

Global Collaboration, Action and Answers for MPS and ML



National
MPS
Society

Support for Families. Research for a Cure.

2018
ANNUAL REPORT



National
MPS
Society

Support for Families. Research for a Cure.

MISSION

*The National MPS Society exists to cure,
support and advocate for MPS and ML.*

P.O. Box 14686
Durham, NC 27709-4686
877.MPS.1001
919.806.0101

MPSSOCIETY.ORG

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PICTURED ON THE COVER: Maura Mongan (MPS I)



CHAIRMAN OF THE BOARD
LISA P. TODD

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*While 2018 was a fabulous year, I am even more
excited about our opportunities in 2019.*



PRESIDENT AND CEO
TERRI L. KLEIN

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*Our MPS and ML team is honored to serve our
members and the broader rare disease community.*

THE NATIONAL MPS SOCIETY CONTINUES to be a global leader and advocate in the fight against MPS and ML. In 2018, the Society continued to maintain its crucial role in global initiatives and secured major gains by bridging our core goals among our primary stakeholders.

The Society is a trailblazer in rare disease research. In 2018, we awarded more than \$550,000 in grants to the world's leading researchers. This was made possible by the incredible dedication of our families, donors and the board of directors at fundraising events nationwide. In the last 20 years, the Society has funded more than \$9 million in research. These are funds provided by you—our members, donors and supporters. Because of your generosity, we funded cutting-edge research in hematopoietic stem cell transplant, gene therapy, substrate degradation, animal models of MPS diseases, chaperone therapy, skeletal deprivation, blood assay development and inflammatory responses science. It is an exciting time in the world of medical advancements; we have witnessed the most clinical trials and research for MPS and ML diseases than ever before. Your support has been critical to this success.

The Society recognizes the importance of collaboration with other organizations and the funding of pivotal research. This collaboration exponentially increases the potential to identify and remove key scientific obstacles within our diseases which will lead to treatments and, ultimately, cures. These partnerships include various MPS family foundations, lysosomal disease advocacy organizations, the National Institutes of Health (NIH), the Lysosomal Disease Network, the University of Pennsylvania/Million Dollar Bike Ride and our sister MPS organizations within the International MPS Network (IMPSN).

A major highlight of 2018 was our hosting of the 15th International Symposium for MPS and Related Diseases. More than 1,000 attendees traveled to San Diego, CA, to participate in a global collaborative meeting. The family and scientific conferences were hosted in tandem, with many attendees flowing freely throughout. Scientists and industry stakeholders were provided three days of networking opportunities to stimulate research and guide future actions in addressing MPS and related diseases. In addition, new insights for breakthrough science in gene therapy and gene editing outcomes were presented. During the symposium, the "Life Achievement Awards in Science and Advocacy" were awarded to Mark Haskins, VMD, PhD, and Flavio Bertoglio, president of Italy's MPS Society. This award is meaningful, as it was voted on by their peers from around the world.

A major role of the National MPS Society is to bridge advocacy gaps for our families with local and federal government agencies. This includes providing testimony to the Federal Drug Administration (FDA), and meeting with the NIH. In late 2018, we met with the NIH and other MPS-related foundations (Team Sanfilippo and The Ryan Foundation) to identify, discuss and build pathways for implementation of compassionate allowance drug access to children and adults with rare diseases.

The Society strengthened its alliance with global MPS organizations. Terri Klein was nominated to the board of directors as the first co-chair for the IMPSN, a global MPS collaborative tasked with fostering underserved countries and gaining key knowledge and insight to expand opportunities for multi-center clinical trials.

Once again the Society was recognized as a national leader among charities. For the eighth year, we received the coveted Four-Star (exceptional) rating from Charity Navigator, an independent charity evaluator, indicating that we operate and perform in the most fiscally responsible way. We are in the top 3% of charities nationwide, outperforming most in the United States. This rating illustrates our dedication to program funding. This past year, we awarded one of the highest levels of research program funding and enhanced our internal family support programs with the continuation of our Pathways program and the addition of our Bereavement Expense program.

As you review the 2018 Annual Report, we hope you note the accomplishments from our board of directors and committees. We can only deliver our mission because of the countless hours our volunteers provide to help our families.

As we transition to the new year, we expect 2019 to be a year of continued growth for the Society with a strong foothold in the global MPS and ML community. The world has focused on the United States, by fostering key MPS clinical trials, leading the world in newborn screening for rare diseases and mentoring underserved countries through educating MPS families via humanitarian programs. The future possibilities are limitless!

LISA P. TODD, chairman, board of directors
TERRI L. KLEIN, president and CEO

Governance Committee

THE GOVERNANCE COMMITTEE plays a crucial role in the National MPS Society's overall guidance and direction by reviewing staff and board member resources, identifying gaps in service delivery, and working to improve overall performance. This is accomplished through several key initiatives, such as annual compensation and benefit evaluation, board member reviews and board election oversight.



2018 INTERNATIONAL MPS NETWORK MEETING, SAN DIEGO, CA

This year began with a full review of staff compensation and benefits, resulting in modifying the structure of the staff's benefit plans to ensure the Society remains a competitive employer.

The committee also determined that board members could benefit from coaching and training to assist in achieving their goals, as well as holding them accountable for their performance.

To obtain this feedback, board members completed an evaluation of the board as a whole, a self-assessment review of their own performance and separate anonymous evaluations for each of their peer board members. This evaluation process provided each board member an opportunity to communicate objectively and openly discuss strengths and weaknesses, ensuring alignment with the Society's identity, mission, values and goals.

Our 2018 annual board election process was completed in late fall. Prior to the member voting process, the committee completed a vigorous vetting process of all applicants to identify a selection of high-quality candidates. With great excitement, the board welcomed three amazing new members with terms beginning in 2019: Sheri Wise, Shelby Lyon and Cristol Barrett O'Loughlin.

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This is my second stint on the Society's board of directors, the first one in the early 2000s. There has been one constant that I have observed: the can-do attitude of the board of directors. It is the hallmark of the National MPS Society. They go the extra mile, and then the mile after that. The board, acting together with our wonderful staff, have had a huge impact on the families we serve.

Through our fundraising efforts and with big hearts, we achieve our mission. The Society has kept its attention focused on what matters most—the members who are affected by MPS and ML. We are a patient-centered organization that funds critical research through global collaboration. The Society maintains a strong foothold in the MPS arena, both here in the United States and internationally.

LARRY KIRCH, National MPS Society board of directors, MPS IIIA parent

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Family Support Committee

SUPPORTING OUR FAMILIES strengthens our community and fulfills our mission. Through a variety of programs, the National MPS Society assists families and individuals throughout their journeys and enables them to reach goals, meet needs and participate in life-enriching programs.

The Bereavement Expense Program started in response to an unmet need of limited financial resources available to families experiencing the loss of a loved one from MPS or ML. This program began in 2018, providing grants to families to assist with funeral costs or other final expenses.

Working on a global level, family support included new and increased partnerships between countries. The Society's expanded reach provided access to humanitarian programs for approved treatments and established connections for referral. At our families' request, the Society implemented strategies and assistance to provide direct tissue donation to researchers. Utilizing third-party, nonprofit sources, tissue donation fostered international research opportunities.

Investments of nearly \$120,000 provided support to families in 2018 through the following programs and initiatives:

Family Assistance Program

- Approved six applications, totaling \$15,491.
- Items funded included hearing aids, wheelchair lifts, vehicle valet seat and eyeglasses.

