2022 Annual Report

Impacting Hope Through Science and Advocacy

National MPS Society

CONTENTS

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

Mission

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

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

MPSSOCIETY.ORG

Follow us!

Pictured on the cover:
Brooks Kauders (MPS II)

"Tackle what is hard—if we don't, then who will? By finding solutions to the hardest obstacles that face our patient community, I guarantee we will get the rest right."

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

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

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

We lead from the front and don't hesitate to tackle controversial issues. When an MPS I family reached out through Pathways and shared their story of their oldest son being left untreated while their newly diagnosed child, through newborn screening, was provided access to treatment options, we stepped in. We were not afraid to acknowledge the inequities presented and responded by legislating for access to equitable healthcare, access to therapies, and newborn screening. Stephanie Cozine and our Education Committee launched the *Our Voices* podcast that covers critical topics for our adult community, research, grief, hope, and the future of our families. Our mission is to bring new gene and cell therapies to all MPS disorders by partnering with sponsor companies.

continued

We identify and engage with strong partners who can work closely with the Society to drive progress. Last year, we traveled while the world was still beginning to open. We forged new relationships with the Association of Public Health Labs and committed to collaborative work with the EveryLife Foundation. We worked internationally with Fabry, the Gaucher Alliance, and Pompe Disorders to describe the importance of real-world data.

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

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

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

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

Lisa P. Todd, chairman of the board

Terri L. Klein, president and CEO

49 YEARS

$21 million in research

2,600 members

$1.5 million+ direct family support grants and scholarships

23 years advocating on Capitol Hill

Family Support

150

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

Family support remains a critical pillar of the mission of the National MPS Society. In 2022, almost $135,000 in scholarship and grant funding was provided to 150 families and individuals with MPS or ML. The 36th Annual Family Conference was held in Nashville, TN, and the Society supported a record number of scholarships for attendees. Most scholarships were awarded to recipients attending their first conference.

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

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

HIGHLIGHTS

Continuing Education Scholarships

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

Extended Hospitalization Relief

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

Family Conference Scholarships

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

Family Assistance Program

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

Journey Assistance Program

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

Extraordinary Experiences Program

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

Medical Travel Assistance Program

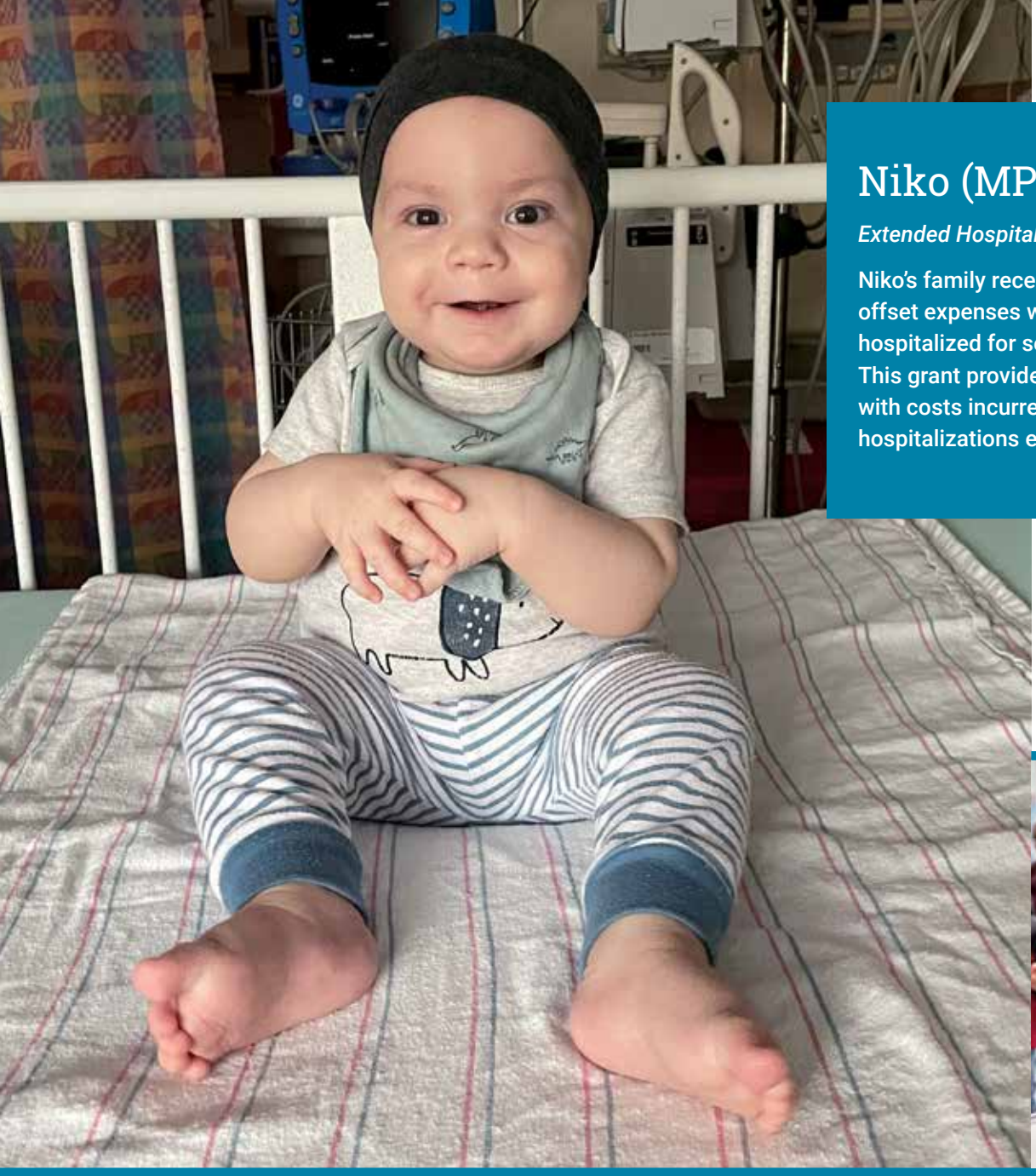
- Funded 21 grants totaling $8,425 to help with out-of-town travel costs for non-recurring medical appointments.

Bereavement Expense Program

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

Regional Social Events

- Provided $750 for an event in Atlanta, GA.



Niko (MPS I)

Extended Hospitalization Relief

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

Lumar (MPS IVA)

Medical Travel Assistance Program

Thanks to the Medical Travel Assistance Program, Lumar was able to attend appointments with her specialists this year. She has MPS IVA and traveled several states away to see experts in Morquio syndrome.

80
SCHOLARSHIPS

Jeffrey Bardsley
Continuing Education
Klenke-Kirch Sibling
Family Conference

68
GRANTS

Extended Hospitalization Relief
Family Assistance
Journey Assistance
Extraordinary Experiences
Medical Travel Assistance
Bereavement Expense

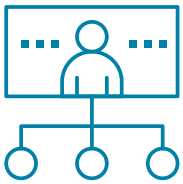
Pathways

The National MPS Society's Pathways program provides families and individuals with education and comprehensive support throughout the first year of diagnosis. To date, the program has served approximately 300 individuals and families.

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

41

individual and family visits

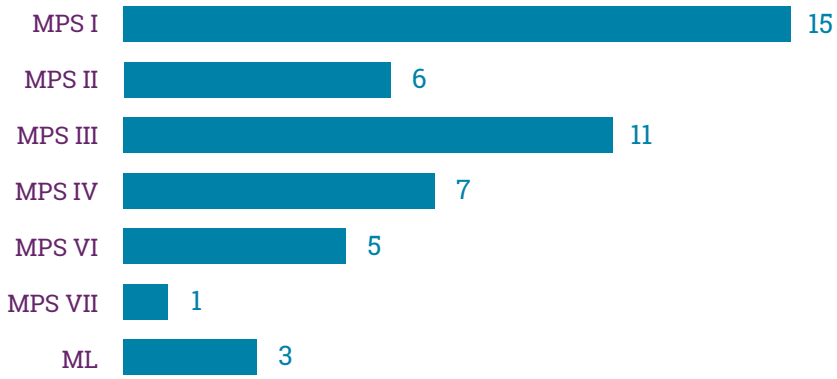


8

virtual support groups attended by 20 families

Syndrome Types

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



HIGHLIGHTS

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

MPS Pathways
TRAVELING THE JOURNEY **TOGETHER**

Wesley (MPS II)

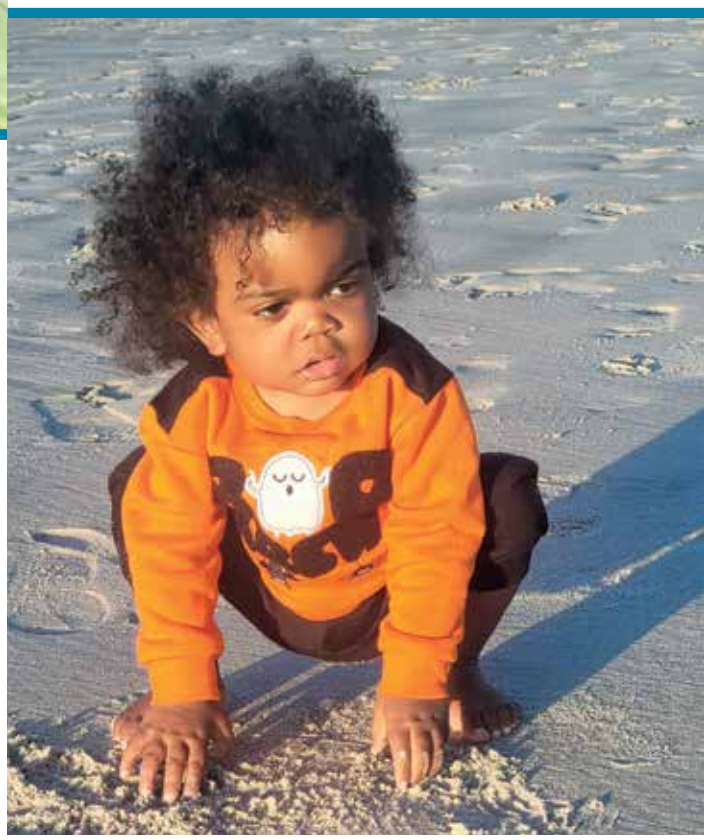
The National MPS Society has been helping our family since before Wesley's official diagnosis. They promptly connected us with an MPS doctor to help confirm a diagnosis, significantly expediting what could have been a very lengthy process. They educated us about ERT and clinical trials for MPS II, allowing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

— Katarina Nelson, mother of Wesley

Kadir (MPS I)

