

CONNECTIVE ISSUES

FALL 2016

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WALK FOR VICTORY
THE MARFAN FOUNDATION

WALK FOR VICTORY
THE MARFAN FOUNDATION

#CREATING
CONNECTIONS





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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CONNECTIVE ISSUES

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COVER: DR. RON LACRO, BOSTON CHILDREN'S HOSPITAL, AND HIS PATIENT, MAGGIE TUCKER, ENJOYED THE BOSTON WALK FOR VICTORY TOGETHER IN JUNE.

VICTORY IS...



Victory is Brie and Jeff getting engaged after meeting at our 2011 Conference.

Victory is Callie and Addison becoming fast friends.

Victory is being inspired by Isaiah.

Victory is honoring David, Alan, and Rebecca.

Victory is recognizing Libby for tireless patient care and compassion.

Victory is _____!

While an often overused word, “unique” really does describe The Marfan Foundation. No other organization offers free patient health assessments with world class medical professionals. No other organization has a more engaged and committed community. Our Board of Directors and Professional Advisory Board provide extraordinary leadership and our staff works tirelessly each and every day to make a life-saving difference. Yes, we truly are unique.

While we have much to celebrate in our fight for victory over Marfan syndrome and related disorders, it is important to remember that our work is far from finished. A young athlete recently died because Marfan went undetected. We lost a young child shortly after conference who was just beginning to experience life. And, countless individuals struggle with quality of life issues daily as they age. While there is no one answer in advancing our life-saving work, “Creating Connections” is the first line of offense against Marfan syndrome and related disorders. And, the more connections we create, the more effective we will be in all aspects of our mission. To be connected is to be informed! To be informed = victory!

As the calendar year winds down, we are focused on continuing to build community, putting plans in place for our most effective campaign ever, building out our Quality of Life movement, extending our prominence in funding research while making certain to align our funding with organizational priorities, building partnerships with complementary organizations, planning the most regional symposiums in our history, and taking advantage of every opportunity to promote the importance of Marfan syndrome and related disorders.

Many thanks to our friends at the Mayo Clinic for an extraordinary conference. Now all eyes are on Atlanta and our 33rd Annual Conference, August 3-6, 2017. We look forward to partnering with Emory University and the Sibley Heart Center for our best conference ever.

Enjoy the Fall season and don't hesitate to contact me to help advance our shared mission. Never forget, YOU are The Marfan Foundation.

Sincerely,

Michael L. Weamer
President & CEO

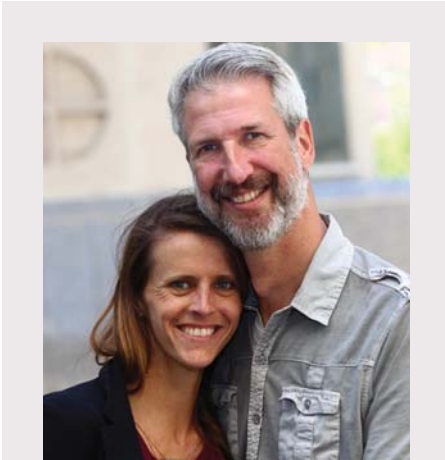
CONNECTIVE ISSUES IS SUPPORTED BY A GRANT FROM THE CHU AND CHAN FOUNDATION.

#CREATING CONNECTIONS



YOUNG ADULTS IN OUR MARFAN COMMUNITY ALSO HAD AN OPPORTUNITY TO CONNECT. PICTURED HERE ARE ROBBIE MURDOCH, OF EDMOND, OK, HALEY GOLEC, OF DYER, IN, AND ADAM HANIFF, OF SOLON, OH.

Creating connections is one of the benefits of attending the Foundation’s Annual Conference. Whether you are young or old or attending your first conference or your twenty-first, connecting with someone else who truly understands is priceless.



Brie Moulton and Jeff Woodruff, of Seattle, who met at our 2011 annual conference in Portland, OR, got engaged in 2015, and attended this year’s conference just a few weeks before their wedding.



CALLIE EFURD, OF THE WOODLANDS, TX, AND ADDISON IZZO, OF MAPLETON, IL, BOTH ATTENDED THEIR FIRST CONFERENCE THIS YEAR AND BECAME FAST FRIENDS.



MEMBERS OF THE MARFAN AND RELATED DISORDERS COMMUNITY FROM ARIZONA GOT TOGETHER AT OUR CREATING CONNECTIONS LUNCHEON, WHERE PEOPLE SAT WITH OTHERS FROM THEIR OWN STATE.

