

## Overview

The National Marfan Foundation, in partnership with Barnes-Jewish Hospital and Washington University School of Medicine, is proud to sponsor the 21st Annual National Conference on the Marfan syndrome and related disorders, August 4-7, at the Marriott Pavilion Hotel in Downtown St. Louis, Missouri. Join our national Marfan community for the rich opportunities this conference offers for learning, support, meeting others and fun. We also welcome a growing number of international attendees.

Conference Activities include:

- Marfan Clinic at Barnes-Jewish Hospital: Echocardiograms on Thursday, August 4 and Medical Consultations on Friday, August 5. (By appointment only.)
- Friday evening Welcome Reception for adults, while children and teens enjoy their own special programs.
- St. Louis Cardinals vs. Atlanta Braves baseball game following the Welcome Reception with complimentary tickets for all provided through the generosity of Mrs. Anne Hinds.
- Expert Medical Panel and Medical Workshops led by world-renowned doctors and researchers on Saturday, August 6.
- Continuing Medical Education course on "State of the Art Management of Aortic Disease" for doctors and other clinicians on Saturday, August 6.
- Workshops featuring peer support and psychosocial aspects for living successfully with the Marfan syndrome on Sunday, August 7.
- Informal social gatherings that provide opportunities to share experiences, meet new friends, and strengthen our Marfan community are provided throughout the conference.

## Meet Me in St. Louis

St. Louis, the gateway to the West, is a world class city, known for its collection of exciting attractions, great restaurants, exciting blues music and nightlife. The famous phrase comes from the 1904 "Meet Me in St. Louis" World's Fair held in Forest Park. Dr. Alan Braverman and the St. Louis Chapter are ready to welcome you to their fascinating city.

The 2005 National Conference is truly family friendly, **thanks to the generous support** of our co-host, the St. Louis community and the successful fundraising of Dr. Alan Braverman and the St. Louis Area NMF Chapter. **Their efforts enable all children to attend at no charge, AND, included in your registration fee, are additional meals, a ball-game at Busch Stadium, an elegant Awards Dinner at the Chase Park Plaza and babysitting** for these special events. On behalf of the NMF membership, we are most grateful for this exceptional opportunity.



Logo design by Chris Ritter, Kurt Tiede and Jonathan Hale at Famous-Barr

## August 4-7, 2005 A Conference on the Marfan Syndrome and Related Disorders For Individuals, Families, and Health Care Professionals

### Co-Host

### Barnes-Jewish Hospital and Washington University School of Medicine

The Marfan Syndrome Clinic at Washington University School of Medicine and Barnes-Jewish Hospital was established in 1992 in response to the needs of affected individuals in the St. Louis area. The clinic has become a nationally recognized center of excellence for the care of people with the Marfan syndrome and related disorders. The National Marfan Foundation is grateful to Dr. Alan Braverman and his staff for making it possible to bring this conference to the St. Louis area. We also thank professionals from the St. Louis Children's Hospital Marfan Syndrome Clinic.

## Conference Supporters

The National Marfan Foundation is grateful to our conference supporters:

Friends of the Marfan Syndrome Clinic at Washington University and Barnes-Jewish Hospital  
Barnes-Jewish Hospital ♥ Centene Corporation ♥ Chase Park Plaza Hotel ♥ Department of Medicine at Washington University  
Heaney Angels Fund ♥ Mrs. Anne H. Hinds ♥ Kurnitz Scholarship Fund ♥ St. Louis Area NMF Chapter ♥ St. Louis Children's Hospital  
Tall Clubs International ♥ The Guidant Foundation ♥ Washington University Medical Center ♥ Weiss Scholarship Fund

## Marfan Clinic

**Thursday, August 4 (Echocardiograms)**

**Friday, August 5 (Medical Consultations)**

The Marfan Clinic is sponsored by Barnes-Jewish Hospital and Washington University School of Medicine. You must make an appointment by *June 1*, separate from Conference Registration. Priority for appointments is given to conference registrants who lack access to Marfan specialty care for either diagnosis or ongoing management. Consultations are available for comprehensive evaluation or for concerns related to a single medical specialty (e.g., eyes, skeleton, heart). The Clinic is staffed by Marfan specialists who are members of the NMF Professional Advisory Board, physicians from Barnes-Jewish Hospital, St. Louis Children's Hospital and other specialists invited to participate. For a clinic appointment, call Cheryl Marshall at 888-210-8375, or 314-362-1291. Appointments are in great demand. If you are interested, do not delay. Round-trip transportation to clinic is provided from the Marriott.

