



NMF



July 12-15, 2007
Stanford University
Palo Alto, California
23rd Annual Conference
National Marfan Foundation

The 23rd Annual NMF Conference on Marfan Syndrome and Related Disorders

July 12-15, 2007
Stanford University
Palo Alto, California



*Workshops led by world-renowned
physicians and researchers*

Individual patient assessments

NMF Awards Dinner

*Fun-filled programs for children
and teens*

*The latest news on research on
Marfan syndrome and related
disorders*



Registration Brochure

Dear Friends,

The National Marfan Foundation and Stanford University School of Medicine invite you to attend the NMF's **23rd Annual Conference** on Marfan syndrome and Related Disorders, July 12–15, 2007, in beautiful Palo Alto, California.

Amidst the sunshine and palm trees of Northern California, conference attendees will be able to attend presentations by some of the world's leading experts on the diagnosis and treatment of Marfan syndrome and its related disorders. Information about the latest advances in research related to the Marfan family of disorders will also be available. The conference is not, however, merely a learning and information gathering experience. It is also a time for us to come together as the "MARFAN COMMUNITY" – to share our stories with new friends and to reunite with those we have met at conferences past. At the same time, our parents, children, siblings, spouses, significant others and loved ones will join with us to share their experiences of traveling with us on our life journey of living with Marfan syndrome.

We look forward to seeing you in July.

Sincerely,



Joseph R. Gagliano, Jr.
Chair, National Marfan Foundation

Patient Assessments

Dates: July 12 – Echocardiograms
July 13 – Consultations and evaluations
To make an appointment or for more information, contact: Sunny Pellone, 650-725-5928 or marfan2007@stanfordmed.org
Deadline for appointments: May 1, 2007

Patient assessments, sponsored by Stanford University School of Medicine, will be held on July 12 and 13. **You must make your appointment by May 1**, separate from Conference Registration. **Appointments are limited**; priority will be given to conference attendees who lack access to Marfan specialty care and need a diagnosis or ongoing management. Consultations are available for full evaluations or for concerns related to a single medical specialty (such as eyes, skeleton, heart, lungs). Evaluations will be conducted by members of the NMF Professional Advisory Board, physicians from Stanford and other Marfan specialists. Appointments are in great demand; if you are interested do not delay. Round-trip transportation will be provided between the Sheraton Palo Alto Hotel and Stanford Medical Center.

Scholarships

The NMF has provided scholarships to more than 300 individuals over the past seven years, enabling them to attend the annual conference. This is only possible because of the generosity of NMF members. We encourage anyone for whom conference costs are a burden to apply for a scholarship.

Awards are made based on financial need. Priority is given to those who have never attended an NMF conference. Apply by sending with your registration form either:

- A letter explaining to the NMF why you want to attend the conference and giving an amount of financial help that will make it possible for you to attend. OR
- A Scholarship Application Form, obtained by calling the NMF at 800-862-7326 ext. 10.

Please submit either your letter or form by the **May 1 deadline**. Everyone will have a decision and grant amount by May 15.

Children's Program

Friday, July 13, 5:30 pm

Children ages 6 to 12 will join their families at the Conference's **Welcome Barbecue**.

Saturday, July 14, 8:30 am

After an orientation session, children will take a chaperoned bus trip to Felton and an **historic narrow gauge railroad through the giant redwood forest** to the summit of Bear Mountain. They will enjoy a chuckwagon barbecue lunch and **explore the redwoods**. They will have dinner with their new friends, followed by a movie and game night.

Sunday, July 15, 8:30 am

Children engage in **arts and crafts, games and activities** that foster friendships and self-esteem. Lunch will be provided. Children ages 8+ will meet with a doctor and social worker for a **Q&A session** about Marfan syndrome. The program is designed for affected children and their siblings.

Teen Program

Friday, July 13, 5:30 pm

Teens (ages 13–18) will join all conference attendees at the **Welcome Barbecue**. Their first teen-only session follows, from 8:30–10:30 pm. Group leaders in their twenties will talk about their journey with Marfan syndrome and lead a discussion.

