ANNUAL REPORT 2024

THE MARFAN FOUNDATION

This year, we proudly celebrated the Marfan Foundation's 43rd anniversary of advancing research, education, and progress to save lives, improve outcomes, and build a thriving community. Through our four divisions - the GenTAC Alliance, the Loeys-Dietz Syndrome Foundation, the Marfan Foundation, and the VEDS Movement, we are honored to serve individuals and families impacted by genetic aortic and vascular conditions. None of this would be possible without our generous supporters and tireless volunteers, who drive the transformative change we achieve together.

In 2024, we funded 18 research grants totaling $2.2 million, reaffirming our commitment to ground-breaking science. Grants included fellowships, career development grants, innovators grants, and the prestigious Everest Award—aimed at improving prevention, treatment, and outcomes for aortic dissection. Our significant investment in science reflects the unwavering generosity of our community and our shared mission.

One of the year's highlights was our five-day Global Virtual Conference, which brought together 804 participants, including 182 from around the world. Attendees engaged with leading healthcare experts to learn about the latest research, medical management strategies, and mental health resources while fostering deeper community connections. The impact continued beyond the event, with conference sessions viewed on demand more than 1,400 times. We encourage you to explore our Annual Report to discover more about our diverse community programs, from symposiums and webinars to support groups and fundraising gatherings. These initiatives are at the heart of our mission, helping to forge lifelong friendships and strengthen community bonds. This year, our social media outreach touched 3.3 million people, while our invaluable Help & Resource Center provided critical medical information to more than 5,000 individuals.

Your passion, energy, and dedication fuel everything we do. Together, we are advancing research, enhancing quality of life, and extending longevity for those we serve. From all of us at the Marfan Foundation, thank you for your steadfast support and for empowering our community. We look forward to continuing this incredible journey together!

Bert Medina
Chair, Board of Directors

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 to 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

Programs & Events

- Marfan Awareness Month
- Loeys-Dietz Awareness Month
- VEDS Action Month
- Aortic Disease Awareness Week
- Educational Webinars
- International Webinars - German, French, English (UK)
- Mindfulness Webinar Series
- 18 Support and Connect Groups
- Regional Symposiums in Austin, Los Angeles, Pittsburgh, Indianapolis, Portland
- Walk for Victory in 22 Cities
- Evening with Heart Scottsdale
- Heartworks in St. Louis, Houston, NYC, Chicago
- UnCorked Wine Event
- Camps in California and Georgia
- Spanish-Language Summit
- New Mental Health Resources
- Pain-Management Study
- Virtual Advocacy Day
- Community Group Meetings
- Disney Half Marathon
- NYC Marathon

2023-2024 THE MARFAN FOUNDATION WALK FOR VICTORY

22 Walks for Victory

Reaching over **6,500** people

99% of participants rated very positive to extremely positive

In 2024-2025 we are planning 24 Walk for Victory events reaching over 6,500 people. Last year we had community chairs from the Marfan, VEDS, and LDS communities.

The Marfan Foundation's 2024 Global *Virtual* Conference

1700+ REGISTRANTS FROM 56 COUNTRIES

ADULTS **91%**
TEENS **5%**
CHILD **4%**

The virtual conference provided attendees with:

- Opportunities for community-building, networking, and support
- State-of-the-art research updates
- Medical management education
- Mental health programming

Spanish-Language Programming

- **2 Spanish-Language Webinars** – Eye Issues and Aortic Surgery
- **3rd Annual Spanish-Language Summit** on Marfan, LDS, and VEDS

In February 2024, the Foundation offered its **first virtual support group called Conexiones** to answer the needs of the Spanish-language community. The group meets monthly and is led by a bilingual staff member.

The Marfan Foundation and its divisions' pages and profiles had

9.9M IMPRESSIONS and reached **7M USERS**

- Posts had **3.8M impressions** with an engagement rate of 5.5% across social channels – more than double industry-excellent standards
- Gained **4.7K followers**
- Posts shared **12K times** with **88K reactions**

Broadening our audience and reach, we added TikTok to our social media.

