NATIONAL MPS SOCIETY | SPRING 2025

COURAGE

50 YEARS

Reflecting on the past 50 years of the National MPS Society

ANNUAL CONFERENCE

Recap of this extraordinary event in Orlando

SOCIETY NAMES NEW CSO

New leadership aims to shape research initiatives, strengthen partnerships, and accelerate progress

TABLE OF Contents

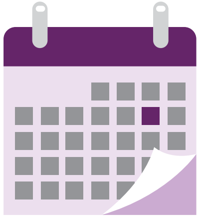
5 NEWBORN SCREENING
Expanding newborn screening remains a top priority for the Society

100% RATING 19
The National MPS Society has received a 100% rating from Charity Navigator

Charity Navigator
✦ ✦ ✦ ✦
✦ FOUR-STAR ✦

21 GIVING TUESDAY
We crushed our goal this year, raising more than $8,000 on this day of generosity

VIRTUAL SOCIALS 29
Save the date for virtual socials held by the Adult Resource Committee



SCIENCE & RESEARCH 3
50 YEARS 6
CONFERENCE RECAP 14
PATHWAYS 16
FUNDRAISING 18
FAMILY SUPPORT 24
ADULT RESOURCE COMMITTEE 29
ADVOCACY 30
RESOURCES 31
DONATIONS 36
CLASSIFICATIONS 44
BOARD OF DIRECTORS 45

National MPS Society

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

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

MPSSOCIETY.ORG

Follow us!

ON THE COVER:
Main photo: Cynthia Alix (MPS VII); Inset photos: Maggie Rose (MPS I) and family, Luna Harwood (MPS VII), Levi Ormeroid (MPS IIIC)

LETTER FROM THE CHAIRMAN

As we step into 2025, it is with immense gratitude that I write to you as the incoming chair of the board of the National MPS Society. While this is not my first time in this role, this year marks the start of a new chapter in our shared journey, one that builds on the incredible legacy of the Society's 50th anniversary, as well as my own personal 30th anniversary since being touched by this disease.

For five decades, this community has been a beacon of hope, resilience, and advocacy. Together, we have championed groundbreaking research, advanced treatments, implemented newborn screening, and supported families facing the challenges of MPS and ML. The road has not always been easy, but every step has been marked by unwavering determination and the belief that we are stronger together.

As we reflect on our past achievements, we also look ahead to the future with a steadfast commitment to the work that remains. There is much to do—developing treatments for those without one, advocating for access to life-changing therapies, funding the next wave of scientific discovery, and ensuring no family feels alone on their journey.

In this edition of *Courage*, you will find stories that inspire, updates that inform, and opportunities to engage in our mission. I invite you to join us as we forge ahead, united by hope and driven by the vision of a brighter future for all those impacted by MPS and ML.

Thank you for your trust, your passion, and your partnership. Together, we will continue to lead the way and change lives!

With gratitude,
Stephen E. Holland, *chairman, board of directors*

SAVE THE DATE

NATIONAL MPS SOCIETY

39th Annual

Family & Scientific Conference

AUGUST 7–9, 2025 • DENVER, CO

LETTER FROM THE PRESIDENT AND CEO

We begin 2025 with a flurry of activity. I cannot thank everyone enough for the extraordinary support and compassion provided to our families at the 38th Annual Family & Scientific Conference this past December. We had more than 650 people in attendance. For those who were unable to join us, conference sessions are available on our YouTube channel. See page 15 for more information.

I am pleased to announce that we have exceeded our goal and raised $367,000 for the 2024 Annual Fund, which means better access to precious resources that will allow us to carry our mission into 2025.

Although it feels as if the conference has only just ended, we have already begun planning for the 2025 conference, which will be held in Denver, CO, Aug. 7-9. This will be the first time we have held an event in Colorado and are thrilled to be hosting at the Sheraton Downtown Denver, a location that is convenient for exploring city markets, zoos, and parks. More details will be forthcoming.

If you are unable to attend the 2025 Annual Family Conference, please note that the Society continues to have a robust schedule of Crossing Paths events, and we will update our membership of any regional family gatherings as they are planned. We hope you will be able to find connections and friendships in your MPS journey through these opportunities. Please reach out to Leslie Urdaneta with questions.

Thank you to board members Rebecca Dopheide, Gordon Wingate, and Mercedes Ramirez Johnson for their time served within their terms. We are grateful for the extraordinary skills they brought to serve our mission and advocate for our families on policies, in research, and for ongoing family support programs. We are pleased to welcome Steven Chesser back to our board of directors. Steven served on the board in the mid-2000s, and his expertise in fund development and organization oversight is welcome.

Finally, I would be remiss if I did not acknowledge that we soon will be saying goodbye to Matthew Ellinwood, the Society's inaugural chief scientific officer. His expertise and oversight have illustrated for all of us the importance of the convergence of science, policy, and research. Even as he moves forward, Matthew will continue to be available to our MPS community, and for this we are grateful beyond measure.

Now we must look ahead, as we dive into yet another busy year at the National MPS Society. We are pleased to present the calendar of conferences which we are scheduled to attend in 2025. Although we are sure other meetings will be added, the following are confirmed:

Mucopolysaccharidosis Newborn Screening Meeting
Minneapolis, MN • **April 14–16, 2025**

39th National MPS Society Family/Science Conference
Denver, CO • **Aug. 7–9, 2025**

Third Consensus Conference on Neurocognitive and Functional Endpoints in MPS Clinical Studies
Kyoto, Japan • **Sept. 1–2, 2025**

CYCLE Retreat (a bereavement retreat)
Fall 2025

As an organization recognized for our increased collaborations, I am also pleased to represent the Society and present at the following meetings:

Somewhere to Go (bone health conference for rare disorders) • Washington, DC

WORLD*Symposium*™ "Patient Voice" • San Diego, CA

IMPSN International Meeting • Amsterdam

Professional Patient Advocates in Life Sciences
Sioux Falls, SD

This will be yet another year of incredible progress at the Society. Yet, I find myself dwelling for a moment on the past. Recently, I received correspondence from a family who attended our conference in which they referred to me as "The Mother of All MPS." This title, and the photos they shared, warmed my heart. Though that is a mighty title, I do see the MPS and ML community as my family. And it is an honor to be a "mother" in whatever capacity that role requires, as we move forward together.

Wishing you a gentle and kind 2025,
Terri L. Klein, *president and CEO*

SCIENCE & RESEARCH

Since the last edition of *Courage*, there have been several exciting developments, and even more are on the horizon. I'm thrilled to share some of these updates with you.

In February 2024, a workshop at the Reagan-Udall Foundation for the FDA explored using heparan sulfate—a naturally occurring sugar molecule that plays an important role in various biological processes—to speed up drug approvals for treating neurological forms of MPS. Thanks to this effort, four groups have been allowed to use this faster approval pathway, and three have already shared the news publicly.

During our annual family conference in December, Ultragenyx gave us an incredible holiday gift: they submitted an application to the FDA for a groundbreaking gene therapy to treat MPS IIIA. If approved, this could become the first FDA-approved therapy for Sanfilippo syndrome. Similar approvals could follow in 2025 for MPS II treatments by other companies.

These advancements were made possible through teamwork between advocacy groups like the National MPS Society, researchers, and industry partners. In Europe, similar efforts are underway, with a meeting planned in Amsterdam this March to discuss using this approach with the European Medicines Agency; I'm honored to be presenting at this event. It is such a privilege to be able to take part in such impactful meetings, workshops, and symposia.

While many advances focus on early diagnosis and new treatments, we also recognize the ongoing challenges faced by individuals already living with advanced stages of MPS. This past fall, researchers published a major study in Nature Medicine on using a drug called anakinra to treat Sanfilippo syndrome. Efforts are underway to expand this research into larger trials, which could lead to a new treatment. I am proud to note that both researchers involved in this effort are members of the Society's Scientific Advisory Board: Dr. Polgreen (past chair) and Dr. Eisengart (current chair).

As I look forward to my last spring as the CSO with the Society, I am pleased to also highlight additional efforts that will be taking place. Newborn screening efforts continue to grow across the nation. More than 85% of U.S. newborns are now screened for MPS I, and nearly 40% are screened for MPS II. In April 2025, we'll co-host the third MPS Newborn Screening Symposium to bring together experts working to identify and treat babies with MPS.

Another exciting milestone will happen in March 2025, when a team of distinguished experts and I will present on a new therapy involving gene editing and stem cells at a major genetics conference. This promising approach could transform treatment for MPS I and beyond.

Finally, I would like to reflect on the Society's Legacy Awards that were presented at the Annual Family & Scientific Conference in Orlando in December. Drs. Barabara Burton and Michael Gelb received the Legacy Award for Clinical Achievement and Research Achievement, respectively. In their talks, they reflected on the incredible achievements they have seen take place and have been part of over these last decades, and they looked forward to a very bright future.

I agree with their observations and will carry that thought, along with the thought of the constant and ongoing needs of all our community, as I move forward from the Society. I am pleased to note that I will continue to represent the Society directly, and their goals indirectly, as I continue to serve the newborn screening efforts of the EveryLife Foundation, to serve on the External Advisory Board of the Lysosomal Disease Network, and the Scientific Organizing Committee for the next International Symposium on MPS and Related Diseases.

I remain committed to do what I can to help this great community.

While I may be departing the Society as the CSO, I remain committed to do what I can to help this great community. Serving the Society, and the families and individuals living with MPS and ML, has been the greatest and most rewarding honor of my professional life, and I look forward to continuing to help as I can in the future.

With wishes of hope and courage, I extend a farewell to all of you at the Society.

N. Matthew Ellinwood, DVM, PhD*, director of Science & Research*

Newborn Screening Developments

ADVANCING NEWBORN SCREENING FOR MPS DISORDERS

There is significant progress to celebrate in the realm of newborn screening. A large portion of the annual U.S. birth cohort is now screened for MPS I (85%), MPS II (40%), and even MPS IVA, with West Virginia initiating screening in March 2023. Expanding newborn screening remains a top priority for the Society and the broader MPS community.

One inspiring example comes from Brooke Thomas, an MPS I mom from Alabama and chief programs officer at Alabama Rare. Brooke, her son Zachary, and their allies successfully advocated for the passage of the Zachary Thomas Newborn Screening Act last May, named in honor of Zachary, for his extraordinary advocacy efforts. This legislation represents a growing movement across the country to promote Recommended Uniform Screening Panel (RUSP) legislation.

RUSP alignment laws provide a clear timeline and process for states to adopt newborn screening for conditions added to the federal RUSP by the U.S. Secretary of Health and Human Services. More than a dozen states, representing more than half of the U.S. population, have passed such legislation. Efforts led by our partners at the EveryLife Foundation for Rare Diseases continue to expand this work, with a current focus on Wisconsin and Virginia. Notably, when Wisconsin adopts RUSP alignment, it will also simplify expanded screening efforts in Montana, as the state relies on Wisconsin's screening infrastructure.

The Society remains at the forefront of these efforts. We participate in EveryLife's advocacy initiatives and Newborn Screening Bootcamp, attend the Association of Public Health Laboratories' Annual Newborn Screening Symposium, and are preparing for our third Symposium on MPS Newborn Screening this April at the University of Minnesota.

We will not stop until every individual with MPS has access to timely diagnosis and the best available treatments. Together, we are creating a future where no child is left undiagnosed or untreated.

National MPS Society Appoints New Chief Scientific Officer

The National MPS Society is thrilled to announce the appointment of Dr. Scott Loiler as its new chief scientific officer (CSO). With more than three decades of experience in virology and gene therapy, Dr. Loiler is no stranger to tackling the toughest challenges in rare disease research. Now, he's bringing his passion and expertise to the MPS/ML community, helping to push the boundaries of science and accelerate the path to new treatments.

If you're familiar with groundbreaking advancements in gene therapy, you may already know Dr. Loiler's work. He has been a driving force behind therapies for more than nine conditions, including MPS IIIA and IIIB, as well as the gene therapies Zolgensma and Elevidys. Most recently, he served as president and chief technology officer at Apic Bio, where he successfully led the development of a gene therapy for SOD1 ALS—now in the hands of UniQure for further clinical development.

A recognized leader in AAV gene therapy, Dr. Loiler has worked alongside some of the most innovative minds in the field. His expertise spans vector design, capsid modification, manufacturing, analytical methods, and regulatory strategy—an invaluable combination that will shape the Society's research initiatives, strengthen partnerships, and accelerate scientific progress for MPS and ML.

"We are thrilled to welcome Dr. Loiler to the National MPS Society," said Terri Klein, CEO and president of the Society. "His deep knowledge of gene therapy and commitment to advancing research in rare diseases will be game changing for our community. As we continue to expand our impact, his leadership will be critical in shaping our scientific strategy, fostering collaboration, and bringing us closer to transformative treatments."

As CSO, Dr. Loiler will oversee the Society's Research Grants Program, fueling discoveries in everything from newborn screening to drug development and regulatory advocacy. His leadership will help ensure that cutting-edge science translates into real-world solutions for individuals and families affected by MPS.

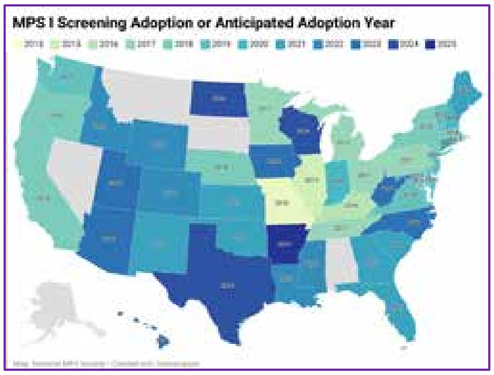
For Dr. Loiler, this work is personal. "I am honored to join the National MPS Society and contribute to the vital efforts to support patients and families," he said. "I look forward to collaborating with this incredible team to advance research and bring new therapies to the MPS community."

With Dr. Loiler at the helm of scientific strategy, the future of MPS research looks brighter than ever. Please join us in welcoming him to the National MPS Society!

Newborn Screening for MPS
Where does your state stand?

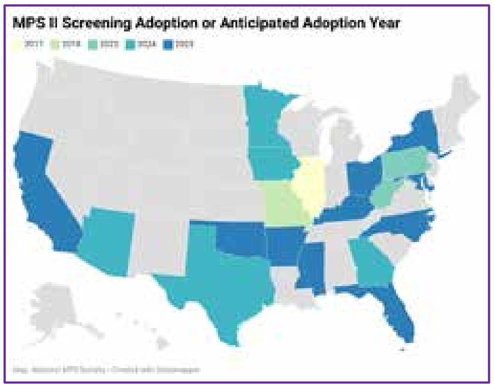
MPS I

Predicted by 2025
At least 45 States and the District of Columbia & ~96% of the US birth population

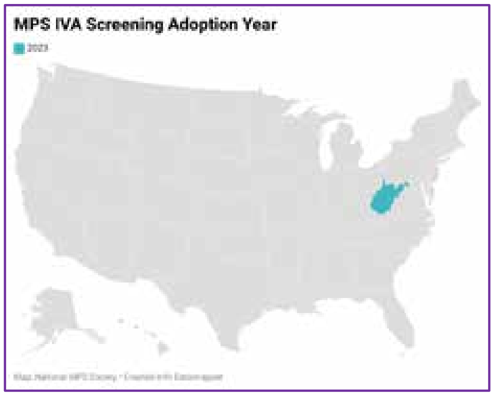


MPS II

Predicted by 2025
At least 19 States and ~57% of the US birth population



MPS IVA



Your State Can Make History

Be the first to start screening for the other MPS conditions with approved therapy including MPS VI or VII

50 YEARS

As we celebrate the 50th anniversary of the National MPS Society, we reflect on a half century of progress, resilience, and unwavering commitment to individuals and families affected by MPS and ML. From humble beginnings in 1974, we have grown into a global force for change, advancing research, awareness, and support for our community.

Together, we have witnessed remarkable milestones that once seemed unimaginable. Over the past five decades, we have:

- **PIONEERED THERAPIES:** The first Food and Drug Administration (FDA)-approved treatments for MPS disorders brought renewed hope to our community, underscoring the power of collaboration between researchers, clinicians, and advocates. These therapies have transformed lives, offering enhanced quality of life and more time with loved ones.

  Discoveries from our research pioneers, Drs. Elizabeth Neufeld and Emil Kakkis, brought life-saving therapies for MPS, with Aldurazyme® for MPS I. Once this first enzyme replacement therapy was approved, others soon followed for MPS II, MPS IVA, MPS VI, and eventually MPS VII.

  The Society learned that building critical relationships with the FDA and the National Institutes of Health for our patient community meant we could impact policy through patient advocacy. Testimonies over the years, approval advisory councils, and patient advisory meetings have guided these stakeholders with an understanding of how our community can have the best quality of life while struggling with an ultra-rare disease.

- **ADVOCATED FOR NEWBORN SCREENING:** Through dedicated advocacy and partnerships, we have worked tirelessly to introduce newborn screening for MPS I and MPS II disorders leading to Recommended Uniform Screening Panel additions and individual state screenings. Early diagnosis and intervention have become critical in improving outcomes, marking a new era in identifying and managing these diseases. These efforts are challenging and not for the faint of heart, but nothing is more essential for a patient fighting against the manifestations of this disease. We must achieve the most difficult regulatory and legislative changes to benefit our community. Newborn screening is extending and improving millions of lives worldwide, and the United States is leading the way.

- **EXPANDED PROGRAMMING:** Our commitment to supporting families has led to the development of a wide range of family support programs. From travel, conference, and educational scholarships through our Pathways, Crossing Paths, and Bereavement programs, the Society is guided by the evolving needs of our families and how we can help them with direct services and compassion. We walk alongside families every step of the way, not only providing education, community, and hope, but creating action and improving outcomes during their disease journey.

- **ADVANCED RESEARCH:** By funding more than $23 million in innovative research, we've propelled the development of treatments, gene therapies, and diagnostic tools. We have implemented the inaugural chief scientific officer position at the Society, and it has changed how science relates with stakeholders through patient advocacy. This year we will embark on two new programs in science—one is the announcement of our Challenge Grants that will address the unmet needs of patients with mucolipidosis (ML) and Maroteaux-Lamy (MPS VI). These grants will be funded at $500,000 each. This is a bold change, but these advancements continue to bring us closer to our goal: curative therapies for all MPS and ML disorders.

