Celebrating
50 YEARS
OF PROGRESS

National MPS Society
50
Years

Honoring Our Legacy

As we mark the 50th anniversary of the National MPS Society, we reflect on an extraordinary year of impact, growth, and momentum. Since 1974, our community has stood together with unwavering resolve—fighting for families, driving innovation, and advocating for our members. In 2024, we honored that legacy by expanding our reach across every pillar of our mission: family support; research, advocacy, and education; and purpose, compassion, and vision.

Through our Pathways and Family Support programs, we reached hundreds of families with direct assistance at critical moments—at diagnosis, during extended hospital stays, and through the many challenges throughout their journeys. We provided more than $130,000 in family support services, including medical travel assistance, adaptive equipment, educational scholarships, and bereavement support. Our dedicated social work team visited families in their homes, building trust and delivering care where it was needed most.

Through our Crossing Paths Program, we explored new ways to engage with families. This transformative outreach program bridges the gap in access to education, clinical studies, and support services for families in underserved communities. Recognizing that geography and socioeconomic status should never be barriers to care, this initiative directly brings vital resources to those needing them most. Also in 2024, the Crossing Paths Program expanded its reach into six cities across the country. The program increased partnerships with local health providers, community centers, and rare disease networks, empowering families with knowledge and ensuring early engagement with care teams. This growing program reaffirms the Society's deep commitment to life-changing access for all individuals affected by MPS and ML.

We awarded more than $450,000 in research funding, domestically and internationally, to support innovative studies that accelerate treatments and deepen our understanding of MPS and ML. Since 2000, we have awarded more than $24 million in research. In 2024, we launched new initiatives to support emerging science in assay development, gene editing, and newborn screening. In addition, we implemented a Challenge Grants program, awarding $500,000 to fund critical research identified in unmet needs. Our partnerships with researchers and biotech companies continue to shape the future of rare disease treatment.

In 2024, the National MPS Society collaborated with sister MPS organizations and industry partners to meet with the Reagan-Udall Foundation and advance the development and regulatory acceptance of meaningful biomarkers for MPS and ML disorders. Through stakeholder engagement, scientific roundtables, and expert consultations, the Society contributed critical patient-centered perspectives and helped identify pathways to accelerate biomarker qualification with the FDA. These efforts culminated in a comprehensive report outlining current gaps, regulatory needs, and strategic recommendations to move the field forward. As a result, the Society strengthened its role as a leader and trusted partner in shaping rare disease policy and laid essential groundwork for future therapeutic advancements that rely on validated, measurable endpoints to demonstrate meaningful clinical benefit.

We made our voice heard on Capitol Hill and in statehouses across the country. With your support, the Society championed legislation to strengthen newborn screening programs, advocated for NIH funding, and played a central role in elevating the Rare Disease Congressional Caucus. As we celebrate 50 years of service, we remain grounded in the values that have defined us from the beginning—compassion, integrity, and an unrelenting drive to make life better for those living with MPS and ML.

Thank you to our donors and families for believing in our mission, and for supporting the MPS and ML community. Together, we are not only honoring the past—we are building a future where no child is left without hope or support. Here's to that critical momentum moving forward in 2025!

— ***Terri Klein***, *president and CEO*
Steve Holland, *chairman, board of directors*

Fueling the Mission

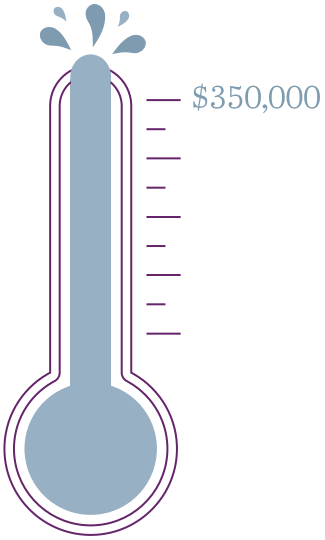
FUNDRAISING HIGHLIGHTS

Donors remained a constant source of inspiration for the National MPS Society, helping surpass our $350,000 goal by raising an impressive $367,887 for the 2024 Annual Fund. These contributions are vital in supporting operational costs and overseeing the mission of the Society.

Fundraising efforts continued to provide support for our national walk/run events. Future efforts will concentrate on the upcoming **gala in Boston**, and strengthening our planned giving programs.

The Fundraising Committee also aimed to **develop partnerships** with new corporations and foundations to further fortify the long-term sustainability of the National MPS Society. We have partnered with the Gail Perry Group to lead our **Capital Campaign** and are incredibly excited about the potential this new initiative holds. Their expertise will be instrumental in cultivating strategic growth to advance our mission, and we look forward to the positive impact this campaign will have on the future of the National MPS Society.

> The **FUNDRAISING COMMITTEE** continues to create unique opportunities to share the journey of MPS and ML.



