

# Forging Ahead

THROUGH DIFFICULT TIMES

NATIONAL MPS SOCIETY — 2021 ANNUAL REPORT





*On the cover and above: Jacob Bohley (MPS I)*



## MISSION

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

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[MPSSOCIETY.ORG](http://MPSSOCIETY.ORG)

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# Contents

- 1 Letter from Chairman and President
- 3 Governance Committee
- 4 Family Support Committee
- 6 Pathways
- 8 Advocacy Committee
- 10 Fundraising Committee
- 14 Research Grants
- 16 Education and Publicity Committee
- 17 Financials
- 18 Contributors
- 33 Board of Directors and Staff



# OPENING LETTER

Anyone who has been touched by MPS or ML can affirm: One moment can change everything. Whether it is when you first hear the words “Your child has MPS” or the moment you hear “We have a treatment to help,” life is forever changed. No matter the type or stage in the rare disease journey, our mission is to support families who hear those words.

For 48 years, the National MPS Society has striven to raise awareness for rare diseases. We stood at the forefront of change and education. We helped families find their voice to be able to talk openly about these devastating genetic diseases and not be shunned. Through advocacy, we mobilized communities nationwide for policy change and research. Recently, we completely revolutionized how our team supports our cause through the Pathways program, and hired a chief scientific officer to expand our global research program.

Though our mission and vision to help families diagnosed with MPS and ML has not changed, how we design our programs has. As one of the world’s leading MPS organizations, we are working directly with sponsor companies, the FDA, National Institutes of Health, National Center for Advancing Translational Sciences, Lysosomal Disease Network, and the U.S. Department of Health and Human Services to succeed at developing

**We are working to succeed at developing treatments for these devastating diseases**

treatments for these devastating diseases and ensure families diagnosed get the care and health equity they deserve.

Together with donors like you, the Society drives research breakthroughs. Guided by world-renowned MPS and

ML researchers, clinicians, and experts, we evaluate and invest in science and technology that will further advance the development of therapies for all diseases. The Society works to lead the way in discoveries, technological advancements, publications, and delivery of care.

We continue to give a voice to thousands affected by MPS by advocating for patients with federal and state

**With the acceptance of MPS II to the RUSP, MPS comprises two of the 36 diseases screened**

policymakers. We are a national leader in newborn screening and continue to push this program forward, having succeeded this year with the addition of MPS II, Hunter syndrome, to the Recommended Uniform Screening Panel. MPS now has two of the 36 diseases screened (out of more than 7,000 rare diseases). We are increasing awareness of health inequities spotlighted through newborn screening and advocating for health equity. We also are committed to championing diversity throughout our programs and organization.

Within family support and the Pathways program, we developed direct-to-patient solutions and education for healthcare workers that reduce barriers to care. We have done this through a clear and simple vision for the future—a more manageable path forward at the time of diagnosis. Our social workers



*Lisa P. Todd, chairman of the board*



*Terri L. Klein, president and CEO*



**48 years**  
of raising awareness  
for rare diseases

*continued*

supported 43 newly diagnosed families in 2021 through virtual contacts and teleconferences. Pathways allows us to have more direct relationships with the

**We continued to reach milestones while still navigating the pandemic**

families we support, unconstrained by limited resources. But the work is not over—there is more to do.

As you flip through the pages of the 2021 Annual Report, you will learn more about how we continued to reach milestones while still navigating the

pandemic. We funded a new level of research at more than \$1 million in 2021 and continued to advance our research program. We worked with families to overcome difficulty accessing care through Medicaid, learned how to create new translational partnerships through critical publications in print and delivered extended patient care during unprecedented times in many program areas. These efforts would not have been possible without the continued support of our donors and members, who are passionate about the National MPS Society and its mission.