## Continuing Medical Education

On Saturday, August 6, the Washington University School of Medicine is sponsoring a course on "State of the Art Management of Aortic Disease" for doctors and clinicians. Topics will include Current Diagnosis and Timing of Aortic Surgery, Familial Thoracic Aortic Aneurysm/Dissection, Imaging of Thoracic Aortic Disease, and Surgical Options. Presentations will include panel discussions and question and answer sessions. Please encourage your doctors to attend. For more information or to obtain a full course brochure, please call 800-325-9862, or 314-362-6891. More information can be found online at <http://cme.wustl.edu>.

## Dealing with a Related Disorder?

Many of the conference presentations and workshops address the concerns of both the Marfan syndrome and related disorders. Of special interest will be the Saturday workshop, Related Connective Tissue Disorders, and the Sunday workshop, Coping with Related Conditions. Those with related disorders are also encouraged to consider workshops devoted to a specific body system in which they have symptoms.

### **HeartMart Needs Your Contribution**

Help raise funds to support the Weiss Scholarship Fund by bringing an item (or two) that has a heart theme for a silent auction at the conference. Items for adults or children can include handicrafts, gifts and jewelry. If you are not attending, you can send it to Diane Harms, 602 South State St., Freeburg, IL 62243. Member participation makes this an engaging and fun annual event that attracts people of all ages. The lucky winners go home with treasured items that remind them of our caring community. Your support helps many, making it possible for them to attend conference.

## Children & Teens

### Child Care

Child care for children ages 5 and under is available at the hotel on Friday and Saturday, while parents are in sessions. Care includes activities, games and videos, with plenty of time for making friends. The program is led by experienced child care workers from an established local agency, TLC Child Care ([www.TLCforkids.com](http://www.TLCforkids.com)). You can also arrange individual babysitting through TLC.

### Friday, August 5

#### Teen Opening Program

**4:00 PM**

Teens gather for a welcome orientation and get-to-know-you session with group leaders, and a theme discussion on "You Are the Artist of Your Life," which will focus on creating the life you want, turning negative into positive, defining values, making healthy decisions, setting goals, and guiding yourselves to maturity. The group will then attend the St. Louis Cardinals baseball game.

#### Children's Opening Program

**4:30 PM**

Children ages 6-12 gather from 4:30 PM to 6:30 PM for a Welcome Party, including a treasure hunt, ice cream social, pet dogs, and an opportunity to meet new friends. Children will join parents for the baseball game.

### Saturday, August 6

#### Teen Program

**8:30 AM**

Venture out for the day, starting at University City Loop's Walk of Fame. Check out the shops and best burgers in town, along with the great jukebox and memorabilia at Blueberry Hill. An afternoon at St. Louis Mills offers shopping, glow-in-the-dark mini-golf, ice skating, go carts, rock wall climbing, laser tag, and arcade games. A Saturday evening Karaoke Party at the hotel and an informal dinner with the group calls for singing your favorite songs or taking the mike with your own music, comedy, poems, and more. Games and movies will also be available.

#### Children's Program

**8:00 AM**

Children ages 6 to 12 take a day's adventure to the St. Louis Zoo in the morning and the City Museum in the afternoon. A Saturday evening pizza dinner, movies and board games will be available for children in their meeting room while parents attend the Awards Dinner.

### Sunday, August 7

#### Teen Program

**8:30 AM**

Teens enjoy a series of interactive workshops, led by skilled leaders and doctors from the NMF Professional Advisory Board, in which they can discuss their physical and emotional concerns about having the Marfan syndrome. Time for fun and socializing is interwoven throughout the day, so teens can count on having new friends and good memories when the conference is over.

#### Children's Program

**8:30 AM**

Children ages 6-12 engage in creative projects and activities that foster fun, friendships and self-esteem. A Pool Party Luau follows lunch. Children ages eight and above will meet with a doctor and social worker for questions and answers on the Marfan syndrome. The program provides a forum for sharing experiences and support for affected children and their siblings.

# Adults

## Friday, August 5

Conference Registration	2:30 – 6:30 PM
Orientation for First Time Attendees	4:00 – 4:30 PM
Welcome Reception	5:00 – 6:30 PM
Cardinals vs. Braves Baseball Game	7:00 PM

## Saturday, August 6

Registration	7:30 – 9:00 AM
Morning General Session	8:00 – 11:45 AM

*Current Diagnosis and Treatment of Marfan Syndrome and Related Disorders*  
Reed Pyeritz MD, PhD

*Cardiac Surgery in the Marfan Syndrome*  
Craig Miller, MD

*Orthopedic Issues in the Marfan Syndrome*  
Paul Sponseller, MD

*Research Update in the Marfan Syndrome*  
Hal Dietz, MD

Box Lunch	12:00 PM – 1:30 PM
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Afternoon Workshops	1:45 PM – 5:15 PM
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Choose one workshop for each of three sessions in table below.

