The Marfan Foundation’s mission is to save lives and improve the quality of life of individuals with Marfan syndrome, Loeys-Dietz, VEDS, and other genetic aortic and vascular conditions.
Well before the world knew what the year 2020 would bring, our eye was on growth. The year brought two new organizations, the Loeys-Dietz Syndrome Foundation and the GenTAC Alliance, into the Foundation and saw the completion of a very successful first year of our VEDS division, the VEDS Movement. We accomplished this while also supporting a thriving and engaged community, providing answers to people around the world through our Help & Resource Center, and educating thousands through our countless webinars and educational sessions.

We did all this while we, along with the entire global community, adjusted to living and working through a once-in-a-lifetime pandemic. More than half of our staff team was already geographically located around the country, so we were able to quickly and nimbly adjust to a completely virtual workplace. This allowed us to forge on with our mission without missing a beat. The needs of our Marfan, Loeys-Dietz, and VEDS community don’t stop during a pandemic, and neither did we.

With the leadership of our Professional Advisory Board and broader medical community, we responded quickly to meet the needs and concerns of our communities, especially about how COVID-19 could potentially affect those living with Marfan, Loeys-Dietz, VEDS, and related genetic aortic and vascular conditions. We initiated new support groups and connection opportunities to help fight off isolation and fear. And our supporters stepped up to make sure nothing, not even a global pandemic, could stop the growth and progress we set out to achieve.

Despite its challenges, 2020 turned out to be one of our most successful years due to the support of so many. Our re-imagined programs met the community’s needs and, by removing geographic barriers, we were able to serve more people than ever before.

Our sights are set on the future as we develop more innovative programs and services to support our community, and we look forward to the better days ahead. No matter what gets in our way.

Thank you for your support and confidence.

Sincerely,

Cory Eaves
Chair, Board of Directors

Michael Weamer
President & CEO

ON THE COVER: Kendra DePinto Roberts: “I’m learning to look at my body with amazement. It is incredible the things my body has endured and overcome. The ways my bones and muscles have adapted to allow me to thrive is nothing short of remarkable. I’m really enjoying learning to love this powerful, resilient body life has given me.”
Help & Resource Center
The Help & Resource Center is the heart of our work. More than 3,000 individuals access this resource annually and receive one-on-one responses from our on-staff nurse. Ongoing communication with other members of the Foundation team ensure that each individual and family can continue to get the answers and connections they need to navigate life with a genetic aortic or vascular condition.

The VEDS Movement
In October 2019, the Foundation launched a new division to provide designated resources, including a full-time director, toward driving research, building awareness, and increasing education and community around Vascular Ehlers-Danlos syndrome (VEDS). The VEDS Steering Committee, composed of the foremost community leaders in this rare condition, as well as the leading patient advocates, helped spearhead this partnership. We made significant progress immediately with the launch of TheVEDSMovement.org and several medical education, awareness, and support initiatives.

Aortic Disease Awareness Day
September 2019 marked the first time that The Marfan Foundation powered the international Aortic Disease Awareness Day. This global movement, which was originated by Timo Söderlund in Sweden, encompasses collaborations with doctors, hospitals, and industry partners all over the world. In addition to individual events held worldwide, the Foundation led an online effort for our community to raise their hands to raise awareness of Marfan, LDS, and VEDS as genetic causes of aortic disease.

35th Annual Conference
The 35th Annual Conference, held in July 2019, brought more than 500 people to Houston to learn from top experts and connect with the Marfan, LDS, and VEDS community. Texas Children’s Hospital, this anniversary event was our first to offer distinct educational tracks for the LDS and VEDS communities, while building upon the sessions and activities that have made Annual Conference a must-attend event for our community. The Health Fair, offered in conjunction with Annual Conference, provided 70 individuals with access to premiere cardiology, genetics, orthopedics, ophthalmology, pulmonology, cardiovascular surgery, orthodontics, and more assessments in one location. Often, access to any of these experts with experience in Marfan or the related conditions is difficult to find, let alone all in one place.

PROGRAMS & SERVICES
Programs and services are at the heart of our mission. Through camps, Annual Conference, webinars, and virtual support groups, we see education and connection improve the lives of the individuals and families affected by Marfan, LDS, VEDS, and related conditions.

When in-person programs and services became impossible in the second half of our year, we quickly pivoted to offer timely and meaningful virtual opportunities. With the incredible support of the Foundation’s Professional Advisory Board, we provided ongoing information and access to the experts for a community trying to navigate rare conditions in a time of COVID-19.
The Marfan Foundation announced $675,000 in new grant awards to seven physicians/scientists as part of its 2020 Research Grant program. This brings the total amount currently being funded -- including the second year of two-year grants awarded last year and other research projects -- to $1.4 million. These new two-year grants, include one fellowship award, one early investigator award, one clinical research award, and four faculty awards.

