

CONNECTIVE ISSUES

SPRING 2016 |

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



**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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CONNECTIVE ISSUES

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COVER: ROANNE WEISMAN AND HER SON, BEN. READ ON PAGE 10 HOW MARFAN SYNDROME HAS PLAYED A ROLE IN THEIR RELATIONSHIPS.

CREATING CONNECTIONS



Recently, I have been thinking a lot about the many faces of Marfan syndrome and related disorders. Although we each travel our own path, “connections” enhance life and often provide a much needed framework and support for health and happiness. As has often been said, strength comes in numbers and victory comes by working as one team focused on shared outcomes.

When I think about The Marfan Foundation, I think about *one* nationwide organization. I truly believe that only by acting in unison and with one voice will we reach our greatest potential. And, I have no doubt our collective passion and ingenuity will overcome individual and collective obstacles for individuals with Marfan syndrome and related disorders and their families.

We can also be more effective in connecting with and serving individuals with related disorders as well as organizations that work tirelessly on their behalf. While there are certainly differences, several connective tissue disorders have similarities and we cannot afford to duplicate resources when our greatest impact can be achieved by working in unison. I welcome suggestions on how we might further strengthen this aspect of our shared mission in the year ahead.

In an effort to further enhance our nationwide volunteer connections, the Foundation’s Board of Directors recently changed its bylaws to create a *Volunteer Leadership Committee*. The Volunteer Leadership Committee will provide an opportunity for lead volunteers nationwide and internationally to have an ongoing dialogue with the Board of Directors and staff about partnering on every level. I see this as another building block for future success!

In closing, making connections can also change your life as it did for me in 1999 when I became a Marfan volunteer! I am forever indebted for being introduced to so many wonderful people, feeling their passion and commitment for our mission, and allowing me to be part of the leadership of this wonderful organization.

I look forward to seeing many of you at our Annual Conference at Mayo Clinic in August. Stay well and never walk alone when the Foundation is here to connect with you in your pursuit of health and happiness.

Sincerely,

Michael L. Weamer
President & CEO

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

CREATING CONNECTIONS



ABOVE: HADLEY'S HEROES CAME OUT IN FULL FORCE FOR THE ATLANTA WALK FOR VICTORY ON APRIL 23.

BELOW: TEAM TY - WASTE CONNECTIONS WAS THE TOP FUNDRAISING TEAM AT THE HOUSTON WALK FOR VICTORY ON FEBRUARY 20, RAISING MORE THAN \$35,000 AS A TRIBUTE TO TY ROBERT (BACK ROW, THIRD FROM LEFT), SON OF WASTE CONNECTIONS EMPLOYEE ALAI ROBERT (FAR RIGHT).



Supporting you on your journey with Marfan syndrome or a related disorder is central to all that we do at The Marfan Foundation. Do you need medical information? Do you need to find a doctor? Do you need to talk with someone who can relate? Do you need a shoulder to cry on?

Our Walks for Victory are a great place for you to create connections to other people with the same diagnosis in your area and to the local medical community. And if there isn't a walk near you, you can participate in the Conference Walk for Victory this summer (details on page 14).

Creating connections provides support and comfort. Creating connections adds to your quality of life. Just check out the happy faces at our 2016 Walks for Victory on this page.



(L-R) TAYLOR DAVIS, TURNER DAVIS, CONNOR DAVIS, MEGAN WELKER, TAMMY DAVIS, AND STEVE DAVIS AT THE TRUSSVILLE WALK FOR VICTORY IN ALABAMA ON APRIL 2.

*“You’re loud like me...
Let’s be friends!”*

Thousands of miles and one sentence later, a life-long friendship was born. Now, closer in miles and closer at heart, these 2 friends have enjoyed 10 conferences together. And that is just the beginning.



Dominga Noe (left) and Michelle Smith

CREATING CONNECTIONS

Dominga and Michelle connected at the annual conference in Palo Alto, CA, in 2007.

Michelle, at age 15, traveled 3,223 miles to the conference from her home in Scarborough, ME.

Dominga, at age 13, traveled 121 miles from her home in Sacramento, CA.

