

CONNECTIVE ISSUES

WINTER 2016

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



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.

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WINTER 2016
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THE MARFAN FOUNDATION
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COVER: KYLE MACARTHUR, 17, OF WILSONVILLE, OR, IS A MEMBER OF OUR TEEN COUNCIL WHO IS GRADUATING FROM WILSONVILLE HIGH SCHOOL THIS SPRING. PHOTO COURTESY OF SARAH META PHOTOGRAPHY.

THIS IS OUR TIME



With every New Year comes new opportunities and enthusiasm for good health and good fortune. As we embark on our 35th year, The Marfan Foundation has much to be proud of as we've made great strides in our fight for victory over Marfan syndrome and related disorders. In the future, the greatest medical advances will continue to come from basic and clinical research; thus, the importance of this edition of *Connective Issues*.

Last year, our "Atenolol vs. Losartan Trial" was one of the American Heart Association's Top 10 Research Advances. A few months ago, who would have ever believed that former President Jimmy Carter would be announcing he no longer has brain cancer? A year ago, how much did we know about immunotherapy? And, who would have believed that immunotherapy is likely to replace chemotherapy in the next five years? To me, these breakthroughs over time speak to the power and importance of having a strong Marfan and related disorders research program.

Remarkably, members of our scientific community believe that research accomplishments in the next few years have the potential to impact the care and treatment of Marfan syndrome and related disorder exponentially more than any time in the past. That's why we need to be vigilant about generating the necessary financial resources to support research and build the finest organization of our type.

In 1975, the life expectancy for a person with Marfan syndrome was in the 40s. Today, life expectancy is nearly the same as the general population, and we are spreading the word like no other time in history so people will know the signs and seek treatment to enhance and extend their lives. And, while our research program remains at the forefront of our mission, we are also working diligently on quality of life issues. We want to make sure that people of all ages—and their families—have the best possible resources to live a healthy, productive life while we continue to shape the future.

Together—with your support, involvement, energy, and commitment—we will make great strides in 2016. Collectively, we will change the landscape for individuals affected by Marfan syndrome and related disorders.

I have no doubt that this is our time. Please join me in getting up every day with an eye to making a life-saving difference.

Wishing you good health and a wonderful year!

All the best,

Michael L. Weamer
President & CEO



EDUCATING MEDICAL STUDENTS

SEVERAL MEMBERS OF OUR COMMUNITY, INCLUDING REBECCA STRODA, RON STANSELL, LAURIE BECKHAM, KYLE MCARTHUR, MELANIE CASE, AND GERRY OORTHUYS SHARED THEIR EXPERIENCES WITH MARFAN WITH FIRST-YEAR MEDICAL STUDENTS AT OREGON HEALTH &

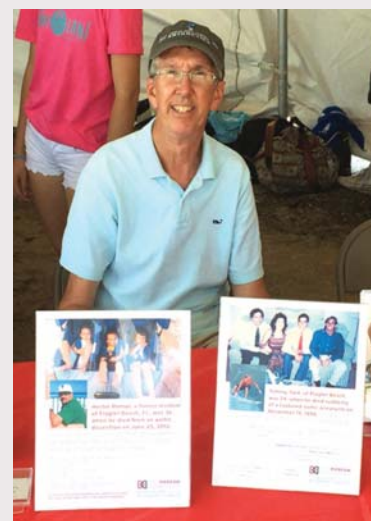
SCIENCE UNIVERSITY IN PORTLAND. ACCORDING TO LYNN SAKAI, PhD, A MEMBER OF OUR PROFESSIONAL ADVISORY BOARD WHO HELPED ORGANIZE THE PRESENTATION:

“These future doctors will always remember Marfan syndrome as they go out into the world to practice medicine. The volunteers with Marfan syndrome made clear impressions on the students, putting real faces and real life experiences onto textbook descriptions of Marfan syndrome.”



PUBLIC AWARENESS

Chris Ihde (below) and Angela and Rob Gordon (above) found it very rewarding to help educate the public about Marfan syndrome and related disorders at the Tommy Tant Memorial Surf Classic in Florida. The event, which is sponsored by Nautica, is a tribute to a local surfer who died of an aortic dissection due to a condition related to Marfan so many of the people on the beach that day were very interested to learn from our members.



STAND UP FOR MARFAN SYNDROME

Comedian Andy Erikson puts Marfan Syndrome in the Spotlight

If you like to laugh, we hope you were watching the most recent season of Last Comic Standing on NBC. Among the finalists was a member of the Marfan syndrome community, Andy Erikson, a lover of unicorns and squirrels who made audiences laugh every time she took the stage.

