

CONNECTIVE ISSUES

FALL 2015

**Know the Signs.
Fight for Victory.**



 THE MARFAN FOUNDATION | ANNUAL FA
FOUNDATION | CONFERENCE

CO-HOSTED BY 2015

 Northwestern
Medicine

& Robert H. Lurie
Hospital of Chicago



THE MARFAN
FOUNDATION



The Marfan Foundation creates a brighter future for everyone affected by Marfan syndrome and related disorders. We work tirelessly to advance research, serve as a resource for families and healthcare providers, and raise public awareness. We will not rest until we have achieved victory.

Learn more and get involved at Marfan.org.

Contents

- REAL ROLE MODELS 4
- A TEEN'S PERSPECTIVE 7
- CONFERENCE AWARDS 8
- LIVING SUCCESSFULLY 10
- MEDICAL INFORMATION 12
- MINDFULNESS 13
- MEDICAL ADVOCACY 14
- TRIBUTES 15

CONNECTIVE ISSUES

FALL 2015
VOLUME 34 | NUMBER 2

THE MARFAN FOUNDATION
22 MANHASSET AVENUE
PORT WASHINGTON, NY 11050
516-883-8712 | 800-8-MARFAN
WWW.MARFAN.ORG

COVER: SAM WOODHOUSE, OF ROGERS, ARKANSAS, GIVES THE CONFERENCE TWO THUMBS UP!

CONFERENCE MAGIC



It would be impossible to attend The Marfan Foundation's Annual Family Conference and not have a life-changing experience. I'm sure that everyone is touched in a different way, but for me the word that comes to mind is "magical!" Magical in the sense of the extraordinary medical evaluations and programs. Magical in the sense of warm moments and friendships. And, magical in the sense of the power of the Marfan and related disorders family, which is at the very core of everything we do in our fight for victory!

Many thanks to our friends at Northwestern Medicine & Ann & Robert H. Lurie Children's Hospital of Chicago for their incredible support. Thanks to our friends at Aetna for having faith in the importance of our mission. And, most importantly, thank you for the spirit, energy, warmth, openness, and knowledge that you bring to our conference for Marfan syndrome and related disorders. You truly are The Marfan Foundation!

As we look to the future, much remains to be done to create a brighter future for everyone with Marfan syndrome and related disorders. We need to build a tighter, more cohesive, nationwide family of affected people and volunteers. We need to focus our energies on "essence of life" issues for people with these conditions of all ages. We need to ensure early identification and treatment. And, we need to continue to support critical research that, over time, will change the course of Marfan syndrome and related disorders. All of this requires additional financial support and we are putting the underpinnings in place that will ensure our growth and success.

As in the case of many people I have spoken with, I am a different person today than when I arrived in Chicago. The "new me" was shaped by knowledge, friendship, experience, and the feeling that collectively we can make a real difference for our friends, family, loved ones, and our community that depends on our success in our fight for victory. We are The Marfan Foundation!

Know the signs! Fight for Victory!

Sincerely,

Michael L. Weamer
President & CEO

JOIN OUR FIGHT FOR VICTORY!

Your donation assists us in creating a brighter future for everyone living with Marfan syndrome and related disorders. It allows us to pursue the most innovative research and makes sure it receives proper funding; informs the public and educates the patient community to increase early diagnosis and ensure life-saving treatment; and provides relentless support to families, caregivers, and healthcare providers. Simply go to Marfan.org and click on "Donate Now." Thank you for your support!



SUSANNA HOLLINGSWORTH, FROM NORTH CAROLINA; CRYSTAL BRIDGES, FROM MONTANA; ERIN VAN ANDEL, FROM WASHINGTON STATE; TERI JOYCE, FROM NEW JERSEY; AND DEBBIE PHILLIPS FROM TENNESSEE — ALL MOMS OF CHILDREN WITH MARFAN SYNDROME, EHLERS-DANLOS SYNDROME, OR LOEYS-DIETZ SYNDROME.

“Getting answers to move past the unknown and enjoy life.”

- DENISE DAMMANN, ROSEBURG, OR



PETER DONATO A COLLEGE STUDENT FROM FRAMINGHAM, MA, WHO HAS LOEYS-DIETZ SYNDROME.

“Having courage even when it’s hard.”

- OWEN GRAY, CYPRESS, TX



KAYLA BRIDGES, OF MONTANA, AND PHOEBE HOLLINGSWORTH, OF NORTH CAROLINA



HEATHER EARNHART, OF CHICAGO, WITH HER DAUGHTER, GABRIELLA, WHO HAS MARFAN SYNDROME

REAL ROLE MODELS

By Will Butler



AUSTIN CARLILE WITH DONOVAN RIVAS, OF FRESNO, CA

When I was diagnosed with Marfan syndrome in 1992, my parents didn't know where to look for answers. It would still be at least a year before the general public started to hear about something called the internet so my parents did what any reasonable person might, and went to the library. But the books there, some of which were published thirty years prior, didn't give them much hope for their baby. Best case, according to those outdated periodicals: my life would be severely limited. Worst case, I wouldn't make it to adulthood.

