MISSION STATEMENT
The National MPS Society exists to find cures for MPS and related diseases. We provide hope and support for affected individuals and their families through research, advocacy and awareness of these devastating diseases.
Reading this publication is a reminder of the growth of the Society and our Annual Reports. Our first Annual Report in 2003 was written one Sunday after a board meeting. Larry Kirch, Steve Holland, Laurie Turner and Barbara Wedehase spent the day in the office, each at a computer, cranking out our assigned sections. In 2003, the first FDA-approved treatment for an MPS disease was approved, the Society was in its third year of our “aggressive research (grant) program,” and Family Support offered three programs—complimentary dues for families in need, conference scholarships and funds for regional social gatherings. The few pictures were not in color nor prominently displayed. Contrast that to this beautiful publication, and you can’t help but be amazed at the Society’s achievements and also those of our members, all of whom have strengthened the Society.

The timeline of our 40 Years of Achievements is a testament to the vision of those families in 1974 who wanted a better life for their children with MPS and related diseases. Alice Kalamar, the Society’s first president, shared stories of hope and love when she gave a keynote address at our 40 Years of Achievements Gala in May 2014. Those stories were an inspiration to our many friends who flew to Chapel Hill, NC, for an elegant evening of celebration, a highlight of 2014 for the Society.

The adage “A photo is worth a thousand words” rings true in these pages. Beth Karas, the person who made our videos a reality, attended the gala and highlights the Society’s achievements leading to our growth. MaryEllen Pendleton focused on fundraising during her tenure on our board, and she and her extended family received the fundraising award at the gala. Then there’s Steve Smith, who advocates tirelessly for the Society and all individuals with MPS and related diseases in Washington, DC. These are only a few stories behind the achievements of our members who have strengthened the Society.

Yes, we’re proud of the many achievements, which represent the work of so many dedicated people, but we aren’t resting on those laurels. We look forward to a future of even more growth, with cutting-edge research and increased support to families, because we insist on a better life for our children.

Thank you for your achievements, for helping us with our past achievements and for those achievements yet to be imagined!

Stephanie Bozarth
President

Barbara Wedehase
Executive Director
After receiving the devastating news that our son, Ross, had been diagnosed with MPS IIIA, I began researching and found information on the 2014 National MPS Family Conference in Disney World. It was the last day of registration so I made a call to inquire. Laurie informed me we were eligible for a scholarship to attend the conference since we were newly diagnosed.

Two weeks prior to the conference our daughter, Meredith, also was diagnosed with MPSIIIA. At the conference we made instant lifelong connections. It was the first time in our journey that we felt accepted, not judged. We were welcomed with open arms by those who have traveled this journey before us. The conference changed our outlook and the self pity ended. We were the ones chosen for this journey and our extended family grew exponentially that day.

Andrew, Jessica, Ross and Meredith Davis
MPS IIIA family
Meeting a Growing Challenge

The **Family Support Committee** strives to meet the developing needs of individuals and families affected by MPS and related diseases. Since the program’s inception, more than $715,000 has been awarded for funding items such as medical goods, continuing education and conference scholarships, medical travel assistance and extraordinary experiences. As the program continues to grow, additional opportunities of support for our families will become available.

- Supported 24 families to attend the **29th Annual Family Conference in Walt Disney World.** Conference scholarships offset the cost of registration and travel, and provide funding for newly diagnosed families.
- Provided scholarships for families to attend CYCLE, the Society’s bereavement conference.
- Provided more than 150 families attending the 29th Annual Family Conference with two complimentary hotel nights at the Walt Disney World conference hotel.
- Awarded 30 $1,000 **Continuing Education Scholarships** to members continuing their post-high school education. Scholarships were awarded to 12 individuals with MPS and related diseases and to 18 siblings.
- Funded $22,245 in Family Assistance Program grants to help families obtain durable medical goods. Grants included scooters, stair lift, tumbler form deluxe chair, car lift (chair carrier), home ramp, WIKE bicycle stroller and adaptive stroller.
- Provided funding to 14 families through the Medical Travel Assistance Program for mileage, airfare and hotel reimbursement. In 2014, $6,500 was awarded to families traveling more than 200 miles (one way) from home for medical appointments.
- Promoted and provided funding for two family organized regional social gatherings in Kentucky and Ohio.
- Funded two Extraordinary Experience applications for children (ages 13 and older) and young adults with MPS.
- Published the 12th annual **Angels Among Us/Remembering Our Special Children** memorial publication.
- Continued the White Rose Program and grief booklet series for families whose child passed away during the year.
- Recognized individuals with MPS and related diseases in **Courage with Standing Ovation awards.** One individual from each MPS syndrome is honored each quarter, acknowledging their courage, resilience, tenacity and passion for life as they face the challenges of living with MPS.
- Introduced opportunity for the Family Assistance Programs to include applications for iPad funding.
- Sent the Award of Courage, signed by National MPS Society President Steve Holland, to all of our affected individuals with MPS and related diseases.

“From our very first conference 21 years ago until today, the Society has provided us with lasting friendships, vital information, supportive programs, pathways to treatment and, above all, a constant hope for the future for all individuals with MPS diseases. When our friends, family and community come together for fundraisers in honor of our children, we are buoyed up beyond the confines of disease, feeling cherished and loved, which sustain us year after year as well as moving the Society ever closer to the cure for all.

Steve, Amy, Maddie and Laynie Holland
*MPS I family*
Embracing New Technology

The mission of the Education and Publicity Committee is to provide educational materials and health-related communications. Our commitment is to provide the most current information about MPS and related diseases through multiple resource channels. The National MPS Society embraces forward-moving technology by maintaining our website, introducing an HTML site for mobile devices and utilizing social media, while not losing site of the essential one-on-one contact with individuals and families affected by MPS.

• Developed a mobile-ready application for Society members, donors and researchers on an HTML platform.
• Promoted the 8th International MPS Awareness Day on May 15.
• Encouraged and thanked our researchers and Scientific Advisory Board on MPS Awareness Day.
• Provided 40 Years of Achievements timeline and awareness pins to membership.
• Produced “This Fight Is Personal, Advocating with the National MPS Society,” the final video in a series which focuses on the stories of those affected by MPS and related diseases, and shares the perspective of both families and legislators.
• Completed MPS video revisions for Courage at Diagnosis, Living with Courage and Journey of Hope.
• Presented the videotaped Disney family conference presentations through link on Society website.
• Updated fact sheets: Orthopedic Disorders in Children with MPS and Related Diseases, A Parents’ Guide Fact Sheet, Tracheostomy and Otitis Media.
• Created new fact sheets: Family Support Programs and Mucopolysaccharidoses and Social Security Benefits.
• Increased social media efforts through Facebook and Twitter.
• Published the Society’s quarterly magazine, Courage, and supplemental newsletters.
It was exciting and inspiring to attend the 40 Years of Achievements Gala and to observe how the National MPS Society has grown. I’ve been a member for the past 15 years and am very encouraged to witness the critical strides in research and treatment, the compassionate outreach to families, and the raised awareness of these rare disorders.

I am a sibling of two ML III brothers born in the 1950s when little was known about ML. It is comforting to know that MPS and ML disorders are not so mysterious today, and that the MPS Society plays a critical role in educating families and professionals who come in contact with these precious souls.

Beth Karas
ML III sibling
The journey of an MPS diagnosis has had many ups and downs. The love and friendship we have felt these last 18 years from Society members, staff and friends has helped sustain us through tough times. I didn’t live with the day-to-day challenges of MPS that my brother’s family—Larry, Susan, Helen and Allison—did, but I hope that hosting golf tournaments and serving as a board member for six years in some small way showed them the love and admiration we felt from afar.

The friends I have personally made through the MPS Society have given me the strength to help fight this fight through fundraising. Hosting fundraisers gives you something tangible to do; it helped us not feel helpless. Being able to raise critical funds for research and family support made us feel we are part of a wonderful extended family.

MaryEllen Pendleton
MPS III aunt
The National MPS Society recognizes our walk/run and other fundraising organizers by saying THANK YOU! Our fundraising program provides essential resources for individuals hosting fundraisers. This past year we increased our efforts with a 40 Years of Achievements Gala, the Annual Fund campaign, visits with major donors and Text to Give, a mobile donation tool.

The Society continues to embrace the fundraising evolution and provides our donors, membership and fund raisers the essential tools for success. With the increased use of social media, the Society is able to reach donors quickly. The Fundraising Committee is dedicated to providing support through the following programs: walk/run events, family fundraisers, Annual Fund, major gifts, Planned Giving, Mobile Giving, Courage Pages, Crowdfunding, Combined Federal Campaign, United Way, Employee Giving and Corporate Matching Gifts.

