



THE **MARFAN**
FOUNDATION

ANNUAL FAMILY
CONFERENCE



AUGUST 6-9 2015 CHICAGO | IL

CO-HOSTED BY

M Northwestern
Medicine®

 Ann & Robert H. Lurie
Children's Hospital of Chicago®



OUR TEAM IS IN YOUR CORNER.

At Northwestern Medicine's Bluhm Cardiovascular Institute we are committed to bringing breakthrough care to the communities we serve. Which is why we are proud to host the 2015 Marfan Foundation Annual Family Conference. Our experts are dedicated to educating, treating and supporting those living with Marfan Syndrome.

To learn more, call **312.NM.HEART (664.3278)** or visit Bluhm Cardiovascular Institute at **heart.nm.org**.



Every breakthrough leads to you.

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WELCOME



Dear Friends,

On behalf of everyone at The Marfan Foundation, we are thrilled to welcome you to our 31st Annual Family Conference! While we are excited to see many of our old friends, we are equally excited to meet the new folks who are joining us for the first time. The friendships you will make this weekend are truly priceless!

We know you are here for medical information and we can assure you that you will learn something new this weekend, whether this is your first conference or your twenty-first. We have over 64 workshops and special tracks for our Spanish speaking friends, young adults, and teens.



We are grateful to Northwestern Medicine® and Ann & Robert H. Lurie Children's Hospital of Chicago for hosting our conference for a second time and for their continued collaboration and partnership. They bring exceptional medical expertise to our conference for the medical presentations and workshops, as well as for the free patient health evaluations that many of our conference attendees had on Thursday and Friday. We are thrilled to offer you this opportunity to get the diagnosis and treatment guidance you need and leave with advice from the country's leading experts on Marfan syndrome and related disorders. Many of these experts will be speaking at our general session and leading workshops throughout the weekend. We encourage you to soak up as much information as you can in the formal sessions, in the small group breakouts, and even at coffee breaks. Our medical experts want to meet you and help you on your medical journey.

We are also very appreciative of the members of our Professional Advisory Board and many other physicians, who are the leaders in patient care and research on Marfan syndrome and related disorders. They come to our conference each year from every corner of the country, volunteering their time to get to know you and bringing the latest information for our patient community. Your concerns are their concerns, and they learn as much from you at the conference as you learn from them.

In addition, we offer a big thank-you to our Northern Illinois Chapter, an energetic and passionate group of volunteers that has worked so hard to ensure that your 2015 conference experience is a memorable one. We would also like to extend our gratitude to Tim Joyce, our photographer, who always provides us with countless memories of this wonderful weekend.

Thank you for joining our community this weekend. We hope you enjoy Chicago and, most of all, we hope you enjoy your "Marf-family." This conference is the highlight of the year for everyone at The Marfan Foundation and we hope it will be one for you too!

A handwritten signature in black ink that reads "Karen Murray".

Karen Murray
Chair, Board of Directors

A handwritten signature in black ink that reads "Michael L. Weamer".

Michael L. Weamer
President and CEO

CONFERENCE SCHEDULE AT-A-GLANCE

Locations listed below: **Navy Pier**, 600 East Grand Ave.; **Northwestern Memorial Hospital (NMH)**, 251 East Huron St.; **Lurie Children's Hospital (LCH)**, 225 East Chicago Ave.; **The Warwick Allerton Hotel (Allerton)**, 701 North Michigan Ave.

THURSDAY | AUGUST 6

By appointment	Lurie Children's Hospital	Patient Health Assessments
8:00 – 11:00 PM	Allerton, Olmstead, 4th Floor	Hospitality Room

FRIDAY | AUGUST 7

By appointment	NMH, Galter, 19th Floor	Patient Health Assessments
9:00 AM – 5:00 PM	NMH, Feinberg, 3rd Floor	Registration/Information Desk
6:00 – 10:00 PM	Navy Pier, Aon Ballroom	Welcome Reception, Dinner & Awards Ceremony
6:00 – 8:30 PM	Navy Pier, 3rd Floor, Room 329	Children's Dinner & Activities
6:00 – 10:45 PM	Navy Pier, Foyer, 2nd Floor	Teen Dinner & Activities

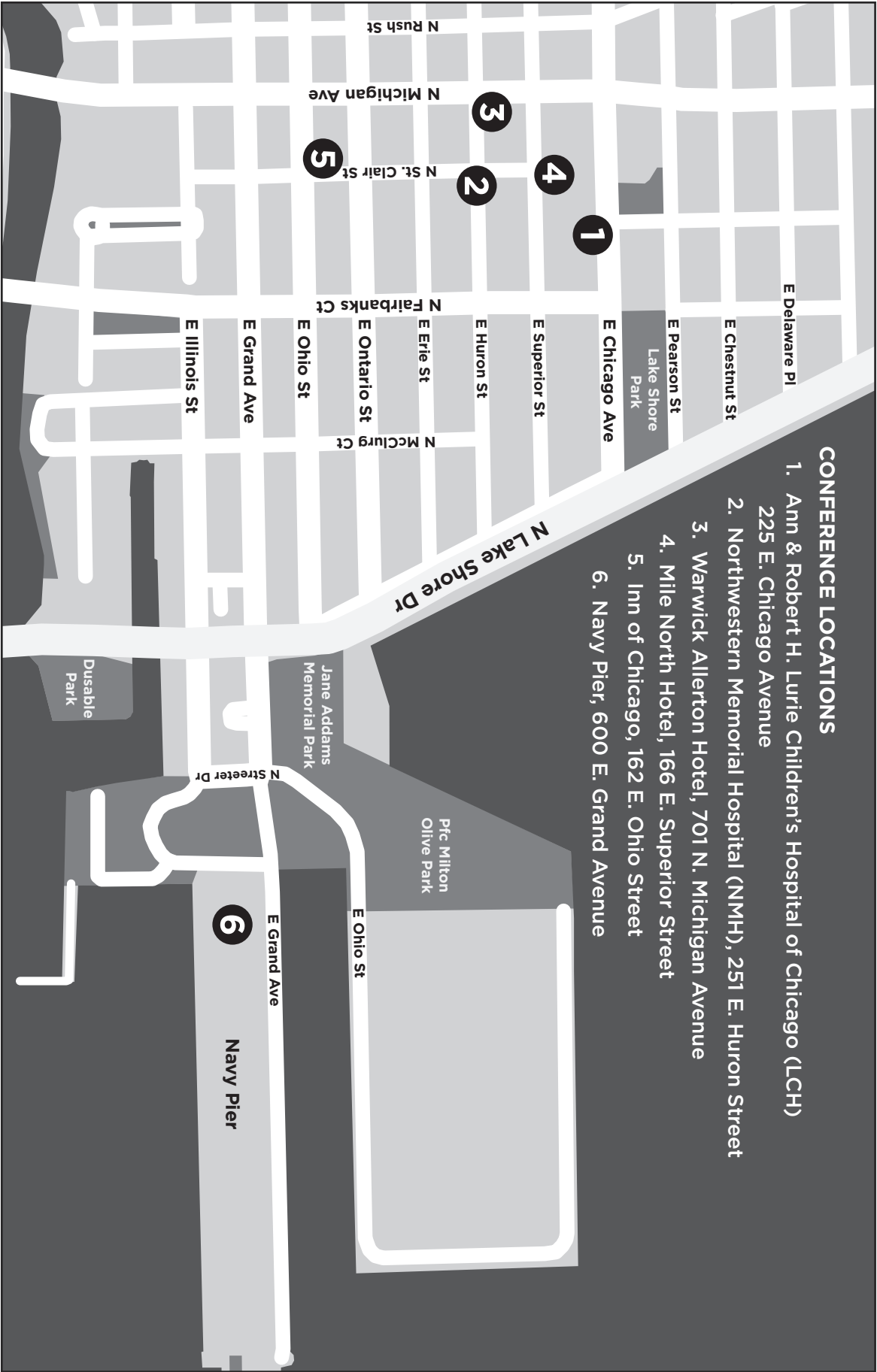
SATURDAY | AUGUST 8

7:00 – 8:30 AM	NMH, Feinberg, 3rd Floor Atrium	Continental Breakfast
7:00 AM – 5:00 PM	NMH, Feinberg, 3rd Floor	Registration/Information Desk
8:00 AM – 5:00 PM	Legoland & Adler Planetarium	Children's Program, Field Trip
8:00 AM – 5:00 PM	NMH, Feinberg, 3rd Floor	Teen Program, Field Trip
8:30 AM – 12:15 PM	NMH, Feinberg, 3rd Floor	General Session
12:30 – 1:30 PM	NMH, Feinberg, 3rd Floor Atrium	Lunch
1:30 – 5:00 PM	NMH, Feinberg, 3rd Floor	Saturday Workshops
6:00 – 10:30 PM	Meet in Allerton Main Lobby	Young Adult Dinner & Show
6:00 – 8:30 PM	Athenaeum Theater	Reception & Dance Performance
8:30 – 11:00 PM	Allerton, Olmstead, 4th Floor	Hospitality Room
8:30 – 11:00 PM	Allerton, Buckingham, 3rd Floor	Teen Dinner & Activities

SUNDAY | AUGUST 9

7:00 – 8:30 AM	NMH, Feinberg, 3rd Floor Atrium	Continental Breakfast
7:00 AM – 3:00 PM	NMH, Feinberg, 3rd Floor	Registration/Information Desk
8:00 AM – 12:00 NOON	LCH, 11th Floor	Teen Program
8:00 AM – 3:00 PM	LCH, 22nd Floor	Children's Program
8:30 AM – 12:00 NOON	NMH, Feinberg, 3rd Floor	Sunday Workshops
12:00 NOON – 3:00 PM	NMH, Feinberg, 3rd Floor	Lunch and Living Successfully Panel

HOSPITALITY ROOM for all conference attendees Thursday and Saturday evening. Stop in to meet fellow conference attendees and their families, share experiences, and connect with others to join you on the town! Hosted by members of the Northern Illinois Chapter.



CONFERENCE LOCATIONS

1. Ann & Robert H. Lurie Children's Hospital of Chicago (LCH)
225 E. Chicago Avenue
2. Northwestern Memorial Hospital (NMH), 251 E. Huron Street
3. Warwick Allerton Hotel, 701 N. Michigan Avenue
4. Mile North Hotel, 166 E. Superior Street
5. Inn of Chicago, 162 E. Ohio Street
6. Navy Pier, 600 E. Grand Avenue

Navy Pier:

Welcome Event
Awards Presentation
Friday Children's Program
Friday Teen Program

Ann & Robert H. Lurie Children's Hospital of Chicago (LCH):

Ophthalmology Appointments
Echocardiograms
Sunday Children's Program
Sunday Teen Program

Northwestern Memorial Hospital (NMH):

Patient Evaluations
Conference Registration
Exhibits
General Session
Teen Program
Adult Workshops
Living Successfully Panel

Warwick Allerton Hotel:

Volunteer Leadership Meeting
Board of Directors Meeting
Friday & Saturday Night Teen Pick-ups
Hospitality Suite

FRIDAY

9:00 – 5:00 PM
REGISTRATION & INFORMATION
 NORTHWESTERN MEMORIAL HOSPITAL
 FEINBERG PAVILION, 3RD FLOOR

4:30 – 10:30 PM

BUS TRANSPORTATION TO NAVY PIER

Buses will depart from the Warwick Allerton Hotel and the Inn of Chicago to Navy Pier starting at 4:30 PM and round-trip service will continue until 10:30 PM.

10:30 PM

LAST BUS DEPARTS FROM NAVY PIER

FRIDAY ACTIVITIES TAKE PLACE AT NAVY PIER, AON GRAND BALLROOM.

