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,

Every day we work towards creating a brighter future for everyone living with Marfan syndrome and related disorders. Every day we strive towards victories for people of every age in our community; for those who are seeking diagnosis, newly diagnosed, and facing medical decisions; and those who are learning to navigate the complexities of living with a chronic and progressive condition. This year was punctuated by triumphs that gave our community comfort, gave them hope, and gave them new tangible ways to live a better and longer life.

In every area of our mission—support, education, and research—we achieved significant progress. Together with our volunteers throughout the country, the expanding base of researchers and clinicians committed to advancing treatment of connective tissue disorders, and our numerous business, hospital, and government partners, we fought for victories and are proud to highlight our accomplishments in this report.

This year, the results of breakthrough research we facilitated gave patients a new medical therapy to slow or prevent major cardiovascular complications. We took awareness to new heights, using innovative strategies to reach previously under-served groups of people. We expanded our education offerings so that people are better equipped to advocate for themselves with the most up-to-date information on their condition. We continued to support our volunteers and group leaders so they are empowered to fuel grass roots efforts that provide community and camaraderie for people in the Marfan community from coast to coast.

The resulting impact of the year’s activities is illustrated best by the stories we hear from members of our community. The dad whose son was diagnosed after learning about the signs of Marfan syndrome on television and can now get life-saving medical treatment. The mom who knows that her child can have a happy and productive future after meeting older members of our community at our annual family conference. The family that no longer feels alone after meeting other families on the same medical journey at a local event. The individual who has lived for decades with Marfan syndrome who has an opportunity to discuss ongoing challenges and solutions with others in the same age group in one of our phone support groups.

Victories big and small define the year we had. Yet we have not reached the finish line. We are continually driven to identify new strategies to ensure that all in our community are diagnosed, all receive appropriate medical management, and all feel empowered and supported to have a great life, despite the condition they live with every day.

This year of victories sets the stage for exponential growth. The stakes are high because lives are still at risk. With new partners, expanded resources, and dynamic strategies, we have no doubt that our community will continue to make great strides in our quest to create a brighter future for all those living with Marfan and related disorders. We are proud to be part of this life-changing organization and this incredible community, and we are grateful for your ongoing support in our fight for victory.

Karen Murray
Chair, Board of Directors

Michael Weamer
President & CEO
The aortic complications of Marfan syndrome are the most frightening for our patient population. Options for slowing the disease process in the fragile aorta of these patients have been limited—until now.

Beta-blockers have been the mainstay of treatment for 30 years. Now, there is another option that has been shown to equal beta-blockers in effectiveness: losartan. The results of a multi-center clinical trial conducted by the Pediatric Heart Network and several leading Marfan clinics around the country on the two drugs confirmed equal effectiveness. The study also opened the door to new questions that will continue to advance the understanding of Marfan syndrome and how it affects the cardiovascular system.

The support of our research grant program has attracted a broader base of researchers—from young scientists to those who are more established—who are driven to unlock the mysteries of Marfan and identify new treatments. Moreover, the new pathways identified through basic research and our focus on cardiac and non-cardiac issues draw researchers from a variety of research backgrounds who are motivated to collaborate with us to advance this body of work.

FACULTY AWARDS: $380,000

- Apolinker P144: A Potential anti-TGF-b Therapeutic Tool to Fight Against Aortic Aneurysms in Marfan Syndrome. Gustavo Egea, PhD, Institut d’Investigacions Biomediques August Pi i Sunyer.

- Zebrafish Models of Human Fibrillinopathies. Christina Gurnett, MD, PhD, Washington University School of Medicine.

- Endothelial Dysfunction as the Trigger of Aortic Aneurysm in the Marfan Syndrome. Francesco Ramirez, PhD, Icahn School of Medicine at Mount Sinai.

- Genetic Interrogation of the Role of LTBPs in Aortic Aneurysms. Daniel Rifkin, PhD, New York University School of Medicine.

EARLY INVESTIGATOR AWARDS: $225,000


- Role of Caveolin-1 in the Progression of Aortic Aneurysm in Marfan Syndrome. Mitra Esfandiarei, PhD, Midwestern University (pictured above).