CONNECT ON SNAPCHAT!

The Marfan Foundation is now on Snapchat. Watch our stories from events throughout the year, including behind-the-scenes highlights, interviews, and much more. Search for MarfanFdn or use our Snapcode.



FIRST EVER CONFERENCE WALK FOR VICTORY

Conference attendees had an opportunity to connect with each other even before the conference welcome reception. Approximately 500 strong gathered in Rochester's Central Park on a picture perfect afternoon to celebrate the Marfan and related disorders community and Walk for Victory together. The walk, led by our National Walk Ambassador Isaiah Austin and Minnesota Chapter President Heather Bergstrom and her family, was accompanied by music, face painting, and more! Many families made signs of encouragement and there were lots of smiles all around!



HEATHER BERGSTROM, PRESIDENT OF THE MINNESOTA CHAPTER, HELPED CUT THE RIBBON FOR THE WALK, ALONG WITH HER DAUGHTER, ALIA, AND ISAIAH AUSTIN.

“The Conference Walk for Victory was a community of strangers and friends brought together by their common experience of living and loving those with Marfan syndrome. It was young and old singing and dancing to music. It was truly a celebration. I can't wait to carry this on and make this a yearly event in Minnesota.”

- HEATHER BERGSTROM

“The walk made me feel like I was part of one big united family. United and strong.”

- PAUL HARTMANN



PAUL HARTMANN, OF CLERMONT, FL, WITH HIS WIFE, ROSELINE.

“It was pretty cool to be at the Walk with so many others from around the country and meeting their families. This is what the Walk for Victory is all about, whether you participate in a Walk for Victory in your home area or at conference.”

- JON RODIS



JON RODIS, PRESIDENT OF THE MASSACHUSETTS CHAPTER, WITH HIS WIFE, KATHLEEN KANE.

Upcoming Walks for Victory St. Louis: October 9 | Fort Lauderdale: January 29 | Houston: March 25 | Cleveland: March 26 | Atlanta: April 29 | Pasadena: May 2 | Dates to be determined Phoenix, Chicago, New York, Boston Get involved at Marfan.org. Questions? Contact Dominga Noe at dnoe@marfan.org.

ANNUAL CONFERENCE HIGHLIGHTS

There was something for everyone at our 32nd Annual Conference



ABOVE: CONFERENCE ATTENDEES WERE TREATED TO MEDICAL PRESENTATIONS ON RESEARCH, GENETICS, ORTHOPEDIC MANAGEMENT, AND CARDIOVASCULAR MANAGEMENT AS WELL AS A PRESENTATION CALLED, *RESILIENCY TRAINING: HOW TO IMPROVE YOUR QUALITY OF LIFE WHEN LIVING WITH A CHRONIC DISEASE* BY DR. AMIT SOOD, FROM MAYO CLINIC.



ABOVE: OUR CONFERENCE TALENT SHOW FEATURED *LET IT GO*, SUNG BY OUR YOUNGEST KIDS. A GROUP OF TEENS SANG *FIGHT SONG* AND ANDY ERIKSON, THE FINALIST FROM NBC'S *LAST COMIC STANDING* WITH MARFAN, ALSO ENTERTAINED CONFERENCE ATTENDEES.



TOP LEFT: NEARLY 100 PATIENTS HAD APPROXIMATELY 250 APPOINTMENTS WITH VARIOUS MARFAN SPECIALISTS AT OUR FREE PATIENT EVALUATION HEALTH FAIR, WHICH IS OFFERED EVERY YEAR AT OUR CONFERENCE. CHRIS RYDZEWSKI WITH KIERRA, FROM SOUTH CAROLINA, HAD AN OPPORTUNITY TO MEET WITH DR. LUCIANA YOUNG, A PEDIATRIC CARDIOLOGIST WHO IS NOW AT SEATTLE CHILDREN'S HOSPITAL.



BOTTOM LEFT: NEARLY 100 CHILDREN AGES 6-12 WERE TREATED TO A SPECIAL PROGRAM JUST FOR THEM THAT INCLUDED A FIELD TRIP TO THE ROCHESTER ART MUSEUM TO CREATE ART PROJECTS AND THE CHILDREN'S MUSEUM. DOMINGA NOE (CENTER), THE FOUNDATION'S SPECIAL EVENTS COORDINATOR, WHO IS THE FIRST STAFFER WITH MARFAN SYNDROME, WAS ONE OF THE CHAPERONES.