6:00 – 10:00 PM

WELCOME RECEPTION, DINNER & AWARDS CEREMONY

All conference attendees. Opportunity to meet other conference attendees and socialize. Enjoy a light dinner and celebrate those who have made outstanding contributions to the Marfan syndrome and related disorders community.

Y YOUNG ADULTS: Meet at designated tables.

C 6:00 – 8:30 PM

CHILDREN'S DINNER & ACTIVITIES

Navy Pier, 2nd Floor Ballroom Balcony

Children will have dinner and play icebreaker games.

Joseff Weismantel, a child life therapist from Lurie Children's Hospital, will lead them in age-appropriate play and self-expression activities. Activities will take place in Room 329.

PARENTS: Pick up your children promptly after the awards ceremony.

T 6:00 – 10:45 PM

TEEN DINNER & ACTIVITIES

Navy Pier, 2nd Floor Ballroom Balcony

Join other teens, including our Teen Council members and teen mentors, for dinner with Isaiah Austin, an overview of the conference, icebreaker games, and gender break-out discussion groups. Bus transportation to the Warwick Allerton Hotel provided for teens at 10:30 PM.

PARENTS: Pick up your teens at the Warwick Allerton Hotel Main Lobby at 10:45 PM

FRIDAY PARENT PICK-UPS

8:30 PM: Pick up your children (ages 5–12) promptly after the awards ceremony at Navy Pier, 2nd Floor Ballroom Balcony.

10:45 PM: Pick up your teens (ages 13–18) at the Warwick Allerton Hotel, Main Lobby.

C Programming for children ages 5–12

T Programming for teens ages 13–18

Y Programming for young adults ages 19–25

 Find us on Facebook

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SATURDAY

7:00 AM – 5:00 PM
REGISTRATION & INFORMATION
NORTHWESTERN MEMORIAL HOSPITAL
FEINBERG PAVILION, 3RD FLOOR

SATURDAY ACTIVITIES TAKE PLACE AT NORTHWESTERN MEMORIAL HOSPITAL (NMH) FEINBERG PAVILION UNLESS OTHERWISE INDICATED.

7:00 – 8:30 AM	CONTINENTAL BREAKFAST All conference attendees.	NMH Feinberg Pavilion, 3rd Floor Atrium
8:30 – 12:15 PM	GENERAL SESSION All adult attendees. Opening Remarks: Josephine Grima, PhD, The Marfan Foundation PART 1 Moderator: Luciana Young, MD Research Update: Hal Dietz, MD Ocular Management: Marilyn Mets, MD Orthopedic Management: Paul Sponseller, MD Q & A + Break PART 2 Moderator: Chris Malaisrie, MD Cardiothoracic Surgery: Craig Miller, MD Cardiac Management: Luciana Young, MD Atenolol vs. Losartan in Marfan Syndrome Clinical Trial Results: Ronald V. Lacro, MD Q & A + Break	NMH Feinberg Pavilion, Conference Rooms A-D
12:30 – 1:30 PM	BOX LUNCH All adult attendees.	NMH Feinberg Pavilion, 3rd Floor Atrium
1:30 – 5:00 PM	SATURDAY WORKSHOPS Choose from a variety of workshop topics that focus on medical issues in each of three 1-hour sessions. See pages 13-18 for descriptions, presenters, and locations. Y YOUNG ADULTS: A workshop track geared specifically to young adults, but you may attend any of the regular adult workshops. See pages 13-18 for descriptions, presenters, and locations.	See pages 13-18
6:00 – 8:30 PM	EXCLUSIVE OPPORTUNITY: RECEPTION & PERFORMANCE <i>All conference attendees, including children and teens.</i> Reception with Tony Award-winning actress and choreographer, Ann Reinking, and Austin Carlile, lead singer of the band Of Mice & Men, followed by a dance performance choreographed by Ms. Reinking. Round-trip bus transportation between the Warwick Allerton Hotel and Inn of Chicago and the Athenaeum Theater will be provided beginning at 5:30 PM.	Athenaeum Theater
Y 6:00 – 10:30 PM	YOUNG ADULT DINNER & SHOW <i>This event is open only to those who have registered for the Young Adult Program.</i> Meet in the main lobby of the Warwick Allerton Hotel and join other young adults for dinner and an improv show at the iO Theater. Bus transportation will be provided to and from show.	iO Theater

SATURDAY CHILDREN & TEEN ACTIVITIES

IMPORTANT: ALL CHILDREN AND TEENS MUST WEAR THEIR CONFERENCE T-SHIRTS AND NAME TAGS FOR ALL SATURDAY ACTIVITIES!

C 8:00 AM – 5:00 PM CHILDREN’S PROGRAM: FIELD TRIP

LEGOLAND & Adler Planetarium

8:00 AM Sharp—PARENTS:

Drop off your children by 8:00 AM at NMH, Feinberg Pavilion, 1st Floor.

Children will be broken into groups of five by age and gender. Each group of five will have a chaperone assigned to them. Children will then board buses and travel to Legoland and Adler Planetarium, where they will explore the exhibits and watch a Grainger Sky Theater show. Lunch will be provided.

5:00 PM Sharp—PARENTS:

Pick up your children at 5:00 PM at NMH, Feinberg Pavilion, 1st Floor.

T 8:30 AM – 5:00 PM TEEN PROGRAM

NMH Feinberg Pavilion, 3rd Floor Atrium

8:30 – 9:15 AM: Teen Breakfast with the Doctors

Have breakfast with a panel of doctors who will answer your questions, followed by a short break. Panelists: Irene Maumenee, MD; Dianna Milewicz, MD, PhD; Mark Lindsay, MD, PhD; Duke Cameron, MD; Heidi Connolly, MD; and Enid Neptune, MD

9:30 – 11:20 AM: Teen Workshops

Choose from one of four workshop topics, all geared specifically to teens, in each of these two 50-minute sessions. There will be a 10-minute break between the two sessions. See page 11 for descriptions, presenters, and locations.

11:30 AM – 5:00 PM: Field Trip

Spirit Cruise & Skydeck

Board buses at 11:30 AM and head out for an afternoon on the water and in the sky. Enjoy lunch on a Spirit Cruise and then get a bird’s eye view of the windy city from the Travel Skydeck, at Chicago’s tallest building.

PARENTS: Pick up your teens at 5:00 PM at NMH, Feinberg Pavilion, 1st Floor.

T 8:30 – 11:00 PM

TEEN DINNER & ACTIVITIES

Warwick Allerton Hotel, Buckingham Room, 3rd Floor

Dinner, dancing, games, and socializing just for teens.

PARENTS: Pick up your teens at the Allerton Hotel, Buckingham Room, 3rd Floor, at 11:00 PM.

SATURDAY PARENT DROP-OFFS AND PICK-UPS

8:00 AM: Drop off your children (ages 5–12) at the NMH Feinberg Pavilion, 1st Floor.

5:00 PM: Pick up your children (ages 5–12) and/or teens (ages 13–18) at the NMH Feinberg Pavilion, 1st Floor.

11:00 PM: Pick up your teens (ages 13–18) at the Warwick Allerton Hotel, Buckingham Room, 3rd Floor.

SUNDAY

7:00 AM – 3:00 PM
REGISTRATION & INFORMATION
NORTHWESTERN MEMORIAL HOSPITAL
FEINBERG PAVILION, 3RD FLOOR

SUNDAY ACTIVITIES TAKE PLACE AT NORTHWESTERN MEMORIAL HOSPITAL, FEINBERG PAVILION, 3RD FLOOR, UNLESS OTHERWISE INDICATED.

7:00 – 8:30 AM	CONTINENTAL BREAKFAST <i>All conference attendees.</i>	3rd Floor Atrium
8:30 AM – 12:00 NOON	SUNDAY WORKSHOPS Choose from a variety of workshop topics that focus on psychological, social, emotional, and lifestyle issues in each of three 1-hour sessions. See pages 19–23 for descriptions, presenters, and locations. Y YOUNG ADULTS: A workshop track geared specifically to young adults, but you may attend any of the regular adult workshops. See pages 19–23 for descriptions, presenters, and locations.	See pages 19–23
12:00 NOON – 1:00 PM	BOX LUNCH All adult and teen attendees.	3rd Floor Atrium
1:15 – 3:00 PM	LIVING SUCCESSFULLY PANEL All adult and teen attendees. The traditional conclusion of our Annual Family Conference is this panel discussion led by a group of adults and teens on coping with Marfan syndrome and related disorders.	Conference Rooms A–D

SUNDAY PARENT DROP-OFFS AND PICK-UPS

8:00 AM: Drop off your children (ages 5–12) and teens (ages 13–18) on the first floor of the NMH Feinberg Pavilion.
3:00 PM: Pick up your children (ages 5–12) and teens (ages 13–18) at the end of the program in Conf. Rooms A–D.

C 8:00 AM – 3:00 PM CHILDREN'S PROGRAM

LCH, 22nd Floor

8:00 AM Sharp—PARENTS: Drop off your children by 8:00 AM at NMH, Feinberg Pavilion, 1st Floor. Children will walk to Lurie Children's Hospital for the following activities:

8:30 – 9:30 AM: Ask the Experts Age-appropriate presentations on Marfan syndrome and related disorders followed by a Q&A.

9:30 AM – 12:30 PM: Fun Activities Age appropriate groups will participate separately in the activities offered, including a game show with prizes, magic show, stuff-a-plush, and color-a-tee.

12:30 – 3:00 PM: Lunch, Movie, Games, and Arts & Crafts Children will have lunch followed by an age-appropriate movie and opportunities to play board games and do arts & crafts. Children will be escorted back to Northwestern Memorial Hospital to join the Living Successfully program.

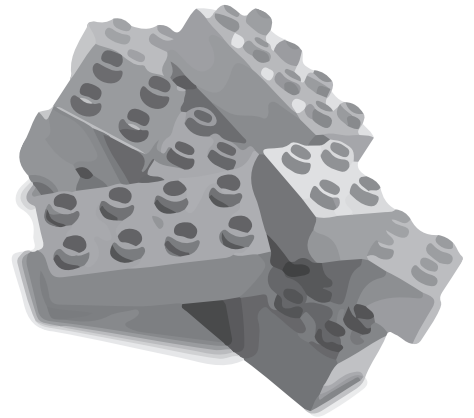
T 8:00 AM – 12:00 NOON

TEEN PROGRAM

LCH, 11th Floor

Meet at 8:00 AM on the 1st floor of NMH Feinberg Pavilion and walk to Lurie Children's Hospital, where you can participate in a variety of games and activities. At noon, join the adults for lunch and the Living Successfully program.

JUST FOR **KIDS!**



AGES
5-12

FRIDAY

While your parents are attending the welcome reception, you will play games, have dinner, and make new friends!



SATURDAY

First, visit LEGOLAND® and explore the world's biggest box of LEGO bricks! Then we'll have lunch and head over to the Adler Planetarium. At the Planetarium, you will take a trip to the future with *Destination Solar System*, a live show that takes explorers on a tour of the sun, moon, stars, and the great big universe that we live in.

At night, you and your parents can go to a special dance performance and meet Ann Reinking, a famous actress whose son also has Marfan syndrome!

**You MUST
wear your
conference t-shirt
and name tag
on Saturday!**

SUNDAY

Learn more about Marfan syndrome and related disorders from the experts! Doctors and other super smart people will talk with you and answer any questions you want to ask them.

Then it's time for fun! You can see a magic show, make your own stuffed animals, and paint a tee-shirt like nobody else's. Older kids can also compete in a game show and win prizes.

Hungry again? We'll have lunch together and then have more fun, doing arts & crafts, playing games, and watching a movie.

SUNDAY LUNCH
SPONSORED BY



A MORE MINDFUL BURGER

JUST FOR **TEENS!** AGES 13-18

SATURDAY

You **MUST** wear your
conference t-shirt and name tag
for all Saturday events.

