

CONNECTIVE ISSUES

SPRING 2017



**KNOW THE SIGNS.
FIGHT FOR VICTORY.
#CreatingConnections2017**



**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.

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COVER: LILLY SHAW, OF CENTRE, AL, AND CASSIE JENNINGS, OF MADISON, NJ, ARE NEW FRIENDS, THANKS TO THE FIRST-EVER MARFAN FAMILY CAMP. FOR DETAILS, PLEASE SEE OPPOSITE PAGE.



THE FUTURE IS NOW!

Someone recently asked me what guides my decision-making as the CEO of The Marfan Foundation and I quickly responded “community first!” In addition, we begin every weekly staff meeting with “community news” because I want our staff team to always be thinking about the people and the stories that are the basis for everyday life at The Marfan Foundation.

In this issue, you will read about our first Marfan Family Camp, a wonderful family weekend for more than 50 individuals. Having a camping experience is something we have been talking about for years and, like so many other happenings across the Foundation, our camp is the result of listening to our community and one of our parents in particular, Becky Gunn of Atlanta, who came forward with the opportunity. Thank you, Becky!

We have also talked about expanding symposiums for Marfan syndrome and related disorders in an effort to make conference-like programs available to families throughout the year in locations closer to home. In response to this need, this year we had symposiums in Houston, Boston, Denver, Cleveland, Phoenix, Fort Lauderdale, and Nashville with more than 400 participants. Next year, look for us in Detroit, Cleveland, Birmingham (AL), Baltimore, and New York City.

Over the past several years, as a result of listening to all of you, we have come to understand that Quality of Life is the single most important issue for our community. In addition to expanded offerings on a monthly basis, I am pleased to announce that we have created a Quality of Life Expert Panel, comprised of professionals in allied health areas who are interested in supporting our community. If you would like to recommend any experts for this panel, please let us know.

We look forward to seeing you at our Annual Conference in Atlanta from August 3-6. Next year, our Annual Conference returns to the West Coast, where it will be hosted by Stanford from July 12-15, 2018.

Never forget . . . YOU are The Marfan Foundation. Your direct involvement makes a real difference.

Victory is . . .

Sincerely,

Michael L. Weamer
President & CEO

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

CREATING CONNECTIONS AT THE INAUGURAL MARFAN FAMILY CAMP

The Marfan Foundation held its first Marfan Family Camp over the weekend of April 21-23 at the beautiful Twin Lakes Campgrounds in Winder, GA. More than 50 people attended, including kids of all ages. They had an opportunity to participate in many traditional camp activities in an environment that was safe for children with Marfan syndrome and related disorders. There was archery and paddleboats, arts and crafts and mini golf, and even a campfire and s'mores!



“Both of my kids (the one who has Marfan and the one who doesn’t) had a blast! Hadley liked meeting other girls her age with Marfan. As a parent, it was great at night to see that she wasn’t the only one who needed to take medicine —something we often try to do discretely.”

– BECKY GUNN, OF ATLANTA

“I loved doing things I don’t usually get to do, like archery, and it was so fun meeting new friends with Marfan syndrome. No one even asked me why I needed a wheelchair to go long distances!”

– CASSIE JENNINGS, 10,
OF MADISON, NJ



“It was important to have camp so that the kids could do things that they might not have had exposure to if they can’t go to a traditional camp. Learning new skills and trying new activities is not only fun, but also shows the kids that they may have talents or interests they didn’t know about. The parents also got to talk and learn from each other and have those conversations that only other parents of kids with Marfan can truly understand.”

– ALIX JENNINGS, CASSIE’S MOM



“Of course one can make friends at any sort of camp. But, to make a friend who understands Marfan is something Bobby wouldn’t get anywhere else, except perhaps at conference.”

– JAY ELLIOTT,
OF ST. LOUIS



TOP STACIE AND DENNIS BAGGETT, OF CARTERSVILLE, GA, AND THEIR CHILDREN, NOLAN AND ADDIE

ABOVE KEVIN AND SOPHIE JOHNSON, OF PITTSBORO, NC

SYMPOSIUM AND WALK CONNECTIONS

“It feels amazing that I am now part of a ‘Marfamily’”



BETSY WITH HOUSTON WALK CHAIR ROD GRAY AND HOUSTON WALK YOUTH CHAIR OWEN GRAY

The Marfan Foundation's Walks for Victory and Regional Symposiums bring people together in locations throughout the U.S. These connections are so valuable in helping individuals and families deal with their medical journey. Jessica Landeo, of West Boylston, MA, and Betsy Matarrita, of Costa Rica, share their experiences.

