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.**
Marfan syndrome and related disorders affect not only individuals but also the people who love them. We stand with and for the whole community.

**We are vigilant in getting people diagnosed.**
Too often Marfan syndrome and related disorders go undiagnosed. A diagnosis followed by proper treatment can save lives.

**We constantly push innovation forward.**
We are relentless in coming up with creative strategies to advance research, using state of the art tools to provide family support, and seeking the best ways to share the latest, most accurate information with our community.

**We create a path if there isn't a clear one.**
A community that has, in the past, felt lost, frustrated, or confused needs a strong leader. We constantly drive progress forward—through research, education, and support for our community.

**We build a welcoming and effective community.**
Partnerships are the key to victory, and we initiate collaborations with those who help us get there. And because we can achieve more by working together, our community welcomes people affected both by Marfan syndrome and other related disorders.

**We have great hope, which is grounded in reality.**
We are heartened by our advances in research, care, and awareness, and although we understand the many challenges before us, we see a bright future for everyone affected by Marfan syndrome and related disorders.
Dear Friends,

In a year in which our victories were many, we couldn’t be more proud of how everyone in our community came together to make life better for those living with Marfan syndrome and related disorders.

The Foundation continues to support the incredible research that is pursued by some of the most brilliant minds in science because we must ensure that affected people are getting the best medical treatments and surgeries so they can live longer lives.

This year, we also committed to more of a focus on quality of life because just living is not good enough for our community of 200,000 people in the U.S. affected by Marfan syndrome and related disorders. Despite the medications and surgeries—and sometimes because of them—their quality of life is severely impacted on a daily basis because of pain, depression, insurance problems, inability to work, financial instability, chronic medical issues, and a whole host of problems that lie outside the specific medical issues that are associated with Marfan syndrome.

We know that quality of life is influenced by many factors, including the connections you have within the community. “Creating connections” became our rallying cry because having a warm and welcoming community for laughing, crying, sharing, and rejoicing enhances quality of life. We saw our strong, unified community grow across the country—a community comprised of individuals and families; friends, neighbors, and co-workers; doctors, nurses, and hospitals; corporations and sports teams; and so many others who care about creating a brighter future for people with Marfan and related disorders.

Through our programs and services, we continue to strive to inform, educate, enlighten, and empower our individuals and families. This year, we expanded our geographic footprint so that more people can get involved and create connections. We’ve also expanded our partnerships and secured new collaborations that hold great promise for improving the lives of people in our Marfan and related disorders community.

We have witnessed a lot of “Marfan magic” this year, but there is still more to be accomplished. Many people continue to struggle with daily life with Marfan and related disorders and face new challenges because of the aging process.

Our team is well-positioned to expand our support, education, and research programs and—with the assistance of our many partners and supporters—we can continue to make life better for all those who are affected.

We are proud of the progress of the past year, and look forward to creating more Marfan magic in the year ahead. With your continued support, we can achieve more victories for the individuals and families in our community.

Karen Murray
Chair, Board of Directors

Michael Weamer
President & CEO
Marfan syndrome has been part of Riley’s family . . . always. Her mom, Dawn, has the condition and so does her older sister, Brooke. Riley, who is 13, and her dad, don’t have Marfan, but to say they are not affected by the condition would be inaccurate.

Riley has participated in Marfan Foundation events with her family as far back as she can remember. She always thought it was cool to see how other people are affected; they aren’t all like her mom and sister. She always looks forward to the annual conference because of the fun she’s had in the kids group and, more recently, with the teens. She’s made very close friends there—some are kids with Marfan and others are siblings, like she is.

Riley, who is very close with her sister despite the three year difference in age, appreciates that the Marfan family can give Brooke something that she can’t. “I like to see how Brooke bonds with people who have Marfan,” said Riley. “I can’t bond with her like that because I don’t have it. It makes me super happy to see her happy with her people.”

Heartworks St. Louis, a glamorous Saturday evening gala to benefit The Marfan Foundation, also has a special place in Riley’s heart. Her family has attended every year as part of the St. Louis Chapter contingent and, while it’s nice to see other chapter members, Riley is most appreciative of all the doctors who attend to support the Foundation.