- **ADVANCED BROADER RARE DISEASE ATTENTION:** The Society has been advocating on Capitol Hill since 1990. Over the years we have successfully submitted language to Congress to include mucopolysaccharidosis research at the NIH. This effort has led to more than $100 million in additional funding for our diseases.

  In addition, our advocacy efforts led to MPS and ML being added to the Compassionate Allowance to have quicker access to Social Security benefits. This was a game-changer for our families.

  Through the Society's advocacy efforts, MPS Awareness Day, May 15, was unanimously voted on by the House of Representatives in 2003. Each year our families have a day dedicated to recognizing their journey.

None of these historic feats would have been possible without **you**. Whether you've been with us since the beginning or joined along the way, your dedication has fueled our progress and strengthened our impact.

The Future Is Bright and Bold

As we honor this golden anniversary, we also look to the future. With therapies advancing, newborn screening expanding, and programming reaching more families than ever, we are poised to make even greater strides in the years ahead.

We will continue our extensive federal and state advocacy efforts for MPS. We will maintain our RareHub office in Washington, DC, as we continue to collaborate our efforts with the EveryLife Foundation on meaningful policy change. We will augment advocacy with more significant effort as we hire our first advocacy team member, once again adding crucial positions to better serve our community.

So many individuals have been part of our extraordinary history: our founders, researchers, board of directors, team members, clinicians, sister patient advocacy organizations, legislators, and, always at the forefront, our patients and their families.

"Do the hardest work. If we do not, who will?"

This is the crucial motto that drives our team.

Amongst this forward motion, we also pause to reflect and pray for all our families and their children who have lost their battle to MPS and ML. They are kept in our hearts forever. We recognize their bravery in carving out the future for those who will be diagnosed and live a life free of pain in the future.

Thank you for being part of our journey. Please join us in celebrating progress, resilience, hope, and most of all **COURAGE**. Let's honor our past, celebrate the present, and improve the future together!

Terri Klein
President and CEO

National MPS Society
50
Years
1974–2024

50 YEARS OF LOGOS

National MPS Society, Inc.

The National MPS Society, Inc.

COURAGE

COURAGE

MPS

COURAGE

The National MPS Society walk/5k run 2004

The National MPS Society, Inc.
MPS
COURAGE

National
MPS
Society
Support for Families. Research for a Cure.

1974

- "Parents for MPS" formed
- $5 membership fee
- Katherine Burdine named president, temporary BOD
- $58.25 reported cash on hand

1975

- MPS Society incorporated
- First seminar held and attended by 33 people
- Attorney McConnell, age 57 with MPS I, wrote a letter for *Courage*

1976

- Membership of 34 families
- New board members elected
- Alice Teetsell Kalamar named acting president and then president

1977

- Society headquarters moved from Washington, DC, to New York

1978

- $10 membership fee
- Fundraising Committee formed
- Dr. Neufeld summarizes MPS/ML research for newsletter
- Mary Majure listed in the BOD as president

1979

- Membership of 150 and mailing list of 250
- First annual fundraiser – a raffle raising almost $1,000

1980

- Brochure explaining MPS/ML published
- Society members in Short Stature Symposium
- First bone marrow transplant performed on 9-month-old boy with MPS I

1981

- Membership of 200 families and mailing list of more than 400
- $2,557.03 reported in treasury

1987

- President Marie Capobianco testifies before Congress
- Ballot nominations for board member appeared for the first time in *Courage*
- Grant awarded to publish book, *All About Me, What About You*

1986

- Society granted federal tax-exempt status
- First major national family conference held
- Brochures, logo wear, and membership directory created
- Membership of 300 families and mailing list of 600
- $15 membership fee

1985

- Society refiled for incorporation as the National MPS Society, Inc. in New York
- Newsletter renamed *Courage*
- First survey is mailed to 232 members

1984

- 10th anniversary of the MPS Society
- Annual fundraiser money used to fund research student
- MPS Midwest Chapter holds first mini conference in Ann Arbor, MI

1983

- BOD voted to add fundraising chairperson as officer
- Dr. Haskins reports to BOD research with MPS I and MPS VI cats and MPS VII dog
- Amniotic membrane transplantation in MPS I, MPS II, MPS III A&B announced

1982

- First conference devoted to MPS/ML at North Shore University Hospital, New York

1988

- Hosted 1st International Congress on MPS and related diseases, Minnesota
- Treasury reported $5,279.19

1989

- Celebrating 15 years of history
- Sanfilippo C research grant awarded
- Two student researchers selected by the Scientific Advisory Board for summer research fellowships

1990

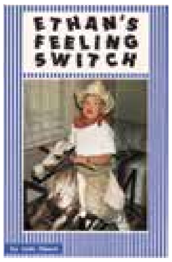
- Membership categories expanded to include professional members and families living outside the United States
- $20 family membership
- First Disney family conference

1991

- National MPS Society meeting – UCLA includes scientific, family, and joint meeting
- Syndrome-specific booklets published
- Establishment of Raymond Bryan IV Fellowship Fund for Sanfilippo research

1992

- *Ethan's Feeling Switch* published
- $25 family membership



1996

- National MPS Society website launched
- MPS Day held in Chapel Hill, NC, with UNC Hospital
- Operating budget renamed to Family Program Services

1995

- 780 members and mailing list of 1,200
- Adults with MPS/ML added as a membership category
- $30 membership fee
- Calendar and note cards created for fundraising

1994

- 20th anniversary of the Society
- Dr. Neufeld awarded National Medal of Science award for her MPS research, presented by President Clinton

Biologist at UCLA Wins Medal

■ **Research:** National Science Foundation award goes to Elizabeth Neufeld for her work on two genetic diseases.

By THOMAS H. MAUGH II
TIMES MEDICAL WRITER

- Budget increased to $106,450
- "Children of Courage" video created by MPS II parent
- Second Disney family conference

1993

- Mark Dant family began large fundraising campaign in Texas to fund Dr. Kakkis' lab and the 1994 Disney family conference

- "Families to Families" column added to *Courage*
- Board votes to waive conference fees for affected individuals

1997

- National Institutes of Health funded $5.9 million in research for MPS/ML diseases
- MPS I phase I/II ERT clinical trial began
- Board voted for one annual family conference platform

1998

- First clinical trial of gene therapy on a human conducted on adults with milder MPS II
- Creation of the Society's Committee on Federal Legislation
- Steve and Amy Holland elected to board of directors

- Movie *Simon Birch* released starring Ian Michael Smith who had MPS IV

1999

- BioMarin/Genzyme provided first operational grant to Society allowing hiring of first employee
- Bylaws of Society amended and restated for first time
- $40 family membership
- Third Disney family conference
- Linda Shine elected president
- Website moved to www.mpssociety.org

The National MPS Society walk/5k run 2002

2002

- Participated in the formation of Global Organization for Lysosomal Diseases
- Annual Fund program established, raising $12,600
- 17 walk/runs raised $285,000
- Awarded $190,000 in research grants
- Hired part-time office assistant

2001

- Co-hosted family and scientific conference at UCLA
- MPS II phase I/II ERT clinical trial began
- Second year of 5K Walk/Run Program raised $170,000 for research with 11 events

- Awarded $100,000 in grants for research
- MPS Society new animation logo developed for website and publications

2000

- MPS VI phase I/II ERT clinical trial began
- Co-hosted International MPS and Related Disease conference in Minnesota
- National MPS Society 5K Walk/Run Program launched with seven events, raising $100,000 for research
- The Society completed its first strategic planning process
- *CBS Evening News with Dan Rather* features the Holland family story
- Barbara Wedehase becomes executive director

- MPS booklets updated
- Les Shaeffer invited by Sen. Spector to write a paragraph for MPS diseases to be included in the FY2002 Senate Appropriations Bill

2003

- 22 5K walk/runs raised $337,500
- Aldurazyme®, the first ERT for MPS I, approved by FDA; Society members testified before FDA as part of the approval process
- Feb. 25 designated National MPS Awareness Day
- MPS II phase III ERT clinical trial began
- MPS VI phase III ERT clinical trial began
- Steve Holland named president
- Reported $2.3 million net assets
- First Society video produced
- Annual Fund raised $59,650
- Awarded $360,000 in research grants
- First Lifetime Achievement Award presented to Dr. Emil Kakkis

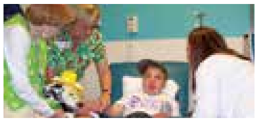
- Bereavement and regional family picnic programs implemented

2004

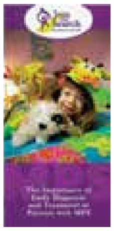
- 30th anniversary of the National MPS Society
- $1 million budget
- Fourth Disney family conference
- $410,000 awarded in research grants
- NIH funded $9.3 million in MPS/ML research
- Hired part-time development director
- Membership of 800, mailing list of 3,500
- $50 membership fee
- Society leased first paid office space in Bangor, ME

2006

- Elaprase® ERT approved by FDA for MPS II



- $450,000 awarded in research grants



- Launched Join the Search campaign
- Participated in NASDAQ closing ceremonies by ringing the bell
- Received four-star charity rating and raised $423,000 through fundraising events
- Published *Daily Living with MPS and Related Diseases* in conjunction with Canadian MPS Society
- Held inaugural CYCLE (Celebrating Your Child's Life Experience) conference for bereaved families

2005

- Naglazyme® ERT approved by FDA for MPS VI
- Received $1 million endowment from Drs. Emil Kakkis and Jenny Soriano

- U.S. Senate unanimously passed resolution marking Feb. 25 National MPS Awareness Day
- Celebrated MPS Awareness Day with NASDAQ by ringing opening bell

- Created Continuing Education Scholarship program – $1,000 grants
- Launched new branding for the National MPS Society with current logo and tagline
- Awarded $220,000 in research grants

2007

- Provided testimony to the Social Security Administration
- Awarded $459,000 in research grants
- Moved the National MPS Society to Durham, NC

- Global MPS advocacy organizations adopt MPS Awareness Day. The day is changed to May 15 and is officially named International MPS Awareness Day.
- Ernie Dummann named president
- Received four-star charity rating and raised $523,000 in fundraising events

2008

- Awarded $528,000 in research grants
- Updated syndrome-specific booklets and developed and distributed comprehensive MPS II and MPS III resource guides

- Provided 37 stipends for member families to attend the 10th International Symposium on MPS and Related Diseases in Canada

- Membership of 800, mailing list of 6,000
- Raised $465,000 through fundraising events

2010

- MPS I, MPS II, and MPS III are added to the Compassionate Allowance Program under the Social Security Administration
- Held first affected adult conference (SPIRIT) in California

- Awarded $471,000 in research grants
- Created the Governance Committee
- Celebrated 10-year walk/run anniversary
- Created National MPS Society Facebook page
- Received four-star charity rating and raised $400,000 through fundraising events

2009

- 35th anniversary of the National MPS Society
- Awarded $432,000 in research grants
- Met with Social Security Administration about adding MPS to the Compassionate Allowance Program
- Provided a record $72,500 through family support programs
- Fifth Disney family conference
- Supported Lysosomal Disease Network with $25,000 for neuroimaging core benefitting four MPS projects
- Annual Fund raised $73,500
- Raised $470,000 through fundraising events

- Terri Klein hired as development director
- Created interactive booths for conferences

2011

- Introduced MPS and rare disease legislation to the caucus in Washington, DC
- Provided first training webinar for Federal Legislative Committee and Society members, "How Advocacy Moves Government"
- Launched Planned Giving program and Rising Sun Legacy Circle
- Launched improved website with increased membership interaction
- Awarded $432,000 in research grants
- Steve Holland named president
- Received four-star charity rating and raised $520,000 through fundraising events

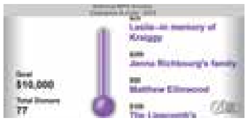
CHARITY NAVIGATOR
★★★★
Four Star Charity

- Created large three-panel displays for annual conferences and fundraising events
- Provided $76,000 in family support and scholarship grants
- 700 members and 10,000 mailing list

2012

- Awarded $547,000 in research grants
- Created teleconferencing opportunities at the Annual Family Conference in Boston
- Provided $114,000 in family support and scholarship grants
- Board member received the "Abbey" rare voices award
- Published 10th *Angels Among Us* bereavement publication
- Annual Fund raised $118,000
- Began three-film video series for fundraising and awareness with TV correspondent Beth Karas

- Introduced mobile pledging and family Courage Pages for fundraising



- Raised $380,000 through fundraising events

2013

- Awarded $445,000 in research grants
- Families testified before FDA on patient results in clinical trials for MPS IVA; FDA recommended approval

- Board traveled to Washington, DC, for large advocacy effort; Sissi Langford presented Sen. Graham with Legislative Achievement Award

- Award of Courage signed by President Steve Holland given to all of National MPS Society's affected individuals with MPS and related diseases

- Annual Fund raised $135,000
- MPS VII phase I/II ERT clinical trial began
- 700 members and 14,000 mailing list
- Raised $400,000 through fundraising events

2015

- Barbara Wedehase retired in October; Society established Research Fellowship Fund in her name
- Adult Resource Committee created, with diversified MPS and ML diseases represented
- National run program launched hosting first two events raising more than $100,000.
- Created MPS IV Resource Guide and revised the *Daily Living* booklet with Canadian MPS Society
- National media tactics provide reach on TV shows and game shows
- Awarded $455,500 in research grants
- Awarded first Fundraiser Directed Research Grant for $94,000
- Created Capitol Hill advocacy video to champion legislative efforts
- Raised $478,500 through fundraising events

2014

- Vimizim® ERT approved by FDA for MPS IVA
- First patient with MPS VII treated with ERT under compassionate use
- First Society fundraising gala held honoring 40th anniversary

2016

- Awarded $485,000 in research grants
- Board of directors created new strategic plan and rewrote mission statement
- Mark Dant hired as CEO
- Introduced e-*Courage*, new digital publications
- Raised $425,600 through fundraising events

- Joined Million Dollar Bike Ride efforts and raised more than $150,000
- Hired first communications director
- Supported first collaborative Consensus Conference on neurological biomarkers
- Legislative efforts on Capitol Hill included 21st Century Cures. Society testified in California to support newborn screening legislation
- Introduced advocacy webinars to members
- Hosted CYCLE conference and provided funding for MPS IV patients to the LPA meeting
- Added physician database to mpssociety.org
- Annual Fund raised more than $185,000
- Increased social media awareness with #scareawaymps and educational videos on YouTube

2017

- Awarded $750,000 in research grants
- FDA granted Ultragenyx approval for Mepsevii ™ for treatment of MPS VII
- Gene editing and gene therapy take the stage as next generation treatments for rare diseases

- Pathways program launched, providing direct family services to newly diagnosed families
- Society celebrated speaker bureau funding to assist with both grass roots and federal advocacy efforts
- Provided more than $120,000 in family support and introduced the Jeff Bardsley Scholarship Program
- Increased newborn screening initiatives throughout the United States
- Developed MPS VII Resource Guide
- Launched new mpssociety.org website
- Adult Resource Committee developed road kit for MPS and ML adults
- Raised $655,000 through fundraising events
- Hosted the Boston Gala, raising more than $250,000
- Social media campaign through partnership with Markiplier raised more than $100,000 in one day for the Society
- Courage Pages reached 50 MPS family stories online

2018

- Awarded $550,000 in research grants
- Hosted the 2018 International Symposium for MPS and Related Diseases in San Diego, CA
- Awarded Mark Haskins, PhD, with Lifetime Achievement Award at the International Symposium
- Terri Klein nominated as chairman of International MPS Network for four years
- Pathways provided direct visits to 84 families since inception and visited 29 states
- Increased membership to 1,700 families
- Efforts resulted in MPS I newborn screening being added in 10 states
- Finalized adult resource materials for road kits around the country
- Provided more than $120,000 through family support programs
- Provided series of four advocacy webinars to increase awareness for rare disease legislation and newborn screening
- Received eighth four-star charity rating from Charity Navigator and raised $530,000 through fundraising events

2019

- Awarded $760,000 in research grants
- Celebrated Society's 45-year anniversary
- Established first MPS physician's masterclass with Joseph Muenzer, PhD, MD
- Obtained largest legacy gift from Christa Armstrong in memory of her brother for $1 million
- Hosted 33rd Annual Family Conference at Disney World

- Provided more than $150,000 through family support grants
- Championed Isabel Bueso, MPS VI, to testify to Congress about vulnerable deportation legislation and medical treatment access
- Increased awareness with publication of article on the Society in *SciTech Europa Quarterly*
- Raised more than $600,000 in walk/run and fundraising events

- Raised a record $245,000 through the Annual Fund
- Traveled with 60 families to Washington, DC, for advocacy days
- Supported almost 1,900 Society members

2020

- Awarded $715,000 in research grants
- Hired Matthew Ellinwood, PhD, DVM, as first chief scientific officer
- Submitted RUSP nomination for MPS II
- Faced challenges of COVID-19 pandemic and administered support to our patient community accessing care centers and therapies
- Created virtual fundraising events across 12 months
- Led the charge with the Centers of Diseases Control and provided commentary for inclusivity for rare diseases and vaccine access
- Hosted Connected Together Family Conference, the first all-virtual conference for families around the world
- Received second largest legacy gift of $500,000 from the estate of Darlene Sweeny
- Awarded $90,000 through family support programs
- Created monthly virtual support Pathways webinars
- Increased membership to 2,300 members
- Raised more than $1 million through fundraising events and the Annual Fund
- Hosted 62 Courage Pages for families

2021

- Funded more than $1 million in outgoing research grants
- Reframed research program to include three cycles of tiered grant funding
- Raised more than $1 million in walk/run and fundraising events

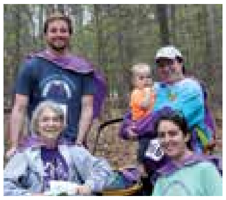
- Managed a second year of global pandemic
- Hosted successful virtual fundraising gala, *A Night Off Broadway*
- Hosted second virtual family conference with more than 400 attendees
- Held advocacy meetings with 94 families and 140 meetings virtually through rare disease week and MPS Awareness Day

- Provided $95,000 through family support programs
- Supported 43 new families through Pathways program
- Managed the technical review
- Participated as authors in four peer-reviewed research articles
- Implemented new podcast, *Our Voices*, to increase communication

2022

- Developed the 2023–2026 Strategic Plan
- Funded $929,000 through research grants
- Moved functions of the office back to in-person
- Awarded Dr. Elizabeth Neufeld the Visionary Award for 40 years of research

- Provided $135,000 in family support programs
- Awarded 80 scholarships to students
- Issued 68 grants for family assistance
- Raised more than $1.2 million in fundraising events
- Raised $324,000 through the Annual Fund – a historic record
- Supported 48 newly diagnosed families through Pathways program
- Maintained four-star charity rating
- Advocated on Capitol Hill with 59 families and held 89 meetings with legislators
- Welcomed more than 500 attendees in Nashville for the Annual Family and Science Conference



2023

- Funded $674,000 through research grants and an additional $30,000 through PENN
- Launched new science research portal for grant submission and oversight
- Established Crossing Paths program – reaching underserved communities through inner-city and rural outreach
- Hosted the Maritime Gala and raised $214,000

- Attended our first Association of Public Health Labs meeting and hosted the first MPS I and MPS II meeting with more than 100 attendees
- Maintained four-star charity rating
- Supported 71 newly diagnosed families through Pathways program
- Hosted more than 400 attendees at the Annual Family and Science Conference
- Awarded Dr. Joseph Muenzer our Life in Medicine Award for more than 40 years of outstanding service
- Supported two master class education opportunities for physicians and genetic counselors with the Muenzer Foundation
- Issued 67 Continuing Education and Family Conference Scholarships
- Awarded 68 grants for family assistance

National MPS Society
50 Years
1974–2024

2024

- Celebrated Society's 50-year anniversary
- 50 States for 50 Years Virtual 5K

CONFERENCE RECAP

Reflecting on the 38th Annual Family & Scientific Conference

The 38th Annual Family & Scientific Conference was an extraordinary event as we came together in Orlando to celebrate 50 years of the National MPS Society. This milestone was a testament to five decades of progress, resilience, and unwavering commitment to our mission. The conference was filled with heartfelt moments of connection, groundbreaking research presentations, and opportunities to reflect on our shared journey while looking ahead to an even brighter future.