With good doctors and the dawn of the World Wide Web, we started to get much better answers, but with those, new questions bothered me. My fear wasn't dying, but rather identifying as different or affected. Growing up in the information age, I wanted to know who these people were, what they looked like, and, most of all, if they were living conventionally successful lives. In its early days, the internet was a tangled mess of medical documents, case studies, and institutional language — hardly the neatly packaged, socially stimulating version we have today. And so I was discouraged. Was it possible that there was no one with my condition worth calling a "role model?"

Today we've reached another turning point. Celebrities with a Marfan diagnosis have started to make headlines from the sports world to the music industry, and kids born today

won't pine for positive role models in the same way that I did. In honor of this turning point, I went to The Marfan Foundation's annual family conference this year, for the first time in decades, to figure out who these role models really were. What I found was a bit surprising.

"It's weird," — that's one of the first things Isaiah Austin says to me after a long conference weekend: "I'm still trying to grasp the whole concept of being a role model because I know that I'm not perfect and I still have a lot of things to work on." Isaiah is dealing with something many never have to deal with: a career-ending diagnosis, which barred him from the NBA last year.

"I know everybody here looks up to me, man, but I'm still scared every day. I still miss basketball every day." This kind of candor is admittedly jarring coming from the young man who has been dubbed the new hope of a potentially life-threatening

condition — but it's also terribly important that people like Isaiah remain honest about what they're struggling with. Even before his diagnosis, he felt that he had to hide things, like the blindness in his right eye, so that he could continue to move forward. In discussing this time in his life, he uses words like "insecurity" — not your typical "role model" jargon. But then, if we asked him to always put on a happy face, that'd be just as deceptive as hiding.

Celebrities with a Marfan diagnosis have started to make headlines from the sports world to the music industry, and kids born today won't pine for positive role models in the same way that I did.

"This convention was going on the year my mom passed away. And they didn't know she had Marfan. What if more doctors would have known what to look for?" — That's Austin Carlile, still grappling a decade later with a deep loss of his own. He's also seen a lot of success — last year his band, Of

Mice and Men, won the Metal Hammer Golden Gods award for “best live band,” a title which, as frontman, he is largely responsible for. Diagnosed shortly after his mother’s passing, though, Austin threw himself into music, and rebelled from Marfan treatment.

“I did what most people do, I ran, I hid, I denied it, hated myself for it, et cetera. Then I had my valve [surgery] and, it took a few years, but I was still never really comfortable talking about it. That’s around when I first heard about The Marfan Foundation.” Austin had to get to the end of his rope before showing up at conference; this summer he cancelled three shows and required two surgeries to treat complications from Marfan syndrome. This too, is perhaps not your typical role model stump speech, but it sure isn’t fake, either.

“I think I’m here for a reason,” he tells me after the conference. “The amount of growth I’ve done from age 21 to 27 is incredible. There’s no way to put into words.” Austin could be found during the conference weekend at Northwestern Hospital sitting attentively in workshops, lending his experience and tips on exercise, pain management, and healthy eating. Between sessions, conference attendees who are fans would approach and ask for autographs. It’s obvious that he’s a little more comfortable with his celebrity status, and so I ask him how he sees it.

“When kids say ‘you’re my idol’ or ‘I look up to you, you’re my role model’, I’m like, that’s great, but guess what: I’m only a few steps ahead of you. I’m just a few years older than you. I don’t have all the answers. I appreciate it, and it’s awesome, but I say, use what I’m doing as a blueprint, or a script, and make it your own.”

Ultimately, as both Austin and Isaiah pointed out to me, they need role models too. And the family conference provided no shortage of young adults who expertly balance their diagnoses with their hobbies, aspirations, and entertainment.

The teens and young adults who’ve spent time at conference have built a strong support network. Bonded both by loss and success, though more so the latter, all of these peer role models are in close touch, sending well-wishes, advice, and feedback whether one of their own is living the dream or in recovery.

And this peer support network is something that Isaiah has come to understand clearly. “Not only am I inspiring them,” he says of the throngs of kids literally looking up to him all weekend, “but they’re inspiring me to become a better person.” The take-home message for him? “[You’re] not out here alone. We’re all going through it. We all have Marfan, but we all have different stories, different paths we have to take. Don’t get discouraged, it’s not the end of the world, for sure.”

Will Butler, 26, is a writer, journalist, and nonprofit consultant living in Berkeley, CA, who is a member of our Marfan community.



TOP: ISAIAH AUSTIN AND WILL BUTLER

BOTTOM: AUSTIN CARLILE WITH LIAHONA PARKS (LEFT) AND SAMANTHA KIPPERMAN

WALK FOR VICTORY



2016 WALKS:

Atlanta, GA

Boston, MA

Houston, TX

Long Island, NY

Scottsdale, AZ

And a few more to come!

Interested in joining us at one of our upcoming walks? Visit Marfan.org/walk and be the first to sign up when registration opens!



