

CONNECTIVE ISSUES

FALL 2017

**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.

Contents

ANNUAL CONFERENCE 4-7

EDUCATION 8-9

ADVOCACY 10

QUALITY OF LIFE 11-12

WALK FOR VICTORY 14

TRIBUTES 15

CONNECTIVE ISSUES

FALL 2017

VOLUME 36 | NUMBER 3

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

COVER: BROOKE PULLIAM, OF GRAY SUMMIT, MO, AND HALEY DOSTALIK, OF URBANDALE, IA, ARE AMONG OUR ACTIVE TEENS WHO HAVE CREATED A SUPPORT SYSTEM FOR EACH OTHER THROUGH THE ANNUAL CONFERENCE AND SOCIAL NETWORKING (ONLINE AND IN REAL LIFE) THROUGHOUT THE YEAR.



If you think you are too small to be effective, you have never been in bed with a mosquito.

– Betty Reese

Since attending our Annual Conference, I have been reflecting on the spirit of volunteerism and the extraordinary impact volunteers have on the success of The Marfan Foundation.

As you flip through this edition of *Connective Issues*, I urge you to pause for a moment or two and enjoy the smiling faces celebrating making a difference in the lives of others and, in many cases, their communities back home on behalf of Marfan syndrome and related disorders.

As I have said on a number of occasions, volunteers really are the lifeblood of The Marfan Foundation and your individual and collective efforts will ultimately determine the outcome of our fight for victory now and in the future. This is your organization! It only exists because of your support and engagement.

There is nothing stronger than the volunteer-staff partnership. It is like the bridge line of a spider web, that super strand of organization upon which everything is built. The Marfan Foundation is looked at by many smaller organizations as something they aspire to become. This didn't happen by chance but is the direct result of early leaders like Dr. Reed Pyeritz, who saw the power of community in a rare disease community, and Priscilla Ciccariello, who had the vision and passion to drive forward our three-pronged mission of education, support, and research, followed by Carolyn Levering and countless additional volunteers and staff who have worked tirelessly to make The Marfan Foundation a leader in serving our community.

Now, it is our time to build upon that super strand and ensure that programs like our Quality of Life Initiative, Annual Conference, and Regional Symposiums, as well as the growth of our services, such as the Help and Resource Center, position us for even greater success now and in the future.

Raising funds to carry out our mission is also critical and we are hopeful that expanding our Walk for Victory Program, holding more Evening with Heart events in major cities, focusing more on major gifts, and growing online giving will provide much needed fuel for our Victory engine.

The Foundation spends just under 80 cents on a dollar on mission, received a 4-star rating (their highest) from Charity Navigator, and earned accreditation from the BBB Wise Giving Alliance, providing yet another level of assurance to individuals who invest in our mission.

In closing, I would like to recognize the long-standing support of the Lerman family and their latest creation, the Sydney Lerman Pediatric Hospitality Program. Barbara, Jonathan, Carly, and Sydney are wonderful examples of the power of volunteerism. Enjoy their story in this issue.

Remember, no one can do everything but everyone can do something!

Michael L. Weamer
President & CEO

#CREATING CONNECTIONS



MORE THAN 100 **CHILDREN**, AGES 6-12, ENJOYED FUN AND GAMES, A TRIP TO THE GEORGIA AQUARIUM, AND HAD A CHANCE TO ASK QUESTIONS TO DOCTORS—WITHOUT THEIR PARENTS AROUND.

Our 33rd Annual Conference in Atlanta this summer was our largest conference ever, with nearly 750 individuals, families, and medical professionals participating. “It was our first time attending and we came away fortified with lots of information and new friends to share our life journey with Marfan syndrome and related health issues!” said Kim Knutson, Suwanee, GA, who attended the conference with her husband, Larry, and her grandson, Brandon, who has Marfan.



THE **YOUNG ADULTS** (MORE THAN 40 OF THEM!) PLANNED THEIR OWN OUTINGS AND ACTIVITIES, WHICH INCLUDED DISCUSSIONS ON TOPICS CRITICAL TO THEIR AGE GROUP, SUCH AS CAREERS, RELATIONSHIPS, WORK, AND MORE.



MORE THAN 100 **TEENAGERS** STRENGTHENED THEIR CONNECTIONS WITH PEERS THROUGH A VARIETY OF WORKSHOPS, INCLUDING GENDER BREAK-OUTS, SELF-ESTEEM BUILDING ACTIVITIES, A TRIP TO THE WORLD OF COKE AND COLLEGE FOOTBALL HALL OF FAME, AND PLENTY OF SOCIAL TIME.



ADULTS WHO HAVE MARFAN OR A RELATED DISORDER, OR WHO LOVE SOMEONE WITH A DIAGNOSIS, PARTICIPATED IN MEDICAL SESSIONS AND WORKSHOPS, ENJOYED SOCIAL GATHERINGS, RECONNECTED WITH OLD FRIENDS AND MADE NEW ONES AT OUR WELCOME RECEPTION, CREATING CONNECTIONS LUNCHEON, AND OTHER PLANNED EVENTS. EVERYONE ALSO ENJOYED DOWN TIME IN THE HOTEL.



PAIN AND EHLERS DANLOS SYNDROME

I have Ehlers Danlos syndrome, hypermobility type, and am in constant joint pain. What can I do for relief?

According to Jan Lynch, MSN, RN, director of our Help & Resource Center, hypermobile joints cause pain because the muscles around them weaken and do not support the joints as well as they should.