The night before she made her television debut in July, Andy blogged about having Marfan syndrome and, in a subsequent post, she explained that she didn't include Marfan in her stand-up routine on NBC because she didn't want to be "the comedian with Marfan."

Fast-forward to the Fall, when Andy was on a whirlwind cross-country tour with the other Last Comic Standing finalists. By the time we caught up with her in West Palm Beach in November, she had incorporated Marfan syndrome into her act—not only making jokes, but also truly educating the audience. She told them to visit Marfan.org and, while the other comedians were only selling their DVDs and posters, Andy gave out educational information about Marfan after the show. She was thrilled to meet members of the Marfan community while she was on tour and looks forward to meeting more at our annual family conference in August 2016.

Visit andyerikson.com to see Andy perform, read her blog, and more.



ANDY ERIKSON WITH HANNAH HARRIS, WHO HAS MARFAN SYNDROME, AT THE CHARLOTTE STOP ON THE LAST COMIC STANDING TOUR.



EXPANDING OUR PATIENT SERVICES

Licensed Clinical Social Worker Added to Senior Staff



SUSAN LESHEN, LCSW, IS PLANNING EXTENSIVE NEW PROGRAMMING FOR MEMBERS OF OUR COMMUNITY, INCLUDING ADDED EVENTS LIKE THE NEW ENGLAND SYMPOSIUM (PICTURED HERE) TO HELP PEOPLE LEARN MORE ABOUT THEIR DIAGNOSIS AND MAKE CONNECTIONS.

The Marfan Foundation has named Susan Leshen, LCSW, the senior director of patient and program services and volunteer leadership, a new position at the Foundation.



In her role, Susan oversees the Help & Resource Center and is responsible for developing programs and resources to assist patients, medical professionals, and others in diagnosis and treatment. In addition, she is responsible for facilitating peer-to-peer connections, working with volunteers, and enhancing collaborations between the Foundation and Marfan syndrome clinics around the country. Susan also oversees the Foundation's annual family conference.

Susan has 25 years of social work experience, including extensive work with the elderly as well as with people who are chronically ill. Prior to joining The Marfan Foundation, she worked with Jewish Home Lifecare. Her previous experience is with the Visiting Nurse Service of New York, Association for Camps, and the Jewish Association of Services for the Aged (JASA).

"We are excited to have Susan join our staff in a position that is absolutely critical to helping our Marfan syndrome and related disorders community," said Michael L. Weamer, President and CEO, The Marfan Foundation. "The breadth and depth of Susan's experience will benefit the youngest to the oldest members of our community. She has a special interest in improving quality of life for people with Marfan and related disorders and is already devising strategies that will directly impact our community in the near term."

OUR HELP & RESOURCE CENTER

Learning anything new is often challenging. This is especially true when you are trying to learn about a complex medical condition. The words and concepts may be unfamiliar. Some of the details can be troubling. It can be difficult to know what to do with all the information you gather.

We are here to help. We offer a wealth of information for you and your loved ones about Marfan syndrome and related disorders, as well as special resources for children and teens. Our goal is to help you learn what you need to know quickly and support your next steps.

We can answer your questions by phone or email. Amy Kaplan, RN, staffs our Help & Resource Center Monday-Friday, 9:00 am to 5:00 pm EST. Contact her at 800-8-MARFAN (800-862-7326) ext. 126, or support@marfan.org. Amy can:

- Answer your questions
- Help you find a doctor
- Help you find local support
- Provide you with fact sheets and other resources
- Let you know about phone and online support groups for families coping with Marfan syndrome and related disorders.

You can also submit questions at Marfan.org—just click on "For Patients and Families" and then "Ask a Question."

"I cannot tell you how much help and support your email has given me. It brought me to tears just knowing there is someone out there who can share this journey. I will follow up on each of the resources you provided—thanks from the bottom of my heart for your kind support and informed resources."

COLOR YOUR STRESS AWAY: A MINDFULNESS PRACTICE



COLORING HELPS CALM DOWN LYNN'S SON, STEPHEN, 8.



By Lynn Ostrowski, PhD

Adult coloring is a trend that has spread nationwide. Did you know that the top four slots on Amazon's 2015 best-seller list are taken up by adult coloring books? It's true.

The adult coloring trend has developed out of the popular mindful meditation movement. Many of the coloring books feature intricate mandalas with circular, radiating, and meditative type designs. These designs help trigger the relaxation response which is what makes it meditative in nature.