“It’s really great to see the doctor who did my mom’s open heart surgery and get to know him as a person,” she said.

From Riley’s perspective, anything the family can participate in that raises awareness for Marfan and provides support for Brooke is a positive.

“It makes Brooke so happy,” said Riley. “I just want to see her happy.”
ADVANCING OUR MISSION FROM COAST TO COAST

**Awareness Events**

- **49**
- Volunteer groups around the country are committed to raising awareness of Marfan syndrome and related disorders through health fairs, school events, and other local activities.

**Fundraising Events**

- **27**
- From penny wars to chocolate sales, birthday fundraisers, and book sale fundraisers—individuals and families from coast-to-coast put their heads together to raise money for our life-saving programs and services.

**Patient Education**

- **13**
- Knowledge is power—that’s why many local community groups invite Marfan-knowledgeable healthcare providers to talk on a specific topic.
We Are Not Fighting Alone

When a little boy is the only one in his family with Marfan syndrome, it can be lonely for both the boy, who doesn’t know anyone else with the medical problem, and his parents, whose friends and other family members can’t relate. Enter The Marfan Foundation’s Walk for Victory. Steve, known around Houston as the Texans’ Ultimate Fan, did not realize what a game-changer the Houston Walk for Victory would be—not only for his son, Hunter, but also for Steve and his wife, Norah.

“Hunter looks like a normal kid, so people didn’t really know about this battle. Once I talked about it, I was amazed at the support. About 100 people from our ‘Texans Army’ came out and walked with us,” said Steve. “Our team raised about $12,000 for the Foundation, and that felt pretty special too.”

The connections the family made at the Walk for Victory are helping them as they continue to navigate Hunter’s Marfan journey. People know about Hunter’s struggles now, and they are providing more support. Norah’s been in touch with more Marfan moms than before; she’s even more in tune now to the issues Hunter may face with Marfan and has a support network to lean on as new challenges arise.

Steve and Norah are excited that the Walk for Victory has motivated the Houston Marfan and related disorders community to become more active. “There are other families here who are also dealing with the same medical issues we are,” said Steve. “And people are talking about Marfan now. Hunter won’t grow up in a town where it’s taboo.”

The Walk for Victory has led to more Marfan connections for the entire family—in Houston and online.

“Before this, we felt alone. There weren’t a lot of people we felt we could talk to,” said Steve. “Now we know. We are not fighting alone.”
More than 2,000 people participated in our Walks for Victory this year. They were led by our National Walk Ambassador, Isaiah Austin, the former Baylor University basketball star who was diagnosed with Marfan syndrome just prior to the 2014 NBA draft.

More than 2,000 people participated nationwide. They raised more than $330,000 for The Marfan Foundation.
**Annual Conference Is an Eye Opener**

The entire Case family is tall so William’s 6’10” Marfan frame is no big deal to his brother, Robert, who stands 6’4” and does not have Marfan syndrome. But at school, Robert knows that people are rude to his brother about his height. And they stare.

Robert says that Marfan is just part of their lives. William was diagnosed when he was young. Their mother has the condition as well. They have never known life any other way. Though the brothers are just a couple of years apart, Robert reports that they’ve always gotten along well. “We can’t fight with each other,” he said. “What if something happens?”

William and Robert have attended several of the Foundation’s annual conferences. Robert calls it “an eye opener” because he gets to see how everyone else deals with Marfan. He notes that William seems to act the same at school as at the conference, but the conference is definitely more fun.

“Everyone there knows why he’s tall. They don’t ask questions or stare. No one is rude,” says Robert. After the last conference they attended, Robert noticed that William came away even more accepting of Marfan—and proud of his height.

The two continue their strong bond, even though Robert is now away at college. They stay connected to each other and to their large group of Marfan friends online and videochat frequently. Every year, they add more teens to their group.

“I would encourage any teen with Marfan or a related disorder to come to the conference because they will meet lots of people going through the same thing as they are. They are not alone,” said Robert. “They might not know anyone when they get there, but by the time it’s over, they will have met others who will become some of their best friends in life. And they won’t want to leave.”
People from 36 states and from five other countries (Canada, Chile, Ireland, Israel, and Japan) attended the conference to learn about the diagnosis and management of Marfan and related disorders, hear the latest research, and create connections to enrich their support system. It is a highlight of the year, where people reconnect with old friends and make new ones.

