

# CONNECTIVE ISSUES

SUMMER 2015

**WHATEVER VICTORY  
MEANS TO YOU,  
THIS COMMUNITY  
MAKES IT HAPPEN.**



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](http://Marfan.org).

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## CONNECTIVE ISSUES

SUMMER 2015

THE MARFAN FOUNDATION  
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[WWW.MARFAN.ORG](http://WWW.MARFAN.ORG)

COVER: ANDREA WITTE, 19,  
OF ANCHORAGE, AK.  
PHOTO CREDIT: JOLIE ROSS

## OUR VICTORIES PROVIDE MOMENTUM

I am really honored to have been selected as the President & CEO of The Marfan Foundation and to follow in the footsteps of Carolyn Levering, whom I believe is one of the great leaders of our time.

Although I have much to learn, I have been a volunteer, donor, board advisor, and passionate supporter of Marfan for more than 15 years. I have also spent over two decades in a leadership role with the American Heart Association and, in my earliest professional days, managed rehabilitation centers for physically disabled children and adults.

One trait that has been consistent throughout all my years as a Marfan volunteer has been my belief that we are blessed with the most dedicated, engaged, and passionate volunteers of any organization. We also have a very loyal, dedicated staff that get up each day with hopes of making a difference for people with Marfan syndrome or related disorders. These are great strengths we can build upon!

As you might imagine, I have many priorities in the early months as your new CEO. They include getting to know volunteers and staff, visiting with members of the Marfan community, identifying additional resources to expand our capacity, and building a great organization to help ensure our success.

In recent months, I have heard many extraordinary stories about the impact of Marfan syndrome and related disorders on kids, families, friends, and loved ones. In almost every case, they are a “victory” of sorts and our victories will provide the momentum for the greatest results in our history. Together, we will win this battle!

One of my favorite quotes is about passion and it goes like this—“When you catch a glimpse of your potential, passion is born.” I could not be more passionate about our potential and together we will forever change the course of Marfan syndrome and related disorders.

I look forward to seeing you at our 31st Annual Family Conference in Chicago.

Onward!

All the best,

Michael L. Weamer  
President & CEO



# VICTORY IS...

## Celebrating almost the end of my heart surgery recovery.

Andrea Witte, of Anchorage, AK, is 19 years old and just finished her freshman year at the University of Nevada, Reno. It was also the year she had aortic surgery—on February 25 at Stanford University Hospital.



Andrea's advice for anyone about to face surgery:

"This will be a great challenge and a great achievement at the same time. Everyone is different,

but the best thing is to trust in your family, friends, doctors, and yourself that everything will be okay. Most of all, when the surgery is over, be proud of what you have survived and wear your scars proudly."



SPECIAL THANKS TO ANDREA'S FRIEND, JOLIE ROSS, FOR TAKING THESE PHOTOS AS PART OF A PHOTOGRAPHY CLASS PROJECT.

## RESEARCH ON PAIN

### SURVEY SUGGESTS PAIN IS UNDERESTIMATED IN MARFAN SYNDROME

Pain is underestimated in people with Marfan syndrome and it is probably under-treated too. This is what researchers at Northwestern Medicine found when they surveyed 993 people with Marfan syndrome. In the survey:

- 67 percent of people said they had pain in the past seven days.
- The average daily pain was a 4 on a pain scale of 1-10 while the worst pain was a 7.
- Pain relief medicine was used by over half of respondents (56%), but about half of the people who used pain relief medicine said that they had less than 50 percent pain relief from the medication.
- More than half of those surveyed (52%) rated “chronic pain care” from their doctors as either “poor” or “fair.”

The survey findings—which were published in the *Journal of Pain*—support the need for improved awareness among patients and doctors about pain management options in Marfan syndrome.

Researchers are continuing to study pain medications and patient outcomes to determine the most effective treatment plan.

Thank you to everyone in our community who completed the survey.