$367,887
RAISED FOR THE
2024 ANNUAL FUND

2024 HIGHLIGHTS

- Maintained four-star rating from Charity Navigator, representing sound fiscal management and commitment to accountability and transparency. This “exceptional” designation differentiates the National MPS Society from its peers and demonstrates that we are worthy of public trust.
- Received 100% grade from Charity Navigator—the highest level of financial health, accountability, and transparency in its operations.
- Supported an active membership roster of more than 2,750 members.
- Hosted four national run events in Raleigh, NC; Long Beach, CA; Napa, CA; and Orlando, FL.
- Raised $367,887 through the 2024 Annual Fund campaign, chaired by Carl Kapes.
- Received Combined Federal Campaign application approval.
- Raised $30,000 for MPS and ML research through the University of Pennsylvania’s Million Dollar Bike Ride fundraiser.

2024 Fundraisers

50 States for 50 Years 5K hosted by National MPS Society

Adam Brennan's Birthday Party hosted by Mary Beth Brennan *in honor of Adam Brennan*

American Golf Foundation hosted by Hugo Vandermoer *in honor of Michelle Hopkins*

Aunt Joan's Pearl City Popcorn Purple Bow Sales hosted by Wayne and Joan Eppehimer

Avery's Army T-shirt Fundraiser hosted by Madison Neuendorf *in honor of Avery Neuendorf*

Blood Drive hosted by Eric McGraw *in memory of Carter McGraw*

Chalk the Walk hosted by Stacey Montgomery *in memory of Lucas Montgomery*

Coin Drive - Aleyah hosted by LE White Middle School *in honor of Aleyah Smith*

Concert for a Cure hosted by Dorothy Mask *in memory of Ryan Mask*

Crop for Rachel hosted by Jim and Michelle Dodson *in memory of Rachel Dodson*

Do It Fore Dan Golf Tournament hosted by Ray and Amy Miller *in memory of Danny Miller*

Garabito Fundraiser hosted by Katherine Garabito *in honor of Emilio Garabito*

Holland Sharing and Caring hosted by Steve and Amy Holland *in memory of Spencer and Maddie Holland and in honor of Laynie Holland*

Hopkins Cabi Party hosted by Lynn Hopkins *in honor of Michelle Hopkins*

Jaela's Courage hosted by Sydnee Rios *in honor of Jaela Hernandez*

Jammin for Julia hosted by Andrea Felten *in honor of Julia Donahue*

Keller's 5K hosted by Clint and Lindsey Blakeley *in honor of Keller Blakeley*

Kramer Chili Cook-Off hosted by Beth Kramer *in honor of Marcus Kramer*

Lilah's Lemonade hosted by Kimber and Lilah Heiling

Long Beach Race for Rare hosted by National MPS Society

Loy Memorial Golf Tournament hosted by Donald and Lynda Witte *in memory of John L. Loy*

Million Dollar Bike Ride hosted by National MPS Society

MPS Jingle Bell Run hosted by National MPS Society

Napa Race for a Cure hosted by National MPS Society

Post Office Café hosted by the Lessing family *in memory of Mark and Casey Lessing*

Raleigh Run for Rare hosted by National MPS Society

Rare Aware Shop hosted by Adult Resource Committee

Ride for Jack hosted by The Dirty Weasels *in memory of Jack "The Beast" Bennett*

Sanofi Pumpkin Smash hosted by Sanofi *in honor of Christopher Hohn*

Shoe Fundraiser hosted by Alicia Bohley *in honor of Jacob Bohley*

Stacey's Sparkles hosted by Terry and Nancy Wain *in memory of Stacy and Matthew Wain*

Stevens Fundraiser hosted by Marla and Randy Stevens *in honor of Meekel Stevens*