One highlight of the event was the SPIRIT Conference for adults with MPS and ML, which provided a dedicated space for education, empowerment, and camaraderie among adults in our community. This special program continues to grow and underscores the importance of lifelong support for individuals living with MPS and ML.

If you couldn't attend or want to revisit the incredible sessions, recordings from the conference are now available on our YouTube channel. Scan the QR code on the following page or visit **youtube.com/NationalMPSSociety** to access these valuable resources.

Thank you to everyone who joined us, whether in person or virtually, to make this conference so memorable. As we celebrate all we have accomplished together, we are filled with hope and determination for the road ahead.

Mark your calendars and save the date for the 39th Annual Family & Scientific Conference, Aug. 7–9, 2025, in Denver, CO. We can't wait to see you there as we continue to connect, learn, and advocate for a better future.

2024 NATIONAL MPS SOCIETY AWARDS

Congratulations to our 2024 award recipients who were recognized at the 38th Annual Family & Scientific Conference in Orlando.

LEGACY AWARD, CLINICIAN:
Barbara Burton, MD

LEGACY AWARD, RESEARCHER:
Michael Gelb, PhD

VISIONARY AWARD:
Lisa P. Todd

CHAIRMAN AWARD:
Norman Matthew Ellinwood, DVM, PhD

DIRECTORS' AWARDS:
Nathan Grant, Lynn Hopkins

ADVOCACY AWARD:
Zachary Thomas

"FRIEND"RAISING AWARDS:
Claire and Jon Trappe and family, Marla Stevens

The following conference sessions are available to review on our YouTube channel:

Bone Health & Growth in MPS, Moderator: Lisa Todd, chairman, board of directors; Klane White, MD, MSc, Colorado Children's Hospital; Lynda Polgreen, MD

2024 Legacy Award Recipient for Clinical Practice & Keynote Address, Reflections on Close to 50 Years of Caring for Patients with MPS Disorders, Barbara Burton, MD

Fireside Chat: Navigating Complexities of Clinical Studies, Moderator: Carl Kapes, National MPS Society; Ryan Watts, PhD, Denali Therapeutics; Curran Simpson, president and CEO, REGENXBIO

Navigating Complexities of Clinical Studies – FDA/Regulatory and Panel Questions, Moderator: N. Matthew Ellinwood, DVM, PhD; Patricia Dickson, MD, Washington University School of Medicine; Rachael Anatol, PhD, OTP super office deputy director, FDA

2024 Legacy Award Recipient for Science, Michael Gelb, PhD

Public Health Newborn Screening: Implications for Society Engagement, Research, Treatment, and Access, Moderator: N. Matthew Ellinwood, DVM, PhD

MPS and ML II/III Newborn Screening: Highlighting Society and Membership Engagement Opportunities, Amy Gaviglio, MS, CGC

GenomeConnect: Importance of Patients Engaging in Data Sharing, Caitlin Cooney, MS, CGC

ClinGen, ClinVar, and Variant Classification: Highlighting Needs and Benefits to Improve Early Clinical Management, Jenny Goldstein, PhD, CGC

Panel Questions, N. Matthew Ellinwood, DMV, PhD; Amy Gaviglio, MS, CGC; Caitlin Cooney, MS, CGC; Jenny Goldstein, PhD, CGC

Research Developments, Moderator: N. Matthew Ellinwood, DMV, PhD

Current and Future Therapeutic Options and Challenges for MPS, Joseph Muenzer, PhD, MD

MPS Study Updates – In Utero Enzyme Replacement Therapy, Emma Canepa, program manager, clinical trials, Center for Maternal-Fetal Precision Medicine at UCSF

Evaluating Ambroxol Hydrochloride as a Therapeutic Approach for MPS III, Ozlem Goker-Alpan, MD

Final Results from a Phase I/II Study of Anakinra in MPS III, Lynda Polgreen, MD

Ultragenyx Pharmaceutical Update: Understanding Accelerated Approval and Path to Access in Rare Disease, Heather Lau, MD, MS

Abilities and Priorities: Expanding the Lens for Neurocognitive Aspects of MPS, Julie Eisengart, PhD

Corneal Transplants in MPS: Navigating Eye Care, Roberto Pineda, MD

Takeda Pharmaceuticals – From Research to Real-World Impact: Our Commitment to Rare Diseases, Mike Denne, PharmD

Orchard Therapeutics Update, Manas Prasad, PharmD

JCR Pharmaceuticals Update, Robin LeWinter, PhD, USA Medical Affairs & Medical Communications lead

Scan to access these sessions:

PATHWAYS

Pathways Committee:

Steve Holland, *chair*
Lisa Berry
Stephanie Bozarth
Carol Bryant
Maureen Cote
Tamara Cullere
Evelyn Fisher
Amy Holland
Terri Klein
Stacey Montgomery
Leslie Urdaneta

As we step into a new year, I want to take a moment to reflect on the incredible impact of the Pathways Program and express my heartfelt gratitude to each of you for your unwavering support. Together, we've built more than a program–we've cultivated a thriving community rooted in connection, understanding, and hope.

The Pathways Program has been a lifeline for so many families, offering resources, guidance, and opportunities to connect with others who truly understand the journey of living with MPS and ML. Each conversation, event, and shared story has strengthened the bonds within our community, reminding us that we are never alone. The connections we create are at the heart of what makes the Pathways Program so successful, and they serve as a testament to the resilience and compassion of our members.

In 2025, we are thrilled to continue our Crossing Paths Program—a series of gatherings designed to bring families together, and foster connections both new and old. These events will provide unique opportunities to meet face-to-face, share experiences, and support one another in new and meaningful ways. While details are still in the works, we can't wait to share more about what's to come.

Building connections isn't just about meeting new people; it's about creating a space where every family feels seen, heard, and valued. Together, we are creating a brighter future for all those affected by MPS and ML, one connection at a time.

Thank you for being an essential part of this journey. Your courage, kindness, and support inspire everything we do.

Carol Bryant, *Pathways Program director*

THE **LISTER** FAMILY

Skylar was born in October 2013 as a completely healthy and happy baby, and she met most of her milestones accordingly. As she began school, teachers and counselors brought it to our attention that she was falling behind her peers. After years of therapies, testing, and an autism diagnosis, at the age of 10 she was diagnosed with MPS III. This diagnosis was a blessing and a curse: this is a terminal disease with no cure, but we finally had answers explaining why our girl is the way she is.

The National MPS Society came into our lives along with Skylar's diagnosis. Evie, our main contact at the Society, takes excellent care of us and is always reaching out to see what else she can do to help. Because of our connection with the Society, we have met other families like ours and will forever be grateful for this wonderful asset in our time of need.

Now that we have this diagnosis, we are free to love Skylar for who she is and enjoy the time we have with her. Skylar loves to ride her bike, run, and play. She loves to chase her big brother and her dog Ruby—and she has no idea that she is different than her peers, or that she has a terminal illness. We are so grateful to have this sweet angel, even if it's just for a short time.

Roberta and Robert Lister

SKYLAR LISTER (MPS III)

SKYLAR (MPS III) AND HER BROTHER

THE **ACLE** FAMILY

ARLO AND OWEN ACLE (BOTH MPS VI)

ACLE FAMILY

Owen, age 3, was diagnosed with Maroteaux-Lamy syndrome (MPS VI) just before his second birthday. Arlo, Owen's younger brother, age 21 months, was diagnosed with the same syndrome at just 8 months old.

Owen was born a healthy baby at 39 weeks. Early on, we noticed he had severe torticollis, a condition which causes tension in the neck muscles and forces an infant's head to lean in one direction. As a result, Owen developed plagiocephaly, or flattening of one side of his skull, which had to be corrected with a helmet. We scheduled physical therapy sessions twice weekly to correct his torticollis, but Owen outgrew his helmet and quickly began to show obvious signs of an enlarged head (macrocephaly).

As time went on our physical therapist began to share concerns that Owen was not meeting typical milestones and advised us to see an orthopedic specialist. This ultimately led Owen to being diagnosed with hip dysplasia, for which he wore a hip brace nightly for about three months. Unfortunately, even after all of that time, he showed no signs of improvement. Around this time, we also noticed that his lower spine had a hump that we later learned was called a gibbus deformity, and he started to become extremely sensitive to light. By the time he was about 20 months old, he was no longer able to raise his arms above his head. Concerned for Owen, and after starting to notice similar diagnoses in Arlo, we decided to schedule an appointment with a geneticist.

Once there, it was clear to the geneticist that they showed signs of MPS. Not long after, they both began to receive weekly enzyme replacement therapy (ERT).

Two months after beginning ERT, Owen fell off our living room couch, resulting in emergency brain surgery. Just as he was recovering incredibly well post-surgery, things took a turn for the worse when Arlo suddenly developed a hernia, which also required surgery. As if that wasn't enough, both Owen and Arlo had to have ear tubes put in. Around the same time, their neurologist suggested they both undergo a sleep study, and Owen's results led to yet another surgery so that he could breathe easier throughout the night.

As you might assume, our family was overwhelmed beyond imagination. My husband and I prayed every single night to get through these difficult times, and it often felt as if we were in the emergency room every weekend. However, as we have adjusted to our new "normal," we are able to breathe again and celebrate all the good in our lives!

As Owen and Arlo healed from surgery, I found the National MPS Society and reached out. Evelyn Fisher called and asked to hear my boys' story, and for the very first time I felt heard and understood regarding all my uncertainty and fear with Owen and Arlo's MPS VI diagnosis. Not long after speaking with Evelyn, Carol Bryant reached out and came to our house to meet and play with our boys while hearing our story for herself. She gave us lots of useful information that has truly helped our family come as far as we have this last year. With the support of the Society our family journey became less overwhelming and we are so grateful knowing that we are not alone!

Jessica and Eugene Acle

MPS Pathways
TRAVELING THE JOURNEY **TOGETHER**

The National MPS Society's Pathways Program provides families with education and comprehensive support throughout the first year of diagnosis. By connecting newly diagnosed members with services, both locally and collectively, as well as trained Society professionals, we equip and strengthen families to manage care and establish resources needed for their MPS or ML journey.

Visit **mpssociety.org/pathways** to learn more or email pathways@mpssociety.org.

FUNDRAISING

As the director of development at the National MPS Society, I am filled with gratitude, inspiration, and a deep sense of purpose. I have the privilege of working alongside an extraordinary team, individuals whose passion and dedication inspire me every day. More than anything, though, it is the families and individuals impacted by MPS and ML who keep me motivated, driving me to do my best for this community.

Fundraising Committee:

Stacey Montgomery, *chair*
Alicia Bohley
Mary Beth Brennan
Stephanie Cozine
Tamara Cullere
Rebecca Dopheide
Sarah Gniazdowski
Chris Hernandez
Malisa Hernandez
Amy Holland
Steve Holland
Lynn Hopkins
Scott Hopkins
Mike Hu
Larry Kirch
Charlotte Tate

Being in this role is both humbling and heartening, challenging and incredibly rewarding. As director of development, my role is to help raise the necessary resources to ensure that the National MPS Society can continue to serve families affected by these diseases, and to advance research toward a cure. It's a responsibility I carry with immense pride, knowing how important our work is to so many people who need support, information, and hope.

Each day, I am reminded of the resilience and courage of the families we serve. From those who are newly diagnosed to those who have been living with these diseases for years, their strength in the face of adversity is inspiring. They are the heart and soul of everything we do, and it is their stories that drive me to go further, to do more, and to never stop working toward a world where no family has to face these diseases without hope.

In my position at the Society, I have the privilege of connecting with so many generous donors who share our vision for a world where MPS and ML are no longer a devastating diagnosis. It's a rare and precious opportunity to be able to speak to people who want to make a difference, who are willing to share their time, resources, and talents to support our cause. Every donation, every partnership, every connection made is a step forward in our mission, and it is an honor to facilitate that progress.

But it's not just about raising funds—it's about building relationships. It's about creating a community of individuals, families, and supporters who are united by a common goal. It's about working together to ensure that the research we support moves forward and that families have access to the resources and care they need, regardless of where they live or their circumstances. Every day brings new challenges, but it also brings new opportunities to make a real and lasting impact on the lives of those impacted by MPS and ML.

There are certainly difficult moments; I can't tell you how many times I've listened to a parent share their fears for their child, their need for treatments, and their dreams of a cure—and left those conversations feeling both heartbroken and determined. These moments are deeply personal, and they remind me why our work is so important. We may not have all the answers yet, but we are fighting every day to bring those answers closer.

The work of the National MPS Society is a collective effort, and I am constantly inspired by the generosity, ingenuity, and compassion of our supporters, our volunteers, and our team. In many ways, this work is like weaving together a tapestry—each piece is essential, each contribution significant. Whether it's helping fund the latest research initiatives or offering a comforting word to a family in need, we all play a role in creating something beautiful, something powerful, and something that will, one day, lead to a cure.

It is an immense honor to serve as director of development at the National MPS Society. The work we do is both a privilege and a passion, and it's one that I carry with deep commitment every single day. I'm proud of what we've achieved, and I'm even more excited for what the future holds as we continue to fight together for a world free from MPS, ML, and related diseases.

Thank you for being a part of this journey with us. Your support, your belief in the work we do, and your commitment to our cause make this work possible. Together, we are stronger and, together, we will make a lasting difference.

Wendy Spaulding, *director of development*

JUNE TRAPPE'S PIG

Last August, celebrity chef Guy Fieri teamed up with an anonymous buyer to purchase a pig for $24,000 at the Sonoma County Fair. The pig was raised by 10-year-old June Trappe, whose 7-year-old- brother, Jett, has MPS I. The best part? June donated half of her earnings to the National MPS Society!

This is the second time that Mr. Fieri has purchased a pig from the Trappe family. Last year, he purchased a pig sold by Jett and June's older brother, Jaxon, who was also raising money for the National MPS Society.

Thank you, Jaxon, Jett, and June, for your outstanding advocacy—and to Guy Fieri and the Guy Fieri Foundation for your incredible support!

MPS JINGLE BELL RUN

The MPS Jingle Bell Run was one of the many highlights of the National MPS Society's 38th Annual Family & Scientific Conference, bringing together families, sponsors, and speakers for a refreshing offsite experience. Participants gathered at a scenic park to run or walk together in honor of the MPS and ML community, which fostered camaraderie and spirit. Following the run, everyone enjoyed a cheerful picnic lunch amidst the park's natural beauty, complete with laughter, shared stories, and holiday themed fun.

NATIONAL MPS SOCIETY RECEIVES 100% RATING FROM CHARITY NAVIGATOR

The National MPS Society is proud to announce that it has received a 100% rating from Charity Navigator, America's largest and most trusted evaluator of nonprofit organizations! Charity Navigator assesses nonprofits based on their financial health, accountability, transparency, and impact. Achieving a perfect score demonstrates the Society's commitment to responsible stewardship of funds, organizational excellence, and delivering meaningful outcomes for the MPS and ML community. This prestigious rating places the Society among the most trusted and effective charities in the country, reinforcing our dedication to advancing research, supporting families, and advocating for change.

HAVE A FUNDRAISING IDEA?

EMAIL WENDY@MPSSOCIETY.ORG TO GET IN TOUCH!

SAVE THE DATE

2025 National MPS Society Events

MARCH 29
Raleigh Run for Rare
Raleigh, NC

APRIL 27
Napa Race for a Cure
Napa, CA

MAY 15
MPS Awareness Day

AUG. 7-9
Annual Family & Scientific Conference
Denver, CO

SEPT.
Long Beach Race for Rare
Long Beach, CA

Delaware Dash
Wilmington, DE

OCT. 11
National MPS Society Gala
Boston, MA

FALL
CYCLE Conference
Charlotte, NC

Facebook Fundraising

Have you ever considered hosting a Facebook/Instagram fundraiser? All it takes is for you to have an account. The average donation through a social media fundraiser is $34 per person!

Create a birthday fundraiser for your big day, or consider starting a campaign to help raise additional funds to coincide with another event. Follow the steps below to start fundraising on Facebook today.

