



ANNUAL REPORT 2023

THE **MARFAN**
FOUNDATION



In 2023, The Marfan Foundation celebrated 42 years of research and progress. And, with every passing year we just keep getting better, thanks to the generosity of our supporters and the resilience of our community members!

With the addition of The Loeys-Dietz Foundation and The VEDS Movement as divisions in recent years, we have vastly expanded our circle of influence and impact. Likewise, we now power The GenTAC Alliance--a global community of healthcare professionals and scientists committed to advancing the understanding and care for all forms of genetic aortic and vascular conditions.

We are so proud to have funded 22 research grants totaling \$2.3M in 2023, which support our strategic focus on transformational science that will save and improve lives and aim toward cures. With our supporters' help, we funded fellowships, career development grants, innovators grants, and our first-ever Everest Award – the largest research grant in our history.

Other highlights of the year included Science in Paris where we convened nearly 300 scientists in-person from around the world in order to share research findings with the potential to advance treatment. Our annual Conference took place in Chicago, with more than 600 people in attendance, 60 medical and wellbeing workshops offered, and a life-changing health fair.

As you review our annual report, you'll learn more about the details of our community programs including symposiums, webinars, support groups, and fundraising gatherings – all of which bring together people with similar experiences who enrich one another's lives. Likewise, you'll see the impact of our Help & Resource Center – which provided medical answers to 5,000 people in 2023 alone.

You fuel the Foundation with your dedication to our mission. On behalf of the communities we serve, we offer our heartfelt thanks.



A stylized black ink signature of Bert Medina.

Bert Medina
Chair, Board of Directors



A stylized black ink signature of Michael Weamer.

Michael Weamer
President & CEO

► OUR MISSION

Save and improve lives, while creating communities, for all individuals with genetic aortic and vascular conditions including Marfan, Loeys-Dietz, and Vascular Ehlers-Danlos syndromes.

► OUR VISION

Cures for genetic aortic and vascular conditions.

**TOGETHER,
WE CAN
KNOW THE
SIGNS AND
FIGHT FOR
VICTORY**

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.



OUR WORK

Our programs and services fuel awareness and connections globally

★ Programs & Events

- Marfan Awareness Month
- Loeys-Dietz Awareness Month
- VEDS Action Month
- Aortic Disease Awareness Week
- International Research Symposium
- International Patient Meeting
- Educational Webinars
- Virtual Support Groups
- Regional Symposia
- Walk for Victory in 22 Cities
- Virtual Global Walk for Victory
- Evening with Heart in Scottsdale, AZ and Raleigh, NC
- Heartworks in St. Louis, Houston, NYC, Chicago
- UnCorked Wine Event
- Camps in California and Georgia
- VEDS Community gathering in Houston
- LDS Community gathering in Chicago
- Spanish Language Summit
- New Mental Health Resources

★ 2023 Spotlight: Expanded Mental Health Resources

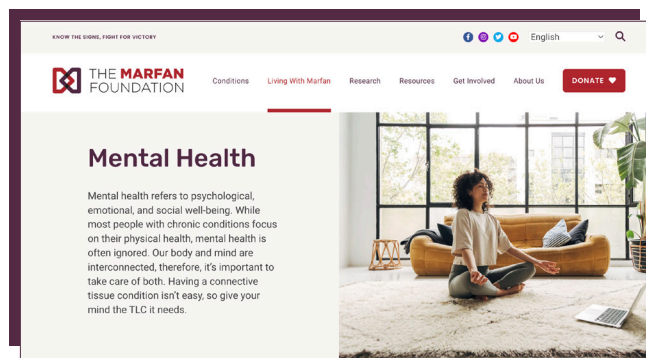
“Mental health is a critical part of overall wellness, and we’re thrilled to be bringing it more to the forefront. This web page is just one of the many initiatives we are implementing to address the mental health of our community. By making it a greater focus, we hope to destigmatize some of these common issues and raise awareness while helping members of our community realize they’re not alone and empower them to seek help.”

