CREATING CONNECTIONS : 2016–2017

THE **MARFAN**
FOUNDATION ANNUAL REPORT

OUR MISSION AND VISION

The Marfan Foundation creates a brighter future for everyone affected by Marfan syndrome and related disorders.

- We pursue the most innovative research and make sure that it receives proper funding.
- We create an informed public and educated patient community to increase early diagnosis and ensure life-saving treatment.
- We provide relentless support to families, caregivers, and healthcare providers.

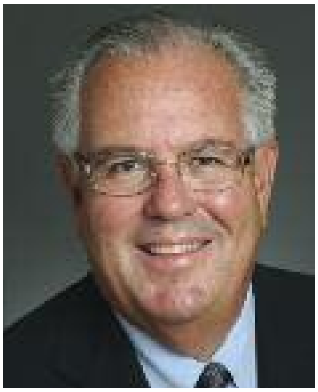
We will not rest until we've achieved victory—a world in which everyone with Marfan syndrome or a related disorder receives a proper diagnosis, gets the necessary treatment, and lives a long and full life.

In our mission to create a brighter future for everyone living with Marfan syndrome and related disorders, we hold a number of core beliefs and values that drive everything we do:

- We put families at the heart of what we do.
- We are vigilant in getting people diagnosed.
- We constantly push innovation forward.
- We create a path if there isn't a clear one.
- We build a welcoming and effective community.
- We have great hope, which is grounded in reality.

Photos appear courtesy of Timothy D. Joyce, as well as from our staff, community members, and research grant recipients.

LETTER FROM THE PRESIDENT AND CEO



> *Connection is the energy that exists between two people when they feel seen, heard, and valued; when they can give and receive without judgment; and when they derive sustenance and strength from the relationship.*
>
> – Brené Brown, University of Houston Professor

Nowhere is the energy of connection more evident than in the Marfan and related disorders community where our strength comes from the patients and families, clinicians and scientists, and the volunteers who are the life-blood of our organization. Bound together by a connective tissue disorder, we are an unstoppable force, with new accomplishments every year that help to create a brighter future for those affected by these potentially life-threatening conditions.

The Foundation made great strides in 2017 because of the support of our community, and we are proud to highlight them in this annual report. In the area of research, we remain committed to funding meritorious projects that investigate basic science, explore new treatments, study ways to prevent medical complications, and address the quality of life issues that impact the community. Importantly, we have funding mechanisms for researchers at every stage of their career, thus attracting young scientists to ensure continued interest in this area of study. The combined efforts of our seasoned researchers and young investigators give us great hope for critical advances in the years ahead.

This year, we expanded our signature programs and launched new programs that emphasize the power of connecting. We created more Walks for Victory and held additional Regional Symposiums in new areas of the country, and we broadened the scope of our annual conference. Additionally, we launched a new mentor program and piloted our Marfan Family Camp.

We also continue to strengthen our local community groups, offer new phone support groups, and provide more educational resources on medical and nonmedical issues through our website and Help & Resource Center. We are committed to the winning combination of connection and education. It is the key to creating a brighter future for all those in our community.

The relationships within the Marfan and related disorders community are stronger than ever. We have accomplished much in the fight for victory and, with your continued strength and support, we look forward to what lies ahead.