Jan suggests a visit to an orthopedist familiar with connective tissue disorders to determine if any surgery or other intervention is needed. The orthopedist can also recommend some pain-relieving medications.

Several members of our 50+ support group, which Jan facilitates, utilize other treatments, such as reputable oils, medical marijuana, lidocaine patches, TENS unit, Epsom salts, massage therapy, acupuncture, and other holistic interventions. Please note: These suggestions are not for everyone.

Please check with your healthcare provider before starting any treatment. Your treatment options will be unique to you and your condition and the status of your joints and spine.

A physiatrist and/or a physical therapist familiar with connective tissues disorders can also help improve the function of your joints and the muscles around them.

If you have any questions about joint pain or other issues related to your diagnosis, please contact Jan at jllynch@marfan.org or 516-883-8712, ext. 126.

MEDICAL PRESENTATIONS



TRACI SPEED, MD, OF JOHNS HOPKINS, SPOKE ABOUT PAIN MANAGEMENT.

Each year, the annual conference features a general medical session that is comprised of esteemed speakers who address key issues related to the diagnosis and treatment of Marfan and related disorders. The topics are determined based on the interests of our community. Here are some highlights.

Pain Management

Traci Speed, MD, Johns Hopkins

Pain is comprised of two parts: a sensory experience associated with physical manipulation and an emotional response or distress and anxiety related to the sensory information. People with Marfan most commonly report pain in their back, feet, hips, shoulders, and knees.

It's important to address pain because it impacts how you function on a daily basis—your relationships, work, finances, energy, social activities, physical health, and mental health.

Treatment strategies include: medications, psychotherapy, interventions/stimulators, education, physical therapy, group therapy, exercise, and family therapy. Additional non-medical options are behavioral approaches, relaxation (yoga and mindfulness meditation), imagery, self-hypnotic analgesia, distraction techniques, graded physical recovery exercises, and assertiveness training.

Everyone benefits from structure, hope, and advocacy. The goal is to be able to function despite having pain.

Exercise and Physical Activity in Marfan Syndrome and Related Disorders

Alan Braverman, MD, Washington University in St. Louis School of Medicine

Routine exercise offers benefits for the health and well-being of everyone. Cardiovascular benefits include lowering heart rate, blood pressure, and cholesterol; less coronary disease; and lower risk of heart attack and stroke. Exercise also lowers blood sugar, lowers the risk of colon and breast cancer, and improves mental health.

For people with Marfan syndrome and other inherited aortic conditions, doctors provide counsel on the type of exercise that is safe and how much exercise is safe. There is no outcomes data to guide them; they typically err on the side of safety.

Recreational athletics, which are non-competitive, involve light-to moderate exercise, and are for fitness and fun, are recommended. Competitive athletics, which involve systematic training and pushing yourself to the highest natural physical limits for the purpose of athletic excellence and achievement, are not recommended.

“YOU DON’T HAVE TO WORRY ABOUT EXPLAINING MARFAN BECAUSE EVERYBODY KNOWS”

Conference attendee has life-changing experience at Annual Conference

Betsy Matarrita, of Costa Rica, can’t stop talking about her experience at the Foundation’s Annual Conference in Atlanta this summer. She took advantage of every opportunity to create connections and returned to her home with a new sense of energy and empowerment.



BETCY MADE AN APPOINTMENT FOR THE PATIENT EVALUATION HEALTH FAIR AND WAS SEEN BY DOCTORS FROM JOHNS HOPKINS, STANFORD, AND CLEVELAND CLINIC. HER RESPONSE: “WOW!” GETTING NEWS FROM THE EXPERTS ABOUT HER HEALTH STATUS AS IT RELATES TO MARFAN GAVE HER A GREATER UNDERSTANDING AND A SENSE OF RELIEF.



THIS YEAR, FOR THE FIRST TIME, THE FOUNDATION OFFERED A MENTOR PROGRAM SO THAT FIRST-TIME ATTENDEES COULD “LEARN THE ROPES” FROM SOMEONE WHO HAD ATTENDED BEFORE. BETCY’S MENTOR, JENNIFER ALVIN, FROM NORTH CAROLINA, WAS IN TOUCH WITH HER BEFORE THEY GOT TO ATLANTA BY TEXT, EMAIL, AND FACEBOOK AND ANSWERED ALL OF BETCY’S QUESTIONS SO SHE KNEW WHAT TO EXPECT. JENNIFER AND HER FAMILY TOOK BETCY OUT TO DINNER AND MADE HER FEEL COMFORTABLE FROM THE OUT-SET. NOW, BETCY IS LOOKING FORWARD TO BECOMING A MENTOR FOR ANOTHER FIRST-TIME ATTENDEE IN 2018.



BETCY LEARNED A LOT AT THE MEDICAL PRESENTATIONS, BUT ADMITTED THAT GETTING TOGETHER WITH THE YOUNG ADULTS ON SATURDAY NIGHT WAS THE BEST OF ALL. “YOU DON’T HAVE TO EXPLAIN ABOUT MARFAN BECAUSE EVERYONE THERE KNOWS,” SHE SAID. “AND THAT MEANS A LOT.” MANY OF THOSE BETCY MET HAD RECEIVED A CONFERENCE SCHOLARSHIP, AND SHE IS SO GRATEFUL TO ALL THOSE WHO SUPPORT THE PROGRAM, LIKE CHRIS HEANEY, A FORMER BOARD MEMBER, WHO HAS CHAMPIONED AND SUPPORTED CONFERENCE SCHOLARSHIPS FOR MANY YEARS.