Almost 10 years later, Michelle and Dominga reunite each year at the conference and remain the best of friends.

PROGRAMS FOR ALL AGES

ADULTS—Get the latest information on diagnosis, treatment, and research, and socialize and network at the welcome & awards reception and farewell luncheon.

YOUNG ADULTS (ages 19–25)—Participate in the same activities as all adults and a workshop track just for you. Fun activities for your group include dinner and local activities that are planned by our Young Adult Council.

TEENS (ages 13–18)—Ask your questions at a Q&A breakfast with expert doctors, followed by small group workshops. Plus, enjoy a trip to Mall of America, a comedy workshop with Andy Erikson (NBC’s *Last Comic Standing*), dancing, games, and more.

CHILDREN (ages 5–12)—Visit the Rochester Art Center, ask questions at a special kids’ Q&A session with expert doctors, and enjoy a magician, games, arts & crafts, and more.



Know the signs. Fight for victory.

IN ASSOCIATION
WITH



THE MARFAN FOUNDATION
32nd ANNUAL CONFERENCE
MINNESOTA | AUGUST 4–7, 2016

NEW THIS YEAR! Quality of Life Workshops • Creating Connections Luncheon • Fashion Show • Comedy Performance by Andy Erikson, finalist in NBC’s *Last Comic Standing* who has Marfan syndrome • Conference Walk for Victory—Create your team at Marfan.org/WalkConference

DON’T MISS THESE IMPORTANT DEADLINES

JUNE 1 Children, Teen, and Young Adult Registration Deadline

JUNE 1 Early Registration Discount Deadline

JULY 7 Hotel Registration Deadline (6:00 PM EST)

LEARN
MORE AND
REGISTER AT
**Marfan.org/
Conference**

FOUNDATION NEWS

Scientific and Professional Advisory Board Updates

Scientific Advisory Board Expands

The Marfan Foundation's Scientific Advisory Board plays a crucial role in evaluating the research proposals we receive for our annual grant program. Using a protocol similar to the National Institutes of Health, the Foundation provides grants to established faculty, early investigators, and fellows.

The Foundation is proud to announce the addition of five highly-acclaimed scientists to this prestigious board: Scott A. LeMaire, MD, Baylor College of Medicine; Joseph Lorenzo, MD, University of Connecticut Health Center; Peter A. Byers, MD, University of Washington; B. Timothy Baxter, MD, University of Nebraska; and Jil C. Tardiff, MD, PhD, University of Arizona.

They join Craig T. Basson, MD, PhD, Novartis Institutes for Biomedical Research, who is chair of the SAB; John A. Elefteriades, MD, Yale School of Medicine; Jonathan W. Weinsaft, MD, New York-Presbyterian Hospital-Weill Cornell Medical Center; Richard J. Wenstrup, MD, Myriad Genetics Laboratories; and Terri L. Young, MD, MBA, University of Wisconsin-Madison.

"We are honored to have such highly regarded scientists collaborate with us on our research grant program," said Josephine Grima, PhD, Chief Science Officer, The Marfan Foundation. "They bring a range of research experience and expertise that is beneficial to the Foundation as we expand our research interests even further into non-cardiac issues of not only Marfan syndrome, but also related disorders."

Professional Advisory Board News

The esteemed members of our Professional Advisory Board, who are world leaders in research and the care of people with Marfan syndrome and related disorders, continue to garner recognition in the U.S. and abroad.

Congratulations to Dr. Hal Dietz, who received the Career Research Achievement Award from the American Heart Association. Dr. Dietz, who has served on our Professional Advisory Board since 1994, is the Victor A. McKusick Professor of Medicine and Genetics; Investigator, Howard Hughes Medical Institute; and Director of the William S. Smilow Center for Marfan Syndrome Research at Johns Hopkins University School of Medicine. He also currently serves as the president of the American Society of Human Genetics.

Congratulations to Dr. Dianna Milewicz, who was awarded the Visiting Professorship of the Princess Liliame Foundation in Belgium. Dr. Milewicz, who has served on our Professional Advisory Board since 1996, is the President George H.W. Bush Chair of Cardiovascular Medicine; Vice Chair, Department of Internal Medicine; Director, Division of Medical Genetics; and Director, John Ritter Research Program, at the University of Texas-Houston Medical Center.

