



THE **MARFAN** FOUNDATION

ANNUAL REPORT **2019**



▶ **\$1,500,000**
TO RESEARCH

▶ **1,000,000+**
SERVED

▶ **8,000**
SUPPORTERS

▶ **38** PROGRAMS
& SERVICES

▶ **1** GOAL

The Marfan Foundation's mission is to save lives and improve the quality of life of individuals with Marfan syndrome, Vascular Ehlers-Danlos, Loeys-Dietz, and other genetic aortic conditions.



PROGRAMS & SERVICES

Meaningful programs and services are at the heart of how we improve the lives of those affected by Marfan, VEDS, Loeys-Dietz, and other genetic aortic conditions every day. Each year, we serve more than one million individuals through our programs and services. This includes over 3,000 requests that are sent to the Help & Resource Center where each one is answered with the compassion and understanding that those struggling with rare conditions most need.

Our programs reach beyond education and awareness, and build connections that are integral in supporting the physical, mental, and emotional well-being of each person we serve.

Thanks to the generosity of individuals and organizations like you, the Foundation's programs and services built a brighter future for people affected by Marfan, VEDS, Loeys-Dietz, and other genetic aortic conditions in 2019.



3,000 INQUIRIES A YEAR

HELP & RESOURCE CENTER

We believe everyone with a genetic aortic condition should have easy access to trustworthy and compassionate guidance and information. In our community, answers and support are literally a call or email away.



1,500 ATTENDEES THIS YEAR

EDUCATIONAL OPPORTUNITIES

We believe that the latest education and information about Marfan, VEDS, Loeys-Dietz, and other genetic aortic conditions should be easily available. Regional Symposiums and webinars bring together experts and those who need their information the most.



536 ATTENDEES THIS YEAR

ANNUAL CONFERENCE

We believe that Annual Conference is the most powerful way we can support our community of patients, caregivers, and physicians. People of all ages and experiences connect at Annual Conference to build networks of support that last a lifetime.



145 ATTENDEES THIS YEAR

CAMP VICTORY

We believe that summer camp is a wonderful way to normalize a childhood that includes a genetic aortic condition. Nothing can build confidence and spark joy like swimming, archery, and boating with new friends in a safe and accommodating environment.



RESEARCH

The Marfan Foundation research grant program reflects our commitment to advancing medical and quality of life issues for people with Marfan syndrome and related conditions. Additionally, the Foundation continues to fund two critical long-term projects, the Aortic Valve Sparing Operative Outcomes Study and the Marfan and Related Conditions International Patient Registry, which is a collaboration with Backpack Health.

In 2019 The Marfan Foundation granted \$1.5 million in research, with half of it for new grants that will address issues for people with Marfan syndrome, thoracic aneurysm syndrome, and Ehlers-Danlos syndrome. They are in the areas of exercise, lung function, gastrointestinal issues, and cardiovascular disease.

Thanks to the ongoing support of donors and the medical community, opportunities for progress continue to expand for the Marfan and related conditions community.

2019 GRANTS

► Faculty Grants

Enid Neptune, MD – Johns Hopkins University
\$100,000 2-year grant

Dieter Reinhardt, PhD – McGill University
\$100,000 2-year grant

Irani Kaikobad, MD – University of Iowa
\$100,000 2-year grant

► Early Investigator Grant

Benjamin Landis, MD – Indiana University
\$75,000 2-year grant

► Victor McKusick Fellowship Grants

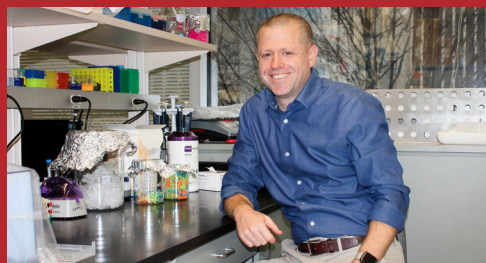
Aline Verstraeten, PhD – University of Antwerp
\$100,000 2-year grant

Abhijnan Chattopadhyay, PhD – University of Texas Health Science Center at Houston
\$100,000 2-year grant

► Clinical Research Grants

Joanne DiFrancisco-Donoghue, PhD, RCEP
New York Institute of Technology
\$100,000 2-year grant