- Received a three-star charity rating from Charity Navigator, representing a good performance that exceeds or meets industry standards and performs as well as or better than most charities in its cause.
- Supported an active membership roster of more than 725 members.
- Raised approximately $522,000 through walk/run and fundraising events.
- Hosted a 40 Years of Achievements Gala and raised $164,000.
- Supported 58 fundraising events and 16 walk/run events, which included sports tournaments, Ironman triathlon, Ask Event (two-hour benefit that educates donors and asks for donations), bake sales, bowl-a-thons, concerts, jeans day, bingo, auctions and more.
- Raised more than $175,000 through the 2014 Annual Fund campaign, chaired by Lynn Hopkins. A 33% increase from 2013.
- Increased efforts to meet with major donor and Society friends nationwide.
- Included mobile pledging successfully at the Annual Family Conference, raising $6,500.
- Hosted 29 Courage Pages on the Society’s website. These informative individual family web pages raised awareness and $33,000 for the Society in 2014.
- Updated website for members with a comprehensive fundraising toolkit.
- Received Combined Federal Campaign application approval.
- Worked with donors to process more than 200 Employee Giving Campaign and Corporation Matching Gifts.
- Increased membership to the Rising Sun Legacy Circle and processed new planned gifts from trusts and wills.
It has always been a privilege to help the MPS cause. In 2000, I called on the FDA with Steve Holland and Mark Dant to ask what could be done to further improve successful clinical trial opportunities. Fifteen years later, patient advocates were invited to the FDA Public Workshop for Inborn Errors of Metabolism. Congress initiated the national discussions with key stakeholders—FDA, pharmaceutical companies and rare disease advocates—to transform the clinical trials process. The National MPS Society is recognized by congressional leaders as a key stakeholder. The credibility of the National MPS Society’s voice in legislative efforts is due in large part to the leadership of Stephanie Bozarth and many other MPS parents, who carry on the inspiration of years of advocates before them.

Today, Congress actively seeks our input and our opinion. Draft legislation resulting from these efforts states, ‘Put patients at the center of drug development.’ As a hard-working advocate, this feels good.

Steve Smith
MPS IVA parent
Aiming High to Change Lives

The Committee on Federal Legislation magnifies its strong message each year on Capitol Hill. The voice of the National MPS Society is recognized and it is the committee’s job to be aware of and capitalize on important moments.

The committee’s platforms include: medical, research, health services, special education and disability policies. Regular correspondence and personal visits with policy makers at the National Institutes of Health (NIH), Department of Education, Alliance for a Stronger FDA, National Organization of Rare Disorders (NORD), Social Security Administration and other federal agencies occur year round.

- Met with 41 senators and representatives over two days during the board of directors’ annual Capitol Hill visit.
- Met with the Food and Drug Administration (FDA) key leadership to discuss how we can partner to speed research and develop life-saving drugs for individuals with MPS and related diseases.
- Attended the FDA Public Meeting on Inborn Errors of Metabolism Patient Focused Drug Development, and provided several perspectives from MPS advocates and families through testimonials and panel discussions.
- Presented MPS parents’ experience and perspectives on enzyme replacement therapy at the FDA Public Meeting on Immune Responses to Enzyme Replacement Therapies: Role of Immune Tolerance Induction.
- Submitted formal comments to the FDA on Docket No. FDA-2014-N-1698, Patient Participation in Medical Product Development and Review.
- Partnered with rare disease groups to advocate on Rare Disease Day in Washington, DC.
- Submitted MPS-related language to the Senate Appropriations Committee Subcommittee on Labor, Health and Human Resources to be included in significant items for 2015. The focus was a directive for the NIH to continue funding MPS research.
- Communicated the critical challenges of those with MPS and related diseases at the NORD Senate Rare Diseases Briefing by Stephanie Bozarth, MPS IVA parent and legislative chair.
- Partnered with Rare Disease Legislative Advocates, a clearinghouse for patient advocacy groups to promote common legislative goals; Global Genes, a patient advocacy forum to make connections and share resources to positively impact affected patients and families; and NORD, an organization committed to identification, treatment and cures for orphan rare diseases.
- Provided member advocacy training webinars on Social Media Advocacy and How to Tell Your Story; both webinars available on the Society’s website.
- Partnered in the production of the Society call to advocacy action 30-second and six-minute video “This Fight Is Personal!”
- Supported the following legislative initiatives: Patients Access to Treatment Act (PATA), Achieving a Better Life Experience (ABLE) Act, Tricare Letter to support genetic testing coverage, Orphan Drug Tax Credit Advocacy (ODTC), Newborn Screen Saves Lives Reauthorization Act, Orphan Product Extensions Now, Accelerating Cures & Treatments (OPEN ACT), Gabriella Miller Kid’s First Research Act, Accelerating Biomedical Research Act, ACT 4 NIH Campaign, Cure the Process Campaign, and Patient Focused Impact Assessment Act (PFIA).
Taking Action Today for Future Generations

Moin Vera, MD, PhD
Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center, Torrance, CA

R. Scott McIvor, PhD
University of Minnesota
Minneapolis, MN
“AAV mediated gene transfer to the CNS for MPS II”

Beverly Davidson, PhD
The Children’s Hospital of Philadelphia
Philadelphia, PA

Calogera Simonaro, PhD
Icahn School of Medicine at Mount Sinai, New York, NY

The National MPS Society allocated $509,500 in grant funding for 2014. Funding the Society provides has been and continues to be critical as we move forward with our mission to find the cures. We received 38 letters of intent from researchers globally for the grants offered.

The board of directors allocated $117,000 to Abeona Therapeutics which has licensed MPS IIIA and MPS IIIB gene therapy technology from Nationwide Children’s Hospital.

The Society also provided $25,000 to support the Lysosomal Disease Network’s NIH grant research goals. The funding is designated for the Neuroimaging Core, which will benefit the four MPS projects. A $10,000 MPS I partnership grant with the Ryan Foundation funds the University of Minnesota project “Longitudinal Studies of Brain Structure and Function in MPS Disorders.” The Society provided funding for post-doctoral fellows to attend the American Society and Gene and Cell Therapy conference.

From the time of the pivotal FDA Advisory Committee meeting in 2003 where MPS families spoke on behalf of treatments needed, we have seen so much more being done for MPS patients. It is never enough or too soon, but there currently are four approved enzyme therapies, and a fifth coming. There are gene therapies and ERT in development for Sanfilippo syndromes, finally getting the attention they desperately deserve. After 20 years since our first ERT experiments, it’s an exciting and new world for kids with MPS.

Dr. Emil Kakkis, UltraGenyx

Money Raised and Awarded for Research

Money Raised
Money Awarded
Money Raised
Drawing on Experience
to Elevate Our Goals

The National MPS Society’s Governance Committee is dedicated to empowering their board of directors. The committee provides an ongoing review of effectiveness, knowledge and leadership to ensure the highest quality board. This committee initiated an extensive planning process related to the 2015 retirement of current Executive Director, Barbara Wedehase. They, along with the board of directors, govern the Society by determining direction, desired outcomes, understanding why the direction and outcomes are beneficial, and determining deadlines while, at the same time, refraining from managing the Society. The Governance Committee helps ensure the Society properly serves its membership and fulfills our mission.

- Completed the second board of directors review and evaluation process. This process is used to identify gaps, improve board performance, and illustrate transparency and credibility of the board.
- Managed individual board evaluation self-assessments.
- Discussed evaluation results and provided valuable feedback with each board member to make process improvements with both the board of directors and staff.
- Engaged in a thoughtful planning process for an executive director replacement in 2015 that included stakeholder surveys, job analysis and detailed review of the Society’s future.
- Completed the 2014 annual board of directors election process.

“When Madison was diagnosed with Muco-lipidosis, we wanted to do anything we could to help find a treatment and raise awareness. We decided to run for the board of directors. Working with the Governance Committee through the board interview process confirmed the level of commitment the Society has for our families in this next decade and beyond.”

Aaron and Holly Thompson ML III parents
2014 was the fourth year for Planned Giving with the National MPS Society. At year’s end we had 20 Planned Giving donors who became part of the Rising Sun Legacy Circle. The Society also continued planning for our parents’ respite night at our annual conferences and for the Family Support Programs from a gift bestowed in 2013.

Planned Giving helps donors maximize the personal benefits of charitable giving and allows donors to make gifts they may not have thought possible. Individuals who make these gifts to the National MPS Society, whether through their estates, wills or other life-income arrangements, share a strong common bond of generosity that will provide security for future generations. Building this community of philanthropy helps our donors achieve their personal vision and desire to give.

Rising Sun Legacy Members Include:
Emil Kakkis and Jenny Soriano, 2011
Becky Clarke, 2011
Christa Armstrong, 2011
Mary Starr Adams, 2012
Terri Klein, 2012
Tracy Szymanski, 2012
Barbara Wedehase, 2013
Brian and Kris Klenke, 2013
Steve and Amy Holland, 2013
Carol Elwell*, 2014
Steve McDonnell*, 2014
Randy McDonnell*, 2014
Austin and Stephanie Bozarth, 2014

* Indicates gift has been received.
Some members wish to remain anonymous.