Advocacy in Action

Our community's voices were heard during Virtual Capitol Hill Advocacy Days in April. More than **30 community members** met directly with **37 congressional staff members** to share stories and advocate for increased funding in research, education, and awareness, including funding for the NIH, CDC, and other organizations and programs. Advocates with Marfan, LDS, and VEDS and their loved ones played a pivotal role in potentially shaping legislation and policies.

OUR WORK

"Research is essential to improving the lives of those in our Marfan, Loeys-Dietz, VEDS, and related conditions communities."
- Josephine Grima, PhD, Chief Science Officer, The Marfan Foundation

Research & Progress

43 YEARS

Serving our global community of individuals, families, caregivers, and healthcare professionals, including doctors, researchers, genetic counselors, nurses, and social workers who treat and care for our community.

Striving for a world in which everyone with genetic aortic and vascular conditions receives a proper diagnosis, gets the necessary treatment, and lives a long and full life.

THE MARFAN FOUNDATION

Research • Education • Community

2024 Research Grant Program

Supports strategic focus on life-changing science and aims for cures for Marfan, Loeys-Dietz, VEDS, and other genetic aortic and vascular conditions.

Funding includes Fellowships, Career Development Grants, Innovators Grants, and the Everest Award. Some areas of study include:

- Developing novel treatment options for the prevention of aortic dissection in Marfan syndrome
- Identifying therapies to mitigate Marfan-associated skeletal fragility
- Building a pre-clinical tool for testing potential LDS therapies that more closely resembles the native aorta

Since 1986

176 FUNDED GRANTS

CURRENTLY FUNDING
18 GRANTS
IN THE AMOUNT OF
$2.2M

THE MARFAN FOUNDATION

Harnessing the Power of Awareness

When my husband, Johnny, was coming up in the early 80s, much about Marfan was unknown. A school nurse's routine check for scoliosis when he was in middle school led to his diagnosis and first Marfan-related surgery, a spinal fusion. Early detection helped save Johnny's life at 21 when he underwent emergency aortic valve replacement. He was blessed to have doctors who were knowledgeable and vigilant. Johnny's medical team encouraged us to begin early cardiovascular testing for our children. We did, and Sky's enlarged aorta was discovered when she was 18 months. Witnessing our daughter's grit and resilience through two surgeries at age four is one of our greatest and deepest inspirations.

-Nosha

"We are so grateful that Sky and Auggie have access to medical advancements, thanks to The Marfan Foundation."
-Johnny and Nosha Whitehead