Medical Travel Assistance Program

- Approved 23 applications, totaling \$11,527.
- Combined travel and lodging to increase eligibility to \$750 per applicant.

Journey Assistance Program

- Approved three applications, totaling \$783.
- Funds awarded assisted families in obtaining an iPad, home pest control, and a chair for home infusions and treatments.

Bereavement Expense Program

- Approved nine applications, totaling \$4,500.
- New program for 2018, providing assistance with final expenses for an individual with MPS or ML.

Conference Scholarships

- Awarded scholarships to assist 41 families and adults with MPS and ML to attend the International Symposium, totaling \$41,576.

Continuing Education Scholarship Program

- Awarded 30 scholarships to students, totaling \$37,500.
- Awarded two Jeffrey Bardsley Scholarships to individuals with MPS, totaling \$10,000.
- Implemented a lifetime cap on the CED program of \$4,000 to increase availability of these scholarships to new applicants (not applicable to the Jeffrey Bardsley Scholarship award).

Extraordinary Experiences Program

- Awarded four grants, totaling \$3,777.
- Grants awarded to assist three individuals with MPS to attend educational conferences outside of the International Symposium and for an individual to attend a unique football event experience.

Regional Social Events

- Provided funding to support events in Ohio, Illinois and Texas, totaling \$2,035.



With a grant from the National MPS Society's Family Assistance Program, Jett received a pair of hearing aids. These will help him to socialize, work and communicate, and enable him to stay connected to the outside world.

CLAIRE TRAPPE, mother of Jett (MPS I)

Advocacy Committee

ADVOCACY IS ONE OF THE BEST WAYS for our rare disease community to share its stories with lawmakers and policy influencers, who are empowered to make a real difference on a federal level. Federal policies can increase life-saving medical research and access to care for our MPS and ML patients.

The Advocacy Committee focuses on a number of goals throughout the year, including regular calls to action on rare disease legislation, disseminating carefully crafted appropriations language to spread our message to new members, collaborating with the rare disease community as a whole, conducting advocacy training webinars and growing and fostering relationships with key decision makers.



NORTH CAROLINA NEWBORN SCREENING APPROVAL MEETING

In 2018, the Advocacy Committee:

- Facilitated Capitol Hill visits with 44 advocates meeting with 51 legislators over two days to advocate for the OPEN Act and increased NIH funding for MPS and ML diseases.
- Provided onsite training in Washington, DC, for our Speaker's Bureau Program.
- Hosted four 30-minute advocacy training webinars: MPS Advocacy: Preparation for Meeting with Your Legislator; How to Tell Your Personal Story; Letters to the Editor and Social Media Advocacy; and Finding, Meeting and Cultivating a Relationship with Your Lawmaker. These webinars can be accessed on our website for continuous training.
- Created membership and public awareness action alerts to support the following: Medicaid formulary access for rare disease patients; the Lifespan Respite Care Program; the National Family Caregiver Support Program; and the RARE Act of 2018.
- Attended the following advocacy and networking conferences: 14th Annual WORLD Symposium; COPA; NORD Rare Awards Gala; EveryLife Congress on newborn screening; Global Genes 2018 RARE Patient Advocacy Summit; NORD Patient Summit.

- Submitted position statements on the following:

1. Opposition letter for the "Right to Try Act"—legislation did not include primary barriers to treatment access outside of the clinical trial design and removed the Food and Drug Administration approval and consultation.
2. Open letter for the Partnership to Improve Patient Care to inform CVS Caremark that the United States has considered and rejected any unacceptable discrimination against patients with disabilities. It is recommended that CVS Caremark not use incremental cost-effectiveness ratio measures for treatment.

- Increased newborn screening awareness opportunities with collaborations led by EveryLife Foundation and patient advocacy within individual states.

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As I reflect on the important tasks the Advocacy Committee was challenged with in 2018, I realize that our goals are common ones shared across the globe. We meet with Congress to continually remind them that our loved ones with MPS and ML need their help. Educating our government is key for continued financial and healthcare support, as well as for funding as new science emerges. In 2018, the Advocacy Committee continued to advocate for NIH and FDA funding, for newborn screening, and for bills that could result in more treatments and cures for MPS and ML—the ultimate goal for all families everywhere.

MARY CAVANAGH, mother of Scott (MPS IVA)



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Education and Publicity Committee

THE NATIONAL MPS SOCIETY CONNECTS AND ENGAGES with the MPS and ML communities through education and publicity efforts. Through social media, educational materials, and printed publications and promotional materials, the Education and Publicity Committee actively seeks new and innovative ways to involve our members and increase public awareness.

In 2018, the National MPS Society hired a communications director to expand committee reach through increased social media, updated educational materials and enhanced email marketing efforts. The Education and Publicity Committee focused on global community awareness as it helped the Society prepare for the 15th International Symposium on MPS and Related Diseases.



WHITECOTTON FAMILY (MPS II)

The International MPS Network is a global collaborative of patient advocacy groups that support the well-being of those affected by MPS and related diseases, and promotes public and professional awareness worldwide. As a united voice, the International MPS Network can play a significant role in patient advocacy to advance research, treatments, diagnostics and patient care.

In 2018, The International MPS Network took a bold step by electing a board of directors to move the mission and mandate of the International MPS Network forward.

The Canadian MPS Society is proud to join efforts with our global partners, including the National MPS Society, to develop clear pathways for sharing information and best practices and enhancing our global communications to further our mission. Together, we are stronger.

KIM ANGEL, executive director, Canadian MPS Society

In 2018, the Education and Publicity Committee:

- Increased efforts to raise awareness for International MPS Awareness Day, May 15.
- Increased *e-Courage* subscriptions to more than 1,700 members. *e-Courage* is a monthly electronic newsletter.
- Implemented the return of the printed *Courage* publication. Distribution of the publication resumed in December.
- Updated the National MPS Society brochure and *e-Courage* online newsletter.
- Began a comprehensive revision of the fact sheet library for the MPS and ML community.
- Developed a full marketing plan to provide publicity for the Society on important initiatives including: advocacy visits, newborn screening and the 15th International MPS Symposium for MPS and Related Diseases.
- Created new strategies and restructured the committee. Our new Education and Publicity Committee is comprised of four sub-committees: Content Development, Design Development, MPS Awareness Day and Strategic Planning. This was done to develop a more meaningful delivery of key communications.



Adult Resource Committee

WITH AN INCREASING NUMBER of individuals with MPS and ML living into adulthood, the Adult Resource Committee (ARC) developed to focus on unique issues among this population. The ARC provides a way for adults with MPS and ML to have a voice within the National MPS Society and encourages the efforts of physicians, families and friends to provide support.

Though it is a recent endeavor, the ARC has developed a solid groundwork for increased advocacy and efforts by individuals with MPS and ML, both within the ARC and the Society as a whole. Increased involvement remains a critical objective in setting goals for the upcoming year. The ARC provides an opportunity for adults to voice individual and collective needs, transition to increased independence and develop strategies for communicating with external supports.

JEREMY GATTA (ML III)



KENDRA GOTTSLEBEN (MPS VI)



JOCELYN WONG (MPS IVA)



TRACY MARIE GREENBERG (MPS IVA)



SELECTED MEMBERS



AUCTIONING QUILT FOR ARC PROGRAMS: JENNIFER KLEIN (ML III), SHERI WISE (MPS IVA), JASON MADISON (MPS II), ERICA THIEL (MPS I), AND TERRI KLEIN

2018 ARC highlights:

- Completion of a "Road Kit" that provides information and resources for adults and those transitioning into adulthood. Distribution of Road Kits will begin in 2019.
- Worked with adults on a global level to host sessions, panel discussions and breakout events at the 15th International Symposium on MPS and Related Diseases.
- Increased planning and coordination of upcoming efforts to drive awareness and advocacy relevant to needs of the adult population.
- Developed adult-specific informational materials and provided content for updates of other Society literature.