This year was my second conference and it is becoming my favorite weekend of the summer. I leave so full of information and excitement over the people I’ve met and connected with. This conference means so much to me as a parent of a young child with Marfan syndrome. I have been filled with hope each year and can’t wait for my daughter to experience the amazing community that gathers together each year.
Connecting with People Who Get It

Jennifer had a feeling of mourning when her three-year-old twins, Aaron and Joshua, were diagnosed with connective tissue disorders that are related to Marfan. She knew they had a rough road ahead.

Early on, Jennifer found The Marfan Foundation online and learned about the Northern Illinois Chapter.

“I knew I had to navigate these waters and figure it out,” said Jennifer, “The chapter members helped me with local medical resources. In addition, I could connect with someone else who knew what it was like—who didn’t have the condition, but had affected kids who were the same age as mine.”

At first, Jennifer remained on the receiving end of the information and support. She attended the Foundation’s annual conference, made connections online, and became empowered to advocate more effectively for her children. When the boys were six and started school, she decided the time had come for her to give back.

Now, Jennifer is president of the local chapter and, while learning from each other is still paramount, there’s a social aspect to everything they do. The chapter’s activities, like their chili and chocolate social and their Costume Bowl for Victory, give everyone an opportunity to meet others with the same issues.

“Through the connections they make, kids and others realize that they are not alone,” said Jennifer.

The chapter doesn’t just attract families with children. They have a number of older people with Marfan who attend events. It gives hope to the parents who are new to the group when they see people living a long life with these conditions.

“When Aaron and Joshua were first diagnosed, I felt like the world was collapsing around me,” said Jennifer. “When I found the local chapter and the amazing people in the online Marfan community, I realized that someone gets it. You immediately feel the support and connection—and that’s what you need.”
Creating Connections

When you have a life-long medical condition, there is no doubt that creating connections in the community can enhance your quality of life. There is power and empowerment when you can share experiences with other people on the same medical journey.

Chapters and Community Groups

7 Chapters
46 Community Groups
A local presence in 31 states & Puerto Rico

Social Media Presence

15,500
CONNECT

2,700
Facebook

4,300

3,000
Twitter

Our presence on every social media platform increased this year—10% on CONNECT, our own social media platform, 20% on Facebook, 20% on Twitter, and more than 400% on Instagram.
Progress Is Only Made When We Test New Treatments

Jim was diagnosed in 1991 with a connective tissue disorder that put him at increased risk of aortic dissection. While it was a time of great hope in the treatment of aortic disease—beta-blocker therapy had proved its worth and surgical repair became available—promising new surgical procedures were still on the horizon. But they were not yet well understood or tested.

Five years later, when it was time for surgery on his aorta, Jim went to one of the foremost surgeons in the field who was performing an innovative operation that could preserve his aortic valve.

Although there was no data on the long-term safety and efficacy of this procedure, Jim had trust in the instincts and experience of his surgeon, who was one of the valve-sparing pioneers. He was also willing to take the risk because preserving the valve offered several benefits—above all, freedom from a blood-thinning medication that carries the risk of many side effects and requires lifestyle changes. The down-side would be the possible need for a re-operation in the future and a mechanical valve, but Jim figured he would take the chance.

In the meantime, The Marfan Foundation had begun funding a multi-year, multi-center study on valve-sparing aortic surgery that specifically looks at the safety and efficacy of the operation. Short-term outcomes proved positive in the initial stages of the study, and longer-term outcomes appear positive so far.

“It’s my strong feeling that progress is only made when caregivers and patients are prepared to test new and unknown treatments and when researchers measure and document the results,” said Jim.

In fact, valve-sparing aortic surgery is quickly becoming the standard of care for the next generation of children and adults with Marfan syndrome and related disorders—thanks to patients like Jim, who were willing to take a risk, innovative surgeons who are performing new and better operations, and funding provided by The Marfan Foundation.

Jim says he is “better off absolutely” because of his decision in 1996. A re-operation of the original procedure was eventually required, but it wasn’t until 2016.