Shaine Morris, MD, MPH – Baylor College of Medicine and Texas Children's Hospital
\$100,000 2-year grant



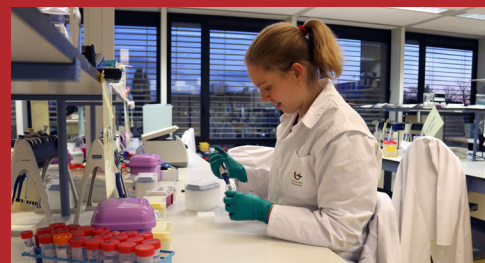
"The award from The Marfan Foundation will help propel my career as a physician-scientist committed to improving the condition of patients with aortopathy."

BENJAMIN LANDIS, MD – INDIANA UNIVERSITY
EARLY INVESTIGATOR GRANT



"The translational nature of this project may result in nutritional recommendations for individuals with Marfan syndrome in the longer term."

DIETER REINHARDT, PhD – MCGILL UNIVERSITY
FACULTY GRANT



"The project's anticipated outcomes are expected to significantly improve current thoracic aortic aneurysm insights and patient management."

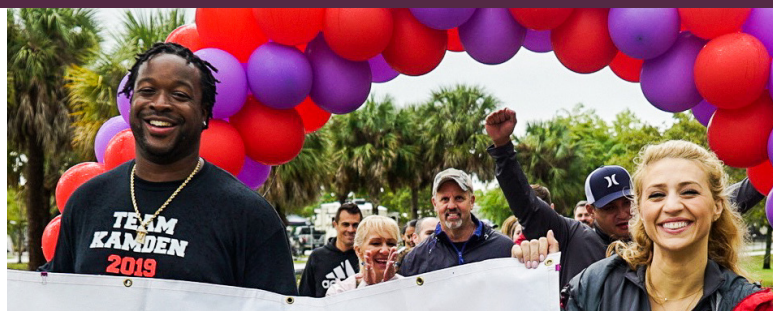
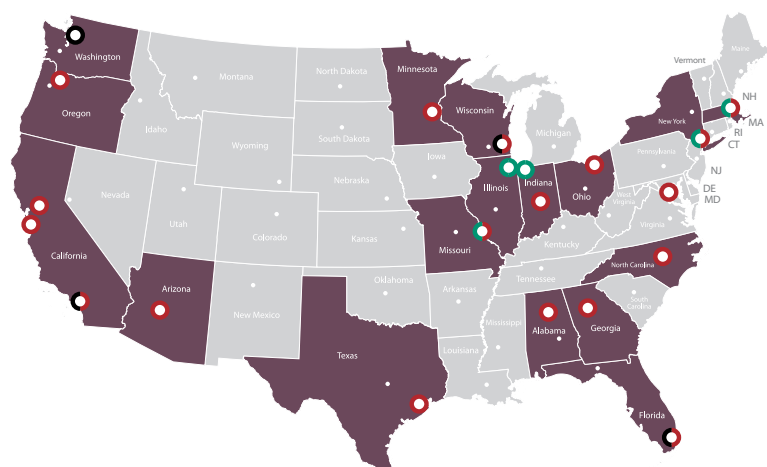
ALINE VERSTRAETEN, PhD – UNIVERSITY OF ANTWERP
MCKUSICK FELLOWSHIP

INDIVIDUAL
CORPORATE
HOSPITALS
VOLUNTEERS

POWER OF COMMUNITY

EVENTS IN 17 STATES

- 18 Walks for Victory
- 7 Special Events
- 4 Symposia



3,000 individuals joined Walk for Victory in 2018, raising \$750,000 toward creating a brighter future for those affected by Marfan and genetic aortic conditions.

But Walk for Victory is more than an opportunity to raise financial support – it helps individuals connect with a supportive and passionate community that understands life with a genetic aortic condition.

Through strategic partnerships, volunteer efforts, and your continued support, The Marfan Foundation is able to strategically leverage each dollar in support of our mission, guided by our values.

Please visit **Marfan.org/2019AnnualReport** for a full set of audited financials and supplemental Annual Report information.

