2022 Annual Report

Impacting Hope Through Science and Advocacy
In April 2022, our board of directors and team met for the first time since the pandemic. It was a chance for all of us to reflect on the past two years, to realize how far we have come, and to build our path forward through the development of our 2023–2026 strategic plan. During the last 49 years, the National MPS Society has funded $21 million in research, increased our membership to 2,600 households, provided more than $1.5 million in direct family support grants and scholarships, and spent 23 years on Capitol Hill advocating for MPS and ML.

At our meeting, we discussed new challenges and opportunities as well as how to expand our existing programs to reach diversified and underserved communities. It was an affirmation of how much is possible with the right team and the right strategy. We acknowledged the expansion of our newborn screening efforts and the success of MPS II being added to the Recommended Uniform Screening Panel by the Advisory Committee on Heritable Disorders in Newborns and Children. It made us think about how, in many ways, this effort has epitomized the following approach that we bring to our mission.

We look for unmet needs and step in where others haven’t to make a difference. We have visited more than 300 families nationwide at their time of diagnosis through our Pathways program. It continues to expand in part because of earlier diagnosis through newborn screening. We embraced the problems our families are facing with inequities beyond diagnosis. We hosted an Atlanta regional family gathering event that taught us the depth of food inequities, housing inequities, and the importance of reaching and communicating with every family.

We lead from the front and don’t hesitate to tackle controversial issues. When an MPS I family reached out through Pathways and shared their story of their oldest son being left untreated while their newly diagnosed child, through newborn screening, was provided access to treatment options, we stepped in. We were not afraid to acknowledge the inequities presented and responded by legislating for access to equitable healthcare, access to therapies, and newborn screening. Stephanie Cozine and our Education Committee launched the Our Voices podcast that covers critical topics for our adult community, research, grief, hope, and the future of our families. Our mission is to bring new gene and cell therapies to all MPS disorders by partnering with sponsor companies.
We identify and engage with strong partners who can work closely with the Society to drive progress. Last year, we traveled while the world was still beginning to open. We forged new relationships with the Association of Public Health Labs and committed to collaborative work with the EveryLife Foundation. We worked internationally with Fabry, the Gaucher Alliance, and Pompe Disorders to describe the importance of real-world data.

We invest in research and data-driven tools that allow us to target our resources effectively and hold ourselves accountable for results. We funded almost $1 million in multiple research grants for MPS I, MPS II, MPS IIIA, IIIC, MPS IVA, MPS VI, and MPS VII. We awarded grants for critical needs for newborn screening, gene and cell therapies, skeletal dysplasia, aortic and airway issues, dementia, and central nervous system pathology. The Christa Armstrong Legacy gift received through planned giving has continued to make a difference in funding researchers worldwide.

We use advocacy and lobbying to back critical federal and state policies and laws. Our advocacy efforts secured a significant victory in the United States for MPS II newborn screening, while we continued to develop a new nomination for MPS VII. Through virtual visits, we met with 89 legislators in February and secured sponsorship for the 2024 federal appropriations legislation, including MPS disorders.

We brought our families together in person and virtually at the Annual Family Conference. We welcomed more than 500 registrants to Nashville, TN, to join the inaugural Science and Family Conference. Our program provided families with free hotel stays and numerous scholarships, hosting the largest number of newly diagnosed families in history. Our families struggled while the pandemic stalled access to critical health updates and access to the best clinicians and researchers in MPS and ML. Families hugged, grieved, and participated in a 5K in support of essential programs. We celebrated our collective community through the banquet, and the talent show brought smiles to everyone who attended. Nashville’s conference provided an opportunity for scientists who have been researching MPS for 30 years to gather as we awarded Dr. Elizabeth Neufeld the Visionary Award for her years of research in MPS. It was a profound moment for everyone to share.

2022 was a year of new paths, programs, hope, and action. We continue to listen and anticipate what our community needs. We will strive to do even more next year and work hard to deliver long-awaited treatments to our Sanfilippo and Mucolipidosis communities.

$21 million in research
2,600 members
$1.5 million+ direct family support grants and scholarships
23 years advocating on Capitol Hill
Family support remains a critical pillar of the mission of the National MPS Society. In 2022, almost $135,000 in scholarship and grant funding was provided to 150 families and individuals with MPS or ML. The 36th Annual Family Conference was held in Nashville, TN, and the Society supported a record number of scholarships for attendees. Most scholarships were awarded to recipients attending their first conference.