Meet and learn from Drs. Dietz, Milewicz, and other members of our Professional Advisory Board at our 2016 annual conference this summer. See the opposite page for more information.



DIANNA MILEWICZ, MD, PHD

WAYS TO SUPPORT THE FOUNDATION

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
- Including the Foundation in your estate plans
- Selecting the Foundation in your employee giving campaigns
- Choose the Foundation as the beneficiary of a percentage of your purchases on Amazon Smile

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.



I am confident Callie's early diagnosis was due to a lot of previous, relentless efforts by those in support of the Marfan community and how can I better repay that than to pass it forward.

- Jamie Efurd, The Woodlands, TX

TAKE ME OUT TO THE BALLGAME: **MARFAN AND BASEBALL**

Physical activity is important for everyone. If you have Marfan syndrome or a related condition, there are considerations regarding the heart and blood vessels, as well as the bones and joints. And there are many “gray” areas when evaluating which sports are safe because it may depend on the intensity of the competition.

According to Dr. Shaine Morris, a pediatric cardiologist at Texas Children’s Hospital, “In general, people with Marfan syndrome, Loeys-Dietz syndrome, and other related disorders should not participate in any competitive sports that involve intense physical exertion or the potential for bodily collision. Baseball is usually off limits. Ultimately, though, the decision is between the cardiologist and the patient, based on the degree of aortic enlargement.”

One of the dangers is the potential for a collision that can impact the heart. Said Dr. Morris, “As far as I know, there is no evidence that chest shields protect the heart. Typically a dissection or rupture in this situation would be from the shear force, not the point impact of the hit (the sternum already is pretty strong). While some of my patients have bought these on their own, I never recommend them because they give a false sense of safety.”

For more information about physical activity and Marfan syndrome, please visit Marfan.org

CLINICAL GENETICIST THE QUARTERBACK OVERSEEING YOUR CARE



DR. ROMAN YUSUPOV IS A MEDICAL GENETICIST WHO IS THE MEDICAL DIRECTOR OF THE MARFAN CLINIC AT JOE DIMAGGIO CHILDREN’S HOSPITAL IN HOLLYWOOD, FL.

By Roman Yusupov, MD

Most people think of geneticists as researchers who work in the lab and do not spend a lot of time with patients. Contrary to popular belief, clinical genetics is a patient-centered specialty, and clinical geneticists spend a great deal of time with each patient for diagnosis, management, genetic testing, and genetic counseling. Marfan syndrome is the perfect example in describing the role of a clinical geneticist.

While other doctors mainly deal with specific parts of the body (for example, a cardiologist mainly treats heart problems and an orthopedist mainly treats joint and back problems), a clinical geneticist looks at the total picture. He/she takes the clinical information from other doctors who evaluate the patient and, along with their own evaluation, figure out if Marfan syndrome is the right diagnosis. It is like putting pieces of the puzzle together to see if they fit.

So how is a genetic evaluation conducted and what should you expect during a genetic evaluation? When you see a clinical geneticist, he/she will obtain a very detailed history, including a prenatal, birth, developmental, and medical history and perform a very thorough physical exam, taking certain measurements of limbs and body proportions. Sometimes pictures of notable abnormalities are taken for documentation purposes.

If a clinical geneticist suspects Marfan syndrome, genetic testing may be ordered. This is usually done through blood, but some laboratories are able to perform genetic testing on saliva samples. The test results can be very technical and filled with medical terminology; a clinical geneticist can explain the test results—and their implications—in a simple way that is understandable to a non-medical person.

Once the diagnosis is made, a clinical geneticist is like a quarterback who directs the overall medical care of patients with Marfan syndrome. He or she follows patients to make sure that problems are not missed and are treated in a timely fashion.

Geneticists also play a role in genetic testing that helps determine which family members are at risk and in guiding couples who are planning to become pregnant.