Super Bowl Fundraiser hosted by Mary Beth Brennan *in honor of Adam Brennan*

Super Bowl Fundraiser hosted by Amy Downen

Team Nora hosted by Trevor and Leanne Spring *in honor of Nora Spring*

T-shirt Fundraiser hosted by Breanne Busterud *in honor of Garrett*

T-shirt Fundraiser hosted by Katarina Nelson *in honor of Wesley*

Facebook Fundraisers

Melissa Anderson
Chloe Baker
Josh Banman
Charlotte Barrett-Weber
Mandy Bellassai
Nichole Bickerton
Darryl Block
Melanie Block
Charity Cook-Blood
Lillian Botsolas
Kathy Boudreaux
Alicia Brooks
Cindy Cancel
Heidi Caswell
Ruth Clancy
Jamie Hemphill Clark
Iyona Cook
Carla Halk Crain
Tamara Cullere
Brandon T. Dee
Amy Diaz
Wilma Dickerson
Kailey Dina
Amy Phillips Downen
Susan Duncan
Cathy Forkas Durman
Anne Elizabeth
Wayne Eppehimer
Brooke Frix
Elizabeth Fry
Katherine Garabito
Sophee Garner
Julie Garrison
Dee Ann Gaston
Tarin Gayles
Hermines Geburtstags-Spendenaktion
Michelle Gordon
Jayne Gray
Larizza Guerrero
Tim Guilfoyle
Alisa Gutierrez-Vitello
Beth Recktenwald Hatton
Shaun Bach-Haynes
Kimberly Heiling
Linda McCarter Hewing
Thomas Hickey
Laynie Holland
Jeremy Howard
Joanne Makris Huff
Alex Huntington
Alyssa Jeanne
Karen Kiker
Brenna Marie King
Debbie Kruse
Emily Layman
Amanda Lee
Katherine Lethia
Kelly Louden
Joanna Guadalupe Magallanes
Kristina Marie
Anne McClelland
Janice McDonagh
Annie McGraw
Rose Merrell
Vicki Michelle
Stacey Harris Montgomery
Jamie Moon
Danielle Murphy
Stephanie Nicole
Tommy O'Brien
Sonshine Paperie
Marla Jane Parkman
Jeff Parks
Travis Parsons
PERMANENT JEWELRY
Kim Phillips
Angelica Prater
Anne Quesenberry
Emily Ramirez
Amber Reynolds
Lina Ricci
Haley Huffman Roth
Krizia Ruano
Karen L.K. Russell
Barbara Bigham Sanders
Holly Scalf
Michael Scoggins
Linda Cebron Shenk
Rachel Sibs
Khris Snow
Cynthia Stephens
Christopher Stetson
Alana Sullivan
Vail Taetum
Charlotte Tate
Janine Taylor
Dominique Thurman-Morgan
Marissa Valenzuela
Christi Wadle
Becca Walker
Tammy White
Sheri Wise
Fanny Zambrano

Champions Circle

Fernando Armendariz
Colleen and Shawn Arni
Carole and John Barnhardt
Melany Bjorkman
Marie Blumeier
Claudina Bonetti
Marc and Beth Brdar
Margaret Cohen
William English
Teresa Everett
Vivian Fernandez
Edward Francisco
Robert and Melanie Franko
Steve and Amy Holland
Jennifer and Bryan Hutcheson
John and Yvette Iannelli
Christine Jocoy
Brian and Rebekah Klutz
Cynthia Kraft
Lauren Louison
Wynona Maxwell
Donny and Molly Merrill
Greg and Jennifer Mincks
Susan Murphy
Kathy and Josh Nay
Thomas and Vickie Patterson
Linda Perrella
Sam and Nancy Ramsey
Edward and Evelyn Schultz
Poonam Scott
Riddhi Shah
Jared Shelton
Mike and Barbara Smith
Angela and Michael Sochacki
Heidi Sosinski
Jeremy and Rena Stearns
Jack Swepston
Anne France Tremege
Leslie and Alex Urdaneta
Josh and Alisa Vitello
Todd Waddell and Sarah Aaserude
Tom and Kim Whitecotton
Rick and Dawn Williams

Claire Trappe and Marla Stevens both received the "FRIENDRAISING AWARD" at the 38th Annual Family & Scientific Conference banquet for their outstanding efforts in fundraising.

Trappe family

Meekel (MPS VI) and Marla Stevens

We are honored to be the recipient of the Friendraising Award. Our fundraising efforts have been supported by our friends, family, and community, and we are forever grateful for all who have put their loving arms around our family and never let go. We will continue our efforts and supporting the mission of the MPS Society. Thank you to the National MPS Society for advocating, supporting, and fighting for a cure.

— *Claire Trappe*

I extend my sincerest gratitude for this wonderful recognition. This achievement would not have been possible without the support of a loving community that views Meekel as a true inspiration, just as I do. The resilience of these children in the face of adversity is a testament to their strength. I am honored to continue raising funds for research, and I shall persist in this endeavor for as long as I am able.

— *Marla Stevens*

Empowering Families

SUPPORT PROGRAMS AND PATHWAYS

As the National MPS Society celebrated its 50th anniversary in 2024, the Family Support Program remained a cornerstone of compassion and connection for families affected by MPS and ML. This year, we awarded more than $130,000 in grants and scholarships, supporting almost 170 families with essential items like medical equipment, technology, and travel assistance.

Because of our Family Support Programs, many families were afforded the opportunity to attend each of our conferences during 2024, such as the **Celebrating Your Cherished Life Experiences (CYCLE) bereavement retreat**, the **SPIRIT conference** for adults diagnosed with MPS or ML, and the **38th Annual Family & Scientific Conference** in Orlando, FL. Our **Pathways Program** also provided more genetic counseling support, access to social workers, resources on mental health and medical care, and education on clinical trials than ever before in the history of the Society. Likewise, members of our team visited cities nationwide through the **Crossing Paths Program** to provide localized support and expand our outreach to underserved families.

Also in 2024, our **Continuing Education Scholarship** program awarded funds to students with MPS or ML and their siblings, parents, and children, who were seeking to achieve their own, unique educational milestones.

> As we celebrate five decades of impact, the **FAMILY SUPPORT PROGRAM** stands as a lasting testament to our commitment—continuing to provide essential resources, empower families, and sustain a strong, supportive community for years to come.