“Being at the 40th Anniversary Gala was such an honor. I felt an overwhelming sense of gratitude and pride for what a small group of parents started at a conference room table 40 years ago. It was a tremendous effort to recognize achievements and raise funds for a mission we fully support. It was a night I will always treasure.

Alice Kalamard, founding member, past president
Financials

The financial information below has been summarized for the year 2014. The Society is a 501c3 nonprofit public charity. The complete audited financial statements and IRS Form 990 are available on request.

## Financial Position

<table>
<thead>
<tr>
<th>Assets</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash</td>
<td>$489,046</td>
</tr>
<tr>
<td>Investments</td>
<td>1,428,572</td>
</tr>
<tr>
<td>Contributions Receivable</td>
<td>4,975</td>
</tr>
<tr>
<td>Prepaid Expenses</td>
<td>8,236</td>
</tr>
<tr>
<td>Endowment Investments</td>
<td>1,001,143</td>
</tr>
</tbody>
</table>

**Total Assets** $2,931,972

<table>
<thead>
<tr>
<th>Liabilities</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts Payable</td>
<td>$219,764</td>
</tr>
</tbody>
</table>

**Net Assets**

- Unrestricted Net Assets: 880,376
- Temporarily Restricted: 831,038
- Permanently Restricted – Endowment: 1,000,794

**Total Net Assets** 2,712,208

**Total Liabilities and Net Assets** $2,931,972

## Activities

### Support and Revenue

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donations – General</td>
<td>$94,853</td>
</tr>
<tr>
<td>Donations – Family Assistance</td>
<td>41,940</td>
</tr>
<tr>
<td>Donations – Research</td>
<td>103,007</td>
</tr>
<tr>
<td>Operating Grant</td>
<td>75,000</td>
</tr>
<tr>
<td>Fundraising</td>
<td>730,104</td>
</tr>
<tr>
<td>Membership Dues</td>
<td>31,740</td>
</tr>
<tr>
<td>Conference Income</td>
<td>303,245</td>
</tr>
<tr>
<td>Sponsored Revenue</td>
<td>121,162</td>
</tr>
<tr>
<td>Investment Income</td>
<td>18,175</td>
</tr>
</tbody>
</table>

**Total Support and Revenue** $1,519,226

### Functional Expenses

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education – Newsletters, Booklets, Web</td>
<td>$80,297</td>
</tr>
<tr>
<td>Conferences, Meetings and Travel</td>
<td>315,041</td>
</tr>
<tr>
<td>Direct Family Assistance and Bereavement</td>
<td>61,659</td>
</tr>
<tr>
<td>Membership Database and Directory</td>
<td>10,296</td>
</tr>
<tr>
<td>Legislative</td>
<td>17,850</td>
</tr>
<tr>
<td>Research Grants*</td>
<td>341,525</td>
</tr>
<tr>
<td>Direct Fundraising</td>
<td>79,004</td>
</tr>
<tr>
<td>Personnel</td>
<td>290,359</td>
</tr>
<tr>
<td>Office and Equipment</td>
<td>43,598</td>
</tr>
<tr>
<td>Other Administrative</td>
<td>51,910</td>
</tr>
</tbody>
</table>

**Total Functional Expenses** $1,291,539

**Change in Net Assets** $227,687

---

*Please note an additional $112,500 was spent on research in 2014 but was classified as an investment due to the nature of the transaction.*
### 1974
- Parents for MPS formed (1974)
- The MPS Society was incorporated (1975)
- First seminar held and attended by 35 people (1975)
- Membership of 34 families (1976)
- Dr. Haskins reports to BOD research with MPS I and MPS VI cats & MPS VII dog (1983)
- Amniotic membrane transplantation in MPS I, MPS II, MPS IIIa/b announced (1985)
- Annual fundraiser money used to fund research student (1984)

### 1975
- Society refiled for incorporation as the National MPS Society, Inc. in New York
- Newsletter renamed Courage
- Aldurazyme®, the first ERT for MPS I, approved by FDA; Society members testified before FDA as part of the approval process
- MPS II phase III ERT clinical trial began
- MPS VI phase III ERT clinical trial began
- First Society video produced
- National MPS Awareness Day established as Feb. 25
- Bereavement and regional family picnic programs implemented

### 1976
- $2,557.03 reported in treasury (1981)
- First conference devoted to MPS/ML diseases at North Shore University Hospital, NY (1982)
- Society headquarters moved from Washington, DC, to New York (1977)
- Dr. Neufeld summarizes MPS/ML research for newsletter (1978)
- First annual fundraiser—a raffle raising almost $1,000 (1979)

### 1980
- $410,000 awarded in research grants
- $1 million budget
- First bone marrow transplant performed on 9-month-old boy with MPS I

### 1983
- First Disney family conference
- Two student researchers selected by the SAB for summer research fellowships
- Elaprase®, ERT for MPS II, approved by FDA
- Launched Join the Search campaign
- Participated in the NASDAQ closing ceremonies—ringing the bell
- Received a four-star charity rating and raised $423,000 through fundraising events
- Published Daily Living with MPS and Related Diseases in conjunction with Canadian MPS Society
- Held the inaugural CYCLE (Celebrating Your Child’s Life Experience) conference for bereaved families

### 1984
- $423,000 through fundraising events
- $459,000 in research grants
- Updated all syndrome-specific booklets, and developed and distributed comprehensive MPS II and MPS III resource guides
- Provided testimony to the Social Security Administration
- Awarded $459,000 in research grants
- Moved the National MPS Society to Durham, NC
- Global MPS advocacy organizations adopt MPS Awareness Day. The day is changed to May 15 and is officially called International MPS Awareness Day.

### 1985
- Provided 37 stipends for member families to attend the 10th International Symposium on MPS and Related Diseases in Canada
- Membership of 800, mailing list of 3,500

### 1987
- Created Continuing Education Scholarship program—$1,000 grants
- Membership of 800, mailing list of 6,000

### 1990
- Awarded $528,000 in research grants
- Updated all syndrome-specific booklets, and developed and distributed comprehensive MPS II and MPS III resource guides
- Provided 37 stipends for member families to attend the 10th International Symposium on MPS and Related Diseases in Canada
- Membership of 800, mailing list of 6,000

### 2004
- $1 million budget
- $410,000 awarded in research grants
- Hired part-time development director
- Membership of 800, mailing list of 3,500
- Society leases first paid office space in Bangor, ME
- Naglazyme®, ERT for MPS VI, approved by FDA
- Received a $1 million endowment from Drs. Emil Kakkis and Jenny Soriano
- U.S. Senate unanimously passed the resolution marking Feb. 25 National MPS Awareness Day
- Celebrated MPS Awareness Day with NASDAQ—ringing the opening bell
- Created Continuing Education Scholarship program—$1,000 grants
- Launched new branding for the National MPS Society with current logo and tagline

### 2006
- Hosted 1st International Congress on MPS and related diseases, Minnesota
- Providing Fall symposium—$1,000 grants
- Facebook launched
- Naglazyme®, ERT for MPS VI, approved by FDA
- Received a $1 million endowment from Drs. Emil Kakkis and Jenny Soriano
- U.S. Senate unanimously passed the resolution marking Feb. 25 National MPS Awareness Day
- Celebrated MPS Awareness Day with NASDAQ—ringing the opening bell
- Created Continuing Education Scholarship program—$1,000 grants
- Launched new branding for the National MPS Society with current logo and tagline
- Hosted 1st International Conference
- First bone marrow transplantation in MPS I, MPS II, MPS IIIa/b announced (1985)
- Annual fundraiser money used to fund research student (1984)
MPS I, MPS II and MPS III are added to the Compassionate Allowance Program under the Social Security Administration

- Held first affected adult conference, SPIRIT, in California
- Created the Governance Committee
- Celebrated 10 year walk/run anniversary
- Created National MPS Society website
- BioMarin/Genzyme provided first operational grant to Society allowing hiring of first employee
- Bylaws of Society amended and restated for first time

2001-2002

- MPS II phase I/II ERT clinical trial began
- 2nd year of 5K walk/run program raises $170,000 for research with 11 events (2001)
- Awarded $100,000 in grants for research (2001)
- Participated in the formation of Global Organization for Lysosomal Diseases (GOLD) (2002)
- Annual Fund program established, raising $12,600 (2002)
- Hired Laurie Turner as part-time office assistant (2002)

2010

- Met with Social Security Administration about adding MPS to the Compassionate Allowance Program
- Provided a record $72,500 through the family support programs
- Annual Fund raised $75,500
- Raised $470,000 through fundraising events
- Hired Terri Klein as development director
- Awarded $547,000 in research grants
- Provided $114,000 in family support and scholarship grants
- Began three-part video series for fundraising and awareness with Beth Karas, TV correspondent
- Introduced Mobile Pledging and Family Courage Pages for fundraising

2011

- Provided first training webinar for Federal Legislative Committee and Society members, “How Advocacy Moves Government”
- Launched Planned Giving program and the Rising Sun Legacy Circle
- Launched improved website with increased membership interaction
- Received four-star charity rating from Charity Navigator

2012

- Families testified before FDA on patient results in clinical trials for MPS IVA; FDA recommends approval
- Board travels to Washington, DC, for large advocacy effort; Sissi Langford presents Sen. Graham with Legislative Achievement award
- Award of Courage signed by President Steve Holland given to all of our affected individuals with MPS and related diseases
- Annual Fund raised $135,000
- MPS VII phase I/II ERT clinical trial began

2013

- Dr. Neufeld presented National Medal of Science award by President Clinton for her MPS research
- Budget increases to $106,450

2014

- National MPS Society 5K walk/run program launches with seven events, raising $100,000 for research
- The Society completed its first strategic planning process
- Barbara Wedehase becomes executive director
In 2014, the National MPS Society was able to provide support to families and funding for research because of the generosity of the following individuals, families, foundations, companies, groups and fundraising events. The board of directors and the Fundraising Committee thank you for your dedication and efforts.