- Predictive Value of Inflammation and Arterial Stiffness in Thoracic Aortic Aneurysm. Parmanan Singh, MD, Weill Cornell Medical College.

MCKUSICK FELLOWSHIP AWARD: $100,000

- Systems Biology of TGF-b in Vascular Complications of Marfan Syndrome. Lakshmi Venkatraman PhD, Beth Israel Deaconess Medical Center.
THE DOSTALIK FAMILY WAS AMONG THE FIRST TO ENROLL THEIR DAUGHTER, HALEY, NOW 16, IN THE CLINICAL TRIAL. HER MOTHER, KARI, SAID, "HAVING TWO GOOD CHOICES FOR TREATMENT IS A WONDERFUL OUTCOME OF THE TRIAL. WE'RE EXCITED TO SEE WHAT THE FUTURE HOLDS FOR OUR DAUGHTER AND OTHERS WITH MARFAN SYNDROME AS THESE TERRIFIC RESEARCH INITIATIVES CONTINUE!"
There is no doubt that people can live long lives with Marfan syndrome and related disorders. However, this is only possible if they are diagnosed and treated according to the most up-to-date medical knowledge. That's why awareness is so critical. Awareness of the signs of Marfan and related disorders. Awareness of the proper exams for an evaluation and accurate diagnosis. Awareness of where to turn for support and community.

“Know the signs” is our battle cry, and that's exactly where the National Basketball Association (NBA) scored high as they were able to identify that Isaiah Austin, one of the projected top selections in the 2014 draft, had Marfan syndrome. Thrust into the spotlight because of his career-ending diagnosis, Isaiah teamed with The Marfan Foundation to heighten awareness of the condition and disseminate our messages among audiences that were not previously aware of Marfan syndrome. Isaiah embraced his diagnosis and change in career path with grace and dignity. His messages about his desire to live a great life with Marfan resonated broadly.

Coverage of Isaiah in media ranging from ESPN and Sports Illustrated, to the Wall Street Journal and Scientific American, to People Magazine and television stations and newspapers around the country put “Marfan syndrome” on the radar of thousands of people nationwide. Our website hits increased nearly tenfold in the first month after Isaiah was diagnosed and inquiries to our Help & Resource Center doubled.

While Isaiah’s physical attributes, which are characteristic of Marfan syndrome, led many people to be evaluated and diagnosed, his grace, demeanor, and acceptance of his new path in life rejuvenated many with Marfan and related disorders who were already diagnosed and, in some cases, struggling with their outlook for the future. By telling his story in the media and becoming part of the Marfan community—which Isaiah calls his “Marfamily”—he encouraged people to pursue their dreams and inspired them to achieve new heights, despite their diagnosis.

Public awareness literally saved the life of Owen Gray, left, a teen from Houston. He and his dad, Rod, were watching the 2014 NBA draft on television and learned about Marfan syndrome when NBA Commissioner Adam Silver made Isaiah Austin an honorary draft pick. Rod took note of Isaiah’s features and thought that Owen shared many of them. The next day, he took Owen to the doctor, starting an array of medical exams; Owen soon received his life-saving diagnosis. Like Isaiah, Owen had to stop playing basketball. Owen says, “You can make it your excuse or make it your purpose.” Grateful for his diagnosis, Owen is now focused on raising awareness of Marfan syndrome and reaching out to other teens living with the condition, so they too can plan for a great life.
WHEN THE BOSTON CELTICS HONORED ISAIAH AUSTIN AT THEIR 2014 SEASON OPENER, IT WAS AN OPPORTUNITY FOR THE MARFAN SYNDROME AND RELATED DISORDERS COMMUNITY TO COME TOGETHER FOR AN EVENING OF HOPE, PRIDE, AND CONNECTION.
We put individuals and families at the heart of all we do. This means providing them with the information and support they need to navigate daily life with a complex and ongoing genetic disorder that may affect one person in their family or many of their loved ones.

Our website, Marfan.org, provides the most up-to-date and accurate information about Marfan syndrome and related disorders, including how the conditions are diagnosed and treated in children and adults. It also addresses concerns that are specific to teens and to parents of affected children.