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

— Ashley Avery, mother of Kadir



Advocacy

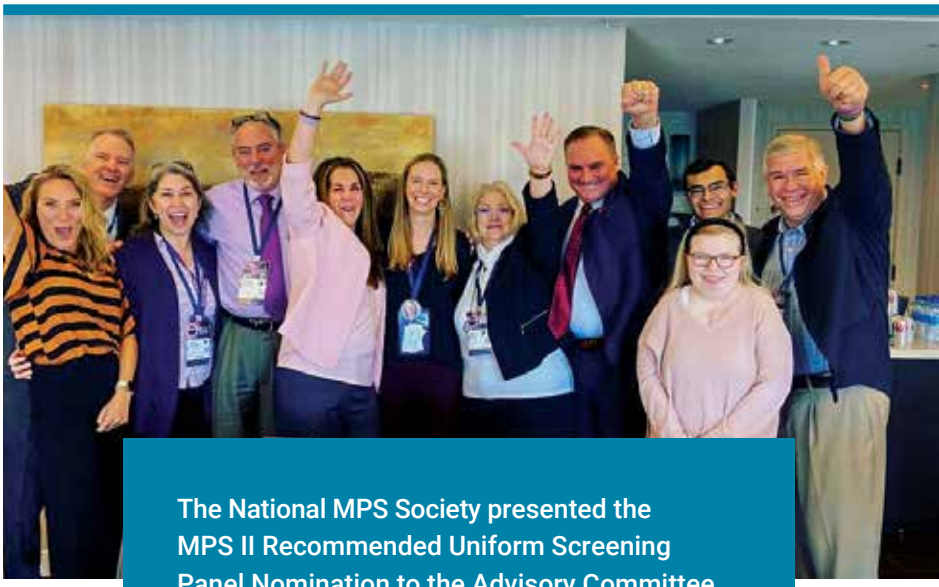
Advocacy is a critical need of the MPS and ML community. In 2022, we expanded our efforts in newborn screening and developed key legislative initiatives to prioritize equity and parity for our patient community. The Society continues to maintain a Rare Hub space at the EveryLife Foundation offices in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

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

59

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

Terri Klein visiting with MPS I family in Washington, DC



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

HIGHLIGHTS

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

Nolan Higginbotham (MPS I)

- Supported the following legislation and signed onto letters for:
  - H.R. 3089/S. 1544—**Accelerating Kids' Access to Care Act**
  - H.R. 482/S. 350—**Newborn Screening Saves Lives Reauthorization Act**
  - H.R. 1730/S. 670—**Speeding Access Therapy Today (STAT Act)**
  - H.R. 5585/S. 3819—**Advanced Research Projects for Agency for Health**
  - H.R. 1092/S. 526—**Better Empowerment Now to Enhance Framework and Improve Treatment (BENEFIT) Act**
  - H.R. 6888/S. 4071—**Helping Experts Accelerate Rare Treatments (HEART Act)**
  - RUSP language support for state reviews
- Attended the following advocacy and networking conferences: 18th Annual WORLD*Symposium*™; *American Society of Gene & Cell Therapy Policy Summit*; *National Organization for Rare Disorders Summit*; *Global Genes*; *Association of Public Health Labs Annual Meeting*.

Fundraising

A nonprofit organization is only as strong as the level of support it receives from its members and benefactors. The National MPS Society and its members moved feverishly into 2022 with hosting in-person events.

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

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

$324,000+

Annual Fund donations

HIGHLIGHTS

- Maintained a four-star charity rating from Charity Navigator, representing sound fiscal management and commitment to accountability and transparency. This "exceptional" designation differentiates the Society from its peers and demonstrates to the public it is worthy of their trust.
- Supported an active membership roster of more than 2,700 members.
- Raised approximately $407,340 through virtual walk/run and other fundraising events.
- Hosted four national run events in Raleigh, NC; Napa, CA; Nashville, TN; and Long Beach, CA.
- Raised more than $35,000 for MPS and ML research through the University of Pennsylvania's Million Dollar Bike Ride.
- Raised $324,387 through the 2022 Annual Fund campaign, chaired by Leslie Urdaneta, director of Family Support and Communications.
- Received Combined Federal Campaign application approval.
- Worked with the Sock It to Hunter Syndrome Foundation in procuring a gift of $75,000 for MPS II research and the 2023 Science and Research Conference.
- Hosted 62 Courage Pages (customized, informative family web pages for awareness and fundraising) on the Society's website.
- Hosted the National MPS Society's third annual Big Bake for MPS and ML, raising more than $17,000.

Everly Reynolds (MPS I)

Maddie (MPS IIIA)

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

— Brittany Richards, mother of Maddie

2022 Fundraisers

ARC Fundraiser, hosted by the Adult Resource Committee

Basketball Fundraiser, in honor of Adam Podesky

Big Bake for MPS and ML, hosted by the National MPS Society

Concert for the Cure, in memory of Ryan Mask, hosted by Dorothy and Jeremy Mask

Crop For Rachel, in memory of Rachel Dodson, hosted by Jim and Michelle Dodson

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

Emilio's 5K, in honor of Emilio Garabito, hosted by Elizabeth Garabito

Hailee & Olivia Together a Future of Hope with YOU, in honor Hailee Fujioka Makuch and Olivia, hosted by Sarah Keren

Holland Sharing and Caring Fundraiser, in honor of the Steve and Amy Holland family, hosted by friends of the Hollands

Hopkins cabi Clothing Party, in honor of Michelle Hopkins, hosted by Lynn Hopkins

Jack "The Beast" Bennett Memorial Ride, in memory of Jack Bennett, hosted by the Bennett family

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

Jacob's Journey Fundraiser, in honor of Jacob Bohley, hosted by Jennifer Hajjar

Jammin' for Julia, in honor of Julia Donohue, hosted by Andrea Felten

John Loy Memorial Golf Tournament, in memory of John Loy, hosted by Lynda Witte

Kramer Chili Cookoff, in honor of Marcus Kramer, hosted by Elizabeth Kramer

Lilah's Lemonade Stand, in honor of Lilah Mueller, hosted by Kimber Heiling

Michelle Hopkins Golf Tournament, in honor of Michelle Hopkins, hosted by Hugo Van der Moer

Million Dollar Bike Ride, hosted by the National MPS Society and University of Pennsylvania's Orphan Disease Center

Napa Race for a Cure, hosted by the National MPS Society

Nashville Walk and Roll 5K, hosted by the National MPS Society

Post Office Café 5K, in memory of Mark and Casey Lessing, hosted by the Lessing family

Raleigh Run for Rare, hosted by the National MPS Society

Rylee Noble Fundraiser, in honor of Rylee Noble, hosted by Rylee Noble

Rylie Hays Fundraiser, in honor of Rylie Hays, hosted by the Hays family

Sprint to Save 5k Run and One-Mile Walk, hosted by the National MPS Society

Spooktacular, in memory of Dorian and Wynn Johnson, hosted by Mercedes Ramirez Johnson

Stevens Family Fundraiser, in honor of Meekel Stevens, hosted by Marla and Randy Stevens

Superbowl Fundraiser, in honor of Adam Brennan, hosted by Mary Beth Brennan

Text to Give, hosted by the National MPS Society

Viti Family Fundraiser, in honor of Christopher Hohn, hosted by Emily Viti

Walk and Roll 5K and One-Mile Family Walk, hosted by the National MPS Society

Youth Against Cancer Fundraiser, in honor of Sydney Waldman, president of Youth Against Cancer, hosted by Suffern High School

2022 Facebook Fundraisers

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

2022 Champions Circle (monthly giving program)

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

Elia and Sohaib Khatibi (MPS VI)

Education & Publicity

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

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

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

Olivia (MPS I)

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

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

— James Lipscomb, father of Olivia

HIGHLIGHTS

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

Research Grants

Dr. Elizabeth Neufeld receiving the Visionary Award with Lisa Todd, Dr. Emil Kakkis, and Steve Holland

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

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

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

Keegan (MPS IIIA)

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

— Monica Alexander, mother of Keegan

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

Society Research Funding

2022 Competitive Program in Innovative Research

2021 CYCLE III GRANTS
(awarded April 1, 2022)

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

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

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

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

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

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

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

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

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

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

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

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

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

Second-Year Grant Award Funding Disbursed in 2022

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

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

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

2022 Partnership Award
The Orphan Disease Center

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

Summary Financial Report

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

Financial Position

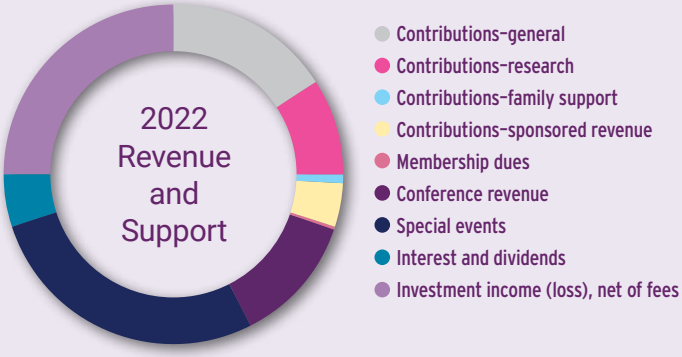
Assets	
Current Assets	
Cash and cash equivalents	$ 969,959
Investments	1,911,190
Accounts receivable	75,705
Prepaid expenses	25,833
Accrued interest	10,132
Total Current Assets	2,992,819
Fixed Assets, Net	
Furniture, fixtures & equipment	3,231
CIP—Website	8,581
Total Fixed Assets	11,812
Other Assets	
Operating leases right of use assets	233,424
Deposits	5,000
Investments—restricted for purpose	143,385
Investments—restriced in perpetuity	1,138,568
Total Other Assets	1,520,377
Total Assets	$ 4,525,008

Current Liabilities	
Accounts payable	$ 150,578
Accrued salaries/vacation	38,463
Refundable program advances	170,000
Current portion of operating lease liabilities	43,977
Total Current Liabilities	403,018
Long-Term Liabilities	
Operating lease liabilities	190,787
Net Assets	
Without donor restriction	
Undesignated	1,450,200
Designated	476,030
With donor restrictions	
Purpose restricted	840,700
Time restricted	25,705
Perpetual in nature	1,138,568
Total Net Assets	3,931,203
Total Liabilities and Net Assets	$ 4,525,008

2022 Statement of Activities

Revenue and Support	
Contributions	
General	$ 417,559
Research	248,594
Family support	37,877
Sponsor revenue	100,000
Membership dues	2,300
Conference revenue	332,384
Special events	731,843
Interest and dividends	139,347
Investment income (loss), net of fees	(653,496)
Total Revenue and Support	$ 1,356,408

Functional Expenses	
Research grants	$ 886,520
Direct family assistance and bereavement	97,402
Advocacy and Speaker's Bureau	32,975
Conferences, meetings, and travel	445,370
Sponsored expenses	185,185
Education—newsletters, booklets, web	111,019
Membership database and directory	28,036
Direct fundraising	90,369
Personnel	724,552
Office and equipment	59,279
Other administrative	58,558
Total Functional Expenses	$ 2,719,265
Change in Net Assets	$ (1,362,857)



2022 Contributors

In 2022, the National MPS Society was able to provide support to families and funding for research because of the generosity of the following individuals, families, foundations, companies, groups, and fundraising events. The board of directors thanks you for your dedication. The Society makes every effort to recognize our supporters through *eCourage* and this Annual Report. The following list represents all donations received in calendar year 2022. If your name is not listed, we apologize and ask that you contact us. If we received your donation in 2023, you will be recognized in the next Annual Report.