RIGHT: A FASHION SHOW FEATURING MOSTLY TEENS IN OUR COMMUNITY (INCLUDING AVA SHAW, OF MILLEDGEVILLE, IL) WAS ANOTHER UPLIFTING PART OF THE WEEKEND, WHICH WAS FULL OF TEEN ACTIVITIES DESIGNED TO INCREASE SELF-ESTEEM AND EMPOWERMENT.



THE MARFAN FOUNDATION PRESENTS AWARDS AT ANNUAL CONFERENCE

In recognition of the significant contributions of volunteers across the country, The Marfan Foundation presented several awards at the 32nd Annual Conference. More than 600 people living with Marfan and related disorders, as well as the leading medical experts in the field, were on-hand at the Foundation's conference to applaud those who were honored for their exceptional efforts.

"The Marfan Foundation is driven by the thousands of volunteers across the country who bring the local community together, conduct local awareness events, and initiate local projects that raise funds for programs and services that enhance the lives of people with Marfan and related disorders," said Michael Weamer, President and CEO, The Marfan Foundation. "While awards are given out at the conference, we appreciate every single volunteer effort that supports our community. Volunteers are truly the life blood of the Marfan Foundation."



DR. DAVID LIANG, RECIPIENT OF THE 2016 ANTOINE MARFAN AWARD, WITH DR. ALAN BRAVERMAN, WHO MADE THE PRESENTATION.

2016 AWARD RECIPIENTS:

Antoine Marfan Award: Dr. David Liang, a member of the Foundation's Professional Advisory Board who takes care of patients at the esteemed Marfan Syndrome and Related Aortic Disorders Clinic at Stanford University.

Priscilla Ciccariello Award: Dr. Alan Braverman, the chair of the Foundation's Professional Advisory Board and the director of the Marfan Clinic at Washington University in St Louis, and his wife, Rebecca, and children, Emily and Jenny, for their long-time commitment to the Marfan syndrome and related disorders community.

Rising Star Award: Owen Gray, 15, of Houston, who has raised public awareness of Marfan syndrome through national and local television interviews, advocated on behalf of the Marfan and related disorders community on Capitol Hill, and served as the Youth Chair of our Houston Walk for Victory.

Heart of the Matter Award: Isaiah Austin, the former Baylor University basketball star who had to withdraw from the NBA draft in 2014 due to his Marfan syndrome diagnosis. In the past year, Isaiah has continued his commitment to the Marfan community through



(L-R): ROD GRAY WITH ISAIAH AUSTIN, 2016 HEART OF THE MATTER AWARD RECIPIENT, AND OWEN GRAY, 2016 RISING STAR AWARD RECIPIENT.

advocacy on Capitol Hill, interviews about Marfan in a range of media, and support of the Foundation's Walk for Victory program as National Walk Ambassador.

Cheryll Gasner Spirit of Service Award:
Tim Joyce, volunteer photographer for the Foundation for more than 15 years.

Cheryll Gasner Spirit of Service Award: Libby Sparks, APNG, Johns Hopkins Hospital, for her outstanding direct patient care and compassion and devotion to the Marfan community.

The Foundation honored many other members of the Marfan and related disorders community for their successes in the areas of education, awareness, and fundraising. The awards were presented at the conference to those who were in attendance. Here is the complete list of individuals, group leaders, and Walk for Victory and marathon fundraisers.

Kid With a Heart Award:
Addison Izzo

Individuals:

- Cheri Benjamin
- Adam Bitterman
- Emily Braverman
- Rod Gray
- Alix McLean Jennings

Chapter/Community Group Leaders:

- Rob Berklite: Mid-Atlantic Chapter
- Jennifer Reisinger and her daughter,
- Kelsey: Tidewater Community Group
- Jon Rodis: Massachusetts Chapter

Walk for Victory Top Fundraiser for each Walk for Victory and Top Marathon Fundraiser:

- Atlanta: Becky Gunn
- Boston: Suzy Chaos
- Houston: Tyrelle Robert
- Pasadena: Kaitlin Mattice
- St. Louis: Gail Johnson



DR. ALAN BRAVERMAN AND HIS WIFE, REBECCA, RECIPIENTS OF THE 2016 PRISCILLA CICCARIELLO AWARD, WITH ISAIAH AUSTIN.

