

# THE **MARFAN** FOUNDATION

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## ANNUAL REPORT 2021





## ► OUR MISSION

The Marfan Foundation is a nonprofit organization that saves lives and improves the quality of life of individuals with genetic aortic and vascular conditions including Marfan, Loeys-Dietz, and Vascular Ehlers-Danlos syndromes.

## ► 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:** Elliott Bobbe, of Kansas City, was diagnosed with Marfan at the age of three. His mom, Nikki, says, “The Foundation has been a significant resource in teaching and guiding us since Elliott was diagnosed.”



In this - our 40<sup>th</sup> year - The Marfan Foundation experienced unprecedented success and growth. Even in the face of an ongoing global pandemic, the Foundation not only survived - we thrived.

We knew that, while the world was changing because of the pandemic, life continued to provide the same challenges - even more - for the people in our community. We were determined from day one to be there for them. We put our strategies to work. Our resolve was undeterred.

Forty years of dedication to our three-pronged mission of education, research, and support - beginning with our Chair Emeritus Priscilla Ciccariello - combined with the strategic vision set forth by our Board of Directors led to a year in which our impact multiplied exponentially.

Our first full year with our new divisions, The VEDS Movement, Loeys-Dietz Syndrome Foundation, and GenTAC Alliance, resulted in considerable growth in the areas of education and support, awareness, and research.

We delivered dynamic, innovative, online programming that informed, empowered, and connected people with Marfan, Loeys-Dietz, VEDS, and other genetic aortic and vascular conditions. We expanded opportunities for connection internationally so that people did not feel isolated and alone, regardless of where they live, and the community became more engaged than ever before.

It was at this crucial juncture that we also relaunched our research grant program, which now offers our largest grant ever, the Everest Award.

Our financial position continued to be strong as well, due to the commitment from our supporters. Despite the challenges we faced, our reimagined strategies combined with creative execution resulted in our most successful fundraising year in our history.

**There is no secret to our success. The key ingredient is you, our community.**

Together with our Board of Directors, Professional Advisory Board, Scientific Advisory Board, volunteer leaders, and hospital and corporate partners, we are changing the world for people with Marfan, Loeys-Dietz, VEDS, and other genetic aortic and vascular conditions.

We are strongest together.

We thank you for going above and beyond at the most crucial time during the pandemic. Thank you for your support and confidence.

Sincerely,



Cory A. Eaves  
Chair, Board of Directors



Michael Weamer  
President & CEO



## AWARENESS

- Aortic Disease Awareness Week
- Marfan Awareness Month
- Loeys-Dietz Awareness Month
- VEDS Action Month



## SUPPORT

- Help & Resource Center facilitates more than 5,000 connections to information, experts, and other sources of support every year
- Virtual Support Groups reach more than 1,000 people who have registered for our 14 groups
- Marfan.org provides information and support to more than 1 million people annually

# OUR WORK

Our programs and  
services fuel  
connections  
globally



## EDUCATION

- Offered an array of medical education webinars
  - Surgical series during Marfan Awareness Month featured leading aortic surgeons from Cleveland Clinic, Massachusetts General Hospital, and Baylor-St. Luke's
  - Other webinars addressed: aortic imaging, lens surgery, headaches and migraines, adult cardiology
- Launched our new mental health program
- Debuted our Personal Perspective webinars addressing quality of life and mental health issues with a session on life after aortic surgery
- Comprehensive COVID-19 video and print resources specifically for our community



## CONNECTIONS

- We connect thousands of individuals and families to the 66 clinics around the country that offer experience and expertise in Marfan, LDS, VEDS, and other genetic aortic conditions
- We offer age-specific virtual opportunities for connection every month: Teen Chat and Kids Club
- Our social media platforms engage 68,000 people around the world



Social Media Impact

**TOTAL FOLLOWERS 68,000**





We first got involved with the Walk for Victory because of the unknown. If Marfan was going to be something we were going to have in our lives, we wanted to know more about it and meet other people who were living with it. Now, we want to help other people learn and connect. Living with Marfan or a related condition can be a daily struggle. You can see it on their faces. But then you also see the relief when they realize they aren't alone and are surrounded by others who understand.