## NEW CARDIAC MANAGEMENT RECOMMENDATIONS



ONGOING MONITORING CONTINUES TO BE A MAINSTAY OF MANAGING THE HEART AND BLOOD VESSELS IN MARFAN SYNDROME.

The Marfan Foundation recently published new cardiac management recommendations for the heart and blood vessels in Marfan syndrome. The changes were made in light of advances in the field, including the results of the losartan vs. atenolol research published last fall.

The new recommendations, which were developed by our Professional Advisory Board of medical experts on Marfan syndrome, advise that people with Marfan syndrome—even the youngest children—begin taking medication to slow the growth of their aorta as soon they are diagnosed with Marfan syndrome. Medication is recommended whether or not the aorta is enlarged.

Another change is that a higher dose of atenolol (a beta blocker medicine) is recommended. People who cannot take beta blockers can instead take losartan, which the research showed to have the same effect on the aorta as the higher dose of atenolol.

The mainstays of managing the heart

and blood vessels in Marfan syndrome remain the same: early diagnosis, ongoing monitoring of the aorta and aortic root, and surgery to replace the aortic root or other enlarged parts of the aorta before a tear occurs.

“The Marfan Foundation continues to prioritize research into new medical therapies that can help people in our community have a better quality of life and live longer,” said Josephine Grima, PhD, senior vice president of research and legislative affairs. “We are gratified to see that research is directly benefiting adults and children today.”

To learn more, please download our revised guide about the management of the heart and blood vessels in Marfan syndrome from the patient resources section of our website. Also let your cardiologist know about the new recommendations specifically for health professionals. They can be downloaded at: [marfan.org/resources/professionals/management](http://marfan.org/resources/professionals/management).

# YOUR QUESTIONS ANSWERED

Is it safe for my child to be a lifeguard? Are stomach problems related to my condition? What should I do if I have osteoporosis? These are some of the questions fielded by Amy Kaplan, a registered nurse who staffs our Help Center. Amy has been with the Foundation for more than ten years and is always in touch with the medical experts on our Professional Advisory Board to make sure she has the latest information on Marfan syndrome and related disorders.

## ARE THESE ACTIVITIES SAFE?

The cold and snow of the past winter is finally behind us. Now that Spring has sprung, we are all ready to take advantage of the warmer weather, get outside, and have some fun. If you have Marfan syndrome, Loeys Dietz syndrome, or one of the other related disorders, make sure that your outdoor activities are safe for you. If you're not sure, check with your doctor.

Some of the activities Amy has been asked about recently that are *not* recommended for people with Marfan syndrome and related disorders are:

- Skydiving
- Board diving
- Life guarding

Safer options include activities that place less strain on the heart and have less risk of injury, such as:

- Bicycle riding (with a helmet)
- Walking
- Golf

Remember to focus on having fun rather than competing. As always, check with your doctor before starting any new activity. For more information, visit [Marfan.org](http://Marfan.org) and download our physical activity guidelines.



SKYDIVING IS NOT RECOMMENDED FOR PEOPLE WITH MARFAN SYNDROME OR A RELATED DISORDER.

## HOW IS OSTEOPOROSIS MANAGED IN PEOPLE WITH MARFAN SYNDROME AND RELATED DISORDERS?

Osteoporosis is a condition that causes bones to become weak and brittle. It seems to be more common in people with Marfan syndrome than in the general population, but the treatment is the same. The standard treatment is taking calcium and vitamin D supplements if you are not meeting daily requirements (which are the same whether or not you have Marfan syndrome), having periodic bone density tests, getting appropriate exercise, and taking medication. We suggest you talk to your doctor who is familiar with your complete medical history, physical status, and your other medications. You may also consider consulting with a specialist, such as an endocrinologist, who diagnoses and treats diseases of the glands.