Brody Lawson

- Ryan Melendez
- Brooke Pulliam
- Alison Weust
- Maya Brown-Zimmerman for Alpha Phi Omega-Theta Upsilon Chapter

- Brandi Smith: Nashville Community Group
- Sara Paul: Staten Island Community Group

- Scottsdale, AZ: Paula Bower
- Tri-State, NY: Michael Kramer
- Trussville, AL: Amber Harbison
- 2015 TCS NYC Marathon: Jamie Grant

CONFERENCE
THANKS

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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Massachusetts Chapter of The Marfan Foundation

Minnesota Chapter of The Marfan Foundation

Contributor

Iowa Community Group

EXHIBITORS

Ambry Genetics

Invitae

PHOTOGRAPHY

Tim Joyce Photography

FIVE THINGS I WISH MARFAN PATIENTS KNEW ABOUT AORTIC SURGERY



OWEN GRAY AND HIS SISTER, OLIVIA, JUST DAYS AFTER OWEN'S AORTIC SURGERY IN MAY.

By Clayton Kaiser, MD

While no one wants to have heart surgery, the majority of those with Marfan syndrome (greater than 90%) will need aortic surgery at some point in his or her life. But take heart! Aortic surgery in the current era has become extremely safe with excellent results and long term outcomes. Of course, as with any surgery, it is completely natural to be nervous, but much of the worry can be mitigated by knowing what to expect and how to proceed. The following information and advice is for anyone needing aortic surgery, now or in the future.

1. Just because you need aortic surgery does not mean there has been a “failure”

The last thing you should do is view surgery as an indication of failure—either of you or your prior medication and treatment protocol. Experiencing a certain amount of stress and pressure is typical when a surgical need arises. However, all too often, patients who need aortic surgery come to my clinic and ask, “Why did this happen?” or “What could I have done to prevent this?” By and large, there is no way to absolutely prevent the need for surgery. While medications

and routine surveillance are critical to slow the progression of disease and certainly help avoid emergency situations such as acute dissections, there is no treatment that can completely eliminate the need for surgery for everyone.

2. The timeline of your aortic surgery does not need to be rushed

Unless you have an emergency condition, such as an aortic dissection, surgery on an enlarged aorta (aka an aortic aneurysm) can be done with a well thought-out game plan. If you have established care with a cardiologist or surgeon with experience in connective tissue disorders, you will likely be able to plan accordingly if and when your aorta reaches a point that needs surgery. While that does not mean you can put off surgery indefinitely, it does afford you the flexibility to arrange your

personal schedule so that time away from home and/or work will be well tolerated.

3. When it comes to aortic surgery, experience matters

Whether it is your first or fourth surgery, this is likely to be one of the most significant events in your life. When choosing a facility and surgeon, you will likely rely on advice from your cardiologist, family and friends, as well as the internet. There are many nuances to aortic surgery, and being at an experienced facility with a properly-trained surgeon is the key to getting the right operation at the right time. You should always be satisfied with your hospital and surgeon selection. If you don't get the right vibe or are not happy with an explanation, seek another opinion. It is truly in your best interest.

4. One size does not fit all

From valve-sparing aortic root to total aortic arch replacements with elephant trunks, not to mention thoraco-abdominal aortic operations, there are many different operations that are available, and you want to have the one that is right for you. Each operation should be tailored for each patient, as there are no two patients that are exactly alike. While it is not your responsibility as a patient to understand the

nuanced differences between different types of operations—that is the job of your surgeon—you should have a sense of (1) what operation you are having, (2) which part of your aorta is being replaced, and (3) why. If your doctor cannot explain all of this to you in a way that allows you to understand the information, then you may need to look for a different surgeon.

5. The future is bright!

No one wants to have aortic surgery, but it is inevitable for some. The aortic research and database registries that are ongoing continue to enrich our knowledge of this disease process and refine our ability to treat aortic disease. Even major aortic surgery can be done with incredibly good outcomes, and the data on the durability of very complex aortic repairs should be encouraging to anyone who may one day need such an operation.



Clayton Kaiser, MD, is an Assistant Professor in Cardiac Surgery at Vanderbilt University Medical Center and the co-surgical director of The Vanderbilt Marfan Syndrome and Aortic Disorders Center.

PARTICIPATE IN RESEARCH

Research studies are critical because they help scientists and doctors find answers to difficult scientific or health questions that identify better ways to diagnose, treat, or cure a disease. It is important to understand that research is conducted to gain information about a disease, condition, drug, or treatment that will benefit people in the future. Although, your family might not benefit from the results of the study, your participation will certainly help the greater community affected with the disorder, including future generations of your family.