The Society makes every effort to recognize our supporters through Courage and this Annual Report. If your name is not listed, we apologize and ask that you contact us. The following list represents all donations received in calendar year 2014. If we received your donation in 2015, you will be recognized in the next Annual Report.
Matt and Rachel Wojnarowski raising funds for the Society at the American Bible Challenge televised game show.

Wayne Haag
Jared Wolff
Eric and Linda Wright
Jim and Amy Yard
Kevin and Peggy Yard
Joseph and Dolores Yestrepisky
York Lawn & Garden
Trustee for Hewlett-Packard - HP Company Match

Bottomline Technologies, Inc.
Amber Booth
Sara Boxer
Edwin Braswell
Vaughn and Nancy Bryson
Nancy Bucher
Michelle and Gerard Buechel
Arlene Burgess
Laura Bustard
Mark and Stephanie Caldwell
Cameron’s Run for a Cure
Capital One Services, LLC
Cardinal FG
Heidi and Keith Caswell
Walter Cavanagh
Cecilton Lions Charities
Douglas Cesnegi
Chapin Automotive
Corey and Janis Cherrstrom
Daniel and Sharon Chisholm
Michael, Margaret and Grace Ciaccarelli
Santo and Elizabeth Cinino
John and Lynn Conley
Coram
David and Kathryn Croson
Lynn Crumling
Peter D’Urso
Caroline Dabney
Deer Valley Properties, LLC
Kathleen Delaney
Geri and Dan Desmond
Kevin and Linda Devine
Mark Dtolria
Paul and Kathy Dobrowolski
duAlaska, Inc., Ernest and Paul and Kathy Dobrowolski
Mr. and Mrs. James and Alice Kalamar
Mr. and Mrs. James and Mary Kalteux
Jerry and Pat Kanney
John and Janet Kappel
Beth Karas
Raimund and Inge Kasner
Paul and Nga Keith
Christopher Kentworthy
Kimberly Clark Foundation
Donna and Daniel Kimmnau
KLC Realty
Knights of Columbus Council
Moffett & Grigorian, LLP,
Martin Moffett
Eric and Amber Mongan
Mitchell and Cheryllyne Moore
Moss Adams Tracey Mummey
Rob and Sharon Muller
James Murphy
Susan Narducci
Marshall Nichols
Andrew Noll
Kim Nunley
Sharon O’Connell
James Olson, DDS
Oracle Corporation Matching Gifts Program

Table: $250 to $499

ABC Pediatrics of Ohio, LLC
About Face Medical Aesthetics, LLC
Lee Ann Adams
Aetna Foundation, Inc.
Amazon Smile
Bill and Mary Andrews
Betty and Barney Arceneaux
Peter and Diana Argeres
Nicholas and Mimi Armellino
Armordel School District No. 9
Atlas Flooring, Inc.
Robert and Marjorie Austin Jr.
Lewis and Marie Babel
Joe and Susan Babic
Baird and Baird, PSC
Bill and Judi Bard
Jeffrey Bardesly
Amy Barkley
Tammymee and Nathan Beam
David and Flori Beauschesne
Michael Beebe
Bill and Kay Bemis
Dr. Jack Berg
Joel and LeeAnn Bernbaum
Michael and Danielle Berster
Dr. and Mrs. Bill Bickham
Cheryl Bien
Bruce Bjorkman
Steve and LaVonne Blechinger
D’Lass Dent Company
Terry Charters and Erica Blight
Robert and Sally Bohanan
Sumner Lipman, Dawn Lieb,
Rob and Sharon Muller
James Murphy
Susan Narducci
Marshall Nichols
Andrew Noll
Kim Nunley
Sharon O’Connell
James Olson, DDS
Oracle Corporation Matching Gifts Program

Volunteer Information

View our volunteer opportunities on our website.
The siblings group at the 2014 Annual Family Conference at Disney.
Emily O'Connor (MPS IIIA) with Mickey Mouse

---

Jill Wieder
Barbara and David Wiedman
Brent Larson and Sylvia Wier
Ron and Kim Wiest
Ronald Wietcha
Adam and Kathi Wietzes
Dana Towle Wing
Richard and Barbara Wington
Joseph Wilck
John and Ellen Williams
Rick Williams
W. Williams
Robert and Nicole Wilson
Neil and Elizabeth Winget
Aaron and Julie Winner
Shirley Winkler
Wischemeyer Trucking, Inc.
Richard and Nicole Withrow
Mellette Wolfe
Josh and Jill Wołoszynek
Howard and Joan Wood
William and Christine
Woodhouse
Donna Woods
Jennifer Wooliscott
Constance Bubdien and Catherine Worva
Kenneth and Catherine Worva
Michael and Laura Way
Garret Wu
Shara Schipper and Roger Wyngarden
Judy and Mansour Yamin
Teresa Yang
Mural Yarida
Richard Zachariason
Joe Zambroni
Jim and Alexandra Zambrano
Melissa Zanatien
Ray and Priscilla Zechender
Janet Ziffer
Doris Zigler
David and Megan Zug

---

Donor
$26 to $99
Mary Abell
Accu Books, Inc.
Anna Adachi-Mejia
Michael and Stephanie Adams
Kenneth and Donna Ahles
Lisa Aisen
Patricia Albritton
David Akin
Hussain Aileen Algabz
Pamela Alexander
Alpine Communications, LC
American Bank of Texas
Donald and Julie Ames
Valerie Amescua
Richard and Carol Anderson
Robert and Karen Anderson
Jane Andrews
Lisa Andrews
Angie’s Artisan Treats, LLC
John and Jennifer Antonakakis
Silvia Aquino
Barbara M. Arbo
Arbonne Independent Consultant
Denise Archuleta
Joanna Arndtino
John and Janet Arendt
Colleen Ami
Ashland Center for Women’s Health
David Auer
Judith Austin
Kelly Austin
Mirella Avalo-Louise
Edith Aycock
Billy and Velta Ayers
Sherri and Scott Baggett
Andrew and Heidi Bahlmueller
Chris and Kristie Bailey
Paul and Rose Bailey
Rebecca and Robert Bailey
Allison Baker
Eddie and Allison Baldomero
George and Kathleen Baldwin
Leonard and Barbara Barcousky and family
Bard Material
Nick Barger
Joy Lynn Barnes
Lorraine Baron
Ellen Barrett
Mary Ellen Barringer
Jannette Barrt
John D. Barron, DDS
Joanna Bartell
Steven and Alice Bartels
Patricia Bates
Jody and Mark Batton
Megan Bauer
Andy and Meghan Beakman
Nathan Beard
Philip Beard
May and Don Beaudin
Lawrence and Ann Beenthum
Vincent and Laurie Beirne
Melissa Belas
Bellissimo Salon
Kevin and Samantha Bendl
Deborah Bennett
Daniel and Christine Bergin
Don and Nina Bergquist
William Berkowitz
Lloyd and Janet Berning
Lisa Berry
Paige Bessick
Phyllis Betz
Darc and Josh Bible
Kathryn Bickham
Lorraine and Frank Bien
Chris Bilardo
Kevin Bille
Mark and Linda Billingsley
Heidi Biron
Todd and Nicole Blancheri
Shelley and Gregory Blood
Miriam Blum
Robert Bodish
Robert and Anne Boggiano, MD
Charles and Elizabeth Bohland
Monica Bolin
Bollwerk & Tatlow, LLC
Jill and Carmen Bosssi
Stephen and Ellen Boush
Melissa and John Carter
Kevin and Kathy Casey
Casey’s General Stores
John and Barbara Casino
Margaret and Michael Cassella
Jeffrey and Michelle Castle
Franklin and Carol Catalafamo
Tom and Laura Catanzarite
Tony and Shirley Catanzarite
Ronnie and Heather Cato
Katherine and Stephen Catton
Liam and Mary Cavanaugh
Joe Cavanaugh
Katherine Cavanaugh
Jaime Chaon
Jessica Chandler
Susie and Louis Chandler
Lewis and Ann Chapman
Andrew Charest
James and Joan Charters
Robin Chermey
Kenneth and Heidi Chiester
Ericka Chirichiello
Stan and Carol Chrest
Kim Chute
Deanna and Fidencio Cienorn
Kelly Clarke
Mildred Clark
Monica Clarke
Ruth Clarke
Steev and Jennifer Clarke
William Clarke
Jerrry and Mary Cmex

---

continued >>
Shire Group with Dr. Joseph Muenzer and Jeff Bardsley at the 40 Years of Achievements gala.