~Dawn Reiner, a Foundation board member and Chair of its Mental Health Task Force.

★ Educational Highlights

Education Webinars

- Eye Issues
- Lung Issues
- Genetics Research
- Occupational Therapy
- New Aortic Disease Guidelines
- Discover Trial for VEDS
- Held second Spanish Summit on Marfan Syndrome, LDS, and VEDS, attracting nearly 250 people from around to the virtual one-day event
- Chief Science Officer presented at the Lifetime Management of the Aorta symposium, a CEU event
- Hosted regional symposia in Atlanta, Colorado, Michigan, New York, Seattle



THE POWER OF OUR COMMUNITY

Research and Education programs fuel connections globally.

2022 CONFERENCE Newport Beach, CA

535 Total Attendees | **70** Children | **65** Teens
7 Countries Represented

Attendee Condition Connections

320 Marfan | **63** VEDS | **74** LDS | **22** Other
Over 40 medical workshops on Saturday and
50 quality of life workshops on Sunday.

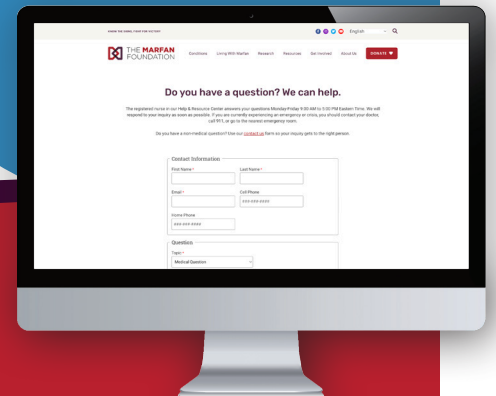
Health Fair at Conference

- 75** Physicians and Healthcare Professionals
- 55** Health Fair Participants
- 150** Multidisciplinary Health Fair Appointments

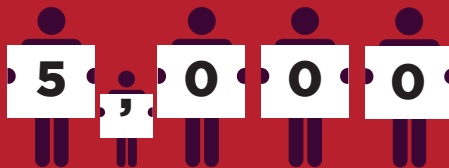


**SOCIAL MEDIA
IMPACT**

**OUR REACH
2.3M USERS**



We reach more than **5,000 people** around the world via emails and one-on-one phone calls with our nurse or social workers through our dedicated Help and Resource

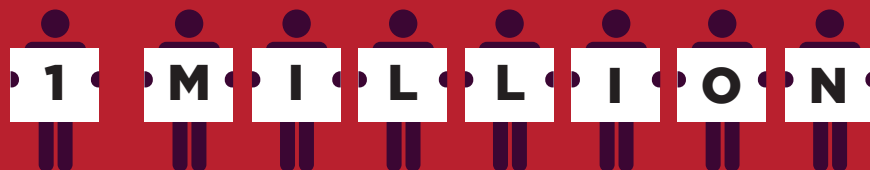


Center. Our nurse and social workers help connect our community with the necessary resources including our institutional directory, mental health resources, support groups, educational materials, and so much more.

We connect thousands of individuals and families to the **70 institutions around the country** that offer experience and expertise in Marfan, LDS, VEDS, and other genetic aortic and vascular conditions.



We continue to reach over a **million people** each year with educational resources.



Through Support and Community, Hope

It's important to build a community because one of the most important things for your mental health is knowing you are not alone. There's a weight lifted when you understand there are people going through something similar, and it's a beautiful thing when you can help other people. We all have gifts and talents and bring value to the world.

I would get emails about the Grief and Loss Support Group and finally decided to attend because I understood in order for me to be the best dad, husband, and human being I could, I needed to take the first step.

Through these groups I've learned to be grateful, and appreciate where I am.

Jerome



“[At Conference] for the first time I felt the sense of normalcy. I was able to be open about everything and not feel like an alien. It was amazing to be in an environment where other people understand and help you. That was one of the greatest experiences I have ever had.”