Several studies are currently seeking patients with Marfan syndrome or a related disorder. These include researchers at:

- The Department of Orthopaedic Surgery at Johns Hopkins Hospital which is investigating post-operative outcomes of anterior cruciate ligament (ACL) reconstruction in people with Marfan syndrome.
- Midwestern University, which is conducting a study on quality of life in people with Marfan syndrome.
- Texas Children's Hospital and Baylor College of Medicine, which is evaluating imaging biomarkers in children and young adults with aortopathy. They are seeking participants with Marfan, Loeys-Dietz, Turner, Shprintzen-Goldberg, and other conditions that cause aortic disease.

For details on these studies and others, please visit Marfan.org/current-studies.

AORTIC SURGERY: A PARENT'S PERSPECTIVE

Rod Gray's son, Owen, had aortic surgery just a week prior to turning 15 in May. Here is his advice for other parents or family members who have a loved one going through this operation.

- Talk to the doctor and nurses ahead of time about what to expect after surgery. I was not prepared to see Owen the first time in ICU with all of the tubes and wires coming out of his body.
- Speak with other patients and parents in advance to fully understand what to expect before, during, and after the surgery. It was very helpful to speak with an adult Marfan patient who had the exact surgery at the exact hospital with the exact surgeon just a few months prior to Owen's surgery. It was also valuable to speak with parents of teens who went through the same surgery. We learned how to encourage Owen and it gave us peace of mind.
- Understand that, as a parent, you set the tone for your children. If we are positive and feel everything will be okay, our kids will feel that way too. The same goes if we are negative.
- It helped to listen to others who had been through the surgery who were positive, as well as to have positive support from our friends, family, and our church family. In addition, posting updates before, during, and after surgery on social media such as Facebook and Instagram provided a lot of positive feedback and encouraging words.

I wish I knew how easy the surgery was going to be and how easy the recovery was going to be. I was expecting the worst, but really focused on being positive. And that is just what I got—a positive outcome and rapid recovery. Talking with my Marfan friends who already had aortic surgery helped more than any research I could have done about the operation.

- Owen Gray

ULTIMATE COURAGE

Congratulations to Steve Beckholt, of Houston, for receiving the Jason “Beardown J” Carlson Courage Award from Pro Football’s Ultimate Fan Association (PFUFA) in Canton, OH, during the NFL’s Hall of Fame weekend in August. This award is presented to the PFUFA member that has personified honor and courage and inspired other ultimate fans with their charitable work in the previous year. Steve, whose son, Hunter, has Marfan syndrome, was a driving force in The Marfan Foundation’s Walk for Victory in Houston, raising Marfan awareness—as well as more than \$12,000—through his efforts.



STEVE BECKHOLT, WHO IS BETTER KNOWN IN THE HOUSTON AREA AS THE TEXANS’ “ULTIMATE FAN.”

“THE WALK FOR VICTORY IS HER SUPER BOWL”



SAMMI (LEFT) WITH MAGGIE (FAR RIGHT) AND ANOTHER MARFAN FRIEND, MADI (CENTER)

Sammi Morrill is the only one in her family with Marfan syndrome. Now 10 years old, the Rockport, MA, youngster had never met anyone else with the condition until two years ago, when she attended The Marfan Foundation’s New England Symposium on Marfan Syndrome and Related Disorders in New Hampshire.

There was only one other child there, Maggie. She was the same age as Sammi and she also had Marfan syndrome. They hit it off immediately.

Sammi’s mom, Kathy, said, “Sammi and Maggie became instant friends. Who has penpals anymore? But they wrote letters to each other and then started texting and emailing. They can’t wait to see each other.”

Sammi has attended every Walk for Victory in Boston. She knows there are

people who are more severely affected by Marfan syndrome than she is and wants to raise money for the Foundation’s programs that will help them. At the Walk for Victory, she also gets to see Maggie, her first friend with Marfan syndrome.

Sammi was diagnosed as a baby, and her mom knows they are fortunate to have had an early diagnosis and great ongoing care. Still, she notes that Sammi was always very shy about her diagnosis until she was about 8. She didn’t want to be the tallest kid, didn’t want people to think she was older than she was, didn’t want to appear different. But, now, that’s all changed, and her mom believes it’s because she’s “found her community.” She tells people about Marfan syndrome now. She’s found her voice.

“Being involved, knowing other people like her, and seeing role models like Isaiah Austin make her that much stronger,” said Kathy. “She can’t play sports, but the Walk for Victory is her Super Bowl.”