Kevin and Kristina Coen
Pat and Bobbie Coffey
Linda Cohen
Don and Sue Colbath
James and Martha Colby
Rick Cole
Mary Jo and Larry Collet
Jocelyn and Vincente Collins
Elston and Arnie Covert
Community Concepts, Inc.
Tiffany Condit
Reia and Rick Connor
Kim Cook
Ross and Monica Cook
Diane McGuire Cooper
John and Joann Cooper
Cooper Elementary School
D.E. Corbin
Bonnie Cors
Cherisha Coughlin
Countryside Animal Clinic
Marianne Reid
Mary E. Couture
Steven and Linda Coyner
Shanetl Crabbe
James and Jo Ann Cradock
Kevin and Djuana Crawford
Crawford Contracting
Sandi Cresciulli
Tara Creswell Thompson
Bob and Denise Crompton
Matthew and Patricia Coyle
Doris Culp
Estelle Culpepper
Marie Cundiff
David and Maureen Cunningham
Steve Cuomo
Anna Czarik
Ursula Dahl
Diane Dalton
Bill and Laura Dapper
Bobby and Kelly Dargara
Richard and Kara Darrell
Mike, Lisa, Maria, Molly, Sarah, Johnny and Gracie Day
Sharon Day
Michael and Amy De Angelis
Pamela and Robert Dean
Christine Deboer
Gordon and Cynthia Debover
James and Melissa Deen
Melanie DeFilippis
Elizabeth and Ann Defrancesco
Robert and Mildred Degraaer
Joe and Lisa Delvax
Raymond and Laura DeMaio
Clinton and Jennifer DeMars
Loren Dempster
Brianna Dennis
Lynn and Nancy DePeal
Patricia Dery
Natanya Desai
James Desiderio
Carole and Conrad D’Esopo
Paul and Joann Desrosiers
Andrea Detamore
Brian Devine
Shannon Dewicki
Prachi Dharwadkar
John and Linda Diamond
Christopher Diano
Kim and Geri Dickerman
Maria Diglio
Alex DiLauro
Christine Diller
Christopher J. Dillon
Patricia DiLuzio
Ellen and Jerry Dimbat
Lori DiPasquale
Market Dixon
Kathy and Paul Dobrowolski
Jim and Michelle Dodson
Jonathan and Lisa Dols
Joyce and James Doss
Christine and Raymond Downey
Kevin Drake
Jeanne and Maurice Drew
Marilyn and Gary Drew
Mark and Louise Duddle
Patrick Duffy
Stephanie and Joseph Duffy
Jennifer and George Dulabon
Timothy and Elaine Dulaney
Jonathan Dunayer
Janet Dunn
Dunn Contracting
Michelle Dunsmore
Chris and Annette Durcholz
Janice Duncholz
Julie Durnen
Katharine K. Duiviver
Angie Dwyer
Eugenie Ebert
Wayne Edwards Sr.
Hannelore Egold
John and Lois Eicholtz
Matt and Cyndie Elliott
Mark Elmer
Darla Elswick
Michele Evander
Grant and Mieke Embry
Rev H. Wayne and
Joan Eppeheimer
Terry Epps
Naomi Eparza
Kenneth and Ruth Espenshade
Steven and Kathryn Espenshade
Rick and Francie Espino
Gloria Espinosa
Steve Espinosa
Coral Espinosa
Salvador Estril
James Evertar
Co Exner
Helen Fallon
Nicholas and Harriett Fargnoli
Dale and Julie Farino
Maureen Farni
Carmen and Don Farrell
Geraldine Faucett
Yolene and Richard Fekel
Pete and Jackie Fanaroli
Cheryl and Ken Ferguson
Suzanne and Kenneth Feustel
Nicole Field
Gail Finney
Lois Finney
Danielle Fischer
Darwin and Carlotta Fischer
Karim Fishe
Mark Knudsen and
Sarah Fiskan
Mike and Cathy Fitzgerald
Cecilia Fitzsimmons
Eric and Marcia Flaim
David and Debbie Flanagan
Erin Fleming
Sherri Fleming
Nancy Flugrath
Andrew and Joan Flynn
Kathryn Flynn
Ruth and Terry Follbaum
Mark Ford
Carolann Forrest
Frances Fournier
Jamie and Jason Fowler
Joyce Fox, MD
Beverly Frank
Paul and Martha Frank
Michael and Susan Frisoni
Lawrence J. and
Stacy Freothlich
Roy and Carrie Fronczyk
Wendy Fuller
Anna Funkhouser
Elizabeth Furnelli
Jose and Fe Gabriel
GAC, Inc., T/A Cherry Hill Health & Racquet Club
Micalla Gadawski
Mark and Krista Galbraith
Judith Gallagher
Richard and Jennifer Gallo
Sonia Galvan
Thomas and Sylvia Garnache
Arthur Garde III
Sally Garrett
Reelyn and Timothy Garvin
Richard and Ronni Gates
Sean and Katy Gavin
Regina Gay
Anissa Gegenheimer
Tracey Gegenheimer
Wendy Gehling
Jeanine Geller
Steven and Kim Gentile
Kevi and Sheila George
Todd Gheidi
Pamela and Robert Gilby
Georgia and Kimberly Gillett
Sharon Gilham
Patrick and Robyn Gilks
John and Lynn Gladsyz
Geraldine and George Glass
Sandy Glass
Andrew and Stephanie Glock
Clarence Glock
Shikako Golden
Bridget Goldfard
Mildred Goldstein
Giana and Paul Golke
Linda and Robert Gonzales
David and Marsha Gorewitz
Jean and Michael Gorman
Lee and Tammy Gottschall
Toni and James Gradeham
Grand Slam Marketing
Robert and Viji Grant
Rose Marie Greco
Lorne and Tamara Green
Molly and John Greene
Brad and Suzanne Gregory
Forrest and Lorena Griffin
Helen Grimes
John Grimes
Dan Griswold
Robert Grobman
Daniel Grund
Jack Grundfest
Marilyn Gude
Maureen Guerrero
Tim and Jenny Guilfoyle
Bob Guletz
Samantha Gulino
Nancy Gull
Donna Gunning
Puttenberg Industries, Inc.
Puttenberg Veterinary Clinic, LLC
Bruce and Cheryl Hack
Carmen Hahn
Laura Hahn
Cheryl and John Hakola
Suzanne and Courtney Hale
Lamar and Warren Hall
Linda and Stephen Halliday
Cindy and Steve Hamblen
Ken Hampel
Holly and Scott Hanewacker
Dan and Connie Hardesty
Kimberly and Frank Harker
Johanna Harmeier
Duane and Connie Harmon
Kim and William Harper
Faith Harris
Mark and Keely Harris
Raymond and Renee Harris
Tamara Harris
Kimberlee Harrison
Harrison Contracting Company, Inc., Larry Harrison
Dan and Mari Anne Hartmann
Tonia and Ronny Harvey
Margaret Hasks
Jeni Hasselbrack
James Hassert
Candy Hausken
Matt and Jennifer Hawes
Megan Haydaz
Stephanie Hayden
Sheri Hayes
Dana Hayner
CalTin Haynes
Dr. and Mrs. Larry and
Barbara Hays
Zachary Hayfer
Jana Hazekamp
Cynthia Hechinger
Steve and Lisa Heck
Gary and Jane Hecken
Glenn and Tammy Heise
Judy Heitman
David and Colleen Heller
Chester and Jennifer Hembree
Donald and Olga Hemmesc
Thomas and Myra Henley
Rebecca Hennessey
Victoria Herman
Robert and Michelle Hess
John Higgins
Michelle Hill
Christine Hilary
David and Ann-Marie Hillyer
Chadwick Hilton
Sallie Hoch
David Hoefert
Amy Hoey
Richard Hoffman
Jeffrey and Carolyn Hoffmann
Chris and Melissa Hogan
Donald Max Holland
Paul and Gina Holleenback
Betty Holleenbeck
Steven Holley
Toni Rhein and Bobbi Nelson
Fred and Donna Reyes
Jim and Jennifer Restemayer
Bonnie and Ralph Rennaker
Christopher Reichel
Ronald Regelski
Patricia Anne Reeves
Ryan and Cassandra Reamer
Braun and Emily Ream
Katie Rae
Tammy and Dan Ragone
Rey Ramos
Maryann Ramshorn
Sara and Brandon Ratiff
Consernette Rawlings-Guy
Samantha Read-Smith
Braun and Emily Ream
Ryan and Cassandra Reamer
Paul and Marie Reeves
Paul and Carol Redmond
Gerard and Kimberly Redublado
Floyd and Sharon Reed
Kathie Reep
Patricia Anne Reeves