Boston Symposium

Jessica Landeo's nine-year-old daughter, Sophia, was diagnosed with Ehlers Danlos syndrome less than a year ago. Prior to attending the Boston Symposium on Marfan Syndrome, Ehlers Danlos Syndrome, Loays Dietz Syndrome, and Related Disorders, she had not had an opportunity to seek out resources. She and her husband, Jorge, were still in the whirlwind of trying to understand the diagnosis, let alone look into future needs. Her questions—even those she didn't know she had—were answered at the April 8 symposium.

“The people I met at the symposium really opened my eyes to everything we are going to have to deal with and gave me information about resources I hadn't ever thought about,” said Jessica.

Importantly, Sophia met other children with Ehlers Danlos and Marfan. Said Jessica, “It was the first time she did not feel alone or that she is the only one.”

Walk for Victory

Betsy Matarrita, who is the only one in her family with Marfan, had never met another person with the condition until she traveled from her home in Costa Rica to the Houston Walk for Victory on March 25.

“It was really important to me to meet other people with Marfan because I've always felt that no one around me understood what I was going through,” said Betsy. “At the Walk, I felt for the first time that there was someone else who had the same experiences, same thoughts, and same feelings as me. I felt understood and supported, and that meant the world to me.”

Betsy advises everyone in the Marfan and related disorders community to participate in events like the Walks for

Victory.

“It's a great opportunity to meet people who understand you and support you. You'll make new friends who are like family. It feels amazing that I am now part of a ‘Marfamily’ forever. Since the Walk for Victory, I am unstoppable.”



CHILDREN WITH MARFAN AND RELATED DISORDERS HAVE A GREAT OPPORTUNITY TO MEET OTHER CHILDREN LIKE THEM AT FOUNDATION EVENTS. THESE KIDS MET AT OUR REGIONAL SYMPOSIUM IN NASHVILLE ON MARCH 11.

Additional regional symposiums are scheduled after the summer in Detroit (Sept. 9), Birmingham, AL (Oct. 28), Houston (Nov. 18), and Cleveland (Dec. 9), as well as in Phoenix, Baltimore, Southern California, and New York (dates TBD). For additional Walk dates, please turn to page 13.

INTRODUCING NEW STAFF

Enhancing Our Help & Resource Center and Volunteer Services

The Marfan Foundation is pleased to announce the addition of two staff members to play a direct role with members of our Marfan syndrome and related disorders community. Suśan Sobers joined the Foundation staff in February as the Volunteer Director and Jan Lynch, MSN, RN, was named Director of the Help & Resource Center in April.

Suśan has spent the last 25 years in the nonprofit arena and brings with her extensive experience in volunteer recruitment and fundraising. Prior to joining The Marfan Foundation, Suśan was at the USO (United Service Organizations) where she spearheaded the development of a robust volunteer recruitment program. Before that, she spent more than 20 years at JDRF (Juvenile Diabetes Research Foundation) in expanding roles to develop and support chapters in the U.S. and international affiliates.

“Our volunteers are so passionate and committed to our mission. We recognize the incredible value they bring to the organization and want to ensure that their time and efforts are allocated in the most effective manner,” said Suśan. “My goal is to empower them to be successful in their communities by giving them the right tools and support. When we operate as one unified body, we can maximize the impact that our volunteers, and our organization on a whole, has from coast to coast.”

Jan, who received her Bachelor’s degree in nursing from Georgetown University and her Master’s degree in nursing education from the University of Pennsylvania, has extensive experience as a nurse educator. Prior to joining the Foundation, she was a nurse editor/nurse executive for OnCourse Learning. She was also an adjunct faculty member at Adelphi University’s College of Nursing and Public Health and at Molloy College’s School of Nursing.