Throughout the year, social workers met with families virtually, face-to-face, and by phone to provide access to resources and support across multiple domains, including mental health, coping, medical care, educational needs, and information about treatment options and clinical studies. A regional social event took place in Atlanta, GA, bringing together families for an afternoon of connection, fun, and discussion of local support. The Continuing Education Scholarship program continues to offer funding for higher education for individuals with MPS or ML, their parents, children, and siblings. In 2022, the Jeffrey Bardsley Scholarship program awarded $5,000 to four individuals diagnosed with MPS, and an inaugural Klenke-Kirch Sibling Scholarship program offered an additional $500 to two individuals to help develop and bolster programs for siblings.

The Society offers support and information from the beginning of the diagnostic journey through the lifespan of individuals with MPS or ML and their families.

**Family Support**

150 families and individuals with MPS or ML received scholarship and grant funding.

**HIGHLIGHTS**

**Continuing Education Scholarships**  
- Awarded four Jeffrey Bardsley Scholarships at $5,000 each and 22 Continuing Education Scholarships.
- Two Klenke-Kirch Sibling Scholarships were awarded (at an additional $500 each to the $1,000 Continuing Education Scholarship).

**Extended Hospitalization Relief**  
- Funded three grants for a total of $1,500 to support individuals with MPS or ML who have experienced an inpatient hospitalization for a minimum of 30 days.

**Family Conference Scholarships**  
- Funded 52 scholarships totaling $45,837, providing necessary financial support for families to attend the conference.

**Family Assistance Program**  
- Funded 10 grants totaling $13,156 to provide assistance items, including a wheelchair lift for a vehicle, hearing aid repairs, drop support harness, car seat for older child, and disaster relief.

**Journey Assistance Program**  
- Funded nine grants totaling $2,227 for items, including a computer for a student, iPads, medical wagon, and safety fencing.

**Extraordinary Experiences Program**  
- Funded two grants totaling $1,000 for a driver's training program and adaptive driving education.

**Medical Travel Assistance Program**  
- Funded 21 grants totaling $8,425 to help with out-of-town travel costs for non-recurring medical appointments.

**Bereavement Expense Program**  
- Funded 23 grants totaling $17,250 to provide support for families experiencing the loss of a loved one with MPS or ML.

**Regional Social Events**  
- Provided $750 for an event in Atlanta, GA.
Niko (MPS I)

Extended Hospitalization Relief

Niko’s family received a grant to offset expenses while he was hospitalized for several months. This grant provides $500 to assist with costs incurred during inpatient hospitalizations exceeding 30 days.

Lumar (MPS IVA)

Medical Travel Assistance Program

Thanks to the Medical Travel Assistance Program, Lumar was able to attend appointments with her specialists this year. She has MPS IVA and traveled several states away to see experts in Morquio syndrome.
The National MPS Society's Pathways program provides families and individuals with education and comprehensive support throughout the first year of diagnosis. To date, the program has served approximately 300 individuals and families.

From the point of contact and initial assessment, families are provided vital education, referrals to MPS specialists and resources, treatment options, trial opportunities, and connection to the MPS and ML community. In the true essence of social work, Pathways meets with families to explore and address unmet needs, and provides support throughout the process. In 2022, Pathways resumed in-person visits post pandemic. These visits offered further insight into family need and strengthened connections to the MPS and ML community. Moving forward, the program seeks to expand its reach by strategically performing outreach to underserved MPS and ML individuals and families. This will allow more families and individuals the opportunity to benefit from the program and be embraced by the community.

### Syndrome Types
of the 48 newly diagnosed individuals with MPS and ML (six of whom were identified through newborn screening)

<table>
<thead>
<tr>
<th>Syndrome Type</th>
<th>Count</th>
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<tbody>
<tr>
<td>MPS I</td>
<td>15</td>
</tr>
<tr>
<td>MPS II</td>
<td>6</td>
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<tr>
<td>MPS III</td>
<td>11</td>
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<tr>
<td>MPS IV</td>
<td>7</td>
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<tr>
<td>MPS VI</td>
<td>5</td>
</tr>
<tr>
<td>MPS VII</td>
<td>1</td>
</tr>
<tr>
<td>ML</td>
<td>3</td>
</tr>
</tbody>
</table>

- Provided services in person, by phone, or by teleconference to 48 newly diagnosed individuals from 42 families.
- Resumed in-person contact post pandemic by conducting 41 visits with individuals and families in 19 states.
- 294 individuals served through the program since inception.
- 20 families participated in eight support groups.
- Provided education, guidance, and referral to families impacted by newborn screening.
- Connected and collaborated with medical and industry partners to promote Pathways.
- Participated in new diagnosis session at the Annual Family Conference in Nashville, and facilitated breakout sessions and sibling panel.
- Initiated planning for program outreach to connect with underserved MPS and ML families and individuals.
**Wesley (MPS II)**

The National MPS Society has been helping our family since before Wesley’s official diagnosis. They promptly connected us with an MPS doctor to help confirm a diagnosis, significantly expediting what could have been a very lengthy process. They educated us about ERT and clinical trials for MPS II, allowing my family an opportunity to discuss the best course before making a decision. The Society was the number one factor for us being able to start treatment for Wesley as quickly as possible. The Pathways program set us up with families that have been through the same thing—I don’t know how we would have survived without them. This continues to be the most difficult time of our lives but the amount of love and help from the community is overwhelming and unforgettable. We are so grateful for the National MPS Society and all of the resources, advice, and connections we have already made in such a short amount of time.