FOR MORE INFORMATION ON GENETIC TESTING AND MARFAN SYNDROME, VISIT Marfan.org

FIVE QUESTIONS

To Ask Your Cardiologist About Your Child's Echocardiogram

By Shreya Sheth, MD, FACC

Picture this: at a routine well-child check, your pediatrician is worried about physical findings in your child. She brings up the possibility of Marfan syndrome, and refers you for further testing, including a visit to a pediatric heart specialist for an electrocardiogram and an echocardiogram. In the whirlwind of visits and testing that follows, it can be confusing to sort out what these tests look for, and what you need to know.

Cardiac abnormalities are a major health concern in Marfan syndrome. It is estimated that about 90% of people with Marfan syndrome have some involvement of the heart. An echocardiogram is a noninvasive test that uses ultrasound to assess the structure and function of the heart. Every patient with known or suspected Marfan syndrome should be evaluated with an echocardiogram at regular intervals. As a parent, you want to be prepared with some basic idea of what your cardiologist is looking for, and what it may mean for your child. Here are five helpful questions to ask your family's cardiologist.

1. Is the aortic root dilated?

Aortic root dilation, or an abnormal enlargement of the area where the aortic valve meets the aorta, is an important factor in the diagnosis of Marfan syndrome. An abnormally enlarged aortic root can lead to one of the most life-threatening complications of Marfan syndrome: aortic dissection. Normal dimensions for the aortic root vary as children grow; so pediatric criteria use a measurement called a z-score, which compares your child's aortic dimensions against the average for children with similar body surface areas. A z-score of greater than +2 may suggest a diagnosis of Marfan syndrome (when coupled with other physical features and eye issues). This measurement is taken at every follow-up echocardiogram, is followed over time, and helps to guide medical therapy and surgical intervention.

2. Does the aortic valve leak?

Aortic valve leakage or regurgitation can be seen with root enlargement, and may influence planning for medication therapy or surgical intervention.

3. Are any other valves or vessels involved?

In addition to aortic root enlargement and aortic valve leakage, people with Marfan syndrome can have abnormal findings in the mitral valve, tricuspid valve, and pulmonary artery.

4. When is our next echocardiogram?

Current guidelines suggest screening echoes every 3–5 years for children who have Marfan in their family, or those who do not meet full diagnostic criteria and have a normal initial echocardiogram. In people with a diagnosis of Marfan syndrome, screening echoes are performed at least yearly, and more frequently if progression of aortic root enlargement is suspected.

5. Do we need to have any other cardiac imaging?

Occasionally the aortic root is not well seen by echocardiogram, especially if the individual has severe scoliosis. Though it is not routinely recommended for screening in children with Marfan, the entire aorta can be imaged by computed tomography (CT) or magnetic resonance imaging (MRI). Such imaging is recommended yearly for anyone with a history of aortic root replacement or dissection, and may be suggested if echo images were not adequate for diagnosis.

Your cardiologist is a great resource for concerns related to your child's heart, and a little pre-visit preparation goes a long way in relieving your anxiety, and strengthening your understanding of what happens next.

Dr. Sheth is a pediatric cardiologist in the Congenital Heart Program at Cedars-Sinai Heart Institute in Los Angeles.



EMRI VAN ANDEL GETS AN ECHOCARDIOGRAM AS HER MOM, ERIN, LOOKS ON.

HEARTWORKS GALA NEW YORK CITY

More than 500 people were on-hand at the 16th Heartworks gala in New York City, helping The Marfan Foundation raise more than \$1.2 million for its life-saving programs and services. It was an emotional evening as the Foundation honored the legacy of Jonathan Larson, the award-winning playwright of *RENT*, who died from an aortic dissection believed to have been caused by Marfan syndrome, and the Weill Cornell Cardiac Care Team—Drs. Richard Devereux, Leonard Girardi, and Mary Roman—who provide outstanding patient care and conduct research on Marfan syndrome and related disorders.



ABOVE: (R-L) **DRS. RICHARD DEVEREUX AND MARY ROMAN**, WITH HEARTWORKS CORPORATE HOST AND FOUNDATION BOARD CHAIR **KAREN MURRAY** AND FOUNDATION PRESIDENT AND CEO **MICHAEL WEAMER**. "THIS YEAR'S HEARTWORKS GALA WAS THE MOST SPECTACULAR AND MOST EMOTIONAL EVENT WE HAVE EVER HAD," SAID MURRAY. "WE ARE SO GRATEFUL TO OUR FRIENDS AND COLLEAGUES WHO JOINED US TO PAY TRIBUTE TO OUR HONOREES AND TO SUPPORT OUR LIFE-SAVING PROGRAMS AND SERVICES."