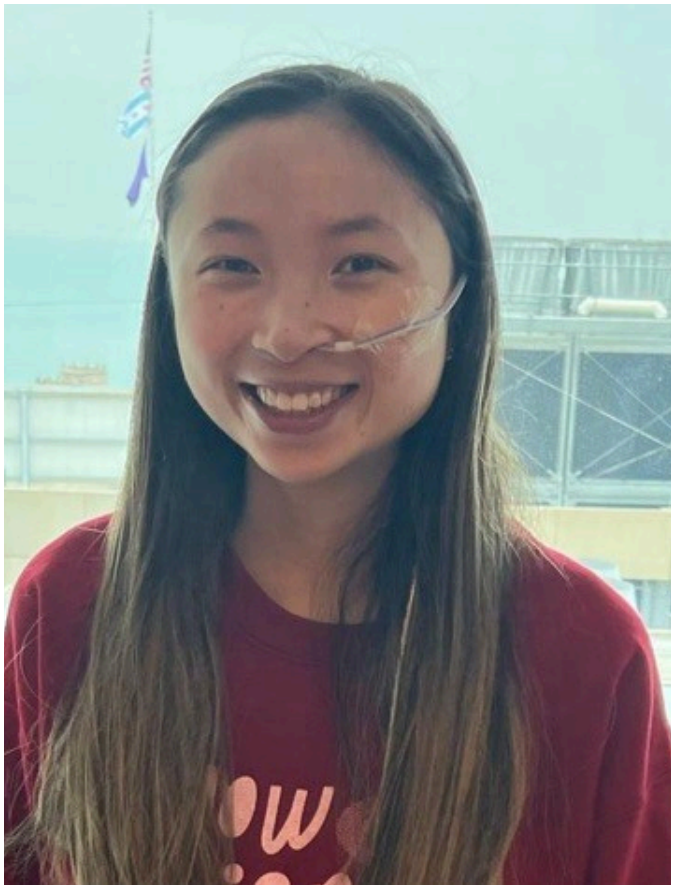
THE VEDS MOVEMENT

A Great Source of Support

"When I got my genetic diagnosis [I learned about] the Marfan Foundation because my family was looking for a group or a community just to support us along the way and to find research."

"It's helpful that the Marfan Foundation is a very big foundation and getting more recognized because it allows others to dive deeper and learn more about other connective tissue disorders that affect your heart. I'm hoping that more medical providers are more aware of VEDS, because a lot of times when I go in to see any new specialist or any new doctors, I'm the one having to explain how serious VEDS is and how serious the complications can be with any given treatment,"

-Maia



"The Marfan Foundation is a great source for people to go to if they have any questions [about] supporting you or to help advocate for you any sort of way."

-Maia Fleener, Living with VEDS

“And there, my life began.”

Rachel Martin points to the 2008 Marfan Foundation Conference, and her surgery thereafter, as her starting point in life and the beginning of living authentically as herself after years without a diagnosis and the emotional toll of being bullied.

In 2024, she shared her story with the Loeys-Dietz Foundation community to help others.

“My reason to tell my story is to give hope to parents with young kids who are struggling,” said Rachel. “None of us know what tomorrow is going to bring… but if I, as a 44-year-old, who has been through not only the medical side but the psychological side [can help]…I need to try.”

Rachel looks forward to continuing to enjoy life, authentic friendships, and helping others. “I’m still here, and I have no plans on going anywhere. I’m not done yet,”

-Rachel

“I’d like new families to know that these [physical and emotional challenges of LDS] are possible to live through.”

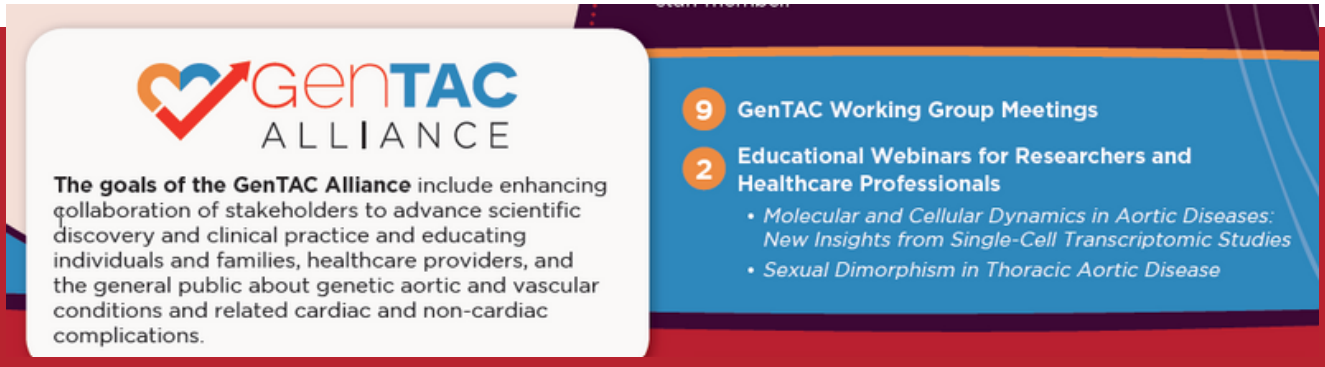
-Rachel Martin, Living with Loeys-Dietz

Inspiring Education and Research

“I'm delighted to work with the Marfan Foundation, helping to lead the GenTAC Alliance -- a global group of scientists, physicians, educators, and clinicians who've been working together now for almost 20 years. When the Foundation convenes these experts to present their findings, I am stunned at the volume and excellence of the work that's being done around the world in understanding the genetic underpinnings of Marfan, Loeys-Dietz, VEDS, and related conditions as well as discovery and collaboration around important areas like imaging, clinical care, and surgical care.