— Katarina Nelson, mother of Wesley

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**Kadir (MPS I)**

The words “MPS” and “Hurler syndrome” were new terms I was faced with in July 2022. I remember crying all the way home after hearing this diagnosis for my son Saeid “Kadir.” I was grateful to find the MPS Hurler Syndrome Support Group on Facebook as well as the National MPS Society because I was able to learn about the disease and read about so many other children diagnosed with this syndrome. I discovered how amazing the Society and Pathways are for newly diagnosed families, as well as other programs and resources available. The beginning of our MPS journey felt discouraging, scary, the end. But when you know you have people who are fighting for answers, resources, and a cure, what seemed like an impossible path you are walking alone ends up being a journey you are walking with many.

— Ashley Avery, mother of Kadir
Advocacy

59 advocates met with 89 legislators to advocate for newborn screening and other key legislation impacting the MPS and ML community.

Advocacy is a critical need of the MPS and ML community. In 2022, we expanded our efforts in newborn screening and developed key legislative initiatives to prioritize equity and parity for our patient community. The Society continues to maintain a Rare Hub space at the EveryLife Foundation offices in Washington, DC, to promote our direct federal policy efforts. As we returned to in-person meetings this past year, we deepened our relationships on Capitol Hill and fostered crucial legislation that was stalled during the pandemic. The highlight of 2022 was the approval of our application to add MPS II, Hunter syndrome, to the Recommended Uniform Screening Panel (RUSP) for newborns by the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC).

Our advocacy efforts focus on several initiatives, including regular calls to action on rare disease legislation, disseminating carefully crafted appropriations language to spread our message, collaborating with the rare disease community as a whole, conducting advocacy training webinars, and growing and fostering relationships with key decision makers.

The National MPS Society presented the MPS II Recommended Uniform Screening Panel Nomination to the Advisory Committee on Heritable Disorders in Newborns and Children, which was approved!

Terri Klein visiting with MPS I family in Washington, DC
• Provided successful final testimony at ACHDNC meetings for the MPS II RUSP nomination and newborn screening. The ACHDNC voted to pass the condition for screening 11-1.
• Facilitated virtual Capitol Hill meetings in February with 59 advocates meeting with 89 legislators to advocate for newborn screening and increased NIH funding for MPS and ML diseases through the appropriations bill, and recruited Rare Disease Caucus members. Nine members of congress and the senate met directly with their constituents.
• Created a newborn screening committee to oversee MPS RUSP alignment language and state grassroots efforts for all MPS disease screening.
• Society members participated in Rare Disease Legislative Advocates’ Rare Across America virtual Hill visits in summer 2022.
• Resolution to recognize National MPS Awareness Day in the United States passes in the Senate.
• Maintained our Rare Hub space in Washington, DC, at the EveryLife Foundation offices and participated in quarterly working group meetings.
• Worked with Rare Disease Advisory Council state committees on their advocacy formation and oversight.
• Began collaborating with patient advocacy organizations on newly proposed legislation—the EPICrd Act. This is a comprehensive approach to ensure parity through individualized care for rare disorders (epicrd.org).
• Continued efforts with rare disease working group and BioMarin on EPICrd Act.
• Participated in quarterly newborn screening and diagnostic meetings held by the EveryLife Foundation.

Nolan Higginbotham (MPS I)

• Supported the following legislation and signed onto letters for:
  – H.R. 3089/S. 1544—Accelerating Kids’ Access to Care Act
  – H.R. 482/S. 350—Newborn Screening Saves Lives Reauthorization Act
  – H.R. 1730/S. 670—Speeding Access Therapy Today (STAT Act)
  – H.R. 5585/S. 3819—Advanced Research Projects for Agency for Health
  – H.R. 1092/S. 526—Better Empowerment Now to Enhance Framework and Improve Treatment (BENEFIT) Act
  – H.R. 6888/S. 4071—Helping Experts Accelerate Rare Treatments (HEART Act)
  – RUSP language support for state reviews
• Attended the following advocacy and networking conferences: 18th Annual WORLDSymposium™; American Society of Gene & Cell Therapy Policy Summit; National Organization for Rare Disorders Summit; Global Genes; Association of Public Health Labs Annual Meeting.
A nonprofit organization is only as strong as the level of support it receives from its members and benefactors. The National MPS Society and its members moved feverishly into 2022 with hosting in-person events.