Karen Murray

Karen Murray
Chair, Board of Directors

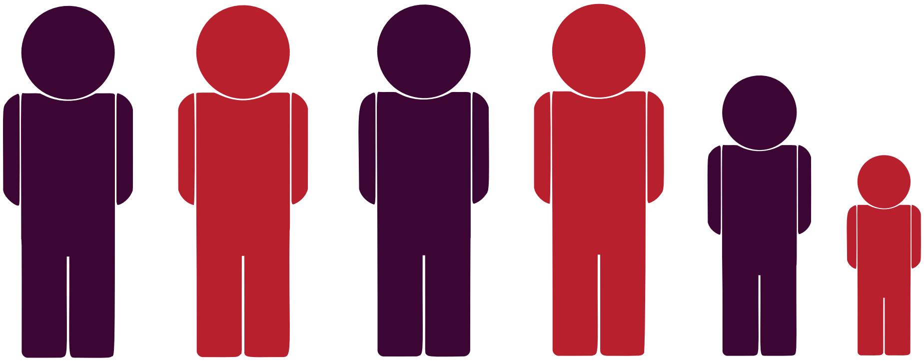
Michael L. Wea

Michael L. Weamer
President & CEO

CREATING CONNECTIONS NATIONWIDE

32ND ANNUAL
CONFERENCE

Our Annual Conference, hosted by Mayo Clinic in Rochester, MN, brought together the Marfan and related disorders community from all corners of the country and all over the world for four days of creating connections that left them better informed, more empowered, and feeling well-supported.



600 PEOPLE ATTENDED OUR CONFERENCE, INCLUDING 100 TEENS AND 100 CHILDREN

60 PHYSICIANS, GENETICISTS, AND OTHER MARFAN EXPERTS CAME FROM THE NATION'S LEADING HOSPITALS AND UNIVERSITIES TO SEE PATIENTS, LEAD WORKSHOPS, AND MAKE PRESENTATIONS.

Boston Children's Hospital
Until every child is well
JOHNS HOPKINS MEDICINE
MGH 1811 MASSACHUSETTS GENERAL HOSPITAL
UTHealth
The University of Texas Health Science Center at Houston
Ann & Robert H. Lurie Children's Hospital of Chicago
University of Washington School of Medicine
Washington University in St. Louis School of Medicine
Stanford MEDICINE
BWH BRIGHAM AND WOMEN'S HOSPITAL
UIC THE UNIVERSITY OF ILLINOIS COLLEGE OF MEDICINE [illegible]
Northwestern Medicine
Perelman [illegible]
THE UNIVERSITY of NORTH CAROLINA at CHAPEL HILL
Weill Cornell Medicine

PRESENTED IN ASSOCIATION WITH MAYO CLINIC

PRESENTED BY aetna FOUNDATION

WORKSHOPS ON QUALITY OF LIFE AND MEDICAL ISSUES

- Relaxation for Pain and Stress
- Mindfulness for Depression and Anxiety
- Staying Fit with Marfan
- Eating for Energy—Nutrition to Reduce Fatigue
- Cultivating Hope
- Gastrointestinal Issues
- Genetic Testing: Limits and Benefits
- Heart Issues in Children/Teens
- Growing Older with Marfan
- Pregnancy Cardiac Concerns

CONNECTING patients with experts in Marfan syndrome and related disorders from the country's top hospitals and universities

CONNECTING people with information and advice through medical presentations, small group workshops, and indvidual evaluations

“The free clinic is a blessing.”

“This conference means so much to me as a parent of a young child with Marfan syndrome.”

“I get so excited to see my teen having a good time with others his age who understand the condition.”

FAMILY CAMP

A long-time dream of the Foundation, to offer a camp for our Marfan kids, came to fruition this year. We piloted Marfan Family Camp in April 2017, with 25 children, ages 4–18, and their families at Camp Twin Lakes in Winder, GA (outside of Atlanta). During this three-day camp experience, families lived in cabins and, while parents took part in support groups, children participated in regular summer camp activities that were safe for them, such as archery, paddleboats, and swimming. Other activities were modified so that all could participate safely. There was a campfire and s'mores, plus special events, such as an Iron Chef competition.

> "It was important to have camp so that the kids could do things that they might not have had exposure to if they can't go to a traditional camp. The parents also got to talk and learn from each other and have those conversations that only other parents of kids with Marfan can truly understand."

