



ANNUAL REPORT 2022

THE **MARFAN**
FOUNDATION





► OUR MISSION

The Marfan Foundation is a nonprofit organization that saves and improve lives, while creating communities, for all individuals with genetic aortic and vascular conditions including Marfan, Loeys-Dietz, and Vascular Ehlers-Danlos syndrome (VEDS).

► OUR VISION

A world in which everyone with genetic aortic and vascular conditions can live their best life.

**TOGETHER,
WE ARE
FIGHTING
FOR
VICTORY**

ON THE COVER: Top: Bella, who has VEDS. Bottom left: Lincoln, who has Loeys-Dietz syndrome. Bottom right: David and Ramiro, who have Marfan syndrome.

THE **MARFAN** FOUNDATION



The Marfan Foundation experienced great growth and momentum during the pandemic, and it continued this past fiscal year. As a result, we reached more people than at any time in our history with Marfan, Loeys-Dietz, VEDS, and related genetic aortic and vascular conditions. With accessible in-person and virtual programs and services, we also extended our international reach and impact.

This year we saw an unprecedented level of connection and support throughout our community. Our Walk for Victory program exceeded \$1 million in critical support and brought people together like never before. The community aspect of the Walk program is absolutely critical for a community of people with relatively uncommon conditions. Connecting adults, teens, and children, and their families through community events like these and our other online programs, reduces feelings of isolation and uncertainty and helps improve the quality of life for those affected.

We are also more committed than ever to research on Marfan, Loeys-Dietz, VEDS, and other genetic aortic and vascular conditions. This past year we launched a redesigned research grant program to drive more collaboration, more focus on patients, and have a greater impact on clinical treatments. Today, we are at the forefront of propelling scientific discovery in genetic aortic and vascular conditions to result in the best possible outcomes for affected individuals.

The Foundation's dedication to the community is supported by the strategic vision provided by our Board of Directors, Professional Advisory Board, and Scientific Advisory Board. These volunteer leaders and giants in the medical and scientific arenas provide the direction and support that drives the Foundation forward. And, yes, we have terrific volunteers and staff partnering every day in supporting our community.

We are most grateful to you, our community, for believing in us, sharing your stories, and coming together to help advance our three-pronged mission of education, support, and research. Our financial resources are strong and with boundless energy, we press forward in our fight for victory.

Thank you for your support and confidence. You are truly at the very center of our energy and success.



A handwritten signature in black ink, appearing to read 'C. Eaves'.

Cory A. Eaves
Chair, Board of Directors



A handwritten signature in black ink, appearing to read 'Michael Weamer'.

Michael Weamer
President & CEO

OUR ORGANIZATION



► The Marfan Foundation

The Marfan Foundation was established in 1981 to provide education and support and fund research on Marfan syndrome. We expanded our mission in 1995 to include related connective tissue conditions. Our commitment to genetic aortic and vascular conditions is reflected in the growth of the organization to include divisions to serve this broader community.



► The VEDS Movement

The VEDS Movement was added as a division of The Marfan Foundation in 2019 to specifically serve people with Vascular Ehlers-Danlos syndrome.



► The Loeys-Dietz Syndrome Foundation

The Loeys-Dietz Syndrome Foundation became a division of The Marfan Foundation in 2020 to provide dedicated programs and support services for those affected by Loeys-Dietz syndrome.



► The GenTAC Alliance

The GenTAC Alliance, a community of scientists, physicians, and healthcare professionals focused on advancing care for all forms of genetic aortic and vascular conditions, became a division of The Marfan Foundation in 2020.

★ Programs & Events

- Marfan Awareness Month
- Loeys-Dietz Awareness Month
- VEDS Action Month
- Aortic Disease Awareness Week
- Educational Webinars
- Covid-19 Resources
- Virtual Support Groups
- Regional Symposiums
- Walk for Victory in 19 Cities
- Virtual Global Walk for Victory
- VEDS Birthday Bash
- Evening with Heart
- HeartWorks in St. Louis, Houston, NYC, Chicago
- UnCorked Wine Event

OUR WORK

Our programs and services fuel connections globally

★ Walk for Victory 2021-22

- 19 Walks for Victory including 1 Global
- Over 3,500 people
- 98% of participants rated very positive to extremely positive

★ 2021 Virtual Conference

- Four-day online event featuring medical presentations, mental health and quality of life sessions, and an array of social opportunities.
- 1,827 registrants from 60 countries

★ Educational Highlights

- **Educational Webinars**
 - Physical activity and exercise
 - Children's Issues
 - Body Image
 - Basics of Marfan Syndrome Management
 - Transitioning from Pediatric to Adult Care
 - Living with Ostomy and VEDS Personal Perspectives Panel
- Held first Spanish Summit on Marfan Syndrome, LDS, and VEDS, attracting nearly 400 people from around to the virtual one-day event
- Published Marfan syndrome fact sheets in German, French, and Italian
- Launched VEDS Emergency Awareness Project, which includes free medical alert bracelets for the VEDS community; recorded emergency physician information line; and developed an emergency physician fact sheet; arranged speaker on VEDS at New York State Emergency Medical Services conference.
- Virtual Grand Rounds on VEDS at Morristown (NJ) Hospital. More than 100 pediatric cardiology and emergency medicine doctors attended. In addition, there were more than 1,000 views on YouTube.
- Launched LDS Connect, a virtual support group, for people affected by LDS.
- Expanded LDS Chat to the UK, which provided greater access to support for people in Great Britain and Ireland.