## ARE GASTROINTESTINAL PROBLEMS ASSOCIATED WITH MARFAN SYNDROME?

There is not much research on any connection between gastrointestinal problems—medical conditions related to the stomach and intestines—and Marfan syndrome. Some doctors believe that IBS (irritable bowel syndrome) is more common in Marfan, Ehlers Danlos and Loeys Dietz syndrome. There also may be a greater frequency of GERD (gastroesophageal reflux) in people with Marfan syndrome. Other gastrointestinal problems, such as food allergies and gastrointestinal bleeding and inflammation, appear to be more common in people who have Loeys Dietz syndrome. More research is needed in this area.

It is possible to have Marfan syndrome or another connective tissue disorder and a gastrointestinal problem as a separate, unrelated condition.

Whether or not the gastrointestinal problem is part of the connective tissue disorder you have, it needs to be treated. We recommend seeing a gastroenterologist, a doctor who specializes in problems related to the digestive tract. It may also be helpful to meet with a nutritionist or dietician.

Last year, many people in our Marfan community participated in a survey on gastrointestinal issues and Marfan syndrome as part of research being conducted by Beth Israel Deaconess Medical Center. We will let you know when the results are published.

DO YOU HAVE QUESTIONS? Call our Help Center at 800-8-MARFAN x 126 (Monday-Friday, 9AM-5PM Eastern Time) or email us at [support@marfan.org](mailto:support@marfan.org). If you leave a message or send an email, please allow two business days for a response. You can always access information on our website, [Marfan.org](http://Marfan.org).

# HEARTWORKS GALA RAISES \$1.2 MILLION

Our annual gala in New York supports our live-saving programs and services



PHOTOS COURTESY OF TIM JOYCE

**ABOVE:** SOME OF THE LUMINARIES AT THE 2015 HEARTWORKS GALA WERE, FROM LEFT: SPECIAL GUEST KNICKS BROADCASTER **JILL MARTIN**; FOUNDATION CHAIR AND GALA CORPORATE HOST **KAREN MURRAY**; HONOREE **ISAIAH AUSTIN**; HONORARY CHAIR **MICHAEL BLOOMBERG**; BASKETBALL HALL OF FAME **WALT "CLYDE" FRAZIER**; HONOREE **CAROLYN LEVERING**; AND MASTER OF CEREMONIES AND TONY-WINNING ACTOR/DIRECTOR **JAMES NAUGHTON**.

**RIGHT:** **ISAIAH AUSTIN**, A POTENTIAL FIRST DRAFT SELECTION IN THE 2014 NBA DRAFT, WAS DIAGNOSED WITH MARFAN SYNDROME JUST A FEW DAYS BEFORE THE DRAFT AND HAD TO STOP PLAYING BASKETBALL. NEVERTHELESS, THE NBA MADE HIM A CEREMONIAL DRAFT PICK. SINCE THEN, HE HAS BECOME AN INSPIRATION TO OUR COMMUNITY, ESPECIALLY CHILDREN AND TEENS LIKE **SYDNEY LERMAN**, WHO WAS DIAGNOSED WITH MARFAN SYNDROME AT BIRTH.

The Marfan Foundation raised more than \$1.2 million at its 15th Heartworks Gala in New York City on April 16. Nearly 550 people were on-hand as the Foundation honored Isaiah Austin, the former Baylor University basketball star, and Carolyn Levering, Emeritus CEO of The Marfan Foundation, with its 2015 Hero with a Heart Award.

"This year's Heartworks is unforgettable," said Karen Murray, president of VF Sportswear, chair of The Marfan Foundation, and corporate host of Heartworks. "The love in the room as we honored Isaiah and Carolyn was palpable. And we can't be more grateful to our many supporters here in New York. Their generosity year after year is so valuable because it goes directly to the Foundation's life-saving programs and services. I am also thrilled that so many Marfan families were with us—including some from as far away as Texas, California, and Alaska."