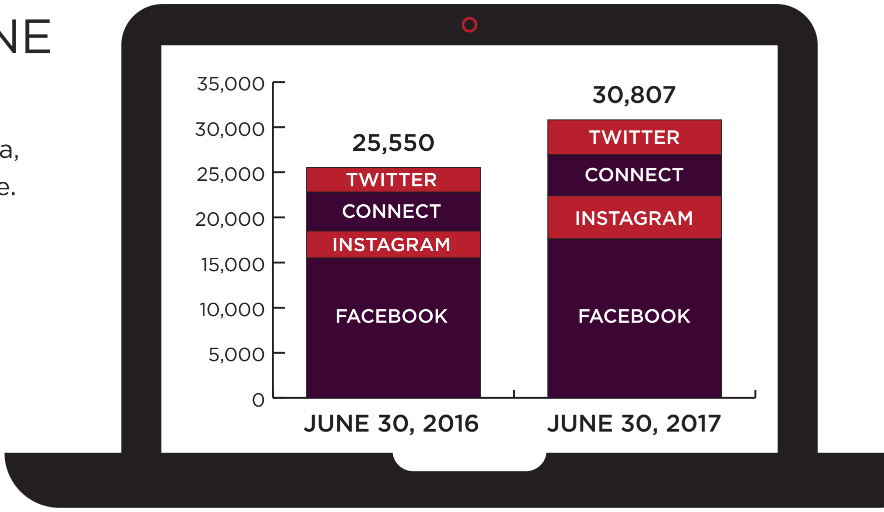
- **CONNECTING** children with a traditional summer camp experience
- **CONNECTING** parents with peers who truly understand

> "it was so fun meeting new friends with Marfan syndrome. No one even asked me why I needed a wheelchair to go long distances!"

> "Of course one can make friends at any sort of camp. But, to make a friend who understands Marfan is something Bobby wouldn't get anywhere else."

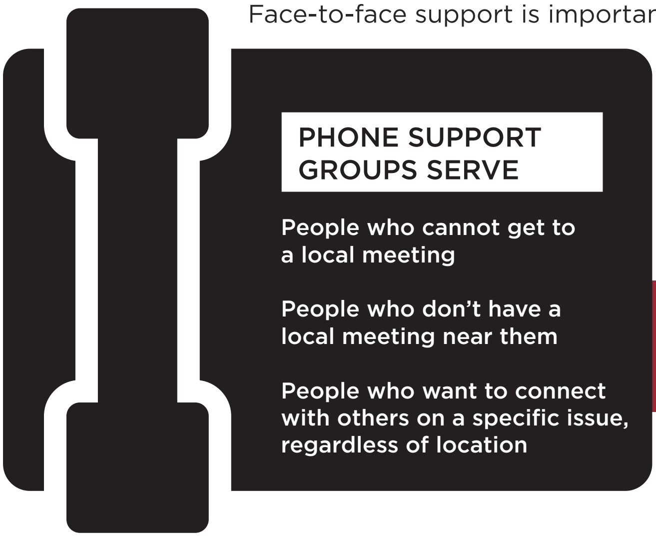
CONNECTING ONLINE

We continue to connect increasing numbers of people through social media, tapping into new platforms as they arise. In the last year alone, 20% more people connected through our social media channels. Users of our own website, Marfan.org, increased even more (37%).



CONNECTING THROUGH PHONE SUPPORT GROUPS

Face-to-face support is important, but sometimes it's not an option. Location, transportation and mobility may make attending a live support group difficult.



PHONE SUPPORT GROUPS SERVE

People who cannot get to a local meeting

People who don't have a local meeting near them

People who want to connect with others on a specific issue, regardless of location

30 PEOPLE PARTICIPATE EACH MONTH

ISSUE-BASED GROUPS INCLUDE THE NEWLY-DIAGNOSED, PEOPLE OVER 50, AND COPING WITH GRIEF AND LOSS

CONNECTING WITH MENTORS

Our newest offering, our mentor program, provides people living with Marfan syndrome or a related disorder a more formal way to connect with others to guide them through their journey. It is an opportunity to create supportive connections when you are newly diagnosed, facing a new challenge, or just need someone to talk to.