8:30 AM: **BREAKFAST WITH THE DOCTORS**

(Northwestern Memorial Hospital—NMH—Feinberg Pavilion, 3rd Floor Atrium)

9:30 AM: **WORKSHOPS** Choose from the workshops on the opposite page.

11:30: **FIELD TRIP—SPIRIT LUNCH CRUISE AND WILLIS TOWER SKYDECK**

(Meet at NMH Feinberg Pavilion, 1st Floor)

Enjoy lunch on Lake Michigan from on-board a Spirit Cruise ship, then head for the top of the tallest building in the Western Hemisphere, Willis Tower, and experience the Skydeck, with views spanning four states, interactive exhibits, and The Ledge, a glass box that let's you look 103 floors beneath your feet. Meet your parents back at the hospital at 5:00 PM.

6:00 PM: **RECEPTION & DANCE PERFORMANCE** (Athenaeum Theater)

Come with your parents to a reception with Broadway actress and choreographer, Ann Reinking, and Austin Carlile, of the band Of Mice and Men, followed by a dance performance. Transportation, specifically for teens, from the event will be provided to the teen activities at the Allerton.

8:30 PM: **TEEN DINNER & ACTIVITIES** (Warwick Allerton Hotel, 3rd Floor, Buckingham Room)

Join other teens for dinner, dancing, board games, and socializing. Your parents will pick you up at 11:00 PM.

SUNDAY

8:00 AM: **TEEN ACTIVITIES**

(Meet at NMH, Feinberg Pavilion, 1st floor; we'll walk over to Lurie Children's Hospital)

Compete in a game show, make tie-dye tee-shirts, and participate in other activities we'll have available.

At noon, we'll come back to Northwestern Memorial Hospital where you'll join the adults for lunch and the Living Successfully program.

FRIDAY

Meet other teens at your own Welcome Dinner at Navy Pier, where you'll play icebreaker games and get an overview of the weekend.

Afterwards, break into separate groups of boys and girls for in-depth conversations about living with Marfan syndrome and related disorders, moderated by teen mentors diagnosed with these conditions and medical experts.

Buses will bring you back to the Warwick Allerton Hotel, where your parents will meet you.

TEEN WORKSHOPS

AT NORTHWESTERN MEMORIAL HOSPITAL, FEINBERG PAVILION

SESSION 1 9:30–10:20 AM

GENETICS 101 (2nd Floor, Room 2-716)

Learn about genetic testing, how Marfan syndrome and related disorders are inherited, and family planning. Have your genetics questions answered. Led by Dr. Dianna Milewicz.

EYE ISSUES (2nd Floor, Room 2-715)

Learn about the eye problems associated with Marfan syndrome and some related disorders and the recommended treatments. Led by Dr. Irene Maumenee.

MEDICATIONS 101 (3rd Floor, Conference Room F)

Learn about the different types of medications used to treat Marfan syndrome and related disorders, how they work, possible side effects, why they are prescribed, and why it's important to take them as prescribed. Led by Dr. Mark Lindsay.

CARDIAC SURGERY (3rd Floor, Conference Room E)

Learn about heart surgery, what to expect, and what you don't need to worry about. Led by Dr. Duke Cameron.

SESSION 2 10:30–11:20 AM

LIFE AFTER HIGH SCHOOL (3rd Floor, Conference Room E)

Talk with a panel of young adults living with Marfan syndrome and related disorders about topics including going to college, getting a job, managing relationships, and more. Panelists are Lou Arias, Allegra Delgado, and Ali Austin.

PREPARING FOR COLLEGE (3rd Floor, Conference Room F)

Learn what to consider when choosing a college, how to apply, about the Americans with Disabilities Act, and more. This workshop addresses everything you need to know to get ready for college. Led by Maya Brown-Zimmerman.

DO'S AND DON'T'S OF RELATIONSHIPS (2nd Floor, Room 2-715)

Talking to family, friends, and peers about living with Marfan syndrome or a related disorder isn't easy. What to share? What not to share? How and when to share it? These and other questions are addressed in this workshop. Led by family therapist, Annie Bao.

MARFRIENDS (2nd Floor, Room 2-716)

Are you the unaffected sibling or friend of a teen diagnosed with Marfan syndrome or a related disorder? Family members and friends need support too. Talk with others who know what it's like. Led by Alix McLean Jennings.

JUST FOR **YOUNG ADULTS!**

AGES 19–25

FRIDAY

6:00 PM
DINNER

Sit together at designated tables during the Dinner & Awards Ceremony. Then at 8:30, a group of young adults will set out to explore Navy Pier together. Just make sure you're back for the last bus back to the hotels at 10:30 PM.

SATURDAY

1:30 – 5:00 PM
WORKSHOPS

The **K workshop track** is geared specifically to young adults, but you can also attend any of the adult workshops described on the following pages.

SESSION 1 | K 1
**Developing an
Emergency Plan**

SESSION 2 | K2
**Transitioning to
Adult Care**

SESSION 3 | K3
**Ask the Doctors/
Gender Breakouts**

6:00 PM
**DINNER &
IMPROV SHOW**

Meet in the Allerton Hotel Main Lobby and we'll head out for an evening of improv at the iO Theater and have dinner as a group. *You MUST have registered for the Young Adult Program in advance to participate.*

SUNDAY

8:30 AM –
12:00 NOON
WORKSHOPS

The **H workshop track** is geared specifically to young adults, but you can also attend any of the adult workshops described on the following pages.

SESSION 4 | H4
**Staying Fit with
Marfan Syndrome**

SESSION 5 | H5
**Family Planning
Decisions**

SESSION 6 | H6
**Facing Your
Fears**

Look for the **Y** in this program—it designates an activity or workshop just for young adults.

SATURDAY WORKSHOPS

Descriptions and presenters appear on the following pages.

	SESSION 1: 1:30–2:30 PM	SESSION 2: 2:45–3:45 PM	SESSION 3: 4:00–5:00 PM
A	A1 Conference Room D Marfan 101	A2 Conference Room E Ehlers-Danlos, FAA, and Other Related Disorders (except Loeys-Dietz)	A3 Conference Room D Children's Issues in Marfan Syndrome
B	B1 Pritzker Bone and Joint Issues	B2 Conference Room F Bone and Joint Issues in Children	B3 Conference Room F Foot and Ankle Issues
C	C1 Conference Room F Heart-Related Issues in Children	C2 2nd Floor, Room 2-716 Heart-Related Issues in Children	C3 Conference Room B Aortic Surgery in Children and Teens
D	D1 Conference Room A1 Genetic Testing: Benefits and Limits in Diagnosis	D2 Conference Room D Evaluating the Aorta: Understanding the Tests and Results	D3 Conference Room E Vascular Surgery: Aneurysms in Blood Vessels Other Than the Ascending Aorta
E	E1 Conference Room E Heart-Related Issues in Adults	E2 Conference Room A1 After a Dissection: Ongoing Heart-Related Care	E3 Conference Room C Heart-Related Issues in Adults
F	F1 Conference Room A2 Aortic Surgery—What are the Options?	F2 Conference Room A2 Planning to Become Pregnant? Heart-Related Care for Before, During, and After Pregnancy	F3 Conference Room A1 Family Planning Options: Preimplantation Genetics, Genetic Diagnosis, and Adoption
G	G1 Conference Room A3 Eye Issues in Marfan Syndrome	G2 Conference Room C Optimizing Your Vision: Correction and Rehabilitation Options	G3 Conference Room A2 Dental Issues
H	H1 Conference Room C Managing Chest Deformities	H2 Conf. Room B Lung Issues	H3 Conference Room A3 Sleep Apnea
I	SPANISH LANGUAGE WORKSHOP I1 Health Learning Center Marfan Syndrome and Related Disorders Diagnosis & Management	I2 Conference Room A3 Loeys-Dietz Syndrome 101 & Surgical Concerns	I3 Health Learning Center Mitral Valve Repair in Marfan Syndrome
J	J1 Conference Room B Growing Older with Marfan Syndrome	J2 Pritzker Exercise and Staying Fit	J3 Pritzker Chronic Pain Problems and Dural Ectasia
K Y	YOUNG ADULT TRACK K1 2nd Floor, Room 2-715 Developing an Emergency Plan	YOUNG ADULT TRACK K2 2nd Floor, Room 2-715 Transitioning to Adult Care	YOUNG ADULT TRACK K3 2nd Fl, Rooms 2-715 + 2-716 Ask the Doctors/Gender Breakouts

SATURDAY WORKSHOPS

WORKSHOP SESSION 1

1:30–2:30 PM

Conf. Room D

A1 | Marfan 101

This session provides a review of the management of the various features of Marfan syndrome. It helps the newly diagnosed understand the big picture and learn about the most important aspects of ongoing management and treatment.

Philip F. Giampietro, MD, PhD, University of Wisconsin School of Medicine and Public Health
Barbara K. Burton, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

Pritzker

B1 | Bone and Joint Issues

Increase your overall understanding of bone and joint issues in adults and how to treat them. In-depth workshops are offered on specific bone and joint topics, for those who need more detailed information.

Paul D. Sponseller, MD, MBA, Johns Hopkins Hospital

Conf. Room F

C1 | Heart-Related Issues in Children

Increase your overall understanding of heart-related issues in children. Topics include medication, exercise guidelines, and timing of aortic surgery.

Ronald V. Lacro, MD, Boston Children's Hospital
Luciana T. Young, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room A1

D1 | Genetic Testing: Limits and Benefits in Diagnosis

Learn about the benefits and limitations of genetic testing for Marfan syndrome and related disorders, such as Loeys-Dietz syndrome.

Peter H. Byers, MD, University of Washington School of Medicine
Hal C. Dietz, MD, Johns Hopkins Hospital
Elizabeth McNally, MD, PhD, Northwestern University Feinberg School of Medicine

Conf. Room E

E1 | Heart-Related Issues in Adults

Increase your overall understanding of heart-related issues in adults, including arrhythmias. Learn about medications, lifestyle modification, and how to prevent aortic dissection and other emergency situations. *Note: There is a separate workshop (C1) that focuses on heart-related issues in children and teens.*

Heidi M. Connolly, MD, FACC, Mayo Clinic
Alan C. Braverman, MD, Washington University School of Medicine
Andrew de Freitas, MD, Northwestern University Feinberg School of Medicine and Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room A2

F1 | Aortic Surgery—What Are the Options?

Learn about the advantages and disadvantages of the current options for ascending and/or descending aortic surgery, and how to decide which option is best for you.

Joseph S. Coselli, MD, Baylor College of Medicine, St. Luke's Episcopal Hospital, and Texas Heart Institute
Chris Malaisrie, MD, Northwestern University Feinberg School of Medicine

Conf. Room A3

G1 | Eye Issues in Marfan Syndrome

Learn about the eye problems associated with Marfan syndrome and options for care. Issues for children and adults are addressed.

Irene Maumenee, MD, University of Illinois Eye and Ear Infirmary
Marilyn B. Mets, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

SATURDAY WORKSHOPS continued

Conf. Room C

H1 | Managing Chest Deformities

Learn about the different types of chest deformities (indented chest, protruding chest), when treatment is necessary, and options for care.

Marleta Reynolds, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

Health Learning
Center

I1 | Spanish Language Track | Marfan Syndrome and Related Disorders

This session provides a review of the management of the various features of Marfan syndrome. It helps the newly diagnosed understand the big picture and learn about the most important aspects of ongoing management and treatment.

Juan Bowen, MD, Mayo Clinic

Conf. Room B

J1 | Growing Older with Marfan Syndrome

People with Marfan syndrome who are diagnosed and treated can expect to live a normal life span. Not only do they deal with progressing issues related to their diagnosis, but also the aging issues that affect the general population. Learn what you can do to take care of yourself as you get older.