You may be saying to yourself that this is just another fad and wonder who would pay \$15.00 for a coloring book! Well,

unlike some fads, this one is actually really good for you. There are a number of health benefits reported by people who engage in this activity.

From the physiological perspective, coloring is a centering activity. Centering activities help the amygdala, a part of the brain that is involved in the processing and expression of emotions, especially anger and fear, to rest and elicits a calming effect over time.

Adult coloring, like meditation, actually helps us to focus on the moment. The repetition and attention to the details and patterns of the pictures not only help us relax, but they also help exercise fine motor skills and train the brain to focus.

Some people report physiological changes such as decreased blood pressure and heart rate. As an avid "colorer," I have experienced these changes myself. While I have been coloring for a few years, I really got into it after an automobile accident that left me with two herniated discs in my cervical spine and unable to release stress through physical activity. I also enjoy the creative expression and outlet that it provides me and have noticed that any negative thoughts present when I begin are soon replaced with positive thoughts.

The repetition and attention to the details and patterns of the pictures not only help us relax, but they also help exercise fine motor skills and train the brain to focus.

I have also begun to use coloring with my eight-year-old son to calm him down and help him focus before we do his homework and daily reading. At first he found it a bit frustrating, so we would just color for a few minutes. He has been at it for a few months now and his ability to spell and reading fluency have increased significantly! And I have some beautiful pieces of art, one pictured here, that he is so proud of. Today, when he is feeling frustrated, angry, or stressed, he takes out a coloring page on his own and works on it. The change in him is almost instantaneous!

I believe the practice of coloring enables us to create a calmness that helps generate overall wellness, while at the same time stimulating motor skills and creativity.

Give it a try and see for yourself!

Lynn Ostrowski, PhD, is the executive director of the Aetna Foundation.

LIVING WELL WITH MARFAN SYNDROME

By Latasha Doyle

Here's an excerpt of how Latasha lives well with Marfan syndrome. Please visit [The Marfan Blog](#) on our website to read the entire article.

From a very young age, I understood that I was not like other kids. I had eyes that didn't see very well, and lungs that didn't breathe very well. I was tall and skinny, and I was not able to participate in physical education like the rest of the kids. I knew there was something wrong with my heart, and that's why I couldn't play too hard or be on the volleyball team. I knew I had Marfan syndrome, and I knew that it made me different. Despite all that, I managed to live a normal life.

Now at the age of 27, I am married, I have an amazing family (most of whom have Marfan syndrome as well), and I have traveled the world with my husband and some of my best friends. I am active, I am fairly healthy, and I have a positive approach to life. When people hear about the gravity of my condition, they often ask me, "But aren't you scared? Isn't that really hard to deal with every day?" And I say no. Why? Because you can live well, even knowing that you have a condition like this.

Taking Care of Yourself

Growing up, I never realized that so many problems with my body were associated with Marfan. Because I now understand my body, I am able to take better care of it. Aside from the basics, like taking my medication and getting my yearly echocardiogram, I try to eat healthy, and I drink more water than I drink anything else. I take care of my body because I want it to be able to weather whatever storms may come.

By focusing on how you can improve your situation, even in small ways, you can make a huge difference. Maybe learning how to cook a vegan meal or going for a walk every night with a friend will help. Get a massage or get a pedicure. Taking care of your body won't make Marfan syndrome disappear, but it will help you feel better.

Accepting Your Limitations

Possibly one of the hardest parts about having Marfan syndrome is accepting that there's a whole long list of things you cannot (or should not) do. But you know what? There's an even longer list of things you can do.

Do yoga. Go for a walk. Even a little bit of movement can change your body's strength and stamina. Visit with friends

and family. Go on a road trip. Read a book. Dance to some music. Play with your dog or cat. Travel the world. Make new friends. Learn a new talent. Start a new hobby. This list is virtually endless. Instead of thinking about all the things you can't (or shouldn't) do, think about the things you can do, and do them. Life is too short to be limited.