Beyond the website, people can contact the Foundation for personalized service. Our Help & Resource Center is a lifeline for the Marfan and related disorders community, whether they are seeking evaluation, facing surgery, or looking for effective ways to deal with everything from schools to health insurance. We have a licensed social worker and a registered nurse on staff who can provide answers specific to the needs of our community.

“I HAD NO IDEA WHAT TO DO WHEN MY DAUGHTER WAS DIAGNOSED. I CONTACTED THE FOUNDATION AND THEY GUIDED ME TO THE ANSWERS THAT I NEEDED.”
THE FOUNDATION CONTINUES TO PROVIDE INFORMATION AND SUPPORT TO THE SPANISH-SPEAKING MARFAN AND RELATED DISORDER COMMUNITY. JOSIE VILLARUBIA, PICTURED HERE WITH HER DAUGHTER, NICOLE, HAS PLAYED A PROMINENT ROLE, RUNNING WORKSHOPS IN SPANISH AT THE FOUNDATION’S ANNUAL CONFERENCE.
ANNUAL CONFERENCE
Nowhere is community victory more evident than at our annual conference, which is held every summer. The four-day event is unique in that it features a patient evaluation clinic for those seeking answers about their medical care from our Marfan-knowledgeable doctors, as well as medical presentations and small group workshops that inform and empower, and networking opportunities for all. In addition, we provide comprehensive children and teen programs, as well as a young adult program, that cater to the needs of the different age groups. It is a life-changing experience as people from all corners of the country—and from all over the world—are filled with knowledge and support that can carry them through their medical journey. Equally important, they come away with a sense of hope and belonging, knowing that our patient community and medical community are there to support them at every step of the way.

2014 ANNUAL CONFERENCE ATTENDEES

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults</td>
<td>335</td>
</tr>
<tr>
<td>Young Adults</td>
<td>39</td>
</tr>
<tr>
<td>Teens</td>
<td>86</td>
</tr>
<tr>
<td>Kids</td>
<td>70</td>
</tr>
<tr>
<td>Medical Professionals/Clinic Observers</td>
<td>27</td>
</tr>
<tr>
<td>TOTAL</td>
<td>557</td>
</tr>
</tbody>
</table>

This year, we celebrated our 30th annual conference at Johns Hopkins Hospital, which has hosted the most Marfan conferences to date. Victories were everywhere:

- Teens embraced their diagnosis after interacting with Isaiah Austin and hearing him speak about his drive to dream again.
- Parents of affected children gained hope as they learned about breakthrough research on medications now available for treating the life-threatening aspect of Marfan syndrome and related disorders, the enlarging aorta.
- Those in our mature population discussed ways to cope with aging with a chronic and progressive condition.
- Individuals and families got the answers they needed to their medical questions and had full confidence in the treatment guidance given to them by the Marfan experts at our free patient evaluation clinic.
- People of all ages from all over the country connected with others facing the same medical challenges, creating bonds that are sure to last a lifetime.
THOSE IN OUR MATURE POPULATION ARE AN INSPIRATION TO THE YOUNGER MEMBERS OF OUR COMMUNITY AND GIVE THEM HOPE FOR THE FUTURE.
WALK FOR VICTORY
This year, our Walk for Victory program, which is only a year old, expanded to include five states: Arizona, Georgia, Massachusetts, New York, and Missouri. The centerpiece of each Walk for Victory is a 1K fun walk, but the real focus of the day is community. People who have attended one of theWalks for Victory have told us that it is priceless to know that you are not alone with your diagnosis and you have the support of your family and friends. The Walk for Victory in each area has been filled with food, fun, friendship, and festivities. In addition, in only the second year of the program, they have raised more than $75,000 for the Foundation’s lifesaving programs and services.

COMMUNITY GROUPS
We continued to expand our network of local community groups this year, establishing new groups in North Carolina, Wisconsin, and Colorado, making our community stronger from coast to coast.

“I can’t cry anymore, but I can speak up. I can talk about Marfan syndrome and I can help raise awareness and money in hopes that my husband and daughter, along with all those out there with this condition, will have a better life. We don’t have any surgeries in the near future and we have an opportunity to get together with others in our community and let them know about Marfan syndrome.”