*Lisa P. Todd, chairman of the board*  
*Terri L. Klein, president and CEO*

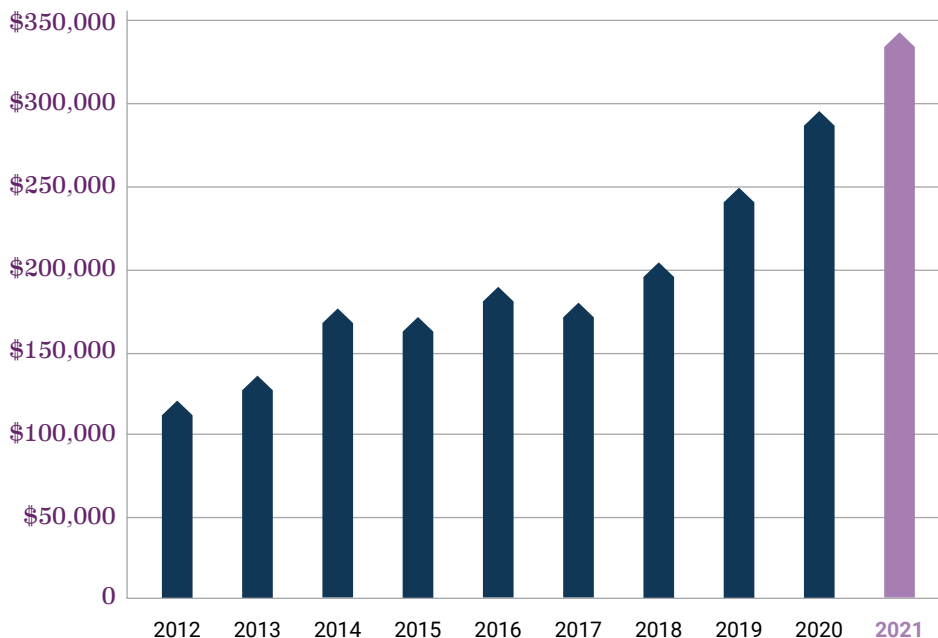


**INCREASED:**

- Awareness for International MPS Awareness Day, May 15
- Presence on social media
- Awareness for the Rising Sun Legacy Circle
- eCourage monthly subscriptions

**ANNUAL FUND DONATIONS**

The National MPS Society’s Annual Fund continued to grow in 2021. This critical funding source plays a direct role in the Society’s ability to carry out all of the initiatives that led to real change last year and for years to come. This progress would not be achievable without generous funding from our donors, who continue to be passionate about driving change to create a better future for those affected by MPS and ML.





*Board of directors members*

The **Governance Committee** plays a crucial role in the National MPS Society's overall guidance and direction by reviewing staff and board member resources, identifying gaps in service delivery, and working to improve overall performance. This is accomplished through several key initiatives, such as annual compensation and benefit evaluation, board member reviews, and board election oversight. In 2021, the Governance Committee considered staffing and personnel needs of the Society, including compensation recommendations. The committee, along with the full board, assessed the preparedness of the organization as they continued to work through a challenging economy and ongoing health crisis.

The Governance Committee also oversaw the employee evaluation process, as conducted by the president and CEO, and was available as a resource as needed. The committee assessed the combined functions of Family Support and Communications and created a dual position. The committee ensured staff was resourced and supported in this effort.

In the final quarter of 2021, the Governance Committee supervised the 2021 annual board of directors election process for the upcoming 2022–2023 term. This consisted of a vigorous vetting process of all applicants, including personal interviews, prior to the membership voting. For the 2022–2023 term, one new member, Tamara Cullere, was welcomed to the board of directors, along with the incumbents. We look to these outstanding volunteers to help guide the Society through strategic decision making.



*Tamara Cullere, board of directors,  
MPS I parent*





# Strengthening Access

TO CARE AND RESOURCES

Scholarships and grant awards in 2021 enabled the **Family Support Committee** to provide more than \$95,000 in funding to 95 families or individuals with MPS or ML. Scholarships assisted those pursuing post-secondary education and were awarded to individuals with MPS or ML, their parents, and their siblings. Attendance at the 35th Annual Family Conference, hosted virtually, was offered free to all members. The COVID-19 pandemic continued to impact families in significant ways, and social work support through our family support programs provided extensive assistance in areas of mental health, educational needs, and access to care. Support sessions, particularly for adults with MPS or ML, offered connection and opportunities for those who were physically distanced to continue to receive care and develop friendships.