Reed E. Pyeritz, MD, PhD, University of Pennsylvania School of Medicine

Y 2nd Floor
Room 2-715

K1 | Young Adult Track | Developing an Emergency Plan

Note: Participation is limited to Young Adult Program registrants.

When an emergency arises, there is no time to organize all the medical information the doctors need to provide appropriate care. Learn tips from the experts in cardiac and lung issues and how to prepare for these emergency situations.

Duke Cameron, MD, Johns Hopkins Hospital

Enid R. Neptune, MD, Johns Hopkins Hospital

WORKSHOP SESSION 2 2:45–3:45 PM

Conf. Room E

A2 | Ehlers-Danlos, FAA, and Other Related Disorders (except Loeys-Dietz syndrome)

Ehlers-Danlos syndrome, Familial Aortic Aneurysm (FAA), MASS Phenotype, Beals syndrome—these are just a few of the disorders that are related to Marfan syndrome. This workshop provides basic information on the similarities and differences, as well as basic management information. *Note:*

Presenters tailor this workshop to the participants' questions, focusing primarily on those disorders that are represented in the room.

Peter Byers, MD, University of Washington School of Medicine

Dianna M. Milewicz, MD, PhD, University of Texas Medical School at Houston

Barbara K. Burton, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room F

B2 | Bone and Joint Issues in Children

This workshop addresses bone and joint issues faced by children. After a brief overview, the presenters take questions from attendees about specific concerns for your child's care.

Paul D. Sponseller, MD, MBA, Johns Hopkins Hospital

John F. Sarwark, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

SATURDAY WORKSHOPS continued

SESSION 2 CONTINUED

2nd Floor
Room 2-716

C2 | Heart-Related Issues in Children

Management of heart-related issues in children are reviewed. Topics include medications, exercise guidelines, and the timing of aortic surgery.

Hal C. Dietz, MD, Johns Hopkins Hospital
Elizabeth S. Capella, ANP, NP, Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room D

D2 | Evaluating the Aorta: Understanding Tests and Results

This workshop addresses imaging (evaluating) the aorta. Topics include advantages and disadvantages of various types of imaging, and how to interpret your Z-score. *Note: This workshop focuses on heart imaging. Please attend the orthopedic workshops for skeletal imaging questions.*

Richard B. Devereux, MD, NewYork-Presbyterian Hospital, Weill Cornell Medical College
Luciana T. Young, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room A1

E2 | After a Dissection: Ongoing Heart-Related Care

This workshop addresses the special issues of heart and aortic care after an aortic dissection.

Alan C. Braverman, MD, Washington University School of Medicine
Andrew de Freitas, MD, Northwestern University Feinberg School of Medicine and Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room A2

F2 | Planning to Become Pregnant? Heart-related Care for Before, During, and After Pregnancy

The management of the heart and aorta before, during, and following pregnancy is reviewed.

Heidi M. Connolly, MD, FACC, Mayo Clinic
Marla A. Mendelson, MD, Northwestern University Feinberg School of Medicine

Conf. Room C

G2 | Optimizing Your Vision: Correction and Rehabilitation Options

"Low vision" describes a visual impairment that hinders a person's ability to perform everyday tasks, despite the use of eyeglasses, contact lenses, and medical or surgical therapy. Learn what visual aids can help you utilize your remaining vision to its fullest potential.

Irene Maumenee, MD, University of Illinois Eye and Ear Infirmary, Chicago, IL
Marilyn B. Mets, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room B

H2 | Lung Issues

Ongoing research is revealing new information about the lungs and Marfan syndrome. Learn how this information might help explain lung problems and affect lung care in people with Marfan syndrome.

Enid R. Neptune, MD, Johns Hopkins Hospital
Susanna A. McColley, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room A3

I2 | Loeys-Dietz Syndrome 101 & Surgical Concerns

Learn about the differences between Marfan syndrome and Loeys-Dietz syndrome (LDS). Learn about LDS-specific diagnosis and management for the heart and blood vessels, gastrointestinal (stomach and intestines), and cranial (skull) issues. This workshop addresses the special considerations for LDS patients concerning surgery for the aorta and blood vessels.

Duke Cameron, MD, Johns Hopkins Hospital
Mark E. Lindsay, MD, PhD, Massachusetts General Hospital for Children
Chris Malaisrie, MD, Northwestern University Feinberg School of Medicine

SATURDAY WORKSHOPS continued

Pritzker

J2 | Exercise and Staying Fit

Exercise is important for physical and psychological well-being. Learn how you can benefit from safe physical activity within the limitations of your diagnosis.

Reed E. Pyeritz, MD, PhD, University of Pennsylvania School of Medicine

Vera H. Rigolin, MD, Northwestern University Feinberg School of Medicine

Y 2nd Floor
Room 2-715

K2 | Young Adult Track | Transitioning to Adult Care

Note: Participation is limited to Young Adult Program registrants.

Transitioning from pediatric to adult care can be overwhelming. Learn how to take control of your care and build relationships with new doctors.

Ronald V. Lacro, MD, Children's Hospital Boston

Parag K. Shah, MD, Northwestern University Feinberg School of Medicine

Rebecca Boudos, LCSW, Ann & Robert H. Lurie Children's Hospital of Chicago

WORKSHOP SESSION 3

4:00–5:00 PM

Conf. Room D

A3 | Children's Issues in Marfan Syndrome

This is a general overview of the care of Marfan syndrome in children. This session helps you formulate questions you can ask your doctor(s) about medical care specific to your child. *Note: This workshop focuses on non-cardiac issues. A separate workshop (C2) specifically focuses on heart-related issues in children and teens.*

Ronald V. Lacro, MD, Boston Children's Hospital

Mark E. Lindsay, MD, PhD, Massachusetts General Hospital for Children

Conf. Room F

B3 | Foot and Ankle Issues

Learn about the different types of foot and ankle issues and options for care.

John J. Grayhack, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room B

C3 | Aortic Surgery in Children and Teens

Learn about the special considerations and options for aortic surgery in children and teens.

Duke Cameron, MD, Johns Hopkins Hospital

Michael C. Monge, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room E

D3 | Vascular Surgery: Aneurysms in Blood Vessels Other Than the Ascending Aorta

This workshop addresses the locations other than the aorta where aneurysms arise, how they are evaluated, and how they are treated.

Joseph S. Coselli, MD, Baylor College of Medicine, St. Luke's Episcopal Hospital, and Texas Heart Institute

Mark K. Eskandari, MD, Northwestern University Feinberg School of Medicine

Conf. Room C

E3 | Heart-Related Issues in Adults

Increase your overall understanding of heart-related issues in adults, including arrhythmias. Learn about medications, lifestyle modification, and how to prevent aortic dissection and other emergency situations. *Note: There is a separate workshop (C3) focusing on heart-related issues in children and teens.*

Richard B. Devereux, MD, NewYork-Presbyterian Hospital, Weill Cornell Medical College

Andrew de Freitas, MD, Ann & Robert H. Lurie Children's Hospital of Chicago and Northwestern University Feinberg School of Medicine

SATURDAY WORKSHOPS continued

SESSION 3 CONTINUED

- Conf. Room A1 **F3 | Family Planning Options: Preimplantation Genetics, Genetic Diagnosis, and Adoption**
This workshop addresses options for planning a family, including prenatal and postnatal genetic testing, preimplantation genetic diagnosis, surrogacy, and adoption.
Dianna Milewicz, MD, PhD, University of Texas Medical School at Houston
Allison Goetsch, CGC, Ann & Robert H. Lurie Children's Hospital of Chicago
- Conf. Room A2 **G3 | Dental Issues**
In this workshop, a dentist answers questions about dental care in people with Marfan syndrome. Topics include management of high palate/crowded teeth, use of expanders and braces, maxio-facial surgery, and the appropriate age to attempt corrections.
Sylvia A. Frazier-Bowers, DDS, PhD, University of North Carolina, Chapel Hill
Ray J. Jurado, DDS, Ann & Robert H. Lurie Children's Hospital of Chicago
- Conf. Room A3 **H3 | Sleep Apnea**
This workshop addresses the diagnosis and management of sleep apnea and other sleep disorders that can affect blood pressure, as well as heart rhythm and function.
Enid R. Neptune, MD, Johns Hopkins Hospital
Lisa F. Wolfe, MD, Northwestern University Feinberg School of Medicine
Darius A. Loghmanee, MD, Northwestern University Feinberg School of Medicine
- Health Learning Center **I3 | Mitral Valve Repair in Marfan Syndrome**
Learn about the advantages and disadvantages of the current options for mitral valve repair.
Hyde M. Russell, MD, Northwestern University Feinberg School of Medicine
- Pritzker **J3 | Chronic Pain Problems and Dural Ectasia**
Learn about the causes of chronic pain, including dural ectasia, and methods for managing chronic pain.
Paul D. Sponseller, MD, MBA, Johns Hopkins Hospital
Santhanam Suresh, MD, Ann & Robert H. Lurie Children's Hospital of Chicago
- Y** 2nd Floor Rooms 2-715 & 2-716 **K3 | Young Adult Track | Ask the Doctors/Gender Breakouts**
Note: Participation is limited to Young Adult Program registrants.
This workshop offers an opportunity to have questions answered in an anonymous way thorough submission of written questions (if desired) as well as in a gender specific manner. Questions are answered by medical experts on Marfan syndrome and related disorders.
Hal C. Dietz, MD, Johns Hopkins Hospital
Luciana T. Young, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

SUNDAY WORKSHOPS

Descriptions and presenters appear on the following pages.

	SESSION 4: 8:30-9:30 AM	SESSION 5: 9:45-10:45 AM	SESSION 6: 11:00 AM-12:00 NOON
A	A4 Pritzker Communicating with Your Child's School	A5 Pritzker The Teen Perspective: A Q&A for Parents Led by Teens	A6 Conference Room F The Teen Perspective: A Q&A for Parents Led by Teens
B	B4 Conference Room D Support Group for Couples	B5 Conference Room C Support Group for Unaffected Spouses and Significant Others	B6 Conference Room B Communicating with Your Doctors
C	C4 Conference Room E Support Group for Fathers	C5 Conference Room F Support Group for Mothers	C6 Conference Room D Developing Your Emergency Plan
D	D4 Conference Room F Physical Therapy and Connective Tissue Disorders	D5 Conference Room B Coping with Related Disorders	D6 Pritzker Depression and Anxiety in Disease Management
E	E4 Conference Room B Support Group for Mature Marfs	E5 Conference Room A1 Medical Insurance and Disability Issues	E6 Conference Room A1 Coping with Marfan Syndrome
F	F4 Conference Room C Preparing Your Child for Surgery	F5 Conference Room E Preparing Yourself for Surgery	F6 Conference Room C Occupational Therapy and Connective Tissue Disorders
G	SPANISH LANGUAGE TRACK G4 2nd Floor, Room 2-715 Support Group for Parents	SPANISH LANGUAGE TRACK G5 2nd Floor, Room 2-715 Coping with Marfan Syndrome and Related Disorders	SPANISH LANGUAGE TRACK G6 2nd Floor, Room 2-715 Medical Insurance and Disability
H	YOUNG ADULT TRACK H4 2nd Floor, Room 2-716 Staying Fit with Marfan Syndrome	YOUNG ADULT TRACK H5 2nd Floor, Room 2-716 Family Planning Decisions	YOUNG ADULT TRACK H6 2nd Floor, Room 2-716 Facing Your Fears
I Y	VOLUNTEER TRAINING I4 Conference Room A1 Town Meeting with President and CEO, Michael Weamer	VOLUNTEER TRAINING I5 Conference Room D Raising Awareness in Your Community	VOLUNTEER TRAINING I6 Conference Room E Fundraising ABCs and 123s

SUNDAY WORKSHOPS

WORKSHOP SESSION 4

8:30–9:30 AM

Pritzker

A4 | Communicating with Your Child's School

Parents offer their insights about how to help school personnel, especially school nurses, and other students understand Marfan syndrome. This workshop includes a discussion on IEPs (Individualized Education Plans) and 504s. What is a 504 regulation, how does it differ from an IEP, is one better for your situation? Understanding these parts of the federal law helps you advocate with the school for your child's special needs.