WALK FOR VICTORY is a nationwide walk program held in various cities across the country to bring the Marfan syndrome and related disorders community together. The walks are non-athletic, family-oriented events focused on fundraising and fun. Walks in 2014 raised over \$100,000 to support The Marfan Foundation's education and research programs, which reach more than 25,000 affected individuals, families, and physicians. In our 2015-2016 season, we are looking to raise over \$200,000 to support quality of life programs for our families, kids, teens, and young adults affected by Marfan and related disorders. These walks provide a great opportunity for the community to come together to raise critical funds for the Foundation.

ONE MORE WALK IN 2015:

St. Louis, MO — October 18

Register at Marfan.org/WalkStLouis

A TEEN'S PERSPECTIVE

Fourteen-year-old Owen Gray, of Houston, recorded his thoughts leading up to his first annual conference and wrote about the highlights each day. Here are some excerpts. You can read it in its entirety on The Marfan Blog at Marfan.org.

August 4, 2015 — In just one day, I will be leaving for the Marfan conference in Chicago. If I had to choose just one thing to look forward to I guess you could say it's just meeting other people who share the same disorder as me.

August 7, 2015 — I started the day off by going to Northwestern Hospital to check in for conference. Then I hung out with some people from the Foundation for a little bit while my parents had a volunteer meeting ... While I was waiting, someone who I have never met but connected through Facebook with contacted me ... I met him in the lobby and we just walked around ... After that I went to the new teen meeting and met all of the people on the Teen Council and we just kind of talked and hung out as friends together. After that we went to Navy Pier for the introductory dinner with all the teens ... it was just fun to just be myself around teens who are just like me. We split off into groups for boys and girls so we could talk about personal stuff that we have to go through.

August 8, 2015 — Started the morning by going to breakfast at Northwestern Hospital with all the other Marfan teens. During breakfast, several different types of doctors from all over the U.S. came and spoke to us. We were able to ask any questions or express concerns that we have with anything on the medical side of the syndrome. After breakfast we broke off into workshops. I chose "Questions about Heart Surgery" and "Life After High School." The first workshop gave me lots of peace about having surgery because I was able to hear from people who have already had it, and hear from the expert doctor who performs the surgery.... [That night, we] went to a teen dance back at the hotel. It was amazing to just be able to hang out with friends and not worry about anything going on. Then, a little bit after we arrived at the dance, Austin Carlile and his girlfriend Pamela came and hung out with all of us until the dance ended. The dance was probably one of my favorite parts of this whole trip!

August 9, 2015 — It was really sad to say goodbye to all the amazing friends I made this week, but I know that we will all stay in touch over social media. My expectations for conference were totally blown out of the water. I came expecting to meet some friends and that was it. All the doctors explained everything so easily which gave me good assurance that when the time comes for something like aortic surgery, I will be in good hands. I left conference with lots of new friends and a sense of peace about my health. Now, I'm just waiting till next year!



OWEN (THIRD FROM LEFT) WITH HIS SISTER (NEXT TO HIM) AND SOME OF THEIR NEW FRIENDS.

TEENS WITH MARFAN SYNDROME AND SOCIAL MEDIA

A pilot study on the social media use of teens with Marfan syndrome was recently published in the American Journal of Medical Genetics (*Am J Med Genet Part A* 9999A:7-6). In this study, Erin Kelleher and Phil Giampietro, PhD, from the University of Wisconsin, and Megan Moreno, from the University of Washington, categorized 147 posts from Instagram, Pinterest, Reddit, Tumblr, Twitter, and YouTube from June 24 through July 22, 2013, and found that close to half (41.5%) featured personal pictures, memes, and pictures depicting features of Marfan syndrome and more than one-quarter (27.1%) shared their personal experiences with Marfan syndrome. Interestingly, one-quarter of posts also mentioned a positive experience or how grateful the individual was for their life. Austin Carlile, a singer with Marfan syndrome (see article on page 4), was referenced as a role model in 13.7 percent of posts.

Following the results of this small study, the researchers are seeking to launch a larger scale project to further study the use of social media by teens with Marfan syndrome and genetic disorders. Their hope is that additional investigation in this area will help physicians and other healthcare providers learn about patient concerns that are not expressed in the clinic and provide additional evidence for the value of social media as a way to connect people with similar conditions.

Know a teen who wants to get connected? Go to Teen Space at Marfan.org.

CONFERENCE AWARDS

Recognizing those who so valiantly fight for victory every day.

Antoine Marfan Award

Awarded to **Dan Rifkin, PhD**, New York University School of Medicine, for his contributions to the advancement of basic knowledge of TGF- β signaling and how it is regulated in diseases such as Marfan syndrome and related disorders.

Priscilla Ciccariello Award

Awarded to the **Sholton and Witte Families**, of Anchorage, AK, for their multi-generational dedication to The Marfan Foundation.

Heart of the Matter Award

Awarded to **Alix McLean Jennings**, of Madison, NJ, for her leadership, spirit, and passion for advancing the mission of the Foundation through fundraising, public awareness, and support.

Rising Star Award

Awarded to **Katie Bridges-Payne**, Helena, MT, for helping other teens in the Marfan syndrome and related disorders community.