“ ”

JOURNEY ASSISTANCE PROGRAM

We are immensely grateful for the invaluable assistance offered by the Journey Assistance Program, as it enables us to procure tools that enhance our family's quality of life. The program's support extends beyond financial aid; it signifies a deeper understanding of the unique challenges faced by MPS families, significantly contributing to easing the difficulties encountered on this arduous journey. We appreciate the generosity and empathy of the donors who have made this support possible.

— Vanessa Lo, mother of Luke (MPS IVA)

2024 HIGHLIGHTS

CONTINUING EDUCATION SCHOLARSHIPS

- Awarded $22,000 through four Jeffrey Bardsley Scholarships at $5,000 each and 23 Continuing Education Scholarships at $1,000 each.
- Awarded two Klenke-Kirch Sibling Scholarships (at an additional $500 each to the $1,000 Continuing Education Scholarship).

EXTENDED HOSPITALIZATION RELIEF

- Funded five grants for a total of $2,500 to support individuals with MPS or ML who have experienced an inpatient hospitalization for a minimum of 30 days.

$130,000+

AWARDED IN GRANTS AND SCHOLARSHIPS

CYCLE CONFERENCE SCHOLARSHIPS

- Funded 16 scholarships totaling $7,348 for bereaved families to attend the Celebrating Your Cherished Life Experience retreat.

SPIRIT CONFERENCE SCHOLARSHIPS

- Provided assistance totaling $13,114 for 19 adults with MPS and ML to attend the Finding Our SPIRIT (Strength, Purpose, Independence, Resilience, and Initiative Together) Conference, which provides a dedicated program for education, empowerment, and camaraderie among adults in our community.

FAMILY CONFERENCE SCHOLARSHIPS

- Provided necessary financial support totaling $22,857 for 22 families to attend the 38th Annual Family & Science Conference in Orlando, FL.

FAMILY ASSISTANCE PROGRAM

- Funded 10 grants totaling $26,225 to provide assistance items, including stair lifts, wheelchair van, activity chair, home lift, hearing aids, mobility devices, and adaptive bicycles.

JOURNEY ASSISTANCE PROGRAM

- Funded seven grants totaling $1,680 for items, including iPads, medical wagon, CCTV, and water heater.

EXTRAORDINARY EXPERIENCES PROGRAM

- Funded one grant for $1,000 for an adult with MPS to be able to attend the International MPS Symposium in Germany.

URGENT NEED FUND

- Funded five grants totaling $4,129 to assist several families who were displaced due to natural disasters and a family facing food insecurity.

MEDICAL TRAVEL ASSISTANCE PROGRAM

- Funded 27 grants totaling $15,555 to help with out-of-town travel costs for non-recurring medical appointments.

BEREAVEMENT EXPENSE PROGRAM

- Funded 27 grants totaling $20,250 to provide support for families experiencing the loss of a loved one with MPS or ML.

22

FAMILIES RECEIVED FINANCIAL SUPPORT
to attend the 38th Annual Family & Scientific Conference in Orlando, FL

Transforming Lives

PROVIDING SUPPORT AND CONNECTION

In 2024, the National MPS Society's Pathways Program continued to make a profound impact, including adding a new team member to help meet our needs as we focused on connecting newly diagnosed families and providing essential support to individuals across the country. Through this program, we provided services to 69 individuals from 62 families spanning 30 states — a powerful reflection of our reach and commitment to the MPS and ML community.

Our **virtual support groups** provided vital spaces for education, connection, and shared experiences throughout the year. Topics included fundraising, the Adult Resource Committee, sibling support, member stories, genetics, "Ask Dr. Matthew," back to school, advocacy, and the Courageous Parent Network.

Crossing Paths events continued to foster community and strengthen local connections, bringing families together in person. In 2024, we held a total of six events in Sacramento, CA; Houston, TX; Boston, MA; Detroit, MI; North Carolina/South Carolina; and Phoenix, AZ. Each of these gatherings provided invaluable opportunities for families to share their journeys, exchange knowledge, and build lasting bonds. Through every visit, meeting, and event, the National MPS Society remains dedicated to serving, supporting, and empowering our community. Together, we continue to strengthen the connections that drive hope and progress for all those affected by MPS and ML.

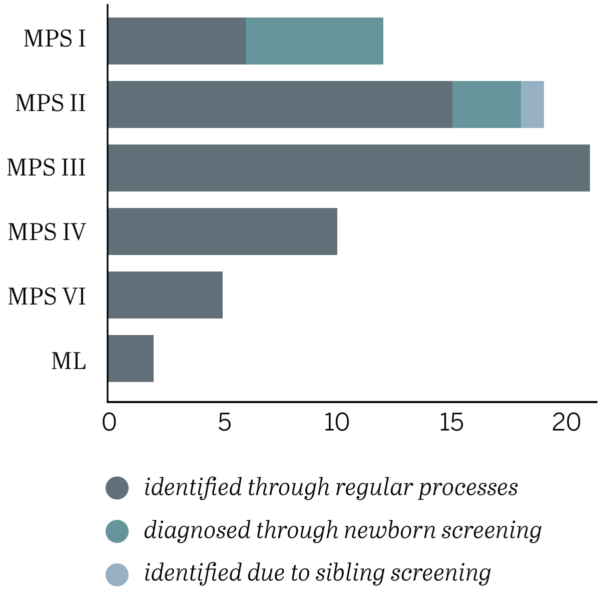
> **Since its inception, the PATHWAYS PROGRAM has served 412 individuals, and in 2024 we completed 56 personalized Pathways visits, offering crucial one-on-one support and resources tailored to the unique needs of each family.**