★ Support

- Help & Resource Center - We reached more than 5,000 people through our dedicated Help & Resource Center, staffed by a registered nurse and social worker.
- Virtual Support Groups

★ Connections

- Guidance on clinics throughout the US that have experience and expertise in Marfan, LDS, and VEDS, and other genetic aortic and vascular conditions
- Social media
- Teen chat
- Kids Club



How wonderful it is that you are all helping us...to have all the information we need while we are trying our best to travel on this road with a life-threatening condition...it is like having someone holding your hand through a very scary journey.



There are never enough words to say to the people who show up and support this cause year after year. When Georgia was born and we learned about her diagnosis at just a few months of age, it became our mission to seek out ways that could improve the quality of life for our little girl. Through this journey, we have learned so much and gained so much more than we could ever have hoped for. I think about every dollar we raise as one small seed of hope. What if the money we raise goes to a research grant that one day gets to the root of the pain that so many children and adults with connective tissue disorders experience on a regular basis? What if one child finds a community and a sense of belonging at a camp that the Foundation sponsors? When I tell you that together we can save lives, I mean it. This work is probably the most important work that we will ever do next to raising our children.

~ Shannon Mace, Cleveland, OH

WALK FOR VICTORY

3,500 PARTICIPANTS

19 WALKS

Walk for Victory raised \$1.1 million, more than in any other previous year. Funds raised go to programs and services that serve people with genetic aortic and vascular conditions, including Marfan, LDS, and VEDS.





CURRENTLY FUNDING **33 RESEARCH STUDIES**

To improve the lives and benefit those living with Marfan, LDS, VEDS, and other genetic aortic and vascular conditions.



RESEARCH

Research Grant Recipients

► **Victor McKusick Fellowship Award \$100,000**

Josephina Meester, PhD, Bart Loeys, MD, Mentor
University of Antwerp (pictured above)

Pathomechanistic Study of Biglycan Mutations in Aortopathy Development

► **Career Development Award \$100,000**

Jefferson Doyle, MBBChir, PhD
Johns Hopkins University (pictured left)

Treatment of Axial Myopia in Marfan Syndrome using Prostaglandin Analogs

There's a Purity of Heart with the Foundation

Joaquin Ramos, Jr., who lives in Miami, was enjoying his best life when he had an aortic dissection, seemingly out of nowhere, in 2020 and was subsequently diagnosed with Marfan syndrome. A few months later, he decided to share his story with the Foundation as part of his healing process. This opened up a whole new avenue to him – a path to understanding, a community of support, and a way to channel his desire to create positivity out of his diagnosis.

It was not an easy road for Joaquin, who went through major relationship changes and had to change his very active lifestyle. He realized quickly that his mental health was as important as his physical health during this time and credits ongoing therapy with the many transitions he's had to make.

When he finally accepted the diagnosis, he said, his anger turned to a shining light.

“Learning more about Marfan puts me at ease,” said Joaquin. “Being part of the Marfan community and meeting so many people puts everything in perspective for me. Getting involved with the Foundation gives me an opportunity to share my experiences and help others. And these connections help me when I’m having a bad day. Coming together gives us a voice.”

“There’s a real purity of heart with the Foundation,” said Joaquin. “I am so grateful to be able to give back because the Foundation is making a real difference in research progress and education. They are the real deal.”



THE VEDS MOVEMENT

Find a New Way to Dance and Shine Your Light

After a long road to diagnosis and the death of her sister, Ashley Rose Koengeter found a new way to shine her light. The family had previously been given a different diagnosis after her mother survived a ruptured splenic aneurysm in 2011. It wasn't until 2017 that Ashley Rose, her sister Allyson, and her mother Dawn had genetic testing and confirmed that their actual diagnosis was VEDS.

From a place of deep sadness following her sister's death in 2020 due to a ruptured aortic aneurysm, Ashley Rose knew that she would have to focus on reinventing herself with positivity and use the inspiration from her sister to not live in fear, but in gratitude.

"Throw all the good you can out into the world and see what comes back" was a saying her sister often said and it guided Ashley Rose's journey to shine her light again.