Teen Mentor Award

Awarded to **Maya Brown-Zimmerman**, Twinsburg, OH, for her ten years of leadership of the Foundation's teen program.



KAREN MURRAY, CHAIR OF THE FOUNDATION'S BOARD OF DIRECTORS (CENTER), WITH (L-R) JOHN WITTE, MARY WITTE, ANDREA WITTE AND THOMAS WITTE. MARY'S MOM, RITA SHOLTON, WAS UNABLE TO ATTEND.

TOP: DAN RIFKIN, PhD, WHO RECEIVED HIS AWARD FROM LYNN SAKAI, PhD, A MEMBER OF THE FOUNDATION'S PROFESSIONAL ADVISORY BOARD. **MIDDLE:** ALIX MCLEAN JENNINGS, WHO RECEIVED HER AWARD FROM BOARD MEMBER BEN WEISMAN. **BOTTOM:** KATIE BRIDGES-PAYNE AND MAYA BROWN-ZIMMERMAN.

Recognizing the Important Work of Our Volunteers

We take great pride in the passion and commitment of our volunteers from all over the U.S. who work so hard to create a brighter future for everyone living with Marfan syndrome and related disorders. We were thrilled to recognize the following people at our 2015 annual conference.

Education & Awareness

Katrina Barracato, Brooklyn, NY
 Colin Beevor, United Kingdom
 Barbara Brownyard, Islip, NY
 Nakia Cole, Wills Point, TX
 Abe DeAnda, MD, New York, NY
 Heather Earnhart, Chicago, IL
 Susan Fernbach, Houston, TX
 Jill Fischer, Greenvale, NY
 The Flanagan Family, Woodway, TX
 San Juana Galvan, Houston, TX
 Marybeth Geronimo, St. Augustine, FL
 Owen Gray, Cypress, TX
 Rod Gray, Cypress, TX
 Rebecca Gunn, Atlanta, GA
 Virginia Hill, Fayetteville, NC
 Betty Hiraga, Hollywood, FL
 Asa Hollingsworth, Salisbury, NC
 Debbie Jones, Heber City, UT
 Joanne Jordan, Corona, CA
 Jess & Chris Keil, Topeka, KS
 Barbara Krueger, Del Mar, CA
 Deeahna Lorenz, Alameda, CA
 Charlotte Lusschen, Castro Valley, CA
 Melixa Mangome, Aguadilla, PR
 Brianna Moulton, Seattle, WA
 Sunny Pellone, Stanford, CA
 Brooke Pulliam, Gray Summit, MO
 Dawn Pulliam, Gray Summit, MO
 Jonathan Rodis, Winthrop, MA
 Kenneth Stockert, Dickinson, ND
 Rebecca Stroda, Saint Helens, OR
 Sara Theriault, New London, CT
 Laura Torode, Collinsville, IL
 Natalie Wenzel, Indianapolis, IN
 Colorado Community Group
 Heart of Iowa Chapter
 Minnesota Chapter
 North Dakota Chapter
 Southwest Florida Community Group



FRONT ROW (L-R): ASA HOLLINGSWORTH, SAMANTHA NOE, DAWN PULLIAM, SELMA KERZMAN, HEATHER EARNHART, ROD GRAY. BACK ROW (L-R): BROOKE PULLIAM, ANDREA WITTE, TRACY STOPPELMOOR, JAY ROMANO, AND OWEN GRAY.

Fundraising

Sharie Acosta, Orlando, FL
 Alyssa Aiello, Jersey City, NJ
 Tonya Archer, Storm Lake, IA
 Natalia Arena, Madison, NJ
 Mark Benjamin, Tampa, FL
 Michele Cripps, Torrence, CA
 Danek Family, Oak Creek, WI
 Linwood DelCorso, Henrico, VA
 Rachel Epperson, Fort Worth, TX
 Scott Griebel, Dover, MA
 Freddy Hainault, New York, NY
 Hannan Family, Chapel Hill, NC
 Mindy Hartzler, Mapleton, IL
 Cassie Jennings, Madison, NJ
 Nicole Kramer, Rockville Centre, NY
 Lyz Kurnitz-Thurlow, Tacoma, WA
 Miranda Leary, Warwick, RI
 Lucie Leone, Woodbridge, Ontario
 Kathy Magee, San Antonio, TX
 Samantha Noe, Carmichael, CA
 Donna O'Sullivan, Cape Coral, FL
 Batia Rabin, Bronx, NY
 Jay Romano, Barrington, RI

Chris Sears, Medford, NY
 Anne Stewardson, United Kingdom
 Glenn Stidham, Nesconset, NY
 Diane Van Horn, Madison, NJ
 Gary & Peggy Wika, Modesto, CA
 Andrea Witte, Anchorage, AK
 Irene Wright, Tarpon Springs, FL
 Vince Yanovitch, East Stroudsburg, PA
 All South Federal Credit Union,
 Columbia, SC
 Greater Philadelphia Area Physician
 Assistant Programs, Glenside, PA
 Case Western's Alpha Phi Omega-
 Theta Upsilon Chapter, Cleveland, OH
 Alabama Chapter
 Northern California Chapter
 Northern Illinois Chapter
 Staten Island Network Group, NY
 Tall Club International Convention