Ronald Regelski
Teresa Regnald
Christopher Reichel
Jon and Vickie Reif
Jeffrey Reineke
Reliant Corp.
Bonnie and Ralph Rennaker
Jim and Jennifer Restemayer
Fred and Donna Reyes
Toni Rhein and Bobbi Nelson
Jimmy and Willow Rice
Virginia Richards
Cheryl Richardson
Dana Riddick
Rael Reel
Timothy and Cindy Riga
Ashley Riggs
Becky Riggs
Rosemary Riney
Emma Ritter
Pamela and Carly Rivera
Paul and Liliane Rivera
Joseph and Catherine Rizzo
Timothy and Heidi Roach
Vincent Roberto
George and Whitney Roberts
Dorothy Robinett
Jared and Breanna Robinett
Brian and Karen Rock
John and Isabella Rodrigues
Christopher and Carolynne Roe
Dave and Janet Roenser
Kay Rogers
Jessica and Eric Rolig
David Rolins
Joel and Beckey Roman
Richard and Darlene Rome
Kelly Rose
Joel and Kate Rosenthal
Marilyn Rossie
Robert Roth
Alan and Lynn Rowley
Douglas and Michelle Rowley
Aaron and Carri Rubinstein
Carol Rucker
Peter-John and Milton Ruiz
Barry and Janne Russell
Kathryn Rutherford
Collette and Lawrence Ryan
Marianne Ryan
Patricia Ryan
Paul and Kathy Rysz
Askar Sabalakov
Edward and Georgette Sadler
Sushil Sanganvala
Steve and Shawn Samuelson
Sanatoga Fire Company Auxiliary
Harry and Laura Sanborn
Joseph Sanfilippo
Araceli and Miguel Sanoguel
Julie Santangelo
Dr. and Mrs. A.L. and Angelia Sarantinos
Darnell and Patty Saylor
Elaine Hendricks and James Schafer Jr.
Toby Schiel
Monica Schmalz
Stephanie Schmehl
Ed Schmidt
Jill and Michael Schmitt
Michael and Kimberly Schneekofl
Jonina and Jonathan Schönfeld
Catherine Dominique Schreiber and Peter Schreiber
William Schroeter
David and Sarah Schuch
Randolph and Brenda Schuett
Rick and Catherine Schuett
Richard and Shirley Schutlz
Ira Schwartz
SCM Co., Charity Prickett
Carole Scott
William Joseph Scott
Thomas and Carole Scully
Timothy and Melinda Scully
Beth Seder
Carolynne Seffert
John and Ann Sennk
Patricia Sennett
Brian Service
Seymour Pediatrics
Sara Sharkey
Danielle Sharpe
Greg Sharritts
Loretta Shaw
Wallace Shaw
Karen Sheaffer
Teri and Les Sheaffer
Debra Harris Shearer
Dennis Shelly
Nancy, Kent and Joe Shelton
Wayne and Glsenda Shelton
Luke Sheppard
Rozann Sheppard
Kevin and Kathy Sheridan
Robert Shepard
Suzanne and Randy Shields
Sally and Warren Shirk
Emily Shockley
Joel Shortlidge
Rosemary Shours
Elizabeth Sidles
William and Alissa Simpson
Chris Sindahl
Anne Marie Siodzinski
Robert Siane
Lou and Chris Slavik
Tami and Don Slawson
Charles and Marie Sledge
Amy and John Sleeper
Lyn and Paul Slinka Roberts
Charles Campbell and Kelly Smith
Darrin and Laurie Smith
Elaine and Mark Smith
Zsuzi Smith
Kathie Smith
Lachlan Smith
Laurie Smith
Linda Smith
Mike and Barbara Smith
Raymond and Julia Smith
Shirley Smith
Steve and Gayle Smith
Susan Smith
Wesley Smith
Smith Joint Rev Living Trust
Carol Snarey
Mr. and Mrs. Terry Snarey
June and Charles Snyder
Levy Solomon
Anthony and Pamela Sosinski
Heidi Sosinski
Joshua and Sheri Sowden
Larry and Janice Spadt
Alice and Paul Spalitta
Michael and Laurie Sparkman
Lois Sparks
Scott Sparling
Jill Spangrove
Richard and Shirley Schutlz
Ira Schwartz
Vicki and Henry Spencer
Robert Sperry
Gerhard Gehrke and Martha Splinter
Michelle Spooner
Louis and Sharon Starnas
Charles Stanley
Max Statham
Mark and Yvonne Steinhauser
Laurie Steinhaus
Myna Steinman
Crystal Stern
Nelson and Barbara Stewart
Jay Stickles
Melissa Stocks
Stacy Stone
Isaac and Brooke Story
Richard and Gall Straughen
Tammie Strickland
Nancy Strigmond
Jeffrey and Margaret Stroehlein
Judy Struck
Andrew and Victoria Stultz
Larry and Diane Sutur
Joel Sullivan
Joseph and Laura Sullivan
Kristen and Michael Sullivan
Diana Suprenant
Arthi Suredy
Dr. and Mrs. Howard Sussman
Leland and Rebecca Swan
Jeff and Lisa Swanson
Richard and Judith Swantz
John and Diane Szuchy
Jeffrey Tall
Jennifer Tansey
Jack and Patty Taormino
Ann, Hannah and Grace Tate
Robert Taulon
Ella and Jeanette Taylor
Team Ruffin/Xerox
Team Utley/Xerox
Marvin and Nancy Teitsma
Paul Thalner
The Mary V. Conner Trust,
Paul Thallner
Team Utley/Xerox
Ellis and Jeanette Taylor
Robert Taulton
Anne Marie Siudzinski
Chris Sindahl
Ann, Hannah and Grace Tate
Robert Taulon
Ella and Jeanette Taylor
Team Ruffin/Xerox
Team Utley/Xerox
Marvin and Nancy Teitsma
Paul Thalner
The Mary V. Conner Trust,
Mary Conner, Trustee
Harry and Janice VanHorne
Edward and Mary Vargas
Helen and Bill Vesper
Dr. Kristy Vetter
Kris and Jeff Vier
Vital Fitness
Charles Vite, DVM, PhD
Emily Vite
David and Lori Vonbeck
Mary and Edward Voss
Gregory and Debra Vreeland
Bevryl Wadddell
Ray and Kelly Waddell
Karen Wagenbrenner
Marty and Sandy Wagner
Ronald and Karen Wahls
Becky and Chris Waibel
Arthur and Carolyn Waldrum
Jay and DeAnna Walker
Sharon Walker
Emearce Wallace
Bonne Walsh
Jim and Kathy Ward
Ronald and Shirley Ward
Krist Warriner
Tressa Watkins-Arnold
Ryan Watson
Kimberly and Jeffrey Watten
Christine Weal
Sheryl and Andy Weatherford
Susie Weber
Brendan Wedehase
Mary Weimer
Chris and Beth Weiss
Martin Weiss
Brian and Jessica Wellman
Dr. and Mrs. Howard Sussman
Leland and Rebecca Swan
Jeff and Lisa Swanson
Richard and Judith Swantz
John and Diane Szuchy
Jeffrey Tall
Jennifer Tansey
Jack and Patty Taormino
Ann, Hannah and Grace Tate
Robert Taulon
Ella and Jeanette Taylor
Team Ruffin/Xerox
Team Utley/Xerox
Marvin and Nancy Teitsma
Paul Thalner
The Mary V. Conner Trust,
Mary Conner, Trustee
Harry and Janice VanHorne
Edward and Mary Vargas
Helen and Bill Vesper
Dr. Kristy Vetter
Kris and Jeff Vier
Vital Fitness
Charles Vite, DVM, PhD
Emily Vite
David and Lori Vonbeck
Mary and Edward Voss
Gregory and Debra Vreeland
Bevryl Wadddell
Ray and Kelly Waddell
Karen Wagenbrenner
Marty and Sandy Wagner
Ronald and Karen Wahls
Becky and Chris Waibel
Arthur and Carolyn Waldrum
Jay and DeAnna Walker
Sharon Walker
Emearce Wallace
Bonne Walsh
Jim and Kathy Ward
Ronald and Shirley Ward
Krist Warriner
Tressa Watkins-Arnold
Ryan Watson
Kimberly and Jeffrey Watten
Christine Weal
Sheryl and Andy Weatherford
Susie Weber
Brendan Wedehase
Mary Weimer
Chris and Beth Weiss
Martin Weiss
Brian and Jessica Wellman
Mr. and Mrs. Don and Lisa Wells
David Wenger
Tracy Wenges
MPS I parent Dawn Checrallah (front center) with the Genzyme Group at the 40 Years of Achievements gala.
continued >>