As our families navigated how to bring their children back to school and critical clinical appointments, we celebrated by raising funds together for our mission. In 2022, we formulated future fundraising through our strategic planning process. We outlined a new Capital Campaign and identified strategies to grow the Planned Giving program. The Sock It to Hunter Foundation gifted funds to the National MPS Society for MPS II research and our scientific conference. We recognize the importance of collaboration with other MPS foundations.

With strategic planning and the emergence of resuming in-person events this year, the commitment from our donors saw us through another incredibly challenging year. The Annual Fund exceeded $324,000 and provided crucial funding for operations and oversight of our mission. We heard the donor's message loudly and clearly—we will continue to sustain you.

$324,000+ Annual Fund donations

• Maintained a 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 2,700 members.
• Raised approximately $407,340 through virtual walk/run and other fundraising events.
• Hosted four national run events in Raleigh, NC; Napa, CA; Nashville, TN; and Long Beach, CA.
• Raised more than $35,000 for MPS and ML research through the University of Pennsylvania’s Million Dollar Bike Ride.
• Raised $324,387 through the 2022 Annual Fund campaign, chaired by Leslie Urdaneta, director of Family Support and Communications.
• Received Combined Federal Campaign application approval.

• Worked with the Sock It to Hunter Syndrome Foundation in procuring a gift of $75,000 for MPS II research and the 2023 Science and Research Conference.
• Hosted 62 Courage Pages (customized, informative family web pages for awareness and fundraising) on the Society’s website.
• Hosted the National MPS Society’s third annual Big Bake for MPS and ML, raising more than $17,000.

Everly Reynolds (MPS I)
Maddie (MPS IIIA)

Madalyn has always loved to travel. We're always taking trips to her favorite spots and enjoying making memories as a family. As Maddie has progressed, riding in the car has become more difficult due to her lack of trunk support. She's either falling over or riding in awkward positions which had become unsafe. Positioning systems are very expensive and not covered by insurance. Thanks to the National MPS Society's Family Assistance Program, we are now able to make memories safely as a family.

— Brittany Richards, mother of Maddie

2022 Fundraisers

ARC Fundraiser, hosted by the Adult Resource Committee
Basketball Fundraiser, in honor of Adam Podesky
Big Bake for MPS and ML, hosted by the National MPS Society
Concert for the Cure, in memory of Ryan Mask, hosted by Dorothy and Jeremy Mask
Crop For Rachel, in memory of Rachel Dodson, hosted by Jim and Michelle Dodson
Do It Fore Dan, in memory of Danny Miller, hosted by Ray and Amy Miller
Emilio's 5K, in honor of Emilio Garabito, hosted by Elizabeth Garabito
Hailee & Olivia Together a Future of Hope with YOU, in honor of Hailee Fujioka Makuch and Olivia, hosted by Sarah Keren
Holland Sharing and Caring Fundraiser, in honor of the Steve and Amy Holland family, hosted by friends of the Hollands
Hopkins cabi Clothing Party, in honor of Michelle Hopkins, hosted by Lynn Hopkins
Jack "The Beast" Bennett Memorial Ride, in memory of Jack Bennett, hosted by the Bennett family
Jacob Keller's 5K, in honor of Keller Blakeley, hosted by Clint and Lindsey Blakeley
Jacob's Journey Fundraiser, in honor of Jacob Bohley, hosted by Jennifer Hajjar
Jammin' for Julia, in honor of Julia Donohue, hosted by Andrea Felten
John Loy Memorial Golf Tournament, in memory of John Loy, hosted by Lynda Witte
Kramer Chili Cookoff, in honor of Marcus Kramer, hosted by Elizabeth Kramer
Lilah's Lemonade Stand, in honor of Lilah Mueller, hosted by Kimber Heiling
Michelle Hopkins Golf Tournament, in honor of Michelle Hopkins, hosted by Hugo Van der Moer
Million Dollar Bike Ride, hosted by the National MPS Society and University of Pennsylvania's Orphan Disease Center
Napa Race for a Cure, hosted by the National MPS Society
Nashville Walk and Roll 5K, hosted by the National MPS Society
Post Office Cafe 5K, in memory of Mark and Casey Lessing, hosted by the Lessing family
Raleigh Run for Rare, hosted by the National MPS Society
Rylee Noble Fundraiser, in honor of Rylee Noble, hosted by Rylee Noble
Rylie Hays Fundraiser, in honor of Rylie Hays, hosted by the Hays family
Sprint to Save 5k Run and One-Mile Walk, hosted by the National MPS Society
Spooktacular, in memory of Dorian and Wynn Johnson, hosted by Mercedes Ramirez Johnson
Stevens Family Fundraiser, in honor of Meekel Stevens, hosted by Marla and Randy Stevens
Superbowl Fundraiser, in honor of Adam Brennan, hosted by Mary Beth Brennan
Text to Give, hosted by the National MPS Society
Viti Family Fundraiser, in honor of Christopher Hohn, hosted by Emily Viti
Walk and Roll 5K and One-Mile Family Walk, hosted by the National MPS Society
Youth Against Cancer Fundraiser, in honor of Sydney Waldman, president of Youth Against Cancer, hosted by Suffern High School
2022 Facebook Fundraisers