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**Brock, Baen, and Bryce Hurst have MPS I and received transplants at the University of Minnesota. The Medical Travel Assistance Program provided grant assistance for the three boys to travel with their parents for post-transplant follow-up care and critical annual appointments.**

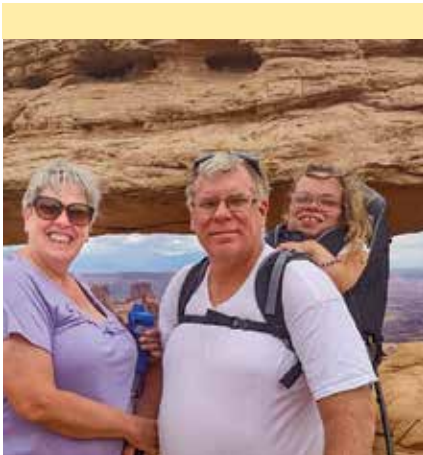
*Hurst family (MPS I)*

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**We have always wanted to provide Martin with the best quality of life. Funding through the Journey Assistance Program helped improved his sleeping area and made bathing and transitioning safer.**

*Gulley family (Martin, MPS IIIA, 2010–2021)*



**Communication is key in life. I began having bilateral hearing loss at age 15 due to MPS IV, and communication became frustrating. Using hearing aids purchased through the Society’s Family Assistance Program helps me to converse with family, friends, and medical professionals.**

*Sarah Van Orden (MPS IVA)*

## 2021 Highlights

### Continuing Education Scholarships

- Awarded four Jeffrey Bardsley Scholarships at \$5,000 each and 23 Continuing Education Scholarships.

### Family Assistance Program

- Funded nine grants totaling \$17,876 to provide assistance items, including a specialized car seat, transport travel chair, hearing aids, cough assist vest, and bed safety accessories.

### Journey Assistance Program

- Funded three grants totaling \$827 for iPads and bathroom remodel items.

### Extraordinary Experiences Program

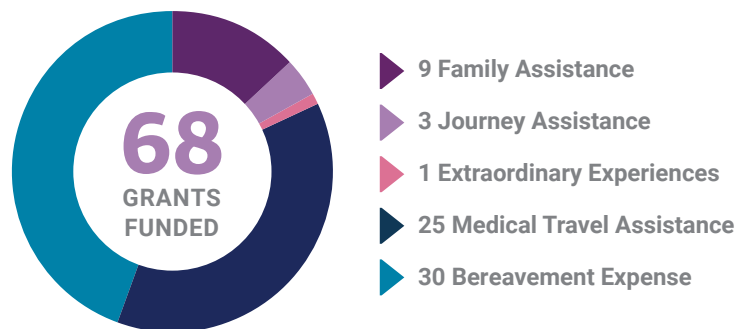
- Funded one grant for \$914 that enabled an individual to attend an MPS family day for disease education and connection with others with similar diagnoses.

### Medical Travel Assistance Program

- Funded 25 grants totaling \$10,998 to help with out-of-town travel costs for non-recurring medical appointments.

### Bereavement Expense Program

- Funded 30 grants totaling \$22,500 to provide resources for families experiencing the loss of a loved one with MPS or ML.



