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 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.

Cory A. Eaves  
Chair, Board of Directors

Michael Weamer  
President & CEO
OUR ORGANIZATION

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.

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.
★ 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 Symposia
- 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

★ 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.
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.

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
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, MBChir, PhD
  Johns Hopkins University (pictured left)
  Treatment of Axial Myopia in Marfan Syndrome using Prostaglandin Analogs

CURRENTLY FUNDING 33 RESEARCH STUDIES
To improve the lives and benefit those living with Marfan, LDS, VEDS, and other genetic aortic and vascular conditions.
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.”
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!”
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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  Seattle Children’s Hospital
- Maya Brown-Zimmerman, MPH  
  PAB Advisor
**STATEMENTS OF ACTIVITIES**

**Year Ended June 30, 2022**

In FY22, the Foundation renewed its multi-year $5 million pledge from Bloomberg Philanthropies to fund our new research grant program and the new $800K Everest Research Grant, and the largest grant mechanism in the Foundation’s 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 its community and donors.

<table>
<thead>
<tr>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>Year Ended June 30, 2022</th>
<th>Year Ended June 30, 2021</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Changes In Net Assets:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Revenues and gains:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Major contributions</td>
<td>$ 688,400</td>
<td>$ 4,939,208</td>
<td>$ 5,627,608</td>
</tr>
<tr>
<td>Other contributions</td>
<td>488,680</td>
<td>39,338</td>
<td>528,018</td>
</tr>
<tr>
<td>Direct response</td>
<td>328,239</td>
<td>328,239</td>
<td>342,421</td>
</tr>
<tr>
<td>Grant Revenue - Govt</td>
<td>491,000</td>
<td>491,000</td>
<td>491,000</td>
</tr>
<tr>
<td>Conferences and symposia</td>
<td>13,464</td>
<td>-</td>
<td>13,464</td>
</tr>
<tr>
<td>Community Events</td>
<td>241,401</td>
<td>-</td>
<td>241,401</td>
</tr>
<tr>
<td>Net investment income</td>
<td>(419,545)</td>
<td>-</td>
<td>(419,545)</td>
</tr>
<tr>
<td>Events, net of expenses of $187,693 and $101,692, respectively</td>
<td>2,379,786</td>
<td>-</td>
<td>2,379,786</td>
</tr>
<tr>
<td>Change in value of beneficial interest charitable remainder trust</td>
<td>-</td>
<td>(194,087)</td>
<td>(194,087)</td>
</tr>
<tr>
<td>Gifts in-kind</td>
<td>110,358</td>
<td>-</td>
<td>110,358</td>
</tr>
<tr>
<td>Net assets released from restriction</td>
<td>688,625</td>
<td>(688,625)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total revenues and gains</strong></td>
<td>5,010,408</td>
<td>4,095,834</td>
<td>9,106,242</td>
</tr>
</tbody>
</table>

| 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 | 1,183,961        | -                        | 1,183,961                | 1,212,699   |
| **Total Program service expenses:** | 3,713,887           | -                        | 3,713,887                | 3,957,508   |

| Supporting services:       |                         |                          |                          |
| Management and general    | 421,725                 | -                        | 421,725                  | 484,778     |
| Fundraising               | 669,533                 | -                        | 669,533                  | 752,891     |
| **Total Supporting service expenses:** | 1,091,258         | -                        | 1,091,258                | 1,237,669   |
| **Total expenses**         | 4,805,145               | -                        | 4,805,145                | 5,195,177   |

| 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** | -                   | -                        | -                        | 929,255     |

| Increase (decrease) in net assets |                         |                          |                          |
| 205,263                          | 4,095,834               | 4,301,097                | 1,702,608               |
| Net assets, beginning of the year | 5,083,998              | 5,707,053                | 10,791,051              | 9,088,443   |
| Net assets, end of year           | $ 5,289,261            | $ 9,802,887              | $ 15,092,148            | $ 10,791,051|
# STATEMENTS OF FINANCIAL POSITION

**June 30, 2022 and June 30, 2021**

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

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!