THE VEDS MOVEMENT

Safety, Support, and a Voice Within the Community

Through the Foundation we have met wonderful people that we can call family. The Marfan Foundation holds a very special place in our hearts.

Our daughter [who lives with VEDS] is an amazing little girl full of care, humor, intelligence and bravery. She brings so much joy to our family. We are incredibly proud to be her parents, and our greatest wish for her is to lead a happy and fulfilling long life.

We hold onto hope that progress is being made in the VEDS community. We remain optimistic that trials and a cure are on the horizon.

Sofia de la Garza



“The Marfan Foundation is incredibly important to my family. They provide us with a sense of safety, support and a voice within the VEDS community.”

Providing Purpose, Growth, and Community

We are very, very grateful for The Marfan Foundation. When we were trying to scramble for answers initially, I called the Foundation. The foundation has been huge for me. The Foundation helps us to connect with other families. It helps us to grow in our knowledge and education for what treatments our son, Noah, may need or what patients with connective tissue disorders may need.

The Foundation also gives me purpose. The Foundation has given our family purpose. It has

allowed us to grow, it has allowed us to spread the word. It has allowed us to just continue to stay positive and hold on to hope.

One of the things the Foundation has done for us: it's brought us a sense of community. The Foundation has allowed us to meet other families who are going through some of the same struggles that we're going through and some of the same triumphs.

-Heide Padilla





Inspiring Education and Research

You know, the Marfan Foundation means the world to me. It is by far the most important entity of its type, which is creating a home, a resource, a community of patients and families interested in fighting rare vascular diseases.

The work of the Foundation has a massive effect on patients and families by bringing together caregivers, scientists and educators around the world. Through the work of the Foundation and its various resources, they can help inspire both further education and research that leads to better outcomes for future generations.

The Foundation is the voice. It's the voice for patients and families providers and scientists. It is the convenor of activity around education, better care, boundary pushing science and a global effort to educate patients, families and caregivers alike so that we can bring to bear the latest knowledge to provide the best possible care to our patients and families around the world. That is what the foundation is. And I'm just delighted to be a small part of that effort in my work with the GenTAC Alliance.

-Dr. Kim Eagle



RESEARCH

Research Grant Recipients

“This award results from a continuous commitment by The Marfan Foundation to support research. Being a grantee provides me and my team with energy and a strong belief that our research matters! Having established a zebrafish model for aortic dissection, this award will allow us to understand the initial molecular drivers and cell types involved in this vasculopathy. We hope this will result in earlier identification and better management of an aortic risk in people with Marfan syndrome and related conditions.” ~*Bert Callewaert, MD, PhD*



► **Joseph W. Turek, MD, PhD, MBA**
Duke University

TRPC4/ATRI Dual Antagonism
Blocks Marfan Aortopathy

Everest Award \$220,000



► **Daniel Martin, PhD** – *Cleveland Clinic Lerner Research Institute*

Mast cell chymase in Marfan
syndrome thoracic aortic aneurysms

\$100,000 2-Year
Victor McKusick Fellowship



► **Bert Callewaert, MD, PhD**
Ghent University

An appraisal of the contribution of
neural crest lineages in a zebrafish
model for aortic dissection

\$100,000 2-Year
Innovators Award



► **Leda Restrepo, PhD**
Johns Hopkins University

Epigenetic determinants and
mechanistic insights into the role
of the long non-coding RNA Meg3
in the pathogenesis of aortic
aneurysm

\$100,000 2-Year
Victor McKusick Fellowship



► **Ketan Ghaghada, PhD**
Baylor College of Medicine

Prediction of aortic dissection and
rupture in Marfan syndrome using
nano-radiomics

\$100,000 2-Year
Innovators Award



► **Simone Saitta, PhD**
Politecnico di Milano

Machine learning for identification
of geometrical and biomechanical
markers of aortic dissection in
Marfan patients