Members of the GenTAC Alliance share an impressive sense of passion, teamwork, commitment, and hope. There's literally an army of scientists attacking genetic aortic and vascular conditions every day on behalf of patients and families. The groundbreaking science we are working on will ultimately lead to more solutions for our community members. And this truly is the magic of the global effort which is supported by the Foundation. Through the GenTAC Alliance and the Foundation as a whole, advancing science and then sharing what we are learning with healthcare providers and our community members is both critically important and a privilege.”

-Dr. Kim Eagle



Tromso, Norway Meeting 2024

NEW GRANT PROGRAM RECIPIENTS

Supports Focus on Life-Saving Science

The Foundation has awarded five new research grants totaling $500,000. Thanks to the generosity of our supporters, these two-year grants include two Innovator Awards, two Victor McKusick Fellowship Awards, and one Career Development Award.

"Research is essential to improving the lives of those in our Marfan, Loeys-Dietz, VEDS, and related conditions communities," said Josephine Grima, PhD, chief science officer for the Foundation. "We are excited about these research studies and the possibility they could lead to advancements in new diagnostics and treatment options."

MEET THE NEW GRANT RECIPIENTS AND LEARN ABOUT THEIR STUDIES:

Matthew Greenblatt, MD, PhD – *Weill Cornell Medical College, New York, NY*

Skeletal Stem Cell Niche Dysfunction in Marfan Syndrome

$100,000 2-Year Innovators Award

Skeletal issues are a significant contributor to the overall impact of Marfan syndrome on an individual's well-being, yet there are currently no drugs approved to manage them. Dr. Greenblatt proposes that the mutations that cause Marfan syndrome disrupt the ability of certain types of stem cells to self-renew and differentiate, producing the condition's signature skeletal features. Using their insights into these stem cells, Dr. Greenblatt's study team will use mouse models of Marfan syndrome to screen existing drugs that may be able to reverse the extreme skeletal fragility and increased risk of fractures that can occur.

Lingling Hu, PhD – *Hospital for Special Surgery, New York, NY*

Tendon/ligament stem cell niche dysfunction underlining musculoskeletal phenotypes in Marfan syndrome

$100,000 2-Year Victor McKusick Fellowship

Tendon/ligament issues are known characteristics (or symptoms) of Marfan syndrome. However, a lack of understanding of the stem cells forming tendons and ligaments has posed a significant roadblock to defining the broader role in Marfan syndrome. Dr. Hu's study team recently discovered the stem cell responsible for forming tendons and ligaments and plans to target it to determine which Marfan-associated skeletal features are due to tendon and ligament changes versus changes in skeletal cells other than tendon or ligament cells. This work will help the group determine the feasibility of using a stem-cell-based therapy to reverse the tendon/ligament changes seen in Marfan syndrome.

Ilse Luyckx, PhD – *University of Antwerp, Antwerp, Belgium*

In-depth exploration of the (epi)genetic landscape of BAV/TAA disease using Smad6-deficiency as an entry point