Pathways Committee



THE NATIONAL MPS SOCIETY'S LONG-TERM VISION includes expanding ways to provide direct services to families in need throughout their journey with MPS or ML. The Society maintains this forward-thinking approach by providing services of skilled social workers who travel the country to meet with newly diagnosed families.

Meeting families and offering assistance at critical times enables the Society to expand its reach into other areas of support. In 2018, the Pathways program completed its first full year of operation, with two staff members and more than 80 families enrolled in the program.

Pathways provides a high level of support and education to families and individuals throughout the first year of diagnosis. Home visits maximize the opportunity to connect and provide meaningful, compassionate and direct lines of support. The Pathways team links families with local and national services, working to ensure they receive high quality care. Families are provided tools to equip and strengthen them to manage care and establish resources as they move forward on their MPS journey.

In 2018, Pathways:

- Provided services to 84 families in their first year of diagnosis.
- Conducted 42 face-to-face visits with families in their homes or at the hospital.
- Completed year-long services with 43 families.
- Averaged three to four newly diagnosed family referrals to the program each month.
- Developed program management materials and tools.
- Implemented program surveys to evaluate progress and understand unmet needs of newly diagnosed families.
- Completed visits in 29 states.
- Generated new materials and created a new branding logo to represent the program.



JEREMIAH (MPS I), MARINA MORENO AND COREEN GRAY



As a newly diagnosed family, we were so heartbroken and lost at the beginning. It was such a blessing to receive support, information and encouragement from the Pathways program, as well as connect with the National MPS Society. Finding community and support through Pathways was and is such a huge help for us, and we now refer and share Pathways with other families across the country. To know that we're not alone through this difficult journey has equipped and educated us, and it makes it a little less overwhelming.

LINDA HEARD, mother of Faith (MPS I)

Research Grants

RESEARCH REMAINS PARAMOUNT to the National MPS Society's mission: to find cures for MPS and ML. Grant funding, research partners, and collaboration ensure key efforts toward a better future for all affected.

For decades, the Society has been funding research projects that directly advance our mission to find cures for MPS and ML. In 2018, the Society's research program allocated one of the highest levels of funding for life-saving and life-changing research.

The National MPS Society allocated and invested more than \$550,000 in total grant funding in 2018, which includes second-year funding for grants awarded in 2017, and \$100,000 in partnership with the University of Pennsylvania through the Million Dollar Bike Ride. The Society also committed \$25,000 to the University of Minnesota, Lysosomal Disease Network for continued Core Imaging Research with the NIH. The funding the Society provides has been, and continues to be, critical as we move forward with our mission to find cures.

We received 32 letters of intent from researchers around the world this past year. After reviewing the letters, our Scientific Advisory Board review committee requested full grant proposals from 16 researchers. Projects selected include research for syndromes in desperate need of funding. Sanfilippo research received \$320,000 and Mucopolidosis received \$90,000. Other projects include substrate degradation enzyme therapy for MPS IVA and critical safety studies for MPS I corneal gene therapy.



2018 INTERNATIONAL SYMPOSIUM ON MPS AND RELATED DISEASES: MARK HASKINS, VMD, PHD, AND PATRICIA DICKSON, MD

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As researchers, we usually tell the stories of our work, whether to the community or through publications, as focused narratives that make the positive results seem self-evident, foregone conclusions. What we don't convey often enough is the trepidation we feel about sustaining our research projects, our careers and our focus on rare diseases. Over the years, the National MPS Society has been a lynch pin that has ensured that careers and research focused on MPS diseases were viable and sustainable. Now more than ever, the research community needs the resources and leadership of the Society so we can continue to make progress for MPS patients and families.

MATTHEW ELLINWOOD, DVM, PhD, chairman, 2019 Scientific Advisory Board

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This innovative research could not be accomplished without the selfless commitment of our global MPS scientists. Our commitment and dedication to advancing our mission through these partnerships is highlighted in these carefully chosen and pivotal research projects:

2018 Two-Year Grant Award Recipients

Dr. Heather Flanagan-Steet
\$90,000 general grant
Greenwood Genetic Center
Greenwood, SC
*"Cysteine Cathepsins as
Therapeutic Targets in
Mucopolidosis II"*

Dr. Kim Hemsley
\$90,000 general grant
SAHMRI
Adelaide, Australia
*"A Window to the Sanfillipo Brain:
Visualizing Experience-Dependent
Plasticity in MPS IIIA Mice"*

Dr. Kazuki Sawamoto
\$75,000 MPS IV grant
Nemours Biomedical Research
Alfred I. duPont Hospital
Wilmington, DE
*"Substrate Degradation Enzyme
Therapy for MPS IVA"*

Dr. Laura Hewson
\$60,000 MPS III grant
University of Australia
Adelaide, Australia
*"Purine Metabolic Enzymes as
Therapeutic Targets in Sanfillippo
Syndrome"*

2018 One-Year Grant Award Recipients

Dr. Timothy Wood
\$30,000 MPS I grant
Greenwood Genetic Center
Greenwood, SC
*"Functional Analyses of IDUA
Sequence Variants – MPS I"*

Dr. Brian Gilger
\$30,000 MPS I grant
NC State University
Raleigh, NC
*"Safety Studies for Corneal AAV-
IDUA Gene Therapy to Reverse
Corneal Blindness in MPS I"*

Lysosomal Disease Network
\$25,000 multi-syndrome grant
University of Minnesota
Neuroimaging Core NIH Project

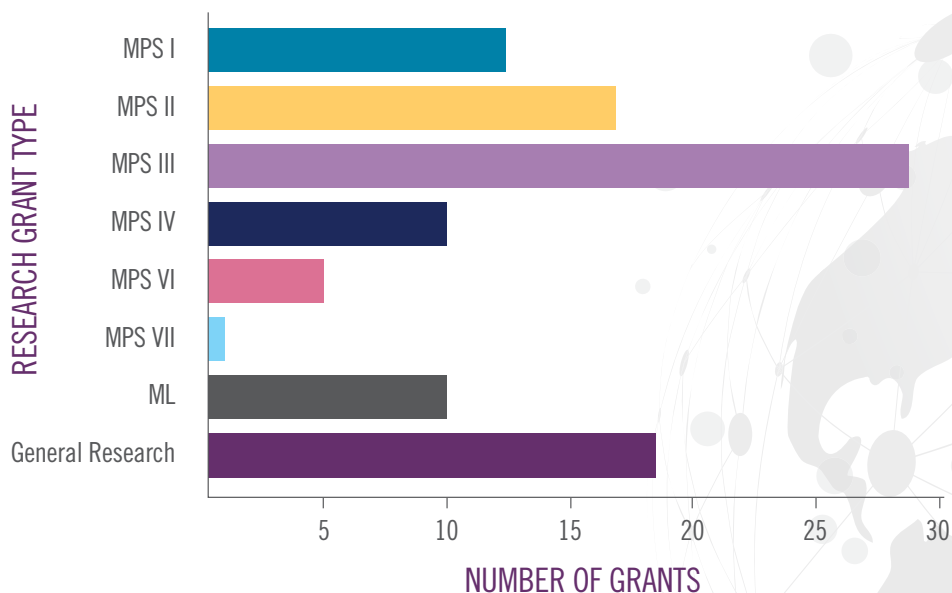
2017 Second-Year Grant Award Funding

Dr. Allison Bradbury
\$15,000 Mucopolidosis grant
University of Pennsylvania
Philadelphia, PA
"AAV Gene Therapy in a Feline"