“In the short time that I’ve been at the Foundation, I see that I can empower individuals and their families in a number of ways,” said Jan. “So far, I am impressed with the Marfan and related disorders community; that is, the knowledge they already possess, the way they reach out and speak up, and the strength they have to move forward, day after day.”

“I am thrilled to welcome Suśan and Jan to our staff,” said Michael Weamer, President and CEO. “They each bring a new skillset to our team that will be extremely valuable to the individuals and families in our community and expand the capacity of the Foundation.”

Both Suśan and Jan are attending the Foundation’s 33rd Annual Conference in Atlanta in August.



SUŚAN SOBERS (LEFT) AND
JAN LYNCH, MSN, RN.

WHY SUPPORT THE FOUNDATION

“I’m grateful to be alive.

I wasn’t supposed to make it this long. But here I am. That’s in huge part due to The Marfan Foundation. A hard-working team fighting to save lives and improve the lives of people and families affected by this disorder. A group of people that have helped change how doctors are informed, how patients are treated and diagnosed, and how we live our lives. That’s why I support The Marfan Foundation.”

– Andy Erikson,
North Hollywood, CA



Your support is vital to:

- Ensure our Help & Resource Center has the most up-to-date information.
- Help us empower people from coast to coast to live a long life with Marfan or a related disorder.
- Expand our Quality of Life movement.
- Increase outreach to doctors and other healthcare providers.

We invite you to donate via our website, Marfan.org. To learn more about how you can help advance our mission, please contact Helaine Baruch at hbaruch@marfan.org.

33RD ANNUAL CONFERENCE IN

The Marfan Foundation, in association with Children’s Healthcare of Atlanta, Sibley Heart Center Cardiology, and Emory Heart & Vascular Center, will hold its 33rd Annual Conference in Atlanta on August 3-6, bringing together more than 600 individuals and families with Marfan syndrome and related disorders from all over the country and from all over the world. The conference gives attendees an opportunity to meet leading Marfan syndrome physicians and scientists as well as hear about new medical and genetic research first-hand. Participants will also learn strategies for improving their quality of life and have numerous opportunities to network with other people who are also living with Marfan and related disorders.

“We are grateful to Children’s Healthcare of Atlanta, Sibley Heart Center Cardiology, and Emory Heart & Vascular Center for making it possible for us to bring our annual conference to the Southeast for the very first time,” said Michael Weamer, President & CEO, The Marfan Foundation. “The conference is a life-changing opportunity for members of our community as they can create connections with leading clinicians and scientists and other individuals and families who are facing similar medical issues. The conference not only provides education, information, and support, but it also empowers community members to live life to its fullest while living with a chronic condition.”

“Meeting with leading medical experts about the latest news and developments with Marfan syndrome and related disorders is an amazing opportunity. Not only is it educational, but it also makes me a stronger advocate for my daughter’s care,” said Becky Gunn, who is the leader of the Foundation’s Atlanta community group. “I am also always inspired by the friendships I see—from adults to teens—and witnessing the excitement everyone has in being together again because we have all experienced similar journeys. Having the conference here in Atlanta is also wonderful for the people of our region who have never had the opportunity to attend the conference before. They can now experience it first-hand.”

IMPORTANT DATES AND DEADLINES

JUNE 1	Children, Teen, and Young Adult Programs Registration Deadline
JUNE 1	Early Registration Deadline
JUNE 17	Marriot Buckhead Registration Deadline (6:00PM EST)
AUG 3-4	Patient Health Assessments (by appointment only)
AUG 4	Conference Welcome and Walk for Victory
AUG 5	Medical Presentations and Workshops
AUG 6	Workshops and Conference Close



ATLANTA—AUGUST 3-6, 2017



CONFERENCE HIGHLIGHTS

- Patient health assessments (by appointment only)
- Conference Walk for Victory at Chastain Park
- General medical session and small group workshops led by experts on Marfan syndrome and related disorders
- Creating Connections luncheon
- Special program for young adults (19-25) that includes a workshop track with topics of interest to this age group. There's also a young adult trip and luncheon.
- Teens (13 to 18) have a complete program that includes a Q&A breakfast with expert doctors and workshops. Then, they have a trip to the College Football Hall of Fame and World of Coke, as well as an interactive mystery experience, movies, games, and other activities that promote friendship and self-esteem.
- Children (5 to 12) take a trip to the Georgia Aquarium and participate in an interactive mystery game, as well as enjoy games, arts & crafts, and more.
- For our Spanish-speaking attendees, a medical workshop, led by a Spanish-speaking physician will be offered.
- Saturday evening program highlighting comedian Andy Erikson and more. Sunday's closing luncheon will feature a tall size fashion show featuring our very own teens and young adults as models.