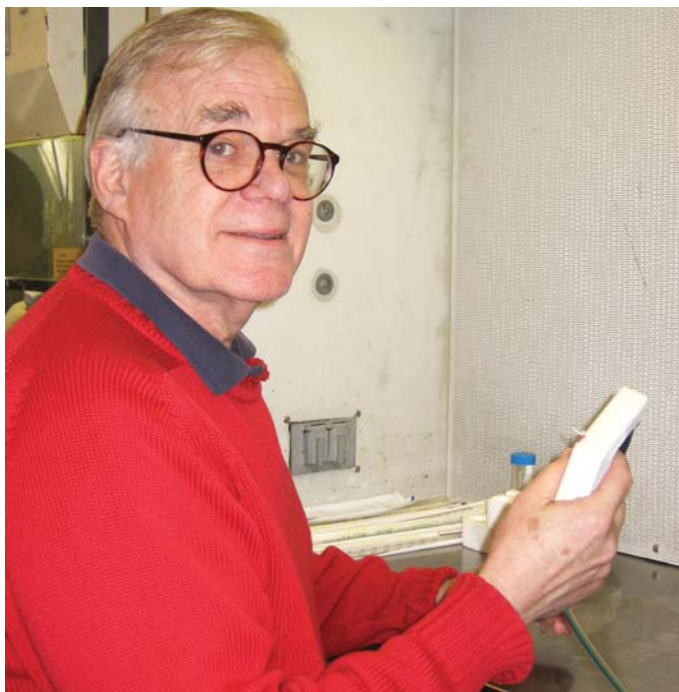
Latasha Doyle is a writer and full-time nanny living outside of Denver. When she's not writing or taking care of children, she enjoys crocheting, Netflix marathons, and planning her next trip. She also just happens to have Marfan syndrome.



TOP: LATASHA DOYLE

BOTTOM: LATASHA (SECOND FROM RIGHT) WITH (L-R) HER AUNT LISA (WHO IS NOW DECEASED), MOM ALICIA, AND SISTER JERRICA.

2015 RESEARCH GRANT AWARDS



DAN RIFKIN, PHD

Funding New Studies

After receiving 34 proposal submissions for grants, The Marfan Foundation is proud to announce that we will sponsor eight projects totaling \$725,000 in 2016: one fellowship grant, three early investigator grants, and four faculty grants. These initiatives are building on our five-year goal to secure the next generation of researchers by developing dedicated investigators at every level of experience.

Fellowship grants allow young scientists and physicians to specialize in a research field before taking on a permanent position. Early investigator grants provide a greater opportunity for young investigators in the first seven years of a permanent position to receive funding, since they are not competing with senior faculty members. Faculty grants are for very experienced scientists/physicians.

Most of the proposals received in 2015 were targeting cardiac questions involving the mechanism of aneurysm development. As a result, seven of our eight grants cover this area. Although their end goals might be similar, each of the seven investigators looks at unique ways to uncover a better understanding of how high levels of TGF β or other molecules play a role in aneurysm development. The eighth grant supports an investigation on how fibrillin variants may be associated with severe scoliosis.

Victor A. McKusick Fellowship Grant

Lakshmi Venkatraman PhD, Beth Israel Deaconess Medical Center, is studying why high levels of TGF β , as seen in Marfan syndrome, may cause an increase in aortic aneurysms via computational modeling (which enables researchers to study the behavior of a complex system by computer simulation). This study will provide insight into the complex biological pathways and, hopefully, pinpoint the exact cause of the TGF β -1 driven switch which causes extensive blood vessel growth.

Early Investigators Grants

Mitra Esfandiarei, PhD, Midwestern University, is focused on a protein called caveolin-1 which is known to regulate the function and activity of TGF β and angiotensin-II pathways within the blood vessel walls and how this interaction may play a role in the development of aneurysms.

Emanuela Branchetti, PhD, University of Pennsylvania, will investigate RAGE/sRAGE, which are biomarkers of inflammation and stress in the vasculature. This study will block RAGE in an animal model to determine if this can help reduce aneurysm formation.

Parmanand Singh, MD, Weill Cornell Medical College, will be conducting an imaging study to help identify new aneurysm wall characteristics or processes that are associated with growth or predictive of rupture. Findings could help guide surgical timing based on several characteristics, not just aortic size.

Faculty Grants

Daniel Rifkin, PhD, New York University School of Medicine, will investigate the function of TGF β during the development of the aorta. The study will determine when increased TGF β is needed for normal vessel growth and when it is detrimental to vessel function. This will help direct therapies to achieve the best management results.

Gustavo Egea, PhD, University of Barcelona, will test the effectiveness of a small peptide (p144) which has been shown to partially inhibit TGF β and its signaling action. The research will look at the ability of this peptide to reduce aortic enlargement in Marfan mice. This peptide may be able to inhibit some of the detrimental effects of TGF β while possibly keeping some of its needed beneficial properties.

Christina Gurnett, MD, PhD, Washington University, will sequence FBN-1 and FBN-2 in 1000 patients with adolescent scoliosis and determine if fibrillin rare variants confer increased risk of scoliosis and specific Marfan syndrome features.