~ Justin Efurd - Houston, Texas

# WALK FOR VICTORY

Walk for Victory had a different look in 2021

**1300 PARTICIPANTS**

**2 IN-PERSON**

North Carolina ~ Nashville

**17 VIRTUAL**

Orlando ~ Washington, DC ~ Canada ~ Global ~ Indiana  
South Florida ~ Atlanta ~ Pacific Northwest ~ NYC  
Michigan ~ Central NY ~ Phoenix ~ Texas ~ Minnesota  
Northern California ~ Southern California ~ Chicago



# International E<sup>3</sup> Summit

Educating, Empowering, and  
Enriching our Community

This three-week virtual educational program was  
the largest in the history of the Foundation.

2,840 ATTENDEES



373 PROFESSIONALS



95 PRESENTERS



75 COUNTRIES AROUND  
THE WORLD



70 PRESENTATIONS



54 MEDICAL SESSIONS



16 QUALITY OF LIFE SESSIONS



7 DIFFERENT LANGUAGES



## TOP REASON FOR ATTENDING

For **89%** of attendees, the top reason for attending  
E<sup>3</sup> was to learn medical information.

INTERNATIONAL  
**E<sup>3</sup> SUMMIT**

EDUCATING

EMPOWERING

ENRICHING

Powered by  
The Marfan Foundation and VASCERN

*"I thought I had a moderate amount of understanding. Now I realize how little I knew. Plus, there have been a lot of new treatments since my daughter was diagnosed 30 years ago. Knowledge is power and I want to keep up for her sake and my grandson."*

*"I still am in awe that I was able to hear from such world-renowned experts. Thank you so much for this opportunity. I now don't feel like such a tiny grain of sand swallowed up by the beach. My condition matters and there is hope."*





## GenTAC Alliance joined the Foundation in October 2020

**The GenTAC Alliance was established in 2017 to harness the synergy and collaborations** created by the GenTAC Registry (the National Registry of Genetically Triggered Thoracic Aortic Aneurysms and Related Cardiovascular Conditions), which was funded by NHLBI and NIAMS, and enrolled and followed over 3,600 patients from 2006 through 2016.

**The goals of the GenTAC Alliance** include enhancing collaboration of stakeholders to advance scientific discovery and clinical practice, and educating individuals and families, healthcare providers, and the general public about genetically-triggered thoracic aortic disease and related cardiac and non-cardiac complications.



*The Foundation has been an extraordinarily important partner and supporter of the GenTAC Registry and, subsequently, the GenTAC Alliance over the past 14 years. In fact, the Foundation's influence in promoting more investment in the science surrounding genetic aortic conditions was at the heart of the GenTAC Registry's creation by the National Institutes of Health in 2006. How fitting it is that the GenTAC Alliance has become part of the rapidly expanding global vision of The Marfan Foundation as together we seek to improve human health surrounding the many types of genetic aortic disorders. By promoting ground-breaking, collaborative research; providing education for care providers, patients, and families; and creating strategic partnerships around the world, the Alliance leverages the work of the Foundation and its partners.*

– Kim Eagle, MD, Director, Frankel Cardiovascular Center, University of Michigan, and Chair, GenTAC Alliance

## 2020 Aortic Summit

This biennial conference, which originated in 2009 as part of the mission of the GenTAC Registry, was created to share current knowledge of the scientific underpinnings of genetic aortic disease; review current best practices related to diagnosis and treatment; and to foster scientific and educational exchange between scientists, clinicians, institutions, and organizations interested in genetic aortic conditions.



Since the last Summit, our Working Group members have continued their commitment to advancing research, education, and treatment of heritable aortic diseases. Most recently, they shared their work and lead discussions at the virtual GenTAC Aortic Summit in October 2020.

**250 CLINICIANS, RESEARCHERS, SCIENTISTS**

**25 COUNTRIES AROUND THE WORLD**

*The GenTAC Aortic Summit is a unique opportunity to share/discuss new science and medicine with international colleagues and to network and collaborate as a 'benchmark' meeting for aortic disease.*

– Professor Toru Suzuki, MD, PhD, FRCP, FHEA, Chair of Cardiovascular Medicine, University of Leicester, England



## 40 YEARS OF RESEARCH & PROGRESS



*We wouldn't have been able to make this impact without the Foundation's support of our work. It allowed us to take on the pilot study, generate the preliminary data and build upon it, and, ultimately, put together an international consortium that could then build the groundwork for larger scale research towards the goal of improved long-term clinical outcomes for people with Marfan syndrome undergoing proximal aortic graft replacement surgery.*