# Meaningful Outreach

## FOR NEWLY DIAGNOSED FAMILIES

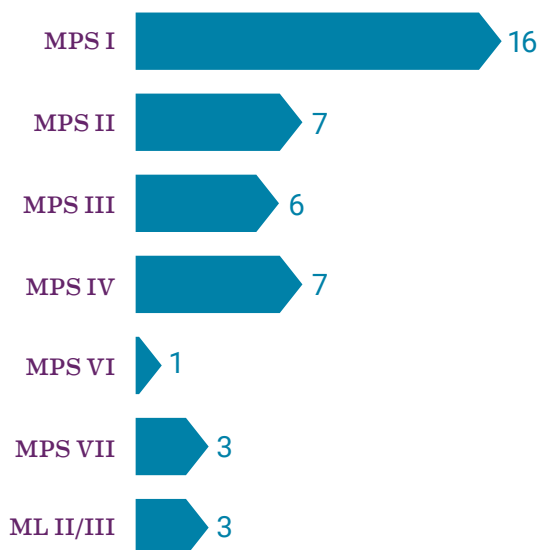
The National MPS Society’s Pathways program exists to provide comprehensive support throughout the first year of diagnosis for families. COVID-19 impacted our families in a tremendous way, with some experiencing delays to diagnosis and treatment and others facing difficulty in accessing care and connecting with needed resources. Through **Pathways**, we worked with parents, individuals, care providers, industry partners, and others to overcome these challenges and expedite access to available treatments.

Reed is 4 years old and was diagnosed with MPS IVA last year. He lives with his mom (Carolyn), dad (Justin), and little sister (Ruby), and now receives infusions at home, which has improved the quality of life for the whole family! Reed loves to play the drums and listen to music by The Beatles. He amazes everyone with his kind, smart, and caring qualities.

*Rinon family (Reed Rinon, MPS IVA)*

### SYNDROME TYPES

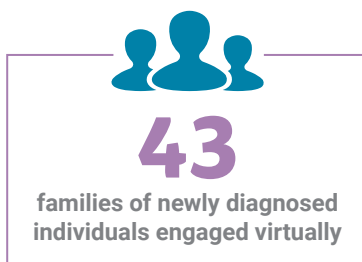
of the 43 newly diagnosed individuals with MPS and ML





A hallmark of the Pathways program is personalized face-to-face visits with those who have received a new diagnosis. Visits were offered virtually, transitioning back to home visits at the end of 2021. Frequent phone and video conferencing sessions were critical to supporting families during this year, and the return to direct, in-person meetings enabled Pathways to enhance the level of care and support.

Families and individuals utilizing Pathways are connected with federal, state, and local resources, linked with other families, and provided direct contacts for urgent needs or situations that arise. Pathways staff act as liaisons to clinicians, researchers, and clinical trials. In factual, unbiased ways, they encourage exploration of every option available to someone recently diagnosed with MPS or ML, including approved treatments, therapies targeted for specific symptom management, and clinical trial opportunities. Emotional support and concrete resources are the capstones of the Pathways program, helping families move forward over the course of the first year of diagnosis.



## 2021 Highlights

- Served 43 newly diagnosed individuals with MPS or ML. Of these newly diagnosed families:
  - All families were engaged virtually due to the continued pandemic.
  - Many families transitioned to teleconference support regularly.
  - Approximately 30 families participated in monthly support webinars throughout the year.
- Distributed the Pathways brochure to industry partners and hosted a virtual booth at the Annual Family Conference.
- Facilitated breakout sessions at the 2021 Annual Family Conference.
- Hired new Pathways director, Carol Bryant, MSW, LCSW.
- Continued providing vital assistance to families diagnosed through newborn screening labs.