Saturday, July 14, 8:30 am

Sessions for the teens in the morning are followed by a **ropes course among the redwoods** in Saratoga, CA. The course, designed for teens with Marfan syndrome, will build character, teamwork, decision-making and risk-taking skills, trust and self-esteem. Dinner will be a **chaperoned trip into Palo Alto**.

Sunday, July 15, 8:30 am

Teens meet with a leading Marfan researcher. In addition, they attend a teen-only session with a patient advocacy expert who will talk to them about their rights. They are invited to the NMF annual meeting luncheon and closing program.

Adult Program

Friday, July 13

Conference Registration 2:00–6:00 pm

Orientation for First Time Attendees 4:00–5:00 pm

Welcome Barbecue 5:30–8:30 pm

Saturday, July 14

Continental Breakfast 7:00–8:30 am

Registration 7:30–9:00 am

Morning General Session 8:30 am–12:25 pm

An Overview of Marfan Syndrome and Related Disorders
Anne DePaepe, MD

Research Update
Hal Dietz, MD

Pain Management
TBD

Cardiovascular Surgery
Craig Miller, MD

Box Lunch 12:30–1:30 pm

Opportunity for Networking with Roundtable Discussions

Afternoon Workshops 1:45–5:15 pm

Choose one workshop for each of the three sessions listed on page 4.

Awards Dinner 7:30–11:00 pm

Buses will leave from the Hotel

Sunday, July 15

Continental Breakfast 7:00–8:30 am

Registration 8:00–8:30 am

Support Day Workshops 8:30 am–12:45 pm

Choose one workshop for each of the three sessions listed on page 4.

NMF Annual Meeting, Lunch and Closing Program 1:00–3:00 pm

The NMF is pleased to offer the children and teen programs free of charge due to the successful fundraising efforts of the Northern California Chapter.

Workshops Listed on Page 4

Workshops

✦ = Lecture style workshop featuring a presentation followed by a question and answer session.
 ☒ = Group discussion workshop with a facilitated discussion led by the presenter.
 Please visit the NMF website (www.marfan.org) for workshop descriptions.

Saturday Workshops

Session I: 1:45–2:45 pm	Session II: 3:00–4:00 pm	Session III: 4:15–5:15 pm
1. Cardiac Concerns ☒	2. Post-Dissection Cardiac Concerns ☒	3. Cardiac Concerns ☒
4. Psychosocial Issues Regarding Affected Children ☒	5. Psychosocial Issues Regarding Affected Children ☒	6. Psychosocial Issues Regarding Affected Adults ☒
7. Growing Older with Marfan Syndrome ✦	8. Growing Older with Marfan Syndrome ✦	9. Growing Older with Marfan Syndrome ✦
10. Pediatric Concerns ☒	11. Pediatric Cardiac Concerns ☒	12. Pediatric Concerns ☒
13. Ophthalmology ✦	14. Ophthalmology ✦	15. Pregnancy Issues ✦
16. Orthopedic Concerns ✦	17. Pediatric Orthopedic Concerns ✦	18. Losartan vs. Atenelol Clinical Trial ✦
19. Issues with Feet in Marfan Syndrome ✦	20. Issues with Feet in Marfan Syndrome ✦	21. Dural Ectasia ✦
22. Pectus Management ✦	23. Dental Concerns ✦	24. Home INR Monitor ✦
25. Radiology ✦	26. Pulmonary Concerns ☒	27. Pulmonary Concerns ☒
28. Marfan 101 ✦	29. Exercise and Staying Fit ✦	30. Exercise and Staying Fit ✦
31. Related Disorders ☒	32. Related Disorders ☒	33. Loeys-Dietz Syndrome ☒
34. What Can You Learn from Genetic Testing? ✦	35. Pediatric Pain Management ✦	36. Adult Pain Management ✦