Ashley Rose connected with The Marfan Foundation in 2019 when she heard about the VEDS track offered at the Foundation's conference in Houston that year. Being part of The VEDS Movement activities – such as the Birthday Bash, Kids Club, Steering Committee, Action Month, fundraisers, Victory Walks, VEDS Bingo, Kids and Family Camps, and Conference – has been extremely impactful to her.

"For me, getting involved with The VEDS Movement (the Foundation's VEDS division) was always about the love and support we have for each other within the community," said Ashley Rose. "It's okay not to feel okay every day. Give yourself the space to heal without judgment and find a new way to do the things you love and let your light shine through. You are beautiful being you!"



Helping Others Provides Valuable Connections

Heide Padilla, of Chicago, knew there was something different about her son, Noah, before he was born. His aortic enlargement was evident through imaging during her pregnancy. At birth, Noah also showed additional features of a connective tissue condition. Heide was directed to The Marfan Foundation for information right away. Noah's diagnosis was Loeys-Dietz syndrome.

Heide joined the strategic advisory board of the Loeys-Dietz Syndrome Foundation (now a division of The Marfan Foundation) in 2014. Over the years, the family has been through many medical challenges with Noah, but being involved has enabled them to stay on top of the issues and new medical advances as they come about.

"Just meeting other families with LDS has been so beneficial because you truly are not alone," said Heide. "It was awful feeling isolated. The outlet that the Foundation provides is amazing."

For Noah, who is now 18, living with LDS has been all he has known. His parents have been upfront with him about the diagnosis and what it means for him. This gives him the power to run his own life. He also shares his story and advocates for others.

"There was a lot of anger and bitterness," said Heide, "But we had a choice and decided to find purpose and get involved. We learned a lot and helping others provides valuable connections."

▼ **Team Noah at the Chicago Walk for Victory.** *Heide is in the middle row (with overalls), Noah is in front of her (light blue hoodie).*





The **GentAC Alliance** community has worked collaboratively for 20 years to help clarify care based on knowledge and data. Through national and international databases and registries, the Alliance seeks to understand natural history and management outcomes to improve care. The Alliance is committed to identifying knowledge gaps, convening researchers and clinicians, and facilitating critical thinking to increase the understanding of genetic aortic and vascular conditions by healthcare providers to achieve better patient outcomes worldwide and increase the pace of research.

Research Highlight

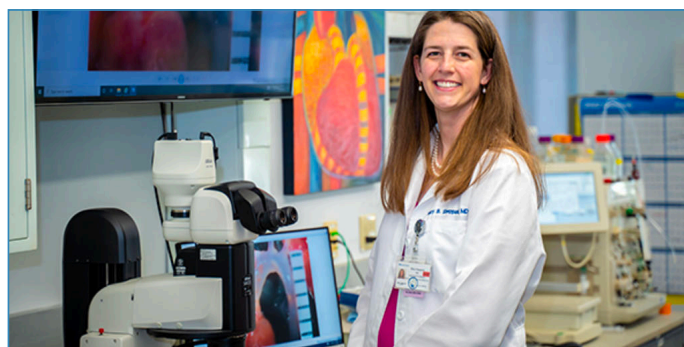
The GentAC Alliance developed a compendium of research registries that can efficiently connect researchers around the world to relevant samples and clinical data for individuals with genetic aortic and vascular conditions.

Medical Education

- Translation of Therapeutics from Mice to Men Webinar
- Biomechanical Factors Driving Thoracic Aortopathies Webinar
- Machine Learning and Cardiovascular Disease: New Tools for Diagnosis and Clinical Risk Prediction

Patient Education

- Living with Risk



GentAC is an incredible organization because it unifies dedicated clinicians, scientists, and patients with a single focus: improving the lives of people with genetically-based aortic disease. GentAC's impact is felt through a broad range of activities, such as hosting conferences to advance scientific discoveries in aortic disease, organizing projects for collaborative research, publishing review articles to educate medical providers, and conducting webinars to answer questions from people affected by aortopathy. It has been a privilege to be part of this talented and inspiring group.

~ Mary B. Sheppard, MD, Assistant Professor and Co-Associate Director, Saha Aortic Center, University of Kentucky

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STATEMENTS OF ACTIVITIES

Year Ended June 30, 2022

In FY22, the Foundation renewed its multi-year \$5 million pledge from Bloomberg Philanthropy to fund our new research grant program and the new \$800K Everest Research Grant, and the largest grant mechanism in the Foundations history. In addition, The Marfan Foundation continued its concerted effort to expand our fundraising strategies leading to increased revenue support from our donors. Thanks to the generosity of our donors, the Foundation utilized these additional revenue resources to expand various programs, such as our Mental Health Program, The VEDS Collaborative, and LDS Connect. The Foundation continues to change more lives than ever before with the help of it community and donors.