Conference Photography

Rick Guidotti, New York, NY
 Tim Joyce, Cape May, NJ

A LIGHT IN THE DARK

Ann Reinking brings special ballet performance to conference

During the conference, attendees were treated to a special performance of *A Light in the Dark*, the story of Helen Keller and Anne Sullivan. The ballet was presented by Thodos Dance Chicago and co-choreographed by Ann Reinking and Melissa Thodos. Reinking, the Tony Award-winning actor and choreographer, has a son with Marfan syndrome and has been a long-time supporter of The Marfan Foundation. "We were thrilled to work with Ann to make this performance possible," said Benjamin Weisman, a member of the Foundation's Board of Directors. "It was a wonderful, moving production and gave conference attendees another opportunity to get together."



LIVING SUCCESSFULLY WITH MARFAN SYNDROME AND RELATED DISORDERS



MEAGHAN JOYCE (FOREGROUND) WITH PANELISTS HEATHER EARNHART AND KYLE MCARTHUR

The closing panel of our annual family conference featured several of our members who are living successfully with their diagnosis. Here are excerpts.

Meaghan Joyce, 20, of Cape May, NJ, who has Ehlers-Danlos syndrome

Being a part of The Marfan Foundation has given me countless blessings. When several children and teens in my hometown were diagnosed with EDS and Marfan syndrome, I was able to be their mentor and help them understand that being a Marf is not such a bad thing. Through the Marfan Foundation I have even narrowed down my career path — my goal is to become the Dr. Dietz of my generation.

Heather Earnhart, of Chicago, who has a daughter with Marfan syndrome

Upon my daughter Gabriella's diagnosis of Marfan syndrome at age five, I spent every free moment delving into documents, articles and papers I could find on Google Scholar related to Marfan. I was also lucky to have a great resource in The Marfan Foundation. I strongly believe that community is probably the best support we can all have. Connecting with people who know and understand the specific trials we are all going through. Remember to get informed and talk to your child about how they feel.

Kyle McArthur, 17, of Wilsonville, OR, who has Marfan syndrome

I found out about The Marfan Foundation during a 7th grade science project and ended up going to the conference that year because it was in Portland. That was possibly the best weekend of my life. I could finally talk to someone about what I was going through. I made a lot of fantastic friends... Sometimes all we need is for someone to be there who understands.

Michael Kramer, of Rockville Centre, NY, who has Marfan syndrome

I became active with The Marfan Foundation so late because of my denial of my condition. The main reason I became involved was because of my seven-year-old daughter, Emily, who is also affected by Marfan syndrome. I want her and the rest of the Marfan community to have a much easier time with this condition than I did... I want Emily to have an easier road ahead of her than me, but if she doesn't, I want her to know that she can do this and I'll be right by her side every step of the way.

SPECIAL THANKS

Special thanks to the following individuals and companies who were instrumental in making our 2015 Annual Family Conference a huge success. We couldn't be more grateful for your time, talent, and support!

HOSTS	Northwestern Medicine and Ann & Robert H. Lurie Children's Hospital of Chicago		
SPONSORS	<p>PRESENTER \$50,000 🏆 Aetna</p> <p>LEADER \$10,000 🏆 Northern Illinois Chapter of The Marfan Foundation</p> <p>CONVENER \$5,000 🏆 Terumo Cardiovascular Systems Corporation</p>	<p>Massachusetts Chapter of The Marfan Foundation</p> <p>Mid-Atlantic Chapter of The Marfan Foundation</p> <p>SUPPORTER \$2,500 🏆 Minnesota Chapter of The Marfan Foundation</p> <p>Michael & Karen Weamer</p>	<p>CONTRIBUTOR \$1,000 🏆 Heart of Iowa Chapter of The Marfan Foundation</p> <p>Northern California Chapter of The Marfan Foundation</p> <hr/> <p>EXHIBITOR Ambry Genetics</p>
PLANNING COMMITTEE	<p>NORTHWESTERN MEDICINE</p> <p>Kevin Bargon Administrator, Department of Medicine</p> <p>Vicki Diep Division Administrator, Cardiology</p> <p>Kerri Evans Nursing Practice Manager, BCVI</p> <p>Jennifer Feld Education Coordinator, Cardiac Surgery</p> <p>Miriam Guzman Operations Coordinator, BCVI</p> <p>Julia Lynch Senior Associate General Counsel</p> <p>Dr. S. Chris Malaisrie Associate Professor of Surgery, Cardiac Surgery</p>	<p>Amy Pastalaniec Nurse Practitioner, Cardiac Surgery</p> <p>Ashley Rego Senior Practice Manager, BCVI</p> <p>Eric Swanson Director, Security Services</p> <p>LURIE CHILDREN'S HOSPITAL</p> <p>Lynn Brown, RDCS Director of Telemedicine and Manager, Echocardiography Lab</p> <p>Jessica Bucher Genetic Counselor</p> <p>Elizabeth Cappella, APN Clinical Coordinator, BAV/Connective Tissue Disorders Program</p>	<p>Patricia Conforti Practice Manager, Division of Ophthalmology</p> <p>Allison Goetsch Genetic Counselor</p> <p>Karen Graham Director, Department of Surgery</p> <p>Gale Morgan-Williams ParentWISE Coordinator, Family Services</p> <p>Soo Shim, MS, LCSW Clinical Coordinator, Social Work Family Services</p> <p>Aaron Wiles Director, Cardiopulmonary Labs</p> <p>Dr. Luciana Young Professor in Pediatrics, Cardiology</p>
PHOTOGRAPHY	Rick Guidotti, Positive Exposure	Tim Joyce Photography	
IN-KIND SUPPORT	Epic Burger The Golec Family	MM Grinnan Neuco	Paramount Tall Club of Chicago