JONATHAN LERMAN



**CLOCKWISE FROM TOP LEFT:** CAROLYN LEVERING WAS HONORED FOR HER 20 YEARS OF SERVICE TO THE FOUNDATION AS PRESIDENT AND CEO. UNDER HER LEADERSHIP, THE MARFAN FOUNDATION GREW FROM A SMALL GRASSROOTS ENTERPRISE TO A NATIONAL NONPROFIT ORGANIZATION CREATING A BRIGHTER FUTURE FOR THE 200,000 PEOPLE IN THE U.S. LIVING WITH MARFAN SYNDROME AND RELATED DISORDERS. CELEBRATING WITH HER ARE FORMER FOUNDATION BOARD MEMBERS HEATHER HOLMES FLOYD (LEFT), STEVE CROMBE, AND CURRENT BOARD CHAIR KAREN MURRAY. | MICHAEL BLOOMBERG WITH THE FOUNDATION'S NEW PRESIDENT AND CEO MICHAEL L. WEAMER. | BEN CARPENTER PLEDGED HIS SUPPORT DURING THE ON-SITE APPEAL AS NBC NEW YORK METEOROLOGIST JANICE HUFF LOOKED ON. | BROADWAY AND TELEVISION STAR AND SINGER MEGAN HILTY DAZZLED THE CROWD WITH HER OUTSTANDING PERFORMANCE.

The Foundation is grateful to the 2015 Heartworks Gala sponsors: the American Heart Association, CBRE, Cushman & Wakefield, Macy's, National Basketball Association (NBA), Nautica, Univision, and VF Sportswear.

# 7TH ANNUAL HEARTWORKS ST. LOUIS

A Celebration of Our Community and Our Mission

Heartworks St. Louis was again a dazzling affair of the heart, with the local business and medical community showing passionate support for The Marfan Foundation's programs and services. More than 400 people, including more than three dozen with Marfan syndrome, attended the gala on March 7 at the Four Seasons St. Louis.

Our Professional Advisory Board Chair, Dr. Alan Braverman, who is professor of medicine at Washington University School of Medicine and director of its Marfan Syndrome Clinic, and his wife, Rebecca, were our hosts as we honored Dr. Patrick Geraghty, associate professor of surgery and radiology and co-director of the Limb Salvage Center at Washington University School of Medicine, with our 2015 Hero with a Heart Award. In addition, we presented our first Distinguished Research Award to Robert Mecham, PhD, alumni endowed professor of cell biology and physiology and professor of medicine, pediatrics, and biomedical engineering at Washington University School of Medicine. We also honored Ron and Pam Rubin with our Community Champions Award for their ongoing and steadfast support of the Foundation.

Isaiah Austin, the former Baylor University basketball standout whose Marfan syndrome diagnosis in June 2014 prevented him from entering the NBA draft, was a featured speaker. Members of the Marfan community were thrilled to meet him and thank him for being such an inspiration to them since his diagnosis.

The Foundation is grateful to the event sponsors and all those who attend each year in support of our life-saving programs and services.



**ABOVE LEFT:** HEARTWORKS ST. LOUIS FOUNDER AND HOST DR. ALAN BRAVERMAN (L) AND DR. ROBERT MECHAM, RECIPIENT OF OUR FIRST DISTINGUISHED RESEARCH AWARD.

**ABOVE RIGHT:** DR. PATRICK GERAGHTY, PICTURED WITH HIS WIFE, DR. CHRISTINE GERAGHTY, WAS HONORED WITH THIS YEAR'S HERO WITH A HEART AWARD.

**BELOW:** THE PULLIAM FAMILY WERE AMONG THE MANY GUESTS EAGER TO MEET FORMER BAYLOR UNIVERSITY BASKETBALL STAR ISAIAH AUSTIN (L), WHOSE MARFAN SYNDROME DIAGNOSIS LED HIM TO BECOME AN ADVOCATE FOR OUR COMMUNITY AND SPOKESPERSON FOR THE FOUNDATION.



