiac Issues
F1 Aortic Surgery—What Are The Options?	F2 Pre-conception, Pregnancy and Post-partum Cardiovascular Management and Related Issues	F3 Planning a Family: Preimplantation Genetics, Genetic Diagnosis, Adoption
G1 General Ocular Issues in Marfan Syndrome	G2 Ocular Corrections and Visual Rehabilitations	G3 Dental Issues
H1 Pectus Management	H2 Pulmonary Issues	H3 Sleep Apnea
I1 Loey-Dietz Syndrome	I2 Surgical Management in Loey-Dietz Syndrome	I3 Loey-Dietz Syndrome
J1 Growing Older with Marfan Syndrome	J2 Exercise and Staying Fit	J3 Growing Older with Marfan Syndrome
K1 Management of Pain in Adults with Marfan Syndrome	K2 Pediatric Pain Management in Marfan Syndrome	K3 Podiatric Issues in Adults and Children

Workshops: Sunday, July 11

SESSION 4 8:30–9:45	SESSION 5 10:00–11:15	SESSION 6 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 Loey-Dietz Syndrome	B6 Developing your Emergency Plan
C4 Communicating with Your Child's School	C5 Facing Surgery: Psychological Issues and How to Cope	C6 Growing Up: Facing the Transition 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 Massage/Physical Therapy and Yoga	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 and Disability Issues	H5 Loss of the Idealized Self	H6 Bereavement: Coping with the Loss of Family and/or Friends
I4 Meditation	I5 Post High School: Planning for the Future, Goal and Career Options	I6 Options for Home INR Monitoring

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WWW.MARFAN.ORG**

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Port Washington, NY 11050

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IMPORTANT DATES & DEADLINES

- March 10** Online Registration begins
- Conference Scholarship Applications available
- Scheduling of Patient Assessments begins
- April 12** Scholarship Applications Due
- May 17** Patient Assessment Appointment Deadline
- May 31** Early Bird Registration Deadline
- Children/Teens Registration Deadline
- June 25** Hotel Reservations at Group Rate Deadline

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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 throughout all Conference programming.

♥♥♥♥♥ **HEARTMART** ♥♥♥♥♥

HeartMart, a raffle and silent auction at the conference, raises funds to support the NMF Conference Scholarship Program. We're looking for donations of higher end items with a value of \$100 or more for the silent auction as well as goods for the raffle (alone or combined with other items into baskets). Donations are now being accepted for the 2010 HeartMart.

If you have any questions or suggestions on how we can obtain items for the silent auction, please contact Kathy McGee, the 2010 HeartMart coordinator, at katachat@hotmail.com. If you have items to donate, please send them to Barbara Butler at the address below by June 15th.

Barbara Butler
1202 Becker Street
Channelview, TX 77530
Home phone: 281-452-2363
Cell phone: 713-202-0666

HOTEL INFORMATION

The InterContinental Houston Near the Galleria is the official hotel of the 26th Annual Conference on Marfan Syndrome and Related Disorders. Located in the heart of the "uptown" section of Houston near restaurants, shopping and entertainment, the InterContinental Houston is adjacent to the Houston Galleria mall—a great place to find shopping and restaurants to fit all styles and budgets.

Group Rate: \$129 (single or double) available until June 25
Parking: \$6.00 per day discounted rate

Reservations:

By telephone: 713-627-7600
Toll-free: 800-316-8645

For more hotel and travel information, including a web link for hotel reservations, visit www.marfan.org.

REGISTRATION FEES

	BY MAY 31	AFTER MAY 31
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 patient assessments, sessions and materials, Friday welcome reception and breakfast and lunch on Saturday and Sunday.