Complete conference details are available at Marfan.org/Conference.

CHOICES IN CHILDBIRTH

Perspectives from Our Community



MAYA BROWN-ZIMMERMAN AND HER HUSBAND, MARK, WITH THEIR CHILDREN, ELIZA, RUBY, MILES, AND JULIAN.

Many childbirth options are available when a couple in which one partner has Marfan wants to have a baby. It is important to understand all the options and then decide what is best for your family.

Michael and Michele Walker, of Massapequa, NY, did not want to have children with Marfan because of Michael's experience with the condition, as well as the medical issues Michael's father faced with Marfan. Though they are not infertile, they decided to pursue pre-genetic diagnosis (PGD), which would also require in vitro fertilization (IVF).

In January 2015, Mike and Michele, as well as both of Mike's parents, underwent genetic testing. After that, Michele started her IVF treatment, which involved hormone treatments, daily blood testing, and frequent sonograms. Then the eggs were retrieved and frozen before transfer of one of the healthy non-Marfan embryos.

"It is a long process, but so worth it when you get to hold your healthy baby in your arms," said Michele. "Make sure to research as much as you can. Do not rely on the fertility center to know everything. They are most likely learning the process with you. Save as much money as you can before you start because you do not know what out-of-pocket expenses might arise."

Adam Bitterman, an orthopedic surgeon who lives in Jericho, NY, and his wife, Jennifer, also went through PGD with IVF to prevent the passage of Marfan, which he has, to their child. Avery was born two years ago, without Marfan.

"By doing this we are improving the chances of not having to battle the everyday issues that those with Marfan syndrome encounter," said Adam. "By choosing to perform PGD, you are forced to then make a decision about how to proceed if and when you have an embryo that is not disease-free. Certainly there is an ethical conversation that must take place, but it is all an individual decision."

Maya Brown-Zimmerman, of Twinsburg, OH, and her husband, Mark, looked into childbirth options before they were married. They met with a genetic counselor who explained both

surrogacy and adoption. Based on the information she had at the time and her own Marfan status, Maya (and Mark) decided to have children naturally, even though there was a 50 percent chance for each pregnancy that the baby would inherit Marfan.

"While some things in my life are harder because of Marfan, I have a pretty good life," said Maya. "I'm really connected to the Marfan community and the doctors and knew I could advocate for my child if he or she was affected."

Maya also knew she would probably adopt at some point too because her doctor made it clear to her that, based on her own medical situation, she wouldn't be able to have as many pregnancies as she wanted.

Of Maya's two pregnancies, her older son, Miles, 8, does not have Marfan, while Julian, 6, does. In the past two years, Maya and Mark have adopted two baby girls to complete their family.

"Adoption has its own kind of stress," says Maya. "But I would not have changed any of the childbirth decisions that we made. This is what felt right for us."

Visit Marfan.org for more information about family planning and pregnancy.

PREGNANCY AND MARFAN SYNDROME

Considerations for Women with a Marfan Diagnosis

By **Melissa Russo, MD**

The decision about whether or not to pursue a pregnancy when a woman has a diagnosis of Marfan syndrome is a complicated and individualized decision. In general, the steps to a successful pregnancy are:

- **Plan Ahead.** Make sure you meet with your doctors and get necessary tests prior to becoming pregnant so you know the risks you are taking with a pregnancy in advance.
- **Assemble Your Team.** Identify a tertiary care center (a hospital with specialized healthcare) that has a cardiovascular surgeon and cardiologists who are familiar with Marfan syndrome as you want to deliver at a hospital with these services available. During pregnancy, you will need a high risk obstetrician, cardiologist, anesthesiologist, nursing, and neonatologist.
- **Follow Directions for Consistent Care.** Getting ongoing care includes going to all your appointments, getting serial echocardiograms to monitor your aorta, and following a multi-disciplinary plan for delivery that has been coordinated by your medical team. This will help you have a good pregnancy outcome for yourself and your baby.