$100,000 2-Year Victor McKusick Fellowship

The aortic valve ensures unidirectional flow of oxygen-rich blood from the heart to the main and major blood vessel of the body, namely the aorta. Usually, this valve consists of three leaflets, though some individuals are born with two leaflets (i.e., bicuspid aortic valve or BAV). Many individuals with BAV develop valvular dysfunction and/or vascular complications, including thoracic aortic aneurysms (TAAs). TAAs entail a high risk for acute aortic rupture and dissection, resulting in severe bleeding and other serious complications. To date, genetic defects in about 30 disease-associated genes explain less than 6% of the BAV/TAA patients. Even though previous studies have been key in acquiring knowledge on BAV/TAA, the incomplete genetic picture hampers the identification of individuals at risk for TAA and the discovery of novel therapeutic targets to prevent and/or stop TAA formation. Dr. Luycxk's team recently identified *SMAD6* as a novel BAV/TAA gene that explains about 4.8% of the genetically affected patients. However, there is evidence that suggests that the primary *SMAD6* mutation alone cannot predict the clinical outcome of a patient. In this project, Dr. Luyckx will use other genetic methodologies to identify additional modifications in individuals with BAV/TAA that have this gene mutation, hoping they may help better predict outcomes. The project's anticipated results will advance the counseling of BAV/TAA patients and add valuable information to our understanding of the molecular basis of other *SMAD6*-related conditions.

Bhama Ramkhelawon, PhD – *NYU Grossman School of Medicine, New York, NY*

Interrogating platelet-derived TGFβ1 signaling in Aortic Aneurysms and Dissections in Marfan Syndrome

$100,000 2-Year Innovators Award

Prior studies of Marfan syndrome have provided critical insights into the role of aberrant TGFβ1, a protein that contributes to the development of aortic aneurysms and dissections; however, the source of aberrant TGFβ1 and the full spectrum of its signaling pathways is not well understood. Circulating platelets, the subset of cells that regulate blood clot formation, are an important carrier of TGFβ1. Dr. Ramkhelawon's team has found that genetically manipulated mice with TGFβ1 missing from their platelets are protected from aortic dilation and dissection. During this project, they will delve into how platelet-derived TGFβ1 contributes to excessive degradation of the aortic tissue and use those findings to determine if anti-platelet drugs can be used to treat individuals with Marfan syndrome.

Aline Verstraeten, PhD – *University of Antwerp, Antwerp, Belgium*

Reinforcement of translational Loeys-Dietz syndrome research through aorta-on-a-chip development

$100,000 2-Year Career Development Award

The advent of technology to create stem cells from skin or blood cells (i.e., induced pluripotent stem cells or iPSCs) of patients and/or healthy individuals has revolutionized the biomedical research field. These cells provide an invaluable tool to study and target early disease processes in the relevant human context. With this project, Dr. Verstraeten's team hopes to significantly expedite bench-to-bedside translation of Loeys-Dietz syndrome research by developing and functionally validating aorta-on-a-chip (AoC) models derived from thoracic aortic aneurysm-presenting LDS Type 3 (SMAD3) patient and control iPSCs. Organ-on-a-chip modeling refers to creating and characterizing miniature organs grown in small silicon channels that can be perfused with fluids of interest (blood, medium, etc.) at various flow rates and/or pressure regimens. It is anticipated this project will result in the development of a novel pre-clinical tool allowing exploration and therapeutic targeting of LDS mechanisms in a human setting that more closely resembles the native aorta than ever before.

In this award cycle, the Foundation also granted its second Everest Award to a team of researchers led by Julie De Backer, MD, PhD, a cardiologist and clinical geneticist at Ghent University in Belgium. Details of this award can be found in the previous edition of Connective Issues, found on our website.