	Without Donor Restrictions	With Donor Restrictions	Year Ended June 30, 2022	Year Ended June 30, 2021
Changes In Net Assets:				
Revenues and gains:				
Major contributions	\$ 688,400	\$ 4,939,208	\$ 5,627,608	\$ 1,158,354
Other contributions	488,680	39,338	528,018	517,828
Direct response	328,239		328,239	342,421
Grant Revenue -Govt	491,000		491,000	491,000
Conferences and symposia	13,464	-	13,464	32,819
Community Events	241,401	-	241,401	266,384
Net investment income	(419,545)	-	(419,545)	756,463
Events, net of expenses of \$187,693 and \$101,692, respectively	2,379,786	-	2,379,786	1,923,708
Change in value of beneficial interest charitable remainder trust	-	(194,087)	(194,087)	166,900
Gifts in-kind	110,358	-	110,358	312,653
Net assets released from restriction	<u>688,625</u>	<u>(688,625)</u>	<u>-</u>	<u>-</u>
Total revenues and gains	<u>5,010,408</u>	<u>4,095,834</u>	<u>9,106,242</u>	<u>5,968,530</u>
Expenses:				
Program service expenses:				
Research initiatives and grants	1,582,843	-	1,582,843	1,836,644
Education and public awareness	947,083	-	947,083	908,165
Patient services and annual conference	<u>1,183,961</u>	<u>-</u>	<u>1,183,961</u>	<u>1,212,699</u>
Total Program service expenses:	<u>3,713,887</u>	<u>-</u>	<u>3,713,887</u>	<u>3,957,508</u>
Supporting services:				
Management and general	421,725	-	421,725	484,778
Fundraising	<u>669,533</u>	<u>-</u>	<u>669,533</u>	<u>752,891</u>
Total Supporting service expenses:	<u>1,091,258</u>	<u>-</u>	<u>1,091,258</u>	<u>1,237,669</u>
Total expenses	<u>4,805,145</u>	<u>-</u>	<u>4,805,145</u>	<u>5,195,177</u>
Change in net assets before Loeys Dietz Syndrome Foundation Contribution	205,263	4,095,834	4,301,097	773,353
Loeys Dietz Syndrome Foundation Contribution	<u>-</u>	<u>-</u>	<u>-</u>	<u>929,255</u>
Increase (decrease) in net assets	205,263	4,095,834	4,301,097	1,702,608
Net assets, beginning of the year	<u>5,083,998</u>	<u>5,707,053</u>	<u>10,791,051</u>	<u>9,088,443</u>
Net assets, end of year	<u>\$ 5,289,261</u>	<u>\$ 9,802,887</u>	<u>\$ 15,092,148</u>	<u>\$ 10,791,051</u>

STATEMENTS OF FINANCIAL POSITION

June 30, 2022 and June 30, 2021

	June 30, 2022	June 30, 2021
ASSETS		
Cash	\$ 1,118,758	\$ 953,839
Investments	8,861,420	8,573,681
Pledge Receivables, net	4,365,270	554,347
Prepaid Expenses and Other Current Assets	406,943	309,031
Property and Equipment, net	632,097	665,147
Beneficial Interest in Charitable Remainder Trust	1,031,118	1,225,205
Other Assets	<u>185,317</u>	<u>186,289</u>
Total assets	<u>\$ 16,600,923</u>	<u>\$ 12,467,539</u>
LIABILITIES AND NET ASSETS		
Liabilities:		
Accrued liabilities	\$ 340,647	\$ 359,104
Deferred income	214,061	496,845
Other payables	185,317	189,289
Grants payable	<u>768,750</u>	<u>631,250</u>
Total liabilities	<u>\$ 1,508,775</u>	<u>\$ 1,676,488</u>
NET ASSETS		
Without donor restrictions:		
General	\$ 3,703,349	\$ 3,535,983
Board designated	1,585,912	1,548,015
With donor Restrictions	<u>9,802,887</u>	<u>5,707,053</u>
Total net assets	<u>15,092,148</u>	<u>10,791,051</u>
Total liabilities and net assets	<u>\$ 16,600,923</u>	<u>\$ 12,467,539</u>



The Marfan Foundation is a 501(c)(3) organization that is fully accredited by the Better Business Bureau's (BBB) Wise Giving Alliance Program for meeting all 20 BBB Charity Standards. The Foundation has met the standards for membership of the National Health Council and also earned the highest marks from Guidestar and Charity Navigator for our program efficiency, public accountability and cost-effectiveness. The Marfan Foundation EIN # is 52-1265361.



THANK YOU

In 2022, we saw our incredible supporters rise to the most significant challenge The Marfan Foundation has ever faced. It is a testament to you, and your tireless commitment to our mission, that we forged forward in this challenging year.

We are stronger together!



THE **MARFAN**
FOUNDATION

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