– Nicole Kramer, of Long Island, on her experience at the Long Island Walk for Victory.

Whether they were listening to local medical experts give presentations or getting together for a social gathering, people who participated in local events benefitted from the connections they made within the Marfan and related disorders community in their area. Not only did the groups meet to help each other, but they also worked together to raise awareness of Marfan syndrome and related disorders among local doctors, heighten the public’s knowledge of these conditions, and raise money to help support the Foundation’s programs and services. Through knowledge and action, they felt more empowered and better able to deal with the challenges they face every day with their diagnosis.
WALK FOR VICTORY EVENTS TOOK PLACE IN ARIZONA, GEORGIA, MASSACHUSETTS, NEW YORK, AND MISSOURI, BRINGING COMMUNITIES TOGETHER FOR FUN AND SUPPORT.
In 2015, we also piloted our regional symposiums with our first event in Atlanta. This made it possible for people who are unable to attend the annual conference to benefit from a similar experience closer to home. More than 125 people from the Atlanta metropolitan area and beyond attended the symposium and luncheon to get up-to-date information on the diagnosis and treatment from local Marfan experts and connect to the Marfan and related disorders community in their area.

In addition, we continued to partner with medical institutions nationwide that are conducting Marfan syndrome and related disorders awareness events. And many of our community groups across the country partnered with local hospitals and doctors on educational events for local families and individuals—in small support group settings and in larger educational formats.

“TALKING WITH ANOTHER COUPLE THAT WENT THROUGH A SIMILAR SURGERY THAT OUR SON IS ABOUT TO UNDERGO.

LEARNING NEW INFORMATION THAT WILL HELP US IN TREATING OUR CHILD.

SEEING HOW OTHERS ARE DEALING WITH THEIR SYMPTOMS.

“I AM PLEASED TO WORK WITH THE DETROIT COMMUNITY GROUP TO RAISE AWARENESS OF MARFAN AND RELATED DISORDERS AMONG MEDICAL STUDENTS. THEIR INTEREST AND GROWING KNOWLEDGE ABOUT THESE DISORDERS GIVES ME HOPE THAT YOUNG PEOPLE NOW HAVE A BETTER CHANCE OF BEING RECOGNIZED AS HAVING MARFAN THAN WHEN MY DAUGHTER DIED IN 1994.”
FUTURE VICTORIES

As we turn the page onto the next fiscal year, we are committed to the fight for more victories for our Marfan syndrome and related disorders community. We will provide more education and support to people nationwide by bringing our regional symposiums and Walks for Victory to their communities. We will work with our incredible volunteers to establish more local groups so that people can connect with others on the same medical journey in their own geographic area. And while we continue to support research that enhances diagnosis and treatment of Marfan and related disorders, we will also address quality of life issues that impact the lives of people in our community every day.

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.
The Marfan Foundation takes a very deliberate, strategic approach to fundraising and plans ahead for major expenditures, particularly in the area of research.

In 2015, 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 $124K for the year.


STATEMENTS OF ACTIVITIES

Years Ended June 30, 2015, and June 30, 2014

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Revenues and gains:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions</td>
<td>$ 1,399,707</td>
<td>$ 318,515</td>
<td>$ 1,718,222</td>
<td>$ 1,416,539</td>
</tr>
<tr>
<td>Memorials</td>
<td>90,706</td>
<td>90,706</td>
<td>90,009</td>
<td></td>
</tr>
<tr>
<td>Annual conference</td>
<td>214,560</td>
<td>214,560</td>
<td>166,459</td>
<td></td>
</tr>
<tr>
<td>Other conferences and symposia</td>
<td>107,915</td>
<td>107,915</td>
<td>1,042</td>
<td></td>
</tr>
<tr>
<td>Net investment income</td>
<td>21,074</td>
<td>21,074</td>
<td>75,430</td>
<td></td>
</tr>
<tr>
<td>Events, net of expenses of $382,798 and $373,623</td>
<td>1,418,022</td>
<td>1,418,022</td>
<td>1,295,701</td>
<td></td>
</tr>
<tr>
<td><strong>Change in value of beneficial interest charitable remainder trust</strong></td>
<td>-</td>
<td>(10,352)</td>
<td>(10,352)</td>
<td>43,258</td>
</tr>
<tr>
<td>Gifts In-kind</td>
<td>496,685</td>
<td>496,685</td>
<td>587,418</td>
<td></td>
</tr>
<tr>
<td><strong>Net assets released from restriction</strong></td>
<td>1,310,160</td>
<td>(1,310,160)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total revenues and gains</strong></td>
<td>5,058,829</td>
<td>(1,001,997)</td>
<td>4,056,832</td>
<td>3,675,856</td>
</tr>
</tbody>
</table>

