

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 |

**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.




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 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

REGISTER ONLINE AT WWW.MARFAN.ORG



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 Magee, 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.

NMF CONFERENCE REGISTRATION FORM

PART 1

INSTRUCTIONS: To register for the NMF Annual Conference, please complete the form below as well as copies of the appropriate individual form for each adult, teen and child in your party, and return with your payment to: National Marfan Foundation, 2010 Conference, 22 Manhasset Avenue, Port Washington, NY 11050. Children and Teens attend free but must be registered by May 31. Early bird discount registration also ends on May 31.

PRIMARY CONTACT

| | |
|-----------------|----------------------------|
| Name: | Tel: |
| Address: | Email: |
| City/State/Zip: | Number of People in Party: |

ATTENDEES IN YOUR PARTY

| | Prefix | First Name (as it should appear on badge) | Last Name | Email Address |
|--------------|--------|---|-----------|---------------|
| ADULT 1 | | | | |
| ADULT 2 | | | | |
| ADULT 3 | | | | |
| ADULT 4 | | | | |
| CHILD/TEEN 1 | | | | |
| CHILD/TEEN 2 | | | | |
| CHILD/TEEN 3 | | | | |
| CHILD/TEEN 4 | | | | |
| CHILD/TEEN 5 | | | | |
| CHILD/TEEN 6 | | | | |

CONFERENCE FEES

OPTIONAL DONATION / DUES / TICKETS

| FULL CONFERENCE | NUMBER | COST | SUBTOTAL | OPTIONAL | NUMBER | COST | SUBTOTAL | |
|---|--------|--------|----------|--------------------------------------|------------------------|-------|----------|----|
| Members (adult*) register by May 31 | | \$ 300 | \$ | Scholarship Fund Donation | NA | \$ | \$ | |
| Members (adult*) register after May 31 | | \$ 400 | \$ | Membership Dues (Individual) | NA | \$ 35 | \$ 35 | |
| Non-Members (adult*) | | \$ 425 | \$ | Membership Dues (Family) | NA | \$ 50 | \$ 50 | |
| ONE DAY ONLY Indicate which day: <input type="checkbox"/> Saturday <input type="checkbox"/> Sunday | | | | Membership Dues (Professional) | NA | \$ 50 | \$ 50 | |
| Members (adult*) | | \$ 175 | \$ | Additional Welcome Reception Tickets | | \$ 20 | \$ | |
| Non-Members (adult*) | | \$ 225 | \$ | Additional Awards Lunch Tickets | | \$ 25 | \$ | |
| TOTAL CONFERENCE FEES: | | | | \$ | TOTAL OPTIONAL AMOUNT: | | | \$ |

*Adult registration is for those over 19 years of age. Children and Teens, ages 5-19, attend free but MUST be registered by May 31, 2010.

Tickets to the Welcome Reception and Awards Lunch are included in registration fees, but additional tickets may be purchased for non-registered guests.

► **TOTAL AMOUNT DUE (CONFERENCE FEES + OPTIONAL AMOUNTS): \$**

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 MasterCard American Express Discover

Card No.: _____ Exp. Date: _____

Full Name on Card: _____ Signature: _____

Billing Address if different from primary contact address above: _____

NMF CONFERENCE REGISTRATION FORM

PART 2

INSTRUCTIONS: Make as many copies of this page as you need and return with Part 1 of the Registration Form.

ADULT REGISTRATION INFORMATION

CONTACT INFORMATION

| | | |
|-------------|--|------|
| Name: | <input type="checkbox"/> Primary Contact Person | |
| Address: | <input type="checkbox"/> Same Address as Primary Contact | |
| City: | State: | Zip: |
| Tel (home): | Tel (work): | |
| Email: | <input type="checkbox"/> Include my contact info on network list to be distributed at conference | |

OTHER INFORMATION

WORKSHOP SELECTIONS

| | | | |
|--|------------------------------|-----------------|-------|
| Is this your first NMF conference? <input type="checkbox"/> Yes <input type="checkbox"/> No | Saturday Workshop Selections | | |
| Are you affected with Marfan syndrome? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe | Session | Number (eg, G2) | Title |
| Are you affected with a related disorder? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe | 1 | | |
| Please list any related disorders: | 2 | | |
| Do you use a wheelchair? <input type="checkbox"/> Yes <input type="checkbox"/> No | 3 | | |
| Meal preference: <input type="checkbox"/> Regular <input type="checkbox"/> Vegetarian | Sunday Workshop Selections | | |
| I will attend (check all that apply): <input type="checkbox"/> Friday Welcome Reception <input type="checkbox"/> Saturday Awards Lunch <input type="checkbox"/> Young Adults 20 & 30-something Activities | 4 | | |
| | 5 | | |
| | 6 | | |