“While a permanent fix would obviously have been preferable, I still had 20 extra years of freedom from blood thinners, which was double my estimated risk ‘break-even’ point,” he said. “During this time, additional techniques for the same operation have emerged that may make the surgery more durable. So my experience has helped to inform those who are seeking to improve the operation, which will benefit all those who come after me.”

“Valve-sparing aortic surgery represents another stepping stone of progress,” said Jim. “I’m delighted that the Foundation is supporting research that has a direct clinical impact on the patient community. As a result, we now have greater information to inform our medical decisions and improve patient outcomes.”
$1.2 MILLION IN RESEARCH FUNDING

THE RESEARCH WE FUNDED IN FY16

Cardiac Research

Investigate therapies for mitral valve prolapse, a leading cause of mortality in infants and children diagnosed with Marfan syndrome before age 4.

Identify blood biomarkers to monitor aortic root size.

Test new therapeutic options on aneurysm growth.

Study whether or not regular exercise improves aortic health.

Develop a new animal model of aortic aneurysm using zebrafish.

Investigate the relationship between abnormally shaped arteries, the size of aneurysms, and their likelihood of dissection.

Quality of Life

Explore coping skills in adolescents with Marfan syndrome.

Orthopedic

Look into the role of proteins in muscle weakness and loose joints seen in Marfan syndrome.

Related Disorders

Study the role of proteins in Beals syndrome.
Thank you to all of our generous donors who made it possible for us to have our most successful year to date. Your contributions helped us provide new research grants, enhance our educational programs, improve our quality of life programs, develop new resources, and make 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.
The Marfan Foundation takes a very deliberate, strategic approach to fundraising and plans ahead for major expenditures, particularly in the area of research.

In 2016, the Foundation’s ongoing commitment to funding several multi-year research studies and initiatives—including the faculty, fellowship, and early investigator grant programs and aortic surgery studies—has continued to be financed by previously raised funds dedicated for these purposes. This, once again, resulted in a planned deficit as we spent down these funds, using them for the purposes for which they were raised. Although this resulted in an overall deficit, there was an operating surplus represented by an increase in unrestricted net assets of $5K for the year.
## STATEMENTS OF ACTIVITIES

**Years Ended June 30, 2016, and June 30, 2015**

### Changes In Net Assets:

#### Revenues and gains:

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Year Ended June 30, 2016</th>
<th>Year Ended June 30, 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>$1,451,032</td>
<td>$142,350</td>
<td>$1,593,382</td>
<td>$1,718,222</td>
</tr>
<tr>
<td>Memorials</td>
<td>73,209</td>
<td>73,209</td>
<td>218,639</td>
<td>214,560</td>
</tr>
<tr>
<td>Annual Conference</td>
<td>218,639</td>
<td></td>
<td>218,639</td>
<td>214,560</td>
</tr>
<tr>
<td>Other conferences and symposia</td>
<td>5,295</td>
<td>5,295</td>
<td>107,915</td>
<td></td>
</tr>
<tr>
<td>Net investment income</td>
<td>32,203</td>
<td></td>
<td>21,074</td>
<td></td>
</tr>
<tr>
<td>Events, net of expenses of $380,066 and $382,798</td>
<td>1,614,045</td>
<td></td>
<td>1,614,045</td>
<td>1,418,022</td>
</tr>
<tr>
<td>Change in value of beneficial interest charitable remainder trust</td>
<td></td>
<td>(12,101)</td>
<td>(12,101)</td>
<td>(10,352)</td>
</tr>
<tr>
<td>Gifts In-kind</td>
<td>248,585</td>
<td>248,585</td>
<td>496,685</td>
<td></td>
</tr>
<tr>
<td>Net assets released from restriction</td>
<td>1,255,062</td>
<td>(1,255,062)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total revenues and gains</strong></td>
<td>4,898,070</td>
<td>(1,124,813)</td>
<td><strong>3,773,257</strong></td>
<td><strong>4,056,832</strong></td>
</tr>
</tbody>
</table>