Humanitarian
$50,000+

BioMarin
JCR Pharmaceuticals
REGENXBIO, Inc.
Sanofi Genzyme
Shanahan Family Charitable Foundation
Sock It 2 Hunter Syndrome, Inc.
Streblow Family Foundation
Takeda Pharmaceuticals
Ultragenyx Pharmaceutical

Visionary
$25,000–$49,999

Homology Medicines, Inc.

Philanthropist
$10,000–$24,999

Wayne and Catherine Bardsley
Marsha Bozarth
Bryson Foundation, Ltd.
Royce Bunce and Elizabeth Sherwood
Denali Therapeutics, Inc.
Brian Gilger
Matthew Hirsch
Scott and Lynn Hopkins
Orchard Therapeutics
Sam and Nancy Ramsey
The Carolyn Smith Foundation

Champion
$5,000–$9,999

Maria Bermudez
Amy and Dan Cherrstrom
Carey and Mary Crumling
Graybug Vision
Mary Hodgdon
Lysosomal & Rare Disorders Research & Treatment Center, Inc.
Janis Miller
Austin and Cheryl Noll III
Patty Paul
James and Pamela Rogers
Seattle Children's Hospital
Larry and Karen Watkins
Gordon Wingate and Cheryl Guidry
Jim and Amy Yard

Leader
$1,000–$4,999

Emily Allen
Helen Allison
W. Andrew and Lauran Jack
Bill and Mary Andrews
Sharon and David Armendariz
Baebies
Banc of California
Carole and John Barnhardt
Olivia Bell
Ross and Hilary Berning
Amber Booth
Austin and Stephanie Bozarth
Brackeen Power Solutions
Jason and Wendy Brackeen
Mary Beth Brennan
Rosemarie Brennan
Dwain Camp
Rob and Diane Cassil
Liam and Mary Cavanagh
Robert Clarke
Michael Clawar
James and Martha Colby
Joel Comer
Maureen Cote
Sarah and Mario Cua
Paul and Cara David
Linda and Dan Day
Jeff and Anne Denneen
Sharon and Robert Dickol
Julie Dopheide
Ernie and Debbie Dummann
Cindi Dunsworth
Nancy and David Edwards
Theodore Eidukas
Ever Freight Transport, Inc.
Marilyn and Gary Figlar
Bart and Sally Finzel
Gerald and Luella Gabriel
GPM Logistics
Jason Grant
Luis and Angela Guajardo
Wallis and Monica Hampton
Alexa Hansen
Deanna and Eldon Hardy
Harris and Associates, Inc.
Lyle and Jade Hays
Stacie Hodgdon
John and Bonnie Hoegl
David and Susan Holder
Jaymi and Jordan Holland
Peggy Holland
Steve and Amy Holland
Hope 4 Hunter
Inspired Financial, LLC
JBMZ Plastering and Stucco
Patricia JoAnn Jennings
Julie and William Johnson
William Johnson
Kajima Foundation
Wendell and Karen Keith
Bob and Ginger Kell

Grayson Ventura (MPS VII)

Kercheville Foundation
Sharon Kinsman
Lawrence and Susan Kirch
Tom and Linda Kirch
Jenny Klein
Terri Klein and Michael Schleter
Brian and Rebekah Klutz
Kayla and Seth Longtin
Wes and Jill Lovell
M6P Therapeutics
Corbett and Brooke Martin
Robert and Constance Martineau
Wynona Maxwell
Cara Mayfield
Joseph and Mary McCafferty
Joyce McCauley
Laura McKeithen
Ann Mclaughlin
Joseph and Jan Melnyk
Greg and Jennifer Mincks
Richard Mosley
George and Kathy Nace
Ncontracts
Austin and Dorothy Noll Jr.
Crystal and Jeffrey Parks
David and Rose Pelton
Mark and MaryEllen Pendleton
Jay and Lori Podesky
Paul Rector
Roy Reuveni
Keith and Sherri Richbourg
Salesforce.com Foundation
Sarantinos Charitable Fund
Peter Schubert
Sigilon Therapeutics
SimonGlover, Inc.
Susan and John Slater
William and Margaret Sly, MD
Maureen Snider
Jack and Barbara Sorter
Jan and Don Sortman
Rosanne and Sam Spear
Leanne and Trevor Spring
Stuart Swiedler and Judy Weiss

continued

Tracy Szemanski
James and Kathleen Tate
Christine and Brian Tippett
Lisa and Jerry Todd
Pam Umstead
Hugo and Marylyn Van der Moer
Josh and Alisa Vitello
Patricia Wagner
Dawn Watkins
Ryan Watts
Bret Weber and Zhesi Chen
Dr. Klane and Mrs. Amy White
Tom and Kim Whitecotton
Roy and Amanda Wilson
Donald and Lynda Witte
Jared and Courtney Wolff
Kitty Yelland

Volunteer

$500–$999

Lee Ann and Derek Adams
Stuart and Karin Adams
Brian Addington
George and Gail Anderson
Joseph and Kristina Ashton
David and Mary Ann Backensto
Bart and Patti Barner
Amanda Bartlett
Rita and Mike Basom
BE Fit Modern Pilates
David Beatty
Alicia and Chad Bohley
Daniel and Debra Brockman
Carol and Spencer Bryant
Bulldog Builders
Scott and Connie Carney
Walter and Gretchen Clayton
Colonial Materials, Inc.
Susan and Gene Corbett
John Cote
David and Kathryn Croson
Dennis Farms Vineyard and Walloon Lake Winery, LLC
D'Lass Dent Co.
Jim and Michelle Dodson
Mark Dorfler
Vidmantas and Cecilia Duda
Nancy Dunn
Stephen Dunn
Candace and Ben Eastman
Eco-Safe Wastewater Technologies
Brian Edling
Christopher Edwards
Marie and Ralph Edwards
Carla Ellard
Envase Technologies
Wayne and Joan Eppehimer
David and Elise Esposito
Margaret Ference
Vivian Fernandez
Letitia Foster

Jolene Funderburk (MPS IIIA)

Robert and Melanie Franko
Chris Frost
Haiyan Fu
Donna Glenn
Peggy and Daryl Glenn
Tom and Anne Gniazdowski
James Groody and Kimberly Krehely
Pam and Richard Gross
Rob Hagelin
Laura Hansen
Diana and Michael Hanson
James and Kelly Hart
Mark and Jane Hauser
Joanne Hayo
Kimberly Heiling
Trish Hejazi
Kathleen Hillyard
Amanda Hoffman
Claude and Andrea Holliman
Zhanzhi Hu and Pei Wang
Brenda and Franklin Hutcheson
Jennifer and Bryan Hutcheson
Mark and Brenda Jones
Jordan Park Mission 1st Fund
Carl Kapes
John and Janet Kappel
Brian and Kris Klenke
Anne and Nathan Krick
Brock Krizan
Noni Langford
Chris and Anna Leatherow
Little Angels Memorial Park, LLC
Lauren Louison
William Massa Jr.
Michael McCarron
James and Kimberly McClelland
Alison McMahon
Chris and Diane Meyerpeter
Joe and Paige Migliozzi
Narsimha Misra and Erika Breen
Eric and Amber Mongan
Sarah and David Moore
Nicole Moss
Alison Myers
Courtney and Michael Nash
Elizabeth Neufeld, PhD
Afshan Numan
Bob and Eleanor Nurre
Joanne O'Brien
James and Mary Olson, DDS
Gerard O'Reilly
Thomas Owens
Mary Jo Page
Michael Pando
Thomas and Vickie Patterson
Nicole Paulsen
Stephanie and Jake Peebles
Alan and Diana Pendley
The Perk South Perkasie Hotel, Inc.
Linda and Dave Perry
Donal and Susan Phillips
Dan and Pam Pierce
Lynda Polgreen, MD
Larry and Annette Pung
John Raidy
Mercedes Ramirez Johnson
Kim Ramsey
Randall Roofing, Inc.
Dennis Reed
Greg Rick
Ron Rineer
Patricia Robbins
Rogers and Company Landscapes, Inc.
Mark and Alice Sands
Sanofi Foundation for North America
Timothy Schaffer Roofing and Siding, Inc.
Schleter Painting and Drywall, LTD
Mathias Schmidt
Jonah Schnel
Edward and Evelyn Schultz
Alexander Schuth
Victor Seropian
Dennis Shelly
Anna and Jake Shermeyer
Erik Shingle
Toby and Stephanie Short
Mahesh Shrestha
Priscilla Slaven
Scott Smith
Marilyn and Willard Sniffin
Bob and Susan Steiner
Andrew and Dianna Stoffel
Brian and Marla Storm
Swinger Coil Systems
Tamalpais Pediatrics
Charlotte Tate and Blair Euverard
Denise Thomas
Sheila and Michael Thornton
Herbert Tilsner
Shirley Todd
Anne France Tremege
Richard Waldman
Raymond Wang
Bob Ward
Ryan and Stefani Watson
Mary and David Whiteman
Jim and Kim Wilsford
Kaitlyn and Adam Wilson
Russell Witt
Kevin and Peggy Yard
James Yates
Danielle and Abe Yokell
Gilda Youdeem

Friend

$250–$499

Raheem Akbari
Dean and Katherine Aker
Amy Alix
Cindy Alix
Dana Andersen
Ralph and Martha Anderson
Peter and Diana Argeres
Steven Ausband
Joe and Susan Babic
Ethert and Pauline Baird
Heather and Nathaniel Barr
Stacey Beckhardt
Ben's Dream
Monika and Jack Berg
Joel and Leeann Bernbaum
Kathryn Bickham
Cheryl Bien
Bruce Bjorkman
Melany Bjorkman
Claudina Bonetti
Wendy and Matt Boyrie
Julia Bradley
Pamela Breuckmann
Dawn Brewer-Reilly
Susan and Dennis Burke
John Burnett
Dennis Burns
Barbara Cabello
Richard and Sue Cadena
Mark and Stephanie Caldwell
Victoria Calzada
Lilian Camacho
Heidi and Keith Caswell
Joseph Catmull