Dr. Charbel Moussa
\$67,500 MPS III A grant
Georgetown University
Washington, DC
*"The Effects of Tyrosine Kinase
Inhibition on MPS IIIA Mice"*

Dr. Chet Whitley
\$35,000 MPS IVA grant
Regents of the University of
Minnesota
Minneapolis, MN
*"Neurocognitive and Neuroimaging
of Morquio Syndrome"*

NUMBER OF RESEARCH GRANTS ISSUED SINCE 2001



15th INTERNATIONAL SYMPOSIUM

LAST SUMMER, THE NATIONAL MPS SOCIETY HOSTED the 15th International Symposium for MPS and Related Diseases in San Diego, CA. This biannual meeting provides the sole opportunity to formally bring together all key stakeholders of the international MPS and ML community. The 2018 symposium was the largest attended event in its history, with more than 1,000 patients, families, researchers, physicians, industry partners and volunteers. In tandem, the symposium provided both a scientific and family conference.

The scientific program provided an overlay of the following topics: disease pathophysiology, diagnostics and biomarkers, clinical research and trials, and preclinical therapy developments. Through global abstract submissions, the organizing committee ensured new scientific discoveries and ground-breaking research would be revealed. Eighty-eight scientific posters were selected and presented over two days. It was an opportunity to witness scientific success and remain awestruck at their achievements.

The family program was held in tandem over the next three days and included the following key topics: 21st Century ecosystems and scientific challenges; cardiac and bone management; newborn screening; neurobehavioral symptoms in clinical trials; rare disease drug development; gene therapies and second generation therapies; combination therapeutic approaches; pediatric to adult transitioning. Preceding the family conference, a full-day meeting was held on Sanfilippo Syndrome, emphasizing efforts for diseases that do not have an approved therapy.

The symposium drew more than 50 adults with MPS and related diseases from around the world to San Diego. Adult keynote speakers opened the symposium using hope as a theme among the attendees. A boat tour and meet-up provided the adults with multiple opportunities for networking and exploring the beautiful western coastline of the United States.

“When a number of researchers and key stakeholders asked us to host the International Symposium again, I realized the National MPS Society succeeded at

delivering one of the most successful events,” said Terri Klein, president and CEO, National MPS Society. “We are proud that this inspirational platform allowed attendees to picture a future where newborns are screened for MPS and related diseases and clinical trials and therapies exist for parents to save their children.”

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Our field has seen a tremendous transformation over the past three decades. Ask an old timer to tell you what it was like at the beginning, before enzyme therapy and bone marrow transplantation changed the face of some forms of MPS. It has not been easy, and we have lost many along the way. But, we've also watched children never expected to reach adulthood do just that. Now, with an enzyme therapy and cell transplantation to gene therapy and gene editing, it seems as though we are again on the edge of a new frontier.

PATRICIA DICKSON, MD, Symposium Scientific program chairman



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ON MPS AND RELATED DISEASES



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When my daughter was diagnosed with MPS IV in 2006 at 4 months old, it seemed the wheels of research were at a crawl. But that changed and the pace continues to increase year after year. It is awe-inspiring to witness more than 13 years of basic research translating into treatments and potential cures for MPS and ML. This investment in our future started more than 44 years ago, when a small group of parents came together initially to just support one another, which led to a focus on seeding promising research and advocating at the federal level for NIH grants. Though progress moved slowly in the beginning and for many years, the last 10 years has been beyond my expectations. My dreams for what can be accomplished have grown exponentially. I feel blessed to be just a small part of the process through advocating and fundraising with the National MPS Society, an organization that has a history built on hope turned into action and realized clinical trials and therapies.

Passion to push beyond expectations will help us achieve all that still needs to be done. Chairing the 15th International Symposium on MPS and Related Diseases in the United States was an honor. We were able to bring together global collaboration and research, all while being transparent and serving our patients and their families. Keep faith, keep striving, keep dreaming and creating. It is more than possible to change the course of this disease. We created new pathways at the symposium. It has been a blessing (in disguise!) and a life-changing experience, to be a part of this community. But I have also had to watch the reality of so much loss. My perspective has changed and I cherish all the memories of those we have lost. Our MPS angels fuel the urgency and passion to keep moving forward to create global change and provide treatment access to every baby diagnosed with MPS. Forty-four years is a lifetime, but science has changed how we will tackle the decades to come. The Society will be front and center collaborating and creating necessary change to save lives.

STEPHANIE BOZARTH, symposium chairman, MPS IV mother

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Fundraising Committee

THE TRUE MEASURE OF SUCCESS for any nonprofit organization is the level of support it receives from its members and benefactors. Through increasing generosity and commitment, donors and benefactors of the Society drive growth and expansion of programs and outreach each year. In 2018, the Society hosted major national events in San Diego, CA, Napa, CA, San Antonio, TX, Babylon, NY, and several other cities. In addition, the Society teamed up for the fifth year in a row with the Million Dollar Bike Ride at the University of Pennsylvania to raise more than \$100,000.

The Fundraising Committee supports the mission of the Society through many programs, such as family fundraisers, walk/runs, the Annual Fund, major gifts, planned giving, mobile giving, Courage Pages, our Champions Circle, crowd rising fundraisers, social media campaigns, the Combined Federal Campaign, United Way, employee giving, and matching corporate gifts and grants. The Fundraising Committee strives to increase donations each year and looks forward to the opportunities in 2019.

In 2018, the Fundraising Committee:

- Received its eighth four-star charity rating from Charity Navigator, representing sound fiscal management and commitment to accountability and transparency. This “exceptional” designation differentiates the Society from its peers and demonstrates to the public it is worthy of their trust.
- Supported an active membership roster of more than 2,975 members.
- Raised more than \$530,000 through run/walk and fundraising events.
- Secured more than \$100,000 for MPS and ML research from the University of Pennsylvania through the Million Dollar Bike Ride.
- Hosted three national run/walk events in Napa, CA, San Diego, CA, and San Antonio, TX.
- Supported more than 30 family fundraisers, including sports tournaments, cycling, bake sales, bowl-a-thons, concerts, bingo, auctions and school relays.
- Increased grant writing efforts to secure new sources of funding for critical research, family support, and our newest programs: Pathways and the Speakers Bureau.
- Raised \$203,359 through the 2018 Annual Fund campaign, chaired by Steve, Amy, Maddie and Laynie Holland.
- Continued efforts to meet with major donors and Society friends.
- Received Combined Federal Campaign application approval.
- Hosted 54 Courage Pages (customized, informative family web pages for awareness and fundraising) on the Society’s website.



POST OFFICE CAFÉ RUN: MARK LESSING (MPS IIIA FATHER)



RISE UP FOR MPS: KEITH AND SHERRI RICHBOURG (MPS I PARENTS)

- Worked with donors to process more than 250 Employee Giving Campaign and corporate matching gifts.
- Increased awareness for the Rising Sun Legacy Circle and processed new planned gifts from trusts and wills.
- Established the Jenna Marie Richbourg Endowment with funds raised through Rise Up for MPS in Waco, TX.