#### Expenses:

**Program service expenses:**

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Year Ended June 30, 2016</th>
<th>Year Ended June 30, 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research initiatives and grants</td>
<td>1,890,723</td>
<td>1,890,723</td>
<td>1,885,273</td>
<td>1,885,273</td>
</tr>
<tr>
<td>Education and public awareness</td>
<td>708,352</td>
<td>708,352</td>
<td>866,572</td>
<td>866,572</td>
</tr>
<tr>
<td>Patient services and annual conference</td>
<td>1,108,727</td>
<td>1,108,727</td>
<td>1,098,465</td>
<td>1,098,465</td>
</tr>
<tr>
<td><strong>Total program service expenses:</strong></td>
<td>3,707,802</td>
<td>-</td>
<td><strong>3,707,802</strong></td>
<td><strong>3,850,310</strong></td>
</tr>
</tbody>
</table>

**Supporting services:**

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Year Ended June 30, 2016</th>
<th>Year Ended June 30, 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management and general</td>
<td>471,340</td>
<td>471,340</td>
<td>540,875</td>
<td>540,875</td>
</tr>
<tr>
<td>Fundraising</td>
<td>713,740</td>
<td>713,740</td>
<td>543,848</td>
<td>543,848</td>
</tr>
<tr>
<td><strong>Total supporting service expenses</strong></td>
<td>1,185,080</td>
<td>-</td>
<td><strong>1,185,080</strong></td>
<td><strong>1,084,723</strong></td>
</tr>
<tr>
<td><strong>Total expenses</strong></td>
<td>4,892,882</td>
<td>-</td>
<td><strong>4,892,882</strong></td>
<td><strong>4,935,033</strong></td>
</tr>
</tbody>
</table>

**Increase (decrease) in net assets**

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Year Ended June 30, 2016</th>
<th>Year Ended June 30, 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5,188</td>
<td>(1,124,813)</td>
<td>(1,119,625)</td>
<td>(878,201)</td>
</tr>
<tr>
<td><strong>Net assets, beginning of the year</strong></td>
<td>4,056,940</td>
<td>6,063,175</td>
<td>10,120,115</td>
<td>10,998,316</td>
</tr>
<tr>
<td><strong>Net assets, end of year</strong></td>
<td><strong>4,062,128</strong></td>
<td><strong>4,938,362</strong></td>
<td><strong>9,000,490</strong></td>
<td><strong>10,120,115</strong></td>
</tr>
</tbody>
</table>
## STATEMENT OF FINANCIAL POSITION

June 30, 2016, and June 30, 2015

| ASSETS                                                                                                                                 |
|---------------------------------------------------------------------------------------------------------------------------------------|-----------------|------------------|
| **Cash**                                                                                                                              | $ 604,429       | $ 886,725        |
| **Investments**                                                                        | 6,677,308       | 6,599,015        |
| **Pledges receivable, net**                                                          | 219,958         | 1,062,550        |
| **Prepaid expenses and other current assets**                                         | 124,696         | 121,498          |
| **Property and equipment, net**                                                       | 691,253         | 796,233          |
| **Beneficial interest charitable remainder trust**                                   | 967,074         | 979,175          |
| **Other assets**                                                                     | 29,758          | 163,016          |
| **Total assets**                                                                      | 9,314,476       | 10,608,212       |

| LIABILITIES AND NET ASSETS                                                                                                               |
|---------------------------------------------------------------------------------------------------------------------------------------|-----------------|------------------|
| **Liabilities:**                                                                                                                       |                 |                  |
| **Accrued liabilities**                                                                                                                  | 147,606         | 166,111          |
| **Deferred income**                                                                                                                     | 136,622         | 158,970          |
| **Other payables**                                                                                                                      | 29,758          | 163,016          |
| **Total liabilities**                                                                                                                   | 313,986         | 488,097          |

**Net Assets:**                                                                                                                         |

| Unrestricted:                                                                                                                          |                 |                  |
| **General**                                                                                                                           | 2,056,018       | 2,141,921        |
| **Board designated**                                                                                                                   | 2,006,110       | 1,915,019        |
| **Temporarily restricted**                                                                                                             | 4,938,362       | 6,063,175        |
| **Total net assets**                                                                                                                   | 9,000,490       | 10,120,115       |

| **Total liabilities and net assets**                                                                                                   | $ 9,314,476     | $ 10,608,212     |

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*The Foundation’s complete audited financial statements for the years ended June 30, 2016, and June 30, 2015, 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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