*Innovative and ground-breaking research in any field cannot be done without pilot funding to support early-stage exploratory studies capable of producing long-term advances that improve clinical care. Large-scale federal research is important and ultimately necessary for this process, but it can't support the process in isolation. Funding from organizations such as The Marfan Foundation enables early-stage research to occur.*

*– Jonathan W. Weinsaft, MD, New York-Presbyterian Hospital, Weill Cornell Medical Center*



**40 YEARS OF RESEARCH & PROGRESS**

# 159 FUNDED GRANTS

~ SINCE 1986 ~

## 2020 RESEARCH GRANT PROGRAM

We are spending over **\$1.4 million** for **20 current studies** including **7 new research projects** which include: **5 in cardiovascular mechanisms** for Marfan and related conditions, **one in structural function studies** in VEDS, and **one in orthopedics** for Marfan.

### TYPES OF GRANTS AWARDED

- 1 Fellowship
- 4 Faculty Grant
- 1 Clinical Grant
- 1 Early Investigator

## UPDATED 2021 RESEARCH GRANT PROGRAM

Supports strategic focus on transformational science.

### NEW GRANT PROGRAM INCLUDES

#### Everest Award - 4 year

\$200,000 per year for a total of \$800,000

#### Innovators Award - 2 year

\$50,000 per year for a total of \$100,000

#### Career Development Award - 2 year

\$50,000 per year for a total of \$100,000

#### McKusick Fellowship - 2 year

\$50,000-\$75,000 per year with institutional match



## MEET TABORSKI

I was diagnosed with Marfan syndrome around the age of 12 years old while growing up in Meridian, Mississippi. My diagnosis was brought about due to poor vision, which, it turns out was caused by dislocated lenses in both eyes. This led to my first surgery related to Marfan syndrome and was the beginning of my life with the condition (four eye surgeries, a lung surgery, and aortic dissection surgery, so far).

When we found out that I had it, my family and I were shocked, scared, and a bit confused. I want to tell all young kids who have been diagnosed with Marfan syndrome or a related condition that you don't have to be afraid because there are people out there with the knowledge, medical expertise, and love for you that will help you and your family through this. You are not alone and there are people who can be with you step-by-step.

It has certainly not all been peaches and cream, but due to The Marfan Foundation and my doctors, life has been a lot easier. The key to winning over Marfan syndrome and any other condition is knowledge. Having the knowledge and awareness of my condition makes life for me and my family so much easier.



Loeys-Dietz<sup>TM</sup>  
Syndrome Foundation

## MEET LAUREL

*Photo by Robin Pagano Photography - Laurel, with her fiancé, Anthony.*



# THE VEDS MOVEMENT

## MEET AARON



I was diagnosed with VEDS in 2017 after my father passed away due to the condition. Other members of his family have since been diagnosed and after I had complications, I decided to get more involved in the VEDS community to help others with their journey as well as to further research.

The VEDS Movement has done an incredible job of not only raising awareness outside the VEDS community, but also giving people with VEDS the tools to navigate emergencies and everyday life. From providing people with information that explains VEDS to their doctors to helping individuals assemble their care teams, The VEDS Movement is creating a safer life for those with VEDS who might otherwise be scrambling for the information they really need.



### VEDS-Specific Programming

- DEFY VEDS Scientific Meeting
- Continuing Medical Education for doctors
- Virtual support groups
- Emergency Preparedness Kit
- Educational webinars
- VEDS track at E<sup>3</sup> Summit
- VEDS Birthday Bash
- VEDS Team at all Walks for Victory

I definitely felt out of place at times during my life, not knowing my identity when I was first diagnosed with Marfan...I had to change my lifestyle, had surgeries, and really felt untethered. Going to the annual conference and meeting people who looked similar to me and understood was so magical. I had a lot more confidence at the conference than in real life.

Two years ago, new genetic testing showed that I have Loeys-Dietz, not Marfan. With the LDS diagnosis, I attended a Loeys-Dietz Syndrome Foundation conference...The following year, the LDSF became part of The Marfan Foundation. I felt that I was reflected in that convergence. These are two big pieces of me, and now it's one bigger community.



### LDS-Specific Programming

- Monthly chats (virtual)
- Educational webinars
- LDS track at E<sup>3</sup> Summit
- LDS Team at all Walks for Victory
- First-ever Loeys-Dietz Awareness Day of Giving



# BOARD OF DIRECTORS



**Cory A. Eaves**  
Chair, NY

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# STATEMENTS OF ACTIVITIES

*Year Ended June 30, 2021*

Thanks to the hard work and the generosity of so many, the Foundation had its most impactful year in 2021. The support of our donors and medical community – combined with our success in securing a PPP loan and strong financial oversight – enabled the Foundation to effectively manage our resources and change more lives than ever before.