Blue Smith

Robert Blaufuss, CCLS, Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room D

B4 | Support Group for Couples

This workshop is for the affected person and their spouse or significant other to attend together. Discussion centers on how Marfan syndrome and related disorders have an effect on each person's daily life and on the relationship.

Tom and Tracy Fitzgerald

Annie Bao, MS, LMST

Conf. Room E

C4 | Support Group for Fathers

Note: Participation is limited to fathers.

Share your concerns with other fathers of children with Marfan syndrome and related disorders.

Tim Austin

Conf. Room F

D4 | Physical Therapy and Connective Tissue Disorders

Learn how physical therapy can be helpful in the management of different connective tissue disorders, such as Marfan syndrome, Loeys-Dietz syndrome, and Ehlers-Danlos syndrome.

Ann Marie Crean, PT, Ann & Robert H. Lurie Children's Hospital of Chicago

Mary Massery, DPT, DSc, Massery Physical Therapy of Glenview, Illinois

Conf. Room B

E4 | Support Group for Mature Marfs

Are you diagnosed with Marfan syndrome or a related disorder? Are you 50 years old or older? Would you like to connect with others in your age group? Aging with a connective tissue disorder can be complicated. This session provides a forum to share medical and emotional issues and tips for coping.

Jon Rodis

Rita Eisman

Conf. Room C

F4 | Preparing Your Child for Surgery

Preparing your child for surgery can be a sensitive and challenging endeavor. This workshop will focus on presenting and discussing potential options to answer your child's questions regarding their anticipated procedure and help them feel at ease with the hospital experience.

Kim Feingold, PhD, Northwestern University Feinberg School of Medicine

Paul Goetz, PhD, Northwestern University Feinberg School of Medicine

Gail Osterman, PhD, Northwestern University Feinberg School of Medicine

Rebecca Mitsos, CCLS, Ann & Robert H. Lurie Children's Hospital of Chicago

SUNDAY WORKSHOPS continued

2nd Floor
Room 2-715

G4 | Spanish Language Track | Support Group for Parents

Note: Participation is limited to parents.

Share your concerns with other parents of children with Marfan syndrome and related disorders.

Josy Villarrubia

Y 2nd Floor
Room 2-716

H4 | Young Adult Track | Staying Fit with Marfan Syndrome

Note: Participation is limited to Young Adult Program registrants.

Exercise is important for everyone's physical and psychological well-being. Learn how you can benefit from safe physical activity within the limitations of your diagnosis.

Ronald V. Lacro, MD, Boston Children's Hospital

Conf. Room A1

I4 | Volunteer Training | Town Meeting with President/CEO Michael Weamer

Participate in an interactive, open forum discussion with our president/CEO.

Michael Weamer, The Marfan Foundation

WORKSHOP SESSION 5

9:45–10:45 AM

Pritzker

A5 | The Teen Perspective: A Q&A for Parents Led by Teens

Are you the parent of a child or teen diagnosed with Marfan syndrome or a related disorder? Do you wonder when and how to share information with your child about their condition? This workshop, developed by our Teen Council, features teen panelists who share their unique perspective on topics they hope parents will talk to their children about. Parents who attend this session have an opportunity to ask their questions and get honest answers from the teen panelists.

Lou Arias, Teen Council Vice Chair
Teen Council Members

Conf. Room C

B5 | Support Group for Unaffected Spouses and Significant Others

Often the primary focus in a relationship is the person who has Marfan syndrome or a related disorder. This workshop provides an opportunity for those who provide love and support to an affected person to discuss their own needs and concerns.

Mark Zimmerman
Lindsey Weisman
Sandy Eisman

Conf. Room F

C5 | Support Group for Mothers

Note: Participation is limited to mothers.

Share your concerns with other mothers of children with Marfan syndrome and related disorders.

Alix McLean Jennings
Blue Smith

Conf. Room B

D5 | Coping with Related Disorders

This workshop provides an open forum to share experiences and concerns about living with a chronic medical condition. Hear tips from others and learn about practical approaches to managing daily life and coping with stress and depression.

Gretchen L. MacCarrick, MS, CGC, Johns Hopkins Hospital

SUNDAY WORKSHOPS continued

Conf. Room A1

E5 | Medical Insurance and Disability Issues

Learn your rights and responsibilities related to medical insurance coverage and disability. This workshop addresses questions such as how to approach your doctor and your insurance carrier for out-of-network care, how to challenge denial of service, who is eligible for disability, how one might increase chances for a successful disability application, and how to appeal a decision.

Jon Rodis
Kathleen Kane, Esq

Conf. Room E

F5 | Preparing Yourself for Surgery

Learn strategies to help you and your family prepare for the challenges of surgery and the road to recovery.

Kim Feingold, PhD, Northwestern University Feinberg School of Medicine
Paul Goetz, PhD, Northwestern University Feinberg School of Medicine
Gail Osterman, PhD, Northwestern University Feinberg School of Medicine

2nd Floor
Room 2-715

G5 | Spanish Language Track | Coping with Marfan Syndrome and Related Disorders

This workshop provides an open forum to share experiences and concerns about living with a chronic medical condition. Hear tips from others and learn about practical approaches to manage daily life and cope with stress and depression.

Josy Villarrubia

Y 2nd Floor
Room 2-716

H5 | Young Adult Track | Family Planning Decisions

Note: Participation is limited to Young Adult Program registrants.

This workshop will allow for open discussion with parents who utilized prenatal and postnatal genetic testing, preimplantation genetic diagnosis, surrogacy, and adoption options for family planning.

Maya Brown-Zimmerman, Teen Council Chair

Conf. Room D

I5 | Volunteer Training | Raising Awareness in Your Community

Learn about the many ways you can raise awareness of Marfan syndrome and related disorders in your community. Foundation staff present a number of awareness projects for volunteers. Attendees also have the opportunity to share their ideas with each other and the staff.

Diane McKenzie, The Marfan Foundation

WORKSHOP SESSION 6

11:00 AM-12:00 NOON

Conf. Room F

A6 | The Teen Perspective: A Q&A for Parents Led by Teens

Are you the parent of a child or teen diagnosed with Marfan syndrome or a related disorder? Do you wonder when and how to share information with your child about their condition? This workshop, developed by our Teen Council, features teen panelists who share their unique perspective on topics they hope parents will talk to their children about. Parents who attend this session have an opportunity to ask their questions and get honest answers from the teen panelists.

Maya Brown-Zimmerman, Teen Council Chair
Teen Council Members

Conf. Room B

B6 | Communicating with Your Doctors

Learn tips for effective communication with your healthcare providers.

Gretchen L. MacCarrick, MS, CGC, Johns Hopkins Hospital

SUNDAY WORKSHOPS continued

Conf. Room D

C6 | Developing Your Emergency Plan

When an emergency arises, there is no time to organize all the medical information the doctors need to provide appropriate care. This workshop teaches you what information you need and how to plan ahead.

Chris Heaney

Rebecca Boudos, LCSW, Ann & Robert H. Lurie Children's Hospital of Chicago

Parag R. Shah, MD, Ann & Robert H. Lurie Children's Hospital of Chicago

Pritzker

D6 | Depression and Anxiety in Disease Management

When a person is diagnosed with a chronic illness, depression and anxiety may result. This workshop provides strategies for coping with these issues.

Kim Feingold, PhD, Northwestern University Feinberg School of Medicine

Paul Goetz, PhD, Northwestern University Feinberg School of Medicine

Gail Osterman, PhD, Northwestern University Feinberg School of Medicine

Conf. Room A1

E6 | Coping with Marfan Syndrome

This workshop provides an open forum to share experiences and concerns about living with a chronic medical condition. Hear tips from others and learn about practical approaches to manage daily life, as well as stress and depression.

Lauren Leviton, LCSW, Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room C

F6 | Occupational Therapy and Connective Tissue Disorders

Learn how occupational therapy can be helpful in the management of the different connective tissue disorders, such as Marfan syndrome, Loays-Dietz syndrome, and Ehlers-Danlos syndrome.

Maribeth Jankowski, OT, Ann & Robert H. Lurie Children's Hospital of Chicago

2nd Floor
Room 2-715

G6 | Spanish Language Track | Medical Insurance and Disability

Learn your rights and responsibilities related to medical insurance coverage and disability. This workshop addresses questions such as how to approach your doctor and your insurance carrier for out-of-network care, how to challenge denial of service, who is eligible for disability, how you can increase chances for a successful application, and how to appeal a decision.

Jon Rodis

Kathleen Kane, Esq

Josy Villarrubia (Translating)

Y 2nd Floor
Room 2-716

H6 | Young Adult Track | Facing Your Fears

Note: Participation is limited to Young Adult Program registrants.

A diagnosis of a chronic, potentially life-threatening disorder raises many fears and concerns. Will I need open heart surgery? How will my boyfriend/girlfriend react if I tell him/her I have a genetic disorder? What if I pass my genetic disorder to my children? In this workshop, you can discuss these issues with others who know what you are going through and learn coping strategies.

Annie Bao, MS, LMST, Ann & Robert H. Lurie Children's Hospital of Chicago

Jessica Bucher, CGC, Ann & Robert H. Lurie Children's Hospital of Chicago

Conf. Room E

I6 | Volunteer Training | Fundraising ABCs and 123s

Learn about the many ways you can raise funds for the Foundation in your community. Our staff presents a number of fundraising opportunities. Attendees also have the opportunity to share their ideas.

Kerri Lynn Powell, The Marfan Foundation

SPEAKERS & PRESENTERS



Lou Arias, of Washington Township, NJ, is an active member of the Foundation. Lou, who has Marfan syndrome, enjoys leading our teen program at the conference.



Tim Austin, of Westside, IA, is a middle school science teacher who, along with his two adult daughters, has Marfan syndrome. A member of the Heart of Iowa Chapter, Tim and his wife, Pam, are leaders of our children's program at the conference.



Annie Bao, MS, LMST, received her Bachelor of Science degree in human development and family studies from Indiana University-Bloomington, a Bachelor of Arts degree in sociology from Indiana University Purdue University-Indianapolis, and a Master of Science degree in marriage and family therapy from Northwestern University. Clinically, Annie has continued developing her therapeutic skills in areas including family systems, grief, trauma, collaborative healthcare, and group therapy.

Robert Blaufuss, CCLS, a former principal, runs the Epilepsy Education Program at Lurie Children's Hospital. He works with up to 125 epilepsy patient families and their school systems each year to help them understand the educational needs of children with epilepsy and make individualized education plan (IEP) recommendations. After 39 years in the education system, Robert is an expert at communicating with both patient families and schools, translating complicated medical information into terms everyone can understand.



Robert Bonow, MD, is the Goldberg Distinguished Professor of Cardiology at the Northwestern University Feinberg School of Medicine, where he is vice chairman of the department of medicine and director of the Center for Cardiovascular Innovation. He received his MD degree from the University of Pennsylvania School of Medicine. He is past-president of the American Heart Association, a Master of the American College of Cardiology, and a Master of the American College of Physicians.



Rebecca Boudos, LCSW, is a chronic illness transition specialist and a social worker in the Spina Bifida Center. She spends most of her time focusing on transition work with teens, and also serves as the hospital-wide transition specialist.



Juan Bowen, MD, is the director of the Marfan and Thoracic Aorta Clinic at the Mayo Clinic in Rochester, MN. A general internist and assistant professor of medicine, he has been an active member of the Mayo Marfan and Thoracic Aorta Clinic since its inception. Dr. Bowen is the Foundation's national spokesperson for its Spanish-language outreach.