Get connected to the Marfan and related disorders community through our Walks for Victory, social networks, and phone support groups. Visit Marfan.org for details.

STATEN ISLAND COMMUNITY GROUP KNOWS THE KEY TO SUCCESS: HAVE FUN!

Sara Paul, of Staten Island, NY, knew her husband, Brian, for two years before they were married in 2010. She knew he had Marfan syndrome and wasn't overly concerned—even after his second aortic surgery just a few days after their wedding. It wasn't until Brian's third aortic surgery—a few months after their daughter, Jane, was born in 2011—that she realized that Marfan was “something big.”

Fortunately for Sara, Brian's third surgery was performed by Dr. Abe DeAnda, who is now Professor and Chief, Cardiothoracic Surgery, at UTMB Health in Galveston, TX. He pointed Sara towards The Marfan Foundation.

“Brian's third surgery was really difficult and there were many complications,” said Sara. “Dr. DeAnda encouraged us to be in touch with other people with Marfan and become educated about the condition.”

Shortly after that, Jane was diagnosed with Marfan. Sara was grateful for the support she received from the Foundation and realized that Marfan was going to be part of her life forever. That was when she knew that she wanted to give back and started the Staten Island Community Group.

Sara started the group with meetings in the back of her church with perhaps six people from three different local families. The group hasn't grown much, but for Sara, it is never about the number of people who attend. It's about the connections they have made with each other and the awareness and fundraising they can do on Staten Island to help the Marfan community.

“We try to have an event every few months,” said Sara. “It's all about outreach for us. We want everyone on Staten Island who has Marfan to be diagnosed and to join our group.”

The events vary—from boating and brunch at a local restaurant to a holiday happy hour to a wine and painting evening—but the theme is always the same: it's got to be fun. Sometimes they raise \$200; their most recent gala raised \$4,500.

What matters most to Sara, however, is the feedback from her group members. “It has truly become a friends group of people with Marfan syndrome and related disorders and their families. They are a happy group and everyone is grateful that we have each other.”

And because of their consistency, they have reached a lot of people in their community who had never heard of Marfan syndrome.

Sara's advice for other groups is to plan events that are stress-free and focus on having fun. Reach out to your local contacts and have your group members do the same because one person can't do it all. “Most people want to be generous,”

said Sara. “You just have to give them the opportunity and ask.”

More than anything, be “positive, positive, positive,” says Sara. Three years after she started the group, this has proven to be the right formula.

And, thanks to the efforts of her mom, as Jane begins kindergarten this fall, there are a lot more people on Staten Island who know about Marfan syndrome and related disorders than there were before.



TOP: BRIAN AND SARA PAUL

BOTTOM: JANE PAUL

ARE YOU READY FOR YOUR CLOSE-UP?

When Marfan Syndrome Interferes With Work



SHELLY MOORE, OF BEAVERTON, OR, IS A TECHNICAL SUPPORT SPECIALIST. HER EMPLOYER ALLOWS HER TO WORK FROM HOME MOST OF THE TIME AND GIVES HER A LATE SHIFT. THIS ENABLES HER TO AVOID A 60 MINUTE COMMUTE THAT IS PAINFUL FOR HER DUE TO MARFAN COMPLICATIONS.

By Roanne Weisman

The good news about advances in the treatment of Marfan syndrome is that many of us are now living—and working—well into midlife and beyond. But this good news may be tempered with new challenges. For some of us, our bodies' response to long-term wear and tear might create obstacles to going to work every day. Such obstacles might include problems with mobility or discomfort with sitting at a computer for long periods. Some of us have trouble finding professional shoes that don't crowd those troublesome Marfan toes.

All the World's a Stage

When we leave home in the morning to go to work, we are entering the world "stage" to perform as employees, says Martin R. Anderson, certified Trager® practitioner and former actor. "The more that we have prepared for our performance, the better we will be." The gentle Trager Approach of mind/body integration and movement education helps free tight bodies for efficient and effortless function.

"As with any performance, we need 'rehearsal time,'" says Martin, particularly when dealing with a chronic musculo-skeletal condition like Marfan syndrome." Martin suggests incorporating movements such as stretching, yoga, or tai chi

into your morning routine before leaving for work. This increases circulation of blood and fluids, reducing joint pain.

"Focus fully on your bodily sensations, without distraction," he cautions. "This can be a form of self-hypnosis, reminding yourself to be at ease during the day."