Sunday Workshops

Session I: 8:30–9:45 am	Session II: 10:00–11:15 am	Session III: 11:30 am–12:45 pm
37. Helping Your Child's School Understand Marfan Syndrome ✦	38. Understanding IEPs and 504s ✦	39. Peer and Sibling Relationships ✦
40. Support Group for Parents of Children ☒	41. Support Group for Mothers ☒	42. Support Group for Fathers ☒
43. Coping with Marfan Syndrome ☒	44. Coping with Marfan Syndrome ☒	45. Coping with Related Disorders ☒
46. Prepare for Surgery; How to Heal Faster: A Complementary Approach ✦	47. Somatic Experiencing (a mind-body therapy using sensations and feelings) ✦	48. Complementary Medicine ✦
49. Benefits of Genetic Counseling ✦	50. Applying for Disability ✦	51. Communicating with Your Doctor and Self-Empowerment ✦
52. Developing Your Emergency Plan Kit ✦	53. Developing Your Emergency Plan Kit ✦	54. Medical Insurance ✦
55. Facing Cardiovascular Surgery ☒	56. Facing Orthopedic Surgery ☒	57. Young Adults Ages 20–30 Something ☒
58. Session for Unaffected Spouses and Significant Others ☒	59. Couples Workshop ☒	60. Planning for a Family: Issues and Options ☒
61. Bereavement: Loss of Friend, Family, Loved One ☒	62. Bereavement: Loss of Idealized Self ☒	63. Becoming an NMF Volunteer ✦
64. Yoga ✦	65. Fundraising for the NMF ✦	66. Yoga ✦

Conference Registration Form

Please complete both sides

1. Individual Registration Form

Please complete a separate copy of the section below for each person, including each child, who will be attending the conference. If you are registering more than one person, please make photocopies.

Last Name		First Name	
Nickname		Country	
Address			
City		State	Zip
Phone		Email	

Include my contact information in networking list to be distributed to conference attendees.

Is this your first NMF Conference? <input type="checkbox"/> Yes <input type="checkbox"/> No	Meal Preference: <input type="checkbox"/> Regular <input type="checkbox"/> Vegetarian
Age (if 18 or younger):	Special Needs (please specify diet, wheelchair, etc.):
Affected with Marfan: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe	
Related Disorder: <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe	

Adults: Please indicate your selections below.

Friday Welcome Barbecue Saturday Awards Dinner 20-30 Somethings Gatherings

Saturday Workshop Selections			Sunday Workshop Selections		
Session	Number	Title	Session	Number	Title
I			I		
II			II		
III			III		

Teens (13-18): Please indicate activity selections below.

Friday Welcome Barbecue & Program Saturday Program Sunday Program

Children (6-12): Please indicate activity selections below.

Friday Welcome Barbecue Saturday Program Sunday Program

Children (0-5): Please indicate activity selections below.

Saturday Child Care Saturday Evening Child Care Sunday Child Care

Please return with payment to: NMF, 22 Manhasset Avenue, Port Washington, NY 11050; fax: 516-883-8040

Conference Registration Form

Please complete both sides

2. Registration Fees

To become an NMF member and receive the conference discount, add \$35 dues per individual or \$50 per family (below, above total).

Fees	Number Attending	Cost per Person	Total Cost
Full Conference			
Members (19+) (Register by May 1)		\$275	\$
Members (19+) (Register after May 1)		\$375	\$
Non-Members		\$400	\$
Children (6-12)		0	
Teens (13-18)		0	
Child Care (0-5)		\$100	\$
One Day Only			
Members (19+)		\$175	\$
Non-Members		\$225	\$
Children (6-12)		0	
Teens (13-18)		0	
Child Care (0-5)		\$50	\$
Optional			
Scholarship Fund Donation			\$
Membership Dues (Individual)		\$35	\$
Membership Dues (Family)		\$50	\$
Total Amount Due			\$

Please note: any cancellations made by June 15th will be refunded less a \$25 administration fee. No refunds will be made after June 15th.