Biomarin Group at the 40 Years of Achievements gala.

Donald and Linda Nelson
Mary Ann Nesitheide
Luke Neuhaus
Tara Nicholas
Steven Nieva
David North
Kate North
Khurshina Numan
Thomas Nuzzala
Miguel and Sarah O’Campo
Teresa Ocot
Ann Oht
Kenichi Okamoto
Margaret O’Neal
Dacie and Mary Jane Onger
Joseph McCarthy and
Ann O’Rourke
John Ordorica
Elias Ortega
Eugene and Elizabeth O’Shea
Natalie Pacheco
Elaine Page
Mary Page
Elisa M. Palacios
Paty Palmer
Salvador Palumbo
Brittania Paris
Alexandra Parker
Rebecca Peary
Jessica Peckel
Shirley Pelletier
Jason and Tasha Pescher
Susan Peters
Marshall Phelan
Pridoux Nicholas
Larry and Deanna Pincombe
Ricky and Mona Plaisance
Jade Plaschka
Mike and Leanne Poellinger
Jay and Jean Politi
Joan Politi
Susan Porter
Positive Waves
Krist Price
Sandy Prosko
Mary and Paul Prues
Kelly Rabacchi
Mary Rankin

Carol Rapp
Louise and Wayne Rasmussen
Branden Ratliff
Sharon Reese
Dominc Regina
Caroline Rehberg
Sara and Len Reich
Brandor Reichert
Pat Reid
Salle Retmeyer
Elyce Rexer
Ann Rezza
Donna Ricca
William and Joan Richner
Jean Risimini
Lanielle Roach
Kristina Robinson
Sharon Rodriguez
John and Mary Rook
Alicia Russo
James and Dawn Ryan
Mildred Ryan
Eileen Saad
Rebecca Sarren
Carol Sarren
HoAnn Scarpelli
Kimberly Schmid
Donald and Janet Schmidt
Jessica Schneider
Mindy Schrader
Karen Schulze
Richard and Diana Schulze
Tracy Schwartz
Thomas and Marilyn Seidel
Stephen Shannon
Joel Bloom and Judy Shapiro
Ron Shebik and Kelly Kraemer
Daniel Sherman
Elizabeth Shirah
Richard and Ellen Sidman
Rose Sime
Jacquely Simmons
Joseph Siry
Bruce and Darlene Slavik
Denise and Matthew Smith
Joan Smith
Connie and Keith Smithson
Elizabeth Snarey
John Snarey
Albert and Christine Snedaker
Kurt and Kristine Sonntag
Patrick Sorgen
Stephanie and Tyler Spence
Alisha Spencer
Scott and Nicoleta Spevacek
William and Patricia Spevacek
Dr. Jeffrey and Dena Stern
Jeremy Stewart
Lynn Stewart
Shawn and Vicki Stone
Kimberly Stribing
Shawn and Lisa Stulting
Studio C Rachele, LTD
Karen Sustakoski
John and Sylvia Suter
Stacee Swee
Donald and Rachel Swicker
Traci and Cristoffer Sykes
Team Hinton/Xerox
Team McKinney/Xerox
Blake Teehan
Jackie and Allen Theriot
Jane Thomas
Carlotta Thompson
Jon Tipple
Kristy Tipple
Mary Top
Mary Trinar
Michelle Turgeon
Dean Turpin
Carolina Uloa
Sue Umemoto
David and Barbara Updegrove
Debi Urschel
Laurie and Ronald Vanderbeck
Roger and Winona VanderWest
Dao Vang
Kerri Vieathan
Sung Waddhana
Mary Vogt
Angela Vokac
Shane and Heather Wagner
Shirley Wain
Daniel Walker
Dennis and Michele Walker
Richard and Rosemarie Walker
Christopher and Denise Walker
2014 Fundraising Events

- 3 V 3 Basketball Tournament hosted by Destin Porche
- 12th Annual BioMarin Run
- Clara’s Courage Walk/Run
- 2014 Walk/Run Events
- Carter Family Ask Event hosted by Brandon Klenke
- Bowl for Kristofer hosted by Carl and Deborah Kruse
- BBQ for Conner hosted by Carl
- Annual Diamondhead Bridge Club Fundraiser for MPS hosted by Janelle Kunitz
- Aurora’s Elementary Dress Down Fridays hosted by Asia
- Messer Elementary School
- BBQ for Conner hosted by Carl and Deborah Kruse
- Bowl for Kristofer hosted by Chris and Jennifer Christianson
- Carter Family Ask Event hosted by Brooke Carter
- Cato Balloon Release
- Fundraiser hosted by Armorel School District Key Club
- Long Drive II Survive for MPS II hosted by Dan and Amy Cherstrom
- Cooper’s Birthday Fundraising Event hosted by Brian and Christine Tippett
- Cross Creek Charity Golf Tournament hosted by William Bagwell
- Crossfit Fundraiser hosted by Sherri Richbourg
- Do It Fore Danny Golf Tournament hosted by Ray and Amy Miller
- Dorian and Wynn’s Birthday and Annual Halloween Spooktacular hosted by Chris and Mercedes Johnson
- Volley for Support for Jackson hosted by Cherry Hill School District
- Eisler Rockland Boulders Fundraiser hosted by Janeen Eisler
- Graven Fundraiser for MPS II Research hosted by Karen Graven
- Halk Fall Festival hosted by Carla Halk
- Christian’s Dress Down Friday hosted by Hampton High School
- MPS Sharing and Caring hosted by Steve and Amy Holland
- Hope for Maura hosted by Amber Morgan
- CaBi Clothing Party for Michelle hosted by Lynn Hopkins
- Alves Ironman Arizona for the Palgrieo family hosted by Jeff Alves
- Poker Tournament for ML hosted by Chris and Mercedes Johnson
- Carter’s Concert and Raffle for MPS II hosted by Dan and Natalie Kanney
- Keep Hope Alive - Ask Event, Final Pledge Drive hosted by Jerry and Lisa Todd
- Kendra’s 30th Birthday hosted by Kendra Gottlieben
- Klenke Bowl-a-Thon in memory of Krag Klenke hosted by Brian, Kris and Chelsey Klenke
- BBQ for Cooper hosted by Carl and Deborah Kruse
- LB Foster Company Denim Day hosted by the Employees of LB Foster Company
- Lemonade Stand for Oliver and Waverly hosted by Mark and Breanne Melkin
- Hats On Day for MPS hosted by Lincoln Elementary School
- Lindsey Efrid’s Sweet 16 Birthday hosted by Karen Efrid
- Livewire Fitness Charity Bootcamp hosted by Yen and Paul Reid
- Lockport Casual for Causes Day hosted by the Faculty of Lockport High School
- Loren’s 16th Birthday hosted by Kimberly McClelland
- Milz T-shirt Fundraiser hosted by Sheila Ford and Kelly, Jill and Miles Young
- MPS Bunco Bash hosted by Carolyn Kanney
- MPS Day Fundraiser for Meekel hosted by Marla Stevens
- National MPS Society 40 Years of Achievements Gala hosted by the National MPS Society
- Old National Bank Fundraiser hosted by Loretta Spiriestphants
- Rachel’s 15th Birthday hosted by Andrea Longston
- Reamer Awareness Day Bracelet Sale hosted by Cassandra Reamer
- Run for Erin - Meet and Greet hosted by Stacy Peterson
- Slide-a-Thon for Max hosted by Milo and Ann Goodell
- Swingin’ Fore MPS Angels hosted by Jon and Teresa Musseleman
- UGI Blue Jeans Fundraiser hosted by the employees of UGI Energy Services
- Hinton Family Mary Kay Fundraiser hosted by Amy VanCleave
- Wedding Dollar Dance for Lucas hosted by Anna Marcotte-Herdina
- Woodsville High School Fundraiser hosted by Lori MacPherson
- Hugo Deseouza Fundraising Event hosted by Bernard Xavier
- Yoga Class Fundraiser in memory of Tejada hosted by Levy Solomon

2014 Walk/Run Events

- Clara’s Courage Walk/Run hosted by Shane Gibson
- Bike and Walk for Brooke hosted by Holly Zimbauer
- Bike and Walk for Brooke hosted by Holly Zimbauer
- Cameron’s Run for a Cure hosted by Julie Mollett
- Holden’s Hope Hero Run hosted by Juliana Hughes
- Hope 4 Hunter hosted by Michelle Hoffman
- Marshall Academy SK hosted by Marshall School and Oaklawn Hospital
- Post Office Café Run hosted by Kerri Rose and Mark Lessing
- Rays of Hope Family Fun Walk hosted by Jennifer Fair and Stephanie Kell
- Rays Race for a Cure hosted by Meredith Pinchak
- River Run for Ryan hosted by Johnathan and Maria Hunt
- Rays of Hope Family Fun Walk hosted by Jennifer Fair and Stephanie Kell
- Rays Race for a Cure hosted by Meredith Pinchak
- River Run for Ryan hosted by Johnathan and Maria Hunt
- Sauk Trail Walk-a-Thon for Austin hosted by Carol Pincombe
- Scrambled Legs Walk/Run for Hannah hosted by Holly Moltwaine