When You Need to Make a Change

Even with careful preparation, however, there may come a time when going to your workplace full-time becomes difficult, and you would like to find ways to work that accommodate your physical constraints. Management consultant Barbara Kivowitz points out that physical pain, mobility problems, and reduced energy can interfere with your confidence in your ability to do a good job.

"Even though it is hard to accept the reality of your body and its limitations," says Barbara, "if you do so early enough, you can work with your manager to

make changes in the way you work. Thanks to the Internet, many jobs can be performed remotely."

As a first step, Barbara advises making sure your supervisor appreciates the value of your contributions. She says, "Then, you can initiate conversations where you ask for the help of your supervisor to figure out how you can continue to contribute to the workplace, while accommodating your physical limitations."

While the Americans with Disabilities Act prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, says Barbara, it is best to approach your employer as a partner, solving this problem together. After the changes are put in place, says Barbara, "It is then important to continue the conversation by checking in every few weeks or months to make sure the system is still working for both you and the workplace."

Adds Martin: "Feel gratitude about all you are able to accomplish."

Roanne Weisman, who has Marfan, has co-authored several award-winning consumer health books with physicians, as well as features for several magazines. She blogs at <https://ownyourhealth.me>.

THE ONLY ONE “NOT AFFECTED”

Stephanie Cooper-Noe shares her perspective

When one parent has Marfan syndrome, there is a 50-50 chance that each child will have the condition. In some families, none of the children inherit the Marfan gene while, in other families, some or all of the children inherit the condition. Stephanie Cooper-Noe, whose husband, David, has Marfan, has two daughters, Dominga, 23, and Samantha, 14. Both have Marfan syndrome. While Stephanie is the only one in the family who does not have the diagnosis, in truth, the entire family is affected by Marfan.

When did you learn that David had Marfan syndrome?

About two or three weeks after we started dating, we were talking about our lives and why David was so tall. He told me about Marfan and I looked into it, but it didn't seem to be serious. David had been followed at Johns Hopkins and hadn't had any major issues with it.

When were Dominga and Samantha diagnosed?

David had told me that the condition was genetic. We knew we wanted kids and it wasn't a big consideration. It wasn't until after David had an aortic dissection in 2002 that we learned at a visit to Stanford that the girls also have Marfan. Prior to that, we had seen a geneticist elsewhere who told us that neither the girls nor David had Marfan. Obviously, the geneticist was very wrong.

What were your thoughts about having to navigate this medical journey with your entire family?

Samantha was only a year and a half old so my first thought was: how am I going to curtail her from doing anything. She was really active! Dominga was about 9, so I could talk to her. I knew I needed more information and started going to the Foundation's Northern California Chapter's meetings.

What have been the most difficult times?

It has been hardest to have discussions with the girls about things they just can't do. For Dominga, that was cheerleading. We just couldn't come to an understanding with the cheer coach to make it work. More recently with Sam, we had to say “no” to a class science trip to Indonesia. We felt that two weeks in the jungle was just too risky.

Medically, I thought the worst thing was David's dissection. But even harder than that was when Dominga had her aortic surgery in 2014. You're completely helpless. It's all in the hands of the doctors. It was helpful that we were at Stanford, where I had confidence that they know Marfan.

Still, I always worry. When Dominga went to college, the



STEPHANIE COOPER-NOE WITH DAVID NOE AND THEIR DAUGHTERS, SAMANTHA (LEFT) AND DOMINGA.

worry quadrupled. When David travels, I wonder if he is taking care of himself. It's always in the back of my mind: are they taking their medications and listening to their body? They have to live their life and I want them to live it to their fullest potential. While Marfan is always a nagging thought, I wouldn't change a thing. I can't imagine life without them.

What has helped you the most?

Once I started making connections at the 2007 annual conference at Stanford, I really got some perspective. As much as the kids look forward to conference, I look forward to it as well. I see the parents I've known for years. We all learn from each other and benefit from the words of encouragement from people who can relate.

What was the best advice you received?

The best advice I've ever received was from Dr. David Liang (Stanford). He said that the girls still need to live a life. I have to temper my worry, know my child, teach her to know herself, and know that we will get through it.

How do you feel being the only one in your family without the Marfan diagnosis?

I don't have Marfan so I will never know what it's like to walk in their shoes. As mom, I am the caregiver, but I feel that even stronger because of their diagnosis. It's also hard because they are all tall and I'm short. It's hard to keep up!

Do you have a perspective on Marfan syndrome or related disorders that you'd like to share? Please contact Eileen Masciale at emasciale@marfan.org. You may be featured in Connective Issues or The Marfan Blog.