ADULT REGISTRATION INFORMATION

CONTACT INFORMATION

| | | |
|-------------|--|------|
| Name: | <input type="checkbox"/> Primary Contact Person | |
| Address: | <input type="checkbox"/> Same Address as Primary Contact | |
| City: | State: | Zip: |
| Tel (home): | Tel (work): | |
| Email: | <input type="checkbox"/> Include my contact info on network list to be distributed at conference | |

OTHER INFORMATION

WORKSHOP SELECTIONS

| | | | |
|--|------------------------------|-----------------|-------|
| Is this your first NMF conference? <input type="checkbox"/> Yes <input type="checkbox"/> No | Saturday Workshop Selections | | |
| Are you affected with Marfan syndrome? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe | Session | Number (eg, G2) | Title |
| Are you affected with a related disorder? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe | 1 | | |
| Please list any related disorders: | 2 | | |
| Do you use a wheelchair? <input type="checkbox"/> Yes <input type="checkbox"/> No | 3 | | |
| Meal preference: <input type="checkbox"/> Regular <input type="checkbox"/> Vegetarian | Sunday Workshop Selections | | |
| I will attend (check all that apply): <input type="checkbox"/> Friday Welcome Reception <input type="checkbox"/> Saturday Awards Lunch <input type="checkbox"/> Young Adults 20 & 30-something Activities | 4 | | |
| | 5 | | |
| | 6 | | |

NMF CONFERENCE REGISTRATION FORM

PART 3

INSTRUCTIONS: Make as many copies of this page as you need and return with Part 1 of the Registration Form.

CHILD/TEEN REGISTRATION INFORMATION

| | | |
|---|---|--|
| Name: | | Age: |
| Phone: | Email: | |
| <input type="checkbox"/> Include my contact info on network list to be distributed at conference | Is this your first NMF conference? <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| Are you affected with Marfan syndrome? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe | WORKSHOP SELECTIONS (TEENS 13-19 ONLY) | |
| Are you affected with a related disorder? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe | Choose one workshop from Session 1 and one workshop from Session 2 | |
| Please list any related disorders: | SESSION 1 | SESSION 2 |
| Do you use a wheelchair? <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> #1 Coping Skills | <input type="checkbox"/> #4 Cardiac Issues |
| Meal preference: <input type="checkbox"/> Regular <input type="checkbox"/> Vegetarian | <input type="checkbox"/> #2 Transitioning to Adult Care | <input type="checkbox"/> #5 Orthopedic Issues |
| <input type="checkbox"/> I will attend the Friday Welcome Reception | <input type="checkbox"/> #3 Marfriends | <input type="checkbox"/> #6 Ask Your Questions |

CHILD/TEEN REGISTRATION INFORMATION

| | | |
|---|---|--|
| Name: | | Age: |
| Phone: | Email: | |
| <input type="checkbox"/> Include my contact info on network list to be distributed at conference | Is this your first NMF conference? <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| Are you affected with Marfan syndrome? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe | WORKSHOP SELECTIONS (TEENS 13-19 ONLY) | |
| Are you affected with a related disorder? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe | Choose one workshop from Session 1 and one workshop from Session 2 | |
| Please list any related disorders: | SESSION 1 | SESSION 2 |
| Do you use a wheelchair? <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> #1 Coping Skills | <input type="checkbox"/> #4 Cardiac Issues |
| Meal preference: <input type="checkbox"/> Regular <input type="checkbox"/> Vegetarian | <input type="checkbox"/> #2 Transitioning to Adult Care | <input type="checkbox"/> #5 Orthopedic Issues |
| <input type="checkbox"/> I will attend the Friday Welcome Reception | <input type="checkbox"/> #3 Marfriends | <input type="checkbox"/> #6 Ask Your Questions |

CHILD/TEEN REGISTRATION INFORMATION

| | | |
|---|---|--|
| Name: | | Age: |
| Phone: | Email: | |
| <input type="checkbox"/> Include my contact info on network list to be distributed at conference | Is this your first NMF conference? <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| Are you affected with Marfan syndrome? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe | WORKSHOP SELECTIONS (TEENS 13-19 ONLY) | |
| Are you affected with a related disorder? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe | Choose one workshop from Session 1 and one workshop from Session 2 | |
| Please list any related disorders: | SESSION 1 | SESSION 2 |
| Do you use a wheelchair? <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> #1 Coping Skills | <input type="checkbox"/> #4 Cardiac Issues |
| Meal preference: <input type="checkbox"/> Regular <input type="checkbox"/> Vegetarian | <input type="checkbox"/> #2 Transitioning to Adult Care | <input type="checkbox"/> #5 Orthopedic Issues |
| <input type="checkbox"/> I will attend the Friday Welcome Reception | <input type="checkbox"/> #3 Marfriends | <input type="checkbox"/> #6 Ask Your Questions |