America's Charities
Robert and Kathryn Coleman
Donna Connely
Odette Cook
Guy and Donna Cooper
Ryan Cote
Gerald Cox
Stephanie and Shawn Cozine
Elaine and Matthew Cramer
Michael and Anne Crecco
Jason and Tamara Cullere
Caroline Dabney
Amelia Defilippis
Gilbert and Julie Di Paolo
Amy and Juan Diaz
Doug and Diane Diehle
Seth and Amy Downen
Ginny Dubose
Charlotte and Ben Dunlap
Elks Lodge 2235 Carteret BPOE
Terry Epps
Teresa Everett
Patrica Farrell
Tim and Tracy Finnegan
Bernadette Fischer
Janet Forde
Teresa Frederick
Gerald and Luella Gabriel
Marian Gardner
Roslynn and Timothy Garvin
Kevin Gates
Nicholas Giglio
Julie Gragowski
Teresa Hallett
Robert Harvey and Roxanne Maffitt
Mark Haskins, VDM, PhD
Kirk Henne
Christine Ho
David Hoffman
Hailey Hoffman
Diedrich Hohn
Travis and Alyssa Holland
Paul Holzapfel
Judy Hughes
Maggie Hupcey
John and Yvette Iannelli
Paul Impagliazzo
Kelly Jackwicz
Amanda and Michael Johnson
JP Morgan Chase Foundation
James and Mary Kalteux
Kathleen and Carl Katitus
Carla Kefallas
Daniel Kehoe
Christopher Kenworthy
Brad and Makena Kimminau
Michele Kinder
Stefanie Kuhnhausen
Derek Land
Laplink Software
Vicki and Stu LaRoche
Doug and Angela Lee
Susie and Glenn Lee
Theresa Leggett
Monica Leone and family
Gib and Sandra Lewis
Kathryn and Hai Lieu
Donald and Karen Louden
Chuck and Nancy Lukondi
Landon Mackie
David Marshall Jr.
Keith and Jennifer Marshall
Laura Marwill
Dorothy Mask
David Massa
Stephen and Marie McClurg
Shane Mericle
Jason and Christie Michaels
Beverly Miller
Cindy and David Miller
John and Rosalind Miller
Jason and Colleen Moore
Melissa Moore
Colie Neidlinger
Aline Newman
Sharon O'Connell
Casey and Jennie O'Connor
Kayla and Pat O'Connor
Dennis O'Donnell
Cristol Barrett O'Loughlin and James O'Loughlin
Thomas and Barbara O'Malley
Thomas and Peggy O'Malley
Amy O'Reilly
Cliff Orvedal
Sheila Payne
Susan Pestrak
Nancy Peterson
Dawn Phillips
Kim and Keith Phillips
Brad Plantiko
Beth Pletcher, MD
Rosalyn Porcano
Prime Global Medical Communications, LTD
Richard Ramsey
Sue Rattman
Tina Ratto
Ilana Richman
Zachary and Alison Rinaberger
Dan and Rita Robertson
Rajat Rohatgi
Glenn Rosenbluth
Joel and Kate Rosenthal
Richard Rowe
Brian and Stephanie Rubinstein
Rural Health Services Consortium, Inc.
Jagdeep Sahota
Claire Salcher
Charlotte and Nate Sanson
Donald Saunders
Sheila and Richard Schlesinger
Riddhi Shah
Andrea Shaughnessy
Brian Shingle
Tami and Don Slawson
Jodi Smith
Angela and Michael Sochacki
Sonnax Transmission Co.
Roseanna Spizzirri
Step Country & Dance
Hilary Streeter
Suffern High School
Joanne and Mike Sundermeier
Jack Swepston
Becky and Robert Tanamachi
Kari Tarvin
David and An Tootill
Michelle Towell
Leslie and Alex Urdaneta
Sagar Vaidya
Todd Waddell and Sarah Aaserude
Terry and Nancy Wain
Donna Weaver
Chrisitine Weeks
Tom and Theresa Weisenbach
Tracy Welch
Colin White
Dax and Cameron Williamson
Amy Winstead
Sheri Wise and Eric Lueb
James and Carol Yard
Ray and Priscilla Zechender

Donor

$100–$249

Faiz Abdul Wahab
Richard and Claudia Ackerman
Jodi Adams
John Agan
Dean and Katherine Aker
Jack and Nell Allen
Robert Allen
Richard and Carol Anderson
Ted Anderson
Trey Anderson
Cindy and Mark Andrews
Shan Andrews
Gerald and Susan Anhalt
Elena and Philip Anischenko
Selina and Chris Arce
Betty and Barney Arceneaux
Colleen and Shawn Arni
David and Stacey Aronson
Cybill and Bruce Aros-Pearson
Robert Astamendi
Camilo Asuncion
Nancy and Marty Athy
B.E. Warfield Contracting
Andrew and Heidi Bahmueller
Kathleen Bailey
Bair's Tree and Lawn Service
Anna Bakardjiev
James and Mary Baker
Ava Baldwin
Julie Ballesteros
Mark and Alberta Balliet
Joseph and Jacqueline Balukin
Len and Barbara Barcousky
Keith Baron
Kirsten Barringer
Kristen Barton
Eileen Basquill
Patricia Bates
Michael Batiller
Mark Beasom
Cecelia Bechelli
Cynthia Beiting
Mary Beiting and Jeff Von Handorf
Mark and Mary Beiting
Michael and Mary Anne Beiting
Linda Benner
Nicole Bennett
Caspar Bentinck
Danielle Berster
Sylvia Bevilacqua
Anne Marie Bisner
Greg Blackburn
Kristie Blackwood
Clinton and Lindsey Blakeley
Joy Bland
Donald and Nancy Bobo
Jeffrey Bodnar
Mike and Grace Bodura Jr.
Robert and Anne Boggiano
Michele Bohley
Betsy Bombola
Bon Voyage Travel
Michele Bonistalli
Dave Bortz
Jeannette Boutin
David Bowling
Nancy and Leister Bowling
Kathy Bowman
James Bradley
Dale and Myriam Brandt
Marc and Beth Brdar
Julie Bremer
Jenna Brennan
Joanne Brennan
Tom and Suzanne Brennan
Thomas Broderick
David and Barbara Brooks
Matthew and Kara Brown
Bruart Collision
James Brubaker
Joan Bucchino
Janice Burns
Mary Burns
Mary Byrnes
Rafaelito Caba
Michael Calderon
Michael and Karen Calhoun
Cathleen and Peter Caliguire
Andrea Hernandez Calle
Kyle Carbert
Claudia Carmichael
Niall Carolan
Madeline and Alex Casper
Randy Castro
Johanna Cepeda
Carmela Cerdena
Mabel Chan
Steve and Sandy Chapman

continued

Maddison Rios (ML II)

Andrew Charest
James and Joan Charters
Aparna Chatterjee
Charlene Chen
Cole Chesney
Steve and Karole Chesser
Peter Chin
Daniel and Sharon Chisholm
Brian Chow
Paul and Diane Christ
Laurie Christiansen
Rob Christiansen
Suzanne Christie
Mary and Mark Cicero
Linda Cimoli
Ann and Rick Clark
Edith Clark
Kerri Clark
Mildred Clark
Susan Clineburg
Ross and Belia Coddington
Kari Cohen
Margaret Cohen
Mary Beth Colatruglio
Justin Colgan
Susan Collins
Valerie Condon
William and Margaret Cook, MD
Gabe and Natalie Corbett
Gary and Linda Corbett
Erin Cosenza
Chris Costello
Country Creek Winery
Tania Cover
Gary and Judith Cox
Katheryn Cox
Jill Crandley
Barbara and Ron Crecco
Kelly Crecco
Patty Cridland
Billi and Jeremy Crockett
Cristina, Calisi, and Courtney Cruz
Jasmine and Emmanuel Cuffee
Jill and Shawn Dahlstrom
Susan and Bob Dahlstrom
Melissa Dalburgs
Bill and Laura Dapper
Bobby and Kelly Daquara
Oliver Davis
Maria De Granillo
Louis Debarberie
Brian Debord
Margaret Dees
Janet and John Dennis
Samantha and Douglas Detmers
Sabine Detweiler
Dolores Diaz
Timothy Dimmick
Leigh Diskin
Darrell and Kay Distefano
Karen Djukic
Kathy and Paul Dobrowolski
Jin Dong
Ido Dotan
Gary Doty
Chris Douville
Doylestown Royal Arch Chapter #270
Betsy Drew and Ken Imagine
Karyn Driessen
Daniel Duffy
Russell Dugoni
Terry and Irene-Mary Dunbar
Pat and Kathy Dunn
Tracy Dunz
Jill Dwyer
Michael Dwyer
William and Carolyn Eames
Herman and Mary Earwood
Pamela Eddy Martineau and Robert Martineau
Helen and Steve Edgington
Charles Ellard
Matt and Cydnie Elliott
Howard and Kathy Elmy
William English
Thomas Ennis
Clark and Susan Ensz
Leah Erikson
Sue Erikson
Josephine Eriole
Patricia Espinal
Steven and Deborah Estes
Cecilia Fairley
Peter Fan
Owen and Helen Farley
Robert and Amy Farrell
Tasha and Bruce Farrell
Geraldine Faucett
Lynne Fenn
Nestor and Mona Fernandez II
Carol Ferry
Anne and Brad Fields
Hildegard and Joseph Filebark
Deborah Finney
Damian Fiore
Michael Fischer
Joseph and Stacey Fisher
Francine Fishman
Jennifer and Chris Fitzgerald
Greg and Sarah Fletcher
Richard and Cheryl Fletcher
Lindsey Flewwellin
Gary Flores
Peter Flottman
Andrew and Joan Flynn
Kay and George Follett
Tim and Laurie Folsom
Kaeline Fontaine
Maria and Steven Foshay
Betsy and Steve Fowler
Marjorie Fowler
Ronald and Sheila Francis
Greg Frank
Erika Freiberger
Sheldon and Jacqueline Friedman
G & F Carpet, Inc.
Jose and Fe Gabriel
Stephen Gagola Jr.
Scott and Gloria Gainforth
Thomas and Sylvia Gamache
Stephanie Gasparovic
Robert Gassman
George and Jaja Gawartin
Damon Gaylor
Thomas and Debra Gebbia
Lisa Gehtland
Angela George
Laura Gerke
Cheri Gey
Sarwa Ghosheh
Dianne Gille
Dennis and Sharon Gillham
Alisha Gilliland
John and Lynn Gladysz
Jeff and Laura Gollehon
Franklin Goodwin
Gene Grabinski
David and Catherine Graham
Anna Gram
Linda Grant
Karen Graven
Robert and Maira Gray
Rose Greco
Kristin Green
Mitchel Greenburg
Sandra Greenland
Matthew and Lauren Greer
Thomas Grierson
Lorelei Griffith
Juan and Sylvia Guajardo
Larizza Guerrero
Stanton and Jean Gunnells
Christopher and Patricia Guyre
Janet Hanna
Tammy Harder
Rodney and Donna Hardy
Paul Harmatz, MD
Jeffrey Harris
Darren Hart
Mary Hart-Burns
Bernard and Betty Harvilla
Andrea Longston Hau
William Hauselt
William and Carly Hausermann
Andrea Haynes
Larry and Barbara Hays
Ashley Haywood
Brenda Haywood
Jessica Haywood
Joyce Haywood
Stephen Hayworth
Erin Heath
Paul and Marjorie Hebert Jr.
Coy Heldermon
Anastasia Henry
Christopher Hernandez
Mark and Darlene Hesprich
Erin Heyert
Gwendolyn Heys
Jerry and Elizabeth Highfill
Tyler Highfill
Carole Ho
Robbin and Anita Hodgkins
Anne Hoffman
Katey and Andrew Hoffman
Mark Hoffman
Melissa Hogan
Jimmy and Sasha Holder
John Holder
Sarah Holland
Steven Holley
Tom and Jackie Holt
David and Linda Hooks
Joe and Tina Hopkins
Paul and Laurie Howard
Todd and Jennifer Howard
Jason Huang
Shelby Hubert
Marianne Hudar
Mike and Joanne Huff
Danielle Hughes
Sheryl Hughes
William and Margaret Hughes
Janice Humphrey
Sheldon and Andrea Hunter
Robert Icard
Jeni Ingersoll
Edith Iserman
Bermans Iskander
David Istock
T. Jackson
Rebecca Jacobsen
Larry and Joy Jeffers
Brian Jeffries
Daniel Jennings
Debora Jennings
Timothy and Jennifer Jennings