Tina Allred
Cindy Anderson
Betty Arceneaux
Barbara Ann
Mandy Bellassai
Jerry Bennett
Kimberly Bergstrom
Nichole Bickerton
Anastasia Black
Melanie Block
Heather Kahgee Boening
Christine Bohley
Jamie P.J. Bordeaux
Rachael Brady Johnson
Drew Brodie
Steve Cardwell
Mary Case
Fidencio Junior Cisneros III
Sharilyn Clevenger
Kaitlyn Corwin
Stephanie Cozine
Carla Halk Crain
Harley Crosby
Jason Cullere
Dakota Marie
Cassie Dearman
Kathi Dee
Drew Delvaux
Loma Greene Denney
Amy Diaz
Wendy Dickerson
Kailey Dina
Kate Drehobl
Shelia Duncan
Susan Duncan
Carrie Dunsword-Todd
Jacob Ellis
Wayne Eppehimer
Daniel Farrell
Andrea Felten
Shaun Flora
Jimmy Fox
Traci Fraga
Elizabeth Fry
Brian Fulghum
Julie Garrison
Roslynn Offutt Garvin
Ketia Gonzalez
Mike Greathouse
Hailey Hajjar
Paige Halk
Faith Hardigree
Kimberly Heiling
Thomas Hickey
Lela Holbrook
Donna Dendy Hood
Brandon Hool
Judy Hughes
Alyssa Jeanne
Mercedes Johnson
Tasha Stuart Johnson
Becky Jordan
Estelle Joseph
Dianne Kelley
Shari Kinsman
Jim LaRue
Haylee Lauren
Jackie Leigh
Madison Litchfield
Theresa Margaret
Kristina Marie
Rosaura Martinez
Amanda May
Trisha Anne McClelland
Jessica McCue
Annie McGraw
Viviana Medina
Carey Mehling
Judy Boudreaux Mericle
Justin Michael
Jennifer Milder
Jamie Moon
Susan Morrow
Eileen Murphy
Monica Nayo
Monika Nels-Dupont
Jamie Thomas Noble
Michael Ostella
Jeff Parks
Theresa Peierl
Kim Phillips
Marsha Brown Polite
Jennifer Polite
Angelica Prater
Cristina Purcell
Anne Quesenberry
Melissa Rachunek-Zielonka
Laurel Radius
Emily Ramirez
Nancy Davis Ramsey
Amanda Reuter
Amber Reynolds
Sarah Michelle Reynolds
Melissa Turner Ronacher
Justin Ross
Rebecca Roxberry
Dana Schroeder
Bonnie Schwab
Heather Shaw
Amrit Singh Daurka
Casey Smith
Danny Smith
Ta-Neha Smith-Parker
Angela Soto
Lacey Sparks
Loretta Oaks
Spreisterbach
Amali Sven
Karah Swails
Bismillah Tahir
Charlotte Tate
Gerald Thomas
Irma Tinoco
Gina Crown Torrans
Hunter Traffanstedd
Evelyn Valentine
Ruth Valles
Candy Vargas
Emily Viti
Denise Walters
Lester Walters
Judy Ward Patrick
Sheri Wise
Laura Workman