PHOTOS COURTESY OF TIM JOYCE



# CAROLYN LEVERING RECEIVES HERO WITH A HEART AWARD

*The Marfan Foundation presented Carolyn Levering, Emeritus CEO, with a 2015 Hero with a Heart Award at the Heartworks gala on April 16. Karen Murray, Chair of our Board of Directors, made the presentation. Here is Carolyn's acceptance speech.*

Thank you everyone. Karen, your comments and the video have flooded me with emotions. I am proud of what we've accomplished in the past 20 years and accept our Hero with a Heart Award in recognition of the part I have played in these meaningful victories. With gratitude and affection, I thank each of you here with me tonight who have been valued colleagues, advisors, and friends. How fortunate I've been that my life's work brought me into this very special community.

I believe the reason the Foundation has successfully moved from the kitchen table to Cipriani is because we've been confident and bold in setting visions to address issues of the greatest immediacy—confident because we knew it was the right thing to do and bold because our resources were limited. It was philanthropic generosity and partnerships with the media and healthcare communities that enabled us to far exceed the reach of those limited resources. To those generous donors and partners in the audience, thank you. I hope you feel as proud as I do.

Karen and I first met at the close of the Stanford annual conference. She was a mom who was desperate for information and support. We had just given her those things and she was grateful. She said to let her know if there was anything she could do to help. Two months later, I called her and said we were planning a small special event and might she have some space available where we could host it. And yes, she did, and more. That first event held in Karen's showroom was an incredible success. That was the genesis of this evening—truly game-changing.

Marfan mothers like Karen are a distinct class of powerful game changers. There are a number of these passionate women here. It's been my privilege to work with them. There is one extraordinary mother not here tonight. My dear friend, Priscilla Ciccariello—still sharp as a tack, just not as mobile at 89.

Twenty-one years ago I received a phone call from Priscilla, then the chairman of The Marfan Foundation. She was retiring and looking to hire the first chief executive. When I went into the office for an interview, I wasn't distracted by the tiny space. All I heard was Priscilla's passion not to be limited by where they currently were. She was determined to make the world safer than it had been for the son she lost. The mission was



CAROLYN (CENTER) AT ONE OF THE FIRST HEARTWORKS EVENTS WITH (L-R) RABBI MARC GELLMAN, CURRENT FOUNDATION CHAIR KAREN MURRAY, DR. VALENTIN FUSTER, AND OUR NEW PRESIDENT & CEO MICHAEL WEAMER

clear and compelling. There were critical structures in place: a professional advisory board of respected doctors and researchers, a scientific advisory board to review our modest grants, advisors such as Dr. Victor McKusick and Dr. Francis Collins, an annual conference and clinic. Clearly strong organizational bones and great aspirations were in place. So while I could picture the scope of the challenge, I could envision working with this dynamic woman to help fully realize the Foundation's potential.

And so I came on board and discovered many other passionate and dynamic people who shared the vision. Together we all, each in different ways, have been game changers.

I would like to express my gratitude to one of those game changers, Michael Bloomberg, for the generosity of Bloomberg Philanthropies in support of global Marfan research.

And to the other Michael, Michael Weamer—I could not be more thrilled about the board's selection of my successor. Michael, you are inheriting a dedicated board of trustees, a professional advisory board of expert doctors and researchers who are miraculously accessible to patients, board and staff, and a dream staff—without whom I could not have done what I did. I thank them from the bottom of my heart and know that together, with you, an even brighter future is possible.