	Without Donor Restrictions	With Donor Restrictions	Year Ended June 30, 2021	Year Ended June 30, 2020
Changes in net assets:				
Revenues and gains:				
Major contributions	\$ 941,524	\$ 216,830	\$ 1,158,354	\$ 879,528
Other contributions	517,828		517,828	584,260
Direct response	342,421		342,421	247,236
Grant Revenue - PPP grant	491,000		491,000	-
Conferences and symposia	32,819	-	32,819	90,758
Community Events	266,384	-	266,384	242,660
Net investment income	756,463	-	756,463	140,881
Events, net of expenses of \$187,693 and \$101,692, respectively	1,923,708	-	1,923,708	1,503,868
Change in value of beneficial interest charitable remainder trust	-	166,900	166,900	(29,416)
Gifts in-kind	312,653	-	312,653	270,671
Net assets released from restriction	<u>1,038,867</u>	<u>(1,038,867)</u>	<u>-</u>	<u>-</u>
Total revenues and gains	<u>6,623,667</u>	<u>(655,137)</u>	<u>5,968,530</u>	<u>3,930,446</u>
Expenses:				
Program service expenses:				
Research initiatives and grants	1,836,644	-	1,836,644	2,791,437
Education and public awareness	908,165	-	908,165	886,210
Patient services and annual conference	<u>1,212,699</u>	<u>-</u>	<u>1,212,699</u>	<u>1,511,228</u>
Total program service expenses:	<u>3,957,508</u>	<u>-</u>	<u>3,957,508</u>	<u>5,188,875</u>
Supporting services:				
Management and general	484,778	-	484,778	516,693
Fundraising	<u>752,891</u>	<u>-</u>	<u>752,891</u>	<u>728,544</u>
Total supporting service expenses:	<u>1,237,669</u>	<u>-</u>	<u>1,237,669</u>	<u>1,245,237</u>
Total expenses	<u>5,195,177</u>	<u>-</u>	<u>5,195,177</u>	<u>6,434,112</u>
Change in net assets before Loeys Dietz Syndrome Foundation Contribution	1,428,490	(655,137)	773,353	(2,503,666)
Loeys Dietz Syndrome Foundation Contribution	<u>-</u>	<u>929,255</u>	<u>929,255</u>	<u>-</u>
Increase (decrease) in net assets	1,428,490	274,118	1,702,608	(2,503,666)
Net assets, beginning of the year	<u>3,655,508</u>	<u>5,432,935</u>	<u>9,088,443</u>	<u>11,592,109</u>
Net assets, end of year	<u>\$ 5,083,998</u>	<u>\$ 5,707,053</u>	<u>\$ 10,791,051</u>	<u>\$ 9,088,443</u>



# STATEMENTS OF FINANCIAL POSITION

June 30, 2021 and June 30, 2020

	June 30, 2021	June 30, 2020
<b>ASSETS</b>		
Cash	\$ 953,839	\$ 1,237,573
Investments	8,573,681	6,136,199
Pledge Receivables, net	554,347	1,706,703
Prepaid Expenses and Other Current Assets	309,031	208,691
Property and Equipment, net	665,147	668,901
Beneficial Interest in Charitable Remainder Trust	1,225,205	1,058,305
Other Assets	<u>186,289</u>	<u>130,399</u>
Total assets	<u>\$ 12,467,539</u>	<u>\$ 11,146,771</u>
<b>LIABILITIES AND NET ASSETS</b>		
Liabilities:		
Accrued liabilities	\$ 359,104	\$ 254,451
Deferred income	496,845	509,427
Other payables	189,289	131,950
Line of Credit	-	500,000
Grants payable	<u>631,250</u>	<u>662,500</u>
Total liabilities	<u>\$ 1,676,488</u>	<u>\$ 2,058,328</u>
<b>NET ASSETS</b>		
Without donor restrictions:		
General	\$ 3,535,983	\$ 2,526,611
Board designated	1,548,015	1,128,897
With donor restrictions	<u>5,707,053</u>	<u>5,432,935</u>
Total net assets	<u>10,791,051</u>	<u>9,088,443</u>
Total liabilities and net assets	<u>\$ 12,467,539</u>	<u>\$ 11,146,771</u>





# THANK YOU

In 2021, 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!