2022 Champions Circle (monthly giving program)

Jodi Adams
Fernando Armendariz
Colleen and Shawn Arni
Robert Astamendi
Carole and John Barnhardt
Melany Bjorkman
Claudia Bonetti
Marc and Beth Brdar
Margaret Cohen
Maria De Granillo
Wilma Dickerson
William English
Terry Epps
Teresa Everett
Gary Flores
Allison Frazier
Erika Freiberger
Denise Glatzmaier
Steve and Amy Holland
Steven Holley
Jennifer and Bryan Hutcheson
John and Yvette Iannelli
Brian and Rebekah Klutz
Tamara Ladd
Theresa Leggett
Wynona Maxwell
Ann Mclaughlin
Anthony Menendez
Donna and Molly Merrill
Greg and Jennifer Mincks
Carmen Mosley
Susan Murphy
Kathy and Josh Nay
Thomas and Vickie Patterson
Linda Perrella
Susan Pestrak
Scott and Lori Phillips
Sam and Nancy Ramsey
Melissa Turner Ronacher
Edward and Evelyn Schutz
Riddhi Shah
Jared Shelton
Angela and Michael Sochacki
Heidi Sosinski
Jeremy and Rena Stearns
Jack Sweeplson
Anne France Tremeg
Leslie and Alex Urdaneta
Todd Waddell and Sarah Aaserude
Rick and Dawn Williams

Elia and Sohaib Khatibi (MPS VI)
The National MPS Society provides information and connections to members and stakeholders across multiple channels. Printed publications, social media, electronic communication, and other avenues enable us to deliver content to those benefiting from the educational and promotional material shared.

We remain a leader in mucopolysaccharidosis and mucolipidosis expertise, offering educational materials, including syndrome booklets, resource guides, and fact sheets, for open distribution through our website, and sharing printed and electronic copies nationwide for clinicians to review with patients and families. We assess the MPS and ML community’s informational needs and increase awareness of MPS and ML specifically and all rare diseases generally.

Our primary goals are to bring attention to MPS and ML and provide the information necessary for effective, comprehensive care and management for those affected by these diagnoses.

**HIGHLIGHTS**

- Completed first full season of *Our Voices* podcasts.
- Achieved successful social media impact:
  - 3,000 signatures on MPS II RUSP nomination.
  - Write for Olivia campaign to request college-level accommodations initially denied, resulting in approved accommodations and support in the interior design program at Mississippi State University, in addition to staff member ADA training.
- Published monthly *eCourage*, the Society’s electronic newsletter.
- Developed two printed *Courage* publications.
- Produced *Angels Among Us* electronic bereavement publication.
- Provided event marketing for WORLDSymposium™, Annual Family Conference, run/walk events, International MPS Awareness Day, Big Bake for MPS and ML, and Advocacy Hill Days.
- Completed interviews for MPS Awareness Day, “Adventure with Us.”
- Authored *Evaluation of Two Methods for Quantification of Glycosaminoglycan Biomarkers in Newborn Dried Blood Spots from Patients with Severe and Attenuated Mucopolysaccharidosis Type II* and *International Journal of Neonatal Screening*, Jan. 21, 2022 (by Terri Klein and Leslie Urdaneta).

**Olivia (MPS I)**

When Olivia was facing discrimination at college due to her disabilities, we felt helpless. One call to the National MPS Society set things in motion. We felt such gratitude to have an army behind us. The Society galvanized efforts to make changes for Olivia and we continue to see ripple effects.

The dean became a mentor and meets with Olivia every couple of weeks to check on her progress. Positive changes are happening in the interior design program due to our call to action. There is still work to be done, but we are encouraged as we learn how to help her navigate. The Society and community’s support gives us the courage to continue to press forward.

— James Lipscomb, father of Olivia
One of the three major tenets of the mission of the Society is research. Finding cures and improved therapies for all of the syndromes is a primary goal. Grant funding, research partners, and collaboration ensure key efforts toward a better future for all those affected by MPS and ML.

In 2022, the National MPS Society’s research program built upon the recent implementation of three annual defined grant submission cycles (Cycles I–III), by approval of a new Tier III grant mechanism of $25,000 designed to fund small novel and valuable work that otherwise would not fit in the Society’s Tier I and II grant mechanisms. The Society, with the continued assistance of the Scientific Advisory Board Guidance Committee, continues to define areas of need and emphasize focus and encourage research in those areas.

The combined total of both newly approved and past funding commitments for 2022 totaled $929,033. This sum includes allocations for new competitive research awards of $766,533, with the balance spent on continued funding for previously awarded multi-year grants. This total also includes $30,000 of Society research funds leveraged through the Orphan Disease Center of the University of Pennsylvania in our partnership with the Million Dollar Bike Ride to fund a total of more than $60,000 in research. Notable again this year was the continued support for MPS II and MPS II relevant research areas, totaling $300,0000 in new and ongoing research commitments, provided from the Christa Armstrong legacy gift.

Keegan (MPS IIIA)

Keegan is an explorer. He has always been fearless in his adventures. Thanks to a grant from the Society’s Journey Assistance Program, his new wagon is now his base camp for his expeditions. It allows him to rest for a minute when he’s tired and provides a spot of calm that is full of his favorite snacks and toys. It is a clean, safe area for him to be if we are going to the aquarium or a doctor’s appointment. The bonding that happens between him and his brother while riding together is a ray of sunshine for anyone watching.