And finally, I must give voice to my ultimate inspiration in all this. It's the courage of the people affected by Marfan syndrome and related disorders that I have witnessed over the past 20 years. They are brave and patient with their lot

*continued on page 15*

# WHATEVER **VICTORY** MEANS TO YOU, **THIS COMMUNITY** MAKES IT HAPPEN



A PLACE TO TURN



LIFE-SAVING RESEARCH



A BRIGHTER FUTURE

## STAND WITH THE COMMUNITY, ENJOY THESE BENEFITS

As a member of our community you get:

- One-on-one consulting with our nurse through our Help Center at 1-800-8-MARFAN ext. 126
- Information when you need it at [marfan.org/resources](http://marfan.org/resources)
- Connection to others in your area or at our Annual Family Conference on August 6-9, 2015 / August 4-7, 2016
- Knowledge that you're saving lives and making victories possible every day

**JOIN OUR COMMUNITY AT  
[MARFAN.ORG/CONNECT](http://MARFAN.ORG/CONNECT)**

# THE POWER OF YOUTH



FOUNDATION BOARD MEMBER MAYA BROWN ZIMMERMAN (RIGHT) IS THE ADVISOR TO ITS TEEN COUNCIL, WHICH CREATED A WORKSHOP FOR THE CONFERENCE THAT INVITES PARENTS TO PUT THEIR QUESTIONS TO A PANEL OF YOUNG PEOPLE.

In 2010, we launched our **Teen Council**, comprised of teens with Marfan syndrome and related disorders, to give voice to this important part of our community. They were already taking charge of their diagnosis and initiating their own fundraising and awareness efforts at home. We wanted to recognize them and give them leadership responsibility on the national level from an early age.

Maya Brown Zimmerman, a member of our Board of Directors who has been a member of the Foundation since she was a pre-teen, is the Teen Council advisor. “We believe the teens are an important part of our Foundation,” she said. “They’re already leaders in their communities. This is their Foundation too. The Teen Council gives them an opportunity to participate more formally now.”

According to Maya, the teens have raised tens of thousands of dollars in two fundraising challenges. They also created a new workshop for the adults at conference. “It’s an opportunity for parents to ask the teens frank questions about what it’s like growing up with Marfan or a related disorder, and how parents can better support their teens,” she said.

The current members of the Teen Council are:

Katie Bridges, 14, Helena, MT

Haley Dostalík, 15, Urbandale, IA

“I hope to help others by sharing my story, offering advice, lending support, and just being there for them.”

– Haley Dostalík,  
Teen Council member

Alyssa Lamberti, 17, St. Augustine, FL

Kyle McArthur, 15, Wilsonville, OR

Samantha Noe, 14 Sacramento, CA

Tizzy Parks, 14, Tulsa, OK

Brooke Pulliam, 14, St. Louis, MO.

Roksna Szczesny, 17, Ireland

Alex Utz, 15, Bowling Green, OH.

Delaney Olson, 18, Plymouth, WI.

Rachel Shapiro, 18, Cerritos, CA

“Being on the Teen Council is important to me because it gives me more opportunities to connect with people my age

who are going through the same things as me,” said Brooke Pulliam, 14, from St. Louis. “Through the Teen Council, I hope to make a difference in someone’s life.”

Haley Dostalík, 15, from Urbandale, IA, is also looking forward to meeting more teens with Marfan syndrome and related disorders. In addition, she said, “I hope to help others by sharing my story, offering advice, lending support, and just being there for them.”

“I have no doubt we’re going to see these Teen Council members as community group leaders, chapter presidents, board members, kid and teen program leaders, and Professional Advisory Board members down the road. Some are already planning careers that relate to their experiences growing up with a connective tissue disorder,” said Maya. “I am so proud of them, and, as a parent, I feel great knowing that someday [my son] Julian will be in the teen program under their leadership. They are fantastic role models for our young kids.”

Do you have a teen who would like to connect with the other teens in our community? Visit Teen Space on our website: [Marfan.org/resources/patients/teens](http://Marfan.org/resources/patients/teens).

## PA STUDENTS SUPPORT MARFAN

### Students compete to raise awareness and funds

Every year, seven physician assistant (PA) programs from the greater Philadelphia area compete in a fundraising “Olympics” to raise money for a selected charity. This year, their inspiration was a personal tragedy that struck one of their own, Samantha Liddy, a PA student at Arcadia University.