Revenue Source	Percentage
Net Special Event	37%
Major Contributions	27%
Other Contributions	12%
Investment Income	6%
Gifts In-kind	6%
Direct Response	5%
Community Events	5%
Conferences & Symposia	2%
Management & Governance	9%

Category	Percentage
Research & Grants	39%
Patient Services	25%
Public Information	14%
Fundraising	13%
Management & General	9%
Other Contributions	2%

ORGANIZATION AWARDS





THE MARFAN FOUNDATION

STATEMENTS OF ACTIVITIES

Year Ended June 30, 2019

	Without Donor Restrictions	With Donor Restrictions	Year Ended June 30, 2019	Year Ended June 30, 2018
Changes in net assets:				
Revenues and gains:				
Major contributions	\$ 888,007	\$ 500,120	\$ 1,388,127	\$ 1,145,596
Other contributions	591,211	-	591,211	403,476
Direct response	254,832	-	254,832	283,922
Community events	251,589	9,065	260,654	188,242
Conferences and symposia	113,490	-	113,490	210,989
Net investment income	278,534	-	278,534	299,139
Events, net of expenses of \$440,331 and \$411,134, respectively	1,922,784	-	1,922,784	1,955,023
Change in value of beneficial interest in charitable remainder trust	-	21,825	21,825	45,559
Gifts in-kind	310,452	-	310,452	323,108
Net assets released from restriction	<u>1,332,075</u>	<u>(1,332,075)</u>	<u>-</u>	<u>-</u>
Total revenues and gains	<u>5,942,974</u>	<u>(801,065)</u>	<u>5,141,909</u>	<u>4,855,054</u>
Expenses:				
Program service expenses:				
Research initiatives and grants	2,231,543		2,231,543	2,271,491
Education and public awareness	816,548		816,548	830,703
Patient services and annual conference	<u>1,456,376</u>		<u>1,456,376</u>	<u>1,378,835</u>
Total program service expenses:	<u>4,504,467</u>	<u>-</u>	<u>4,504,467</u>	<u>4,481,029</u>
Supporting services:				
Management and general	525,714		525,714	525,590
Fundraising	<u>737,325</u>		<u>737,325</u>	<u>682,224</u>
Total supporting service expenses:	<u>1,263,039</u>	<u>-</u>	<u>1,263,039</u>	<u>1,207,814</u>
Total expenses	<u>5,767,506</u>	<u>-</u>	<u>5,767,506</u>	<u>5,688,843</u>
Increase (decrease) in net assets	175,468	(801,065)	(625,597)	(833,789)
Net assets, beginning of the year	<u>4,162,024</u>	<u>8,055,682</u>	<u>12,217,706</u>	<u>13,051,495</u>
Net assets, end of year	<u>\$ 4,337,492</u>	<u>\$ 7,254,617</u>	<u>\$ 11,592,109</u>	<u>\$ 12,217,706</u>



STATEMENTS OF FINANCIAL POSITION

June 30, 2019 and June 30, 2018

	June 30, 2019	June 30, 2018
ASSETS		
Cash and cash equivalents	\$ 641,800	\$ 777,754
Investments	6,552,335	6,438,849
Pledge receivables, net	2,775,803	3,373,109
Prepaid expenses and other current assets	212,186	171,431
Property and equipment, net	701,711	730,146
Beneficial interest in charitable remainder trust	1,087,721	1,065,896
Other assets	<u>104,997</u>	<u>80,600</u>
Total assets	<u>12,076,553</u>	<u>12,637,785</u>
LIABILITIES AND NET ASSETS		
Liabilities:		
Accrued liabilities	252,171	237,353
Deferred income	108,030	102,126
Other payables	104,997	80,600
Line of credit	<u>19,246</u>	<u>-</u>
Total liabilities	<u>484,444</u>	<u>420,079</u>
Net Assets:		
Without donor restrictions:		
General	2,926,080	2,441,548
Board designated	1,411,412	1,720,476
With donor restrictions:	<u>7,254,617</u>	<u>8,055,682</u>
Total net assets	<u>11,592,109</u>	<u>12,217,706</u>
Total liabilities and net assets	<u>\$ 12,076,553</u>	<u>\$ 12,637,785</u>

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