— Monica Alexander, mother of Keegan
Innovation is driven by the work of our MPS and ML research community. Their dedication and commitment to our shared mission make possible the treatments and outcome improvements of the future.

**Society Research Funding**

**2022 Competitive Program in Innovative Research**

**2021 CYCLE III GRANTS** *(awarded April 1, 2022)*

**Tier II: $50,000 for a one-year MPS III award to Dr. Michael Lardelli**
The University of Adelaide, Adelaide, SA, Australia
*Iron Supplementation for Treatment of Sanfilippo Syndrome Childhood Dementia*

**Tier II: $50,000 fellow-initiated research for a one-year MPS II Christa Armstrong legacy award to Geoffrey Eill (Dr. John Wolfe, mentor)**
The Children’s Hospital of Philadelphia, Philadelphia, PA, USA
*MPS VII Myelin Pathology*

**Tier II: $50,000 for a one-year MPS VI award to Dr. Lachlan J. Smith**
The University of Pennsylvania, Philadelphia, PA, USA
*Expansion of a Research Colony of Mucopolysaccharidosis VI Dogs*

**Tier II: $50,000 for a one-year MPS II Christa Armstrong legacy award to Dr. Emma Parkinson-Lawrence**
The University of South Australia, Mawson Lakes, SA, Australia
*Quantification of Airway Disease in MPS I Mice Via Laboratory X-Ray Velocimetry*

**2022 CYCLE I GRANTS** *(awarded Aug. 1, 2022, unless noted otherwise)*

**Tier I: $100,000 for a one-year MPS III general research award to Dr. Stephanie Cherqui**
The University of California at San Diego, San Diego, CA, USA
*Treating Mucopolysaccharidosis Type IIIC with Hematopoietic Stem Cell Gene Therapy*

**Tier I: $100,000 for a two-year MPS II Christa Armstrong legacy award/general research award to Dr. Allesandro Fraldi (awarded Dec. 1, 2022)**
The University of Naples “Federico II,” Naples, Italy
*Exploring the Role of Neurotoxic Reactive Astrocytes in Neuronopathic Mucopolysaccharidoses*

**Tier I: $100,000 for a one-year MPS II Christa Armstrong legacy award/general research award to Dr. Isaac Canals**
Lund University, Lund, Sweden
*Neurodevelopment and Neurodegeneration in Human iPSC-derived Models of MPS III*

**Tier I: $86,533 for a two-year MPS II Christa Armstrong legacy award to Dr. Liz Braunlin**
The University of Minnesota, Minneapolis, MN, USA
*MPS I Aorta*

**Tier I: $100,000 for a one-year MPS IVA award to Dr. Scott McIvor**
University of Minnesota, Minneapolis, MN, USA
*Lentiviral Gene Therapy in a Novel Porcine Model of Mucopolysaccharidosis IVA*

**Tier II: $50,000 for a one-year MPS II Christa Armstrong legacy award to Dr. Laura Pollard**
Greenwood Genetics Center, Greenwood, SC, USA
*UPLC-MS/MS CSF GAG Methods*

**2022 CYCLE II GRANTS** *(awarded Dec. 1, 2022)*

**Tier I: $100,000 for a two-year MPS II Christa Armstrong legacy award/MPS I award to Dr. Richard Steet as a competitive renewal**
Greenwood Genetic Center, Greenwood, SC, USA
*IDUA/IDS Variant Classification*

**Second-Year Grant Award Funding Disbursed in 2022**

**$62,500 for year two of a MPS II Christa Armstrong legacy award to Dr. Nicolina Cristina Sorrentino**
The Telethon Institute of Genetics and Medicine, Pozzuoli (Naples), Italy
*Induction of Autophagy Pathway as New Therapeutic Option to Prevent the CNS Pathology Progression in Mucopolysaccharidosis Type II*

**$50,000 for year two of a Tier I general MPS/MPS III award to Dr. Cologera (Lilla) Simonaro**
The Icahn School of Medicine at Mount Sinai, New York, NY, USA
*Investigation of the Endocannabinoid System (ECS) as a Novel Therapeutic Target for the MPS*

**$50,000 for year two of a Tier I MPS IVA/ML award to Dr. Heather Flanagan-Steet**
Greenwood Genetic Center, Greenwood, SC, USA
*Comparative Analysis of Mechanisms Driving Skeletal Dysplasia*

**2022 Partnership Award**
**The Orphan Disease Center**
*$60,350 (Million Dollar Bike Ride & $30,000 from the National MPS Society funding) to Dr. Margret L. Casal**
University of Pennsylvania, PA, USA
*IV Delivery of Ex Vivo Lentiviral Corrected CD34+ Bone Marrow Cells to Treat Systemic Disease in a Canine Model of Mucopolysaccharidosis VI*
Summary Financial Report

The financial information below has been summarized for the year 2022. The Society is a 501c3 nonprofit public charity. The complete audited financial statements and IRS Form 990 are available on our website or upon request.