50 PEOPLE WERE MENTORED IN THE FIRST SIX MONTHS

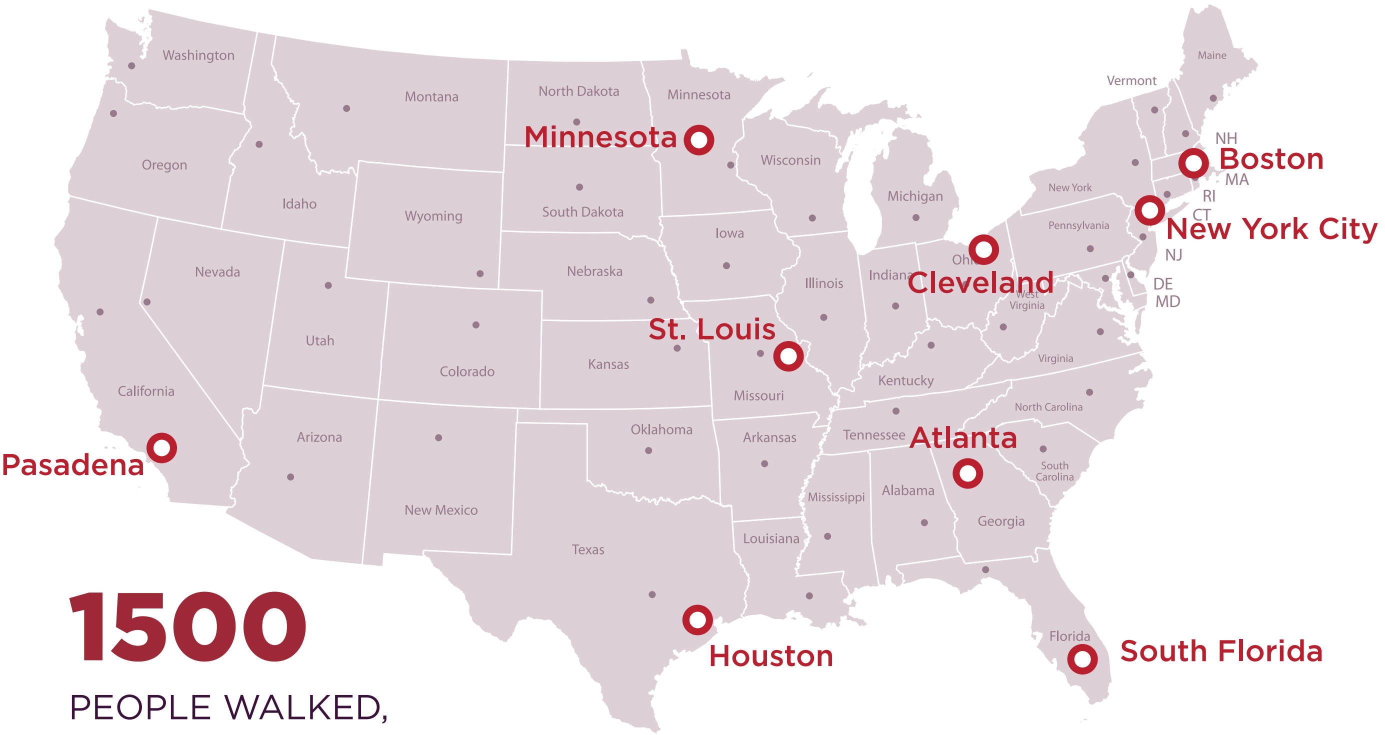
> "I'm happy to be a mentor to a teen with Marfan syndrome because I know what it's like to experience the highs and the lows, and how to combat those issues and live a complete life."

> "It is nice to talk with someone with Marfan to bounce ideas off of and perhaps come up with creative ways of dealing with certain Marfan related issues."

CREATING CONNECTIONS LOCALLY

WALK FOR **VICTORY**

At every walk there are people who have never met another person with Marfan syndrome; for them, the walk experience opens up a door to so many possibilities in their life. For those with Marfan and related disorders, it is revolutionary—they finally feel like their community understands them.



1500

PEOPLE WALKED, VOLUNTEERED, CHEERED, AND TOOK PART IN OTHER WAYS AT

9

WALK FOR VICTORY EVENTS AROUND THE COUNTRY

CONNECTING local residents who share a rare disease with one another for mutual support

CONNECTING our community with hospitals, sports teams, and businesses to raise awareness and funds

CONNECTING unaffected family members and friends with ways to support the patient population

CONNECTING people all across the country with The Marfan Foundation

"Just to know you're not alone and for the kids to feel 'normal' makes my heart happy!"

"Today was the kind of day that reminds us of the love and support we have from our family and friends!"