CONTRIBUTORS

Justin Jessee
Nicole Johnson
Alicia Jones
Celia Jones
Jeff Joslin
Laura Judge
Alice Kalamar
Jerry and Pat Kanney
Joseph and Michelle Karl
Evgeniy Kashchenko
Raimund and Inge Kasner
Jon Kasuboski
Paul and Nga Keith
Kristine Kelly
Lawrence and Jacqueline Kelly
Mark and Michelle Kesselmayer
Mary Pat and John Kessler
Ardis Ketterer
Jeanne Kiefner
Karen Kiker
Kristin Kilburg
Donna and Fred Kimbro
Isabelle King
Gary and Janet Kirch
Tom and Julie Kirch
Thomas Klem
Jerry and Katherine Klemm Jr.
Megan Klenow
Stephani and John Klopmeyer
Shelly Knapp
Linda Knight
Michael Knudsen
M. Lucie Kober
Ivan and Leann Koblitz
Fred Koehler
Louise Kofron
Cathryn Kohlman
Neil and Terri Korte
Edward Kowalski
Robert and Jennifer Kozlowski
Molly and Mika Kozma
Peter and Joann Krajewski
Clint and Nikki Kremer
Carol Krizan
Jill Krizan
Kelly Kroeger
Carl and Deborah Kruse
Margaret Kruse
Mary and Keith Kruse
Alberta Kuhlman
Carol and Thomas Kuhn
Dan Kulbieda
Amy Kwan
Tamara Ladd
Cheryl Lahm
Karen Lai
Shawn Lamb
John and Joyce Lane
Steven and Cam Lanier
Jill Lanois
Jeff LaPrete
Eileen Larence
Catherine Latella
Helen Lau
Ellen Laves
Lisa Leavitt
David Lebec
Mary and Dave Leckrone
Jina Ledbetter
Rebecca Ledbetter
Eric Lee
Hui-Li Lee
Ron and Naomi Lee
Sadie Lee
Eric Lefkof
Danny and Sally Leinen
John and Linda Lejeune
Lemon Drops Apparel and Gifts
Elena Leon
Patricia Leonard
Elizabeth and Robert Leski
Alexie Lessing
Peter and Gerilyn Lessing
Joan and Mark Lessing
Janine Levitch
Michael Lew
Michael and Karen Lewandowski
Wayne and Sharon Lewis
Scott and Gabriella Lich
James and Debra Lindsey
Dawn Lingo
Jenn and Jamie Lipscomb
Lucy and Bob Little
Donna and David Littrell
John and Millette Litzinger
Sharon Lockhart
Holly Logan
Beth and Nick Lombardo
Sandra Louis
Karen Loveless
Judy and Donald Maas
Dutch MacDonald and Becky Mingo
Pren Maddi
Sharyn Madison
Maurice Malfatti
Barbara and George Malina
Jennifer Mallare
Lori Manering
Don and Carol Manning
Gary and Lana Marble
Eileen Marchica
Wayne Marshall
Mary Martin
Sarah Martin
Jocelyn Mason
Meghan Matt
Carol and Darren May
Jeffrey and Karen Mays
Ally McAllister
Sean McCabe
Brian McCann
Laura McCann
Anne McClelland
Scott and Evelyn McClelland
Eric McGraw and Annie Hancock
Ryan McGraw
McGraw Chiropractic, LLC
Amy McGuire
Michael and Kim McGurk
Robert and Lorie McKaig
Laura McLennan
William and Karen McNeil
Elizabeth McWhirt
Eric Meier
Rene Meisner Williams
David Melian
Alishah Merchant
Amber Merrell
Terrence and Elizabeth Merrill
Kathleen and Stanley Meyer-Tamaki
Cynthia and David Miller
Cynthia and Kent Miller
Eric Miller, OD
Lynne Miller
Ray and Amy Miller
Sandra Miller
Patrick Milligan
Milo's Tea Company
Richard and Leslie Mindemann
Miriam Mohler
Gary and Carol Moll
Edith Monachello
Dolores Monterosa
Kristin and Brian Moore
Mitchell and Cherylynne Moore
Jeanne Morgan
Ron Morrissey
Carmen Mosley
Stephen Mothes
Rene and Patricia M'Sadoques
Stacey Mumbower
Michael and Anita Muonio
Carolyn Murphy
Sharon and Thomas Murphy
Susan Murphy
Michael and Amy Murrell
Gabrielle Muse
David and Cathy Musselman
Lisa Nakasone
Susan Narducci
Debbie Nash
Katherine Neff
Ross and Shawna Nelle
David and Karen Newman
Vickie and Scott Newman
Arian and Yvonne Nickel
Beverly Nivens
Shaun Noble
Jessica Nolan
Anne Novak
Rita Nunag
Cynthia Nussbaumer
Kathleen O'Brien
Shannon O'Brien
Connie and Jim O'Connell
Deborah O'Connor
Leonardo and Andrea Ojeda
David Oleander
Mary Oliger
Glenn and Cara O'Neill
Jason and Christi Ormeroid
Debra Osifat
Eileen and Larry O'Steen
Carol Oswald
Amy Owens
Angie Owens
Chris Owens
Daniel and Tanya Oxman
Michael Palumbo and Elizabeth McCarthy
Jeanne and Bruce Palzer
Andrea Papa
Jae Park
Shana and Dan Parker
Reagan Passant
Melvaree Pate
David Paul
Joseph Pederson
Linda Perrella
Perry Hospitality
Ashley Peruski
Thomas and Stacy Peters
Frances and David Peterson
Robert and Nancy Peterson
Marietta and George Petters
Patricia Phillips
Vernon and Patricia Phillips
Janice Picerno
Marion Pierce
Sherry Pierson
Elizabeth Pillsbury
Pine Tree Baptist Church
Justin Pineda
Sarah Pinkley
Laura Pisani
Rachel Pitcher
Linda and Lamar Pittman
Deborah Plotts
Cindy and Bill Plunkett
Poettker Construction
Katherine Ponder, MD
Alan and Kathy Portnoy
Tom and Carrie Porzel
Susan Proctor
Vijay Pulijal
Lewis and Salli Pung
Barbara and Keith Pushee
Mark Pyper, Esq.
Thomas and Lisa Qvistgaard
Katie Ragle
Jay Raju
Carlos Solis Ramirez
Linda Ramirez
Ralph and Marva Ramsey
Susan Ramsey
David and Bette Rattan
Kay Rattan
Brittini Ray
Patrick Ray Jr.
Celeste and Stephen Raydo
Re/Max 440 Realty, Inc.
Shirley Reber
Paula Rector
Debra Reed
Elaine Reed
Timothy and Deborah Reed
Denise and Loren Reit
RaeMarie Renna
David and Julie Renshaw
Amanda Reuter
Kirk and Kathy Reuter
Carol Reynolds
Thomas Rezmer