MPS Pathways

TRAVELING THE JOURNEY **TOGETHER**

Syndrome Types

OF INDIVIDUALS SERVED IN 2024



2024 HIGHLIGHTS

- Provided education, support, and resources to 69 individuals from 62 newly diagnosed families in 30 states.
- Served 412 individuals through the program since inception.
- Completed 56 personalized visits.
- Hosted 10 virtual support groups for family support, advocacy, and science.
- Hosted six Crossing Paths events for 46 families across the country.

56
PERSONALIZED VISITS
providing one-on-one support

30
STATES ACROSS THE COUNTRY
where families received support

412
INDIVIDUALS SERVED
throughout program history

> Payton was diagnosed with MPS IIIA right before she turned 6 years old. It was a difficult time as we navigated through what the diagnosis meant and what we were headed toward. The first year after diagnosis was overwhelming and we needed help. Fortunately, we learned about the National MPS Society's Pathways Program and built a relationship that would last forever. Our program manager was the light we needed in the dark place we were in. She listened to our story and what we needed to best care for Payton, helping us organize Payton's providers under one roof and connect with specialists who focus solely on her rare condition. We joined Pathways support groups, attended in-person events, and met professionals who were passionate about their work, listening to families and sharing their knowledge. We started to understand what it meant for both grief and joy to coexist. For the first time since the diagnosis, we felt a sense of peace and community. We were not alone anymore.
>
> *— the Geronzin family*

Advocacy Achievements

POLICY AND AWARENESS BREAKTHROUGHS

Advocacy efforts continue to be a driving force for the National MPS Society. Expanding and maintaining public awareness of MPS and ML and those affected by it is critical for driving policy creation and change.

For the first year of our **Youth Advocacy Program**, we hosted four webinars, coaching more than 20 youth and their families. Topics included how to develop your story, the junior speaker's bureau, and self-advocacy, with an emphasis on health literacy and developing autonomy. The goal of this program is to empower our youth to advocate for themselves, not only through legislative efforts, but throughout the daily aspects of their life and journey with MPS/ML.

Zachary Thomas, MPS I advocate for newborn screening

Stephanie Cozine, Advocacy Committee chair, represented the National MPS Society and the MPS/ML community at the **FDA Center for Biologics Evaluation and Research Patient Listening Meeting: Patient Perspectives on Safety Considerations for Approved Gene Therapy Treatments for Rare Diseases**. Stephanie presented unique considerations of the MPS/ML community when determining a treatment plan when multiple treatment options are available. Stephanie and Leslie Urdaneta, Family Support director, educated and supported families with their public comment submissions. Matthew Ellinwood, chief scientific officer, submitted a research and advocacy driven public comment. This collective effort was aimed to ensure that the voices of those affected by MPS and ML were heard and considered in the FDA's evaluation of gene therapy safety. By sharing personal experiences, scientific insights, and community specific challenges, the National MPS Society emphasized the importance of patient-centered approaches in regulatory decisions, advocating for continued progress in treatment accessibility, safety, and long-term outcomes.

> The Society's **ADVOCACY COMMITTEE** spearheaded several impactful initiatives in 2024 and looks to expand its reach in 2025.

Perhaps most noteworthy was the significant advancement of the **newborn screening** landscape in 2024. As of Dec. 31, a total of 48 states are screening or have committed to adding MPS I to their state newborn screening panels. MPS II is making traction with a total of 15 states screening or have committed to adding MPS II to their state newborn screening panels. West Virginia is leading the country by being the only state screening for three MPS conditions: MPS I, MPS II, and MPS IV. Our Advocacy Committee is dedicated to seeing that every baby in the United States is screened for all MPS conditions.

2024 HIGHLIGHTS

- Facilitated 50 virtual Capitol Hill meetings on May 15, 2024 (MPS Awareness Day) with 29 advocates who met with legislators representing 17 states. This included three member-level meetings with a total of 28 Senate and 22 House meetings; 24 with Democrat offices, 25 with Republican offices, and one Independent office.
- Supported the following legislation:
    - — H.R. 4758/S. 2372—**Accelerating Kids Access to Care Act**
    - — H.R.7384/S. 4583—**Creating Hope Reauthorization Act**
    - — Appropriations language
- International MPS Awareness Day was officially recognized by state proclamations for Delaware and Oklahoma.
- Launched Youth Advocacy Program designed to assist our youth to independently navigate daily aspects of their life and their journey with MPS and ML.
- Represented the Society and the MPS/ML community at the FDA Center for Biologics Evaluation and Research Patient Listening Meeting: Patient Perspectives on Safety Considerations for Approved Gene Therapy Treatments for Rare Diseases.
- Continued newborn screening efforts.