DO IT YOURSELF *Facebook Fundraiser*

IMPORTANT STEPS:

1. **Go to your Home page.**
    - Look at the left side of your Home page.
2. **Find Explore.**
    - Under explore click on FUNDRAISERS.
3. **Click on Raise Money.**
    - It is a green bar.
4. **Who are you raising money for?**
    - Click Non-profit.
    - Type in National MPS Society. Select.
5. **Determine how much money you want to raise.**
    - Fill in amount in the box.
6. **Choose an end date.**
    - Click next.
7. **Name your fundraiser.**
8. **Explain why are you raising money.**
    - The Society has information that automatically populates in that box.
    - Click next.
9. **Pick a cover photo for your event.**
10. **Click Create.**
11. **Share your fundraiser with friends, family, etc!**

TIPS:

- Share with as many people as possible.
- Ask friends and families to share as well.
- Write a personal story in the WHY box.
- Make sure to share your fundraiser multiple times during the timeframe.

MPS CHAMPIONS CIRCLE

Join the Champions Circle by making a monthly recurring donation. The impact of a recurring gift is felt for years to come. Families often use this method to distribute their Annual Fund gift, or another form of annual giving, on a monthly basis.

50 years ago, the National MPS Society began the fight of a lifetime. Together we can finish that fight. Become a member of the MPS Champions Circle today. Contact Wendy Spaulding at wendy@mpssociety.org or 919.806.0101. You can also register your monthly contribution online at **mpssociety.org/recurringdonation/** or by scanning the QR code.

2024 FUNDRAISING EVENTS

THIRD AND FOURTH QUARTERS

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

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

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

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

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

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

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

Lilah's Lemonade
hosted by Kimber Heiling and Lilah Mueller

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

MPS Jingle Bell Run
hosted by National MPS Society

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

Rare Aware Shop
hosted by Adult Resource Committee

Sanofi Pumpkin Smash
hosted by Sanofi in honor of Christopher Hohn

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

GIVING TUESDAY'S GREAT NEWS

Giving Tuesday is a global day of giving celebrated every year on the Tuesday following Thanksgiving. It's a day dedicated to unleashing the power of kindness and generosity to create meaningful impact in communities worldwide.

Thanks to your generosity and enthusiasm, we crushed our 2024 Giving Tuesday $5,000 goal, raising more than $8,000 to support the National MPS Society's mission of advancing research, advocacy, and support for those affected by MPS and ML.

Your contributions on this special day have a direct impact on the lives of individuals and families within our community. Together, we are making a difference, and we couldn't do it without you. **Thank you!**

GIVING
TUESDAY

National MPS Society NEW MEMBERS

Linda Bartham, parent, Joseph Nagy, ML II/III, IL
Ryan Ferguson, stepfather, Marshall Gavin, MPS II, PA
Christina Griffith, parent, Scarlett Griffith, MPS IVA, NJ
Kaitlin Haber, parent, Liam Haber, MPS II, NY
Zaw Htet, parent, Khant Nyan, MPS IVA, CA
Feiyang Hu, MPS VI, NJ
Jennifer Jacobson, parent, Jacob Paecht, MPS IIIB, CT
Nicole Kladky, parent, Avery Ellis, MPS I, WV
Allie and Chris Layko, parents, Dimitri Layko, MPS IIIC, AZ
Irlanda Revilla Legglew, adult with MPS I, AZ
Dustin Mans, parent, Caelum Mans, MPS IIIA, AZ
Stephanie McSheehy, parent, Nora McSheehy, MPS IV, MA
Stephanie Picas, parent, Eleanor Picas, MPS I, GA
Mairenys Ramos, cousin, Patricia Espinal, MPS VI, NY
Latavia Shaw, parent, KyAire Shaw, MPS II, IL
Nina Summerlin, parent, Travis Summerlin, MPS IIIA, FL

HOPE IS THE FOUNDATION OF EVERY STEP FORWARD…

Ways to Give

Supporting the National MPS Society through fundraising can be a rewarding way to contribute to our mission to cure, support, and advocate for people with MPS and ML. Following are several ways to get involved in fundraising efforts:

MAKE A DIRECT DONATION: One of the simplest ways to support the Society is by making a financial donation. This could be a one-time gift or a recurring donation that provides consistent support for our programs and initiatives.

- Contribute through the Combined Federal Campaign (if you are employed by the Federal Government—CFC #10943)
- United Way—using the Society's name, address, and Federal ID# (FEIN #11-2734849)

ORGANIZE A FUNDRAISING EVENT: Participating in one of our fundraising events, such as a walk/run, golf tournament, or gala, can raise both funds and awareness. You can even partner with the Society to organize an event of your own.

START A PEER-TO-PEER FUNDRAISING CAMPAIGN: Set up a fundraising campaign where friends, family, and colleagues can contribute to the Society. This could be tied to a special occasion, such as a birthday or anniversary, or in memory of someone impacted by MPS or ML. Peer-to-peer fundraising leverages personal connections to spread awareness and encourage donations.

CORPORATE PARTNERSHIPS AND SPONSORSHIPS: If you work with a company or have connections in the business world, consider forming corporate partnerships or sponsorships with the National MPS Society. Companies can support the Society through financial contributions, matching gift programs, or by sponsoring fundraising events.

DONATE IN HONOR OR MEMORY OF SOMEONE: You can make a tribute gift to honor someone special, whether it's for a birthday, anniversary, or in their memory. These types of donations can be meaningful and provide comfort to the families who have been personally affected by MPS or ML.

COURAGE PAGES: Looking for a place to share your story, fundraise, and honor someone you love with MPS or ML? Scan the QR code to create or update your Courage Page on our website. Your Courage page is a space for you to share your story, and can be used to fundraise for the Society, or any of our specific funds or programs that mean the most to you.

SOCIAL MEDIA: Use social media platforms to spread awareness and encourage donations. By sharing the Society's mission, your personal connection to the cause, and fundraising goals, you can tap into your network to support the National MPS Society.

Tip: *Be sure to follow the Society's accounts so you can share our content directly with your friends, family, or colleagues!*

PLANNED GIVING PROGRAM: For those interested in supporting the Society long term, planned giving allows individuals to contribute through their estate, whether through a will, life insurance policy, trust, or other legacy gifts. This provides sustained support to the organization for years to come. Contact our office at info@mpssociety.org to learn more.

BECOME A VOLUNTEER OR ADVOCATE: While volunteering doesn't directly raise money, your time and efforts directly support the Society's ability to host successful fundraising events. Volunteering for events, assisting with outreach, or advocating for MPS and ML awareness can help drive successful fundraising initiatives.

DONOR-ADVISED FUND (DAF): This allows you to make a meaningful contribution that supports research, families, and advocacy for those impacted by MPS and ML. By recommending a grant from your DAF, you can maximize your tax benefits while helping to advance the Society's mission to improve lives and find a cure. Your generous support through a DAF provides a flexible and efficient way to make a lasting impact on the MPS community.

DAF
DONOR ADVISED
FUND

* *Gifts can be applied to the Society's general operating purposes or restricted to one of our research, family support, or legislative programs.*

Each of these methods help raise crucial funds and increase awareness for MPS and ML. Additionally, by fostering relationships with donors, partners, and the community, you can help sustain the Society's long-term goals of research, family support, and advocacy.

For more information, contact Wendy Spaulding at 919.806.0101 or wendy@mpssociety.org.

On behalf of the National MPS Society, I am writing to express our deepest gratitude for your extraordinary generosity and support during our 2024 Annual Fund Campaign. Thanks to you and countless others who believe in our mission, we have achieved an unprecedented level of success this year in our pursuit of a world free of MPS/ML.

Your contribution is a vital part of our collective effort to end MPS, and we are thrilled to share that the campaign has surpassed its fundraising goals. Your commitment to our cause ensures that we can continue to fund groundbreaking research, provide crucial services for those living with MPS, and advocate for policy changes that improve the quality of life for all those affected by the disease.

The impact of your gift cannot be overstated. In 2024, we have made tremendous strides toward discovering better treatments and, ultimately, a cure. The funds raised will allow us to support ongoing research initiatives that are bringing us closer to understanding the complexities of MPS and developing effective therapies. Moreover, your support allows us to offer a range of services that empower people with MPS to live their fullest lives—whether through educational programs, support groups, or financial assistance.

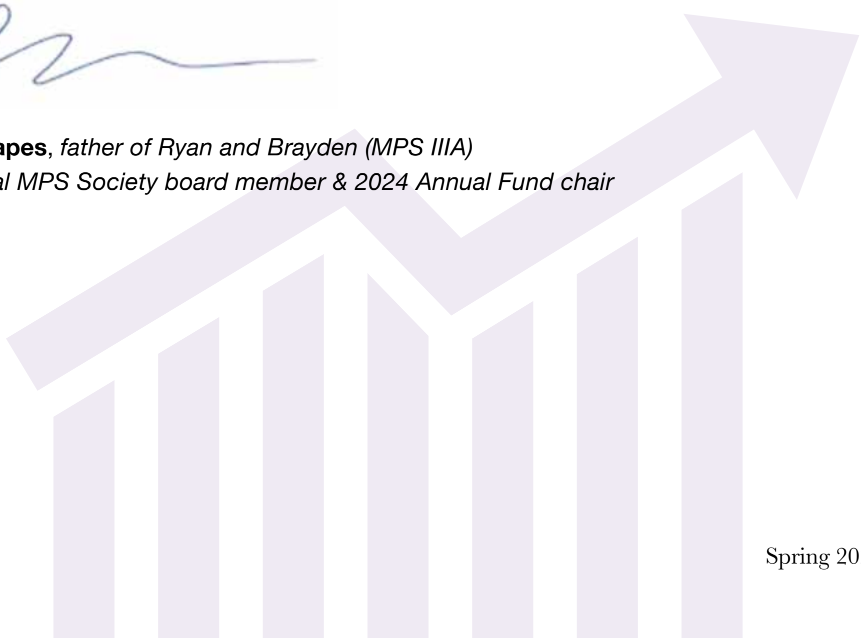
But the success of this campaign isn't just about the dollars raised—it's about the relationships, the shared vision, and the community we are building together. Your donation exemplifies a commitment to a brighter, healthier future, and we are truly honored to have you as part of the National MPS Society family. Together, we are showing those affected by MPS that they are not alone and that we will never stop fighting for a cure.

As we reflect on the success of this campaign, we are reminded that the fight against MPS is not over, and that there is still much to be done. We hope that you will continue to stand with us as we move forward into 2025 and beyond, working relentlessly to achieve our mission. Your partnership gives us the strength to keep pushing forward, to keep innovating, and to keep advocating for those whose lives are touched by MPS, ML, and other related diseases.

Thank you once again for your incredible contribution. With your continued support, we are confident that a world without MPS is within our reach.

With deepest appreciation,

Carl Kapes, *father of Ryan and Brayden (MPS IIIA)*
National MPS Society board member & 2024 Annual Fund chair



FAMILY SUPPORT

Your journey with a rare disease is unique. As we walk this path with families and adults nationwide, we renew our commitment to provide exceptional, comprehensive care and support. Listening to our community, we continue to uncover ways to support those who may be underserved, have limited access to resources, or face challenges beyond their MPS or ML diagnosis.

This year, we are excited to offer opportunities for families to connect and build relationships through our Crossing Paths events. These gatherings provide a welcoming space to meet others, share experiences, and learn more about the resources available through the National MPS Society. These gatherings are always free, family friendly, and include food and fun activities. Above all, these events are an opportunity to meet and talk with families and individuals who live close to you. We encourage you to keep an eye on your email for invitations to events in your area, and please spread the word to others in the MPS and ML community who may benefit from joining us. Don't forget, for those families who may be new to our community, we also offer the Pathways Program for the newly diagnosed and/or their caregivers.

Later this year, we are looking forward to hosting the CYCLE (Celebrating Your Cherished Life Experiences) retreat for bereaved families. This special event provides a supportive environment for reflection, connection, and healing and is guided by experienced professionals. Information will be provided as it becomes available, but in the meantime please reach out if you are interested in helping with programs like this that support families who have lost someone to MPS or ML.

Additionally, we invite all members to our 39th Annual Family and Scientific Conference, which will be held in Denver, CO, Aug. 7–9, 2025. More information and registration details will be available soon.

In case you missed it, we are now accepting Family Support Program applications for 2025 on our website, **mpssociety.org**. Visit the "Support" section for more information and application details. Continuing education scholarship applications are open through mid-March for those enrolled in higher education programs.

Finally, we are always looking for new voices to join our committees. Please contact us if you are interested in sharing your talents and making a difference. Do not hesitate to email me at leslie@mpssociety.org for resources, support, or connections.

As the year unfolds, I hope you find joy in our connections and the progress we make as a community. Thank you for being an invaluable part of the National MPS Society!

Leslie Urdaneta, *director of family support and Pathways*

Family Support Committee:

Tamara Cullere, *chair*
Ginger Beverly
Carol Bryant
Patricia Espinal
Amy Fadden
Bethany Greene
Angela Guajardo
Amy Holland
Steve Holland
Scott Hopkins
Jerry Kanney
Terri Klein
Katherine Klemm
Kris Klenke
Sheri Lueb
Jason Madison
Amber Mongan
Carolina Montoya
Melissa Thompson
Leslie Urdaneta
Rebecca Walker
Amy White

Follow Us on Social Media!

@NationalMPSSociety on Facebook

@mpssociety on Instagram

National MPS Society on LinkedIn

Family Support Programs

mpssociety.org/support

EXTENDED HOSPITALIZATION RELIEF

The Extended Hospitalization Relief grant provides financial support to an individual with MPS or ML who has experienced inpatient hospitalization for a minimum of 30 days.

CONTINUING EDUCATION SCHOLARSHIPS

The Continuing Education Scholarship Program awards post-secondary education scholarships for individuals with MPS or ML and their siblings, children, and parents. Scholarships are awarded to full-time students at $1,000 each and $500 for part-time students. The Jeffrey Bardsley scholarship is available to individuals diagnosed with MPS or ML and awards up to $5,000. The Klenke-Kirch Sibling Scholarship awards an additional $500 to siblings who assist with programs to support sibling efforts. Scholarships are paid directly to the school or institution. Applications are open now for the 2025–2026 academic year.

FAMILY ASSISTANCE PROGRAM

The Family Assistance Program offers grants of up to $3,000 per individual with MPS or ML per 12-month period to help fund special equipment or medical aids not covered by insurance. Members must submit an insurance denial and medical order as part of the application process. Families and individuals are asked to cover 10% of the item's cost. Grants are awarded directly to a vendor.

MEDICAL TRAVEL ASSISTANCE PROGRAM

The Medical Travel Assistance Program assists families and individuals who need to travel to consult with medical professionals knowledgeable about MPS and ML by reimbursing travel expenses for appointments 125 or more miles away from home. This program may reimburse up to $550 for travel and lodging expenses per individual with MPS or ML per 12-month period. Appointments must be approved in advance to ensure adequate funding is available for reimbursement.

JOURNEY ASSISTANCE PROGRAM

Journey Assistance Program grants are available to help purchase items needed to make life easier or more enjoyable. Items covered under this program are often what families pay out-of-pocket. Grants through this program will be awarded for 40% of the total purchase price, not to exceed $500 per individual with MPS or ML. Grants cannot exceed $500 in 12 months per individual.

EXTRAORDINARY EXPERIENCES

Extraordinary Experiences grants are available to individuals diagnosed with MPS or ML to provide a life-enriching extraordinary experience. This program is for individuals age 13 and older to help achieve a personal goal. Grants can be used to support a special trip for education purposes or personal growth, such as a camp, program, or other sponsored activity that would offer the individual a chance to enhance his or her life. The focus of this program is to provide an experience that will build peer relationships, increase interactions with others, and provide an enriching opportunity for an individual. It does not fund wish-granting requests. Grants are available for up to $1,000.

BEREAVEMENT EXPENSE PROGRAM

Assistance with final expenses for an individual with MPS or ML is available through the Bereavement Expense Program.

REGIONAL SOCIAL EVENTS

Families interested in hosting a gathering in their area can request up to $750 in funding. Regional Social Events are open to anyone interested in attending, and the Society will provide support by marketing and sending information out to members.

Contact Leslie Urdaneta at 919.806.0101 or leslie@mpssociety.org with questions or more information about Family Support programs.

FAMILY SUPPORT GRANT RECIPIENTS

FAMILY ASSISTANCE PROGRAM

ZULIEKA-DANIELLA (MPS IIIA)

"The electric transfer system we acquired through the Family Assistance Program will help me move Zulieka-Daniella and transfer her from bed to chair and wheelchair. It will also allow me to transfer her into a vehicle so that I am able to continue taking her to doctors' appointments, visit family, and take her on outings. The float will allow her to have physical movement of her legs and therapy while in the water and be able to enjoy time outside in the sun. I believe that with this electric chair lift, we will both benefit. I won't be at risk for hurting my back and she will be able to be positioned in different areas of the house. I will be able to transfer her in and out of the vehicle so that we can be able to travel more."

— **Carmen Camacho-Mora**, *mother of Zulieka-Daniella (MPS IIIA)*

JOURNEY ASSISTANCE PROGRAM

BARCELLOS FAMILY

"Malachi (age 7) received an iPad through the Journey Assistance Program to watch shows on while he has his infusions and countless other doctors' appointments. Our family must relocate to a new city and will be away from home for at least a month. This iPad will be a little bright spot in all of that, something special just for him."

— **Callie Barcellos**, *mother of Malachi (MPS II)*

MEDICAL TRAVEL ASSISTANCE PROGRAM

JOAN AND WAYNE (MPS II) EPPEHIMER

"Living in Jamestown, NY, a small city in a rural area, we must travel at least 50 miles for most of our specialists. Wayne has never gone to a geneticist because there are none within 100 miles. Last spring we discovered not only a geneticist, but a rare disease clinic at UPMC in Pittsburgh, PA. The clinic is three hours away and the visit would be another three hours. Wayne did not have the stamina to make the round trip all in one day, so the visit required an overnight stay.

We are very grateful for the Medical Travel Assistance Program which enabled us to make this trip. Not only was the visit to the clinic helpful, but Wayne was also asked to speak about MPS at an upcoming seminar at the University of Pittsburgh. He deferred the opportunity to his nephew, Jason Madison, who did an excellent job helping the participants learn about MPS and the National MPS Society. Thank you so much for making this trip possible for us."

— **Joan Eppehimer**, *wife of Wayne (MPS II)*

Our incredible, loving son Sam lost his 28-year battle with MPS I on Oct. 9, 2024, from heart and lung complications. Despite his 38 surgeries and severe joint pain throughout the years, Sam never complained. He always kept a positive attitude and did not allow his disease to define him. What *did* define him was the way he embraced life with extreme courage, grace, and hope. Always full of joy, he lived life to the fullest and accomplished many of his goals during his 28 years.