continued

Francoise Ribitzki
Patricia Richlin
Judith Ries
Patricia and Jim Rigby
Mary Ann Rios
Gary and Bonita Ritondaro
Holly Rivera
Gretchen Roberts
Ann Robertson
Rusty and Alison Rochelle
Vanessa Roennigkev
Nina Rogers
Michael and Jesse Rollier
Sherrie and Tony Roman
Richard and Darlene Rome
Debbie Rood
Jill Rose
Tracy and Thomas Rose
Rossetto Realty, LLC
Craig Rubens
S&T Bank
Sara Sabin
Christopher Sadler
Randy Saitta
Eduardo Salas
Lysa and Adolfo Saltzman
Carmen Sanchez
Srinath Sanda
Victor Santoro
Dr. George and Mrs. Athena Sarantinos
Karen Saunders
Joseph Scalice
Kimberly Scearce-Levie
Jean and Todd Scheffler
Judy Schirripa
Alan and Deborah Schmidt
Edward Schmidt
Victor and Marion Schoenbach
Mike Schwarz
Bruce and Lisa Scott
David and Diane Scotting
James Seaton
Clover Sellden
Lynn Ann Sembach
Christopher Shahrooz-Foo
Lorna Shannon
Muhanad and Jumana Shawkat
Adam Shaywitz
Arthur and Marilyn Sheekey
Jared Shelton
Julie Shih
Anna Shimanek
Patricia Shore
Rosemary and Michael Shourds
Katie Shropshire
Rodney Shute
Adam Sigelman
Marilyn Sigsbury
David and Rebecca Silkey
Cass Silletti
Edward Simcox II
Donna Simon
Bruce and Sherrie Simpson
Patrick Skacel
Burt and Leenie Skolnik
Carol Slater
Douglas Slawson and Linda Lepeirs
Mike and Barbara Smith
Stephen and Sara Smith
William Smith
Anthony and Pamela Sosinski
Michael and Laurie Sparkman
John Specht
Speech Pathology Services of WNY, PLLC
Kelly Spicher
Bridget Spoleta
Victoria and Mike Spring
Diane and John Stabb
Charles Stamm
Don and Cathy Stapleton
Starbucks Store 2985
Steam Logistics
Jeremy and Rena Stearns
David and Kathy Stembridge
Kenneth Stewart
Jay Stickles
Maureen Stickney
John Stio
Benita Stone
Glen Stout
Eric Strait
Kevin Sullivan
Michael and Candace Sullivan
Richard and Nancy Sulzberger
Eugenie Super
Kathy and Vic Surma
Laura Survant
Rose Sweet
Clayton and Kay Swenson
Stephen Swift
Noel and Nancy Talcott
Irene Tan
Michelle and Seiji Tanenbaum
Jack and Patty Taormino
Kristi Tatarian
Susan Taylor
Daniel and Valerie Teitsma
Deborah Telch
The Boyles Firm
Ilene Thompson
Julie Thompson
Jessica Thrasher
Timothy and Gretchen Tierney
Steven Tietz
Alex and DeAnna Timbrook
Kathleen Tobin
Lorie Tolson
Debra Tomasone
Jane and David Tomick
Jon and Ellie Totz
Joan Trainor
Mike Trivisonno
William and Faye Trotter
Melissa Turner Ronacher
Edward and Lauren Underwood
Michael Urtel
USA Couriers, Inc.
Diana Vaillancourt
Kelsie and Bryan Vander Meiden
Rich and Debbie Vanderpool
Lavonne and Dennis VanderWeide
Edward and Mary Vargas
Robert Vega
Kristy Vetter
Susan Villar
Keith Vogt
Jerry and Sue Von Handorf
Lucy Wagner
John and Shirley Wake
Nancy Wallace
Cortney Walters
Helene and Jason Walters
Sara Ward
Kenneth and Victoria Warner
David and Cheryl Warning
Steve and Martha Waters
Brooke Wehbe
Matthew Wehren
Laura Weidner
Deirdre Weil

Jamie Hart (MPS IVA)

Donald Weimer
Brian and Jessica Wellman
Mark and Cindy Wellman
Don and Lisa Wells
Dick and Kay Werth
Gregory Wetzelberger
Margaret White
Sarah and James White
Thomas and Blanca Wier
Allison Wik
Lois and Truett Wilburn
Thomas and Kathy Will
Brian and Dolores Williams
James Williams and Rosie Oakley
Jeffrey Williams
Joseph and Jacqueline Williams
Kimberly Williams
Rick and Dawn Williams
Catherine Wilson
Celine and Theodore Lee Wilson
Matthew Wilson
Women of the Moose
Connie Wong
Cynthia Wong
Susan Woodward
Jimmy and Susan Workman
Jason Wright
Stanley Yang
Sharon Yergeau
Michale Yocum
Christopher Young
Leslie Young
Richard Zachariason
Denise Zahn
Joe and Jennifer Zamboni
Cynthia and Kenneth Zawacki
Cecilia Zhou
Karen Zinn
Evelyn Zohlen
Debra and Dennis Zurek
Dennis Zurek
Edie Zusman

Advocate

$1–$99

Kay Anne and Peter Abbott
Omowale Abdul-Rahman
Jessica Abel
Matthew Ackmann
Joseph and Roberta Adam
Barbara Adams
Beckie Adams
Kenneth and Donna Ahles
Allan Aks
Linda Alegria
Beau Alesi
Brett Alexander
Lorena Almanzar
Jackie Almodovar
Elizabeth Alvis
Donald and Julie Ames
Jasmine Anaya
Peter Andersen
Bridget Anderson
Dave and Cindy Anderson
Beth Andretich
Sara Andrew
Alice and Frederick Andrus

Steven and Trudy Anolik
Juan Aponte-Ubillus
Mariana Aragon
Seyede Ardakani
Fernando Armendariz
Elizabeth Armstrong
Audrey Arnold
Tressia and David Arnold
MaryBeth Aylward
Glenn Babula
Marissa Baclig
Thomas Baeza
Jeff Bahm
Russell and Catherine Bahm
Pat and Michelle Baldwin
Scott Baldwin
Candice Balloue
Allison Bannick
John and Shantell Barbour
Corazon Barcelona
Charles Barhold
James and Barbara Barker
Mia Barker
Amy Barkley
Dwight and Debbie Barkley
Beth Barnes-Dent
Gabriele Barnett
Lorraine Baron
Rik Barr
Mary Barringer
Cathleen Barrows
Dillon Bartlett
Sheryl Bates
Jody and Mark Batton
Alice and Ron Beam
Geoffrey and Brenda Beard
Jamie Beasley
Karen Beatty
Tim Beck
Natalie Beckman
Vera Belamide
Janice Belter
Samuel and Kristin Benedict
Tony Bertauski
Ginger Beverly
Gary and Louise Bezecny
Dorothy Bhola
Melissa Biddle
John and Jenny Birmingham
Billy Bishop
Blake and Kacee Blackwell
Jeanne Blair
Cristina Blakeman
Todd and Nicole Blancheri
Roberta and William Bloomer
Alison Blue
Lawrence and Kathleen Boemker
Heather and Mack Boening
Jacqueline Bogucke
Joseph Bonville
Mary Bonville
Corrine Boot
Robert Borgman
Richard and Bonnie Borresen
Scott and Marcia Bosak
Thomas and Joyce Boster
Paula Bothwell
Liz and Colby Bowles
Christina and William Bradford
Kathleen Brady
Catherine and Timothy Brand
Ellen Brennan
Kathleen Brennan-Miller
Hal Brigham
Kristen and Joshua Brodie
Chris Brodmerkel
Adele Brogli
Curt and Lou Brooks
Connor Brown
Margaret and Milton Brown
Robert and Marianne Brulhardt
Carol Bruner
Karla and Alberto Bueso
Jane and Kevin Bugler
Larry and Myrl Burdett
Clive Burger
Jenna Burke
Melissa Burrows
Linda Burtt
Tony and Claudia Busse
Susan Byers
Otis Byrd
Maria Calabro
Marguerite Caldwell
Corbin Caliguire
Ericka Caliguire
Joshua Caliguire
Sage Callaway
Richard Campbell
Tina Carmo Canavan
Judith Candiano
Lori and Russell Canning
Keith and Jennifer Cantin
Michael and Stephanie Caracalas
Kelly and Matt Caram
Vito Caravella
Brenda Carbon
Lauren Carrasco
Barbara Carroll
John Cary
Alexis Calle Casablanca
Kevin and Kathryn Casey
Jonelle Castiglia
Renee Castiglione
Maria Castillo
Peter and Joan Castle
Walt and Mary Castleman
Abraham Castro
Mary Cavanagh
Katherine Cavanaugh
Sylvia Cavins
Christopher Censullo
Sandra Champman
Lewis and Ann Chapman
Bin Chen
Hway Helen Chen
Jackie-Lyn Christner
Julianne and Stephen Christy
Amy and Terry Clark
Barbara Clark
Haylee Clark
Jordan Clark
Kent and Karlene Classen
Terry Clayton
Jo Coan
Dana Cobb
Kate Cockroft
Jennifer Coker
Nancy Cole
Rick Cole
Zandra Cole
Ilse Collazos
Mary Jo and Larry Collet
Shaoling Combs
Lisa Common
Leo Compton
Lois Conklin
Mark and Theresa Connaughton
Angela and Jason Cook
Kate Cook
Katie Cook
Sharon and William Cook
Travis and Janee Cook
William and Peggy Cook
Ashley Cooley
Kimberly Cooper
Susan Cornelius
Doug Corsette
Christl Cortes
Laura Corzine
Kirsten Cowley
Amelia Coyne
Christopher and Ann Crawford
Stan Crawford
Samantha Crawford
Patrick Cronin
Matthew and Patricia Croyle
Blesilda Cruz
Elizabeth and Lowell Culley
Edward and Ann Cummiskey
Marie Cundiff
Brendan Cunningham
David and Maureen Cunningham
Steve Cuomo
Ryan and Kelly Curry
Stacey Curtiss
Susan Cykman
Andrea Cyr
Allison Czapracki
Jeanne Dant
Sharon and Sean Darnell
Dianna Davidson
Daniel Davies
Jay Davis
John Davis
Joscelyn Davis
Pat and Thomas Davitt
Krystle De Guia
Brian J. De Leon
Lori Decuir
James and Melissa Deen
Andreina Delacruz
Paula Delury
Malcolm and Garnelle Dent
Michelle DeSilva
Cheryl Deutschle
Christie Devine
Elizabeth Devlin
Thierry and Elizabeth Dewaghe
Lori Dewald
Teresa Dibley
Amy Dickerson
Chase Dickerson
Wilma Dickerson
Michael DiComo
Jaymie and Troy Dietrich
Patricia Diluzio
Connie Dirks
Amy Dittman
Jaimi and Jeffrey Dodson
Brian and Jennifer Dolan
Yuko Doll
Jonathan and Lisa Dols
Timothy Donnelly
Sarah Donovan
Brett Dooies
Megan and Paul Doran
Diane Doughty
Tom and Darla Dressman
Carolyn Dreyer
Elisabeth Druther
Mark and Jill Dry
Marissa Duarte
Courtney Duggan
Lori and Doug Dunbar
Caroline Eagan
Rachel Eastman
Peter and Sarah Ebelhar
Stephanie Edson
Geri Edwards
Lisa Edwards
Elizabeth and Joshua Eickman
Geoffrey Eill
Shyamala Ekambara
A.J. Elacqua
Colleen Ellenbecker
Christina Elliott
Martin Elliott
Matthew Elliott
Cathy Else
Tara and Jack Elston
Emergency Skills
Brian Engel
Michael Engel
Adrianne Enriquez
Ramona and Peter Erickson
Howard and Ellen Eshelman
Kenneth and Ruth Espenshade
Steven and Kathryn Espenshade
Jim Essig
Michael Eudy
John and Geraldine Euliano
Elisabetta Fabiani
Faith Falk
Helen Fallon
Susan Farrell-Melick
Nira Feeley
Jason Fenn
Fay Ferguson
John and Wendy Ferguson
Laarni Fernandez
Lucille Fernandez
Shantae Fernandez
Vivian Ferreira
Vernon and Misty Ferrell Jr.