50
VIRTUAL CAPITOL HILL MEETINGS
on MPS Awareness Day

4
WEBINARS
hosted by Youth Advocacy Program

FAMILY ASSISTANCE PROGRAM

Travis is thrilled to be able to transport himself to and from work on his e-bike obtained through the Family Assistance Program, giving this teenager the independence he craves and the dignity of not having to call his mom and dad for a ride. He also is excited to be able to join the rest of the family on social bike rides and outings and get together with his friends in town via his own transportation.

— Stephanie Glock, mother of Travis (MPS I)

Learning and Leading

EDUCATIONAL AND COMMUNITY PROGRAMS

Communication is at the heart of everything we do at the National MPS Society. In the rare disease space—where information can be scarce and the need for connection is critical—clear, compassionate, and timely communication becomes even more vital. For families affected by MPS and ML, access to accurate resources, updates on research and advocacy, and shared stories of hope and resilience provide both knowledge and a sense of community. In 2024, the Society made significant strides in strengthening its communications to better serve our members and advance our mission. Through every story we tell and every message we share, we honor the voices and experiences of those we serve and strengthen our collective impact.

> We remain committed to refining and expanding our **COMMUNICATIONS**, always striving to meet the needs of the MPS and ML community.

50 STATES FOR 50 YEARS VIRTUAL 5K

The 50 States for 50 Years Virtual 5K was a standout fundraising and awareness campaign for the National MPS Society in 2024. By inviting participants from every state to run, walk, or roll in their own communities, the event created a powerful sense of unity and purpose, amplified through personal stories and local advocacy. Leveraging social media, email outreach, and storytelling to inspire participation and share the mission of the Society far and wide, participants from 48 states were encouraged to participate and share photos and messages online, creating a ripple effect that spread awareness of MPS and ML across the nation.

2024 HIGHLIGHTS

- Hired a full-time communications director, marking a pivotal investment in our ability to share our mission and message. Filling this role brings strategic vision and dedicated leadership to our outreach efforts. This position empowers the Society to enhance our voice, streamline content creation, and ensure consistent and high-quality communication across all platforms.

2

PRINT EDITIONS OF *COURAGE*
to keep our community informed

- Revitalized *eCourage* and published print editions of *Courage*. Our monthly *eCourage* publication received a fresh look and renewed focus in 2024, delivering timely news, advocacy updates, and heartfelt stories to our members' inboxes. In addition, we produced two beautifully crafted print editions of *Courage*, providing an in-depth reflection of our community's experiences and our organization's work.
- Prioritized amplifying the voices of individuals and families impacted by MPS and ML by collecting and sharing more than 10 unique feature stories on our website and in our publications. Personal journeys and member achievements raised awareness of the challenges and triumphs within our community.
- Expanded digital and social media outreach. In 2024, our social media channels saw increased engagement and thoughtful content. From educational posts and event highlights to advocacy calls-to-action and celebratory moments, we used digital platforms to reach broader audiences and create meaningful conversations around MPS and ML.
- Strengthened conference and event communications. Our 38th Annual Family & Scientific Conference set a new standard for engagement. Through tailored messaging, comprehensive guides, and interactive campaigns, attendees were kept informed and connected, making the event even more memorable and impactful.
- Enhanced advocacy and research messaging. Ensuring our members stay informed and empowered in the fight for better treatments and policies is central to our work. This year, our communications played a critical role in mobilizing support for legislative efforts and sharing breakthroughs in research, helping our community take action and stay hopeful.

INCREASED DIGITAL AND SOCIAL MEDIA OUTREACH

BLAST OFF FOR A CURE

The 2024 Blast Off for A Cure campaign was a powerful communication campaign that set the stage for a successful MPS Awareness Day. With a dynamic and educational countdown on social media, we effectively engaged our community, fostering a deeper understanding of the mission of the National MPS Society. By utilizing clear, compelling messaging, we raised awareness, ignited participation, and celebrated 50 years of progress at the Society.

Driving Research Forward

SCIENTIFIC MILESTONES

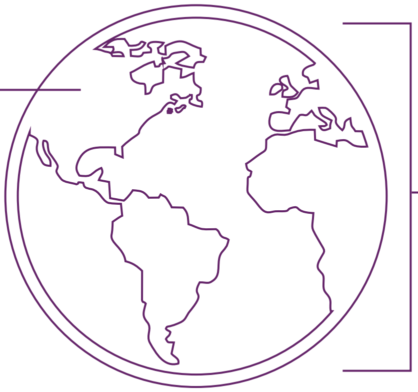
Although research and science saw many successes in 2024, we remained ever mindful and worked diligently toward a meaningful treatment option for those diseases and syndromes that do not have one. Increasingly, many aspects of progress involve regulatory review and approval of treatments for MPS and ML syndromes. Seeing this need, the Society began, with a group of like-minded stakeholders and advocacy organizations, to engage with the FDA some years ago. This led to an understanding and a need for an important milestone we met in 2024: a meeting at the **Reagan-Udall Foundation for the FDA**, a fully independent nonprofit foundation that is designed to assist the FDA in confronting regulatory challenges and hurdles.