LEFT: MORE THAN TWO DOZEN *RENT* CAST MEMBERS, INCLUDING **DAPHNE RUBIN-VEGA** (LEFT) AND **FREDI WALKER-BROWNE** FROM THE ORIGINAL BROADWAY CAST, ENTERTAINED THE CROWD WITH SONGS FROM THE HIT SHOW.



TOP: BROADWAYS' **ANN REINKING**, WHOSE SON HAS MARFAN SYNDROME, WITH HEARTWORKS HONORARY CHAIR **MICHAEL R. BLOOMBERG**.

BOTTOM: ACTOR/COMEDIAN **JULIE HALSTON** (LEFT, WITH MARFAN FOUNDATION MEMBER **TRACY FITZGERALD**) WAS THE MASTER OF CEREMONIES.



AL LARSON (CENTER), FATHER OF JONATHAN LARSON, AND **JULIE LARSON**, THE PLAYWRIGHT'S SISTER (SECOND FROM RIGHT), FELT THE LOVE FROM JONATHAN'S FRIENDS, WHO CAME FROM ALL OVER THE COUNTRY TO SUPPORT THE FOUNDATION AS A TRIBUTE TO JONATHAN.

HEARTWORKS ST. LOUIS

The 8th Annual Heartworks St. Louis Gala was a huge success, with more than 400 people attending this sparkling event to support the Marfan syndrome 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.



2016 HERO WITH A HEART AWARD RECIPIENT, **DR. CHARLES HUDDLESTON**, CARDIOTHORACIC SURGEON, SSM CARDINAL GLENNON CHILDREN'S MEDICAL CENTER, AND PROFESSOR OF SURGERY AT SAINT LOUIS UNIVERSITY SCHOOL OF MEDICINE, WITH **EMILY RAUSCHENBACH**, A MEMBER OF OUR ST. LOUIS CHAPTER AND ONE OF DR. HUDDLESTON'S PATIENTS.



TOP: 2016 CORPORATE CHAMPIONS **ROBERT & DONNA PLUMMER**, RP LUMBER (RIGHT), WITH **DR. ALAN BRAVERMAN**, CHAIR OF OUR PROFESSIONAL ADVISORY BOARD, AND HIS WIFE, **REBECCA**, WHO CO-HOSTED HEARTWORKS ST. LOUIS.

BOTTOM: MEMBERS OF OUR ST. LOUIS CHAPTER (L-R) **PINAR COONAN** AND **PATTI KINSAL-DAVIS**, WITH **TERRI CROSBY**, FROM THE CARLILE SAILING CLUB WHICH HOSTED A FUNDRAISER FOR THE MARFAN FOUNDATION IN MAY.

THANK YOU TO OUR LEAD SPONSORS

HEARTWORKS GALA NEW YORK CITY

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HEARTWORKS ST. LOUIS

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- Ms. Phyllis R. Tirmenstein
- Division of Cardiothoracic Surgery and Vascular, Washington University School of Medicine
- Dr. Virginia V. Weldon & Mr. Francis M. Austin, Jr.

COUPLE CONNECTIONS: When Marfan Syndrome Creates a “Ménage à Trois”



BEN WEISMAN, AND HIS WIFE, LINDSEY, WHO WERE MARRIED IN 2008.

By Roanne Weisman

Marfan syndrome may reside in one person’s body, but if you are part of a couple, both lives are affected. Marfan syndrome becomes the uninvited third member of your relationship. Even if the condition is stable and well-managed, there may be physical limitations or unexpected pain. For many people with Marfan syndrome, every day is an adventure and a challenge: How will the joints shake out today? Which activities will be possible or compromised? For couples, these kinds of questions are joined by a third: How to preserve the romance, the shared joy, and the just plain fun of being together?