continued

Dawn Ferruggiari
Brenda Fillman
Gary and Carolyne Filsinger
Michelle Finelli
Joanna Finkle
Brian and Kathleen Finn
First Baptist Church
Jared Fischer
Darsie Fisk
Amy Fitts
Christine Fitzgerald
Gillian Flynn
Laverne and Peggy Foess
Lorie Fong
Chris Foo
Jen Forshan
Katie Fortun
Cynthia Foster
Gina Foster
Jamie Fowler
Christos Fragkoulis
Amy Francek
Anthony Frangie
Paul and Martha Frank
Allison Frazier
Erin Frey
Janet and Leo Froehlich
Lawrence and Stacey Froehlich
Mark and Marie Frost
Elena Fuentes-Afflick
Jessica and Josh Funderburk
Patricia Fuqua
Annette and John Furr
Scott Furuoka
Marci Furutani
Douglas and Linda Fussinger
Stephen Gagola III
Marcia Galan
Hope Gallagher
Nicole Gallant
Sam Gallishaw
Stephen Gamp
Hector and Nancy Garces
Blanca Garcia
Elex Garcia
Victoria Gardner
Julie and Wayne Garrison
Jordan and Shawn Garvin
Jorge Garza
Sandra Gass
M. Gay-Griffin
Millicent Gebilaguin
Jane Gehring
Steven and Kim Gentile
Katherine Georgely
Beverly Gerard
Rajarshi Ghosh
Arthur and Joan Giammarino
Laura Giardino
Jenifer Gibson
Michelle Gilmor
Tiana Gimbrone
Eileen and Harry Gittins
Denise Glatzmaier
Andrew and Stephanie Glock
Brian and Linda Glover
Jeffrey Goddard
Kathy Godegast
Wayne and Susan Goeldner
Wendy Gonzalez
Marisa Goo
Kathryn Good
Richard and Shirley Goolsby
Julia Gossett
Lee and Tammy Gottschall
Erika Goyzueta
Douglas and Michele Graham
Toni and James Graham
Caitlin Graves
Paul Greely
Tina Green
Delynn Greenfield
Fran and Rob Greenstein
Coyte and Jilian Greer
Forrest and Lorena Griffin
John Grimes
Karina Guevara
Tim and Jenny Guilfoyle
Kevin and Jackie Gull
Jessica Gumerson
Jing Guo
Cheryl and William Guthman
Trudy Guyton
Roger Hacker
John Hackett
Alexa Haines
Jennifer and Jason Hajjar
Yvette Hajjar
Jan Hajnosz
Sheryl and Gerald Hall
Sarah Hamilton
Ted and Char Hamilton
David and Cathy Hamm
Dana Hancock
Addie Hanebury
Erik Haneman
Carol and Bruce Hanford
Douglas Hannah
Randy and Kim Hardesty
Yvonne Harman
Elizabeth Harper
Jeff and Kris Harper
Kim and William Harper
Jeffrey and Barbara Harrell
Cara Harrington
Mark and Keely Harris
Matthew Harris
Julianne Hart
Ryan Hart
Chris Hartigan
Tim Hartigan
Susan Hatch
Joel and Julie Hawkins
Michelle and Steven Hayes
Kelly Haznaw
Michelle Heffner
Erin Hegland
Katriana Hehir
Ron Heideman
Jack and Phyllis Helemes
Dr. Kim Hemsley
Jeanette and Fredy Henriquez
Eloise and Fred Henry
Candice Herber
Bill Herbert
Carrie Herbert
Sandra and Michael Herrera
Marlys Herring
Iris Hicks
Shannon Hicks
Ryo Higurashi
Michelle Hill
Coleen Hiller
Donita Hinckley
Alicia Hoffman
Betsy Hoffman
Kara Hoffman
Mayme Hoffman
Cyndie Hohenberger
Margaret Holley
Ashley and Cody Holm
Melodie Homer
Allison Honer
Susan Hool
Mark Hopkinson
Linda Horrell
Tahmina Hossain
Seid Hourani
Nancy Houston
Lois Howard
Bonnie and Frank Howarth

William Wells (MPS IIIA)

Stephanie Howell
Laura Howley
Debra Hoyopatubbi
Raymond Hrinko
Taylor Hudson
Catherine and David Huey
Joan Huffman
Jean Hummel
Julia Hummel
Patricia and Mark Hunt
Barbara Hunter
Erin Hurley
Kimberly Hutchens
David Hutton
Robert and Marguerite Iannacone
Linda and Allan Iezzi
Kourosh and Leticia Iranpour
Steve and Melanie Irish
Harold and Laura Ives
Jessica Iwanicki
Helen Jacobsen
Joanna and Brian Janssen
Fausto Jaquez
Jeffrey and Valorie Jellerson
Camilla Jenkins
Christine Jocoy
Janet Johansing
Anna Johnson
Callum Johnston
Harper Johnson
Jeanne Johnston
Sherrie Johnson
Charlene Joyce
Noreen Joyce
Nicole Jurik
Eric and Amy Kaiser
Stephanie Kalinowski
Meredith Kalman
Samantha Kamras
Erika Kane
Faye Kangas
Rick and Beth Kania
Stephanie Kareht
Pamela Kato
Gail Katz
James Keane
Christine and Kirk Kehrley
Rolla and Kathryn Kehrman
Sherry Keithly
Mary Kelleher
Jennifer Kelly
Peter Kennedy
Anita and William Kennelly
Allison and Cory Kerndt
Marie Kester
Ron and Carol Ketterer
Anna and Dave Kidwell
Yoon Kim
Leigh Kimbro
Kevin and Mary Kimmet
Pamela King
Josh and Katie Kirby
Whitney Kirkland
Jennifer Klein
David Kleinschmidt
Jake Klingler
Ray and Margo Knabusch
Susan Kolkmeier
Suty Komsonkeo
Harold Kozlowski
Cynthia Kraft
Andrew Kraus
Mary Krause
Michael and Melissa Kreuser
Maggie Kroeker
Deborah Kruzel

CONTRIBUTORS

Yifang Kryger
Nicole Kuertz
Steven Kuhl
Jerry and Delores Kunz
Debbie Kuo
Amy Kurth
Diane LaForges
Robert and Vivian Lamond
Bridget and Thomas Lamont
Megan Lanese
Julie Lange
Michelle Lankford
Dawn and Philip Laorenza
Stacey Lapine
Karen Larson
Dulce Lasa
Erin and Shea Laughlin
Elizabeth Lawrence
Michael Lawrence
Bruce and Judith Lawson
Curi Lawson
Robert and Katie Lawson
Brian Ledermann
Kenneth and Sandra Ledford
Ellias Lee
Dallas Leeah
Susan Leger Ferraro
Kory and Karen Leppo
Barry and Barbara Lewis
Curtis and Michelle Lewis
Alex Liberman
Joella and Eric Liddle
Lynn and John Lilore
Jeff Linehan
Kyle Lingo
Coryne Lippert
Madison Lippert
Barbara Lipps
Seth and Keyla Longtin
Irving Lopez
Valerie Lopez
Loughridge, Inc.
Kirstie and James Lowe
Alayne and William Lowenberger
Michelle Luangpraseuth
Jim and Karen Lubbers
Nicholas and Christina Lubbers
Rebecca Luchenbill
Lucky Leprechaun Vineyard & Winery, LLC
Stefanie Lukins
Jim and Doris Lupardo
Judy MacKay
Patricia Madeux
Jeanora Mairs
Beth Makela
Josephine Malinoski
Maryanne Maliwat
Susan Mandilag
Charles Manzi
Andre and Melissa Marcotte
Teresa and Thomas Marino
Michael and Lori Martin
Alina Martinez
Mollie Martinez
Rut Martinez
Melvin Mason
Shababa Masoud
Marilyn and Paul Massaro
Jonathan Mast
Shirley Mathewson
William Matlach
Cara Mattson
Michaelle and Wolfgang Mauch
Jeff Mausolf
Bryan and Alma Mazur
Sara McAlmond
Debra McArdle
Rileigh McCabe
Ted and Susan McCannon
Paula McChristian
Jim and Martha McCormick
Amber McCullough
John McDermott
Maureen McDermott
Diane and Robert McGraw
Amelia McHugh
Katherine McKenzie
Brenda McKinney
Michelle McKinney
Judith McKinstry
Karen McSorley
Matthew Meahan
Sean Mecca
Daryl and Lisa Mejeur
Will Mejia
Deborah Melnick
Anthony Menendez
Bette Mergen
Gary Mericle
Donny and Molly Merrill
Jennifer and Scott Mestan
Katie Metzinger
Kathryn Meyers
Christine Michaud
Janice Middleton
Anne and Donald Millard
Donald and Joan Miller
June Miller
Rose Miller
Krisitina Miranda
Jackie Mitchell
Mobilecause
Lynn Moffett
Nicolette Moinet
Linda and James Moody
David Moon
Carmi Moore
Wes and Kimberly Morgan
Mariellen Morissette
Diane Morris
Carol Morrison
Nicole Morrissey
Madeline and Merritt Moseley
Ken and Jackie Mueller
Joseph Muenzer, MD
Lisa Muller
Kiraat Munshi
Judith Munyon
Tom Murgatroyd
Brian and Virginia Murphy
Christine Murray
Harlan and Sheri Murrell
Darlene Muscanell
Kristie Musick
Christine and William Muzio
Ryan Muzzy
Kevin Myers
Paul and Gail Myers
Richard Myers
James and Margaret Myrick
James and Susan Napieralski
Kimberly Navillio
Kathy and Josh Nay
Katelyn Neckel
Amber Negele
Denise Negley
Chelsea Nelson
Janice and Brian Nelson
Roberta Nelson
Igor Nestrasil
Aywon and Krystal Nguyen
Nina Ni
Emily Nichols and Xan Weaver
Dan Nolen
Andrew Noll
Andrew Norton
David and Frances Notley
Julie Null
Annette Numrich
Anne and Daniel O'Brien
Analette Ochoa
Amie O'Connor
Kevin and Danielle O'Connor
Nan O'Connor
Julia O'Hara
Maureen O'Kane
Jason O'Keefe
Michael O'Keeffe
Amanda and Shaun O'Neal
Nadia Ono
Lauren Oraham
Leanna Ordanza
Naomi O'Reilly
Eric Ortiz
Eugene and Elizabeth O'Shea
Dorothy and Ralph Ostella
Michael and Evelyn Ostella
Kim and John Outten
Anzonetta Overstreet
Shaunte Padilla and Jeremy Hunter
Caleb Pagliero
Laura Painter
Carmela and Estelito Panghulan
Kristen Pappas
Martha Parker
Rick and Debbie Pastura
Dhawal Patel
Toni-Ann Paulicelli
Kitty Payne
Simone Marie Pearson
Michaela Pease
Robert and Megan Pecl
Janice Pegg
Theresa Peierl
Lisa Pena
Katie Peng
Sophie Pepin
Ana Perez
Coryell Perez
Gemma Perez
Shirley Perkins
Mika Perrine
Catherine Perry
Sarah Peters
Susan Peters
Andre Petersen
Cheryl Peterson
Scott and Lori Phillips
Jacklyn Pierce
Judy Pinsonnault
Cynthia Planeaux
Dianne Ploof
Stephen and Kathryn Pollard
James Popp
Linda Post
Cynthia and John Prediger
Heather Preiss
Cindy Preuss
Alexander Price
Lisa Pyne
Melissa Quigg
Felicidad Quilo
Karen Quinn
Stephanie and Edmund Rabuse
Manmeet Rai
Michael Ramsey
Renee Randolph
Heather Ransom
Suzanne and Ethan Ransom
Nancy Rapoport
Cyrena Rashotte
Melissa Raspa Kick
Dorothy Ray
Mekenna Raymer
Paul and Carol Redmond
Michael Renaud
Bonnie and Ralph Rennaker
Elizabeth Rhodes
Bethanie Rice
Jeffrey and Rebecca Rice
Courtney Richard
Crystal Richard
Joanne Richardson
Richard and Debra Riekkoff
Joseph and Aurie Riley
Becky Ritz
Andrew Roberts
Chelsey and Matthew Robertson
Gisele Robertson
Sabrina Robichaud
Jennie Robin
John and Isabella Rodrigues
Janet Rodriguez
Melinda Roelfs
Nadia Roessler
Dana Rokodz
Casey Romer
John and Cathy Roohan
Michael Rosa
Elizabeth Rose
Jeffrey and Geralyn Roskopf
Mary Jo and Gary Rossignol
Barbara Roth
Mark Rowen
Gayla Royer