"For a few hours [at the Walk], we created a community that defies superlatives."

REGIONAL SYMPOSIUMS

Our Regional Symposium program was started three years ago to directly impact people around the country who are unable to travel to our annual conference. These one-day meetings feature many of the same types of programs as the annual conference—medical presentations, workshops, Creating Connections luncheon, and programs for teens and children.

300 ATTENDED **4** REGIONAL SYMPOSIUMS

> "The symposium introduced me to many wonderful people and opened up a wealth of knowledge I never knew was available to me."

> "My daughter is 25 and this was her first chance to meet other people with Marfan. It was very informative."

> "It was worth the trip just to be in a room with people like me."

> "It was empowering for my daughter to interact with other kids who know exactly what she is going through so that she realizes she isn't alone."

CONNECTING people with many of the benefits of our annual conference closer to home

CONNECTING AT THE NEW YORK CITY MARATHON

“Through the Foundation, we have found **a resource to keep us updated and to give us guidance and comfort** as we navigate ahead. We truly feel this is our new mission in life and want to do everything possible to help The Marfan Foundation further their research, advocacy, and education to ensure Lulu, and others, are able to live healthy and fulfilled lives.”

– Bryan Butvick, pictured with his wife, Sara Maher, after raising $35,670 for the Foundation at the 2016 New York City Marathon in honor of their young daughter, Lulu, who has Marfan.

CONNECTING AT BOSTON’S FENWAY PARK

“Connecting with other parents whose children have the same condition as our son has been tremendously helpful in not only assuring that we are getting the best care for our child, but also helping us find common ground with others who have gone through experiences similar to ours. **It’s a wonderful feeling knowing that we are not alone in this journey.**”

– Lynette Elam, at Marfan Awareness Night at Fenway Park in Boston

CONNECTING WHERE YOUR CHILD HAS SURGERY

“Not everyone is as fortunate as we are to have an extensive support network, which is so crucial when a child is hospitalized. Sydney and Carly realized this during Sydney’s many hospitalizations and then created the Sydney Lerman Pediatric Hospitality Program through the Foundation. Sydney and Carly want to let families know that they are not alone and, **even if they don’t have a support network, the Marfan family is there for them.**”

– Barbara Lerman, Sydney and Carly’s mom

CONNECTING THROUGH CHAPTERS AND GROUPS

47 LOCAL CHAPTERS AND GROUPS ACROSS THE COUNTRY

offer support groups, organize social events, conduct outreach and awareness programs, and provide medical education in their communities.

RESEARCH CONNECTIONS

Our accomplishments this year will result in critical scientific discovery and expand the continuum of care to drive best possible outcomes for people of all ages living with Marfan and related disorders. A record $1.5 million in funding extended the Foundation's prominence in Marfan syndrome and related disorders research and other scientific commitments. In addition, a new $5 million gift from Bloomberg Philanthropies will ensure a competitive pipeline of scientists including seasoned faculty, early investigators, and fellows.

27

GRANT PROPOSALS RECEIVED

4
Faculty Grants
3
Early Investigator Grants
1
Victor A. McKusick Fellowship Grant
1
Clinical Research Grant

9

GRANTS AWARDED

Areas of Research:

Eyes

Bones

Basic Science

Aortic Growth

Cardiac Surgery

$1.5 MILLION

INVESTED IN GRANTS AND OTHER RESEARCH COMMITMENTS

> "People with Marfan are living healthier, longer lives because of the research. My daughter lost her father when he was only 39. She is now 47 and looking forward to many more years of active living."

> "My son has Marfan. He faced life-saving surgery this past June. Knowing there is research being done is helping him and his wife get through this trying time of recovery."