CONTINUES ON OPPOSITE PAGE

MARFAN SYNDROME AND WORK PARTICIPATION

A new study published in the *American Journal of Medical Genetics* sheds light on how Marfan syndrome impacts work participation among adults. In the study, which was conducted in Norway, those with Marfan syndrome had significantly less work participation than the general population, yet they had greater work participation rates than the population of people with disabilities.

While 50 percent of adults with Marfan syndrome who were surveyed worked full-time despite their health problems, they also left the work force at an earlier age than the general population. Few said they had received any adaptations at their place of employment while they were working. Surprisingly, Marfan-related health problems and chronic pain were not associated with low work participation. Rather, age, lower educational level, and fatigue were factors that made a difference.

The researchers—who hail from the Sunnaas Rehabilitation Hospital, University of Oslo, and Altershus University College of Applied Sciences—note that vocational guidance early in life, more appropriate work adaptations, and psychosocial support might improve the possibility for sustaining work for adults with Marfan syndrome. They also cite the importance of better strategies to deal with the chronic pain and fatigue that accompany Marfan syndrome.

“These findings are valuable to us as we identify new programs and services to improve the quality of life of people in the Marfan syndrome and related disorders community,” said Susan Leshen, LCSW, senior director of patient and program services and volunteer leadership at The Marfan Foundation. “By pinpointing the challenges in the workforce, we can focus on how we can improve the work life, and thus overall life satisfaction, for the people we serve. It also provides insights into how we can prepare our young people for their future.”

If you would like to share your work experience with us or if you have recommendations in this area, please contact Susan at sleshen@marfan.org.



DONNA SCHELL, OF CHAMPAIGN, IL, HAS WORKED AT A RESEARCH LAB SINCE 1989, BUT IS CONSIDERING EARLY RETIREMENT DUE TO PAIN AND FATIGUE CAUSED BY MARFAN SYNDROME.

PARTICIPATE IN RESEARCH

You can play an important role in research on Marfan syndrome and related disorders by enrolling in a research study. There are usually several criteria to meet, depending on what the researchers are studying. Three studies currently looking for participants are:

- A study on pregnancy in women with connective tissue disorders, including Marfan syndrome, Loeys Dietz syndrome, and vascular Ehlers Danlos syndrome, that only requires the completion of a questionnaire.
- A study on people with Marfan syndrome, Loeys-Dietz syndrome, vascular Ehlers-Danlos, or familial thoracic aortic aneurysm and dissection that is trying to develop a blood test that reflects aortic enlargement in these conditions.
- A study on the outcomes of ACL (anterior cruciate ligament) reconstruction in people with Marfan syndrome.

More details about these studies, including the criteria for enrollment and how to enroll, are in the current research section of our website.

CONTINUED FROM OPPOSITE PAGE

These variants will then be utilized in a zebrafish animal model to test whether or not activation of the TGF β pathway is required for scoliosis development.

Francesco Ramirez, PhD, Icahn School of Medicine, Mount Sinai Hospital, is looking at the importance of the cell layer closest to the blood stream in the aorta which may malfunction after birth with the lack of normal fibrillin-1 in Marfan patients. This cell layer may then be unable to accommodate changes after birth and, as a consequence, trigger a cascade of events that results in degrading the aortic wall's integrity. This study will utilize a new Marfan mouse model in which fibrillin-1 is removed from this cell layer.

WALK FOR VICTORY



UPCOMING WALKS:

Houston, TX	February 20
Scottsdale, AZ	March 20
Trussville, AL	April 2
Atlanta, GA	April 23
Long Island, NY	May 14
Pasadena, CA	May 21
Boston, MA	June 11
Rochester, MN	August 5

(at our annual conference!)



Interested in joining us at one of our upcoming walks? Go to Marfan.org/walk to register!

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 more than \$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 more than \$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.

HOUSTON'S ULTIMATE MARFAN DAD

By Steve Beckholt

Most people around Houston know me for my passion for the Houston Texans. You'd think a football player would be my biggest hero, but it's not. My biggest hero is my son Hunter, who is 11. You see, he's fighting a battle that many people just don't know about. He's got Marfan syndrome, but we are among the lucky ones. We know about Marfan and Hunter is getting the care he needs. Hunter was diagnosed when he was three years old. We had never even heard of Marfan syndrome. All at once we engulfed ourselves in information about the condition. Today, for the most part, Hunter is doing great. He needs to get his aorta checked every six months and deals with scoliosis. He has aches and pains and sees a lot of doctors. Otherwise, he's a regular kid who is passionate about acting and loves to draw and read.