Betsy encourages anyone who hasn’t been to an annual conference to attend, if possible. And, if you’ve attended before, then come again. She said, “There is always something new to learn and new people to meet. Everyone is so friendly, and seeing people with the same features that you have is so comforting. I can’t wait until next year.”

SAVE THE DATE
34TH ANNUAL CONFERENCE
 JULY 12-15, 2018 | SANTA CLARA, CA
 HOSTED BY **STANFORD UNIVERSITY**

2017 ANNUAL CONFERENCE AWARDS

Volunteers from coast to coast are the life-blood of The Marfan Foundation. They work hard to advance our mission on the local level while dealing with all that comes with Marfan syndrome and related disorders. Each year at the annual conference, the Foundation recognizes members of our community and medical professionals who have made significant volunteer contributions in the areas of awareness, education, support, and fundraising.

Cheryll Gasner Spirit of Service Award **The Kauffman Family**



THIS AWARD IS PRESENTED TO PEOPLE WHO, LIKE CHERYLL GASNER, ARE LEADERS BOTH NATIONALLY AND LOCALLY, DESPITE THE MEDICAL PROBLEMS THEY FACE DUE TO MARFAN SYNDROME OR A RELATED DISORDER.

Community Leadership Award **Heather Bergstrom** President, Minnesota Chapter



BOARD MEMBER MAYA BROWN-ZIMMERMAN, LEFT, PRESENTED THE AWARD TO HEATHER BERGSTROM IN RECOGNITION OF HER OUTSTANDING EFFORTS TO CREATE CONNECTIONS FOR THE MARFAN SYNDROME AND RELATED DISORDERS COMMUNITY.

Antoine Marfan Award **Heidi Connolly, MD** Mayo Clinic



BOARD MEMBER BERT MEDINA PRESENTED THE AWARD TO DR. CONNOLLY IN RECOGNITION OF HER OUTSTANDING ACHIEVEMENTS AS A CONSUMMATE CLINICAL CARDIOLOGIST AND ADVOCATE FOR PATIENTS AND FAMILIES, AND FOR BEING A LONG-TIME, VALUED ADVISOR TO THE MARFAN FOUNDATION.

Priscilla Ciccariello Award **Scott Avitabile**



BOARD MEMBER CORY EAVES, RIGHT, PRESENTED THE AWARD TO SCOTT AVITABILE IN RECOGNITION OF HIS OUTSTANDING DEDICATION AND SERVICE TO THE MARFAN COMMUNITY.

Heart of the Matter Award
Austin Carlile



DR. DAVID LIANG, LEFT, PRESENTED THE AWARD TO AUSTIN CARLILE IN RECOGNITION OF HIS COMMITMENT TO EDUCATION AND AWARENESS, WHICH INSPIRES THE MARFAN SYNDROME AND RELATED DISORDERS COMMUNITY.

Rising Star Award
Liam Nelson



BOARD MEMBER BEN WEISMAN, RIGHT, PRESENTED THE AWARD TO LIAM NELSON IN RECOGNITION OF HIS COMMITMENT TO PUBLIC AWARENESS AND SUPPORT FOR THE MARFAN AND RELATED DISORDERS COMMUNITY.

Chapter Recognition
Massachusetts Chapter

Volunteer Recognition Awards

Latasha Doyle, Thornton, CO
Sandy Eisman, Springfield, OH

Kid with a Heart Award

Jordan Hannan, Chapel Hill, NC
Cassie Jennings, Madison, NJ
Matthew Lutz, Madison, NJ
Ansley Siano, Holly Springs, NC

Fundraising and Awareness Recognitions

Mary Ahearn, Silver Spring, MD
Tonya Archer, Storm Lake, IA
Jeff Bednar, Allen, TX
Chester M. Stephens Elementary School, Budd Lake, NJ
Michele Cripps, Torrance, CA
Scott Griebel, Dover, MA
Scott Harrington, Charlotte, NC
Jeff Hoberman, Jersey City, NJ
Tanner Hoops, Storm Lake, IA
Alix & Ezra Jennings, Madison, NJ
Patti Kinsall Davis, Lebanon, IL
Alyssa Lamberti, Orlando, FL

Appreciation Award

The Chu and Chan Foundation
Kathleen Kane, Winthrop, MA

Teen with a Heart Award

Trent Blanton, Fort Lauderdale, FL
Jacob Hariton, Weston, CT
Sinclair Schuetze, Manheim, PA

Becky Lee, Decatur, TN
Ashley Miller, Indianapolis, IN
Shelly Moore, Beaverton, OR
Sheila Murray, Erie, PA
Chris & Veronica Rydzewski, Greenville, SC
Kevin Songer, Fort Myers, FL
Glenn Stidham, Nesconset, NY
Whitney Stoker, Viroqua, WI
Sunnyvale Community Players, San Jose, CA
Tera & Keith Woodhouse, Rogers, AR
Josy Villarubia, Hoffman Estates, IL

CONFERENCE
THANKS

Special thanks to everyone who made our 33rd Annual Conference possible. We couldn't be more grateful for your time, talent, and support!

