MISSION

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

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MPSSOCIETY.ORG
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CHAIRMAN OF THE BOARD
LISA P. TODD

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

PRESIDENT AND CEO
TERRI L. KLEIN

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 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.

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.

"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"
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.

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**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.

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*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.

• 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.

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.

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)
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.

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.

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

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**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.

**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.

**Auctioning Quilt for ARC Programs:** Jennifer Klein (ML III), Sheri Wise (MPS IVA), Jason Madison (MPS II), Erica Thiel (MPS I), and Terri Klein
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.

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 Mucolipidosis received $90,000. Other projects include substrate degradation enzyme therapy for MPS IVA and critical safety studies for MPS I corneal gene therapy.

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
2018 Two-Year Grant Award Recipients

Dr. Heather Flanagan-Steet
$90,000 general grant
Greenwood Genetic Center
Greenwood, SC
“Cysteine Cathespins as Therapeutic Targets in Mucolipidosis 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 Sanfilippo 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 Mucolipidosis 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”

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### NUMBER OF RESEARCH GRANTS ISSUED SINCE 2001

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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:
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.”

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
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
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.
- 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
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 Tippett
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

Courage Pages at www.mpssociety.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
Michelle Hopkins
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 Tippett
Jack Todd
Easton Walker
Trinity Walker
Michael Whitaker Russell
Scotty Whitecotton
Christian Yard
Emily Yurkins
Roy Zeighami
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
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Reverend Ted and Kathy Nace
Julie Patricia
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Jack Sweepston
Sarah and Todd Waddell
Christi Wadle
Curt Walsder

Paige Stolberg
Heather Stephens
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Dana Stapley
Shantrice Stanley
Tessa Skelton
Melissa Skelton
Niki Dale Simpson
Julie Simpson
Julien Tom Simo
Katie Simmonds
Juliet Simms
Julie Tompkins
Melissa Sloane
Niki Dale Simpson
Melissa Skelton
Shantrice Stanley
Dana Stapley
Dianne Stefani Williams
Heather Stephens
Paige Stolberg

Lynda Sweeney Jondle
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Matt Thompson
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Dannette Toole
Maria Garcia Tuckett
Cihan Tur
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Leslie Urdaneta
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Miranda Walsh
Lester Walters
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Wendy Whitt
Augusta Wickman
Tara Williams
Sarah Williams
Amanda Wishon
Laura Workman
Susan Workman
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2018 Social Media Fundraisers

Lee Ann Adams
Dwaa Al
Bob Allen
Mitch Andreotta
Betty Arceneaux
Emma Armatr
Ron Atkinson
Francie Barbella
Aleta Bart
Amanda Bayne
Maurizio Bellali
Oftelia Beltraine
Katie Bennett
Jerry Bennett
Nico Bennett
Darryl Black
Geri Boneske
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Rose Bougeois
Austin Bozarth
Stephanie Bozarth
Jefferey Brown
Liz Brown
Rachel Burns
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Adriana Caraballo
Carla Hark Crain
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Kaelin Gontaine
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Kendra Gottslenben
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Emily Johnson
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Terri Klein
Willis Kleinian
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Heather Lee
Matthew Lemke
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Morgan Lewis
William Lewis
Mary Katherine
Livingston
Zach Longston
Lissette Lopez-Sanchez
Paul Lorber
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Jamie Lynn
Kari Lynne
Will Mallia
Lucas Marcotte
Tatum Marie Knight
Linda Martin
Stephen Mask
Shannan Rene May
Trisha Anne McLelland
Jesycia Rene
McCacken
Anna Medele
Aless Nicole Meyers
Korin Miluck
Maria Elizabeth Miranda
Piper Dotty Mitchell
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Lillyana Morrison
Victoria Mortensen
Kathryn Murphy
Aaysa Nguyen
Styron Nichole
Ursula Nicole
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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

<table>
<thead>
<tr>
<th>Assets</th>
<th>Liabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents $ 443,245</td>
<td>Accounts payable $ 18,963</td>
</tr>
<tr>
<td>Contributions receivable 70,500</td>
<td></td>
</tr>
<tr>
<td>Prepaid expenses 2,216</td>
<td>Net Assets</td>
</tr>
<tr>
<td>Accrued interest 4,861</td>
<td>Without donor restriction</td>
</tr>
<tr>
<td>Property and equipment, net 10,267</td>
<td>Undesignated $ 1,447,995</td>
</tr>
<tr>
<td>Investments with donor restriction for endowment 1,097,988</td>
<td>Designated $ 289,179</td>
</tr>
<tr>
<td>Investments without donor restriction 2,125,254</td>
<td>With donor restrictions 1,998,194</td>
</tr>
<tr>
<td>Total Assets $ 3,754,331</td>
<td>Total Net Assets $ 3,735,368</td>
</tr>
</tbody>
</table>