continued

Paul and Elizabeth Royer
Suzanne and Ronald Ruchti
Carol and Karima Rucker
Vickie Ruegemer
Ronald Russell
Fay Ryan
Nancy Ryan
Paul and Kathy Rysz
Carol Sabine
Scott Sackett
Sushil Sagarwala
Johanne Saichek
Alexander Salas
Mary Jean Salcido
Emma Samelson-Jones
Alyssa Samuelsen
Blanca Sanchez
Monica Sanchez
Bennett Sanderson
Anthony Sanson
Michael Sanson
Ian and Kelly Santarinala
Don Savino
Darrell and Patty Saylor
Eric Scanlan
Jamie Schacher
Louise Schalow
Madeline Schehl
Rebecca Schell
Laura Schierberl
Jaime and Tyler Schiferl
Patricia Schlabach
Joe and Ginnie Schmidt
Norma Schoen
Catherine and Peter Schreiber
Patricia Schultz
Meredith Schwerdt
Brilla Scott
John and Rebecca Scott
Thomas and Carole Scully
Giselle Secor
Maria Segebart
Robert and Carmel Seifert
Richard Sentochnik
Brian Service
Albert Seymour
Nancy Sforza
Zaheer Shaikh
Kerry and Josephine Shamaly
Lilly Shapiro
Helen Shareshian
Donna Sharp
Greg Sharrits
Linda Sheehan
Nancy and Kent Shelton
Willliam Shen
Kathy and Craig Shepard
Robert Sheridan
William Sherrill
Marika Shimkus
Christine Shuler
Roger and Tara Shultz
Pam Shurmantine
Stuart and Jennifer Siedman
Angelica Sierra
Cassidy Signor
Danielle Signor
Kathleen Silletti
Margot Simmons
Jack and Kathy Simoson
John Simpson
Julie Simpson
Katherine Sippel
Anne and Bob Siudzinski
Juliet and Dean Skuldt
Lou and Chris Slavik
Danielle Sliter
Bette Smart
Brenda Smith
Elaine and Mark Smith
Laura Smith
Pamela Smith
Salina Smith
Teri Smith
Tommy and Barbara Smith
Amber Snow
Heidi Sosinski
Joshua and Sheri Sowden
Barbara Spangler
Kelly Spencer
Laura Spencer
Samantha Speruggia
Jacob Spitz
Patty Spring
Nancy Sprosty
Don Startt
Max and Marilyn Statum
Lynn and Thomas Steinbach
Kim Stephens
Alicia Stephenson
John Stephenson
Mark and Kathy Sterling
Meghan Stilson
Tracy Stock
Kristin and Matthew Stockin
Elizabeth Stoltz
Natasha and Terry Stringer
Nancy Stringham
Thomas and Barbara Stroinski
Jung Suh
Larry and Diane Suhr
Scott Sullivan
Melanie Suliveras
Elizabeth Sun
Karen Sun
Ronald and Nancy Swank
Rachel Sweatland
Bill and Lisa Sweeney
John and Kathy Sweet
Sara Szkola
Jenilyn Tabalon
Hanny Tan
Richard Tate
Linda Teeter
Amber TerBeest
Mary Terrell Parnell
Dana Tester
Sharon Thayer
Lynn Theder
Vickie and James Tholen
Mich and Brooke Thomas
Chandler Thurman
Jennifer Till Photography
Margaret Tison
Debra Tobias
Ashley Tomei
Kevin Tonn
Linda Toomey
Denise Townsend
Robert and Janine Townsley
Frank and Susan Trainor
Mary Trainor
Kim Trede
Carol Treutlein
Sherri and Alan Tribuzio
Sandy Tuney
Barbara Turner
Bill and Patty Turney
Daniel Tyminski
Rupali Ullal
Justine Underhill and David Mauroff
Jennifer Underwood
Jill Underwood
John and Jeanene Underwood
Samuel Underwood
Debi Urschel
Timothy and Sharon Vaclavek
Serafina Valles
Remco Van den Elzen
Sabine Van der Sluis
Susan and Mick Vank
Carole and Jim Vater
Olivia Vaughan
Katherine Vellucci
Elizabeth Vielhauer
Olga Vilella
Akriti Virdi
Michael and Dianne Von Handorf
Paul and Annette Von Handorf
Rose Von Handorf
Austin Vonderhaar
James Walker
Lisa Walker
Lynn Walker
Chad and Kathleen Wallace
Linda Wallace
Tayler Wallace
Jonathan Waltman
Xiang Wang
Michael Ward
Ronald and Shirlee Ward
Heather Wareing
Dan Warning
Michael and Ruth Warning
Dr. Cara Weismann
Margaret Welter
Kathleen Weltzin
Brooke Wenzel
Joan Werner
Melissa Westerberg
Joy Whitbeck
Christopher White
Jennifer White and Glen Reindl
Susan White
Wesley and Brenda White
Aloma Whitley
Leanne Whitlock
Kimberly Wigglesworth
Amy Williams
Cristine Willis
Angela Wills
Echo Wilson
Sheila Wilson
Jan Wimberley
Donna and Rick Woeste
Robert and Constance Wolf
Wolf Hills Quilters
Mary Wolfe
Claire Wood
Denise Wood
Joe and Georgene Wood
WoodmenLife
Rhonda Wright
Robin Wright
Chen-Han Wu
Corinne Wyllins
Judy and Mansour Yamin
Shay Yarborough
Autumn Yates
Lorie Young
Marcus and Angela Young
Sarah Young
Anjela Yumul and Jason Cruz
Janine Zacchino
Anthony and Gladys Zeller
Bob and Kate Zimmerman
Andrew and Louise Zygmuntowicz
Angela and Roger Zylstra
Lisa and Brian Zylstra

Adrian Romero (MPS IVA)

2022 Board of Directors

Chairman
Lisa P. Todd
(MPS II parent)
Albuquerque, NM
lisa.todd@mpssociety.org

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

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

Secretary
Christine Tippett
(MPS IVA parent)
Littleton, CO
christine.tippett@mpssociety.org

Nicole Bennett
(MPS II sibling)
Simi Valley, CA
nicole.bennett@mpssociety.org

Stephanie Bozarth
(MPS IVA parent)
Alexandria, VA
stephanie.bozarth@mpssociety.org

Maureen Cote
(MPS VI aunt)
Anna Maria, FL
maureen.cote@mpssociety.org

Stephanie Cozine
(MPS I parent)
New Castle, DE
stephanie.cozine@mpssociety.org

Tamara Cullere
(MPS I parent)
New Milford, NJ
tamara.cullere@mpssociety.org

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

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

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

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

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

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

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

Staff

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

Chief Scientific Officer
N. Matthew Ellinwood, DVM, PhD
matthew@mpssociety.org

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

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

Administrative Specialist
Sydnye Doctor
sydnye@mpssociety.org

Development and Program Specialist
Bethany Greene
bethany@mpssociety.org

Controller
Angela Guajardo
angela@mpssociety.org

Chairman of the Board Emerita
Stephanie Bozarth
Marie Capobianco
Ernie Dummann
Steve Holland
Alice Kalamar
Mary Majure Couture
Linda K. Shine

2022 Scientific Advisory Board

Guidance Committee Members
Kim M. Hemsley, PhD, *chair*
Julie B. Eisengart, PhD, LP, *associate chair*
Allison M. Bradbury, PhD
Lynda E. Polgreen, MD, MS, ex officio *(past chair)*
Calogera M. Simonaro, PhD
Richard Steet, PhD
Klane K. White, MD
Raymond Y. Wang, MD

At Large Members
Barbara K. Burton, MD
Alessandra d'Azzo, PhD
Robert J. Desnick, MD, PhD
Patricia I. Dickson, MD
Paul Harmatz, MD
Mark E. Haskins, VMD, PhD
William G. Mackenzie, MD
Adriana M. Montano, PhD
Joseph Muenzer, MD, PhD
Matthew Pendleton, PhD
Beth A. Pletcher, MD
Mark S. Sands, PhD
Edward H. Schuchman, PhD
William S. Sly, MD
Lachlan J. Smith, PhD
Steven U. Walkley, DVM, PhD
Chester B. Whitley, MD, PhD
John H. Wolfe, VMD, PhD

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

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

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

MPS & ML Classifications

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

MPS I

MPS I H Hurler

MPS I S Scheie

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

MPS II

MPS II Hunter
Enzyme / Iduronate sulfatase

MPS III

MPS III A Sanfilippo A
Enzyme / Heparan *N*-sulfatase

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

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

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

MPS IV

MPS IV A Morquio A
Enzyme / Galactose 6-sulfatase

MPS IV B Morquio B
Enzyme / β-Galactosidase

MPS VI

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

MPS VII

MPS VII Sly
Enzyme / β-Glucuronidase

MPS IX

Enzyme / Hyaluronidase

ML II/III

ML II I-Cell

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