“My niece, Angelina, passed away on May 20, 2010, from complications due to Marfan syndrome. She was two years old at the time and it deeply affected our family,” said Samantha.

Touched by Angelina’s story, the event organizers chose The Marfan Foundation as the 2015 beneficiary and raised \$11,581—far surpassing their original goal of \$5,000.

“We recently learned about Marfan syndrome in our connective tissues disorders lecture, but it was really just a light introduction,” said Bridget McHugh, chairperson of the event. “Because of this fundraiser, we all have a much greater awareness of Marfan syndrome and know that the money we are raising will help patients in the future, patients we may see when we are in practice.”

The participating PA programs represented Drexel University, Arcadia University, Philadelphia College of Osteopathic Medicine, DeSales University, University of the Sciences in Philadelphia, Philadelphia University, and Salus University.

If you are interested in holding an event to raise awareness of Marfan syndrome and related disorders and money for The Marfan Foundation, we’re here to help. Contact Kerri Powell at [kpowell@marfan.org](mailto:kpowell@marfan.org) or 516-883-8712 ext. 138 to get started.

## 2015 WALKS FOR VICTORY BRING OUR COMMUNITY TOGETHER



### Fun. Friends. Community. Victory.

That’s what our Walk for Victory is all about. After our kick-off in Arizona in 2014, we held a Walk for Victory in Massachusetts, New York, Texas, and Missouri. This year, we added Georgia and New Jersey to this important program, which provides a way for individuals and families to get together to raise critical funds for our programs and services.

Brianna Griffith, college student from Cumming, GA, was one of the many walkers at the Georgia Walk for Victory on April 25. She has already had many victories over Marfan syndrome since she was diagnosed at the age of 9. Brianna, who has overcome several surgeries on her back, was excited to

participate in the Walk for Victory. “Anything we can do to raise money for The Marfan Foundation and awareness of Marfan syndrome is a good thing,” said Brianna. “Mostly, I hope we can help others get diagnosed as a result.”

The other 2015 Walks include Arizona in April, New York and Massachusetts in May, New Jersey in June, and Missouri in the fall.

“The Walk for Victory is a great way to raise awareness and funds, and to connect Marfan families within their own communities,” said Kerri Powell, the Foundation’s manager of community events.

To join our Walk for Victory, please go to [Marfan.org/get-involved](http://Marfan.org/get-involved)

## NO MORE SURPRISES!

With their medical situation under control, Milwaukee family gives back

By Lorena Danek

**My husband Jesse and I have been married for 13 years** and we have three wonderful children, Evan 9, Anna, 8, and Keli, 6. Five years ago, when Evan was 4 years old, we had a surprise that changed our life. He was having trouble seeing, so we took him to an eye doctor. After she was done with the exam she told us that Evan might have something called "Marfan." He had a dislocated lens in his eye and needed an echocardiogram to check his heart and blood vessels. That was a lot more information than we expected! We were thinking that we were going to walk out with a glasses prescription.

We were very confused. Evan had had regular check-ups with his primary physician and Marfan syndrome had never been mentioned. We did some research and took Evan to Herma Heart Center in Milwaukee. We learned that his aorta was already enlarged and he was put on daily medication.

We still had to deal with Evan's worsening vision. The eye doctor recommended removal of the lens from both eyes. Evan had that surgery in January of 2010 and the results were immediate. I clearly remember Evan's post-surgery check-up. I was holding Evan and he grabbed my face and said, "Mommy, you have lines on your lips and you look different!" Evan was able to see things like he had never seen before. We took him to Disney again and that summer he got to see his first starry night!

What's most scary to us is that, at the time of Evan's diagnosis, we had no idea what Marfan syndrome was, yet it would have only taken a fall or blow to the chest to cause a very serious problem.