### Statement of Activities

<table>
<thead>
<tr>
<th>Support and Revenue</th>
<th>Functional Expenses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td></td>
</tr>
<tr>
<td>General $ 228,889</td>
<td>Research grants $ 342,206</td>
</tr>
<tr>
<td>Research 113,848</td>
<td>Direct family assistance and bereavement $ 80,145</td>
</tr>
<tr>
<td>Family support 15,038</td>
<td>Advocacy and speakers bureau 39,731</td>
</tr>
<tr>
<td>Endowment 59,186</td>
<td>Conferences, meetings and travel 951,497</td>
</tr>
<tr>
<td>Membership dues 3,323</td>
<td>Education—newsletters, booklets, web 115,550</td>
</tr>
<tr>
<td>Conference income 723,922</td>
<td>Membership database and directory 10,855</td>
</tr>
<tr>
<td>Fundraising 675,507</td>
<td>Direct fundraising 93,349</td>
</tr>
<tr>
<td>Interest and dividends 121,030</td>
<td>Personnel 470,581</td>
</tr>
<tr>
<td>Net realized and unrealized loss on investments (223,266)</td>
<td>Office and equipment 54,261</td>
</tr>
<tr>
<td>Total Support and Revenue $ 1,717,477</td>
<td>Other administrative 83,523</td>
</tr>
<tr>
<td></td>
<td>Total Functional Expenses $ 2,241,698</td>
</tr>
<tr>
<td></td>
<td>Change in Net Assets $ (524,221)</td>
</tr>
</tbody>
</table>
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.

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.

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- 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
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
- Streblow 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

### Continued...
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Leader
($500 to $999)
36th District Masonic School
Mary Starr Adams
Michael and Stephanie Adams
Stuart and Karin Adams
W. Andrew and Lauran Jack
Robert and Marjorie Austin
Heather and Nathaniel Barr
David Beatty
Ronnie and Jaye Beck
Emily Bennett
Biogen MA, Inc.
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Steve and Lavonne Blechinger
Bluestar Bioadvisors, LLC
Bob Utter Lincoln
Jeffrey Bridge
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Susan and Dennis Burke
Dennis Burns
Mark and Stephanie Caldwell
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Scott and Connie Carney
Amy and Dan Chesterstrom
Walter and Gretchen Clayton
Coventry Corners, Inc.
Karyn Cronin
David and Kathryn Croson
Carey and Mary Crumling
Jasmine and Emmanuel Cuffee
Erin Davis

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Erin Davis
Emmanuel Cuffee
Jasmine and Carey and Mary Crumling
Croson
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Caldwell
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Scott and Connie Carney
Amy and Dan Chesterstrom
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Carey and Mary Crumling
Jasmine and Emmanuel Cuffee
Erin Davis

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Ronnie and Jaye Beck
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Carey and Mary Crumling
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Erin Davis

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Joe and Susan Bacic
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David Coffman
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Maria De Granillo
Delta Construction
Benjamin Dewees
William and Bonnie Doster
Hank and Suzanne Durham
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Elizabeth and Joshua Eickman
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Carla Ellard
Charles and Josie Ellard
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George and Jaja Gawartin
Tom and Anne Gniazdowski
Kendra Gottsleben
Michael and Susan Graff
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Martha Gunn
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Julia Hejduk
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Kendra Lezita
Kathryn and Hai Lieu
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Chuck and
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Thomas Owens
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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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Joanne Abbruzzesi
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Claudia Ackerman
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Anischenko
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Michelle Annis
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Arceneaux
Sharon and
David Armendariz
Colleen and Shawn Arni
David and
Stacey Aronson
Bill Atkins
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B.E. Warfield Contracting
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Lawn Service
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Joseph and
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Eileen Basquill
Charlie and
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Kristi Bloomer
Jeffrey Bodnar
Mike and Grace Bodura
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Anne Boggiuno
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C laudina Bonetti
Amber Booth
Robert Borders
Alok Bose

**Rachel Eichler and Mikal Sue Besse (MPS IIIA)**

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Joyce Boster
Nancy and
Leister Bowling
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Brandy and
Beau Bozarth
Jim Bradley
Ann Bratt
Marc and Beth Brdar
Tom and
Suzanne Brennan
Daniel and
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Kaye Hughes
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Margaret Hughes
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Jay Hutson
John and Yvette Iannelli
Joseph and Lorie Imbo
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Kevin Joseph and
Beth Johnson
Erie Johnsrud
Tina Johnston
Alicia Jones
Skip and Jane Jones
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Reagan Passant
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Beth Patrick
Casey Payne
Deborah Payne
Paula and Fred Pedro
Cristil Pellizzari
Penn Lodge #709
F & AM Concordville
Masonic Temple
Rob Perez
Sara Perry
Perry Hospitality
Jeffrey and Karen Peters
Thomas and Stacy Peters
Nancy Peterson
Darrell and Stacey Peveler
Patricia Phillips
Ronald and Vicki Phillips
Vernon Phillips
Sarah Pick
Dan and Pam Pierce
Rhonda Pletsch
Holly Piper
Beth Pletcher, MD
Cindy and Bill Plunkett
Point Pleasant Panther
Athletic Booster Association
Katherine Ponder

Pop Doodle Art
Alan and Kathy Portnoy
Tom and Carrie Porzel
Keith and Barbara Powers
Susan Powers
Preschool 101
Cindy Preuss
Tracy Price
Anne Prigent
Joan Prokop-Roberts
Michael and Valerie Province
Randal Pruitt
Shane Purcell
Barbara and Keith Pushee
Charlene Quinn
R. Brooks Mechanical, Inc.
Lisa Radcliff
Erin Radford
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**MPS I**
- MPS I H Hurler
- MPS I S Scheie
- MPS I H-S Hurler-Scheie
  - Enzyme / a-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 / a-N-Acetylglucosaminidase
- MPS III C Sanfilippo C
  - Enzyme / Acetyl CoA: a-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-Acetylgalactosamine 4-sulfatase

**MPS VII**
- MPS VII Sly
  - Enzyme / B-Glucuronidase

**MPS IX**
- Enzyme / Hyaluronidase

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- ML III Psuedo-Hurler polydystrophy
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