Alan Braverman, MD, FACC, is Alumni Endowed Professor in Cardiovascular Diseases at Washington University School of Medicine. He is director of the Marfan Syndrome and Related Disorders Clinic and chief of service of the Inpatient Cardiology Firm at Barnes-Jewish Hospital and Washington University. He is also chair of the Professional Advisory Board of The Marfan Foundation. An adult cardiologist, Dr. Braverman specializes in diseases of the thoracic aorta, Marfan syndrome, bicuspid aortic valve aortopathy, and clinical cardiology.



Katie Bridges-Payne is a first year member of the Teen Council and a 14-year old from Montana who has Marfan syndrome. She enjoys painting, hiking, fishing, camping, volunteer work, and trying new things. She is also a competitive equestrian. She is very outgoing and loves making new friends.



Maya Brown-Zimmerman has been volunteering with the Foundation since she was 14 years old. She currently serves as a teen program leader, member of the Board of Directors, and chair of the Education and Awareness Committee. Maya lives in Ohio with her husband, Mark, and their children, Miles, Julian, and Ruby. In her spare time, she blogs about being a "Marfan Mom" at marfmom.com.



Jessica Bucher, MS, CGC, is a genetic counselor at Ann & Robert H. Lurie Children's Hospital of Chicago in the Division of Genetics, Birth Defects, and Metabolism. Jessica helps to coordinate a transition program teaching young adults with connective tissue disorders independent life skills as they prepare for adulthood.



Barbara K. Burton, MD, is a professor of pediatrics at the Northwestern University Feinberg School of Medicine and is co-director with Dr. Luciana Young of the Connective Tissue Disorders Program at Ann & Robert H. Lurie Children's Hospital of Chicago. She is a clinical geneticist with over 30 years' experience in the diagnosis and treatment of patients with Marfan syndrome and other connective tissue disorders.



Peter H. Byers, MD, is a professor of pathology and medicine (division of medical genetics) at the University of Washington in Seattle, and a member of our Professional Advisory Board. Dr. Byers is a medical geneticist who specializes in inherited disorders of connective tissues, both in the clinic and in the laboratory.



Duke E. Cameron, MD, is the cardiac surgeon-in-charge and the James T. Dresher Sr. Professor of Surgery at the Johns Hopkins Hospital, and the director of the Dana and Albert "Cubby" Broccoli Center for Aortic Diseases at Hopkins. A member of our Professional Advisory Board, Dr. Cameron specializes in valve-sparing aortic root surgery.



Elizabeth Cappella, APN, NP, is a pediatric nurse practitioner in the Connective Tissue Disorders Program at Ann & Robert H. Lurie Children's Hospital of Chicago. She earned her Masters of Science in nursing at the University of Cincinnati and subsequently went on to finish a post Master's degree in pediatric acute care at Rush University. She is the recipient of the Daisy Award for excellence in nursing.



Heidi M. Connolly, MD, FACC, is the director of the Congenital Heart Center at the Mayo Clinic in Rochester, MN. She is also a professor of medicine at the Mayo Clinic College of Medicine, and a consultant in cardiovascular diseases at the Mayo Clinic. A member of the Foundation's Professional Advisory Board, Dr. Connolly was awarded the Foundation's imaging core laboratory grant for the Aortic Valve Operative Outcomes in Marfan Patients Study.



Joseph S. Coselli, MD, is professor, chief and Cullen Foundation Chair of the division of cardiothoracic surgery in the Michael E. DeBakey Department of Surgery at Baylor College of Medicine. Dr. Coselli is also chief of adult cardiac surgery at the Texas Heart Institute, as well as chief of the adult cardiac surgery section and associate chief of the cardiovascular service at Baylor St. Luke's Medical Center. Dr. Coselli specializes in aortic and cardiothoracic surgery, particularly the care of patients

with Marfan syndrome and other connective tissue diseases. He is currently a member of the Foundation's Professional Advisory Board and has been a recipient of the Foundation's Antoine Marfan Award. He is the principal investigator of the Aortic Valve Operative Outcomes in Marfan Patients study. Dr. Coselli is currently the president of the American Association for Thoracic Surgery and is past president of the Southern Thoracic Surgical Association as well as the Texas Surgical Society.



Ann Marie Crean, PT, is a pediatric physical therapist at Ann & Robert H. Lurie Children's Hospital of Chicago. She received her Bachelor of Science degree in exercise science and Doctorate of Physical Therapy degree from Marquette University in Milwaukee, WI. She works with patients 0-18 years old with a variety of diagnoses. She has enjoyed working with patients with Marfan syndrome to help improve mobility following surgical intervention in the hospital and to help improve postural alignment in the outpatient setting.



Jessica Davis, MD, is an associate professor at the Hospital for Special Surgery. A member of our Professional Advisory Board, Dr. Davis is an accomplished clinician who has conducted research with a focus on cytogenetics.



Andrew de Freitas, MD, is a pediatric cardiologist at Northwestern Memorial Hospital, attending physician in cardiology at Ann & Robert H. Lurie Children's Hospital of Chicago, and assistant professor of pediatrics at Northwestern University Feinberg School of Medicine. His clinical interests are in cardiac MRI, non-invasive cardiology, and congenital heart disease.



Hal Dietz, MD, is director of the William S. Smilow Center for Marfan Research, Victor A. McKusick Professor of Medicine and Genetics, and investigator in the Howard Hughes Medical Institute, all at Johns Hopkins University School of Medicine. A current member and former chair of the Foundation's Professional Advisory Board, Dr. Dietz's specialties include pediatrics, cardiology, and genetics.



Haley Dostalick, of Urbandale, Iowa, was diagnosed with Marfan syndrome when she was 2 years old. Her hobbies include playing clarinet, reading, watching *Sherlock* and *Doctor Who*, and hanging out with friends.



Heather Earnhart is a freelance musician and writer living in the Albany Park neighborhood of Chicago with her husband, David, her daughter, Gabriella who has Marfan syndrome, her son, Nicholas, and her beagle, Winston. She received her master's degree in music from DePaul University.



Rita and Sandy Eisman are long-time members of the Foundation from Springfield, OH, who have attended every one of the Foundation's annual family conferences since 1987. Together they have led several workshops at the conference for many years. Rita has Marfan syndrome as did her son, Anthony, who passed away in 2006 at the age of 41.



Mark Eskandari, MD, is professor of vascular surgery with adjunct appointments in cardiology and radiology at Northwestern University's Feinberg School of Medicine. He serves as the co-director of the Northwestern Endovascular Center, director of carotid and peripheral artery interventions, associate director of the Bluhm Cardiovascular Institute, medical director of the Carotid Stenting Program, and director of the Vascular Laboratory.



Kim L. Feingold, PhD, is founder and director of the Cardiac Behavioral Medicine Service of the Bluhm Cardiovascular Institute of Northwestern Memorial Hospital, and assistant professor of surgery and assistant professor of psychiatry at Northwestern University's Feinberg School of Medicine. Her specific areas of specialization include stress management, women and heart disease, coping with a medical diagnosis, and the interplay between depression, stress, and heart disease.



Thomas P. Fitzgerald (Tom) is an architect that specializes in disaster restoration and consulting for non-profits. He has been involved in the Foundation in different aspects since his wife's diagnosis in 1995. Tom resides in Hunterdon County, NJ, with his wife, Tracy, and German shepherd, Riley.



Tracy A. Fitzgerald is an artist who paints and creates glass mosaics that teaches middle school art. She has been involved in the Foundation in different aspects since her diagnosis in 1995 at the age of 25. Tracy resides in Hunterdon County, NJ, with her husband, Tom, and German shepherd, Riley.



Sylvia A. Frazier-Bowers, DDS, PhD, is an associate professor at The University of North Carolina at Chapel Hill (UNC-CH) in the department of orthodontics. A current member of the Foundation's Professional Advisory Board, Dr. Frazier-Bowers also serves on various editorial boards including the Journal of Dental Research and on the Scientific Advisory Board for the Consortium on Orthodontic Advances in Science and Technology.



Philip F. Giampietro, MD, PhD, is a professor of pediatrics and medical director of the genetic counseling program at the University of Wisconsin School of Medicine and Public Health. His research interests include Marfan syndrome and congenital and idiopathic scoliosis.



Allison Goetsch, CGC, graduated from the genetic counseling program at Northwestern University in 2014. She currently works at Lurie Children's Hospital in the department of genetics, birth defects, and metabolism, where she provides pediatric genetic counseling with a focus on cystic fibrosis, neurofibromatosis, and general genetics. Allison is also actively involved at the Oncofertility Consortium at Northwestern University where she creates provider and patient educational materials for genetic conditions known to impair fertility.



Paul Goetz, PhD, is an assistant professor of surgery in cardiac behavioral medicine at the Bluhm Cardiovascular Institute and an assistant professor of psychiatry at Northwestern University's Feinberg School of Medicine. He is a licensed clinical psychologist specializing in cardiac psychology. He works with cardiac patients on psychological issues related to their cardiac health, including anxiety before and after surgery, post-surgical depression, anxiety about implantable cardioverter defibrillators (ICD), and health behavior changes. Dr. Goetz utilizes cognitive behavioral techniques to address anxiety and depression symptoms, emotional adjustment after surgery, health behavior changes, and improving the overall quality of life for patients with cardiac issues.



John J. Grayhack, MD, is an attending physician at Ann & Robert H. Lurie Children's Hospital and an associate professor of orthopaedic surgery at Northwestern University Feinberg School of Medicine. His special interests include abnormalities in foot and hip, complex limb reconstruction, limb lengthening, scoliosis, and trauma. A lifelong resident of Chicago; an avid sports fan and outdoorsman, he has suffered through innumerable disappointing sports seasons, but remains optimistic. Dr. Grayhack will be discussing foot and ankle issues.



Josephine Grima, PhD, is the Foundation's senior vice president of research and legislative affairs. She is responsible for developing and coordinating our research program. In addition, she conducts outreach to Congress and government agencies and serves as our liaison with the National Institutes of Health.



Chris Heaney is a frequent workshop leader at the annual family conference, most notably sharing what he has learned about preparing for aortic surgery and advocating for yourself in the hospital emergency department. He has been involved with the Foundation for many years and has served on the Board of Directors and various Board committees.



Christopher Hogrefe, MD, received his undergraduate training in biology and philosophy at Creighton University prior to attending medical school at the University of Iowa. In 2014 he matriculated to Northwestern Medicine and the Feinberg School of Medicine, where he works in the departments of medicine, emergency medicine, and orthopaedic surgery. His academic interests include the cardioprotective effects of exercise, traumatic brain injuries/concussions, and the mechanisms of throwing-related injuries.



Maribeth Jankowski is a senior occupational therapist at Ann & Robert H. Lurie Children's Hospital of Chicago. She received her Bachelor of Science degree in occupational therapy from St. Ambrose University in 1994. Maribeth has worked at Lurie Children's for 13 years in both in-patient and out-patient settings, as well as multiple clinics. She has worked with children with connective tissue disorders during her time in rheumatology clinic, as well as treating this population in the out-patient clinics.



Meaghan Joyce is a 20-year-old pre-med student who enjoys Chicago deep dish pizza and watching *Last Week Tonight* with her cat, Kitty. Meaghan, who has Ehlers-Danlos syndrome, has been volunteering for The Marfan Foundation for eight years and hopes to give back to her community by becoming involved with connective tissue disorder research.



Ray J. Jurado, DDS, is the division head of the dentistry department and the program director for the postdoctoral program in pediatric dentistry at Ann & Robert H. Lurie Children's Hospital of Chicago. His special interests include hospital dentistry for patients with special needs, preventive and restorative pediatric dentistry, and infant oral health.