CONFERENCE HOSTS

Children's Healthcare of Atlanta

Sibley Heart Center
Cardiology

Emory Heart & Vascular Center

SPONSORS

Presenter

Aetna Foundation

Leaders

Children's Healthcare of Atlanta

Sibley Heart Center
Cardiology

Emory Heart & Vascular Center

Conveners

Backpack Health

GeneDX

Invitae

Contributor

Ambry Genetics

IN-KIND DONATIONS

Philips Ultrasound

ScImage, Inc

PHOTOGRAPHY

Timothy D. Joyce
Photography

NEW PARTNERSHIP WITH AMERICAN MEDICAL ID

The Marfan Foundation is partnering with leading medical ID manufacturer, American Medical ID, to empower people with Marfan syndrome and related disorders in case of emergency.

This partnership makes medical alert jewelry more accessible. People who order medical ID jewelry through the Foundation's partnership with American Medical ID receive a 10% discount off the purchase price (5% off gold). In addition, for each purchase, American Medical ID will give 10% of the purchase price to the Foundation to support patient programs and services.

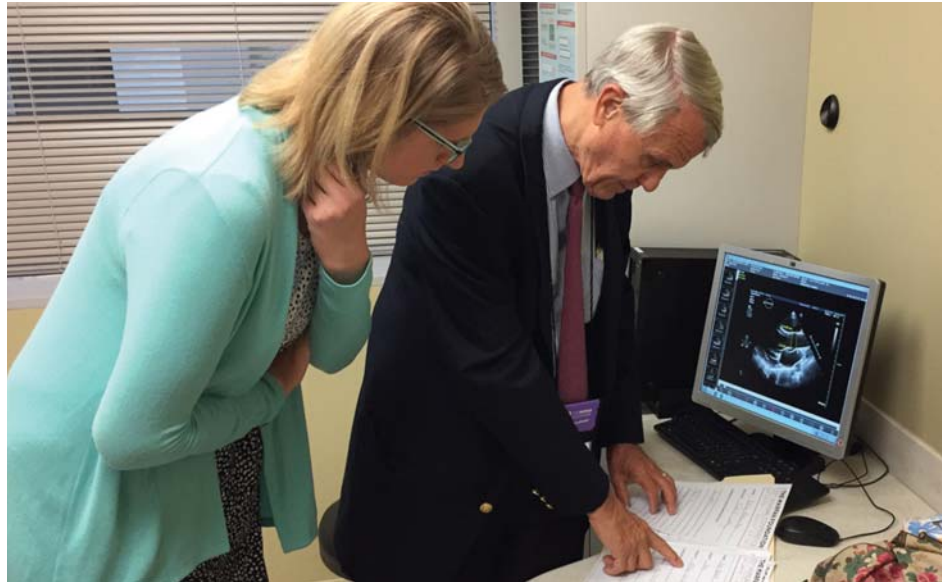
"Medical ID bracelets are an important tool in helping people get appropriate evaluation and treatment in an emergency situation," said Jan Lynch, MSN, RN, director of the Foundation's Help & Resource Center. "Aortic dissection may not be the first problem that emergency personnel think of, especially in individuals who may be younger and—on the outside—appear to be healthy. Emergency healthcare providers are accustomed to looking for medical ID jewelry; having a bracelet that indicates the risk of aortic dissection can expedite life-saving treatment."

Please visit our website to learn more, including how to order.



WHEN YOUR DIAGNOSIS PAVES THE WAY TO YOUR CAREER

The next generation of doctors with a diagnosis in common



DR. CRAIG MILLER, STANFORD UNIVERSITY, MENTORS ANDREA WITTE, OF ALASKA, AS SHE PURSUES HER MEDICAL INTERESTS.

Andrea Witte, of Anchorage, AK, was diagnosed with Marfan syndrome before the age of two. Now an undergraduate student at the University of Nevada at Reno, she is preparing to apply to medical school.

Seth Tennant, a high school senior in Tampa, FL, also has his eye on a career in medicine. He always knew he wanted a career in the sciences and zeroed in on medicine after his Marfan diagnosis at the age of ten.

Mary Sheppard, MD, of Lexington, KY, also knew she wanted to be a physician at a young age. Now, the 31-year-old—who was diagnosed with Marfan at the age of five—is an assistant professor at the University of Kentucky. She sees patients in clinic, conducts research on Marfan syndrome, and teaches genetics (including Marfan syndrome) to medical students.

Kathleen Mimmagh, MD, a member of the Foundation's Board of Directors, was 14 years old when she decided she

wanted to be a doctor. However, it wasn't until she was in her third year of medical school that she discovered she has Marfan. Kathleen, who is an internist in West Virginia, explained how it's given her an added benefit as a doctor. "I totally empathize with the pain and fears my patients experience because I've been there and done that. I can pass along the resiliency I've gained in my 30 years as a physician and a patient with the condition."

Members of the Foundation's Professional Advisory Board are extremely supportive of the next generation of physicians who have an interest in Marfan and related disorders.

Andrea, who wants to pursue a career in cardiology, credits Dr. David Liang, at Stanford, with not only her transition to adult care, but also for being such a great mentor. "He has spent a lot of time with me, shared his knowledge, and ignited my passion," said Andrea. Dr. Craig Miller, who



DR. MARY SHEPPARD, PICTURED WITH DR. DAVID LIANG, IS NOW A FAMILY MEDICINE DOCTOR IN KENTUCKY.

performed Andrea's aortic surgery, has also assisted Andrea as she pursued her medical interests. Andrea also notes that Dr. Irene Maumenee has been a big inspiration to her as a woman in medicine.

Mary's mentor is Dr. Clair Francomano, a former member of the Foundation's Professional Advisory Board. "She allowed me to do research with her at the National Institutes of Health on Marfan syndrome and other connective tissue disorders. I have always been inspired by her amazing bedside manner, endless compassion, and selfless devotion to her patients."