Gala Awards Dinner at Chase Park Plaza Starlite Room	7:00 PM – 10:00 PM
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## Sunday, August 7

Registration	8:00 AM – 8:30 AM
Coping and Caring Workshops	8:30 AM – 12:45 PM
NMF Annual Meeting Luncheon	1:00 PM – 3:00 PM
Closing Program	

## Friday Evening Baseball

Through the generous donation of Mrs. Anne H. Hinds of Prospect, Kentucky, everyone is invited to attend the St. Louis Cardinals vs. the Atlanta Braves major league baseball game on Friday, August 5, at 7:00 PM at Busch Stadium, which is directly across the street from the Marriott Downtown Hotel. Anne lost her son, James, to Marfan syndrome two years ago. Her gift to you is in memory of him and his passion for baseball. Mrs. Hinds has also donated copies of Jim's book of poetry, "Circle of Life," to share his insights as a sensitive, appreciative, intelligent seeker. Although Jim was shy and very private, he made his dream clear: "We can conquer the world if we stay connected."

## Saturday Afternoon Workshops

*Session I 1:45 – 2:45	*Session II 3:00 – 4:00	*Session III 4:15 – 5:15
1 Pediatric Pain Management	2 Adult Pain Management	3 Adult Pain Management
4 Cardiac Concerns	5 Post Dissection Cardiac Concerns	6 Cardiac Concerns
7 Aortic Surgery	8 Aortic Surgery	9 Aortic Surgery
10 Marfan 101 for Newly Diagnosed	11 Psychosocial Issues Regarding Affected Children	12 Psychosocial Issues Regarding Affected Adults
13 Growing Older with Marfan Syndrome	14 Growing Older with Marfan Syndrome	15 Exercise and Staying Fit
16 Pediatric Concerns	17 Pediatric Cardiac Concerns	18 Pediatric Cardiac Concerns
19 Ophthalmology	20 Pregnancy Issues	21 Ophthalmology
22 Orthopedic Concerns	23 Related Connective Tissue Disorders	24 Orthopedic Pediatric Concerns
25 Radiology 101 Aortic Imaging	26 Pulmonary Concerns	27 Pulmonary Concerns
28 Pectus Management	29 Radiology 101 Aortic Imaging	30 Familial Aortic Aneurysm
31 Family Genetics		

## Sunday Morning Workshops

*Session I 8:30 – 9:45	*Session II 10:00 – 11:15	*Session III 11:30 – 12:45
32 For Parents: Communicating with School, Doctor & Family	33 For Parents: Self Image, Peer/Sibling Relationships	34 Patient Rights, Resources & Responsibilities
35 Bereavement: Loss of Idealized Self	36 Support Group for Parents of Children Under 18	37 Support Group for Parents of Children Under 18
38 Coping with the Marfan Syndrome	39 Coping with the Marfan Syndrome	
40 Introduction to Integrative Medicine	41 Introduction to Integrative Medicine	42 Healing Touch Energy Therapy
43 Coping with Related Disorders	44 Benefits of Genetic Counseling	45 Communicating with your Doctor & Self Empowerment
46 Alternatives in Buying and Paying for Health Care	47 Developing your Emergency Plan Kit	48 Developing your Emergency Plan Kit
49 Facing Cardiovascular Surgery	50 Facing Orthopedic Surgery	51 Young Adults Ages 20-30 Something
52 Session for Unaffected Spouses & Significant Others	53 The Adoption Option	54 Couples Workshop

\*Choose one workshop for each of three sessions in table above.

# Registration Form

*please complete both sides*

## 1. Individual Registration Information

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		
<input type="checkbox"/> 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			Age (if 18 or younger):		
Special Needs (please specify diet, wheelchair, etc.):			Affected with Marfan:		Related Disorder:
			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe		<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Maybe
			Meal Preference: <input type="checkbox"/> Regular <input type="checkbox"/> Vegetarian		
<b>Adults:</b> Please indicate your selections below.					
Which of the following will you attend?					
<input type="checkbox"/> Friday Welcome Reception <input type="checkbox"/> Friday Baseball Game <input type="checkbox"/> Saturday Gala Awards Dinner <input type="checkbox"/> 20-30 Something Gatherings					
Saturday Workshop Selections			Sunday Workshop Selections		
Session	Number	Title	Session	Number	Title
1			1		
2			2		
3			3		
<b>Children (6-12):</b> Please indicate activity selections below:			<b>Teens (13-18):</b> Please indicate activity selections below:		
Friday <input type="checkbox"/> Opening Program <input type="checkbox"/> Ballgame			Friday <input type="checkbox"/> Opening Program <input type="checkbox"/> Ballgame		
Saturday <input type="checkbox"/> Saturday Trip <input type="checkbox"/> Pizza Dinner			Saturday <input type="checkbox"/> Saturday Trip <input type="checkbox"/> Dinner & Karaoke		
Sunday <input type="checkbox"/> Sunday Program & Pool Party			Sunday <input type="checkbox"/> Sunday Program		
<b>Children (0-5):</b> Please indicate child care needs:			<input type="checkbox"/> Friday Child Care <input type="checkbox"/> Saturday Child Care		