Kathleen Kane, Esq. (Rodis), of Winthrop, MA, is an attorney who has devoted extensive time to representing people who have been denied Social Security disability benefits since her husband, Jon, became disabled. She has been successful in obtaining benefits for Marfan syndrome claimants in many states.



Michael Kramer is a volunteer for The Marfan Foundation and was diagnosed with Marfan syndrome at the age of 9. He currently resides on Long Island, NY, with his wife and two children. His daughter is affected with Marfan syndrome as well.



Sudhi Kurup, MD, is a pediatric ophthalmologist at Ann & Robert H. Lurie Children's Hospital of Chicago and instructor in ophthalmology at Northwestern University Feinberg School of Medicine. He has interests in strabismus, childhood cataracts, imaging modalities, and medical education. He received his medical degree from University of Michigan Medical School, completed his ophthalmology residency at Northwestern University, and did a pediatric ophthalmology & strabismus fellowship at Ann & Robert H. Lurie Children's Hospital through Northwestern University.



Ronald V. Lacro, MD, is director of the cardiovascular genetics clinic and Marfan syndrome program at Boston Children's Hospital, an associate in cardiology at Boston Children's Hospital, and assistant professor of pediatrics at Harvard Medical School. Board certified in pediatric cardiology and clinical genetics, Dr. Lacro works in the non-invasive imaging laboratory, specializing in echocardiography. He is the recipient of the Antoine Marfan Award in 2014.



Alyssa Lamberti is 16 years old and a member of the Teen Council. She is a junior at St. Joseph Academy in St. Augustine, FL. The stage is her second home, whether acting or working behind the scenes.



Lauren Leviton, MA, LCSW, is a social worker case manager with the Lurie Children's Health Partners Care Coordination Entity. Ms. Leviton previously served as the social worker in the division of genetics at the Ann & Robert H. Lurie Children's Hospital of Chicago. As a part of her clinical work, Ms. Leviton worked with individuals and families with connective tissue disorders. With support from her team members, Ms. Leviton helped initiate a Transition to Independence program to address the needs of adolescents and young adults as they prepare for adulthood.



David Liang, MD, PhD, a cardiologist, is an associate professor of medicine and the director of the Stanford University Center for Marfan Syndrome and Aortic Disorders. A member of our Professional Advisory Board, Dr. Liang is dedicated to both taking care of patients with these disorders and conducting research to enhance treatment of the associated cardiac problems.



Mark E. Lindsay, MD, PhD, is a member of the cardiology division faculty within the thoracic aortic center at the Massachusetts General Hospital (MGH) in Boston. He is investigating the genetic etiology and pathophysiology of human aortic disease focusing on gene discovery, the developmental underpinnings of aortic aneurysm, and mechanisms of aortic dissection.



Darius Loghmanee, MD, is the director of the Pediatric Sleep Network for Advocate Children's Hospital. He has board certifications in internal medicine, pediatrics, and sleep medicine, and focuses his practice on optimizing sleep health for infants, children, adolescents, and adults. He has a special interest in the treatment of sleep disordered breathing in patients with genetic syndromes, neuromuscular disease, and unique craniofacial features.



Gretchen MacCarrick, MS, CGC, is a board certified genetic counselor who works in the connective tissue clinic at the Johns Hopkins Hospital. She received her graduate degree from the Medical College of Virginia. She is a co-founder of the Loeys-Dietz Syndrome Foundation.



S. Chris Malaisrie, MD, is a cardiac surgeon and the co-director of thoracic aortic surgery, associate director of the Center of Heart Valve Disease, and surgical director of the Martha and Richard Melman Bicuspid Aortic Valve Program at Northwestern's Bluhm Cardiovascular Institute. He is a member of the Northwestern Medical Group and an associate professor of surgery at Northwestern University Feinberg School of Medicine. His clinical interests include minimally invasive valve surgery as well as endovascular/transcatheter procedures.



Mary Massery, DPT, DSc, received her BS in physical therapy from Northwestern University in 1977, her DPT from the University of the Pacific in 2004, and her DSc from Rocky Mountain University in 2011. Her publications and interests focus on linking motor behaviors to breathing and/or postural mechanics in both pediatric and adult patient populations.



Irene H. Maumenee, MD, is director of the ocular genetics laboratory and research director of ophthalmology at the University of Illinois College of Medicine at Chicago. A member of the Foundation's Professional Advisory Board, Dr. Maumenee specializes in hereditary diseases of the eye.



Kyle McArthur, a senior at Wilsonville High School in Oregon, is a member of the Foundation's Teen Council. He has also given presentations to medical students at OHSU in Portland to help them learn about Marfan syndrome and related disorders. Kyle, who was diagnosed with Marfan syndrome shortly after birth, has a great interest in music and singing. He loves to hang out and is always up to talk.



Susanna A. McColley, MD, is director of clinical and translational research at the Stanley Manne Children's Research Institute of the Ann & Robert H. Lurie Children's Hospital of Chicago. She is professor of pediatrics-pulmonary medicine at Northwestern University Feinberg School of Medicine, where she serves as associate clinical director of child health for the Northwestern University Clinical and Translational Sciences Institute.



Diane McKenzie received her Bachelor's degree in sociology and is currently completing her Masters of Health Administration. Joining The Foundation in January 2014, Diane began her role as the program associate. In her position, she manages support services and volunteer development. Diane is responsible for developing conference programs and conference registration. She is the assistant to the sr. vice president of research and legislative affairs, who is responsible for coordinating research programs among scientists worldwide. Diane enjoys spending time with her family, playing her violin, traveling, and volunteering with Hospice Care Network.



Alix McLean Jennings, a trained social worker, is a member of the Foundation's Board of Directors and serves on the support and volunteer development committee. She lives in Madison, NJ, with her husband, Ezra, and two daughters, Penelope, 10, and Cassie, 8, who has Marfan syndrome.



Elizabeth McNally, MD, PhD, is the Director, Center for Genetic Medicine, at Northwestern Medicine Feinberg School of Medicine and board certified in cardiovascular disease. She also runs a research lab studying genetic mechanisms responsible for inherited human diseases including heart failure, cardiomyopathy, muscular dystrophy,

arrhythmias, aortic aneurysms. Working with individuals and families, her team is defining the genetic mutations that cause these disorders. By establishing models for these disorders, they can now begin to develop and test new therapies, including genetic correction and gene editing.



Marla Mendelson, MD, is a cardiologist at the Northwestern Feinberg School of Medicine and Northwestern Memorial Hospital. An associate professor of medicine and pediatrics at Northwestern University's Feinberg School of Medicine, who directs the Center for Women's Cardiovascular Health of the Bluhm Cardiovascular Institute, Heart Disease and Pregnancy and Adult Congenital Heart and Marfan Center.



Marilyn B. Mets, MD, is an ophthalmologist with clinical interests in glaucoma management, congenital syndromes, cataract and implant surgery, strabismus, retinoblastoma, retinal disease, pediatric ophthalmology, and cataract implant surgery. She received her medical degree from George Washington University School of Medicine and Health Sciences, completed her residency at Cleveland Clinic Hospital, and did fellowships at George Washington University Hospital and Johns Hopkins Hospital.



Dianna M. Milewicz, MD, PhD, is the President George H.W. Bush Chair in Cardiovascular Medicine, vice chairman of the department of internal medicine, and director of the division of medical genetics at the University of Texas Medical School at Houston (UT Health). In addition, Dr. Milewicz is the director of the John Ritter Research Program in Aortic and Vascular Diseases. She is a former chair and current member of our Professional Advisory Board and chairs the Thoracic Aortic Disease Coalition, which we convened to increase public and medical awareness of the diagnosis and treatment of thoracic aortic disease. She is also scientific chair of the Montalcino Aortic Consortium, which was organized to identify novel genes for thoracic aortic aneurysms and acute aortic dissections and characterize the clinical phenotype associated with these novel genes by sharing data.



D. Craig Miller, MD, professor of cardiovascular surgery at Stanford University School of Medicine, is a member of our Professional Advisory Board. He is a past-president of the American Association for Thoracic Surgery and the Western Thoracic Surgical Association, and former chairman of the American Heart Association's Cardiovascular Surgery Council. Dr. Miller is responsible for major advances in the understanding and treatment of mitral and aortic valve disease, thoracic aortic diseases, heart physiology, and cardiac mechanics.



Rebecca Mitsos is a Certified Child Life Specialist who works at Lurie Children's Hospital. She provides developmentally appropriate education, preparation, and procedural support to patients and families of all different kinds who are seen by Lurie Children's staff for a wide variety of surgeries and procedures. She works closely with pre/post as well as OR staff to provide pristine family-centered care throughout patients' surgical experience.



Michael C. Mongé, MD, is an assistant professor of surgery at Northwestern University Feinberg School of Medicine and an attending cardiovascular-thoracic surgeon at Ann & Robert H. Lurie Children's Hospital of Chicago. Dr. Mongé is board certified by the American Board of Thoracic Surgery in both congenital heart surgery and thoracic surgery. He and his wife, Allie, live in Chicago with their four children.



Karen Murray is president of VF Sportswear, a wholly owned subsidiary of VF Corporation, the world's largest apparel maker. Her son, Michael, was diagnosed with Marfan syndrome in 1996. Since then, she has worked tirelessly to advance all areas of The Marfan Foundation's mission: education, support, and research. Karen has served on the Foundation's Board of Directors since 1998 and is the corporate host of the Heartworks gala in New York City. In addition, she has served on the national Board of Directors of the American Heart Association and was instrumental in the development of the Go Red Campaign.



Enid Neptune, MD, is an adult pulmonologist and developmental biologist at the Johns Hopkins University School of Medicine. A member of the Foundation's Professional Advisory Board, her research and clinical practice focuses on genetic determinants of airspace disorders, and clinical evaluation of lung disease in patients with Marfan syndrome.



Samantha Noe is a member of the Teen Council and a freshman at Christian Brothers High School in Sacramento, California. She was diagnosed with Marfan syndrome at the age of one. She loves science, cooking, and making people laugh.



Delaney Olsen is a member of the Teen Council and is a rising sophomore at Lawrence University in Appleton, WI. She is 19 years old and was diagnosed with Ehlers-Danlos type 3 when she was 12 years old. Her goal is to be a professional oboist!



Gail M. Osterman, PhD, is an assistant professor of surgery in the Cardiac Behavioral Medicine Service of the Bluhm Cardiovascular Institute and assistant professor of psychiatry at Northwestern University's Feinberg School of Medicine. She is a licensed clinical psychologist with specialization in health psychology and an emphasis in cardiac psychology. Her clinical interests include the interplay of social support and health status, varying informational needs throughout medical care, and enhancing the quality of life and adjustment of cardiac and transplant populations.



Tizzy Parks, of Tulsa, OK, is 14 years old. She loves to read, run, and hang out with friends. This is her first year being a Teen Council representative, and although she does not have Marfan syndrome, the majority of her family does.



Sunny Pellone is the coordinator of the Marfan Center at Stanford Hospital and Clinics in California and an active member of the Foundation. In 2007, she led the clinic at the Foundation's annual family conference and has volunteered her time to assist with the clinic each year since. She regularly participates with the teen group and attends national scientific meetings. Sunny has become a trusted patient advocate and is an invaluable resource to the many people she has met through the years.



Kerri Lynn Powell is the manager of community events for The Marfan Foundation. She oversees our new Walk for Victory program and our endurance program, Team Victory. In addition, she works with our volunteers to create their own local fundraising and awareness events.



Brooke Pulliam is 15 years old, lives outside of St. Louis, and was diagnosed with Marfan syndrome at birth. She has been in dance for 11 years and Girl Scouts for 9 years. In addition, she enjoys playing the clarinet, riding her bike, and just hanging out with friends.