2018 Fundraising Events

36th Masonic District of Pennsylvania Fundraiser,
hosted by Josh Nay

Adam Podesky Fundraiser,
*hosted by National Jr. Honors Society
Joseph Case Jr. High School*

Anniversary Celebration,
in honor of Mel and Millie Anhalt

Anniversary Celebration,
*in honor of Jonathan Cino and Shirley
and Peter Cino*

**Annual Family Support Program
Fundraiser,** *hosted by Junior
Woman's Club of Hilton Village, Inc.*

Cooper's Troopers BBQ, *hosted
by Christine Tippet*

Do it Fore Dan Golf Tournament,
hosted by Ray and Amy Miller

Dave Pizzaworks Fundraiser,
hosted by Keith and Sherri Richbourg

Fundraiser in Honor of Ava Kreme,
hosted by Fort Recovery Schools

Halk Family Fundraiser, *hosted by
Carla Halk Crain*

Holland Caring & Sharing Event,
hosted by Steve and Amy Holland

**Hopkins 9th Annual CABI Clothing
Party,** *hosted by Lynn Hopkins*

Houston Kendra Scott Fundraiser,
hosted by Trisha Jensen

**John Thornton's 16th Birthday
Fundraiser,** *hosted by Sheila Thornton*

Karina's Birthday Fundraiser,
hosted by Luis and Angela Guajardo

Kendra Scott Fashion Island,
hosted by Lynn Hopkins

Kramer Chili Cookoff, *hosted by
Elizabeth Kramer*

Klenke Bowl-a-Thon, *hosted by
Kris Klenke*

Mask Concert for a Cure,
hosted by Dorothy Mask

Million Dollar Bike Ride, *hosted
by Penn Medicine Orphan Disease
Center*

**MPS III Fundraiser in Memory of
Ryan Mask,** *hosted by
St. Paul's United Church*

**Mrs. Radcliff's 3rd Grade Class
Mini Mall for Taylor Wojnarowski,**
hosted by Lisa Radcliff

Pig Roast, *hosted by Knights of
Pennsylvania, RC*

Rise Up for MPS, *hosted by
Keith and Sherri Richbourg*

**Sarah Van Orden 21st Birthday
Fundraiser,** *hosted by
Sarah Van Orden*

Toss for Tony Washer Tournament,
hosted by Katie Willmann

Traveling Through Memories,
hosted by Michelle Dodson

Virginia Charity Tennis Tournament,
in honor of Annabelle Bozarth

Volleyball Tournament, *hosted by
Molly Birmingham*

2018 Walk/Run Events

**Alamo Battle for MPS 5k
Run & Memorial Walk,** *hosted by
National MPS Society*

Napa National Run, *hosted by
National MPS Society*

San Diego National Run,
hosted by National MPS Society

Posted Office Café Run,
hosted by Mark Lessing

Courage Pages at www.mpsociety.org

The following families have their own website through Courage Pages at the National MPS Society. Whether hosting an event or raising awareness for MPS or ML, these custom pages are an effective way to reach donors and help enhance fundraising efforts, with no expense. These inspirational sites can be found under the "Give" section of the Society's home page.

Evan Abel
Ashley Allen
Aaron Athy
Hunter Beam
Ryder Belisle
Colin Berning
Keller Blakeley
Annabelle Bozarth
Tyson Brown
Sam Caswell
Alan Charest
Alex and Nick Cherrstrom
Jackson Dunn-Kraus
Julia Ann Donahue
Antonio Estrada Willmann
Kali Gegenheimer
Shane Gibson
Owen Groesch

Karina Guajardo
Faith Heard
Makenzie and Isabella Hardesty
Holland family
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Analynn Hughes
Fiona Humphrey
Kathleen Joyce
Carter Kanney
Beth Karas
Eddie Kimminau
Allison Kirch
Jennifer Klein
Kraig Klenke
Drake Lucas
Shane McGoey
Caleb Michalik
Danny Miller

Maura Mongan
Xavier Patton
Analee Perez
Raymond Pinchak
Hudson Roman
Christopher Sanchez
Elijah Story
Katie Swanson
Madison Thompson
Cooper Tippet
Jack Todd
Easton Walker
Trinity Walker
Michael Whitaker Russell
Scotty Whitecotton
Christian Yard
Emily Yurkins
Roy Zeighami



ALAMO BATTLE FOR MPS 5K

Fundraising, *continued*

2018 Social Media Fundraisers

Lee Ann Adams
Dwaa Al
Bob Allen
Mitch Andreotta
Betty Arceneaux
Emma Armato
Ron Atkinson
Francie Barbella
Aleta Bart
Amanda Bayne
Maurizio Bellassi
Ofeslia Beltrain
Katie Bennett
Jerry Bennett
Nicole Bennett
Darryl Block
Geri Boneske
Jason Boni
Dawn Booster
Rose Bougeois
Austin Bozarth
Stephanie Bozarth
Jefferey Brown
Liz Brown
Rachel Burns
Mariah Campagna
Matthew David Campbell
Adriana Caraballo
Carla Halk Crain
Elyse Cataldi
Anthony Catanzarite
Laura Catanzarite
Olivia Cecere
Jennifer Nicole
Chambers
Jamie Tarquin Chapman
Andrew Charest
Ruth Clancy
Tela Clancy
Vicki Clayton
Melissa Cleroux
Alayna Coates
Allison Cochran
Ilyona Cook
Jodie Costello
Ashley Crist
Jason Cullere
Karen Cutrer
Keena Davis
Nancy Davis-Ramsey
Loren DeSouza
Sue Miller Deuster
Addrea Downs
Jull Duclos
Leslie Duncan
Tamiko Dunson
Mark Dunson
Meghan Eaton

Jennifer Lee Eickman
Wayne Eppenhimer
Amanda Fern
Ashley Ann
Fortheringham
Ashley Frix
Elizabeth Fry
Jerod Fults
Marcia Galan
Kali Gegenheimer
Tracey Gegenheimer
A.J. Gegenheimer
Lola Gindrat
Miranda Giselle Cesmegi
Kaelin Gontaine
Cassidy Gosey
Kendra Gottslenben
Jessica Grantham
Dewayne Green
Monica Green
Rebecca Green
Andrea Gribble Holliman
Cat Griffith
Megan Griffith
Brenda Haggett
Bethany Hampton
Jennifer Hardy
Brittney Hartline
Kim Harvey
Laura Harvey
Taylor Harvey
Rhonda Hathcoat Baugh
Jessie Haugen
Andrew Hayes
Linda Stephany Heard
Paul Heard
Kimberly Heichel Forand
Kimberly Heiling
Jennifer Hembree
John Hennebry
Ashley Hills
Melissa Hockenberry
Lynn Hopkins
Eddie Hopwood
Jennifer Howard
Melissa Hurt-Crawford
Nadia Hussain-Atif
Bridget Hysell
Andrea Jackson
Lauren Jacob
Jessie James
Deanne James
Dana James Stapley
Alyssa Jeanne
Justine Johnson
Emily Johnson
Samantha Kali Keenan
Tammy Kassa