I believe at least one answer to the last question lies in the story of three generations of Marfan syndrome in my family. My father hid his condition from my mother, who did not discover the truth until after his premature death at 36 from an aortic aneurysm. He died decades before effective medical and surgical treatments became available. Because of those treatments—due in large measure to clinical research funded by The Marfan Foundation—I have survived surgeries and other medical complications and am now doing well in my sixties. My son, Ben, has improved the family legacy even

more. He is not only thriving, but also seizing the opportunity to serve the Marfan community as an active volunteer with The Marfan Foundation.

The Perils of Secrecy

One obvious lesson here is that secrecy is bad for any relationship, but especially when it involves a serious medical condition. When Ben and his wife, Lindsey, started dating, one of the first things he did was to tell her that he had Marfan syndrome and explain what it is. “Rather than try to hide it or run away, I decided to steer directly into it,” he says. Lindsey’s reaction? “It didn’t faze me,” she says. “It went along with the other things I was learning about him: He loves the Patriots, hates spicy food, has skinny fingers, and nice eyes.” They have been married since 2008 and attend every Marfan conference together. From their experiences, along with those of other

couples, as well as advice from some of the experts interviewed for my book, *In Sickness As In Health*, here are some suggestions for successful Marfan relationships.

Partnership is Power

Perhaps the most important benefit of Marfan transparency is that you don’t have to go it alone, as my father obviously did. As many of us know, we usually walk out of the doctor’s office having retained less than half of the information we heard. The non-Marfan partner (henceforth called NMP) plays an important role as another set of ears, a question-asker, a note-taker, a post-visit debriefer, and, when necessary, a cheerleader. “My partner was the guardian of hope for me when I was at a low point after Marfan-related heart surgery,” said one member of a couple. “He held onto that hope until I could take it over on my own.”

Speaking the Unspeakable

Sometimes, when there are physical setbacks due to surgery or new onsets of joint pain, the routines of life may need to change. The NMP may need to take over new household and family responsibilities and tasks. One by-product of these changes might be troublesome emotions. The NMP may feel sadness, worry, and even anger, while the person with Marfan

may experience guilt, frustration with a body that is not “doing its job,” and worry about the result of added stress on the NMP. It’s natural to want to keep these feelings from your partner—for fear that speaking them aloud will cause harm. But silence only widens the gap between you. You can learn to use these feelings as bridges rather than have them remain as obstacles. Here is one way to do that, suggested by an expert interviewed for my book on couples and illness:

Emptying Your Cup

Expressing feelings that are painful or “unspeakable” strips them of their power to derail your relationship and exposes them to the clear light of understanding. In this activity, one partner shares his thoughts and feelings (without blaming the other), while the other partner listens with empathy, without trying to solve problems. Whenever the speaker pauses, the listener says, “Tell me more,” until the speaker has emptied himself. Switch roles. Go through the steps with the other partner as speaker. When you finish, sit quietly and summon the empathy you have for each other’s experiences.



TRACY FITZGERALD, WHO HAS MARFAN SYNDROME, AND HER HUSBAND, TOM, SAY: REMEMBER THAT YOU ARE A TEAM. YOU BOTH HAVE NEEDS AND ARE AFFECTED BY THIS DISEASE.

Expressing feelings that are painful or “unspeakable” strips them of their power...

Reach for the Strength

The last thing any person with Marfan syndrome wants is to be treated as an invalid. So while it is important for the NMP to recognize limitations (as in, let’s take the elevator instead of climbing two floors to the movie theatre), this recognition should be free of value judgments. Think of taking an umbrella when it is raining. This is just something you need to do, without judging the rain. At the same time, it is important to encourage the person with Marfan to do what is possible, whether it is taking a walk, swimming, playing golf, or learning to kayak. And it is the responsibility of the Marfan person to make these preferences clear.

Respect Differences

What if the NMP is an avid skier or tennis player? One of the realities of a relationship that includes Marfan syndrome is that couple togetherness may not always be possible, but this can be managed without resentment or frustration. Each member of the couple should be free to engage in activities individually. The togetherness comes later with the stories! Respecting and honoring individual preferences—and physical abilities—is the key to success.