Here are some of the most common questions regarding pregnancy and family planning:

What effect does pregnancy have on my body and my health if I have Marfan syndrome?

Pregnancy places additional stress on the aorta, blood vessels, and heart, as well as increases the amount of blood being pumped through the body. There are also thought to be effects on the blood vessels from hormones that are elevated during pregnancy. Pregnancy and the postpartum period are higher risk times for aortic root growth, aortic aneurysm, and dissection in women with Marfan syndrome. A majority of women will have successful pregnancies; however, there is risk for aortic dissection.

Pregnancy also puts additional strain on joints and can increase joint pain, especially in the lower back and pelvis.

Am I considered a high-risk pregnancy because I have Marfan syndrome?

Yes, there are significant complications to the maternal heart and blood vessels (aortic dissection) that can occur in pregnancy. Additionally, women with Marfan can have pregnancy complications of:

- Heart arrhythmias in labor
- Preterm birth
- Fetal growth restriction or smaller babies
- Spontaneous collapsed lung
- Blood clots
- Anesthesia complications

Because of the potential complications, it is important that women with Marfan who are pregnant have a high-risk obstetrician or maternal-fetal medicine specialist as their doctor.

What should I do and who should I see prior to becoming pregnant?

- Have an exam by your doctor (clinical geneticist, family doctor, or internist).
- Meet with a high-risk obstetrician (or maternal-fetal medicine specialist) prior to pregnancy.
- Visit a cardiologist and have an echocardiogram and CT or MRI to examine your aorta, aortic root size, and the rest of your blood vessels.
- Have an evaluation of your spine by MRI or CT to determine if you have dural ectasia, a condition where the sac around the spinal cord balloons out. This is not harmful during pregnancy, but, if present, may influence whether or not an epidural will be effective for pain relief during delivery.
- Meet with a genetic counselor and discuss the chance your baby will also have Marfan syndrome. The genetic counselor can also explain genetic testing options that are available prior to and during pregnancy



MELISSA L. RUSSO, MD, OF BAYLOR COLLEGE OF MEDICINE, IS ABOUT TO JOIN THE STAFF OF WOMEN AND INFANTS HOSPITAL, WARREN ALPERT MEDICAL SCHOOL AT BROWN UNIVERSITY IN PROVIDENCE, RI. A MORE EXTENSIVE VERSION OF THIS ARTICLE IS AVAILABLE ON THE MARFAN BLOG.

BENEFITS OF MARFAN CLINICS

THE VALUE OF COORDINATED CARE

There's no doubt that it's challenging to coordinate medical care when you or a family member has a multi-system condition like Marfan syndrome or one of the related connective tissue disorders. Regular check-ups with several specialists who are experts in treating patients with these conditions are needed. Then there are more doctors to see when additional problems arise. Receiving expert care in a setting where doctors can easily communicate with each other and coordinate appointments is a real benefit to patient care.

That's why a coordinated clinic is the best place to go for Marfan syndrome and related disorders care. A coordinated clinic provides expertise in all specialties integral to the primary features of Marfan and several of the related connective tissue disorders: genetics, cardiology (heart) and cardiac surgery, ophthalmology (eyes), and orthopedics (bones and joints).

Worth the trip

For a military family like Tasha Smith's, living within driving distance from the Marfan Clinic at Children's Health-care of Atlanta is a huge benefit. It's a four and a half hour drive, but worth it because of the care they receive for their 15-year-old son Rolfe, who has Marfan.

"It has been a breath of fresh air to feel, as a parent, that you're working with the medical team as opposed to trying to teach them. I have no anxiety about surgery in two weeks because I know my son is in great hands," said Tasha, who references the Foundation's clinic directory when they need to select their next duty station.

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TAKING CHARGE OF CHRONIC PAIN



AUSTIN CARLILE HAD TO LEAVE HIS BAND, OF MICE & MEN, BECAUSE OF CHRONIC PAIN AND OTHER COMPLICATIONS OF MARFAN SYNDROME. PHOTO COURTESY OF RICK GUIDOTTI.