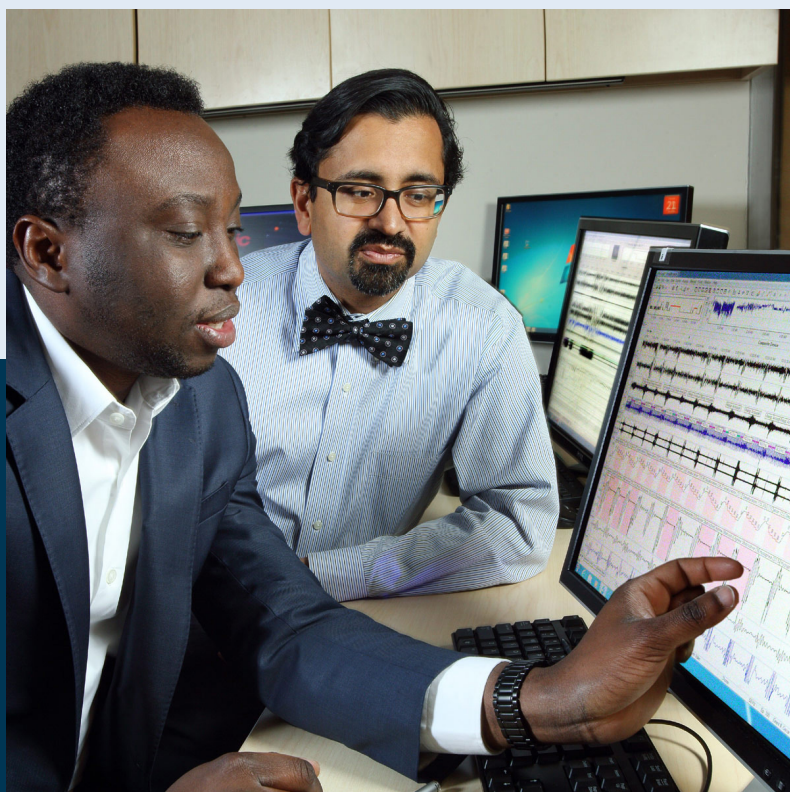
\$100,000 2-Year
Victor McKusick Fellowship



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.

★ Highlights

- 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.
- 6 GenTAC Scientific Working Group Meetings
- 2 Educational Webinars for Affected Individuals and Families
- Genetic Testing: US and Europe
- 4 Educational Webinars for Researchers and Healthcare Professionals
- Exploiting Advantages of the Zebrafish Model for the Study of Aortopathies
- Accessing GenTAC Data and Biospecimens Using BioLINCC
- Transcriptional and Epigenetic Factors in the Generation of Thoracic Aortic Disease
- iPSC Models of Thoracic Aortopathies: Possibilities and Challenges
- 1 GenTAC International Research meeting in Paris attended by over 100 researchers and physicians



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PAB Advisor

STATEMENTS OF ACTIVITIES

Year Ended June 30, 2023

Our commitment to programmatic activities remained unwavering in FY23, focusing on expanding patient support services, raising awareness, and advancing research initiatives. This past year was marked by resilience, growth, and tremendous impact as we continued to advance our mission of improving the quality of life for individuals and families affected by Marfan, Vascular Ehlers-Danlos (VEDS), Loeys-Dietz (LDS) and related genetic aortic and vascular conditions.

We experienced significant growth in revenue, driven in part by unexpected bequests received during the fiscal year. These bequests boosted our total revenue, exceeding expectations and highlighting the generosity and commitment of our supporters.

As we reflect on the achievements of Fiscal Year 2023, we are filled with gratitude for the support of our donors, partners, volunteers, and staff. Together, we have made significant strides in advancing our mission.