After receiving his associate degree in English from Manchester Community College, along with the Inspiration Award, he went on to Southern New Hampshire University (SNHU) where he majored in communications. He loved public speaking and had done a lot of it from a very young age, speaking at Make-A-Wish Foundation events and Genesis Foundation fundraisers. Sam graduated summa cum laude from SNHU in 2022; one of the proudest moments of his life, and ours. The night before graduation he was awarded "Outstanding Student" in his major and was chosen to give the speech at the Honors Convocation Ceremony. Sam was a member of the Student Government and CAPE, a student run organization committed to enriching campus life at SNHU. The only time he ever missed a meeting for either organization was when he had his aortic valve replacement in 2020 and nearly lost his life. Since we were told when he was a baby that he may never be able to read, his academic achievements were even more important to him. Of course we are proud of them, but we know his most important achievement was the way he lived every day of his life, being kind and caring to others, and lighting up a room with his friendly, humorous personality.

Sam was loved by all who knew him, and his kindness, thoughtfulness, and the way he deeply cared for everyone in his life drew people to him. And boy, was he full of life! He always had your back if you were lucky enough to be in his life and he was the most forgiving person we have ever known. During his long stays at Boston Children's Hospital, he had more concern for the babies he heard crying than he did for himself. He was always cooperative and considerate to every nurse and doctor who entered his room, whether it was 2:00 in the afternoon or 2:00 in the morning and they had to wake him up.

I believe there are people who truly touch the lives of everyone they meet; Sam was one of those people, as is the case with many afflicted with MPS.

Sam had a bone marrow transplant in Minneapolis, MN, shortly after his first birthday. His 6-year-old selfless sister Jenna was a perfect match, and willing to do anything to help her baby brother.

> *I believe there are people who truly touch the lives of everyone they meet...*

As lucky as we were that he finally got diagnosed after many months of us pleading that something wasn't right, things are so much better today thanks to newborn screening, enzyme replacement therapy, and the fact that full-body radiation is no longer used as part of the bone marrow transplant protocol.

Sam was passionate about newborn screening and traveled to Washington, DC, several times with me and other members of the National MPS Society to advocate for it. We both spoke at the board meeting the night MPS I was being voted on to be added to the newborn screening panel in New Hampshire. The vote was unanimous and he was very excited when it was officially added a few months later. He knew that families of babies born with MPS I would now find out shortly after birth and treatment could start immediately, unlike the long and difficult diagnosis road that many of us have had and continue to have in states that do not have MPS on their newborn screening panel. He understood these babies would have so much more hope for a brighter future.

Sam was the biggest movie enthusiast. He knew who directed just about every movie, and every movie a particular actor on the screen had been in before. Playing movie trivia with him was so unfair, because he truly knew it all and no one else had a chance of winning. The Oscars were his Super Bowl! He saw many movies throughout the year and posted superbly written movie reviews on his social media accounts.

Sam had perfected his motivational speech that focused on the importance of perseverance, and was asked to be the keynote speaker at one of the major Make-A-Wish Foundation fundraising luncheons last year, where he received a standing ovation from about 250 people. He had so much more to give the world, and has changed our lives forever for the better. Keith, Jenna, and I have always been in awe of how he handled all the challenges that MPS threw his way. The way he walked on campus with so much confidence while everyone towered over him, and the way he was so willing to share his story with anyone who wanted to hear it. Keith and I feel so blessed and thankful that God chose us to be Sam's parents, despite the heartbreak of losing him. We are better people because Sam was part of our family, and always will be.

Heidi Caswell, *mother of Sam (MPS I)*

Bereavement Support

The National MPS Society supports families in times of loss and throughout the bereavement and grief process. We understand the importance of personal connection and creating opportunities to share memories and receive direct support during this time. Our **White Rose Program** provides booklets, resources, and mementos and our **Bereavement Expense Program** offers financial assistance. These programs are available in memory of anyone with MPS or ML. Our team members are also available to speak with you and make additional connections for grief support as needed. Call 919.806.0101 or email leslie@mpssociety.org for assistance or more information about our bereavement programs.

IN MEMORIAM

The entire MPS and ML community lifts up family members and friends of those listed here and others remembered in our hearts. We travel with you through grief and recognize this journey's beauty and joyful memories. We honor and remember the lives of those who have passed away.

Jon Bresnahan, MPS II
12/12/80–8/26/24

Sam Caswell, MPS I
4/5/96–10/9/24

Adyan Ershad, MPS I and MPS II
8/11/08–11/18/24

Aysel Faqery, MPS I
11/28/23–1/4/25

Iverie Kelley, MPS II
4/29/09–9/11/24

Jaxon Ray, MPS IIIA
3/31/08–8/25/24

John Thornton, MPS IIIA
12/9/02–8/25/24

Nicholas Trombino, MPS IIIB
7/13/01–8/3/24

Jill Underwood, MPS I
11/3/88–8/15/24

Remembrance Committee:

Kris Klenke, *chair*
Laura Catanzarite
Tom Catanzarite
Monica Green
Steve Holland
Larry Kirch
Terri Klein
Noni Langford
Dorothy Mask
Robin Piefer
Leslie Urdaneta
Nancy Wain
Amy White

ANGELS AMONG US

Each year, we remember individuals with MPS or ML who have passed away but remain in our thoughts and hearts. We invite families and loved ones to share their memories with others.

Through the *Angels Among Us* publication, we encourage you to join the community in lifting up, remembering, and honoring their lives as you read their names and reflect upon their memories.

To view the 2024 edition or to submit for 2025, visit **mpssociety.org/angels-among-us**. Submissions for the next edition are due by April 1, 2025.

ADULT RESOURCE COMMITTEE

The Adult Resource Committee (ARC) was formed to advocate for the unique needs of adults with MPS or ML, and provide opportunities for connection and support. The committee is composed of adults with one of these diagnoses who lead fulfilling and active lives with varied interests, while taking time to give back to their community. ARC meets each month on Zoom to plan activities and events, and advocate for resources that will benefit adults and adolescents transitioning into adulthood.

Activities include quarterly social hours and virtual events, support sessions, and connecting on social media, as well as gathering in person at conferences and events. The committee works to brainstorm awareness campaigns for events such as Rare Disease Day and MPS Awareness Day, and for the Society as a whole. One of ARC's main goals is to show that adults with MPS or ML lead fulfilling lives with a rare condition.

Email arc@mpssociety.org if you are interested in joining the committee, to provide input, or with questions. Any adult with MPS or ML (ages 18+) may join ARC. We encourage you to reach out!

Adult Resource Committee:

Autumn Mortensen, *chair*
Isabel Bueso
Patricia Espinal
Kendra Gottsleben
Steve Holland
Carlton Hutcheson
Jenny Klein
Jason Madison
Kyle Underwood
Sheri Wise
Jocelyn Wong
Fanny Zambrano

SAVE THE DATE

Mark your calendars for the 2025 virtual socials hosted by the Adult Resource Committee (ARC). These events are open to adults (age 16 or older) who have MPS or ML.

- **March 28**
- **June 20**
- **Sept. 12**
- **Dec. 12**

Registration details will be shared via email with members and on our social media channels as each event approaches.

We look forward to seeing you there!

SUPPORT THE SOCIETY WITH LOGO WEAR

cafepress.com/rareawareshop

Support the Adult Resource Committee by ordering from the Rare Aware Shop. Items are for anyone in the rare disease community and proceeds go directly to programs for adults diagnosed with MPS or ML. Designs in the Rare Aware Shop were created by ARC members, and proceeds directly benefit programs for adults with MPS or ML.

Rare Disease Day—Advocating for Change!

Rare Disease Day, Feb. 28, saw us unite with the global community to shine a light on the 300 million people worldwide living with rare diseases, including MPS and ML. This day is about raising awareness, empowering our community, and ensuring that rare diseases like MPS and ML receive the attention they deserve from policymakers, researchers, and the public.

Advocacy plays a critical role in driving progress for the rare disease community. By raising awareness and speaking up, we help secure funding for research, push for equitable access to treatments, and ensure that policies reflect the urgent needs of those affected by rare diseases. Every voice matters, and together, we're building momentum toward a brighter future—one where cures for MPS, ML, and other rare diseases are within reach.

MPS Society advocates traveled to Washington, DC, to share their stories, making a powerful impact by speaking directly with representatives about the challenges and opportunities facing the rare disease community.

Thank you for your commitment to the MPS and ML community. Together, we are stronger, louder, and unstoppable.

RAREDISEASEDAY.ORG

Sharing your stories, experiences, and support makes a difference in the lives of those with MPS and ML today, and those who will be diagnosed in the future. Every advocate helps further our mission to find a cure, and to support and advocate for MPS and ML causes. If you are interested in participating in future advocacy efforts, visit **mpssociety.org/advocate**.

Advocacy Committee:

Stephanie Cozine, *co-chair*
Carl Kapes, *co-chair*
John Barbour
Amy Barkley
Eileen Basquill
Claudina Bonetti
Stephanie Bozarth
Madeline Casper
Mary Cavanagh
Hannah Clark
Kayla DelBoverlando
Nicholas DiTommaso
Christine Dwyer
N. Matthew Ellinwood
Wayne and Joan Eppehimer
Angela Guajardo
Kimber Heiling
Annie and Austin Henry
Michelle Hill
Elizabeth Hoff
Andrew and Katey Hoffman
Ashley and Cody Holm
Lynn Hopkins
Mike Hu
Tanya Kimbrel
Terri Klein
Noni Langford
Kristin Mattheson
Chrissie McKaig
Carmen Ordaz
Mercedes Ramirez Johnson
Suzanne and Ethan Ransom
Steve Smith
Leanne Spring
Kristin Stockin
Rebecca Stoffer
Elizabeth Stoltz
Julie Sykes
Brooke Thomas
Cara Thomas
Chris Tippett
Leslie Urdaneta
Ann Wynegar

RESOURCES

Newborn Screening Resources

Baby's First Test

babysfirsttest.org

The Baby's First Test website provides current educational and family support and services information, materials, and resources about newborn screening at the local, state, and national levels. This resource is dedicated to educating parents, family members, health professionals, industry representatives, and other members of the public about the newborn screening system. The site also provides many ways for people to connect and share their viewpoints and questions about the newborn screening system.

Expecting Health, Navigate Newborn Screening Modules

https://expectinghealth.myabsorb.com

To help families navigate their child's health during a critical period of development, Expecting Health created free online educational modules. Families can find answers to questions like, What is the process of screening? What do newborn screening results mean? What should I ask my healthcare provider about newborn screening? What are the state and federal laws around screening?

Association of Public Health Laboratories, NewSTEPs

newsteps.org

The Newborn Screening Technical assistance and Evaluation Program (NewSTEPs) is a national newborn screening resource center that provides data, technical assistance, and training to newborn screening programs and assists states with quality improvement initiatives. It includes resources and profiles of state- and condition-specific screening. If you are interested in learning more about state lab newborn screening programs, this is a helpful resource.

Screen Baby Screen: Perspectives on Newborn Screening

youtube.com/watch?v=cCQScP9zqGQ

This webinar is a great resource for understanding why each state has its own individual screening program and why early detection of a disease is crucial. It addresses intervention and shares how newborn screening is important for babies to achieve their full potential.

EveryLife Foundation

everylifefoundation.org

The EveryLife Foundation has been providing tools for newborn screening advocacy for more than 10 years. From Capitol Hill advocacy, bootcamp webinars, downloadable toolkits, and crucial policy action alerts, this is an excellent resource to help you become a strong advocate for your family.

National Family Caregivers Association

caregiveraction.org

As a care provider, it is easy to become so focused on the person you are caring for that you forget to take care of yourself. The National Family Caregivers Association (NFCA) educates, supports, and empowers individuals who care for a loved one with an illness or disability. From tips and how-to guides to a story bank and pen pal program, the NFCA caregiver resource center provides a wealth of resources to support you as a caregiver.

MPS I

aldurazyme.com

This website, developed by Genzyme, provides parents and patients with information on Aldurazyme®, an enzyme replacement therapy for MPS I. The site includes a link to ask questions regarding MPS I or anything else related to treatment. The site also can reach healthcare professionals at Genzyme who will respond to your query in a timely manner.

MPS IVA

morquiosity.com
This website offers a variety of information for MPS IVA patients, including a description of the disease, cause, early signs, symptoms, management, and tests and diagnosis. Learn more about the people who make up the Morquio A community, discover helpful online resources, and create a list of questions to bring to your next doctor's appointment.

morquioanswers.com
This resource for healthcare professionals provides information on pathology, systemic effects, natural history, management, and resources and publications.

MPS VI

Naglazyme.com

This site provides expanded content about MPS VI, its diagnosis, and treatment with Naglazyme® (galsulfase) enzyme replacement therapy.

National Parks Access Pass

nps.gov/subjects/accessibility/access-pass.htm

Individuals with MPS or ML are eligible for the Access Pass, part of the America the Beautiful—National Parks and Federal Recreational Lands Pass Series. This grants free access to the National Parks. Applicants must provide proof of residency or citizenship and documentation of disability.

Hearing Aid Funding Assistance

sertoma.org
The primary focus of international service organization Sertoma is to assist the more than 50 million people with hearing health issues and educate the public on the issues surrounding hearing health. The organization offers a hearing aid recycling program, a college scholarship program for young adults with hearing loss, as well as various community support programs.

starkeyhearingfoundation.org
Hear Now is a national non-profit program sponsored by The Starkey Hearing Foundation that provides hearing aids for people with limited income.

Legal and Assistive Technology Funding Assistance

nls.org

Neighborhood Legal Services, Inc. (NLS) provides free legal services to persons with low income and persons with disabilities. It also provides a wide range of technical assistance and support services. NLS's National Assistive Technology Project supports advocacy efforts of attorneys, advocates, service agencies, persons with disabilities, and their families as they seek funding for assistive technology services and devices.

ERT Resources

Syndrome Type	Enzyme Replacement Therapy	Website
MPS I	Aldurazyme® (laronidase)	aldurazyme.com
MPS II	Elaprase® (idursulfase)	elaprase.com
MPS IVA	Vimizim® (elosulfase alfa)	vimizim.com
MPS VI	Naglazyme® (galsufase)	naglazyme.com
MPS VII	Mepsevii® (vestronidase alfa)	ultragenyx.com/medicines/mepsevii

Transitioning to Adulthood

Life is full of transitions. An important transition for youth with special healthcare needs and their families is the transition to adulthood. To make this process smooth, begin early. Create a statement of needed transition services, addressing areas such as instruction, employment, community experiences, and adult living. For more information, check out these transition resources:

- Healthcare transition—resources and information focusing on a young adult's transition from pediatric to adult healthcare (**gottransition.org**).
- PACER Center—resources for parents of children with special needs, and extensive information for transitions and creating transitioning plans (**pacer.org**).

Furniture for Little People

lpbigdesign.com

Little people, BIG DESIGN is designer furniture for short people, and people with dwarfism or short stature. Created by Tracy Steele Designs, this furniture meets the ergonomic challenges of little people without sacrificing good design. Little people, BIG DESIGN furniture features:

- short seat depth and straight backs to help support the back and neck
- low seat height so legs rest comfortably on the ground
- high arms to rest on while reading
- solidly built to support the weight of adults
- steps for easy accessibility
- adjustable for the height of guests

Parent Educational Advocacy Training Center

peatc.org

The Parent Educational Advocacy Training Center (PEATC) serves families and professionals of children with disabilities in the Commonwealth of Virginia. PEATC promotes respectful, collaborative partnerships between parents, schools, professionals, and the community that increase the possibilities of success for children with disabilities. PEATC's mission is to build positive futures for Virginia's children by working collaboratively with families, schools, and communities to improve opportunities for excellence in education and success in school and community life.

Bereavement Resources

Bereavedparentsusa.org provides support groups and information for family members after the loss of a child. BPUSA hosts an annual family conference for support.

Compassionatefriends.org provides support groups and information for family members after the loss of a child. Information regarding state and local support is available.

Courageousparentsnetwork.org was created for and by parents, and provides support, information, and knowledge based around issues of parenting and caring for children with illnesses, as well as bereavement and loss support.

HealthTalker—An MPS II Online Community

hunterpatients.com

The Hunter Parents Community is an online community sponsored by Shire. The website is an exclusive forum for primary caregivers of children with MPS II to connect and share their personal stories and experiences, as well as give and receive tips for facing everyday challenges. In addition to strengthening the network of MPS II parents, the community aims to increase awareness about MPS II by encouraging primary caregivers to talk about Hunter syndrome with members of their community and to use their personal experience to help others understand this life-altering condition. The Hunter Parents Community is not a forum to discuss medical, product, or treatment options, but rather allows MPS II parents to support and learn from each other, and to raise awareness.

TITUS BARRETT-WEBER (MPS I)

Miracle Flights

miracleflights.org

This travel resource provides free flights for low-income children and their families to distant, specialized care and second opinions.

Wrightslaw

wrightslaw.com

Wrightslaw offers information about education and special education law, and supports families through advocacy for children with disabilities.

Takeda OnePath®

onepath.com

Takeda provides support for eligible patients in the United States. Through the OnePath program, Takeda assists with access to treatment and provides patient support managers.

Ultragenyx UltraCare Program

ultracaresupport.com

The UltraCare program demonstrates the commitment of Ultragenyx to support patients with rare diseases, and can help with understanding coverage, determining access to assistance programs, and providing information about patient support programs for patients with MPS VII. Visit the website above or call 1.888.756.8657.

Resources for Siblings

siblingleadership.org
The mission of the Sibling Leadership Network is to provide siblings of individuals with disabilities the information, support, and tools to advocate for their brothers and sisters, and to promote the issues important to them and their entire families.

siblingsupport.org
SibNet, the first and largest online community for adult siblings from around the world, is co-sponsored by the Sibling Support Project and the Sibling Leadership Network.

theblairconnection.org
This network for siblings of children with terminal illnesses allows opportunity to share stories and provides support.

siblingswithamission.org
Siblings with a Mission seeks to provide support internationally, raise awareness, and inspire siblings to make a difference.

Electric Scooters for Little People

assistinglittlepeople.com

Assisting Little People offers the GoGo Elite electric scooter for little people. With a shorter seat height, crutch holder and extra-large rear basket, the GoGo Elite provides a comfortable solution for those with a smaller stature.