"It's wonderful to see so much interest in the medical field among the young people in our community," said Josephine Grima, PhD, the Foundation's chief science officer. "More doctors with a special interest in Marfan and connective tissue disorders are needed to better serve people all over the country and it's such a benefit to have doctors who have personal experience with these conditions."

"It was a hardship for my family to drive to Baltimore every year for my medical care," said Mary. "Therefore, my dream was to become a physician so that I could provide world-class care for people with Marfan syndrome in Kentucky. I selected family medicine as my specialty because it enables me to provide comprehensive medical care for people of all ages with Marfan syndrome."

It's no surprise that Seth, who has already undergone multiple spine and bone surgeries, wants to become an orthopedic surgeon. "Having lived most of my life in crippling pain due to orthopedic problems, I know how big of a difference it makes to have a doctor who understands and knows how to treat Marfan syndrome with knowledge and compassion," he said. After spending two summers interning at the National Institutes of Health, Seth also has an appreciation for the countless hours of research and testing that are needed to advance medical knowledge.

Mary, who now has a young daughter with Marfan syndrome, is well on the way to achieving her career goal of improving the quality of life for people with Marfan syndrome by performing cutting-edge research on Marfan syndrome, providing world-class clinical care to patients with Marfan syndrome, and educating the next generation of physicians about Marfan syndrome. There is no doubt that Andrea and Seth will be following in her footsteps.

REGIONAL SYMPOSIUMS

Our full-day **Regional Symposia on Marfan Syndrome and Related Disorders** bring our conference experience to different regions of the country. Each symposium has a full schedule of presentations from medical experts, including members of the Foundation's Professional Advisory Board, and experts on quality of life issues that affect people living with Marfan and related disorders. They also feature a Creating Connections luncheon to give attendees an opportunity to network with others who have the same diagnosis.

Upcoming symposiums are:

October 28, 2017
Birmingham, AL

December 9, 2017
Cleveland, OH

January 6, 2018
Houston, TX

Krista Brack, of Warwick, Rhode Island, who has Ehlers Danlos syndrome, has attended two regional symposiums, including the one in Boston in May 2017. Although she attended her first annual conference this year, she said, "The symposiums will always be special to me. They introduced me to many wonderful people and opened up a wealth of knowledge I never knew was available to me."

Additional symposiums are planned for New York and Baltimore in 2018. For details on all upcoming regional symposiums, please visit Marfan.org.

OUR LEGISLATIVE AGENDA

The Marfan Foundation works with the Health and Medicine Counsel of Washington to advance its legislative agenda. Our goals are to:

- Raise awareness of Marfan syndrome and related disorders and cultivate champions who can carry the torch for the community in Congress.
- Increase the size of the Marfan and related disorders federal medical research portfolio.
- Make sure the voice of the Marfan syndrome community is represented on Capitol Hill.

People with Marfan or a related disorder can affect change by:

- Participating in the Foundation's Hill Day.
- Participating in Legislative Action Alerts sent out by the Foundation.
- Visiting locally with their member of Congress and Senators.
- Contacting their local member of Congress' and Senators' offices.
- Inviting members of Congress and Senators to local events (Walks for Victory, support group meetings, etc.).
- Connecting with their representatives via social media.

"Folks sometimes think their representatives are unapproachable or won't listen, but I can tell you first-hand there is nothing further from the truth," said Dale Dirks, president of the Health and Medicine Counsel of Washington. "Only by hearing from their constituents can your representatives make decisions and take action on your behalf."

MAKING OUR VOICE HEARD ON CAPITOL HILL



MARY AHEARN, SECOND FROM LEFT, WITH A GROUP FROM THE MARFAN FOUNDATION ON ONE OF HER VISITS TO CAPITOL HILL.

Legislative advocacy is important for a rare disease community. Talking with legislators to raise awareness can lead to progress on policies that positively impact people living with this condition; hearing from constituents is the most effective motivator for representatives to take action on their behalf. The Marfan Foundation's representatives in Washington, DC, work to make sure the voice of the Marfan syndrome community is represented on Capitol Hill. Through the connections that Marfan community advocates create through Hill Day (when we meet with legislators and their aides) and other efforts throughout the year, the Foundation takes steps to encourage Congress to continue to make decisions with the Marfan syndrome and related heritable connective tissue disorders community in mind.

Mary Ahearn, of Silver Spring, MD, has visited her representatives on Capitol Hill many times because she, and many family members, are affected by Marfan.

"It is very easy to tell my story. I am

always accompanied by a few others from the Marfan community and we each contribute to the discussion," said Mary. "Many staffers have not heard of Marfan and are especially interested to learn how individuals manage it. I am especially motivated to tell them about the progress that has been made in such a short time due to research investments and increased awareness."

Mary's daughter and niece have also gone with her on several occasions. In Mary's opinion, staffers are especially attentive when young people tell their stories, and it is incredibly empowering for young patients to advocate for themselves.

She encourages others to visit their representatives, too, to share their experience with Marfan, saying "Who knows your story better than you?"

If you'd like to know more about the Foundation's work in Washington and get involved, please download the advocacy guide from the volunteer section of our website.