3. Payment Method

I am applying for a conference scholarship. Attach this registration form to your scholarship request.
Do not send payment until you hear from the scholarship committee. Scholarship information is on the back of this brochure.

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

<input type="checkbox"/> Please charge my credit card:	<input type="checkbox"/> Visa	<input type="checkbox"/> MasterCard	<input type="checkbox"/> American Express
Card No.			Exp. Date
Full Name on Card			
Billing Address (if different from primary contact)			
Cardholder Signature			

Please return with payment to: NMF, 22 Manhasset Avenue, Port Washington, NY 11050; fax: 516-883-8040

Hotel Information

The NMF has arranged for a block of rooms at the Sheraton Palo Alto Hotel (625 El Camino Real), located across the street from Stanford University. Our group rate is a vastly reduced \$129 per night. **The deadline for reservations is May 15.** To make your reservation, please call the hotel directly at 650-328-2800 and state that you are with the NMF conference. Transportation will be provided to the conference programs on Stanford's campus.

Travel Arrangements

- **By Car:** Highway 101 and Highway 280 are minutes away.
- **By Air:** San Francisco Airport and San Jose Airport serve the Palo Alto area.
- **Other Transportation:** Caltrain, Santa Clara Valley Transportation Authority, SamTrans and Dumbarton Express offer train service to the Stanford area.

20 & 30-Somethings

If you are in your 20s or 30s, meet your peers at the Welcome Barbecue on Friday evening. Join in activities for this age group throughout the weekend, including the 20–30 something workshop on Sunday which will deal with age-appropriate topics.

Dealing with a Related Disorder

Many of the conference presentations and workshops address the concerns of both Marfan syndrome and related disorders. Of special interest will be the Saturday workshops on Related Connective Tissue Disorders, and the Sunday workshop, Coping with Related Conditions. Those with a related disorder will also be able to gain a wealth of information from the medical panel and from workshops devoted to the specific body system in which they have symptoms.

Registration Fees

Included in the registration fees are:

- Welcome Barbecue on Friday night
- Breakfast, lunch and dinner on Saturday
- Breakfast and lunch on Sunday
- Adult sessions and materials
- Programs for children (6–12) and teens

If you have questions or concerns, please call the NMF office at 1-800-8-MARFAN, extension 10. Payment is by check or credit card. There is no online registration; however, the conference brochure and registration form are posted on the NMF website at www.marfan.org.

Child Care

Child care for children ages 5 and under is available for an additional fee (see registration form) on Saturday and Sunday, while parents are in sessions and during the awards dinner.

Heart Mart

The Heart Mart, a raffle featuring heart-themed items, is a fun NMF Annual Conference tradition that allows members and friends to show off their creativity while also raising funds to support the NMF Conference Scholarship Program. Donations of heart-themed items, such as gifts, jewelry, works of art, handicrafts, and trinkets for adults or children, are currently being accepted for the Stanford Conference Heart Mart Raffle. Please send your donated heart-themed items (new items only please) by June 30 to:

Susan Meier, NMF Heart Mart
2207 Invar Court
Rocklin, CA 95765
susan.meier@starstream.net
916-632-3214

We will also be accepting donated items at the Heart Mart on the first day of the conference.



NMF

July 12-15, 2007
 Stanford University
 Palo Alto, California
23rd Annual Conference
National Marfan Foundation

Registration Brochure

66 workshops and presentations to choose from

Talk one-on-one with leaders in the field of Marfan research, diagnosis and treatment

Educational and recreational activities for children and teens

Networking and social events for everyone

All in sunny Palo Alto, California!

Visit www.marfan.org for more information.



National Marfan Foundation
 22 Manhasset Avenue
 Port Washington, NY 11050

Non-Profit Org.
 U.S. Postage
PAID
 Permit No. 262
 Port Washington, NY
 11050

Deadlines	
May 1	Scholarships Patient Assessment Appointments Conference Registration with Discount
May 15	Hotel Reservations

Join Us in California for the 23rd Annual Conference!