NeedyMeds

needymeds.com

NeedyMeds is a non-profit resource devoted to making information about assistance programs available to low-income patients and their advocates at no cost. Databases such as patient assistance programs, disease-based assistance, free and low-cost clinics, government programs, special needs camps, and other types of assistance programs are just some of the resources available.

Support Services for Patients and Families through CareConnectPSS™

careconnectpss.com

Sanofi offers case management services to people living with genetic diseases, offering access to a dedicated team of professionals who provide disease education and help address needs, including assistance with health insurance issues. A Sanofi team works together to help resolve any issues that may arise and provides personalized support when you need it. Call 1.800.745.4447, option 3, or visit the website above to connect with a case manager online.

Frank Mobility Systems

frankmobility.com

Wheelchairs differ in many ways. Some are made for persons in need of intensive care, some are designed for very active persons using the wheelchair all day long. In order to cover the individual needs of wheelchair occupants, Frank Mobility Systems, Inc. offers a variety of add-on drives and portable wheelchair motors that enhance the benefits of a manual wheelchair. All of these power add-on drives can be retrofitted to an existing wheelchair with a special bracket. The wheelchair does not need to be modified and maintains its characteristics, such as portability. Frank Mobility also offers solutions for climbing stairs without renovations being made to the home, and recreational products such as the Duet Wheelchair Bicycle Tandem.

College Resources for Students with Disabilities

bestcolleges.com/resources/disabled-students

Prospective college students with disabilities find that many campuses are equipped with offices and services that address accessibility, accommodation, and assistive technology for a diverse range of needs. Student services offices and disability coordinators at many colleges work to make campuses inclusive environments through specialized advocacy, support, and academic services. The increased visibility of these resources makes college a very compelling option for people with disabilities. In addition to campus-based resources, students with disabilities also are protected by state, federal, and local laws prohibiting discrimination and requiring equal levels of access to academic services, environments, and resources. This guide explains the legal rights of students with disabilities—both physical and learning—and the campus resources that can provide assistive services and tools. Additionally, a number of sites, apps, and software resources are listed that are designed to aid students with specific types of disabilities, be they physical impairments or learning disabilities.

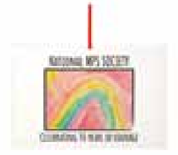
Cord Blood Banking

viacord.com/cord-banking/sibling-connection

ViaCord's Sibling Connection program is available for families who have a child with MPS or ML and are expecting another child. ViaCord offers no-cost cord blood collection, processing, and lifetime storage for full siblings (same biological parents) of a child with an eligible diagnosis.

National MPS Society Shop

When you shop with the National MPS Society, you’re making a meaningful impact. Our collection of apparel and accessories spreads awareness and fuels hope for the future. Scan the QR code to shop now, or visit **www.cafepress.com/shop/NationalMPSSocietyShop**.



2025 BOARD OF DIRECTORS

2024 Donors

Quarters 3 and 4

General Donations

110% Nutrition
AbbVie Employee Engagement Fund
Accenture LLP*
Amber Adams
April Adams*
Katherine Aguilar*
Kenneth and Donna Ahles*
Vic Akemann
Gregg Allison
Donald and Julie Ames*
Daniel Amey
Andersen Corporation
Amy Anderson*
Bill and Mary Andrews
Cindy and Mark Andrews*
Severin Andrieu-Delille
Kim Angel
Apella Capital, LLC
ARC fundraiser
Betty and Barney Arceneaux
Freddy Argueta
Sharon and David Armendariz
Kirsten Arndt-Hutson*
Cybill and Bruce Aros-Pearson*
Ashfield Meeting & Events, Ltd.
Banc of California
Baraboo Growth, LLC
Len and Barbara Barcousky*
Emily Barrett
Sandra Barstow*
Rita and Mike Basom
Melanie Baudille
Alice and Ron Beam*
Stacey Beckhardt*
Patrick and Susan Bell*
Belleville Township High School
Benevity UK
John and Maria Bereschak
Lisa Berry
Ginger Beverly
BioMarin
Jamie Blackmon*
Haley Blackwell
Cory and Jason Blain
Roger Blain
Michael Blatherwick
Jim Blum
Doretta Boden
Mike and Grace Bodura Jr.*
Thea Bogenschutz*
Theresa Bonapace
Bonfire
Joseph Bonville
Ava Boyle*
Austin and Stepanie Bozarth
Marsha Bozarth*
BPO of Elks Lodge 2235*
Bonner Brackeen
Jason and Wendy Brackeen
Gretchen Brainard*
Karen Branda*
Mary Beth Brennan
Kern Briggs
Daniel and Debra Brockman*
Nancy Brockman
Ashley Brooks*
Lauryn and Matt Brown
Emily Brutko
Carol and Spencer Bryant
Susan and Dennis Burke
John Burnett
Tony and Claudia Busse*
Susan Byers*
Mary and Matthew Byrnes*
CafePress
Joshua Call
Dwain Camp
Katie Campbell
Richard Campbell*
Brook Carlsen
Alexis Calle Casablanca
Luke Cataldo
Gregory and Angela Cathey
Mary Cavanagh
Liam and Mary Cavanagh*
Shannon and Emma Cavanagh*
Donald Ceplina
Elle Champion*
Lewis and Ann Chapman*
Sandy Chapman*
Charities Aid Foundation of America
Bin Chen
Amy and Dan Cherrstrom*
Steve and Karole Chesser
Daniel and Sharon Chisholm
Ashley Chrisinger
Michael Christophersen
CHS, Inc. c/o YourCause
Thomas and Melissa Ciuffini
Kirk and Ruth Clancy
Hannah and Allan Clark
Jamie and Chad Clark
Elizabeth Clarke
Robert Clarke
Charles Cleveland
Jo Coan*
Justin Colagan
James and Martha Colby
Mitchell Coleman
Robert and Kathryn Coleman*
Mary Jo and Larry Collet
Joel Comer*
Donna Connely
Carol Conti
Angela and Jason Cook*
Sharon and William Cook
William and Margaret Cook, MD
Krystal Cooley
Will Cooper Jr.

WALTER NORDGREN (MPS I) AND HIS SISTER CAROL

Cord for Life
Rebecca Cornell
Costco Wholesale Corp.
Maureen Cote
Stephanie and Shawn Cozine
Daniel Cozzolino
Robert Cripe
Daryl Crompton
David and Kathryn Croson
Jason and Tamara Cullere
Edward and Ann Cummiskey*
Marie Cundiff
Peter and Kimberly Cunneen
Brendan Cunningham
Cami Cuomo*
Ryan and Kelly Curry
Susan Curry
Stacey Curtiss
James and Mary Olson, DDS*
Pavan Dama
Susan Danielson*
Jeanne Dant
Paul and Cara David
Kathryn and Tim Davidson*
Gerald Davis
Louis Debarberie
John Defilippis*
Patricia Delaney*
Jeremy Demarco
Denali Therapeutics, Inc.
Jeff and Anne Denneen
Patricia Dickson
Doug and Diane Diehle
Patricia Diluzio*
Disciplined Growth Investors, Inc.
Disney Conference
Kathleen and Albert DiStasio
Elizabeth Djukic
Jim and Michelle Dodson*
Daniel Dojillo
Brian and Jennifer Dolan
Jin Dong
Rebecca Dopheide
Amy and Seth Downen
Ann Doyon
Heather Drucker
Devika Del Duca
Duke Energy Foundation
Terry and Irene-Mary Dunbar
Carrie Dunn and Melissa Kraus
Dutch's Daughter, Inc.*
Eugenie Ebert
Julie Eisengart
Michael and Theresa Elgin*
Carla Ellard
Charles Ellard
Carmona Ellese
Mark Elmer*
Tara and Jack Elston*
Nathalie and Clayton English
Thomas Ennis
Enterprise Rent-A-Car
Wayne and Joan Eppehimer
Lourdes Espinosa*
John Exner*
Samantha Failla
Peter Fan
Tasha and Bruce Farrell
Geraldine Faucett
Erin Fellinger*
John and Wendy Ferguson
Vivian Fernandez
Dawn Ferruggiari
Hildegard and Joseph Filebark*
Brian and Kathleen Finn*
Michael Finn*
Rebecca Finn*
Tim and Tracy Finnegan
Bart Finzel
Evelyn Fisher
Joan Fisher
Bryan Fissell
Tim and Laurie Folsom*
Janet Forde
Brent Forester
Dan Forker
Maria and Steven Foshay*
Foundation for the Carolinas
Betsy and Steve Fowler*
Paul and Martha Frank
Tina Frank
Frontstream (formerly Truist)
Mark and Marie Frost*
Dorothy and Louis Fucito*

continued

** Annual Fund gift*

General Donations, *continued*

Gerald and Luella Gabriel
Jeff Gabriel
Carolyn Galvan
Atul and Surabhi Garg*
Stephen Garrett
Julie and Wayne Garrison
Marcus Garvin*
Kevin Gates
Robin Gaulke-Czarny
Brody Gendreau
Makayla Gendreau
Debra Giles*
Sarah Gillen
Alex Gingrow and Michael Scoggins*
Sharon Glasscock
Wayne and Susan Goeldner*
Dennis and Chris Goggins*
Jenny Golstein
Julie Gragowski
Scott Gralla
Nick Gray*
Lorne and Tamara Green
Mitchel Greenburg
Bethany and Chance Greene
GreenPoint
Coyte and Jilian Greer
Matthew and Lauren Greer
Brad and Suzanne Gregory
Jaci Griffin
Anyssa Guajardo
Luis and Angela Guajardo

GABRIEL (MPS II) AND NIC REESE

Larizza Guerrero
Cheryl and Gordon Guidry*
Gwen Gunn
Kaitlin Haber
Thomas Haber
Hadlei Hale
Audrey Hall
Walsh Hannah
Billy and Sheila D. Hardison*
Deanna and Eldon Hardy*
Yvonne Harman*
Paul and Peggy Harmatz, MD
Ryan Hart
Sharon and Alvin Harvell*
Mark Haskins, VDM, PhD*
Andrea Longston Hau
Andrea Haynes*
Ashley Haywood
Linda and Robert Heard
Hearst Media
Wanda Hedgepeth*
Greg Hendry
Kirk Henne*
Stacie Henry
Eloise and Fred Henry*
Shana Hernandez
Marlys Herring*
Eli Herschthal
Nathan and Leah Hersey
Ryo Higurashi
Alexander Hill
Chris Hill

Kathleen Hillyard*
Robbin and Anita Hodgkins*
John and Bonnie Hoegl*
Frannie Hoffman
Frederick and Kathleen Hoge
David and Susan Holder
Thomas Holder
Denise Holland
Jaymi and Thomas Holland
Peggy Holland
Travis and Alyssa Holland
Claude and Andrea Holliman
Jennie Hong
Scott and Lynn Hopkins
Allan Horton
Sammie Houchen
Catherine and David Huey*
Mike and Joanne Huff
Humana
Jean Hummel*
Tod and Angie Hummert*
Janice Humphrey
Maggie Hupcey*
IBM Employee Services Center
Idex Corporation
John Jamison
Zayd and Muhanad Jawad*
JBMZ Plastering and Stucco
JCR Pharmaceuticals
Brian Jeffries*
Timothy and Jennifer Jennings
Justin Jessee
Saichek Johanne
Julie and William Johnson
Darlene Johnston*
Kevin Joseph and Beth Johnson
Joseph Muenzer MPS Research and Treatment Center
Darshan and Amrita Joshi*
Eric and Amy Kaiser*
Carl Kapes
John and Janet Kappel*

Cathleen Keane
Daniel Kehoe
Kristine Kelly
Richard Kelly
Leslie and Marilyn Kelman*
Peter Kennedy
Gavin Kent
Christopher Kenworthy
Sharon Kinsman
Lawrence and Susan Kirch
Judy Kirschling
Jenny Klein
Terri Klein and Michael Schleter
Michael Knudsen
Dave Koch
Louise Kofron*
Kathryn Koonce
Neil and Terri Korte*
Robert and Jennifer Kozlowski
Cynthia Kraft*
Peter and Joann Krajewski*
Krista Krenz
Steven LaFrance
Dan and Heidi Lambert
David Lampert
Derek and Brianne Land
Donna Larson
John Larson
Erin and Shea Laughlin
Michael Lawrence
Emily Layman*
Daniel and Kelsey Lee
Doug and Angela Lee
Kevin and Robyn Lee
Susie and Glenn Lee*
Mike and Amy Legendre
Lenovo Employees Care Campaign
Douglas and Grace Lessing
Mark Lessing Jr.
Donna Levine
Robin Lewinter
Rebekah Lewis
Liberty Mutual
Joella and Eric Liddle
Grant and Alex Lieberman
Danielle Lillis
Joseph Lilore*
Cruz Limayry

Philippe Lindsay*
Laura Lipps
Roberta Lister
Losing Balls Fore A Cause
Genevieve and Clifton Loomis*
Valerie Lopez*
Molly and Kyle Lorek
Debra Lounsbury
Wes and Jill Lovell
Joyianna Luc
Lameka Lucas
Lysosomal & Rare Disorders Research & Treatment Center, Inc.
Donald MacMillan*
Macy's
Harry and Alice Madison*
Matt and Diane Maguire*
Karl and Lisa Makinen
Mantech International Corp.
Marielle and Jason Marinoff
Bob Marion*
Laura Marquez
Keith and Jennifer Marshall
Corbett and Brooke Martin
Mollie Martinez
Vanessa Martinez
Kailey and William Mascara
Dorothy Mask
Lee Mcana*
Sean McCabe
Devin McCarthy
Cathleen McClosky
Robbie McDonald
McKain Power Systems Consulting, LLC
Judith McKinstry*
William and Karen McNeil*
Chuck McQuillan
Tim McSheehy*
Rachel Meier
Steven Melnick
Rite Melton
Christina Menezes*
Kenneth Menningen
Shane Mericle
Kristen Merigliano
Eric and Vicki Merrell

Chris and Diane Meyerpeter*
Kathleen and Stanley Meyer-Tamaki*
Microsoft
Jennifer Milder*
Tyler Millage*
Beverly Miller*
Janis Miller*
June Miller*
Raymond Miller
Milo's Tea Company*
Ishrat Mohammed
Stacey and Lew Montgomery
Carolina Montoya
David and Jamie Moon
David Moon*
Jonathan Moore
Sarah and David Moore
David and Cheryl Morris
Carmen Mosley
Margaret Moustafa
Paul and Ruth Mulder
Jodie Muller
Brian and Virginia Murphy
Mairead Murphy
Harlan and Sheri Murrell
Michael and Amy Murrell
Stefani Murrell
David and Cathy Musselman
Jon Musselman
Susan Narducci
National Financial Services, LLC*
Nave Newell, Inc.
Colie Neidlinger
Ross and Shawna Nelle*
Christopher Nelson*
Elizabeth Neufeld, PhD*
NextEra Energy
Beverly Nivens*
Anne Novak*
Rita Nunag
Nurre-Pinkley Building Co.
Francis Nuzzo

continued

** Annual Fund gift*

General Donations, *continued*

Sharon O'Connell*
Sidney O'Gorman*
Michael Ogushwitz*
Leonardo and Andrea Ojeda
Jason Okeefe
Kevin Okula
OLAPLEX, Inc.
Mary Oliger*
Bart Olsen
Ashley Olshove
Brigid O'Malley
Michelle Omalley*
Thomas and Barbara O'Malley*
Alan Oman
Glenn and Cara O'Neill
Tom and Joanne O'Neill
Oracle
Orchard Therapeutics
Jason and Christi Ormeroid
James and Mary O'Rourke
Dorothy and Ralph Ostella*
Kim and John Outten
Thomas Owens
Pacific Gas Electric
Carolyn Pannenbacker
Andrea Papa
Karen Paper*
Paragon Medica Limited
Reagan Passant
Melvaree Pate
Thomas and Vickie Patterson*
Christopher Paulicelli
PayPal Giving Fund
Sheila Payne
Laura Pearce
Zachary Pearson
Mark and MaryEllen Pendleton*
Linda and Dave Perry
Janelle Perry*
Matthew and Claudia Peterson*
Eileen Pettit
Melinda Pettit
William Pettit
Kim and Keith Phillips
Dawn Phillips*
Patty Phillips*
Vernon and Patricia Phillips*
Andrew and Robin Piefer*
Marion Pierce*
Pincrossing at the Railroad Street Bar & Grill
Laura Pisani
Cindy and Bill Plunkett*
Lynda Polgreen, MD
Katherine Ponder, MD*
James Popp
Monica Prendergast
Alexander Price*
Protiviti
Kimberly and Billy Pruett
Shane Purcell
Nakeeta Queen
Susan Rackley
Nick and Ann Marie Raddell
Steve and Laurel Radius
John Raidy
Kim Ramsey
Sam and Nancy Ramsey*
Kay Rattan
William and Olivia Ray
Raytheon Technologies
Paul Rector
Autumn and Nic Reese
Jenessa Reid
Dan Remington
REGENXBIO, Inc.
RaeMarie Renna
Keith and Sherri Richbourg
Steven Richtmyer
Patricia and Jim Rigby
Rick Rineer
Ron Rineer
Theresa Ring*
Becky Ritz*
Rita Robertson
Parise Robichaud
Delores Rodriguez*
Maggie Rose
David Rosenthal
Jill Rosenthal*
Linda Rotondaro
Royal Business Bank
Lyssa Rupert
Danielle Rush
Ariel Russ
Thomas Russell
Muzzy Samantha
Lourdes Sanchez
Michelle Sanchez
Monica Sanchez
Sanofi Genzyme
Victor Santoro
Tim Schaffer
Shawn Schatzle
Jeanine Schmidt
Mathias Schmidt*
Mike Schwarz*
Ricardo and Lenora Scorzelli*
Bruce and Lisa Scott
Nicole Scully
Kristy SeBlonka
Sedgwick
Nicole and Rob Seeley*
Joann Sellmeyer*
Ed Selser
Lynn Ann Sembach*
Michael Sendlinger
Richard Sentochnik
Kerry and Josephine Shamaly
Andera Shaughnessy
Adam Shaywitz*
Danielle Signor
David and Rebecca Silkey*
Silicon Valley Community Foundation
Edward Simcox II*
The Siragusa family
Haldri Ann Sjovold*
Lou and Chris Slavik*
Chad and Erin Slone
Sanofi Pumpkin Smash
Stacey and Cory Smith
Mike and Barbara Smith*
Maureen Snider
Jaquelin Solis
Brakeen Solutions
Nicole Sordello
Southland Restaurant Corp.
Hunter Sowers
Michael and Laurie Sparkman
Wendy Spaulding
Jessica Stankard
Brittney Starzee
William Staton Jr.*
Fred Stein
Jeremy Stewart
Jay Stickles
Natasha and Terry Stringer
Studio G Home*
Kevin Sullivan
Denise Sundeen
Jennifer Sutton
Daren Sweeney*
Beverly Sweeny*
Stuart Swiedler and Judy Weiss*
Marlene and Ronald Takakjy*
Takeda Pharmaceuticals
Becky and Robert Tanamachi*
Michelle and Seiji Tanenbaum*
Jack and Patty Taormino*
TASC Total Admin Service Corp. for CFC Distribution
Charlotte Tate and Blair Euverard
Susan Taylor*
The Anne and Edgar Lackner Charitable Foundation*
The Carolyn Smith Foundation*
The Megan Weisenbach Foundation, Inc.*
The Sanfilippo Hope Initiative
Thrivent Charitable Impact & Investing*
James and Melissa Thomas
Janet Thomas*
Claire Thornton
Herald Thorsrud
Matt Thura
Lisa and Jerry Todd
Jane and David Tomick*
Frank and Colleen Trainor
Joan Trainor
Anne France Tremege*
Jacques Tremege*