CONNECTING scientists with funds to pursue research into Marfan and related disorders

CONNECTING researchers with one another to share ideas and findings and expand possibilities

CONNECTING the next generation of researchers with the resources needed to ensure a competitive pipeline of scientists

CONNECTING research and care to drive the best possible outcomes for affected individuals

James Foster, PhD
Johns Hopkins
School of Medicine
2017 Victor A.
McKusick
Fellowship Grant
Recipient

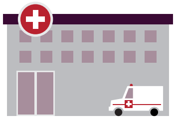
Gillian McLellan,
BVMS, PhD, DACVO
University of
Wisconsin-Madison
2017 Early
Investigator Grant
Recipient

Pascal Bernatchez, PhD
University of British
Columbia
2017 Faculty Grant
Recipient

THANK YOU

THANK YOU TO ALL OF OUR GENEROUS DONORS WHO MADE IT POSSIBLE FOR US TO HAVE OUR MOST SUCCESSFUL YEAR YET. YOUR CONTRIBUTIONS HELPED US PROVIDE NEW RESEARCH GRANTS, ENHANCE OUR EDUCATIONAL PROGRAMS, IMPROVE OUR QUALITY OF LIFE PROGRAMS, DEVELOP NEW RESOURCES, AND MAKE VITAL INFORMATION READILY ACCESSIBLE TO ALL WHO NEED IT. NONE OF THIS WOULD HAVE BEEN POSSIBLE WITHOUT ALL OF YOUR SUPPORT. EACH AND EVERY DONOR MAKES A DIFFERENCE IN OUR COMMUNITY AND WE ARE TRULY GRATEFUL FOR YOUR COMMITMENT TO THE MARFAN FOUNDATION.

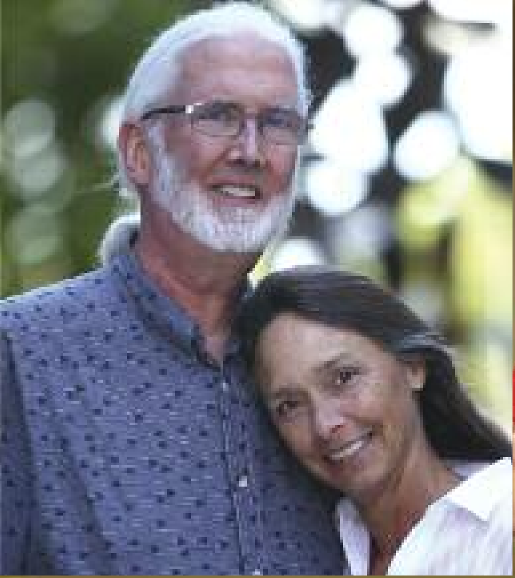
OUR DONORS INCLUDE HOSPITALS, CORPORATIONS, AND INDIVIDUALS.



16
HOSPITALS

280
CORPORATIONS

7,411
INDIVIDUALS



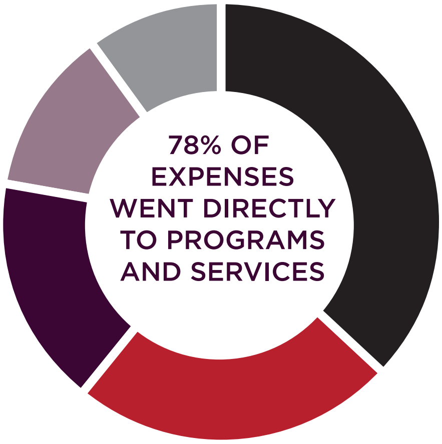
MAKING
FRIENDS,
SHARING
EXPERIENCES,
BONDING AS
FAMILIES,
SHARING
RESEARCH,
GETTING
TREATMENT...
THESE ARE
THE WAYS
YOUR SUPPORT
CREATES
CONNECTION.
THANK YOU!

FUNDING OUR MISSION

This past year, The Marfan Foundation continued our concerted effort to expand our fundraising strategies to provide additional resources to expand our life-saving programs and research. In addition, the Foundation decreased special event expenses while increasing program expenditures, resulting in 78% of every $1.00 being spent on mission, a 2% increase over the previous year.

The Foundation was successful in securing a multi-year $5 million pledge from Bloomberg Philanthropies to fund key research initiatives over the next five years. These initiatives include the faculty, fellowship, and early investigator grant programs, aortic surgery outcome studies, and creation of a patient and medical registry.