UNDERSTANDING THE BENEFIT OF PHYSICAL THERAPY

Knowing the goals of PT and finding the right physical therapist are key

By Michael P. Healy, PT, DPT DOMTP (Canada), IOMT, CSN, CPT, TPI GFI, MBA

People everywhere are experiencing the transformative effect physical therapy can have on their daily lives. In fact, as experts in the way the body moves, physical therapists help people of all ages and abilities reduce pain, improve or restore mobility, and stay active and fit throughout life. This is true for people with Marfan syndrome, Ehlers Danlos syndrome, and other connective tissue disorders, as well as for the general public.

Normally, muscles should be “off tension” and only actively contract when you want them too. Ligaments should always be “on tension” to stabilize and support your body and joints. However, in individuals with hypermobility connective tissue disorders, such as, Ehlers-Danlos syndrome and Marfan syndrome, the muscles are on tension (spasms) attempting to co-stabilize your spine and joints while your ligaments are off tension providing no structural stability. The end results of muscles continually on tension are pain, numbness, tingling, burning, pins and/or needles sensations through your body, muscle tightness, spasms, trigger points, tender points and weakness. The end results of ligaments off tension are joint pain, instability, subluxations and/or dislocations.

The physical therapy deficits are joint laxity, joint and spinal instability, muscle weakness from underused muscles, muscle weakness from muscle spasms, poor proprioception (knowing where your body is in space), poor cardiovascular endurance, and poor muscle endurance.

The goal of physical therapy is to reverse the process and put the muscles off tension and attempt to get the ligaments back on tension while maintaining proper body and postural alignment. According to the literature, the best treatment approach consists of manual therapy (muscles energy techniques (MET), myofascial release (MFR), Jones Strain Counter Strain (JSCS), cranial therapy, craniosacral therapy (CST), visceral mobilization/manipulation, manual lymph drainage and zero balancing), core stabilization exercises, joint stabilization exercises, proprioception exercises, cardiovascular exercises, and muscular endurance exercises.



Michael P. Healy, PT, DPT DOMTP (Canada), IOMT, CSN, CPT, TPI GFI, MBA, is the president and CEO of Healy Physical Therapy & Sports Medicine, Inc., in Rhode Island.



MICHAEL HEALY PERFORMS A CRANIOSACRAL FRONTAL BONE RELEASE ON A PATIENT.

Having a physical therapist who understands the special circumstances surrounding someone with a connective tissue disorder can help you achieve the best outcomes. Look for a physical therapist who:

- Works with you one-on-one with a hands-on approach.
- Understands that your progression in PT rehabilitation is going to be slower and different than their typical patient population.
- Treats you in a private quiet treatment room, especially during manual therapy sessions, rather than in an open noisy gym.
- Has a working knowledge of your connective tissue disorder or is willing to learn more about it.
- Is willing to work with you and your team of medical care providers.
- Has a good manual therapy skill set combined with a good working knowledge of therapeutic functional exercises and appropriate progression with individuals with connective tissue disorders or is willing to learn.
- Knows that cervical manipulations (high velocity, low amplitude neck adjustments) should not be performed on individuals with connective tissue disorders because they could cause serious injuries or death.

For more on physical therapy, please visit The Marfan Blog on our website.

BOARD NEWS

The Foundation is grateful to the leaders in research, medicine, and business who serve on our Board of Directors, Professional Advisory Board, and Scientific Advisory Board. There are several changes for the new fiscal year.

Mary Roman, MD, Professor of Medicine in the Division of Cardiology at Weill Cornell Medicine, has been named to the Foundation's Professional Advisory Board. Dr. Roman, who served as a member of the Board of Directors from 2008–2017, is a long-time clinician, researcher, and patient advocate for the Marfan and related disorders community.

New to the Board of Directors:

Dr. Alan Braverman, Professor of Medicine, Washington University School of Medicine; **Sinclair Li**, Executive Vice President, CBRE; **Jeff LeSage**, Vice Chairman, KPMG; and **Patricia McCabe**, an experienced public relations executive. With their business acumen and commitment to the Foundation's mission, our new Board members will be great assets to the leadership of the organization.

Scott Avitabile has completed his service as a member of the Board of Directors. He continues on as a Board Advisor.

Dr. Francesco Ramirez is stepping down from the Professional Advisory Board after serving since 1988.

Dr. Richard Wenstrup, Myriad Genetics Laboratories, is completing his service to our Scientific Advisory Board.

Thank you to all who have served.

SYDNEY LERMAN PEDIATRIC HOSPITALITY PROGRAM



SYDNEY AND CARLY LERMAN

Sydney Lerman, of Westchester, NY, has endured more hospital stays than any 14-year-old should—including three months for a heart transplant and various hospitalizations for seven back surgeries. Sydney's mom, Barbara, remembers clearly how the support from her family, friends, and community got them through these challenging times. The family was grateful for the incredible generosity of their community, but Sydney and her sister, Carly, realized right away that not everyone is as fortunate as they are.

As Sydney neared her 13th birthday and her Bat Mitzvah, the family brainstormed ways Sydney could give back as part of her mitzvah project and came up with the idea of sending care packages to kids with Marfan syndrome and related disorders who are in the hospital. They raised \$32,000 by reaching out to their friends and family, but they wanted to do more.

That's when the Sydney Lerman Pediatric Hospitality Program was born.

Sydney and Carly want to let families who have a child in the hospital know

that they are not alone and, even if they don't have a support network, the Marfan family is there for them. The Sydney Lerman Pediatric Hospitality Program will provide a customized care package filled with goodies from coloring books and board games to local restaurant gift cards and other basic essentials to help them stay positive.