KYNZLEIGH SLADE (MPS I) AND SAMANTHA BROWNFIELD

William and Faye Trotter
Elisa Tseng
Leigh Ann Turner
Steve Tutolo
Daniel Tyminski
Ultragenyx Pharmaceutical
United Health Group
United Way of Central New Mexico
United Way of Central Ohio
Leslie and Alex Urdaneta
Kathleen Urquidez
USA Couriers*
Sagar Vaidya*
Sydney Valone
Vanguard Group Financial Services
Jennifer VanHoutan
Cynthia Varacalle
Robert Vega*
Kristy Vetter
Samuel Villalobos
Desiree Vogt
Lewis and Pamela Waber
Sheila Wallin*
Jonathan Waltman
Ronald and Shirlee Ward
Larry and Karen Watkins
Bret Weber and Zhesi Chen
Donald Weimer*
Dr. Cara Weismann
Wells Fargo Community Support
Annie Wetter
Jennifer White and Glen Reindl
Mary White
Mary and David Whiteman*
David Wiese
Kevin Williams
John and Ellen Williams*
Terry Williams*
Matthew Wilson
Sheila Wilson*
Gordon Wingate and Cheryl Guidry
Amy Winstead
Sheri Wise and Eric Lueb*
Sheri Wise Facebook Fundraiser
Margaret Witt
John Wolfe*
Connie Wong
Victor Wong
Denise Wood*
Worldwide Clinical Trials
Eric Wright
Jim and Amy Yard
James Yates
Michael Yocum
Marcus and Angela Young*
Priscilla Zaehringer
Joe and Jennifer Zamboni
Fanny Zambrano
Samuel Zamet
Anne Zepp
Nicole Zuccaro
Andrew and Louise Zygmuntowicz

** Annual Fund gift*

Donations Given in Memory of

Paul Adams
Stuart and Karin Adams*
Geoffrey and Brenda Beard*
Raimund and Inge Kasner*
Michaelle and Wolfgang Mauch*
Stephanie and Edmund Rabuse*

Sam Aker
Kathy Aker*

Connor Anhalt
Dr. Mel and Mrs. Millie Anhalt*
Jon and Ellie Totz*

Kristofer Arnold
Monica Leone and family*
Beth and Nick Lombardo*
Julia O'Hara*
Sherrie and Tony Roman*
Paul and Kathy Rysz*

McKenna Bailey
Steve and Lavonne Blechinger*

Richard and Jennifer Balliet
Mark and Alberta Balliet*

Jeffrey Bardsley
Bill and Laurie Matchneer*

Jack "The Beast" Bennett
Michael and Kim McGurk*

Mark Bernbaum
Joel and Leeann Bernbaum*
Alan and Deborah Schmidt*
Joan Werner*

Colin Berning
Connie and Jim O'Connell*

Cecilia Rose Bien
Cheryl Bien*

Robert Boggiano III
Robert and Anne Boggiano*

Melanie Brannan
Richard and Blanche Cochran*
Claire and Ray Cox*
Linda Lee
Julie Simpson*

Melanie and Terry Brannan
Richard and Blanche Cochran*

Blakely Brown
Aaron Smith

Russell and Alexandria Browne
Sharon Browne-Davis*
Larry and Janice Spadt*

Edie Burke
Denmar and Ellen Dixon*
Cynthia Foster*
Laura McKeithen*
Madeline and Merritt Moseley*
Greg Sharrits*

Edie and Liza Burke
Laura McKeithen*

Josh and Jake Burt
Renee Randolph*

Matthew Caldwell
Mark and Stephanie Caldwell*
Andrew and Joan Flynn*

Matthew Cassil
Rob and Diane Cassil*

Sam Caswell
Karen Arsenault
Danielle Barrett
Michele Bates
Michelle Bianchi
John and Jenny Birmingham
Nancy Brock
Angie Cande
Gretchen Cecere
Karen Cicciarella
Kimberly Cicciarella
Samantha DeMello
Barry Donegan
Barbara Donnellan*
Judith Donovan-Hann
Ada Dowd
Samantha Fraser
Pamela Gelante
Sue Gobel
Andrea Goodnow
Karen Hagy
Emily Hann
Hawkins family
Betsy Hoffman*
David Hutton
Jean Izzicupo
Heather Karolian
Diane Klos
Nancy Lavin
Stephen Lawlor
Darren Lucas and Jill Schindler
Kathleen Nicholson
Maureen O'Connell
Doris Oneil
Rebecca Palumbo
Sherie and Warren Parr
Charles Peters
Jeanne and Stan Popielarz*
Richard Rowe
David and Elizabeth Sang
Poonam Scott
Jamie Soileau
Andrea Sousa
Tracie Stone
Michael Vailas
Nancy Vardaro
Kimberly Williams*

T.J. Catanzarite
Rich Corfman*
Nancy Sprosty*

Bradley Chapman
Kenneth and Victoria Warner

Karlee Rae Classen
Kent and Karlene Classen*

Georgette Cote
Gabrielle Malman*

Amanda Crawford
Christopher and Ann Crawford*
Kenneth and Sandra Ledford*

Mark Crecco
Barbara Crecco*
Kelly Crecco*
Michael and Anne Crecco*

Matthew and Camden Crockett
Billi and Jeremy Crockett*

Kelley Crompton
Joseph and Janet Ann Vieira*

John Dalton
Raymond Wang*

John Dapper
Bill and Laura Dapper*

Karly Davis
Bernard and Betty Harvilla*

Jonathan Dean
Pamela and Robert Dean*

Stephanie Eleanor DeAngelis
Carol Treutlein*

Amelia DeFilippis
Terry Anglin*
Helene Ashukian
John Azzatori
John Defilippis*
John and Rosemarie Golombos
Helena Martin
Lisa Moran
Nancy Myrtetus*
Judy and Nicholas Rolli
Richard and Judith Rosenberg
Thomas and Elaine Smith*

Daniel Dobrowolski
Kathy and Paul Dobrowolski*

Rachel Dodson
Steven and Kathryn Espenshade*
Kenneth and Ruth Espenshade*

Lindsey Efird
Mark and Jill Dry*
Patricia Thompson*

Maci Eickman
Jennifer Eickman*
Diane LaForges

Josie Ellard
John Bernard, PhD*
Ross and Belia Coddington*

Petey Feibelman
Joan Smith*

Jonathan Fischer
Michael Fischer*

Katie Foshay
Maria and Steven Foshay*

Kimberly Fowler
Dennis Burns*
Betsy and Steve Fowler*
Jeffrey and Barbara Harrell*

Jack and Stephen Frye
Sharon Frye

Michelle Gittins
Eileen and Harry Gittins*

Danny Gniazdowski
Tom and Anne Gniazdowski*
Lee and Tammy Gottschall*

Karina Guajardo
Isabel Anzaldua*
John Bernard, PhD*
Ross and Belia Coddington*
Carla Ellard*
Charles Ellard*
John and Yvette Iannelli
Christine and Kirk Kehrley*
Catherine and Peter Schreiber*
Melissa Wademeyer

Zach Haggett
James and Barbara Barker*

Adam Tyler Hardy
Rodney and Donna Hardy*

Tad Harvey
Ronald and Janis Harvey*

Devin Heise
Suzanne and Ronald Ruchti*

Grant, Kent, and Garrett Hickman
Kari Tarvin

Joshua Mark Hicks
David and Barbara Brooks*

Elizabeth Hogan
Arthur and Joan Giammarino*

Maddie and Spencer Holland
Herman and Mary Earwood*
Aaron Gann
Steve and Amy Holland*
Jaymi and Thomas Holland*
Brian and Rebekah Klutz
Gib and Sandra Lewis*
Harlen and Donna Moore*
James and Margaret Myrick
Joseph and Aurie Riley

Clay Howard
Lois Howard*

Ryan Hunt
Kevin and Jackie Gull*

Kyle Hampton Jack
Anonymous*

Aaron Jackson
Susan Woodward*

Jenny Jeffers
Larry and Joy Jeffers*

Dorian and Wynn Johnson
Dave and Gerry Johnson*

Daniel M. Jones
Stanton and Jean Gunnells*

Ryan Kapes
Daniel Brazeau
Kathleen Kapes*
Joanne Lennon

Billy and Bobby Kehoe
Daniel Kehoe*

Thomas J. Kehoe
Kyrsten Rodriguez

continued

** Annual Fund gift*

Donations Given in Memory of, *continued*

Amanda Keith
George and Gail Anderson*
Ralph and Martha Anderson*
Wendell and Karen Keith*
Andrew and Louise Zygmuntowicz*

Margaret Ketterer
Ardis Ketterer*

Ashleigh Kidwell
Robert Allen*

Allison Kirch
Lorraine Baron*
Katherine Cavanaugh*
Margaret Cohen
Nancy and David Edwards*
Gary and Janet Kirch*
Lawrence and Susan Kirch
Tom and Linda Kirch*
Donna and David Littrell*
Dan Mcauliffe*
Andy and Joanne Nordeen*

Kraig Klenke
Terry Clayton*
Lori and Doug Dunbar*
Brian and Kris Klenke*

Jarrett Koblitz
Ivan and Leann Koblitz*

Joyce Koehler
Frances Demarco*

Fred "Fritz" Koehler
Nancy Vander Zwan*

Tyler Langan
Joanne Beemiller
Chris Bottger
Bob and Linda Carey
Michael Consiglio*
Court Security Officer's
Lisa Daris
Angie Dye
Amanda Endy
Jaclyn Hoosier*
Anna Kipp
Joseph and Anne Kotch
Gabriel Metric*
Joseph Myers*
Kathy and Josh Nay
Paul Scott*
Tamara Simpson
Cindy and Kurt Voggenreiter*
Justin Waynick*

Joe and Maggie Langford
Laurie and Dawn Ulmer*

Catherine E. Latella
Ronald and Kimberley Fragetta

Audrey K. Lawson
Julie and Russell George*
Robert and Katie Lawson*

Ryan Leonard
Cynthia and Kenneth Zawacki*

Mark and Casey Lessing
Christopher and Ann Donaldson*
Barbara and Keith Pushee*
Nancy Sforza*

Madison Lewis
Paige Lewis*

Logan Locascio
Judy and Mansour Yamin*

Alyssa Brooke Louden
Donald and Karen Louden*

Joseph Carroll Louison
Lauren Louison

Olivia Lovell
Wes and Jill Lovell*

John L. Loy
Donald and Lynda Witte

Craig Lupardo
Jim and Doris Lupardo*

Derek Maas
Judy and Donald Maas*

Glen Malina
Barbara and George Malina*

Sarah Mallia
Joseph and Jeanne Mallia*

Kyle Manning
Don and Carol Manning*

Logan Marcotte
Pat and Michelle Baldwin*
Patrick and Kelly Carroll*

Francesca Martin
Isabella and Talor Martin*
David and Leslie Simenz
Ronald and Janet Stein

Frankie Martinez
Raymond Wang*

Ryan Mask
Lori and Russell Canning
Frances Demarco*
Timothy Dimmick
Dorothy Mask*
Raymond Miller
Ronald and Roslinda Seliger
Lou and Chris Slavik

Dylan McClurg
Stephen and Marie McClurg*

Carter McGraw
Donna and Fred Kimbro*
Cindy Jones
Diane and Robert McGraw*

Michael McGuinnis
Pat and Thomas Davitt*

Traci Mericle
Roger and Robin Coleman*

Christopher Joseph Migliozzi
Joe and Paige Migliozzi*

Danny Miller
Andrew and Heidi Bahmueller*
Lee Ann Fulmer*
Christopher and Patricia Guyre*
Carol and Darren May*
Susan Narducci
Alan and Kathy Portnoy*
Brian Shingle*
Diane and John Stabb*
Lisa Sweeney

Max and Toby Mingo
Dutch MacDonald and Becky Mingo*

Cameron Mollett
Johnda Adkins*

Lucas Montgomery
Sarah Brown
Stacey and Lew Montgomery*

Mitchell W. Moore II
Mitchell and Cherylynne Moore*

Matthew Morris
Diane Morris*

Cade Morrissey
Ron Morrissey*

Anthony M'Sadoques
Rene and Patricia M'Sadoques*

Joseph and Zachariah Muonio
Michael and Anita Muonio*

Miriam Nay
Kathy and Josh Nay
Susan Roncoroni*
Royce Bunce and Elizabeth Sherwood*
Jan and Don Sortman*

Ronald Nay
Jaime LaBonte
Jessica Reichert
Susan Roncoroni
Edward and Christy Saling
Jan and Don Sortman*

Filson Newman
Vickie Newman*

Austin Francis Noll Jr.
Joann Bigler*
Michelle and Steven Hayes*
Henry Johnson
Bruce and Judith Lawson*
Chuck and Mary Miller
Andrew Noll*
Daniel and Pamela O'Brien*
Bill and Cathy Pantuso

Austin Noll IV
James and Mary Baker*
Andrew Noll*
Austin and Cheryl Noll III*
Daniel and Pamela O'Brien*
Larry and Annette Pung*
Thomas and Kathy Will*

Ryan Patrick O'Steen
Eileen and Larry O'Steen*

Paul Page
Matthew Harris*

Jay Palmer
Ann Mclaughlin*

Steven Ward Paullin
Ronda Paullin*

Erin Peters
Jeni Ingersoll*

William Peterson
Stephen and Sara Smith*

Logan Piefer
Kathleen Brady*
Darrell and Kay Distefano*

Thomas C. Purwin
Kathleen Tobin*

Chip and David Radius
David and Rose Pelton*
Daniel and Valerie Teitsma*
Lavonne and Dennis VanderWeide*

Adam Rattman
Faith Rattman*

Jenna Richbourg
Richard and Brenda Fillman*
Beth and Jeremy Hudson*

Michael Rome
Richard and Darlene Rome*

Terry Romo
Julie Simpson*

Daniel Rudny
Michelle Towell*

Laura and Michael Sheekey
Arthur and Marilyn Sheekey*

Katie Shine
Lee Ann Fulmer*

Ganesh Shrestha
Mahesh Shrestha*

Alex Sobie
Kimberly Swartz*

Michael Sochacki Jr.
Angela and Michael Sochacki

Griffin Sosinski
Anthony and Pamela Sosinski*

Jennifer Steiner
Bob and Susan Steiner*

Timmy Stringer
Natasha and Terry Stringer

Elizabeth, Luke, and Ethan Swabick
Scott and Marcia Bosak*

Clinton and Zachary Szemanski
Mary Barringer*
Kathy and Vic Surma*
Tracy Szemanski*

Natalie Talcott
Noel and Nancy Talcott

Amy and Angela Taylor
Marie Blumeier

John Thornton
Michael and Regina Bailey*
Melanie Bowden
Kristine Cabanban
Richard and Sue Cadena*
Jennifer Ermoian*
Renee Hammond*

** Annual Fund gift*

continued

Donations Given in Memory of, *continued*

Terri Klein and Michael Schleter

Nancy McTygue

Robert and Nancy Peterson*

Christine Totah

Max Tilsner

Elizabeth Armstrong*

Herbert Tilsner*

Shannon Tootill

David and An Tootill

Patrick Trainor

William and Carolyn Eames*

Laura Giardino

James Keane*

Thomas and Peggy O'Malley*

John and Kathleen Simpson*

Frank and Colleen Trainor*

Nicholas Palph Trombino

Joan Cullen

Maxine Kugelman*

Luke Valdez

Jeffrey and Deb Reinke*

Aly Von Handorf

David and Cathy Hamm*

Donald and Janet Schmidt*

Mary Beiting and Jeff Von Handorf*

Drew Wanstall

Marguerite Caldwell*

Lee Ann Fulmer*

Andrew Watkins

Lauren Watkins

Peter Wehrle

Paul and Kristin Wehrle*

Susannah Jacqueline White

Christine Ho*

Dr. Klane and Mrs. Amy White*

Scotty Whitecotton

Barbara Betti*

Sherri and Alan Tribuzio*

Franky Wier

Gene Grabinski*

Jimmy Wimberley

Jan Wimberley*

Jennifer Wingate

Howard and Sallie Namkin*

Emily Claire Workman

Deborah Cohn

Jimmy and Susan Workman*

Dr. Wraith, MBBS

Gerald Cox*

Christian Yard

Carey and Mary Crumling*

Sherry and Rick Dandrea*

Marcy King*

Dan Kulbieda*

William Massa Jr.*

Anne McClelland*

Christine and Jeffrey Miller*

Celeste and Stephen Raydo*

James and Carol Yard*

Richard Zachariason*

Donations Given in Honor of

Helen Allison

Alice and Frederick Andrus*

Mel and Mille Anhalt

Gerald and Susan Anhalt

Sheila and Richard Schlesinger*

Gabriela and Vincent Arellano

Lourdes Espinosa*

Davis Barkley

Amy Barkley*

Dwight and Debbie Barkley*

Robert Harvey and Roxanne Maffitt*

Margaret Maffitt

Blake Barnhardt

Carole and John Barnhardt

Arion Batton

Gary and Louise Bezecny*

Paula and Fred Pedro*

Graysen Joe Bean

Patricia Bean*

Molly Birmingham

Nan O'Connor*

Brittany Bjorkman

Melany Bjorkman

Wyatt Blancheri

Todd and Nicole Blancheri*

Michael Bodura Jr.