### Financial Position

**Assets**

**Current Assets**
- Cash and cash equivalents: $969,959
- Investments: 1,911,190
- Accounts receivable: 75,705
- Prepaid expenses: 25,833
- Accrued interest: 10,132

**Total Current Assets**: $2,992,819

**Fixed Assets, Net**
- Furniture, fixtures & equipment: 3,231
- CIP—Website: 8,581

**Total Fixed Assets**: 11,812

**Other Assets**
- Operating leases right of use assets: 233,424
- Deposits: 5,000
- Investments—restricted for purpose: 143,385
- Investments—restricted in perpetuity: 1,138,568

**Total Other Assets**: 1,520,377

**Total Assets**: $4,525,008

**Current Liabilities**
- Accounts payable: $150,578
- Accrued salaries/vacation: 38,463
- Refundable program advances: 170,000
- Current portion of operating lease liabilities: 43,977

**Total Current Liabilities**: 403,018

**Long-Term Liabilities**
- Operating lease liabilities: 190,787

**Net Assets**
- Without donor restriction
  - Undesignated: 1,450,200
  - Designated: 476,030
- With donor restrictions
  - Purpose restricted: 840,700
  - Time restricted: 25,705
  - Perpetual in nature: 1,138,568

**Total Net Assets**: 3,931,203

**Total Liabilities and Net Assets**: $4,525,008

### 2022 Statement of Activities

**Revenue and Support**
- Contributions
  - General: $417,559
  - Research: 248,594
  - Family support: 37,877
  - Sponsor revenue: 100,000
  - Membership dues: 2,300
  - Conference revenue: 332,384
  - Special events: 731,843
  - Interest and dividends: 139,347
  - Investment income (loss), net of fees: (653,496)

**Total Revenue and Support**: $1,356,408

**Functional Expenses**
- Research grants: $886,520
- Direct family assistance and bereavement: 97,402
- Advocacy and Speaker’s Bureau: 32,975
- Conferences, meetings, and travel: 445,370
- Sponsored expenses: 185,185
- Education—newsletters, booklets, web: 111,019
- Membership database and directory: 28,036
- Direct fundraising: 90,369
- Personnel: 724,552
- Office and equipment: 59,279
- Other administrative: 58,558

**Total Functional Expenses**: $2,719,265

**Change in Net Assets**: $(1,362,857)
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(ML II parent)
Lewisville, TX
mercedes.johnson@mpssociety.org

Carl Kapes
(MPS IIIA parent)
Wilmington, DE
carl.kapes@mpssociety.org

Noni Langford
(MPS IIIA parent)
North Charleston, SC
noni.langford@mpssociety.org

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

Sheri Wise
(MPS IVA adult)
Del City, OK
sheri.wise@mpssociety.org

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teri@mpssociety.org

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N. Matthew Ellinwood, DVM, PhD
matthew@mpssociety.org

Director of Family Support and Communication
Leslie Urdaneta, MSW, LCSW
leslie@mpssociety.org

Pathways Director
Carol Bryant, MSW, LCSW
carol@mpssociety.org

Development and Program Specialist
Bethany Greene
bethany@mpssociety.org

Administrative Specialist
Sydney Doctor
sydney@mpssociety.org

Controller
Angela Guajardo
angela@mpssociety.org

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## MPS & ML Classifications

Mucopolysaccharidoses (MPS) and Mucolipidosis (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-Acetylgalactosaminidase
- MPS III C Sanfilippo C
  Enzyme / Acetyl CoA: α-glycosaminide acetyltransferase
- MPS III D Sanfilippo D
  Enzyme / N-Acetylgalcosamine 6-sulfatase

### MPS IV
- MPS IV A Morquio A
  Enzyme / Galactose 6-sulfatase
- MPS IV B Morquio B
  Enzyme / β-Glucosidase

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

### MPS VII
- MPS VII Sly
  Enzyme / β-Glucuronidase

### MPS IX
- Enzyme / Hyaluronidase

### ML II/III
- ML II I-Cell
- ML III Psuedo-Hurler polydystrophy
  Enzyme / N-acetylglucosamine-1-phosphotransferase