If you know your child will be hospitalized soon, please visit our website (look for Sydney Lerman Pediatric Hospitality Program under resources for patients and families) and complete the questionnaire with your child. Once you submit the completed questionnaire, Sydney, Carly, and other volunteers will create your customized basket and send it to you.

If you would like to make a donation to support this program that helps families around the country while their children are in the hospital, please donate on the Sydney Lerman Pediatric Hospitality Program page on our website. Any contribution, large or small, is greatly appreciated.

4-STAR RATING FROM CHARITY NAVIGATOR

The Marfan Foundation's strong financial health and commitment to accountability and transparency have earned it a 4-star rating from Charity Navigator, America's largest independent charity evaluator. This is the second consecutive time that the Foundation has earned this top distinction.

Since 2002, using objective analysis, Charity Navigator has awarded only the most fiscally responsible organizations a 4-star rating. In 2011, Charity Navigator added 17 metrics, focused on governance and ethical practices as well as measures of openness, to its ratings methodology. These Accountability & Transparency metrics, which account for 50 percent of a charity's overall rating, reveal which charities operate in accordance with industry best practices and whether they are open with their donors and stakeholders.

On June 1, 2016, Charity Navigator upgraded its methodology for rating each charity's financial health with CN 2.1. These enhancements further substantiate the financial health of four star charities.

"The Marfan Foundation's exceptional 4-star rating sets it apart from its peers and demonstrates its trustworthiness to the public," according to Michael Thatcher, President & CEO of Charity Navigator. "Only a quarter of charities rated by Charity Navigator receive the distinction of our 4-star rating. This adds The Marfan Foundation to a preeminent group of charities working to overcome our world's most pressing challenges. Based on its 4-star rating, people can trust that their donations are going to a financially responsible and ethical charity when they decide to support The Marfan Foundation."

"It's important to us for our donors to



trust that we're using their donations wisely to educate the patient, public, and medical community; provide support for affected individuals and families; and fund research on Marfan and related disorders," said Michael Weamer, President and CEO, The Marfan Foundation. "Our 4-star Charity Navigator rating demonstrates to our supporters our good governance and financial accountability."

The Marfan Foundation's rating and other information about charitable giving are available free of charge on www.charitynavigator.org. More detailed information about the Foundation's rating is available to Charity Navigator site visitors who become registered users, another free service.

About Charity Navigator

Charity Navigator, www.charitynavigator.org, is the largest charity evaluator in America. The organization helps guide intelligent giving by evaluating the Financial Health and Accountability & Transparency of more than 8,000 charities. Charity Navigator accepts no advertising or donations from the organizations it evaluates, ensuring unbiased evaluations, nor does it charge the public for this trusted data. As a result, Charity Navigator, a 501 (c) (3) public charity itself, depends on support from individuals, corporations and foundations that believe it provides a much-needed service to America's charitable givers.

BBB WISE GIVING ALLIANCE

By meeting key standards of board oversight, finances, results reporting, and fundraising appeals, The Marfan Foundation



achieved accreditation by the BBB (Better Business Bureau) Wise Giving Alliance. This accreditation signifies that The Marfan Foundation is deserving of donor trust as a well-run nonprofit organization.

"We are proud to be accredited by the BBB Wise Giving Alliance, which recognizes excellence in leadership, finances, and mission-driven work," said Michael Weamer, president and CEO, The Marfan Foundation. "This provides yet another level of assurance to our community that we meet the highest standards in fiscal responsibility and maximize our funding for the benefit of all those living with Marfan syndrome and related disorders."

Donors know they can trust a charity if it is accredited by the BBB Wise Giving Alliance (BBB WGA). Each BBB WGA charity report process involves a rigorous review using 20 holistic BBB Charity Standards, interaction with charity officials about corrective actions needed to address deficiencies, and quality control measures to assure report accuracy. Charity reports are available at Give.org.

"The public can be assured that every charity evaluation is completed with careful, objective analysis of charity information," says Art Taylor, president and CEO, BBB Wise Giving Alliance. "By achieving accreditation, The Marfan Foundation has earned public trust having demonstrated its commitment to sound governance, transparency, and achieving its mission."

VOLUNTEER CHAIRS FOR WALK FOR VICTORY LEAD THE WAY!

Our 2017-2018 Walks for Victory are underway! The walks are non-athletic, family-oriented events that are focused on fundraising and fun. Last year, we raised more than \$420,000 at our eight Walks for Victory. This year, we are doubling the number of Walks and aim to raise \$800,000 for the Foundation's life-saving and life-enhancing programs and services for our families, kids, teens, and adults of every age affected by Marfan syndrome and related disorders.

The Walk for Victory program is only successful because of the hard work and commitment of our volunteers. We are especially grateful to our Walk chairs who are committed to taking the lead in our efforts in the new Walk season.

NOT PICTURED: MINNESOTA WALK CHAIR: **HEATHER BERGSTROM**; SACRAMENTO WALK CHAIR: **STEPHANIE COOPER NOE**; WASHINGTON DC WALK CHAIRS: **CARYN KAUFFMAN, DR. HAL DIETZ** (JOHNS HOPKINS), AND **PATRICIA MCCABE ESTRADA**; BOSTON WALK CHAIRS: **LYNETTE AND NATHAN ELAM**



STEVE BECKHOLT (LEFT) AND **JUSTIN EFURD** (RIGHT), WITH BOARD MEMBER **ROD GRAY**, ARE CHAIRING THE THIRD ANNUAL HOUSTON WALK FOR VICTORY SCHEDULED FOR MARCH 3, 2018.