Joseph and Jacqueline Balukin*

Helen Fallon*

David Lebec*

Alayne and William Lowenberger*

Jacob Bohley

Guy and Donna Cooper*

Cindy and David Miller*

Judy Pinsonnault*

Danica Boni

John Mountain*

Emma Bowles

Cheryl Jackson*

Annabelle Bozarth

Lee Bloemendal, MD*

James Groody and Kimberly Krehely*

Brenda Lacombe*

John Willis

Adam Brennan

AT&T Campaign

Sueanne and Robert Belicose

Rosemarie Brennan*

Kelly Jackwicz

Sharon Kinsman*

Erin McBride*

Joanne O'Brien*

Matt Brown

Aaron Smith

Carol Bryant

Janis Miller*

Rev. Dr. Keith W. Byrd Sr.

Ginger Beverly*

Aiden Jack Carter

Monika and Jack Berg*

Roseanna Spizzirri*

Sam Caswell

Cathy Foutz*

Charlotte Cavanagh

Jessica Smallwood

Connor Charters

James and Joan Charters*

Maureen Cote

Andrea and Tim Collins*

John Cote*

Sandra Cote*

Elizabeth Djukic*

Mara Fizdale*

Frannie Hoffman*

Kristine Kelly*

Tom Knott*

Angela Mikles*

Kendall Van Dyk*

Paul Zurawski*

Ethan Cozine

Stephanie and Shawn Cozine*

Stella Cua

Sarah and Mario Cua*

Benji Cullere

Jason and Tamara Cullere*

Joanne Hayo*

Megan Silletti*

Kathleen Tobin*

Zoe Dewaghe

Priscilla Slaven*

Patricia Dickson

Barnet and Eunice Krinsky

Julia Dopheide

Julie Dopheide*

Rebecca Dopheide*

Levi Dunlap

Mary and Mark Cicero*

Colin Dwyer

Maren Becknell*

Michael Dwyer*

Robert and Lorie McKaig*

Wayne Eppehimer

Sandra Miller*

Keira Esposito

David and Elise Esposito*

Braden Farrell

Betty and Barney Arceneaux*

John and Louise Farrell*

Freya Finn

Jill and Robert Mason*

Helen Meyers

Erin Fitzgerald

John and JoAnn Bird*

Sabrina Gabriel

Felicidad Quilo*

RYAN DANT (MPS I), MARK DANT, ALLISON WILLIAMS (MPS I)

Marcus Garvin

Roslynn and Timothy Garvin*

Travis Glock

Betty Glock*

Kendra Gottsleben

Denise and Loren Reit*

Molly Greeno

Amy Gabay*

Jax Gunnar

Edward and Evelyn Schultz

Julie Hall

Sheryl and Gerald Hall

Sara Ward

Madison Hayden

Rosemary and Michael Shourds*

Rylie Hays

Lyle and Jade Hays*

Jerry and Elizabeth Highfill*

Danny and Sally Leinen*

Fletcher Henry

Charles Stamm*

Nolan Higginbotham

Robert Gassman*

Peter Hoffman

Michelle Cove*

Sally Fleming*

The Hoffman family

Marietta and George Petters*

continued

** Annual Fund gift*

Donations Given in Honor of, *continued*

Christopher Hohn
H. and Nancy Blake*
Diedrich Hohn*
Judith Levine*
Paul and Lu Ann Malnati
Maryrose Murphy*
Susan Murphy*

The Holland family
Bill and Mary Andrews*
Taylor Tang

Laynie Holland
Jaymi and Thomas Holland*
Steve and Amy Holland*
Brian and Rebekah Klutz
Harlen and Donna Moore*

Michelle Hopkins
Kathleen Bailey*
Ethert and Pauline Baird*
Donna Becker
Tom and Suzanne Brennan
Kari Desoto
Dana Devore*
Vidmantas and Cecilia Duda*
Stephen Dunn
Eugenie Ebert
Geraldine Faucett*
Kay and George Follett*
Robert and Melanie Franko*
Carissa Hernandez
Scott and Lynn Hopkins
Rena Johnson
Margaret Kinal*
Terri Klein and Michael Schleter
Kelly Kroeger
Carol and Thomas Kuhn*
Lori Manering*
Brad Plantiko
Lysa and Adolfo Saltzman
William Smith*
Krista Snelling
Michele Steward
Lisa Taranto
Hugo and Marylyn Van der Moer
Dawn Watkins
Stanley Yang
Robert and Janice Yates-Valone
Gilda Youdeem
Evelyn Zohlen

The Hopkins family
Vivian Fernandez

Jonathan Huang
George and Jaja Gawartin

Wesley Huntington
Deborah Dunn*

Jacob Irish
Mark and Cindy Wellman*

JoAnn Jennings
Jennifer and Chris Fitzgerald*

Sydnee Jensen
Joe and Susan Babic*

Carter Kanney
Jerry and Pat Kanney*
Julie Lange*
Bruce and Darlene Slavik*

Brayden Kapes
Kathleen Kapes*

Ryan and Brayden Kapes
Sofia Castellanos*

The Kapes family
Robert and Barbara Stanziola*
Laurieann Tebben*

Deborah Kappel
Deborah Kappel*

John Kell
Bob and Ginger Kell*

Anna and Dave Kidwell
Beverly Sweeny*

Eddie Kimminau
Jim and Maureen Basting*

Jenny Klein
Terri Klein and Michael Schleter*
John and Shirley Wake*

Carter Korth
Teresa Korth*

Team Kozlo
Kristine Kelly*

Layla and Gianna Kozlowski
Shane Carignan*
Ryan Cote*
Sandra Cote*
Elizabeth Djukic*
Amy and Seth Downen*
Katie Fleck*
Allison Hardy*
Barbara Jampolis*
Christopher Joseph*
Charlene Joyce*
Kathleen and Carl Katitus*
Lawrence and Jacqueline Kelly*
Mary Ellen Kelly*
Gabrielle Malman*
Emily Patterson*
Sarah and Wes Pinkley*
Charlotte and Nate Sanson*
Leslie and Alex Urdaneta*
Debra and Dennis Zurek*

Mira Kozma
Justine Underhill and David Mauroff*

Jameson Kraft
April Kraft*
Cynthia Kraft*

The Carrie Dunn-Melissa Kraus family
Sharon Lockhart*

Jackson Dunn Kraus
Gary and Linda Corbett*
Nancy Dunn*
Marilyn and Gary Figlar*
Joe and Tina Hopkins*
Jeanne Kiefner*
Patricia Shore*

Trey Lane
John and Joyce Lane*

Joe and Maggie Langford
Robert and Amy Farrell*

Erin and Shea Laughlin
Sarah Peterson

Olivia Lawson
Joanna and Brian Janssen*

Rebekah Esther Lehto
Thomas and Joyce Boster*

Brittany Lejeune
John and Linda Lejeune*

Michael Lewandowski
Apolito family*
Sheryl Bates*
Michael and Karen Lewandowski*
Anne and Bob Siudzinski*

Megan Lich
Scott and Gabriella Lich*

Gavin John Lindsey
James and Debra Lindsey*

Olivia Lipscomb
Jenn and Jamie Lipscomb*

Rachel Longston
Cynthia and Kent Miller*

Allison and Lacey Lukondi
Elena and Philip Anischenko*
Chuck and Nancy Lukondi*

Jason Madison
Sandra Miller*

Catarina Marcus
Claudina Bonetti*

Jaxon Maxwell
Sandra Tallbear*

Loren McClelland
Kathryn Bickham*
Scott and Evelyn McClelland*

Jim and Martha McCormick
James and Kathleen Tate*

Kierean McKelton
Wynona Maxwell

Nick Melnyk
Joseph and Jan Melnyk*

Finnley Mercer
Gina Hildebrand

Team Michelle
Patrick Kinsella
Richard Lashley

Danny Miller
Brenda Carbon*

Alexander Mincks
Greg and Jennifer Mincks

Declan Mitchell
Nancy Stringham*

Zeyad Mizerek
Amina Mizerek

Jessica Moore
Judith Ries*

Austin Nace
Theresa Stoveken*

Wesley Nelson
Laura Carey
Hillary Kral
Jean and Todd Scheffler*

Avery Neuendorf
Denise Brillhart

Shepard Nickel
Arian and Yvonne Nickel*

Austin Noll III
Angela and Roger Zylstra*

James Oliger
Brian and Hela Oliger*

Kiernan O'Neal
Teresa Everett

Levi Ormeroid
Jason and Christi Ormeroid

Lucas Ostella
Michael and Evelyn Ostella*

Lukas Pell
Samantha Kohlman

Team Peter
Marita Anderson*

Erin Peters
Mark and Jane Hauser*

Richard Raup
Linda Post*

Myles Richardson
Joanne Richardson*

Nathan Roma
Jonathan and Lisa Dols*

Keaton Schanely
Andrea and Donald Swavely*

Scout Scoggins
Chris Avent
Sydney Gingrow

Sydney Sherrill Gingrow and Scout
Carolyn Schneider

Sasha Segal
Linda Burtt*
Heidi and Keith Caswell
Jessica Jenness
Len Rieser

Alba Sether
Angela and Jim Sether

Michael Sheridan
Robert Sheridan*

Samantha and Jacob Slawson
Douglas Slawson and Linda Lepeirs*

Meekel Stevens
Marla Stevens

Logan Stout
Ralph and Marva Ramsey*

Cody and Alex Stultz
Christine and Troy Stultz*

Catherine Tate
James and Kathleen Tate*

Richard and Margie Tate
James and Kathleen Tate*

Jimmy and Jean Tate
James and Kathleen Tate*

Bill and Letty Tate
James and Kathleen Tate*

** Annual Fund gift*

continued

Donations Given in Honor of, *continued*

Charlotte Tate and Blair Euverard
James and Kathleen Tate*

Henry Tate
James and Kathleen Tate*

Rebecca Tate
James and Kathleen Tate*

BioMarin Clinical Coordinator Team
Margaret Ference*

Brynlee Thompson
Joanne and Robert Ames

John Thornton
Alicia Jones
Sharon Mioduch*
Sheila and Michael Thornton*

Juliana Katheryn Thorsrud
Katheryn Cox*

Savannah Timbrook
Jack Swepston*

Robyn Timmons
James and Kathleen Tate*

Cooper Tippett
Colleen and Shawn Arni
Torch Barr*
Greg Frank*
Kathleen and Michael Heymans*
Rolla and Kathryn Kehrman*
Margaret Kruse*
Alberta Kuhlman*
Rusty and Alison Rochelle*
Elizabeth Vielhauer*

Jack Todd
Lisa and Jerry Todd*

Jett Trappe
Freddy Gonzalez
Pisenti & Brinker, LLP
Diamond Ranch
Denise and Doug Wood*

Freya Tremege
Anne France Tremege

Leslie Urdaneta
Mildred Clark*

Caitlin Vespe
Helen and Bill Vespe*

Karsyn Wallace
Linda Wallace*

Susanne Waters
Marty Waters

Harrison Weber
Bret Weber and Zhesi Chen*

Matt Wells
Don and Lisa Wells*

Paige Makenzie Whorton
Belinda Whorton

A.J. and Sean Wiegert
Kellie and Correy Rahn*

Allison Williams
Joseph and Jacqueline Williams*
Kimberly Williams*

Josie May Williams
Rick and Dawn Williams*

Evelyn Zohlen
Pam Umstead

Champion Circle

Todd Waddell and Sarah Aaserude
Fernando Armendariz
Colleen and Shawn Arni
Carole and John Barnhardt
Melany Bjorkman
Marie Blumeier
Claudina Bonetti*
Marc and Beth Brdar
Margaret Cohen
Lucia Cuenca
Rebecca Derwin
William English
Teresa Everett
Robert and Melanie Franko*
Steve and Amy Holland*
Jennifer and Bryan Hutcheson
John and Yvette Iannelli
Kelly Jackwicz
Christine Jocoy
Brian and Rebekah Klutz
Cynthia Kraft*
Lauren Louison
Wynona Maxwell
Donny and Molly Merrill
Greg and Jennifer Mincks
Hugo and Marylyn Van der Moer
Susan Murphy*
Kathy and Josh Nay
Thomas and Vickie Patterson
Sam and Nancy Ramsey*
Edward and Evelyn Schultz
Poonam Scott
Riddhi Shah
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
Rick and Dawn Williams*

Corporate Matching Gifts

AbbiVie
Allstate
Andersen Corporation
AT&T
Bank of America
BestBuy
Chevron
CHS, Inc.
Costco
Duke Energy
Greenpoint
Hearst
Hewlett Packard
INCYTE
L'Oreal USA
Lenovo
Liberty Mutual
Markel Corporation
Microsoft
Oracle
Pacifica Gas & Electric
Paramount
Piper Sandler Company
Raytheon Technologies
United Health Group
Vanguard

Facebook Fundraisers

Shaun Bach-Haynes
Mandy Bellassai
Nichole Bickerton
Darryl Block
Iyona Cook
Charity Cook-Blood
Tamara Cullere
Brandon T. Dee
Amy Diaz
Wilma Dickerson
Kailey Dina
Susan Duncan
Anne Elizabeth
Wayne Eppehimer
Brooke Frix
Elizabeth Fry
Julie Garrison
Dee Ann Gaston
Hermines Geburtstags-Spendenaktion
Jayne Gray
Larizza Guerrero
Alisa Gutierrez-Vitello
Joanne Makris Huff
Alyssa Jeanne
Emily Layman
Amanda Lee
Katherine Lethia
Rose Merrell
Vicki Michelle
Jamie Moon
Danielle Murphy
Tommy O'Brien
Marla Jane Parkman
Travis Parsons
Kim Phillips
Anne Quesenberry
Emily Ramirez
Krizia Ruano
Holly Scalf
Linda Cebron Shenk
Rachel Sibs
Cynthia Stephens
Christopher Stetson
Alana Sullivan
Janine Taylor
Marissa Valenzuela
Sheri Wise
Fanny Zambrano

** Annual Fund gift*

MPS CLASSIFICATIONS

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

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

SYNDROME	EPONYM	ENZYME DEFICIENCY
MPS I	Hurler, Scheie, Hurler-Scheie	α-L-Iduronidase
MPS II	Hunter	Iduronate sulfatase
MPS IIIA	Sanfilippo A	Heparan *N*-sulfatase
MPS IIIB	Sanfilippo B	α-*N*-Acetylglucosaminidase
MPS IIIC	Sanfilippo C	Acetyl CoA: α-glycosaminide acetyltransferase
MPS IIID	Sanfilippo D	*N*-Acetylglucosamine 6-sulfatase
MPS IVA	Morquio A	Galactose 6-sulfatase
MPS IVB	Morquio B	β Galactosidase
MPS VI	Maroteaux-Lamy	*N*-Acetylgalactosamine 4-sulfatase (arylsulfatase B)
MPS VII	Sly	β-Glucuronidase
MPS IX		Hyaluronidase
ML II/III	I-Cell, Pseudo-Hurler polydystrophy	*N*-acetylglucosamine-1-phosphotransferase

BOARD OF DIRECTORS

Chairman
Steve Holland
(MPS I parent)
steve.holland@mpssociety.org

Vice Chairman
Maureen Cote
(MPS VI aunt)
maureen.cote@mpssociety.org

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

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

Lisa Berry, CGC (MPS advocate)
lisa.berry@mpssociety.org

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

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

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

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

Scott and Lynn Hopkins
(MPS I parents)
scott.hopkins@mpssociety.org
lynn.hopkins@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

Lisa P. Todd (MPS II parent)
lisa.todd@mpssociety.org

SCIENTIFIC ADVISORY BOARD

Julie B. Eisengart, PhD, LP, *chair*

Guidance Committee
Barbara K. Burton, MD
Amy Gaviglio, MS, CGC
Adriana M. Montaño, PhD
Matthew Pendlton, PhD
Lachlan Smith, PhD, *assoc. chair & chair designate*
Ray Y. Wang, MD

At Large Members
Guilherme Baldo, PhD
Allison M. Bradbury, PhD
Elizabeth Braulin, MD
Alessandra d'Azzo, PhD
Robert J. Desnick, MD, PhD
Patricia I. Dickson, MD
Maria Fuller, PhD
Natalia Gomez-Ospina, MD, PhD
Paul Harmatz, MD
Mark Haskins, VMD, PhD
Simon Jones, MBChB, BSc, MRCPCH
W. G. Stuart Mackenzie, MD
William G. Mackenzie, MD
Joseph Muenzer, MD, PhD
Lynda E. Polgreen, MS, MD
Deepa Rajan, MD
Mark S. Sands, PhD
Edward H. Schuchman, PhD
William S. Sly, MD
Cologera Simonaro, PhD
Richard Steet, PhD
Klane K White, MD
David Whiteman, BM, BCh, FAAP, FACMG
Chester B. Whitley, PhD, MD
John H. Wolfe, VMD, PhD

STAFF

President and CEO
Terri L. Klein, CNPM, MPA
terri@mpssociety.org

Chief Scientific Officer
Scott Loiler, PhD, CSO
scott@mpssociety.org

Director of Science & Research
N. Matthew Ellinwood, DVM, PhD
matthew@mpssociety.org

Communications Director
Amber Adams, MS
amber@mpssociety.org

Pathways Program Care Coordinator
Carol Bryant, MSW, LCSW
carol@mpssociety.org

Pathways Program Care Coordinator
Evelyn Fisher, MSW, GC
evelyn@mpssociety.org

Development and Program Support Specialist
Bethany Greene
bethany@mpssociety.org

Office Management and Support
Joseph Jackson
joseph@mpssociety.org

Director of Development
Wendy Spaulding
wendy@mpssociety.org

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

Controller
Angela Guajardo
angela@mpssociety.org

President Emerita
Stephanie Bozarth
Marie Capobianco
Ernie Dummann
Steve Holland (two terms)
Alice Kalamar
Mary Majure Couture
Linda K. Shine
Lisa P. Todd

National
MPS
Society
Support for Families. Research for a Cure.

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

NON-PROFIT ORG.
U.S. POSTAGE
PAID
CHAPEL HILL, NC
PERMIT #74