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.
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.
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
OUR SUPPORTERS

We are fortunate to have the trust and support of organizations and individuals who help lead the way to achieving our mission. People like you provide the everyday support we need to create a better world for individuals living with Marfan, VEDS, Loeys-Dietz, and other genetic aortic conditions. Because of you, our past, present, and future is making a daily impact.

POWER OF COMMUNITY
Walks, special events, & symposiums fuel connections from coast to coast

EVENTS IN 17 STATES
○ 18 Walks for Victory
○ 7 Special Events
○ 4 Symposiums

WALK FOR VICTORY
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.

FUNDING MIX
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.

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

ORGANIZATION AWARDS
## STATEMENTS OF ACTIVITIES

**Year Ended June 30, 2019**

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

*June 30, 2019 and June 30, 2018*

<table>
<thead>
<tr>
<th>ASSETS</th>
<th>June 30, 2019</th>
<th>June 30, 2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$641,800</td>
<td>$777,754</td>
</tr>
<tr>
<td>Investments</td>
<td>6,552,335</td>
<td>6,438,849</td>
</tr>
<tr>
<td>Pledge receivables, net</td>
<td>2,775,803</td>
<td>3,373,109</td>
</tr>
<tr>
<td>Prepaid expenses and other current assets</td>
<td>212,186</td>
<td>171,431</td>
</tr>
<tr>
<td>Property and equipment, net</td>
<td>701,711</td>
<td>730,146</td>
</tr>
<tr>
<td>Beneficial interest in charitable remainder trust</td>
<td>1,087,721</td>
<td>1,065,896</td>
</tr>
<tr>
<td>Other assets</td>
<td>104,997</td>
<td>80,600</td>
</tr>
<tr>
<td>Total assets</td>
<td>12,076,553</td>
<td>12,637,785</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>252,171</td>
<td>237,353</td>
</tr>
<tr>
<td>Deferred income</td>
<td>108,030</td>
<td>102,126</td>
</tr>
<tr>
<td>Other payables</td>
<td>104,997</td>
<td>80,600</td>
</tr>
<tr>
<td>Line of credit</td>
<td>19,246</td>
<td>-</td>
</tr>
<tr>
<td>Total liabilities</td>
<td>484,444</td>
<td>420,079</td>
</tr>
</tbody>
</table>

Net Assets:

- Without donor restrictions:
  - General                     | 2,926,080 | 2,441,548 |
  - Board designated            | 1,411,412 | 1,720,476 |
- With donor restrictions:
  - Total net assets            | 7,254,617 | 8,055,682 |
  - Total liabilities and net assets | 11,592,109 | 12,217,706 |
  - Total liabilities and net assets | $12,076,553 | $12,637,785 |
2019 BOARD LEADERSHIP

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