We are grateful to all our volunteers and chaperones who donated their time to the children and teen programs.

GIVE BACK WITH MODIFY



50% OF ALL SALES
GO TOWARDS
THE MARFAN FOUNDATION

20% OFF CODE **GIVE20**

MODIFYWATCHES.COM/MARFANFOUNDATION

YOUR MEDICAL QUESTIONS AND ANSWERS



DR. PAUL SPONSELLER CONDUCTS AN ORTHOPEDIC EVALUATION AT NORTHWESTERN HOSPITAL DURING THE CONFERENCE HEALTH FAIR.

Medical advances have increased the understanding of Marfan syndrome, identified new treatments, and resulted in better surgeries. However, Marfan syndrome affects everyone a little differently; each person faces different challenges. At our annual family conference, we offered general medical presentations about Marfan syndrome and related disorders and gave people an opportunity to ask questions of the presenters. Several questions related to the bones and joints in Marfan syndrome. Dr. Paul Sponseller, director of pediatric orthopedics at Johns Hopkins and a member of our Professional Advisory Board, provided the answers.

Is there any benefit to pestering a teenager with kyphosis about maintaining good posture?

Posture is controlled by bone structure, ligament character, and muscle activation. Since muscle control plays a part in maintaining posture, it is helpful to remind a teenager of how to use his or her muscles to control the posture. The more upright the spine, the less there will be fatigue or deformation over time. Nevertheless, there will always be variation between kids regarding what is feasible for them.

What percentage of people with Marfan syndrome who have protrusio acetabulae have hip replacement?

Only about 10-15% of Marfan individuals with protrusio acetabulae will have a hip replacement.

How can we know if a stomach ache or headache is related to dural ectasia or a dural leak?

Stomach aches are not common symptoms of dural ectasia, but pain in the lower abdomen and pelvis may be. Headaches are a common symptom of dural ectasia. These symptoms are more likely to be related to dural ectasia if they are relieved by recumbency (laying down), even if it takes a few minutes to notice the difference. Interestingly, there are some patients with dural ectasia who have no symptoms at all.

How should dural ectasia be treated in children? How often should it be monitored or measured by MRI?

There is no treatment to prevent dural ectasia from enlarging. It does not enlarge in adulthood, in the vast majority of people. It may increase in childhood. MRIs should only be ordered if there is a change in symptoms which requires attention.

Why is there so much pain with Marfan syndrome and what treatments are there?

The mechanisms for pain may have to do with mechanical as well as biochemical factors in the connective tissue matrix. There are a range of treatment options, including physical measures (yoga, physical therapy, low-intensity exercises, braces), acupuncture (if an individual is not taking anti-coagulants), oral analgesics, topical analgesics or patches, and spinal cord stimulators. The proper treatment is best determined by your primary doctor, pain specialist, or orthopaedic specialist (if the pain is musculoskeletal in nature).

How does one get a hip replacement in their mid-forties when co-morbid health issues warrant it, but the doctors and insurance say no?

You can expect a hip replacement to last 10-20 years; maybe longer if activity levels are low and bone density is reasonable. Hip replacements do not last forever; that may be why the physician is recommending against it for the time being. We all know why the insurance company may be against it. To resolve any difference, it never hurts to obtain a second opinion.

Read more about how the bones and joints are affected at Marfan.org.



DR. LYNN OSTROWSKI

MINDFULNESS IS MORE THAN A PRACTICE, IT IS A LIFESTYLE

By Dr. Lynn Ostrowski

Mindfulness is truly getting a lot of attention these days, but what is it? According to Jon Kabat-Zinn, who many consider the father of mindful-

ness, “mindfulness means paying attention in a particular way; on purpose, in the present moment, and nonjudgmentally.” We have a natural tendency to be easily distracted which causes us to not be present; we dwell on the past or think about the future, we multi-task to keep up with our busy lives and we run on auto-pilot. You can probably remember a time when you arrived at school, work, or a doctor’s appointment and you had no recollection of the ride there? This is a classic example of being on auto-pilot! Many of us go through most of our day like this.