Brenna King
Terri Klein
Willis Kleinian
Zach Kramer
Mary Ann Kruse
Susan Elizabeth Ladewig
Tiffany Strickland Lala
Heather Lee
Matthew Lemke
Michael Lewis
Morgan Lewis
William Lewis
Mary Katherine
Livingston
Zach Longston
Lissette Lopez-Sanchez
Paul Lorber
Courtney Lynn
Jamie Lynn
Kari Lynne
Will Mallia
Lucas Marcotte
Tatum Marie Knight
Linda Martin
Stephen Mask
Shannan Rene May
Trisha Anne McClelland
Jessyca Rene
McCracken
Anna Medeles
Alesix Nicole Meyers
Korin Milucky
Maria Elizabeth Miranda
Piper Dotty Mitchell
Amber Mongan
Lillyana Morrison
Victoria Mortensen
Kathryn Murphy
Aysia Nguyen
Styron Nichole
Ursula Nicole
Roslynn Ofuitt Garvin
Deb Olsen
Katie Orr
Robert Ostwalt
Vangie Par
Amanda Petersen
Stacey Pelter
Angelica Prater
Savannah Prince
Mason Propst
Amanda Sears
Quesenberry
Michaela Quinn
Steve Radius
Evee Ramirez
Traci Ramirez
Penny Rawlinson Cole

**Members of the MPS Champions Circle
generously support the Society by
making a monthly recurring donation.**

2018 Champions Circle

Amy Barkley
Melany Bjorkman
Toni Bowen
Marc and Beth Brdar
Maria De Granillo
Justin Dickerson
Lola Gindrat
Heiz Holba and Karina Roman
Steve and Amy Holland
Jennifer Hutcheson
Bryan Kirch
Lori Lazarescu
Lauren Louison
Donny and Molly Merrill
Greg and Jennifer Mincks
Eric and Amber Mongan
Susan Murphy
Reverend Ted and Kathy Nace
Julie Patricia
Linda Perrella
Jared Shelton
Jack Swepston
Sarah and Todd Waddell
Christi Wadle
Curt Walder

Bonnie Rennanker
Joyce Rhodes-Barrett
Gretchen Riggan
Carmen Rodriguez
Darling Romero
Emma Rotchell
Denis Roubion-Johnson
Katie Royer
Erica Ruiz
Marla Sailor
Shawn Samuelson
Lissette Sanchez
Sara Sedam
Travis Sevilla
Shaina Runs For
Matthew
Christina Shaughnessy
Elizabeth Stanton Sibert
Katie Simmonds
Julien Tom Simo
Julie Simpson
Niki Dale Simpson
Melissa Skelton
Tessa Skelton
Shantrice Stanley
Dana Stapley
Dianne Stefanic Williams
Heather Stephens
Paige Stolberg

Lynda Sweeney Jondle
Karolina Szarejko
Matt Thompson
Brian Tippet
Dannette Toole
Maria Garcia Tuckett
Cihan Tur
Jennifer Underwood
Leslie Urdaneta
Evelyn Valentine
Kim Vang
Melissa Verville
Cecille Vincent
Eileen Walsh
Susie Walsh
Miranda Walsh
Lester Walters
Judy Ward Patrick
Julia Whalen
Kim Whitecotton
Wendy Whitt
Augusta Wickman
Tara Williams
Sarah Williams
Amanda Wishon
Laura Workman
Susan Workman
Pat Young
Jodi Zukasky-Andino

Financials

The financial information below has been summarized for the year 2018. The National MPS Society is a 501(c)(3) nonprofit public charity. Complete audited financial statements and IRS Form 990 are available by request and on our website.

Financial Position

Assets

Cash and cash equivalents	\$ 443,245
Contributions receivable	70,500
Prepaid expenses	2,216
Accrued interest	4,861
Property and equipment, net	10,267
Investments with donor restriction for endowment	1,097,988
Investments without donor restriction	2,125,254
Total Assets	\$ 3,754,331

Liabilities

Accounts payable	\$ 18,963
------------------	-----------

Net Assets

Without donor restriction	
Undesignated	1,447,995
Designated	289,179
With donor restrictions	1,998,194
Total Net Assets	3,735,368

Total Liabilities and Net Assets	\$ 3,754,331
---	---------------------

Statement of Activities

Support and Revenue

Contributions	
General	\$ 228,889
Research	113,848
Family support	15,038
Endowment	59,186
Membership dues	3,323
Conference income	723,922
Fundraising	675,507
Interest and dividends	121,030
Net realized and unrealized loss on investments	(223,266)
Total Support and Revenue	\$ 1,717,477

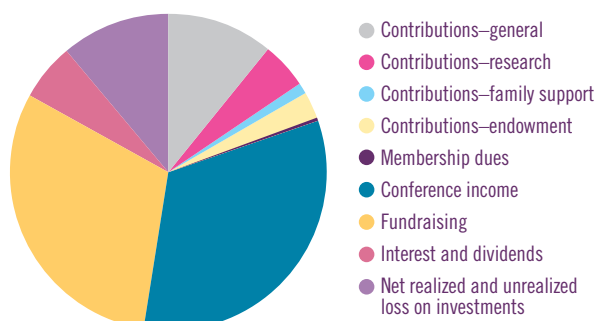
Functional Expenses

Research grants	\$ 342,206
Direct family assistance and bereavement	80,145
Advocacy and speakers bureau	39,731
Conferences, meetings and travel	951,497
Education—newsletters, booklets, web	115,550
Membership database and directory	10,855
Direct fundraising	93,349
Personnel	470,581
Office and equipment	54,261
Other administrative	83,523

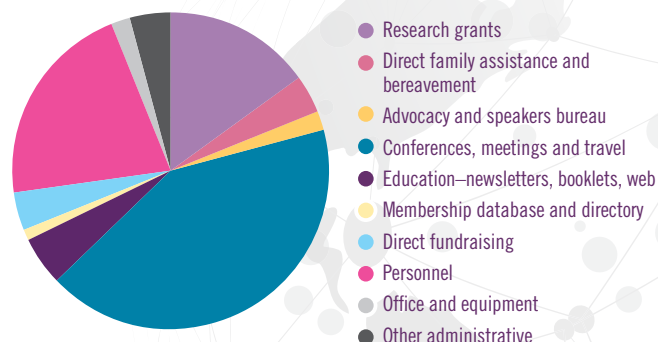
Total Functional Expenses	\$ 2,241,698
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Change in Net Assets	\$ (524,221)
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2018 Support and Revenue



2018 Functional Expenses



Rising Sun Legacy Circle

2018 WAS THE EIGHTH YEAR for Planned Giving with the National MPS Society. By year's end, 29 Planned Giving donors became part of the Rising Sun Legacy Circle.

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.

In 2018, the Society's Planned Giving initiative:

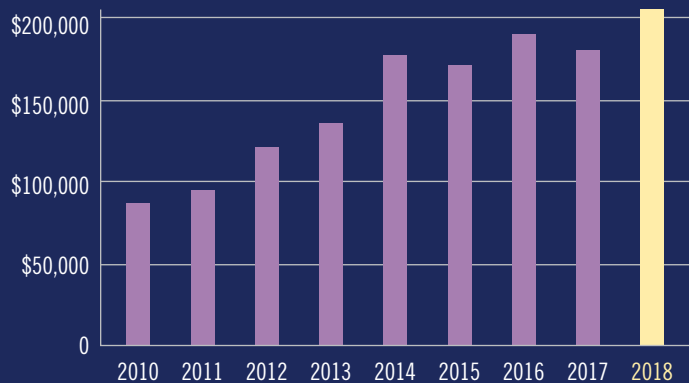
- Secured a large stock gift.
- Included Planned Giving articles in *Courage* publications.
- Continued stewardship with donors.
- Acknowledged two future gifts to the Society.
- Maintained a Planned Giving website to help members and friends of the Society become acquainted with Planned Giving and gifts the Society accepts.