STATEMENTS OF ACTIVITES
FISCAL YEAR 2024

	Without Donor Restrictions	With Donor Restrictions	2024	2023
Revenues and Gains				
Contributions	1.447.028	50.147	1.497.175	4.157.76
Direct response	331	128	3.115	276
Government grant revenue	331.150	-	331.150	225.01
Net investment income	995.942	-	3.049.741	2.59.35
Events, net of direct expenses 9.37.45 and 5.573.780, respectively	3.049.741		3.049.741	2.593.51
Change in value of beneficial interest in charitable remainder trust	66.911	43.522	43.522	26.16
Contributions of nonfinancial assets	1.456.625	(1.456.623)	43.811	674
Total revenues and gains	**7.478.423**	(1.362.954)	**6.115.469**	8.550.01
Expenses				
Program service expenses:	2.219.095		2.213.095	2.40.85
Research initiatives and grants	1.155.544	-	1.155.544	1.207.705
Patient services and annual conference	2.074.821	-	2.074.321	1.900153
Total program service expenses	**5.449.560**	-	**5.449.560**	5.508703
Supporting service expenses:				
Management and general	468.085	-	468.085	519.147
Fundraising	783.766	-	785.766	770.877
Total supporting service expenses	**1.251.851**	-	**1.251.851**	1290.024
Total expenses	**6.701.411**	-	**6.701.411**	
Changes in net assets	777.012	(1.362.954)	-585.942	1.761.348
Net Assets, Beginning	7.373.915	9.469.581	16.843.981	
Net Assets, Ending	**8.150.927**	-	16.257.554	16.843.496

STATEMENTS OF FINANCIAL POSITION
FISCAL YEAR 2024

Inderjeet Kaur, CPA
Chief Financial Officer

	2024	2023
Assets		
Cash and cash equivalents	$2,029,5585	$2,029,585
Investments	11,853,616	$826,752
Pledges receivable, net	2,096,801	3,194,059
Prepaid expenses and other current assets	220,708	387,901
Beneficial interest in charittole remainder trust	556,480	1,057,281
Other assets	1,100,303	1,057,281
	260,077	219,091
Total assets	$18,118,070	$18,561,612
Net Assets		
Without donor restrictions:	$6,446,721	$5,744,754
General	1,704,206	1,629,161
With donor restrictions	8,106,627	9,469,581
Total net assets	16,257,554	16,843,496
Total liabilities and net assets	$18,118,070	$18,561,612

Our commitment to mission-driven programmatic activities remained steadfast in FY24. We continued to focus on advancing research, expanding patient services, and raising awareness for individuals and families affected by Marfan syndrome, Vascular Ehlers-Danlos (VEDS), Loeys-Dietz syndrome (LDS), and related genetic aortic and vascular conditions.

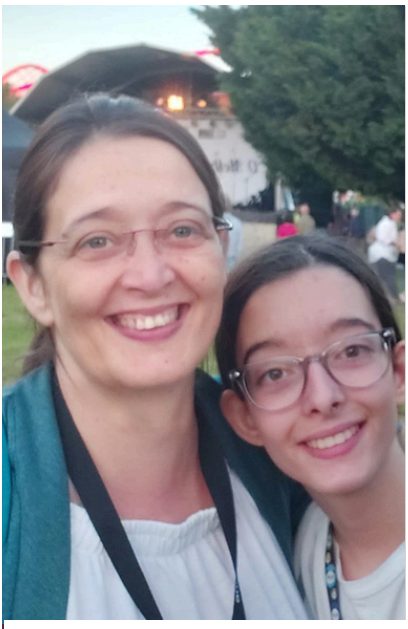
In FY24, total revenue reached $6.1 million, largely driven by the unwavering support of our community and the success of our fundraising initiatives. Event revenue, which included the Walks, which raised over $1 million, and Special Events, which raised over $2 million in gross revenue, totaled $3.05 million after direct expenses. These events illustrate the remarkable generosity, dedication, and enthusiasm of our supporters, whose engagement is essential to advancing our mission.

While contributions totaled $1.5 million, and overall revenue decreased compared to the previous year due to fewer one-time bequests, our dedicated supporters played a crucial role in the success of key fundraising initiatives. The generosity of our donors and the introduction of new giving opportunities are vital for sustaining our programs and services.

We extend our heartfelt thanks to everyone who has supported us—your generosity drives our progress, fuels our programs, and ensures we continue to deliver on our mission.

THE **MARFAN** FOUNDATION

THANK YOU



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