By Roanne Weisman

For many people with Marfan syndrome, chronic pain is an annoying part of daily life. But there are ways to manage and reduce its intensity. I learned several useful techniques from physical therapist Sharlene Wing, PT. First, a little background from Sharlene about why the Marfan body gets uncomfortable:

Reduced amounts of fibrillin (the elasticity) in our connective tissue causes some joints to become hypermobile, meaning that they move beyond the normal range of motion with little effort. This floppiness can occur in knees, hips, ankles, spine, fingers, and wrists, and can often result in pain, says Sharlene.

"Even if you have had surgery for scoliosis (curvature of the spine), there may still be some parts of the body that are misaligned," she explains. "There may be a leg length difference, one hip or shoulder may be higher, or one side of the ribcage may protrude more than the other."

Another health professional I know has called this imbalance the "creative alignment of Marfan syndrome." But

whatever you call it, the result is often extra stress on the structure, causing pain.

"The hypermobility in some joints makes it hard to find a stable, neutral position that would naturally hold a person upright," says Sharlene. "So if the positions of sitting, standing, and walking are not well-supported, or are out of alignment, this puts more wear and tear on the joint surfaces, as well as on their supporting structures, such as ligaments.

The Gravity of the Situation

The challenge for the Marfan body is to deal with gravity, finding positions where we can exercise or do repetitive activities without causing harm. Besides motion, gravity also causes problems when we are still, as sleeping in bed or sitting for long periods.

"Even when you are still, gravity is a constant force," says Sharlene, "causing joint creep, as joints succumb to gravitational pull and become misaligned." This joint creep contributes to stiffness in the morning or when we stand up after a two-hour movie.

Strategies to Deal with Creative Alignment

Sharlene suggests several easy and safe exercise suggestions to do at home. I have tried them and have noticed a significant reduction in back and joint pain.

1. **Before getting out of bed**, spend about ten minutes stretching your legs out and doing ankle pumps and ankle circles. Gently move hips and knees to get the synovial fluid moving. (This fluid bathes the joints to reduce friction.) If the back feels stiff, one option is to create gentle traction while holding onto the headboard and pulling only as much as is comfortable. If you do this before your feet hit the floor, it gets all the joints ready for weight-bearing. (Sharlene advises caution if your shoulders are bothersome).
2. **Practice posture on a wall.** With the back against the wall, touch the backs of the hands against the wall, arms turned outward to open the shoulders. Try to have the head, buttocks, and calves also touching the wall as much as possible, but not the lower back. Even if you can't do all of this, says Sharlene, it is a good alignment practice, to lengthen and straighten as much as possible. If anything hurts, cautions Sharlene, don't do it without consulting with a physical therapist.
3. **Try to be conscious of good posture alignment during day**, whether getting in and out of the car, carrying things, sitting at a desk, using a computer, or even during a movie. If you slouch, it should only be for a short time.

Pain is a Warning Sign

Even though pain is annoying, says Sharlene, we can also think of it as a protective mechanism.

“Your body is telling you that something is wrong and you should pay attention,” she says. “Often, for people with chronic pain, the symptom gets heightened, and can become a constant, dull ache. It often helps to work with a physical therapist to unlearn problematic positions or behavior, strengthen muscles to compensate for overstretched Marfan ligaments, and learn new ways of using the body to reduce pain.”

Roanne Weisman, of Brookline, MA, is an award-winning author specializing in science, medicine and healthcare. She also has Marfan syndrome. For more of Roanne's work, please visit: TheWriteWaytoHealth.com

COMING SOON: MENTORSHIP PROGRAM

The Marfan Foundation will soon be launching a mentoring program to provide people living with Marfan syndrome or a related disorder a more formal way to connect with others to guide them through their journey.

“The new mentorship program will provide supportive connections for those who are either newly diagnosed, facing a new challenge, or just need someone to talk to,” said Susan Leshen, LCSW, the Foundation's Senior Director of Patient & Program Services and Volunteer Leadership.