WORKPLACE GIVING

If you work for a corporation, non-profit organization or the federal government, chances are you've had the opportunity to participate in a workplace giving program. Workplace giving is an easy and efficient way to make tax-deductible donations to The Marfan Foundation, typically with donations taken directly out of your paycheck. Most companies hold workplace giving campaigns between September and December.

How Workplace Giving Works:

- Designate a set amount of money you would like to donate to The Marfan Foundation. Submit your pledge and you're done! (You may find The Marfan Foundation on a drop-down menu of choices or you can write us in.)
- Your donation will be deducted automatically from your paycheck (or whatever payment method you selected) for a one-year period, and that money will be distributed to The Marfan Foundation, as you designated during the campaign.

Matching Gifts

Some employers offer to match your contributions to The Marfan Foundation (often up to a specified amount). This leverages your employer's philanthropic support and maximizes your gift to the Foundation. Check with your company's human resources department or community relations department to see if they have a matching gift program.

Don't forget your year-end gift to The Marfan Foundation! Please donate at Marfan.org. We gratefully accept gifts by credit card, check, cash, and stock. For additional information, please email Helaine Baruch at hbaruch@marfan.org.

STORIES FROM THE HEART

Like her mother, Sinclair Schuetze was diagnosed with Marfan syndrome at a very young age. At the beginning her medical issues were minor. But that changed in the summer of 2015 when she required orthopedic surgery. Not only did it give her a new perspective on Marfan syndrome, but it also gave her the motivation to inspire other teens like herself.



SINCLAIRE SCHUETZE, A 15-YEAR-OLD WITH MARFAN, WHO WANTS TO ENCOURAGE OTHER AFFECTED TEENS.

Last summer, I underwent spinal fusion surgery, which involved putting two titanium rods on either side of my spine. The operation was

scary, and I did not look forward to the many weeks of recuperation. When the day came to go to the hospital, I was nervous but also hopeful that the surgery would increase my quality of life exponentially. Two days after surgery, I was able to get out of bed, and I vividly remember walking to the mirror and immediately turning to my side to look at my shoulder blades. I was overjoyed to notice that they were not only even, but also that I was standing straight and tall.

It has been more than a year since my spinal fusion surgery, and I have no scoliosis and no back pain. Before the surgery, it was difficult to play cello and piano because after a short time my back would start to ache. Now I have no trouble playing my instruments. I am active, healthy, and grateful to have such a successful outcome of my surgery. I feel confident in my appearance and my ability to handle life's difficult situations. Although Marfan syndrome will present me with challenges, I am extremely grateful that there are medical advancements and research available today that enable people with Marfan syndrome to live longer and more fulfilling lives.

When I was going through these stressful years, I wished I would have had another teen to guide and encourage me. I want other teens to know that they can live a wonderful life with Marfan syndrome, if they just stay positive. Although Marfan syndrome affects us all in unique ways, there is still a common theme in all our stories. I would like to spread a positive message about living life to the fullest.

As a result, Sinclair who is 15 and a sophomore in high school, is creating Stories from the Heart, a book of joyful, uplifting, and encouraging stories. Her hope is that teens will find comfort in the positive experiences of other people within the Marfan and related disorders community. Sinclair invites members of the Marfan syndrome and related disorders community to submit their stories (200-500 words) to her (soschuetze@gmail.com) for consideration by December 31, 2016. She is also happy to answer any questions about the project.

To read Sinclair's story, please visit The Marfan Blog on our website.

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:	Kyle Kinsall	Bryan & Sara Butvick
Adrian Adame	Allen Knollenberg	Ardie Christensen
Carol Adame	Julie Kurnitz	Nettie Cores
Elias Adame	Anthony Longo	Michele Cripps
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Is there someone you would like to honor or memorialize with a donation to The Marfan Foundation?

Simply go to the Foundation's website, www.marfan.org, and click on "Donate."

Then, check "Dedicate my donation in honor or in memory of someone." That will enable you to make a donation of any amount in honor or in memory of a loved one.

The name of the person you are honoring or memorializing will be listed here (unless you indicate otherwise) and The Foundation will acknowledge your gift by sending a letter or email to the person you designate.

If you would like to request donation envelopes to have available at a memorial service or special event, please send an email to staff@marfan.org.



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Creating connections is a key component of increasing quality of life when you have a condition like Marfan syndrome or one of the related disorders. We are committed to helping our community enhance quality of life. In this issue, topics include how to navigate the workforce and how to more positively face aortic surgery.