| Expenses: |                        |                        |                          |                          |
| Program service expenses: |                        |                        |                          |                          |
| Research initiatives and grants | 1,885,273 | 1,885,273              | 1,409,045                |                          |
| Education and public awareness | 866,572 | 866,572                  | 1,087,341                |                          |
| Patient services and annual conference | 1,098,465 | 1,098,465              | 1,049,918                |                          |
| **Total program service expenses:** | 3,850,310 | -                        | 3,850,310                | 3,546,304                |

| Supporting services: |                        |                        |                          |                          |
| Management and general | 540,875 | 540,875                  | 419,798                  |                          |
| Fundraising           | 543,848       | 543,848                 | 648,615                  |                          |
| **Total supporting service expenses** | 1,084,723 | -                        | 1,084,723                | 1,068,413                |
| **Total expenses** | 4,935,033 | -                        | 4,935,033                | 4,614,717                |

| Increase (decrease) in net assets | 123,796 | (1,001,997) | (878,201) | (938,861) |
| Net assets, beginning of the year | 3,933,144 | 7,065,172 | 10,998,316 | 11,937,177 |
| Net assets, end of year | 4,056,940 | 6,063,175 | 10,120,115 | 10,998,316 |
## STATEMENT OF FINANCIAL POSITION

June 30, 2015, and June 30, 2014

<table>
<thead>
<tr>
<th>ASSETS</th>
<th>June 30, 2015</th>
<th>June 30, 2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash</td>
<td>$ 886,725</td>
<td>$ 573,482</td>
</tr>
<tr>
<td>Investments</td>
<td>6,599,015</td>
<td>6,605,155</td>
</tr>
<tr>
<td>Pledges receivable, net</td>
<td>1,062,550</td>
<td>2,110,830</td>
</tr>
<tr>
<td>Prepaid expenses and other current assets</td>
<td>121,498</td>
<td>200,786</td>
</tr>
<tr>
<td>Property and equipment, net</td>
<td>796,233</td>
<td>902,171</td>
</tr>
<tr>
<td>Beneficial interest charitable remainder trust</td>
<td>979,175</td>
<td>989,527</td>
</tr>
<tr>
<td>Other assets</td>
<td>163,016</td>
<td>142,869</td>
</tr>
<tr>
<td><strong>Total assets</strong></td>
<td><strong>10,608,212</strong></td>
<td><strong>11,524,820</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>LIABILITIES AND NET ASSETS</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Liabilities:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accrued liabilities</td>
<td>166,111</td>
<td>183,291</td>
</tr>
<tr>
<td>Deferred income</td>
<td>158,970</td>
<td>200,344</td>
</tr>
<tr>
<td>Other payables</td>
<td>163,016</td>
<td>142,869</td>
</tr>
<tr>
<td><strong>Total liabilities</strong></td>
<td><strong>488,097</strong></td>
<td><strong>526,504</strong></td>
</tr>
</tbody>
</table>

| Net Assets:                                 |                |                |
| Unrestricted:                                |                |                |
| General                                     | 2,141,921      | 2,023,793      |
| Board designated                            | 1,915,019      | 1,909,351      |
| Temporarily restricted                       | 6,063,175      | 7,065,172      |
| **Total net assets**                        | **10,120,115** | **10,998,316** |
| **Total liabilities and net assets**        | **$ 10,608,212** | **$ 11,524,820** |

The Foundation’s complete audited financial statements for the years ended June 30, 2015, and June 30, 2014, 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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(1936–2012)

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