No matter what the cause, the result is the same. We fail to listen to our bodies, our thoughts, or control our self-talk. We operate reactively as opposed to proactively. We may experience high levels of stress which, over time, has negative impacts on our health; physically, mentally, and spiritually. Ultimately, we miss out on what is truly important in our lives; health, happiness, family, friends, and being productive.

As a health psychologist, I believe that mindfulness is truly the path to well-being. Regardless of your age, gender, race, socio-economic status, or health condition, mindfulness is for everyone. Contrary to popular belief it is not a religion. While it is true the origins of mindfulness lay in ancient meditation and religious practices, you do not need to be “religious” to experience the numerous benefits.

Research has demonstrated that mindfulness can have a positive impact on both physical and psychological symptoms, as well as health attitudes and behaviors. A few of the positive impacts on well-being include:

- Increased resilience (our ability to bounce back from traumatic events, significant stressors, etc.)
- Stress relief
- Improved sleep
- Lowered blood pressure
- Reduction in chronic pain
- Decrease in feelings of depression and anxiety

If I told you that you too could achieve these benefits, would you be interested? What if I told you it was easy? What if I added that it is free? And there truly are no catches, just

willingness on your part to train yourself through daily practice. While there are a number of forms of mindfulness, the most common are yoga and meditation (formal and informal) that builds concentration. Following is a simple informal mindfulness mediation practice:

Go with the flow. In mindfulness meditation, once you establish concentration, you observe the flow of inner thoughts, emotions, and bodily sensations without judging them as good or bad.

Pay attention. You also notice external sensations such as sounds, sights, and touch that make up your moment-to-moment experience. The challenge is not to latch onto a particular idea, emotion or sensation, or to get caught in thinking about the past or the future. Instead you watch what comes and goes in your mind, and at times, discover which mental habits produce a feeling of well-being or suffering.

Stay with it. At times, this process may not seem relaxing at all, but over time it provides a key to greater happiness and self-awareness as you become comfortable with a wider and wider range of your experience.

Excerpt from www.helpguide.org/harvard/benefits-of-mindfulness

The key is to find a mindfulness practice that you enjoy and that works for you. My favorite is coloring. There are numerous adult coloring pages on the internet as well as coloring books. I find that when I am coloring it is not only a creative expression, but also I am able to let thoughts flow in and out of my mind without assigning judgment. I can focus on my breathing and am aware of my body. I find myself relaxed and at peace. I have introduced this coloring to my children as well.

Whether formal or informal, once you learn to become more aware of what is going on in your mind and body, your concentration will improve. You will also notice that you are more in control of your reactions, which can decrease your feelings of stress. This decrease in stress gives your body more regenerative time allowing healing to occur and resilience to build.

Join the thousands that feel like a million; harness the power of mindfulness to build well-being and inner strength.

aetna® *Dr. Lynn Ostrowski is the Executive Director of the Aetna Foundation.*

WHAT MIGHT THEY BE INTERESTED IN LEARNING FROM ME? TIPS ON MEDICAL ADVOCACY

By Jon Rodis

Many people throughout the years have asked me why I became an advocate, and my answer is found in what was a perfect storm of several factors. One large one was losing my ability to work in the executive career that I had made major advancements in. This loss, coupled with having to navigate the social security disability system and the back-and-forth with my private disability insurance company, made my overall health (both physical and mental) much worse. It's one thing to have to suffer with one's health (or lack thereof), but to have to fight for benefits that you've earned and payments from a private insurance policy that you've paid decades for, while dealing with the many financial challenges that accompany the incredibly difficult decision to stop working, make for a very lonely and aggravating time.

By going through rough times, I learned what works and what to avoid — and I made a promise to myself that I would help others through the process. I want to be a source of support and let patients know that they're not alone and that there are better days ahead. Not only am I helping others advocate for themselves, but also, by doing so, I help myself. It's a good feeling to help another person; it's my medicine for dealing with my day-to-day health challenges.

It can be daunting, however, to do advocacy work and to reach out to the medical community, whether it be a hospital, a medical school, a local health fair, a private medical practice, or your own doctor/healthcare provider's offices. In the last 15 years of working on various forms of medical advocacy, I've found through trial and error some useful steps in obtaining the best results in each area of the medical community and all health-related entities.

Step back and think, 'What might they be interested in learning from me about my condition that they could utilize to help future patients with my condition?'

There are several suggestions you can make to a hospital representative regarding medical advocacy. You could ask for an awareness table at the hospital, to be manned by knowledgeable support staff, on your condition; suggest that you provide literature to various departments on the condition that pertains to their particular specialty; or

inquire about the opportunity to tell your personal story and answer questions from individual departments/staffs at the hospital.

One way to improve your chances of gaining an opportunity for advocacy is to ask your own doctors to help, especially if they're affiliated with a local medical school or have good contacts at the hospital and/or medical school where you would like to advocate. They may teach or present at affiliated hospitals and medical schools and/or know doctors or key administration representatives to talk to.