	Without Donor Restrictions	With Donor Restrictions	Year Ended June 30, 2023	Year Ended June 30, 2022
Revenues and gains:				
Contributions	\$ 3,118,705	\$ 1,039,071	\$ 4,157,776	\$ 6,155,626
Direct response	357,901		357,901	328,239
PPP loan forgiveness	-		-	491,000
Employee retention credit	547,701	-	547,701	-
Conferences and symposia	225,206	-	225,206	13,464
Net investment income	574,327	-	574,327	(419,545)
Special events, net of direct donor benefits of \$679,790 and \$490,775, respectively	2,593,551	-	2,593,551	2,621,187
Change in value of beneficial interest in charitable remainder trust	-	26,163	26,163	(194,087)
Contributions of non-financial assets	67,456	-	67,456	110,358
Net assets released from restrictions	<u>1,398,540</u>	<u>(1,398,540)</u>	<u>-</u>	<u>-</u>
Total revenues and gains	<u>8,883,387</u>	<u>(333,306)</u>	<u>8,550,081</u>	<u>9,106,242</u>
Expenses:				
Program service expenses:				
Research initiatives and grants	2,400,851	-	2,400,851	1,582,843
Education and public awareness	1,207,705	-	1,207,705	947,083
Patient services and annual conference	<u>1,900,153</u>	<u>-</u>	<u>1,900,153</u>	<u>1,183,961</u>
Total program service expenses	<u>5,508,709</u>	<u>-</u>	<u>5,508,709</u>	<u>3,713,887</u>
Supporting service expenses:				
Management and general	519,147	-	519,147	421,725
Fundraising	<u>770,877</u>	<u>-</u>	<u>770,877</u>	<u>669,533</u>
Total supporting service expenses	<u>1,290,024</u>	<u>-</u>	<u>1,290,024</u>	<u>1,091,258</u>
Total expenses	<u>6,798,733</u>	<u>-</u>	<u>6,798,733</u>	<u>4,805,145</u>
Changes in net assets before Loeys Dietz Syndrome Foundation Contribution	2,084,654	(333,306)	1,751,348	4,301,097
Loeys Dietz Syndrome Foundation Contribution	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
Changes in net assets	2,084,654	(333,306)	1,751,348	4,301,097
Changes in net assets	<u>5,289,261</u>	<u>9,802,887</u>	<u>15,092,148</u>	<u>10,791,051</u>
Net Assets, Ending	<u>\$ 7,373,915</u>	<u>\$ 9,469,581</u>	<u>\$ 16,843,496</u>	<u>\$ 15,092,148</u>

STATEMENTS OF FINANCIAL POSITION

June 30, 2023 and June 30, 2022

	June 30, 2023	June 30, 2022
ASSETS		
Cash and cash equivalents	\$ 826,752	\$ 1,118,758
Investments	12,270,093	8,861,420
Pledges receivable, net	3,194,059	4,365,270
Prepaid expenses and other current assets	387,901	406,943
Property and equipment, net	606,435	632,097
Beneficial interest in charitable remainder trust	1,057,281	1,031,118
Other assets	219,091	185,317
Total assets	<u>\$ 18,561,612</u>	<u>\$ 16,600,923</u>
LIABILITIES AND NET ASSETS		
Liabilities:		
Accrued liabilities	\$ 482,564	\$ 340,647
Deferred income	216,461	214,061
Other payables	219,091	185,317
Grants payable	800,000	768,750
Total liabilities	<u>\$ 1,718,116</u>	<u>\$ 1,508,775</u>
NET ASSETS		
Without donor restrictions:		
General	\$ 5,744,754	\$ 3,703,349
Board designated	1,629,161	1,585,912
With donor Restrictions	<u>9,469,581</u>	<u>9,802,887</u>
Total net assets	<u>16,843,496</u>	<u>15,092,148</u>
Total liabilities and net assets	<u>\$ 18,561,612</u>	<u>\$ 16,600,923</u>



**81¢ OF EVERY \$1 RAISED
GOES TO OUR MISSION**

WHERE DOES THE MONEY GO?

35%

RESEARCH

28%

**PATIENT
SERVICES**

18%

**EDUCATION & PUBLIC
INFORMATION**

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.





THE **MARFAN**
FOUNDATION



THANK YOU