Courage Pages at www.mpssociety.org

The following families have their own website in Courage Pages through the National MPS Society. Whether you are hosting an event or raising awareness for MPS and related diseases, these custom pages are a terrific way to reach donors and help enhance your fundraising efforts. Consider building your Courage Page, there is no expense! To view these inspirational sites click Courage Pages on the right margin of our homepage www.mpssociety.org. Thank you to the following families:

Evan Abel
Aaron Atty
Hunter Beam
Annabelle Bozarth
Michael Campbell
Sam Caswell
Todd and Penny Wesolowski
Darrick and Melissa Westphal
Aileen and Mark Weycer
Leah White
Rick and Rebecca Wildman
Jack and Betty Willet
Robert and Gloria Williams
Elizabeth Wilson
Ellen Windau
Tanner Windau
Dawn Windover
Beverly Wingham
Jessica Wolf
Jeffrey and Laurie Wood
Neil and Karen Wood
Savannah Wyatt
Bernard Xavier
Shannon Yarbrough
Rebecca and Angel Zambrano
Heather Zehringer
Ronald Zike
Bob and Kate Zimmerman
Joseph M. Zlomek
Angela and Roger Zylstra
Classifications

Mucopolysaccharidoses (MPS) and related diseases are genetic lysosomal storage diseases caused by the body’s inability to produce specific enzymes.

<table>
<thead>
<tr>
<th>SYNDROME</th>
<th>MPS I</th>
<th>SYNDROME</th>
<th>MPS IVA</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPONYM</td>
<td>Hurler, Scheie, Hurler-Scheie</td>
<td>EPONYM</td>
<td>Morquio A</td>
</tr>
<tr>
<td>ENZYME DEFICIENCY</td>
<td>α-L-Iduronidase</td>
<td>ENZYME DEFICIENCY</td>
<td>Galactose 6-sulfatase</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SYNDROME</th>
<th>MPS II</th>
<th>SYNDROME</th>
<th>MPS IVB</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPONYM</td>
<td>Hunter</td>
<td>EPONYM</td>
<td>Morquio B</td>
</tr>
<tr>
<td>ENZYME DEFICIENCY</td>
<td>Iduronate sulfatase</td>
<td>ENZYME DEFICIENCY</td>
<td>β Galactosidase</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SYNDROME</th>
<th>MPS IIIA</th>
<th>SYNDROME</th>
<th>MPS VI</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPONYM</td>
<td>Sanfilippo A</td>
<td>EPONYM</td>
<td>Maroteaux-Lamy</td>
</tr>
<tr>
<td>ENZYME DEFICIENCY</td>
<td>Heparan N-sulfatase</td>
<td>ENZYME DEFICIENCY</td>
<td>N-Acetylglucosamine 4-sulfatase (arylsulfatase B)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SYNDROME</th>
<th>MPS IIIB</th>
<th>SYNDROME</th>
<th>MPS VII</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPONYM</td>
<td>Sanfilippo B</td>
<td>EPONYM</td>
<td>Sly</td>
</tr>
<tr>
<td>ENZYME DEFICIENCY</td>
<td>α-N-Acetylgalactosaminidase</td>
<td>ENZYME DEFICIENCY</td>
<td>β-Glucuronidase</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SYNDROME</th>
<th>MPS IIIC</th>
<th>SYNDROME</th>
<th>MPS IX</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPONYM</td>
<td>Sanfilippo C</td>
<td>ENZYME DEFICIENCY</td>
<td>Hyaluronidase</td>
</tr>
<tr>
<td>ENZYME DEFICIENCY</td>
<td>Acetyl CoA: α-glycosaminide acetyltransferase</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SYNDROME</th>
<th>MPS IIID</th>
<th>SYNDROME</th>
<th>ML II/III</th>
</tr>
</thead>
<tbody>
<tr>
<td>EPONYM</td>
<td>Sanfilippo D</td>
<td>EPONYM</td>
<td>I-Cell, Pseudo-Hurler polydystrophy</td>
</tr>
<tr>
<td>ENZYME DEFICIENCY</td>
<td>N-Acetylgalactosamine 6-sulfatase</td>
<td>ENZYME DEFICIENCY</td>
<td>N-acetylgalcosamine-1-phosphotransferase</td>
</tr>
</tbody>
</table>

Normally, the body uses enzymes to break down and recycle materials in cells. In individuals with MPS and related diseases, the missing or insufficient enzyme prevents the proper recycling process, resulting in the storage of materials in virtually every cell of the body. As a result, cells do not perform properly and may cause progressive damage throughout the body, including the heart, bones, joints, respiratory system and central nervous system. While the disease may not be apparent at birth, signs and symptoms develop with age as more cells become damaged by the accumulation of cell materials.
2014 Board of Directors

Steve Holland, **PRESIDENT**
Amy Holland
4908 Barbara Road
River Oaks, TX 76114
817.625.6999
steve.holland@mpssociety.org
amy.holland@mpssociety.org
MPS I H-S parents

Stephanie Bozarth, **VICE PRESIDENT**
1314 Elsinore Avenue
McLean, VA 22102
703.256.1980
stephanie.bozarth@mpssociety.org
MPS IV parent

Tom Gniazdowski, **TREASURER**
Anne Gniazdowski
315 Meadowview Court
Springboro, OH 45066
937.748.8809
tom.gniazdowski@mpssociety.org
anne.gniazdowski@mpssociety.org
MPS II parents

Kim Whitecotton, **SECRETARY**
1413 Emigrant Way
Modesto, CA 95358
209.544.2708
kim.whitecotton@mpssociety.org
MPS II parents

Jeff Bardsley
1209 Daviswood Drive
McLean, VA 22102
703.547.7087
jeff.bardsley@mpssociety.org
MPS II adult

Erica Blight
10661 Armstead Ave.
Indianapolis, IN 46234
Home: 317.473.1137
erica.blight@mpssociety.org
MPS II parent

Dawn Checrallah
58 Leroy Drive
Riverside, RI 02915
401.839.2689
dawn.checrallah@mpssociety.org
MPS I parent

Carrie Dunn
920 Edgemoor Road
Cherry Hill, NJ 08034
856.795.4528
carrie.dunn@mpssociety.org
MPS II parent

Kristine Klenke
7604 Sherry Creek Road
Worden, IL 62097
618.888.2204
kris.klenke@mpssociety.org
MPS II parent

Amber Mongan
5330 Saratoga St.
Eugene, OR 97405
509.475.6453
amber.mongan@mpssociety.org
MPS I parent

Austin Noll
9805 Fallen Leaf Drive
Middleton, WI 53562
608.203.6086
austin.noll@mpssociety.org
MPS III parent

MaryEllen Pendleton
56 E. Vinedo Lane
Tempe, AZ 85284
480.831.2157
maryellen.pendleton@mpssociety.org
MPS III aunt

Lisa Todd
11111 Jordan NE
Albuquerque, NM 87122
505.797.3603
lisa.todd@mpssociety.org
MPS II parent

Gordon Wingate
16319 Jordyn Lake
Tomball, TX 77377
832.498.1724
gordon.wingate@mpssociety.org
MPS III parent

**PRESIDENT EMERITA**
Marie Capobianco
Mary Majure Couture
Ernie Dummann
Steve Holland
Alice Kalamar
Linda K. Shine

STAFF

**EXECUTIVE DIRECTOR**
Barbara Wedehase, MSW, CGC
barbara@mpssociety.org

**DEVELOPMENT DIRECTOR**
Terri Klein
terri@mpssociety.org

**PROGRAM DIRECTOR**
Laurie Turner
laurie@mpssociety.org

**CONTROLLER**
Angela Guajardo
angela@mpssociety.org

**TECHNICAL AND DEVELOPMENT SUPPORT**
Kelly Rose
kelly@mpssociety.org

**ADMINISTRATIVE SUPPORT SPECIALIST**
Alison Blue
alison@mpssociety.org

**SCIENTIFIC ADVISORY BOARD**

Matthew Ellinwood, D.V.M., Ph.D.
Committee Chair
Alessandra D’Azzo, Ph.D.
Lorne Clarke, M.D.
Robert Desnick, M.D., Ph.D.
Patricia Dickson, M.D.
Mark Haskins, V.M.D., Ph.D.
John Hopwood, Ph.D.
William G. Mackenzie, M.D.
Joseph Muenzer, M.D., Ph.D.
Elizabeth Neufeld, Ph.D.
Kathy Ponder, M.D.
Mark Sands, Ph.D.
Edward H. Schuchman, Ph.D.
Calogera Simonaro, M.D.
William S. Sly, M.D.
Charles H. Vite, D.V.M., Ph.D.
Steve Walkley, D.V.M., Ph.D.
David Wenger, Ph.D.
Chester Whitley, M.D., Ph.D.
John H. Wolfe, V.M.D., Ph.D.
2014 Board of Directors