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

**NEW RESOURCE:
PARENT TOOLKIT**

Do you wonder if you should tell your child that he or she has Marfan syndrome? When should you talk to your child about the diagnosis? How can you advocate for your child in school?

To answer these and many more questions, The Marfan Foundation launched a new online parent toolkit. Funded by the American Legion Child Welfare Foundation, the toolkit helps parents deal with issues related to school, doctors, and healthcare, and provides links for resources and support.

Each section of the toolkit features short videos of parents who share their tips. Many parents have already found them useful.

“What I’ve learned is that it’s important to draw the child into the understanding, and management, and decision-making process as early as possible,” said Jeff Edstrom, of Chicago, who has a 14-year-old son with Marfan. “Ultimately, he is the one dealing with it. He needs to understand his body and signs. We can work on building self confidence and trust for him.”

The parent toolkit can be found at Marfan.org. Click on the link for patient resources in the section for parents and families.

SPOTS AVAILABLE IN NYC MARATHON

FIGHT FOR VICTORY IN THE TCS NEW YORK CITY MARATHON

People with Marfan syndrome and related disorders can't run in a marathon (competitive sports are detrimental to their fragile aorta), but their friends and unaffected relatives can! And we have secured hard-to-get slots in the TCS New York City Marathon this Fall!

The Marfan Foundation is proud to be a charity partner of the 2016 TCS New York City Marathon on November 6. We have 10 slots for runners who will raise funds for the Foundation and help increase awareness of Marfan syndrome and related disorders. All donations directly benefit The Marfan Foundation's life-saving programs and services.

So if you have a family member or friend who wants to run in one of the world's premier marathons in your honor, tell them to contact Helaine Baruch at hbaruch@marfan.org to find out how to join our team. It's a wonderful tribute to you and will make a real difference in creating a brighter future for all those living with Marfan and related disorders.



STEPHANIE FISHMAN, WHO RAN FOR THE MARFAN FOUNDATION IN 2015.

NUTRITION, WEIGHT, AND QUALITY OF LIFE

By Alix McLean Jennings

Being underweight is such a big issue for so many in our community. It seems there is a question weekly in one of the Marfan Facebook groups about how to help a child or adult gain weight. In some cases, like my daughter Cassie's, it can get very serious to the point where you are malnourished. The other problem with being underweight is that it contributes to the lack of stamina that so many people with Marfan suffer from. There are other factors at play with stamina, but not having the energy stores that some fat can give you makes it worse.

Cassie's doctors talked to us about placing a g-tube (which stands for gastrostomy tube and is a feeding tube that goes directly into the stomach). My husband and I resisted the g-tube placement at first because we did not want to "medicalize" our lives further than they already had been and we were not convinced it would make a difference.

When we finally met with a gastrointestinal doctor, he told us that Cassie's BMI (body mass index) was the lowest of any patient he'd ever seen. Even though I could see how thin Cassie was, hearing it in those words made us realize just how desperately she needed more nutrition.

Cassie's g-tube was placed a couple of months later in September 2014 when she was 7.5 years old and weighed 37 pounds, and since that time I am very proud to say that she has gained 23 pounds! When I recently entered her height and weight in a pediatric BMI calculator, her BMI fell into the normal range (even though it was at the very lowest end of normal). Her stamina is still an issue, but it's so much better than it was.

The g-tube alone didn't fix everything. We had nutrition issues and a lot of



CASSIE JENNINGS WAS SO UNDERWEIGHT THAT IT INTERFERED SIGNIFICANTLY WITH HER QUALITY OF LIFE. EVERYTHING CHANGED AFTER HER PARENTS MET THE RIGHT GASTROINTESTINAL DOCTOR AND NUTRITIONIST.

food issues in our home because we had focused on food for so long. I was referred to a nutritionist/therapist who specialized in helping people with eating disorders get back to a healthy weight. Seeing this nutritionist, Hien Nguyen-Le, changed everything.

There is a lot I worry about as the mom of a child with Marfan, but the worry about her weight is off the table. And we don't talk about food nearly as much in our house. And all of that is good for my quality of life too.