EXPENSES FY 2017



RESEARCH & GRANTS : 37%
PUBLIC INFORMATION : 17%
PATIENT SERVICES : 24%
FUNDRAISING : 12%
MANAGEMENT & GENERAL : 10%

SEAL OF TRANSPARENCY
2017 GOLD
GUIDESTAR

BBB
ACCREDITED CHARITY
give.org

REVENUES FY 2017

MAJOR CONTRIBUTIONS : 63%
NET SPECIAL EVENTS : 19%
OTHER CONTRIBUTIONS : 4%
DIRECT RESPONSE : 3%
ANNUAL CONFERENCE : 3%
INVESTMENT INCOME : 3%
GIFTS IN-KIND : 3%
COMMUNITY EVENTS : 2%

CHARITY NAVIGATOR
★★★★
Four Star Charity

STATEMENTS OF ACTIVITIES

Years Ended June 30, 2017, and June 30, 2016

	Unrestricted	Temporarily Restricted	**Year Ended June 30, 2017**	Year Ended June 30, 2016
Changes In Net Assets:				
Revenues and gains:				
Major contributions	$ 932,979	$ 4,605,010	**$ 5,537,989**	$ 825,244
Other contributions	327,475	26,140	**353,615**	432,719
Direct response	260,892	-	**260,892**	235,285
Community events	182,311	8,830	**191,141**	173,343
Annual conference	159,730	50,000	**209,730**	218,639
Other conferences and symposia	19,918	-	**19,918**	5,295
Net investment income	212,275	-	**212,275**	32,203
Events, net of expenses of $337,580 and $380,066	1,677,851	-	**1,677,851**	1,614,045
Change in value of beneficial interest charitable remainder trust	-	53,262	**53,262**	(12,101)
Gifts In-kind	264,177	-	**264,177**	248,585
Net assets released from restriction	741,143	(741,143)	**-**	-
Total revenues and gains	4,778,751	4,002,099	**8,780,850**	3,773,257
Expenses:				
Program service expenses:				
Research initiatives and grants	1,720,485		**1,720,485**	1,890,723
Education and public awareness	801,211		**801,211**	708,352
Patient services and annual conference	1,147,193		**1,147,193**	1,108,727
Total program service expenses:	3,668,889	-	**3,668,889**	3,707,802
Supporting services:				
Management and general	482,013		**482,013**	471,340
Fundraising	578,943		**578,943**	713,740
Total supporting service expenses	1,060,956	-	**1,060,956**	1,185,080
Total expenses	4,729,845	-	**4,729,845**	4,892,882
Increase (decrease) in net assets	48,906	4,002,099	**4,051,005**	(1,119,625)
Net assets, beginning of the year	4,062,128	4,938,362	**9,000,490**	10,120,115
Net assets, end of year	$ 4,111,034	$ 8,940,461	**$ 13,051,495**	$ 9,000,490

STATEMENT OF FINANCIAL POSITION

June 30, 2017, and June 30, 2016

	June 30, 2017	June 30, 2016
ASSETS		
Cash	**$ 459,043**	$ 604,429
Investments	**6,983,908**	6,677,308
Pledges receivable, net	**4,065,160**	219,958
Prepaid expenses and other current assets	**223,351**	124,696
Property and equipment, net	**660,404**	691,253
Beneficial interest charitable remainder trust	**1,020,337**	967,074
Other assets	**54,706**	29,758
Total assets	**13,466,909**	9,314,476
LIABILITIES AND NET ASSETS		
Liabilities:		
Accrued liabilities	**247,343**	147,606
Deferred income	**113,365**	136,622
Other payables	**54,706**	29,758
Total liabilities	**415,414**	313,986
Net Assets:		
Unrestricted:		
General	**1,945,282**	2,056,018
Board designated	**2,165,752**	2,006,110
Temporarily restricted	**8,940,461**	4,938,362
Total net assets	**13,051,495**	9,000,490
Total liabilities and net assets	**$ 13,466,909**	$ 9,314,476

The Foundation's complete audited financial statements for the years ended June 30, 2017, and June 30, 2016, may be viewed online at www.marfan.org or obtained by writing to The Marfan Foundation, 22 Manhasset Avenue, Port Washington, NY 11050.

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