Marfan syndrome is a lifetime problem and Evan sees many doctors because of it. We don't want any more medical surprises.

Thanks to great doctors and early detection, we were able to begin treatment, and our son can live a normal lifespan.

Now that Evan's issues are under control, we decided this year that it was time for us to get involved and do something for people going through what Evan is going through. During Marfan Awareness Month, we got together with Carrollton Elementary School, where Evan is a fourth grader, to bring awareness to Marfan. We raised more than \$1,300 through a Penny War! We already have set up a meeting for future events and, hopefully, we will be able to help another little girl or boy get the diagnosis and treatment to live with this condition. We don't want anyone else to be faced with surprises like we were.

We are starting a community group in our area so we can get together with others in the Marfan syndrome and related disorders community. We are looking forward to the 2015 annual family conference this summer and meeting the experts and other families just like us.

*Lorena Danek, 31, was born and raised in Albania. She moved to the U.S. when she was 12 and now lives in Milwaukee, WI. As the leader of the Foundation's new Milwaukee community group, she plans to focus on public awareness in Southeast Wisconsin. She is especially interested in reaching out to elementary schools so that children can get diagnosed early.*



CARROLLTON ELEMENTARY SCHOOL PRINCIPAL MR. KENWOOD (L), WITH LORENA AND JESSE DANEK, AND THEIR CHILDREN (L-R) ANNA, EVAN, AND KELI.



# JOIN US!



## ANNUAL FAMILY CONFERENCE

Co-hosted by Northwestern Medicine and Ann & Robert H. Lurie Children's Hospital of Chicago

THURSDAY — SUNDAY  
AUGUST 6 — AUGUST 9

# 2015 CHICAGO

## 2015 CONFERENCE HIGHLIGHTS

### 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 an improv comedy show.

**Teens** (ages 13–18)—Ask your questions at a Q&A breakfast with expert doctors, followed by small group workshops. Plus, enjoy a boat cruise, Willis Tower Skydeck tour, dancing, games, and more.

**Children** (ages 5–12)—Visit the Adler Planetarium and Legoland, ask your questions at a special kids' Q&A session with expert doctors, and enjoy games, arts & crafts, and more.

### SPANISH LANGUAGE PROGRAM

A special track of Spanish language workshops and a support group are offered for adults.

### DON'T MISS THESE IMPORTANT DEADLINES:

- JUNE 1** Children, Teen, and Young Adult Registration Deadline
- JUNE 1** Early Registration Discount Deadline
- JULY 7** Warwick Allerton Hotel Reservation Deadline (6 PM EST)
- JULY 15** Inn of Chicago Reservation Deadline (6 PM EST)

**REGISTER AND LEARN MORE AT**  
[MARFAN.ORG/CHICAGO15](http://MARFAN.ORG/CHICAGO15)



# 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:**

Adrian Adame  
 Carol Adame  
 Elias Adame  
 Diane Albano  
 R. Karl Anderson  
 David Barry  
 Dr. Michael Beardslee  
 Elissa Faith Bell  
 Doris Bernstein  
 Ruth Naomi Sharp Berven  
 John Bianchini  
 Trevor Blanton  
 Barbara Bowling  
 Jennifer Buffone  
 Gabrielle Ruelos Cannistraci  
 Toni Carson  
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# CAROLYN LEVERING AWARD

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and optimistic that there will be a brighter future. It's been life-affirming to know you and to work alongside you. I was most recently inspired by the courage of tonight's first honoree, Isaiah. I am proud of you. And I believe the work that we've been doing for years to promote sports screenings in schools and in the pros assured that you received a diagnosis through the NBA's heightened awareness of the

signs of Marfan syndrome. I know it abruptly and painfully changed your life's path, but it saved it as well. Your powerfully moving experience has brought yet again another game changer to this community.

So, as I transition away from daily life in the Marfan world, I have memories I will treasure. This evening is one of them. Thank you.



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PAGE 14 FOR DETAILS