To read Alix's full story about how she worked with a nutritionist to bring her nine-year-old daughter Cassie, who has Marfan syndrome, up to a healthy weight, please visit [The Marfan Blog at Marfan.org](http://TheMarfanBlog.com).

NUTRITION Q&A

Nutritionist/therapist Hien Nguyen-Le answers common questions about nutrition and Marfan syndrome

Alix McLean Jennings worked closely with a nutritionist/therapist, Hien Nguyen-Le, on the food and nutrition issues that plagued her daughter, Cassie, who has Marfan. Here are excerpts from Alix's Q & A with Hien.

Q: How can proper nutrition improve your quality of life?

A: Nutrition affects every organ system in the human body, as well as our emotional and psychological state. In a nutshell, nutrition enhances our well-being by giving us more energy on every level—physical, emotional, and mental. In addition to having more energy and increasing our vitality, it also increases our resilience to tolerate stress in our lives.

Q: If you are better nourished, will you have more stamina, less fatigue, and feel more balanced?

A: You would have more sustained energy. And you definitely would feel more balanced and grounded—the word I like to use is anchored—in your body and in yourself. If you think about individuals who don't have nutritional issues but, let's say, they missed a meal or they went too long without eating, we know how hunger can affect their mood. Now, imagine that on a longer term basis in someone who's chronically malnourished. Yes, absolutely.

Q: Why am I not hungry when I am so thin?

A: When a person's body is malnourished, it affects every system in the body, including the neurochemical system that regulates appetite, hunger, and fullness cues. Because that system gets broken, our body experiences skewed hunger and fullness cues. If hunger becomes suppressed, then a person who is chronically malnourished doesn't experience hunger. Their body is hungry, but they don't experience hunger cues as much. Hunger becomes a delayed reaction and fullness becomes premature. That's called early satiety or premature fullness, which means that when a person who is malnourished starts to eat they'll complain about feeling full pretty quickly. They might feel full after a small amount of food is eaten.

Q: How can I make myself eat if I'm not hungry?

A: That is a tough one. The first thing is to find palatable foods. If you're not hungry, try to find the things that you like the most. The second thing is psychological acceptance and having a good understanding of the re-feeding process and knowing that this is temporary, that this is something that you need to do to get to the other side.

How do you learn to do your homework when you don't

feel like it? The short answer is using will power to a certain degree, but really understanding that this is what you need. It might not be what you feel like doing, but it's what you need. It's difficult, but it might just be accepting that sometimes we need to do things to take care of ourselves that we don't want to do. I wish there were a better answer, but it's a hard thing and it's about accepting that and understanding the process. I wish there was a way to make somebody suddenly want to eat, but there isn't.

Q: Are there things a person with Marfan syndrome or a related disorder should consider in weight restoration that may be different than the general population?

A: As a whole, I would say that if a person with Marfan syndrome has specific gastrointestinal issues, that wouldn't be different than anyone else with those same GI issues. If someone with Marfan syndrome had digestive issues, I don't know that I would look at that any differently than someone else who also had digestive issues. I would still treat based on that person's individual medical profile.

TO READ THE FULL CONTENT OF ALIX'S Q & A WITH HIEN, PLEASE GO TO THE MARFAN BLOG ON OUR WEBSITE.

Hien Nguyen-Le, EdM, RD, of Hillsborough, NJ, is a nutrition therapist who has specialized in the treatment of eating disorders and disordered eating for nearly 20 years.



NUTRITIONIST/THERAPIST HIEN NGUYEN-LE

WALK FOR VICTORY



UPCOMING WALKS:

- | | |
|--|------------|
| Boston, MA | June 11 |
| Rochester, MN
(at our annual conference!) | August 5 |
| St. Louis, MO | October 9 |
| San Antonio, TX | November 6 |



Interested in
joining us at an
upcoming walk?
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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 2015-2016 raised more than \$200,000 to support The Marfan Foundation's education and research programs, which reach more than 25,000 affected individuals, families, and physicians each year. In our 2016-2017 season, we are looking to double the amount raised to support quality of life programs for our families, kids, teens, and young adults who are living with Marfan and related disorders. These walks provide a great opportunity for the community to come together to raise critical funds for the Foundation.

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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