The results were impressive. Even though this was not a formal regulatory meeting, it had a tremendous impact, and within six months, three drug therapy programs addressing neuropathology in MPS syndromes announced that they had a pathway toward Accelerated Approval using heparan sulfate in the cerebrospinal fluid. This marks a momentous change at the FDA in regulatory flexibility.

In addition to these three innovative therapies, 2024 also brought a potential pathway to approval involving two gene therapies for MPS disorders and our first prospective treatment for Sanfilippo syndrome, an extraordinary set of achievements.

Also in 2024, we expanded our **Scientific Advisory Board** to include individuals representing new disciplines, new institutions, and new countries. This esteemed group of scholars and researchers will be an important addition and will meaningfully assist in the development of better research and approaches to treatment.

Seeing the need for a larger grant platform to overcome significant hurdles, in 2024 the Society launched a challenge grant initiative whereby researchers submit large programmatic research objectives for specific syndromes to overcome hurdles to therapy. The Scientific Advisory Board has approved two such challenge grants.



$260,000+
IN GRANTS AWARDED
within United States

NEARLY
$200,000
IN GRANTS AWARDED
Internationally

INVESTING IN INNOVATION:
2024 Research Funding and Grants Overview

U.S. GRANTS

$11,347 awarded to Dr. Magi Casal
University of Pennsylvania, Philadelphia, PA
"Odiparcil, Substrate Reduction Therapy to Treat MPS VI in a Canine Model MPS VI"

$50,000 awarded to Dr. Richard Steet
Greenwood Genetic Center, Greenwood, SC
"Functional Characterization of Novel IDS Variants in Cells and Zebrafish"

$100,000 awarded to Dr. Stephanie Cherqui
Regents of the University of California San Diego, La Jolla, CA
"Treating MPS IIIC with Hematopoietic Stem Cell Gene Therapy"

$100,000 awarded to Dr. Patricia Dickson
Washington University, St. Louis, MO
"Brain-directed Gene Therapy for ML II/III with S1S3 Phosphotransferase"

INTERNATIONAL GRANTS

$50,000 awarded to Dr. Alessandro Frialdi
Department of Translational Medical Sciences – Ceinge BioTecnologie Avanzate Franco Salvatore, Napoli, Italy
"Exploring the Role of Neurotoxic Reactive Astrocytes in Neuronopathic Mucopolysaccharidoses"

$50,000 awarded to Dr. Elvira De Leonibus
Telethon Institute of Genetics & Medicine, Roma, Italy
"Targeting Sleep Disorders in MPS IIIA with Sustainable Strategies"

$48,700 awarded to Dr. Emma Parkinson-Lawrence
University of South Australia, Research and Innovation Services, Australia
"Quantification of Airway Disease in MPS I Mice Via Laboratory X-ray Velocimetry"

$50,000 awarded to Dr. N. Brunetti-Pierri
Telethon Institute of Genetics & Medicine, Roma, Italy
"Understanding the In Vivo *Consequences of GALNS Pathogenic Variants"*

MEDICAL TRAVEL ASSISTANCE PROGRAM

> **We couldn't have gotten this far without the National MPS Society. Back in 2011, it was our life-saving resource. From then on, we have donated as much as possible and continue to encourage new families to reach out to the Society to learn the facts. We appreciate all the help the Society has given us!**
>
> *— Brian and Casey Hurst, parents of Baen, Bryce, and Brock (MPS I)*

FINANCIAL STRENGTH: TRANSPARENCY AND STEWARDSHIP

The financial information below has been summarized for the year 2024. 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	$ 427,185
Investments	1,590,648
Promises to give	56,450
Prepaid expenses	64,269
Interest receivable	7,631
Total Current Assets	2,146,183
Fixed Assets, Net	
Furniture, fixtures & equipment	7,086
CIP—website	23,216
Total Fixed Assets	30,302
Other Assets	
Operating leases right of use assets	138,982
Investments—restricted for purpose	419,625
Investments—restricted in perpetuity	1,139,068
Total Other Assets	1,697,675
Total Assets	$ 3,874,160

Current Liabilities	
Accounts payable	$ 15,307
Grants payable	50,000
Accrued salaries/vacation	51,166
Current portion of operating lease liabilities	49,698
Total Current Liabilities	166,171
Long-Term Liabilities	
Operating lease liabilities	94,313
Net Assets	
Without donor restriction	
Undesignated	849,737
Designated	413,803
With donor restrictions	
Purpose restricted	1,154,618
Time restricted	56,450
Perpetual in nature	1,139,068
Total Net Assets	3,613,676
Total Liabilities and Net Assets	$ 3,874,160