The newly funded projects address issues that affect cardiovascular mechanisms in Marfan syndrome and related conditions, structural function in VEDS, and orthopedics for Marfan.

In addition to the newly awarded research grants, the Foundation is currently providing an additional $725,000 this year in research support for the Aortic Valve Sparing Operative Outcomes Study, the Marfan and Related Conditions International Patient Registry with Backpack Health, as well as funding for 20 researchers who were awarded multi-year grants in the past two years.

“The grants we funded this year reflect the Foundation’s commitment to research that supports investigating new mechanisms for drug therapy intervention in hopes to eliminate aortic enlargement, dissection and the need for surgery,” said Dr. Josephine Grima, chief science officer, The Marfan Foundation. “With the inclusion of this year’s grants, we are now funding 27 research studies. Research is the hope that fuels our community and we are gratified by the number of researchers who are passionate about advancing the field for the benefit of those living with these Marfan, Loeys-Dietz, VEDS, and other genetic aortic conditions.”
The 2020 Walk for Victory reflected the way of the world pre-pandemic and when covid changed everyday life. The first half of the year featured eight in-person Walks with 1,684 participants. By the second half, however, the Walk for Victory program transitioned into a fully online program, with thirteen Walks done virtually.

By March 2020, the Walk program had raised 35% more as compared to the same time period the previous year and participation was up 20%.

Not surprisingly, our community stepped up despite the change in circumstances.

By the final virtual Walk in May, 142 teams, including Team VEDS at each Walk, raised $650,000 to support the Foundation’s education, patient support, and research programs. These programs reach more than 200,000 patients, families, and physicians annually.

POWER OF COMMUNITY
Walks, special events, camps, & symposiums fuel connections from coast to coast.

EVENTS IN 18 STATES

23 Walks for Victory
10 Special Events
6 Camps
4 Symposia

GLOBAL
Virtual Walk for Victory
The Global Virtual Walk for Victory was introduced in late 2019 as a way to connect our community abroad and in parts of the United States where we did not schedule in-person Walks. As the year progressed, it proved to be a fortuitous plan, as many of the traditionally in-person Walk for Victory events also went virtual!

The inaugural Global Walk for Victory was the first virtual fundraiser to bring every member of our community together no matter where they live. As we have seen, “community” is not about living in a specific zip code; rather it is a place where people feel a sense of belonging. Led by Community Chair, Amy Flannigan (South Carolina), and Medical Chair, Mary B. Sheppard, MD (University of Kentucky), the Global Walk raised over $23,000, surpassing its goal, and bringing together more than 230 participants from Canada to Zimbabwe.

FUNDING MIX
During these unprecedented times, the generosity of our donors, the support of our medical community, the securing of a PPP Loan, and strong fiscal oversight enabled the Foundation to effectively manage our resources.

DETAILS
Please visit Marfan.org/2020AnnualReport for a full set of audited financials and supplemental Annual Report information.

