



THE **MARFAN**
FOUNDATION

ANNUAL REPORT 2020

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."

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.



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.



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.



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.



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.



RESEARCH

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."

▲ Marfan & Orthopaedics

This study is the first to mechanistically assess the effects of Marfan syndrome on hip joint muscle function and joint mechanics that may be involved in development of hip osteoarthritis in this population. The results of this study will provide insight into the development of targeted muscle-based interventions that will reduce hip joint pain and hip joint cartilage degeneration within the Marfan population.

Pictured above: Michael Samaan, PhD, University of Kentucky studies muscle-based interventions that may lead to reduction in hip joint pain and cartilage degeneration within the Marfan population.



VEDS Research

This research will increase understanding of how specific mutations in collagen-III lead to altered blood vessel structure and/or cell behavior in VEDS. By studying how the mutations in collagen-III affects blood vessel strength, the hope is to understand the impact of specific mutations on the severity of VEDS and to open new therapeutic avenues for patients with VEDS, including potential targets for gene editing.

Pictured: David Shreiber, PhD, Rutgers University received a Faculty Award for his VEDS research.

Early Investigator

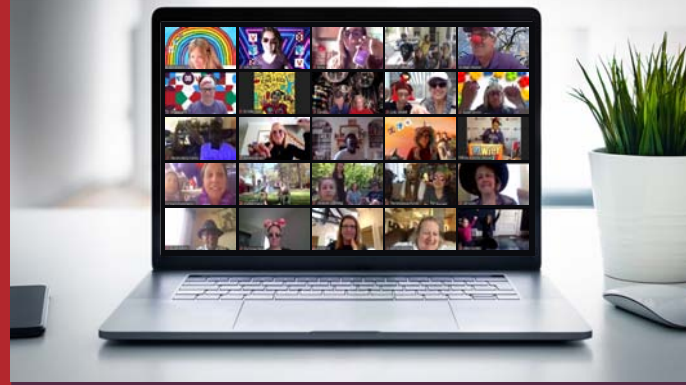
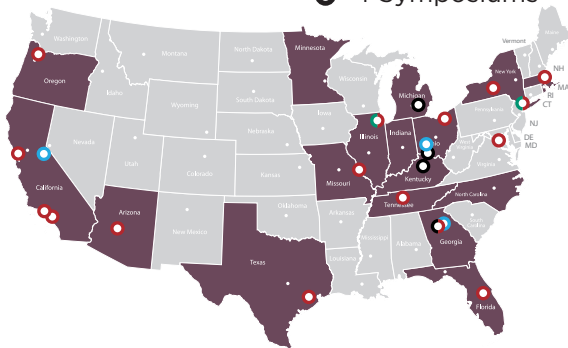
This study hopes to identify new factors of TAAD (thoracic aortic aneurysm with dissection) in Marfan syndrome that can be blocked collectively or separately using drugs that are already approved or can be defined. Together, these animal studies will provide evidence-based support for testing new compounds in clinical trials involving TAAD patients. **Pictured:** Dr. Anna Cantalupo, Icahn School of Medicine at Mount Sinai received the Early Investigator Award.



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.

EVENTS IN 18 STATES

- 23 Walks for Victory
- 10 Special Events
- 6 Camps
- 4 Symposiums



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.

**NPT's BEST
NONPROFITS
TO WORK FOR
★2020★**



Category	Percentage
Res & C	41%
Patient Services	24%
Public Information	14%
Fundraising	11%
Management & General	8%
Other	2%

Funding Source	Percentage
Net Special Event	38%
Major Contributions	23%
Other Contributions	15%
Gifts In-kind	7%
Direct Response	6%
Community Events	6%
Investment Income	3%
Conferences & Symposia	2%

STATEMENTS OF ACTIVITIES

Year Ended June 30, 2020

	Without Donor Restrictions	With Donor Restrictions	Year Ended June 30, 2020	Year Ended June 30, 2019
Changes in net assets:				
Revenues and gains:				
Major contributions	\$ 634,724	\$ 244,804	\$ 879,528	\$ 1,388,127
Other contributions	584,260	-	584,260	591,211
Direct response	247,236	-	247,236	254,832
Community events	239,998	2,662	242,660	260,654
Conferences and symposia	65,758	25,000	90,758	113,490
Net investment income	140,881	-	140,881	278,534
Events, net of expenses of \$101,692 and \$440,331, respectively	1,503,868	-	1,503,868	1,922,784
Change in value of beneficial interest charitable remainder trust	-	(29,416)	(29,416)	21,825
Gifts in-kind	270,671	-	270,671	310,452
Net assets released from restriction	<u>2,064,732</u>	<u>(2,064,732)</u>	<u>-</u>	<u>-</u>
Total revenues and gains	<u>5,752,128</u>	<u>(1,821,682)</u>	<u>3,930,446</u>	<u>5,141,909</u>
Expenses:				
Program service expenses:				
Research initiatives and grants	2,791,437		2,791,437	2,231,543
Education and public awareness	886,210		886,210	816,548
Patient services and annual conference	<u>1,511,228</u>		<u>1,511,228</u>	<u>1,456,376</u>
Total program service expenses:	<u>5,188,875</u>	<u>-</u>	<u>5,188,875</u>	<u>4,504,467</u>
Supporting services:				
Management and general	516,693		516,693	525,714
Fundraising	<u>728,544</u>		<u>728,544</u>	<u>737,325</u>
Total supporting service expenses:	<u>1,245,237</u>	<u>-</u>	<u>1,245,237</u>	<u>1,263,039</u>
Total expenses	<u>6,434,112</u>	<u>-</u>	<u>6,434,112</u>	<u>5,767,506</u>
Increase (decrease) in net assets	(681,984)	(1,821,682)	(2,503,666)	(625,597)
Net assets, beginning of the year	<u>4,337,492</u>	<u>7,254,617</u>	<u>11,592,109</u>	<u>12,217,706</u>
Net assets, end of year	<u>\$ 3,655,508</u>	<u>\$ 5,432,935</u>	<u>\$ 9,088,443</u>	<u>11,592,109</u>

STATEMENTS OF FINANCIAL POSITION

June 30, 2020 and June 30, 2019

	June 30, 2020	June 30, 2019
ASSETS		
Cash	\$ 1,237,573	\$ 641,800
Investments	6,136,199	6,552,335
Pledge Receivables, net	1,706,703	2,775,803
Prepaid Expenses and Other Current Assets	208,691	212,186
Property and Equipment, net	668,901	701,711
Beneficial Interest in Charitable Remainder Trust	1,058,305	1,087,721
Other Assets	<u>130,399</u>	<u>104,997</u>
Total assets	<u>11,146,771</u>	<u>12,076,553</u>
LIABILITIES AND NET ASSETS		
Liabilities:		
Accrued liabilities	254,451	252,171
Deferred income	509,427	108,030
Other payables	131,950	104,997
Line of Credit	500,000	19,246
Grants payable	<u>662,500</u>	<u></u>
Total liabilities	<u>2,058,328</u>	<u>484,444</u>
NET ASSETS		
Without donor restrictions:		
General	2,526,611	2,926,080
Board designated	1,128,897	1,411,412
With donor restrictions	<u>5,432,935</u>	<u>7,254,617</u>
Total net assets	<u>9,088,443</u>	<u>11,592,109</u>
Total liabilities and net assets	<u>\$ 11,146,771</u>	<u>\$ 12,076,553</u>

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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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!