Emil Kakkis and Jenny Soriano*, 2011
Becky Clarke, 2011
Christa Armstrong*, 2011
Mary Starr Adams, 2012
Terri Klein, 2012
Tracy Szemanski, 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
Ron and Barbara Crecco*, 2015
Cheryl Sorter*, 2015
Pamela M. Daoust*, 2016
Gordon R. Case Trust*, 2017

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



Annual Fund Donations



“

The National MPS Society has been an integral partner in caring for Spencer, Madison and Laynie on our journey with MPS. We are elated that sharing our family's story of reliance on the Society helped propel the Annual Fund to a historic new high, even surpassing our \$200,000 stretch goal!

AMY AND STEVE HOLLAND, MPS I parents



2018 Contributors

with sincere thanks to our supporters...

In 2018, 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.

The Society makes every effort to recognize our supporters through *e-Courage* and this Annual Report. The following list represents all donations received in calendar year 2018. If your name is not listed, we apologize and ask that you contact us. If we received your donation in 2019, you will be recognized in the next Annual Report.

Humanitarian

(\$50,000+)

Genzyme Corporation
REGENXBIO, Inc.
Shire Global Finance
Shire Human Genetic Therapies
Streiblow Foundation
Ultragenyx
Pharmaceutical

Visionary

(\$10,000 to \$49,999)

AssetMark, Inc.
Wayne and Catherine Bardsley
BioMarin
Marsha and Robert Bozarth
Bryson Foundation, Ltd.
Royce Bunce and Elizabeth Sherwood
Chiesi Farmaceutici SPA
Pamela Daoust
Diplomatic Specialty Infusion Group
Gordon Trust
Scott and Lynn Hopkins
Hunter Syndrome Foundation
Magnolia Foundation
Robert and Katharyn Molinaro
Sangamo Therapeutics, Inc.

Philanthropist

(\$5,000 to \$9,999)

Angel's Hands Foundation
Design Superstore
Joseph and Jan Melnyk

Mirabito Philanthropy, Inc.
Sam and Nancy Ramsey
James and Pamela Rogers
TEGA Therapeutics, Inc.

Champion

(\$1,000 to \$4,999)

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Helen Allison
Amazon Smile
Bill and Mary Andrews
Dr. Mel and Mrs. Millie Anhalt
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Artisan SG, LLC
Joseph and Kristina Ashton
Simone Azevedo
Maurizio Bellassai
Stephanie and Austin Bozarth
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Jeff and Anne Denneen
Julie Doppeide
Kathleen Dull

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David and Susan Holder
Steve and Amy Holland
Julie and William Johnson
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Kerzner Contracting Group
Mark and Dana Kinslow
Lawrence and Susan Kirch
Tom and Julie Kirch
Terri Klein and Michael Schleter
Elizabeth and Jayson Kramer
Kainani and Walter Kraut
Doug and Heidi Kreul
Lansdowne Lodge 711
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Gerald Lauria
Lawrence and Peg Lessing
Dawn Lietz
Olivia Lovell Family Fund
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Jeff and Sara Jane Ranney
Paul and Katie Rector
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William and Margaret Sly
Maureen Snider
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Marla and Randy Stevens
Strike, LLC
Darlene Sweeney
Steven Teitelbaum
The Vocal Majority Dallas Metropolitan Chapter
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Leslie Thompson
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Timothy Schaffer Roofing and Siding, Inc.
Christine and Brian Tippet
Hugo and Marylyn Van der Moer
Vanguard
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Britney and Matthew Weidert
Stuart and Judy Weiss
Sue Weng
Harold and Janet Whartnaby
Dr. Klane and Mrs. Amy White
Tom and Kim Whitecotton
Gordon Wingate and Cheryl Guidry
Wonderful Giving
Arthur Woods
Eric Wright
Teresa and Alan Wulff
Jim and Amy Yard

continued...

2018 Contributors

Leader

(\$500 to \$999)

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Michael and Stephanie Adams
Stuart and Karin Adams
W. Andrew and Lauran Jack
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David and Kathryn Croson
Carey and Mary Crumling
Jasmine and Emmanuel Cuffee
Erin Davis

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Jim and Michelle Dodson
Jani Domire
Mark Dorfler
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Pat and Kathy Dunn
Stephen Dunn
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Terry Epps
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Kelsey Holder
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Darren Houk
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Heather Kesner
Jenny Klein
Donna Kleinert
Knights of Columbus, Pennsylvania, RC

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Corbett and Brooke Martin
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William Massa Jr.
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Justin and Marie Watkins
Tom and Theresa Weisenbach
Ron and Kim Wiest
Joe Williams
Leigh Woodworth
Kevin and Peggy Yard
Kelly and Patricia Young

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(\$250 to \$499)

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Peter and Diana Argeres
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Joe and Susan Babic
Ethert and Pauline Baird
James and Mary Baker
Bank of America
Amy Barkley
Dwight and Debbie Barkley
Joel and Leeann Bernbaum
Ross and Hilary Berning
Best Buy
Cheryl Bien
John and Jenny Birmingham
Melany Bjorkman
BPO of Elks Lodge 2235
Dawn Brewer-Reilly
Max Burnham
Mary Burns

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Kenneth Cavanaugh
Center Academy
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David Coffman
Margaret Cohen
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Gail Zerby Cook
Costco
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Dayton Gastroenterology
Maria De Granillo
Delta Construction
Benjamin Dewees
William and Bonnie Doster
Hank and Suzanne Durham
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Michael Elgin
Carla Ellard
Charles and Josie Ellard
Margaret Ference
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George and Jaja Gawartin
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Martha Gunn
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Felynn Haberecht
Carol Hack
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Joanne Hayo
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Julia Hejduk
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 Jennifer Howard
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 Kris Johnson
 Heidi Kanealy
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 Benjamin and
 Elizabeth Neufeld
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 Jo Paterniti
 Norman and
 Sheila Payne
 Alan and Diana Pendley
 Linda and Dave Perry
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 Greg and Paige Posey
 Christopher Ramirez
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 Joseph Riley
 Mary Beth Romani
 Tracy and Thomas Rose
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 Benji Shake
 Arthur and Marilyn
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 Spacciapoli
 Ruth Stallings
 Don and Deirdre
 Strassman
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 Becky and Robert
 Tanamachi
 Susan Taylor
 Pamela and Dana Teich
 Dana Teoli
 Dave and Hiromi Tilsner
 Jerry and Lisa Todd
 Jerry and Shirley Todd
 David and An Tootill
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 Joseph Vieira
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 Kolleen Weihrauch
 Ron Weist
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 Wendel
 Crystal Whittlesey
 Heidi and Erik Williams
 Hubert and Elaine
 Willman
 Marlis and William Wilson
 William Wilson Jr.
 Woodstock Power
 Company
 Evelyn Zohlen

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(\$100 to \$249)

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 Partnerships
 A-1 Services
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 Aaserude
 Simon and Sylvia
 Abboud
 Joanne Abbruzzesi
 Academy Mortgage
 Corporation
 Richard and
 Claudia Ackerman
 Lee Ann Adams
 Johnda Adkins
 Bob and Caryn Ahern
 Thomas Ahern
 Dean and Katherine Aker
 David Akers
 Duffield Aldoraine
 Cheri Alexander
 Suzanne Alexander
 Robert Allen
 Annie Allison
 Jane Allison
 Bonnie Anderson
 George and
 Gail Anderson
 Laura Anderson
 Ralph and Martha
 Anderson
 Elena and Philip
 Anischenko
 Timothy and
 Michelle Annis
 Kimberly Anstey
 Keely Apple
 Apple, Inc.
 Betty and Barney
 Arceneaux