UPCOMING WALKS	
St. Louis	10/1/17
Minnesota	10/8/17
Sacramento	12/3/17
South Florida	1/21/18
Houston	3/3/18
Atlanta	2018
Boston	2018
Cleveland	2018
Los Angeles	2018
Nashville	2018
New York City	2018
Portland, OR	2018
Washington, DC	2018



DR. ERIC ROSELLI, OF THE CLEVELAND CLINIC, IS CHAIRING THE CLEVELAND WALK FOR VICTORY TO TAKE PLACE IN 2018.



NICOLE PEREZ, REPORTER FOR WPLG LOCAL 10 NEWS, IS CHAIRING THE SOUTH FLORIDA WALK FOR VICTORY ON JANUARY 21, 2018, IN HOLLYWOOD, FL.

Watch for details at Marfan.org and on our new Walk for Victory Facebook page. Join us at a Walk for Victory in your area!

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:

Carol, Adrian, and Elias Adame
 Jarrell Advincula
 Clara Askew
 Richard Alan Banks
 David Barry
 C. Bartolomel
 John Berger
 Shane Berger
 William Biehl
 Thea Grace Briscoe
 Billie Jean Buckalew
 Lynn Campbell
 Sarah Cayo
 Mary Clayton
 Kathy Marie Codiroli Robinson
 Connie Cooke
 Alyssa Cornn
 Michael Crites
 Michael Daly
 Julio DelCorso
 Jacquie Dixon
 Robert Donelan
 Rita Eisman
 Dean Michael Falci
 Ben Faust
 Beth Freeman
 Amelia Giampietro
 Mickey Grossberg
 Mabel Heller
 Kyle Hempstead
 James Hinds
 George Hollenberg
 Roger Holley
 Max Hommel
 Eileen Ilberman
 Allen Jacobs
 Christopher Jemma
 Gail Johnson
 Michael Jordan
 Maria Kass
 Amy Kimm-Rainey
 Julie Kurnitz

Betty Lamb
 Sandra Marinbach
 Elizabeth Meyers
 Chanel Michaud
 Patricia Moran
 Anne Newman
 Michael Nygaard
 Eileen Orlick
 Robert Oswald
 William Otterson
 Michael Pass
 Christopher Paulsen
 Dale Randant
 Andrew Rexroth
 Ilene Roberts
 Nancy Roe
 Anthony Rogers
 Maryann Roney
 Howard Rosenberg
 Gary Salzman
 Betty Santina
 Frannie Schuster
 Penny Sims
 Elizabeth Sparks
 Casey Sprouse
 Bridget Stewart
 Alice Ungles
 Robert Walker
 Lisa Marie Wheeler
 David Willson

Donations In Honor of:

Douglas Aach
 Marie Abbruzzese
 Joseph Argabright
 Reed Berhalter
 Abrie Berkowitz
 Charles Berst
 Alan Braverman
 Marissa Broady
 Bryan Butvick
 Austin Carlile
 Leo Cole
 Robert Croston
 Shayna Dennis

James Dickey
 Haley Dostalick
 Andy James Elam
 Andrea Erikson
 Jessica Falco
 Beverly Feinstein
 Leonard Girardi
 Jack Guglielmo
 Hadley Gunn
 Connor Hajj
 Ethan Horger
 Asia Houston
 Cassandra Jennings
 Ethan Johns
 Jane Kohuth
 Peter Lang
 Edward Lebeda
 William Lefevre
 Sydney Lerman
 Sinclair Li
 Linda Marquis
 Georgia McKee
 Ben Meiner
 Autumn-Sky Miranda
 Shelly Muisse
 Karen Murray
 Dominga Noe
 Beth O'Connor
 Anu Paturi
 Eric Petty
 Brooke Pulliam
 Reed Pyeritz
 Amy Raney
 Arnold Rosenthal
 Wade Ruddock
 Kierra Rydzewski
 Alexis Scholle
 Benjamin Smith
 Susan Sobers
 Jason Stuart
 Bart Supple
 James Ulmer
 Hannah Villani
 Marie Walker

THE MARFAN LEGACY SOCIETY

We created the Marfan Legacy Society to recognize special friends who value the work of the Foundation and want to make a difference in the future lives of all those living with Marfan and related disorders by including The Marfan Foundation in their estate plans.

Philanthropy comes in many forms, and is often the best way for you to support the organizations that matter most in your life. When you make a planned gift to The Marfan Foundation, you leave a personal legacy of support for the future.

Planned gifts, also called deferred or estate gifts, are ways for you to manage your affairs, plan for the future, and make a gift to the Foundation. Among the most common types of planned gifts are bequests (a gift by will), life insurance, and gifts of IRA and other retirement assets.

If you have included the Foundation in your estate plans and wish to be recognized as a member of the Marfan Legacy Society, or if you would like to learn how to establish your Marfan legacy, please contact Megan Martin, the Foundation's director of national philanthropy at mmartin@marfan.org or 516-883-8712 X160. All inquiries are held in confidence with no obligation.



Our Boston Walk for Victory top fundraisers were treated to a night of Red Sox baseball at Marfan Night at Fenway Park! Pictured here for an on-field presentation are Duke Cameron, MD, Massachusetts General Hospital; Ron Lacro, MD, Boston Children's Hospital; Michael Weamer, Foundation President and CEO; and Ben Weisman, Foundation Board member. Upcoming Walk for Victory information is on page 14.