We know we are not alone. We attended The Marfan Foundation's annual family conference when it was in Houston in 2010. It opened our eyes to what to expect with Marfan. We met older kids and found out how they coped. Most important, we learned that you can live a long life with Marfan if you take care of yourself. The thought of an aortic dissection is the scariest thing (that's why Hunter has his aorta checked every six months).

If you know me, you know I'm not one to sit on the sidelines. We enrolled Hunter in the national clinical trial at Texas Children's Hospital and he did very well on the test medicine. And now, as the Foundation brings their Walk for Victory to Houston for the first time, we are stepping up again.

Getting the opportunity to raise awareness and raise money for something that affects my son leaves me speechless. I want everyone to know about Marfan, to know why my son isn't out there running and playing sports. The Marfan Foundation needs the support from me and from our huge, caring Houston community to make sure everyone knows about Marfan and gets the diagnosis and treatment they need to live with it.

Houston is a big and caring city. I would love to see Houston support Marfan in a BIG way for this Walk for Victory. As the Ultimate Fan, I'm involved in charities and enjoy putting a smile on kids' faces. As the Ultimate Dad, there's nothing I like more than seeing a smile on my own son's face.

If you have Marfan syndrome or a related disorder and there's a Walk for Victory in your area, I encourage you to get involved. If there's not a Walk near you, please visit the Foundation's Walk page and support one of the Walk teams. Everyone can play a part in the fight for victory over Marfan and related disorders!

Steve Beckholt is known around Houston as the "Ultimate Fan" of the Houston Texans. He lives in Tomball, TX, with his wife, Norah, and son, Hunter.



TOP: STEVE BECKHOLT WITH HIS WIFE, NORAH, AND SON HUNTER
BOTTOM: STEVE AND HUNTER READY TO CHEER ON THE TEXANS

HOUSTON WALK FOR VICTORY SPONSORS



SAVE THE DATE

SAVE THE DATE FOR OUR ANNUAL FAMILY CONFERENCE: AUGUST 4-7, 2016

Our 32nd Annual Family Conference will take place on August 4-7, 2016, in Rochester, MN.

Co-hosted by the Mayo Clinic, this year's conference will offer all of the features that people come for every year, including workshops, special programs for children, teens, and young adults, updates on the latest advances in research and treatment, free medical assessments (application required), and the opportunity to connect with others who are on the same medical journey.

Our 2016 conference will also offer the following new features:

- Special focus on quality of life issues with new workshops run by professionals in their fields.
- Medical workshops with formal presentations based on questions that are submitted ahead of time by conference attendees.
- Enhanced networking opportunities throughout the weekend so you can make more connections.
- Our first National Walk for Victory to raise awareness and strengthen our community.
- Saturday night event featuring comedian Andy Erikson, who was featured on NBC's *Last Comic Standing*.

Watch our website for registration information this spring!



WAYS TO SUPPORT THE MARFAN FOUNDATION



I support The Marfan Foundation because they are like a family. They helped my daughter feel more comfortable with her condition. She has made so many friends at the annual conferences and has connected with people just like her.

- Christina Treadwell, Oklahoma

The Marfan Foundation creates a brighter future for everyone living with Marfan syndrome and related disorders. We pursue and fund the most innovative and life-saving research. We support individuals, family members, and medical professionals through our education programs and resources with the most up to date information on Marfan syndrome and related disorder. Your support enables our patients and families to receive vital information, get the necessary treatment, and live a long and full life. You can support us by:

- Becoming a sustaining donor and giving a monthly donation
- Making a gift in honor or in memory of a loved one
- Leaving a planned gift in your will
- Selecting the Foundation in your employee giving campaigns

If you'd like to learn more about how you can help advance our mission by supporting the Foundation, please contact Helaine Baruch, hbaruch@marfan.org.

APRIL 14, 2016 CIPRIANI 42ND STREET NEW YORK CITY
THE MARFAN FOUNDATION **HEARTWORKS**

Gala

Honoring

The Legacy of Jonathan Larson,
Award-Winning Playwright of RENT

Weill Cornell Medicine Cardiac Team
Richard B. Devereux, MD
Leonard N. Girardi, MD
Mary J. Roman, MD

 **Weill Cornell Medicine**  **New York-Presbyterian**

SAVE THE DATE

Honoring

THE MARFAN FOUNDATION

HEARTWORKS

St. Louis

Entertainment
provided by Groovethang

HERO WITH A HEART

Charles Huddleston, MD

Cardiothoracic Surgeon,
SSM Cardinal Glennon Children's Medical Center
Professor of Surgery,
Saint Louis University School of Medicine