Community members who are interested in becoming a mentor will be asked to provide information about themselves and the kind of people they would like to be matched with (e.g., age, medical situation). Those who would like mentors can request one through Diane McKenzie, dmckenzie@marfan.org. Matches will be made based on information provided by the mentor and the individual seeking a mentor.

Please sign up for the Foundation's emails to be among the first to learn when the mentorship program becomes available.

MARFAN CLINICS

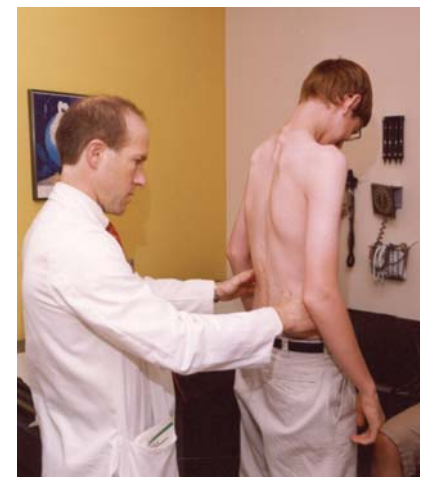
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Maggie Ann Mafiol, formerly of Miami, now lives in Panama City, FL, but still takes her daughter to the Marfan Clinic at Joe DiMaggio Children's Hospital in Hollywood, FL—more than eight hours away—once a year for her annual evaluation. She said, “I am very excited that everything will get done in one day!”

“We continue to work with physicians who are Marfan champions all over the country to encourage them to create coordinated clinics to best serve our patient community,” said Josephine Grima, PhD, Chief Science Officer at The Marfan Foundation.

Find a coordinated clinic

For a complete list of Marfan and related disorders clinics, please visit Marfan.org and then click on “Patients and Families” and “Find a Doctor.” You can also contact Jan Lynch, MSN, RN, director of our Help & Resource Center, to find experienced doctors in your area who are not affiliated with a Marfan clinic. She can be reached at 516-883-8712, ext. 126, or jlynch@marfan.org.



PAUL SPONSELLER, MD, JOHNS HOPKINS HOSPITAL, EVALUATES A YOUNG MAN WITH MARFAN SYNDROME.

MARFAN AWARENESS TO THE EXTREME

“I hope I can be an inspiration to never give up.”



STEPHEN STRAWN RAISES MONEY AND AWARENESS OF MARAN IN ENDURANCE EVENTS ACROSS THE COUNTRY.

Stephen Strawn is not your average runner. He's a triathlete and an ultra runner. That means he not only pushes himself for iron man triathlons, but he also competes in ultra 24 hour events. He's also dad to step-daughter, Savannah, 12, who has Marfan syndrome. And now, with his custom-made Marfan bib, which he wears for every race, he has become a tremendous champion for the Marfan and related disorders community.

Prior to Savannah's diagnosis in 2016, Steve's focus was raising awareness for veterans' causes, which he continues to support. But when the family learned that Savannah had Marfan, Steve decided to help in the way he knew how—through his sport.

“I had never heard of Marfan syndrome until my step-daughter was diagnosed with it last June. After learning more about it, I realized that it isn't a very well-known disorder. I want to make sure that I take an active role with our kids so I wanted to ensure I am as educated about it as possible,” said Steve.

While wearing his Marfan race bib (which also shows support for veterans through Team Red, White, and Blue), Steve gets a lot of questions about Marfan and is happy to share information. He also raises money for the Foundation through his efforts. Most recently, Team RWB Savannah was among the top fundraisers in the Foundation's Walk for Victory in Cleveland.

It was great to see other people with the same disorder that she has so that she knows she isn't alone.

“It was such a cool experience to participate in the Cleveland Walk for Victory with Savannah and our family/team. Seeing the support and watching Savannah carry the banner the whole distance was outstanding. It was great to see other people with the same disorder that she has so that she knows she isn't alone,” said Steve. “Until the Cleveland Walk for Victory, Savannah hadn't met anyone else with Marfan syndrome (other than her father) so it was great to watch her interact with

kids her age and make some friends that share the same disorder that she has.”