2024 STATEMENT OF ACTIVITIES

Revenue and Support	
Contributions	
● General	$ 606,018
● Research	123,621
● Family support	38,283
● Planned giving	8,606
● Endowment	500
● Membership dues	3,900
● Conference revenue	414,716
● Special events (net of $33,856 direct expenses)	788,881
● Interest and dividends	93,562
● Investment income, net of fees	322,187
Total Revenue and Support	$ 2,400,274

Functional Expenses	
● Research grants	$ 455,079
● Direct family assistance and bereavement	174,010
● Advocacy and Speaker's Bureau	26,467
● Conferences, meetings, and travel	577,747
● Education—newsletters, booklets, web	92,891
● Membership database and directory	41,113
● Fundraising expenses	60,164
● Personnel	914,468
● Office and equipment	81,487
● Other administrative	90,990
Total Functional Expenses	$ 2,514,416
Change in Net Assets	$ (114,142)

2024 Contributors

In 2024, 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 thanks you for your dedication. The Society makes every effort to recognize our supporters through *eCourage* and this Annual Report. The following list represents all donations received in calendar year 2024. If your name is not listed, we apologize and ask that you contact us. If we received your donation in 2025, you will be recognized in the next Annual Report.

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Cassidy Gosey (MPS I) with Jeremy Mask and friend

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FAMILY ASSISTANCE PROGRAM

Skylar is not able to walk very far without needing to sit down. The adaptive bike we were able to purchase through the Family Assistance Program will help her be able to go for walks with her family and to the park with her peers and enjoy the outdoors.

— Roberta Lister, mother of Skylar (MPS IIIB)

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lisa.todd@mpssociety.org

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steve.holland@mpssociety.org

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lynn.hopkins@mpssociety.org

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maureen.cote@mpssociety.org

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lisa.berry@mpssociety.org

Steven Chesser (MPS II parent)
steven.chesser@mpssociety.org

Stephanie Cozine (MPS I parent)
stephanie.cozine@mpssociety.org

Tamara Cullere (MPS I parent)
tamara.cullere@mpssociety.org

Rebecca Dopheide (MPS IIIA parent)
rebecca.dophiede@mpssociety.org

Patricia Espinal (MPS VI adult)
patricia.espinal@mpssociety.org

Amy Holland (MPS I parent)
amy.holland@mpssociety.org

Scott Hopkins (MPS I parent)
scott.hopkins@mpssociety.org

Mercedes Johnson (ML II parent)
mercedes.johnson@mpssociety.org

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

Colleen Kraft, MD (MPS advocate)
colleen.kraft@mpssociety.org

Sheri Lueb (MPS IVA adult)
sheri.lueb@mpssociety.org

Jason Madison (MPS II adult)
jason.madison@mpssociety.org

Stacey Montgomery (MPS IIIB parent)
stacey.montgomery@mpssociety.org

Gordon Wingate (MPS IIIA parent)
gordon.wingate@mpssociety.org

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Klane K. White, MD
Chester B. Whitley, MD, PhD
John H. Wolfe, VMD, PhD

Staff

PRESIDENT AND CEO
Terri L. Klein, CNPM, MPA
terri@mpssociety.org

CHIEF OPERATING OFFICER
Sharon King
sharon@mpssociety.org

CHIEF SCIENTIFIC OFFICER
Scott Loiler, PhD, CSO
scott@mpssociety.org

DIRECTOR OF SCIENCE & RESEARCH *(through May 2025)*
N. Matthew Ellinwood, DVM, PhD
matthew@mpssociety.org

COMMUNICATIONS DIRECTOR
Amber Adams, MS
amber@mpssociety.org

PATHWAYS PROGRAM DIRECTOR
Carol Bryant, MSW, LCSW
carol@mpssociety.org

PATHWAYS PROGRAM CARE MANAGER
Evelyn Fisher, MSW, GC
evelyn@mpssociety.org

ASSOCIATE DEVELOPMENT DIRECTOR
Bethany Greene
bethany@mpssociety.org

DIRECTOR OF DEVELOPMENT
Wendy Spaulding, CNPM, MBA
wendy@mpssociety.org

DIRECTOR OF DEVELOPMENT
(through Sept. 2024)
Amy Downen

DIRECTOR OF FAMILY SUPPORT
Leslie Urdaneta, MSW, LCSW
leslie@mpssociety.org

ADMINISTRATIVE SPECIALIST/ GIFT PROCESSOR
Tivianna Webster
tivianna@mpssociety.org

ADMINISTRATIVE SPECIALIST
(through March 2025)
Joseph Jackson

CONTROLLER
Angela Guajardo
angela@mpssociety.org

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National MPS Society
P.O. Box 14686
Durham, NC 27709-4686

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

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Durham, NC 27709-4686
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919.806.0101

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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*-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 / β-Galactosidase

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

Pictured on the cover: Carol Bryant with the Lopez brothers (MPS IVA)