# 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
<b>Full Conference</b>			
Members (19+)(Register by June 1)		\$275	
Members (19+)(Register after June 1)		\$375	
Non-Members		\$400	
Children (6-12)		- 0 -	
Teens (13-18)		- 0 -	
Child Care (0-5)		- 0 -	
<b>One Day Only</b>			
Members (19+)		\$175	
Non-Members		\$225	
Children (6-12)		- 0 -	
Teens (13-18)		- 0 -	
Child Care (0-5)		- 0 -	
<b>Optional</b>			
Scholarship Fund Donation			
Membership Dues (Individual)		\$35	
Membership Dues (Family)		\$50	
<b>Total Amount Due</b>			

## 3. Payment Method

I am applying for a conference scholarship. (Attach this registration form to your scholarship request (see reverse). 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.

Please charge my credit card:       Visa       Mastercard       American Express

Card No.

Exp. Date

Full Name on Card

Address (if different from primary contact)

Signature of Cardholder

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

## Hotel Information

The conference programs will be held at the Marriott St. Louis Downtown, One S. Broadway, St. Louis, MO 63102. Located in the heart of St. Louis' rich history, bustling activity and excitement, this hotel is an oasis with unrivaled views of the Civic Center setting: Busch Stadium to the south, Kiener Plaza to the north, the Gateway Arch and Mississippi River to the east, and all the wonders of the city to the west. Our group rate is \$119 per night. Deadline for reservations is July 5. For room reservations call (314) 421-1776, or 1-800-MARRIOTT, and state you are with the NMF conference

## Parking

Self Parking is across the street at Stadium East at \$10 per night; daytime charge is \$5 on Friday (if in between 5 am–9 am and out between 3 pm–6 pm). Due to a ballgame on Saturday, the day rate is \$15. Valet parking on the hotel property is \$15.

## Scholarships

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 either:

- a letter telling the NMF why you want to attend 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 office at 800-862-7326 ext.10.

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

The generosity of our members makes scholarships possible. For those able to make a contribution to the scholarship fund you can:

- Send a check, payable to the NMF, to NMF, 22 Manhasset Ave., Pt. Washington, NY 11050. Put "Scholarship Fund" in the memo line.
- Include a donation with your registration
- Use the "scholarship" option in the donation section of the NMF website: [www.marfan.org](http://www.marfan.org)

## Travel Arrangements

- By car: Four interstate highways (I-70, I-55, I-64 and I-44) all converge on the downtown area from six different directions.
- By air: Lambert-St. Louis International Airport is 15 miles (20 minutes) from downtown. Transportation from the airport is available via shuttle, limousine, taxi service and by MetroLink light rail.
- Other public transportation: Greyhound Bus Lines and Amtrak rail service have arrival stations within one mile of the hotel.

Travel details and maps are included in your Registration Confirmation packet sent after you register.

## Registration Fees

Included in the registration fees are:

- Welcome Reception
- Baseball Game
- Breakfast, Lunch and dinner on Saturday
- Breakfast, Lunch on Sunday
- Adult sessions and materials
- Children and teen programs and activities
- Babysitting for Ballgame & Awards Dinner

If you have questions or concerns, please call the NMF office at 800-8-MARFAN, x 10. Payment is by check or credit card. There is no on-line registration; however, the conference brochure and registration form are posted on the NMF website at [www.marfan.org](http://www.marfan.org).

### "20 and 30-Somethings"

If you are in your 20s or 30s, meet your colleagues at the Welcome Reception and travel together to the Friday baseball game, Saturday Gala Awards Dinner, and the special Sunday workshop dealing with age appropriate topics. Look for signs showing gathering point.



National Marfan Foundation  
22 Manhasset Avenue  
Port Washington, NY 11050

### Deadlines:

June 1: Scholarships

June 1: Clinic Appointments

June 1: Conference Registration with discount

July 5: Hotel Reservations

Non-Profit Org.  
U.S. Postage  
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Port Washington, NY  
11050

**Meet Us in St. Louis for the 21st Annual Conference!**