CORPORATE CHAMPIONS

Robert & Donna Plummer

President & Vice President
R.P. Lumber Company

SAVE THE DATE SATURDAY **MARCH 5** 2016 **FOUR SEASONS HOTEL ST. LOUIS**

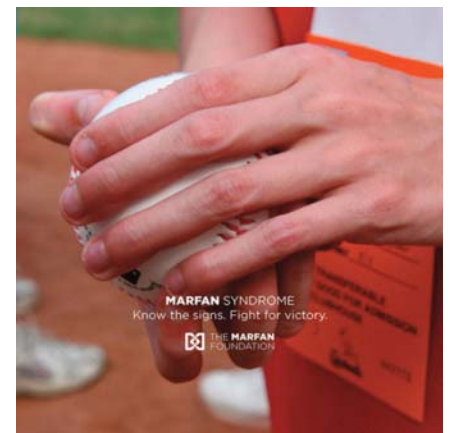
MARFAN AWARENESS MONTH IS FEBRUARY!

How are you going to help increase awareness of Marfan syndrome and related disorders?



ABOVE: DAWN PULLIAM, WHO RECENTLY SET UP A MARFAN TABLE TO INCREASE AWARENESS AMONG SCHOOL NURSES IN MISSOURI, AGREES THAT “SPREADING AWARENESS ABOUT MARFAN SYNDROME IS AN OPPORTUNITY TO SAVE A LIFE.” DAWN IS PICTURED HERE WITH MEGAN BRINKER. **BELOW AND RIGHT:** GRAPHICS YOU CAN USE TO SPREAD AWARENESS THROUGH SOCIAL MEDIA. THEY ARE AVAILABLE ON OUR WEBSITE.

Awareness of Marfan syndrome and related disorders leads to early diagnosis, treatment, and an extended lifespan. It also helps people in our community get connected to each other. Together, accurate information, appropriate medical treatment, and strong connections give people a solid foundation for living well with Marfan syndrome and related disorders. February is Marfan Awareness Month and we hope you can do your part—in your local community, at your workplace, or online. We have new tools and graphics on our website to help! To learn more, visit Marfan.org or contact publicity@marfan.org.



GIVE BACK WITH MODIFY WATCHES



25% OFF WITH CODE
MARFANMONTH

MODIFYWATCHES.COM/MARFANFOUNDATION

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:

Roy L. Abbott
 Adrian Adame
 Carol Adame
 Elias Adame
 Anthony Albano Sr.
 Shane Albaugh
 David P. Barry
 Dr. Michael Beardslee
 Barry Bellerose
 Jeff Berkowitz
 Vincent D. Bitowf
 Trevor Blanton
 Barbara Bowling
 Marissa Broady
 Dennis Bryant
 Gregg Bulis
 Paul J. Burke, III
 Gabrielle Cannistraci
 Ben Carlson
 Ann, Jim & MaryLynn Carrier
 Sarah Cayo
 Paul Chandler
 Brooke Chapman
 Elvira Chicarelli
 Brian Cosgrove
 Leo D'Agostino
 Kevin Thomas Delange
 Essie M. DePung
 Christy Dermer
 Kelsey Dresser
 Donald DuBoice
 Sean C. Elmore
 Ida Fee
 Carl Friedman
 Chris & Greg Gilmore
 Steven Michael Goode
 Montie Gregory
 Esther Grushkin
 Steve Haag
 Fred Hearn
 Jim Hinds
 Kevin Hoffman
 Dwight Hurst
 Eileen M. Ilberman
 Jeff
 Steve Jerkins
 Herschel Johnson
 Jill Stacey Sheiner Kaeppl
 Mimi McDonald Kelly
 Scott Kiefer
 Julie Kurnitz
 Jonathan Larson
 Quin Leone
 Richard P. Linkie
 Pearl Lonardo
 Gary Luedde
 Alexandria Macaluso
 Dr. Jack Matloff
 Dustin Kyle McCrum
 Brad McReynolds
 Patricia Moran