ORGANIZATION AWARDS
# STATEMENTS OF ACTIVITIES

**Year Ended June 30, 2020**

<table>
<thead>
<tr>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>Year Ended June 30, 2020</th>
<th>Year Ended June 30, 2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in net assets:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Revenues and gains:</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Major contributions</td>
<td>$ 634,724</td>
<td>$ 244,804</td>
<td>$ 879,528</td>
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<tr>
<td>Other contributions</td>
<td>584,260</td>
<td>-</td>
<td>584,260</td>
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<tr>
<td>Direct response</td>
<td>247,236</td>
<td>-</td>
<td>247,236</td>
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<tr>
<td>Community events</td>
<td>239,998</td>
<td>2,662</td>
<td>242,660</td>
</tr>
<tr>
<td>Conferences and symposia</td>
<td>65,758</td>
<td>25,000</td>
<td>90,758</td>
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<tr>
<td>Net investment income</td>
<td>140,881</td>
<td>-</td>
<td>140,881</td>
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<tr>
<td>Events, net of expenses of $101,692 and $440,331, respectively</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Change in value of beneficial interest charitable remainder trust</td>
<td>-</td>
<td>(29,416)</td>
<td>(29,416)</td>
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<td>Gifts in-kind</td>
<td>270,671</td>
<td>-</td>
<td>270,671</td>
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<td>Net assets released from restriction</td>
<td>2,064,732</td>
<td>(2,064,732)</td>
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<tr>
<td>Total revenues and gains</td>
<td>5,752,128</td>
<td>(1,821,682)</td>
<td>3,930,446</td>
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<tr>
<td>Expenses:</td>
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<td></td>
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<tr>
<td>Program service expenses:</td>
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<tr>
<td>Research initiatives and grants</td>
<td>2,791,437</td>
<td>2,791,437</td>
<td>2,231,543</td>
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<td>Education and public awareness</td>
<td>886,210</td>
<td>886,210</td>
<td>816,548</td>
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<tr>
<td>Patient services and annual conference</td>
<td>1,511,228</td>
<td>1,511,228</td>
<td>1,456,376</td>
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<tr>
<td>Total program service expenses:</td>
<td>5,188,875</td>
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<td>5,188,875</td>
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<tr>
<td>Supporting services:</td>
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<td></td>
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<tr>
<td>Management and general</td>
<td>516,693</td>
<td>516,693</td>
<td>525,714</td>
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<tr>
<td>Fundraising</td>
<td>728,544</td>
<td>728,544</td>
<td>737,325</td>
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<tr>
<td>Total supporting service expenses:</td>
<td>1,245,237</td>
<td>-</td>
<td>1,245,237</td>
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<tr>
<td>Total expenses</td>
<td>6,434,112</td>
<td>-</td>
<td>6,434,112</td>
</tr>
<tr>
<td>Increase (decrease) in net assets</td>
<td>(681,984)</td>
<td>(1,821,682)</td>
<td>(2,503,666)</td>
</tr>
<tr>
<td>Net assets, beginning of the year</td>
<td>4,337,492</td>
<td>7,254,617</td>
<td>11,592,109</td>
</tr>
<tr>
<td>Net assets, end of year</td>
<td>$ 3,655,508</td>
<td>$ 5,432,935</td>
<td>$ 9,088,443</td>
</tr>
</tbody>
</table>
## STATEMENTS OF FINANCIAL POSITION

*June 30, 2020 and June 30, 2019*

<table>
<thead>
<tr>
<th>ASSETS</th>
<th>June 30, 2020</th>
<th>June 30, 2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash</td>
<td>1,237,573</td>
<td>641,800</td>
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<tr>
<td>Investments</td>
<td>6,136,199</td>
<td>6,552,335</td>
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<tr>
<td>Pledge Receivables, net</td>
<td>1,706,703</td>
<td>2,775,803</td>
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<tr>
<td>Prepaid Expenses and Other Current Assets</td>
<td>208,691</td>
<td>212,186</td>
</tr>
<tr>
<td>Property and Equipment, net</td>
<td>668,901</td>
<td>701,711</td>
</tr>
<tr>
<td>Beneficial Interest in Charitable Remainder Trust</td>
<td>1,058,305</td>
<td>1,087,721</td>
</tr>
<tr>
<td>Other Assets</td>
<td>130,399</td>
<td>104,997</td>
</tr>
<tr>
<td>Total assets</td>
<td>11,146,771</td>
<td>12,076,553</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>LIABILITIES AND NET ASSETS</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Liabilities:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accrued liabilities</td>
<td>254,451</td>
<td>252,171</td>
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<tr>
<td>Deferred income</td>
<td>509,427</td>
<td>108,030</td>
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<tr>
<td>Other payables</td>
<td>131,950</td>
<td>104,997</td>
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<tr>
<td>Line of Credit</td>
<td>500,000</td>
<td>19,246</td>
</tr>
<tr>
<td>Grants payable</td>
<td>662,500</td>
<td></td>
</tr>
<tr>
<td>Total liabilities</td>
<td>2,058,328</td>
<td>484,444</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NET ASSETS</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Without donor restrictions:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General</td>
<td>2,526,611</td>
<td>2,926,080</td>
</tr>
<tr>
<td>Board designated</td>
<td>1,128,897</td>
<td>1,411,412</td>
</tr>
<tr>
<td>With donor restrictions</td>
<td>5,432,935</td>
<td>7,254,617</td>
</tr>
<tr>
<td>Total net assets</td>
<td>9,088,443</td>
<td>11,592,109</td>
</tr>
<tr>
<td>Total liabilities and net assets</td>
<td>$ 11,146,771</td>
<td>$ 12,076,553</td>
</tr>
</tbody>
</table>
MISSION STATEMENT

The Marfan Foundation's mission is to save lives and improve the quality of life of individuals with Marfan syndrome and other genetic aortic conditions.

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Yale School of Medicine

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University of Arizona
Thank you supporters

In 2020, 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 this mission, that we forged forward in this challenging year.

Better days are ahead, thanks to you!