Remember that your message is an important one when it comes from your own or a close loved one's experience. When you have a condition, know all the facets of its symptoms, and can talk about the key factors that most doctors and medical students may not know, you have powerful information that should be an integral part of your message.

No matter what type of medical advocacy you want to start first, take time to consider what message best fits the individual or organization you're interested in contacting. It's always a good idea to step back and think, 'What might they be interested in learning from me about my condition that they could utilize to help future patients with my condition?'

Armed with factual information and the power of your own story, you can improve not only the awareness of your condition in the medical community, but also hopefully the quality of care for all those with your condition who walk through their doors in the future.

Jon Rodis, who has Marfan syndrome, is president of the Massachusetts Chapter of The Marfan Foundation. This article was originally published in Stanford Medicine's Scope in August 2015



JON RODIS

Read more about raising awareness among doctors at Marfan.org—click "Volunteer."

WE REMEMBER AND HONOR

We are grateful to our members and friends who have made contributions in memory of, or in honor of, the following individuals. These donations are fully appreciated and support our programs and services that create a brighter future for all those living with Marfan syndrome and related connective tissue disorders.

Donations In Memory of:

Adrian Adame
 Carol Adame
 Elias Adame
 Beverly Auker
 Dr. Michael Beardslee
 Bud Beck
 Jason Matthew Beck
 Barry C. Bellerose
 Michael Brandt
 Scott Boegle
 Lucy Carrubba
 Joseph Carney
 Sarah Cayo
 Robert Michael Dane
 Cristi Dermer
 Francine Drexler
 Donald K. DuBoice
 Beverly Eckhart
 Jonathan Efraim
 Kae S. Einfeldt
 Michael Enbar
 Sarka Friedrichs
 Melodie K. Friesen
 Justin Theodore Gee
 Sonia Handler Gerber
 Donald Glass
 Jason Serge Grossi
 Earl Hamm
 Kyle Hempstead
 Wesley Hickenbottom
 Jim Hinds
 Richard Horowitz
 Susan M. Huber
 Eileen Ilberman
 Barbara Harden Johnson
 Herschel E. Johnson

Jill Sheiner Kaepfel
 Kyle Matthew Kinsall
 Dr. Stephen Kobernick
 Troy J. Kramer
 Julie Kurnitz
 Harold Landau
 Ronald M. LeHew
 Leonard D. (Lenny) Leonard
 Anne Lerman
 Martin Lerman
 Bernard Levinton
 Richard P. Linkie
 Fred Lonas
 Sylvia Love
 Susan Manuel
 Dustin Kyle McCrum
 Patricia Moran
 William J. Murray, Jr.
 Robert G. Oswald, MD
 Stephen Parfenoff
 Hattie Parmele
 Dr. Neera K. Patel
 Christopher Paulsen
 Walter Pickens
 Andrew Rexroth
 Edmund Francis Rigney
 Brock Robertson
 Gary and Ryan Sanderson
 Spencer N. Sellas
 Lisa Sidweber
 Kathryn L. Simpson
 Mindy Skelton
 Bridget Stewart
 James W. Sylvester
 Sita Thomas
 Barbara Toshach
 Alphonso Troncone

Rosanne Wakat
 Victor Alexander Willhoite
 David M. Willson
 Jack Young
 Edward R. Yurkonis, Jr.

Donations In Honor of:

Marie Abbruzzese
 Victoria Arias
 Amy Avitabile
 Irene Bishop
 Jennifer Cowart
 James Dickey
 Hannah Dixon
 Nancy Driftmyer and family
 Victoria Falcone
 Dr. Leonard N. Girardi
 Heather Gooch
 Connor Hajj
 Rocco Hermogenes
 Cassie Jennings
 Jerry Lerman and family
 Christine Linkie
 Emma Lynch
 Heidi Moore
 Carole Nowak
 Lauren Phipp
 Brooke Pulliam
 Mary Roe
 Peter & Lizz Roos
 Alex Schmidt
 Mr. & Mrs. Peter Siciliano
 Vincent & Katrina Tomeldan
 Ellen & Richard Wells
 Andrea Witte
 Alan & Debbie Zwillinger

HONOR/REMEMBER YOUR LOVED ONES

Making a gift to The Marfan Foundation is a meaningful way to remember a loved one. It is also a great way to celebrate a friend or relative's birthday, anniversary, or marriage. Many people in our community express gratitude to their doctors and other caregivers by honoring them through a gift to the Foundation. We acknowledge every gift by sending a letter to the honoree or person you designate. Please allow at least two weeks for the letter to arrive. No matter what the occasion, your contribution helps us create a brighter future for everyone living with Marfan syndrome and related disorders. To make a contribution, please go to Marfan.org and click on "donate."



Our online thrift store is open!



SHOP

for designer goods at a fraction of the price



DONATE

your excess like iPhones, jewelry, and purses



SUPPORT

every purchase supports The Marfan Foundation

marfan.webthriftstore.com

WebThriftStore



Austin Carlile, lead singer of the band Of Mice & Men, was diagnosed with Marfan syndrome ten years ago and just attended his first annual conference. Read more about Austin on page 4.