Reed Pyeritz, MD, PhD, is the chief of the division of medical genetics, William Smilow Professor of Medicine, and professor of genetics at the Smilow Center for Translational Research at the University of Pennsylvania. Dr. Pyeritz, a founding member of The Marfan Foundation, also directs Penn CIGHT, the Center for the Integration of Genetic Healthcare Technologies. A current member of our Professional Advisory Board, he was its first chair when it was established in 1982.



Bahram Rahmani, MD, is an attending pediatric ophthalmologist at Ann & Robert H. Lurie Children's Hospital of Chicago and an assistant professor of ophthalmology in the Feinberg School of Medicine. He trained at Northwestern University with fellowship at Children's Memorial Hospital in Chicago. He received a Master of Public Health from Johns Hopkins School of Public Health in Baltimore. His research interests include pediatric oculoplastic disorders and outcome research.



Marleta Reynolds, MD, is head of the department of surgery and surgeon-in-chief at Ann & Robert H. Lurie Children's Hospital of Chicago. Dr. Reynolds is also currently the division head of pediatric surgery, director of the ECMO Program (extracorporeal membrane oxygenation), pediatric surgery fellowship director, and a co-director of the Institute for Fetal Health at Lurie Children's. She holds the Lydia J. Frederickson Professorship in Pediatric Surgery and is a professor of surgery at the Northwestern University Feinberg School of Medicine. Dr. Reynolds is board-certified by the American Board of Surgery in three specialties including general surgery, pediatric surgery, and surgical critical care. She is also board-certified by the American Board of Thoracic Surgery.



Vera H. Rigolin, MD, is professor of medicine at the Northwestern University Feinberg School of Medicine in Chicago, Illinois. She is also a cardiologist and medical director of the echocardiography laboratory at Northwestern Memorial Hospital and the associate medical director of the Center for Women's Cardiovascular Health of the Bluhm Cardiovascular Institute. She specializes in echocardiography, valvular heart disease, and women's heart health. Dr. Rigolin's major research focus is the use of basic and advanced echocardiographic imaging for the assessment of patients with valvular heart disease, particularly those undergoing surgical or interventional correction.



Jon Rodis is president of our Massachusetts Chapter and chair of the Chapter's Physicians Awareness Committee. Permanently disabled in 2001, Jon is involved with several Marfan awareness initiatives, including a website about his experiences with Marfan syndrome.



Hyde McKinney Russell, MD, is a cardiac surgeon at both Northwestern Memorial Hospital and Children's Memorial Hospital and the surgical director for the Program for Adult Congenital Heart Disease at the Bluhm Cardiovascular Institute. Dr. Russell's special interests include adult and pediatric congenital heart surgery, complex reoperations in congenital heart surgery, heart

transplantation, valve repair and replacement, and coronary artery surgery. Dr. Russell is board certified in surgery, thoracic surgery, and congenital cardiac surgery.



Ajay Sampat, MD, is a resident physician in neurology at Northwestern University Feinberg School of Medicine. He has prior experience in anesthesiology as a former resident at the University of Michigan

Medical School. He is involved in several clinical research projects in the neurosciences, with a growing interest in pain medicine and its interface between neurology and anesthesiology. His project with Dr. Walega focuses on pain characteristics of patients with Marfan syndrome, with the hope to better understand this unique population and to ultimately find a more effective way to treat their pain.



John F. Sarwark, MD, is head of the division of pediatric orthopaedic surgery at Anne & Robert H. Lurie Children's Hospital of Chicago, and a professor in the department of orthopaedic surgery at Northwestern

University Feinberg School of Medicine. He is co-editor of AAP's Pediatric Orthopedics and Sports Injuries, and is a reviewer for JBJS, SPINE, and Journal of Pediatric Orthopedics, among others. Dr. Sarwark currently serves as sole associate editor for the American Academy of Orthopaedic Surgeons' online program Orthopaedic Knowledge Online.



Parag K. Shah, MD, is a general pediatric hospitalist who is currently serving as the medical director of the Chronic Illness Transition Team at Lurie Children's Hospital in Chicago. The Transition Team at Lurie

Children's was created to help integrate transitioning best practices into various divisions within the hospital and help youth make the transition successfully. The mission of the team is to engage in clinical activities, research, and education for families and staff, with events such as a life skills program for adolescents, independent research, and consultation and educational sessions for divisions and staff.



Rachel Shapiro is a 17 year old junior at Tracy High School with Ehlers-Danlos syndrome. She enjoys classic literature and music. She hopes to one day be in a band of her own, writing meaningful lyrics and

making a positive difference in people's lives. She always tries her best to make others smile.



Blue K. Smith, of Scarborough, ME, is a special education advocate who has been assisting parents in their attempts to successfully negotiate the "maze" of special education rules, regulations, mandates, and laws for more than 23 years. Blue has a daughter with Marfan syndrome and a son who is bipolar with multiple learning disabilities.



Paul D. Sponseller, MD, MBA, is head of the division of pediatric orthopedics and professor of orthopaedic surgery at Johns Hopkins Hospital. A member of our Professional Advisory Board, Dr. Sponseller specializes in pediatric spine and orthopaedics.



Santhanam Suresh, MD, is chair of the department of anesthesiology at Ann & Robert H. Lurie Children's Hospital of Chicago and an Arthur C. King Professor of Anesthesiology and Pediatrics at Northwestern University Feinberg School of Medicine. His major area of research is in post-operative pain control and management of chronic pain in children and adolescents. He is internationally recognized for his innovations in the use of nerve blocks for postoperative pain control in infants and children.



Rokšana Szczesny is a member of the Teen Council and is originally from Poland, but has lived in Ireland for nine years. She loves to read, draw, take pictures of nature, and write stories. She would like to become a psychiatrist. She loves raising awareness about Marfan syndrome and related disorders and giving support to others who are affected.



Alex Utz is currently a junior at Bowling Green High School in Ohio. He was diagnosed with Loeys-Dietz syndrome in 2005, and had open-heart surgery in 2006. He enjoys filmmaking and playing the piano.



Josy Villarrubia, of Chicago, is the founder of our first Spanish community group and a leader of our Spanish-language track at the conference. Josy and her two daughters have Marfan syndrome.



Michael Weamer joined The Marfan Foundation as president and CEO earlier this year after more than two decades with the American Heart Association. Michael has been a board member and board advisor to The Marfan Foundation and was awarded the Foundation's Hero with a Heart Award in 2009. Michael is also chair of the Board of Directors of the New York Society of Association Executives and serves on the Board of Directors of the Association of Black Cardiologists. He and his wife, Karen, have four children, Mollie, Caitlin, Sean, and Daniel, and a grandchild, Max.



Ben Weisman is a member of the Board of Directors of The Marfan Foundation and a 3rd generation Marf. Since relocating from Boston, he is now working as a development consultant and a film and theatre producer. Benjamin and his wife, Lindsey, live in Montclair, NJ, with their dog and two cats, while unapologetically maintaining their love of all Boston sports.



Lindsey Weisman lives in Montclair, NJ, where she has been living successfully with her husband, Marfan Foundation Board member, Benjamin Weisman. She is a web designer and developer at Merrill Lynch. In her spare time, she loves knitting and listening to National Public Radio.

Joseff Weismantel, CCLS, is a Certified Child Life Specialist and Life is Good™ Playmaker. He provides developmentally appropriate education and procedural support to the patients, siblings, and families of the Cardiac Care Unit at Lurie Children's Hospital. As a vital member of the health care team, Joe is there to deliver relationship based care to children from all over the world.



Lisa F. Wolfe, MD, is an associate professor of medicine and neurology at Northwestern University Feinberg School of Medicine. She is the pulmonary consultant to the Les Turner ALS foundation, The Chicago MDA, and the Rehabilitation Institute of Chicago. She has been a member of the sleep medicine team at the Lurie Children's Hospital.



Hawke Yoon, MD, received his medical degree from the University of Utah and then did his ophthalmology residency training at the Storm Eye Institute of the Medical University of South Carolina where he was the chief resident of ophthalmology during his final year. His pediatric ophthalmology fellowship training was done at the Kellogg Eye Center of the University of Michigan before coming to Children's Memorial Hospital/Lurie Children's.



Luciana T. Young, MD, is co-director of the Connective Tissue Disorders Program at the Ann and Robert H. Lurie Children's Hospital of Chicago and a professor of pediatrics at Northwestern University Feinberg School of Medicine. Dr. Young's clinical and research interests include non-invasive imaging, bicuspid aortic valve, and cardiac manifestations of connective tissue disorders.



Mark Zimmerman, of Twinsburg, OH, is an electronic engineer who is married to Maya Brown-Zimmerman, a member of the Foundation's Board of Directors who has Marfan syndrome. They have two sons, Miles and Julian, who also has Marfan syndrome, and a newly adopted daughter, Ruby.

Patient Evaluations Disclaimer

The Marfan Foundation is a health advocacy organization. The Marfan Foundation does not provide medical advice or treatment. We are not a health-care provider. Patient evaluations are being provided as a service to help assess and evaluate your condition and, if appropriate, to provide you with contact information for healthcare providers who are known to have seen patients with Marfan syndrome and related disorders.

It is important to realize that an evaluation by The Marfan Foundation is not meant as a replacement for proper care from a doctor or therapist. Information provided by The Marfan Foundation is not a substitute for medical treatment or psychological care. It is vital that you talk with your healthcare providers regarding the diagnosis and treatment of Marfan syndrome and related disorders and your particular symptoms and features. Minors should consult with a parent or legal guardian when considering treatment and healthcare providers.

Healthcare provider information is supplied solely by the providers themselves and is not checked or warranted by The Marfan Foundation. The Marfan Foundation does not endorse or recommend individual healthcare providers. By requesting healthcare provider resources, you understand and agree that The Marfan Foundation and its affiliates are not responsible for any such providers' services or lack thereof.

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The Marfan Foundation is a health advocacy organization. The Marfan Foundation does not provide medical advice or treatment. We are not a health-care provider. All information provided by The Marfan Foundation is general information about Marfan syndrome and related disorders. Information provided by The Marfan Foundation is not a substitute for medical treatment or psychological care. It is vital that you talk with your healthcare providers regarding the diagnosis and treatment of Marfan syndrome and related disorders and your particular symptoms and features. Minors should consult with a parent or legal guardian when considering treatment and healthcare providers.

THANK YOU



Special thanks to the following individuals and companies who were instrumental in making this year's conference a huge success. We couldn't be more grateful for your time, talent, and support!

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THE MARFAN FOUNDATION

Know the signs. Fight for victory.

The Marfan Foundation, established in 1981, creates a brighter future for everyone affected by Marfan syndrome and related disorders by pursuing the most innovative research and making sure that it receives proper funding; creating an informed public and educated patient community; and providing relentless support to families, caregivers, and healthcare providers.

Through its research grant program, the Foundation has strengthened a growing community of expert researchers committed to victory over Marfan syndrome and related disorders. It pushes the government to fund the research that will improve and save lives.

The Foundation provides a supportive community for everyone affected by Marfan syndrome and related disorders, with a help center staffed by a social worker and registered nurse; special resources for children, teens, parents, teachers, nurses, and other specialized groups; an annual family conference and free clinic; and an active volunteer network.

The Foundation always has the latest and most accurate information, and educates everyone—from patients and families to medical professionals and the general public—about Marfan syndrome and related disorders. Information is available on its website, Marfan.org, as well as through its help center, 800-8-MARFAN, ext. 126.

The Foundation is a founding member of the International Federation of Marfan Syndrome Organizations, which strengthens the Marfan community worldwide.

The Foundation will not rest until it has achieved victory—a world in which everyone with Marfan syndrome or a related disorder receives a proper diagnosis, gets the necessary treatment, and lives a long and full life.

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