Dorothy Morreale
 John Morris
 Paula R. Neil
 Joe Neustadt
 Robert G. Oswald, MD
 Linda Parman
 Christopher Paulsen
 Roberta Pflieger
 Jackie Prindle
 Brian Randall
 David A. Ricca, MD
 Harold Riddell
 Edmund Rigney
 Ilene Roberts
 Brock Robertson
 Maryann Roney
 Julie Roos
 Regina "Jean" Kathleen
 Rotenberry
 Dr. Herbert Roth
 Rob Sadler
 Ari Safier
 Barbara Safranski &
 Elizabeth Neill Hermann
 Spencer N. Sellas
 David Simons
 Kathryn Simpson
 Bridget Stewart
 Tommy Tant
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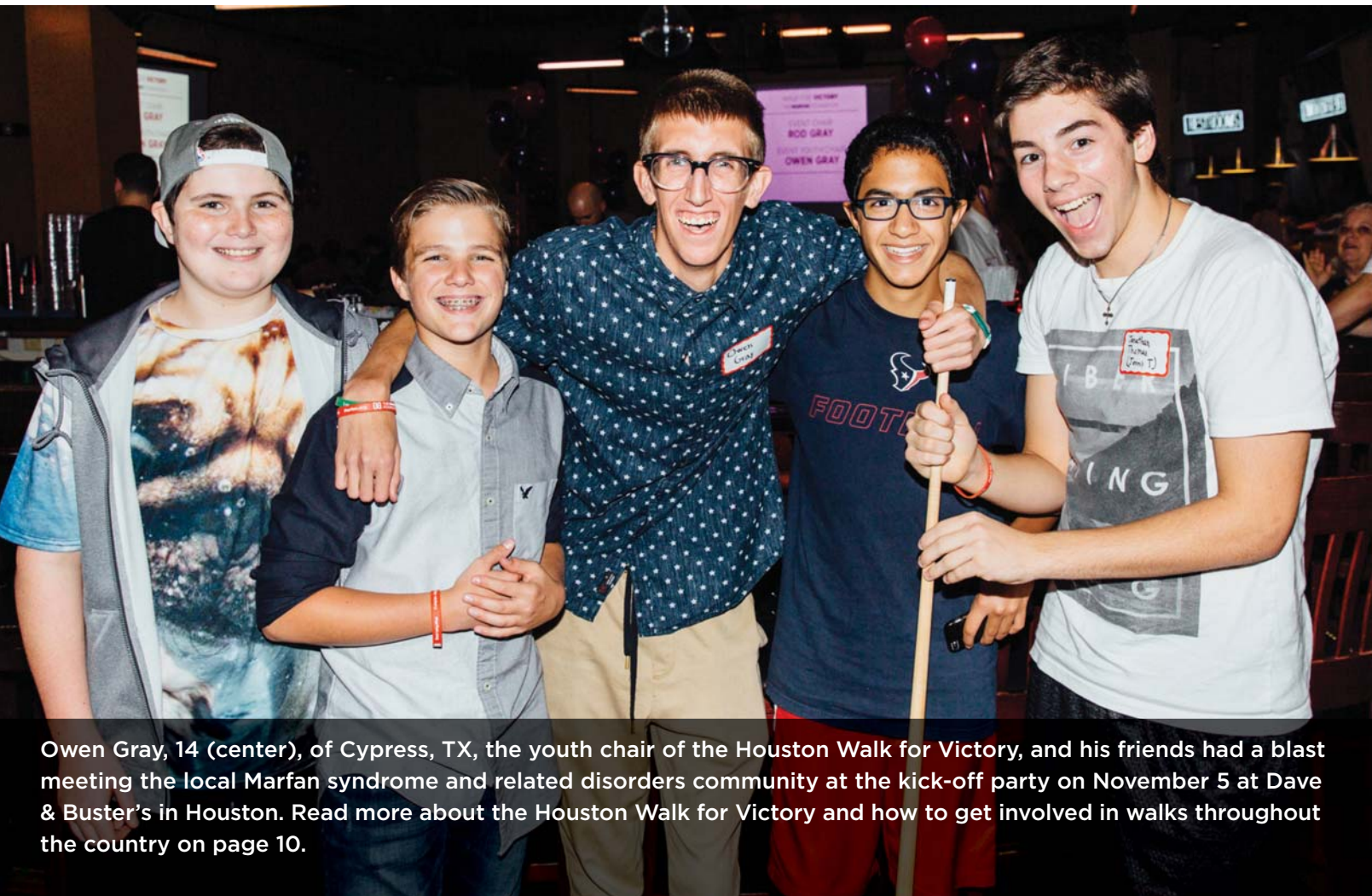
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Making a gift to The Marfan Foundation is a meaningful way to remember a loved one. It is also a great way to celebrate a friend or relative's birthday, anniversary, or marriage. Many people in our community express gratitude to their doctors and other 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."



Owen Gray, 14 (center), of Cypress, TX, the youth chair of the Houston Walk for Victory, and his friends had a blast meeting the local Marfan syndrome and related disorders community at the kick-off party on November 5 at Dave & Buster's in Houston. Read more about the Houston Walk for Victory and how to get involved in walks throughout the country on page 10.