Sharon and
 David Armendariz
 Colleen and Shawn Arni
 David and
 Stacey Aronson
 Bill Atkins
 Charles Attix
 Steven Ausband
 B & M Trailers, Inc.
 B.E. Warfield Contracting
 Laurie Bagby
 Andrew and
 Heidi Bahmueller
 Megan Baierlein
 Bair's Tree and
 Lawn Service
 Mark and Alberta Balliet
 Joseph and
 Jacqueline Balukin
 Rita and Mike Basom
 Eileen Basquill
 Charlie and
 Danielle Bateman
 William Bauer
 Patricia Baxendale
 Angela Beam
 Olin and Cheryl Beaver
 Cheryl and Mike Beckles
 Mary Beiting and
 Jeff Von Handorf
 Amy Bennis-Kimball
 John and Maria
 Bereschak
 John Bereschak
 Monika and Jack Berg
 Angela Bergmann
 Bernard Suess Funeral
 Home, Inc.
 Barbara Bernhard
 Michael Berster
 Laura Bettge
 Kevin Beverly
 B.L. Bickham
 H. and Nancy Blake
 Joy Bland
 Jason Blaneck
 Kristi Bloomer
 Jeffrey Bodnar
 Mike and Grace Bodura
 Robert and
 Anne Boggiano
 Bon Voyage Travel
 Claudina Bonetti
 Amber Booth
 Robert Borders
 Alok Bose



RACHEL EICHLER AND
 MIKAL SUE BESSE (MPS IIIA)

Thomas and
 Joyce Boster
 Nancy and
 Leister Bowling
 Wendy and Matt Boyrie
 Brandy and
 Beau Bozarth
 Jim Bradley
 Ann Braff
 Marc and Beth Brdar
 Tom and
 Suzanne Brennan
 Daniel and
 Debra Brockman
 Vince Buccellato
 Karen Buchanan
 Nancy Bucher
 Patricia Buchman
 Eileen Buckley
 Justin Buice
 Mark and Leslie Bundy
 Tracy Burger
 Kevin Burke
 Tammy Bush
 Todd and Janice Butler
 Tammy Calandro
 Michael and
 Karen Calhoun
 Robert Calkins
 David and
 Mary Ann Campe
 Tony Cano
 Jane Cantrell
 Jeff Cantwell
 Thomas and
 Kristine Cantwell
 David Carey
 Cheryl and Peter Cario
 Desmond Carson
 Case Junior High School
 Town of Swansea
 Maria Castillo
 Jeffrey and
 Michelle Castle

continued...

2018 Contributors

Peter Castle
Denise Caswell
Heidi and Keith Caswell
Franklin and Carol Catalfamo
Gregory and Angela Cathey
Laura Celli
Susan and Roger Chapin
Steve and Sandy Chapman
James and Joan Charters
Steve and Karole Chesser
Jonathan Christian
Michael and Margaret Ciacciarelli
Rodney Ciafre
Heather Clark
Melissa Clark
Patricia and Francis Clark
Kent and Karlene Classen
Ross and Belia Coddington
Jerrold and Marilyn Cohen
Linda Cohen
Heather Coker
James and Martha Colby
Rocco and Derith Colicchia
Edward Conner
Esther Conrad
William and Peggy Cook
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Gary and Linda Corbett
Ronald Core
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Barbara and Ron Crecco
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Edward Cwierniewicz
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Dell
Paul and Joann Desrosiers
Thierry and Elizabeth Dewaghe
Rachel Diana
Dolores Diaz
Patricia Dickson
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William Dollar
Jonathan and Lisa Dols
William and Kim Dougherty
Jeanne and Maurice Drew
Roger and Ann Drinkwalter
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Vidmantas and Cecilia Duda
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MPS and ML

Mucopolysaccharidoses (MPS) and Mucopolipidosis (ML) are genetic lysosomal storage diseases (LSD) caused by the body's inability to produce specific enzymes.

MPS I

MPS I H Hurler

MPS I S Scheie

MPS I H-S Hurler-Scheie
Enzyme / α -L-Iduronidase

MPS II

MPS II Hunter
Enzyme / Iduronate sulfatase

MPS III

MPS III A Sanfilippo A
Enzyme / Heparan N-sulfatase

MPS III B Sanfilippo B
Enzyme / α -N-Acetylglucosaminidase

MPS III C Sanfilippo C
Enzyme / Acetyl CoA:
 α -glycosaminide acetyltransferase

MPS III D Sanfilippo D
Enzyme / N-Acetylglucosamine
6-sulfatase

MPS IV

MPS IV A Morquio A
Enzyme / Galactose 6-sulfatase

MPS IV B Morquio B
Enzyme / B-Galactosidase

MPS VI

MPS VI Maroteaux-Lamy
Enzyme / (arylsulfatase B)
N-Acetylgalac-tosamine 4-sulfatase

MPS VII

MPS VII Sly
Enzyme / B-Glucuronidase

MPS IX

Enzyme / Hyaluronidase

ML II/III

ML II I-Cell

ML III Psuedo-Hurler polydystrophy
Enzyme / N-acetylglucosamine-1-
phosphotransferase

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stephanie.bozarth@mpssociety.org

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kim.whitecotton@mpssociety.org

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(MPS II parent)
Albuquerque, NM
lisa.todd@mpssociety.org

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(MPS I parent)
Eugene, OR
amber.mongan@mpssociety.org

Austin Bozarth
(MPS IV parent)
McLean, VA
austin.bozarth@mpssociety.org

Caroline Dabney
New York, NY
caroline.dabney@mpssociety.org

Amy Holland
(MPS I parent)
River Oaks, TX
amy.holland@mpssociety.org

Steve Holland
(MPS I parent)
River Oaks, TX
steve.holland@mpssociety.org

Lynn Hopkins
(MPS I parent)
Long Beach, CA
lynn.hopkins@mpssociety.org

Scott Hopkins
(MPS I parent)
Long Beach, CA
scott.hopkins@mpssociety.org

Larry Kirch
(MPS III parent)
Scottsdale, AZ
larry.kirch@mpssociety.org

Kris Klenke
(MPS II parent)
Worden, IL
kris.klenke@mpssociety.org

Jason Madison
(MPS II)
Seattle, WA
jason.madison@mpssociety.org

Austin Noll
(MPS III parent)
Middleton, WI
austin.noll@mpssociety.org

Christine Tippet
(MPS IVA parent)
Littleton, CO
christine.tippet@mpssociety.org

STAFF

President and CEO

Terri L. Klein
terri@mpssociety.org

Development Director

Brian Buechler
brian@mpssociety.org

Communications Director

Jacob Desjarlais
jacob@mpssociety.org

Controller

Angela Guajardo
angela@mpssociety.org

Family Support Lead

Coreen Gray
coreen@mpssociety.org

Family Program Coordinator

Leslie Urdaneta
leslie@mpssociety.org

Program & Development Coordinator

Katelyn Blackman
katelyn@mpssociety.org

Program Support

Meredith Gray Stone
(thru June 2018)

Administrative Support Associate

Rebecca Schranz
rebecca@mpssociety.org

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