More About Savannah

Savannah is a sixth grader who loves to read, draw, sew, and do crafts with her grandmother. She also plays drums and xylophone. Her diagnosis followed several orthopedic issues which eventually required her to wear a brace and led to the need for back surgery. Her diagnosis saved the life of her father, Wade, who was then confirmed to have Marfan syndrome and immediately needed aortic surgery.

Next Up for Steve

In the coming months, Steve is participating in a 24-hour endurance race, a 100 mile trail race, a spring triathlon, and an Olympic triathlon.

He said, “I hope I can be an inspiration to never give up.”



WALK FOR VICTORY



UPCOMING WALKS

- New York, NY June 10
- Boston, MA June 11
- St. Louis, MO October 1
- St. Paul, MN October 8

Stay tuned for 2018 Walks for Victory in: Sacramento, Houston, Cleveland, Fort Lauderdale, Pasadena & Atlanta!

Walk for Victory is our 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 2015-2016 raised more than \$300,000 for the Foundation's programs and services, which reach more than 100,000 affected individuals, families, and physicians each year. In our 2016-2017 season, we hope to raise more than \$500,000 to support quality of life programs for our families, kids, teens, young adults, and seniors living with Marfan and related disorders.

Interested in joining us at one of our upcoming walks? Go to Marfan.org/Walk to register. If you have questions or want to learn more, contact Kim Huddleston, our national walk director, at khuddleston@marfan.org.

HEARTWORKS NEW YORK CITY

As this issue was going “to press,” the Foundation was looking forward to Heartworks New York City on May 10, where it was honoring **Karen Murray**, the recently named CEO of Sequential Brands Group and Chair of the Foundation’s Board of Directors, with its first Inspiration of Excellence Award. The Foundation was also looking forward to presenting its prestigious Hero with a Heart Award to **Joseph Coselli, MD**, Professor of Surgery, Baylor College of Medicine, and **Sinclair Li**, Executive Vice President, CBRE Inc. More than 500 people will be in attendance. For photos from the gala, please check the Foundation’s website.



UPCOMING EVENTS

Evening with Heart

October 5, 2017 | New York City

Oktoberfest

October 28, 2017 | Houston

HEARTWORKS ST. LOUIS



(L-R) BARB STEHMAN, BSN, RN, ALAN BRAVERMAN, MD, CHERYL MARSHALL, AND DANA GIMA, BSN, RN

The 9th Annual Heartworks St. Louis Gala was a huge success, with more than 400 people attending this sparkling event to support the Marfan and related disorders community. This year, Heartworks St. Louis raised \$275,000 to help us continue our vital work of advancing research, serving as a resource for families, and raising public awareness of Marfan syndrome and related disorders. Special thanks to Dr. Alan Braverman and his wife, Rebecca, and their daughters Emily and Jenny, for hosting this spectacular gala and for all they do for the Marfan and related disorders community in St. Louis and throughout the country.

Christina Gurnett, MD, PhD, Associate Professor of Neurology, Washington University School of Medicine, was the recipient of the Foundation’s 2017 Distinguished Research Award. In addition, the Foundation honored Dana Gima, BSN, RN, and Barb Stehman, BSN, RN, Barnes-Jewish Hospital, with the Hero with a Heart Award and Cheryl Marshall, Washington University School of Medicine, with the Spirit of Service Award.

“I am so proud to present awards this year to Dr. Christina Gurnett, a leading

researcher, Dana Gima and Barb Stehman, two outstanding patient-focused nurses, and Cheryl Marshall, who plays an indispensable role in our Marfan Clinic,” said Dr. Braverman. “I am so grateful to the St. Louis and the Metro East community and our gala committee which, year after year, supports this event. Awareness of Marfan syndrome and related disorders is critical and, through Heartworks St. Louis, we have successfully kept these life-threatening conditions top-of-mind in our region.”



ALAN BRAVERMAN, MD, AND CHRISTINE GURNETT, MD, PHD

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.

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Carol Adame, Adrian Adame, and Elias Adame
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Rosemary Austin
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Shirley Wittenauer
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The Stanford Marfan Clinic:
Dr. David Liang, Char Yang-lu, Sunny Pellone, and Staff
Barb Stehman
Jacki and Chris Stone
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Conference in Atlanta
is August 3-6, 2017.
Early registration
closes on June 1.
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More information
on pages 6-7.