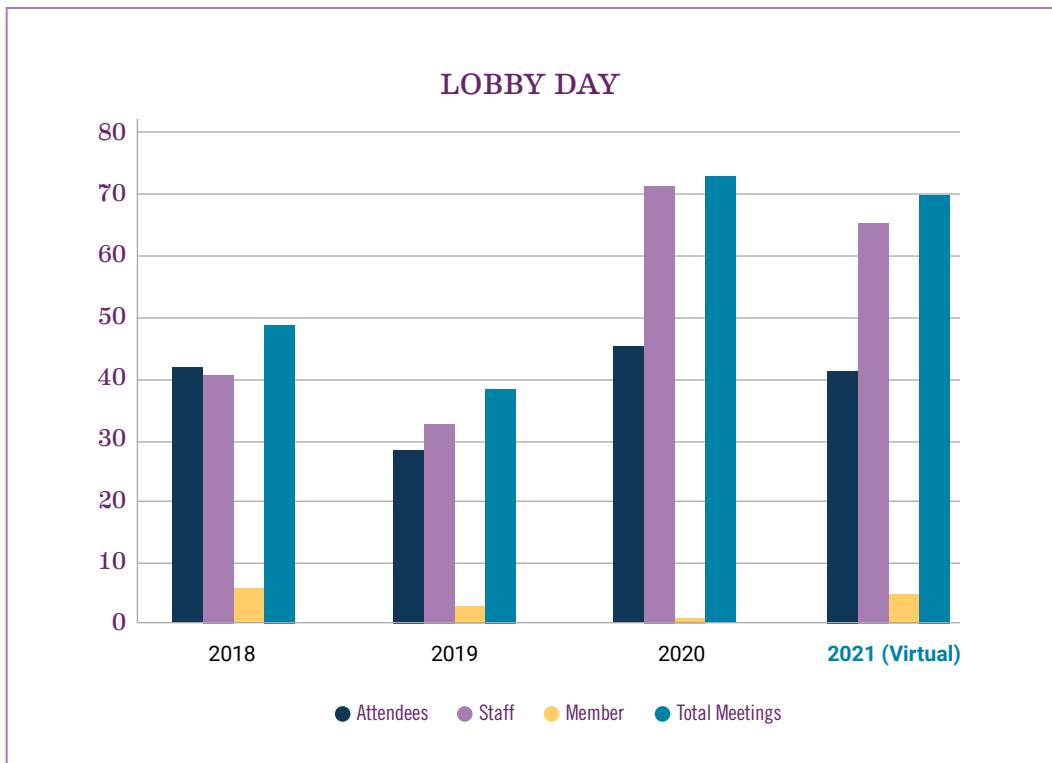
*Kalel Joseph and Adam Tobar (MPS II)*



# Reaching New Milestones

The **Advocacy Committee** champions the critical needs of our community. In 2021, this committee continued to respond to COVID-19 policy and collaborative efforts to ensure the voice of the rare disease patient was considered.

The Advocacy Committee focuses on a number of 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.



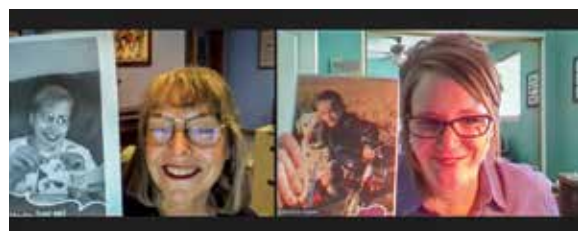
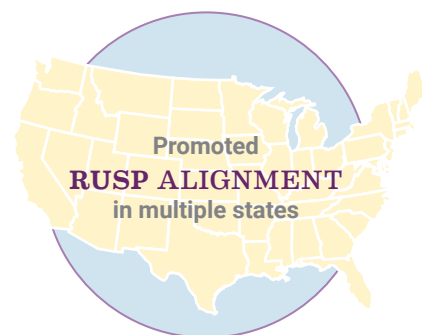
# 2021 Highlights

- Provided testimony at Advisory Committee on Heritable Disorders in Newborns and Children meetings for MPS II Recommended Uniform Screening Panel (RUSP) nomination and newborn screening.
- Facilitated virtual Capitol Hill meetings in February with 46 advocates meeting with 74 legislators to advocate for newborn screening and increased NIH funding for MPS and ML diseases through the appropriations bill, as well as recruit Rare Disease Caucus members.
- Facilitated virtual Capitol Hill meetings in May with 48 advocates meeting with 66 legislators for International MPS Awareness Day.
- Promoted RUSP alignment legislation in multiple states.
- Participated virtually in Rare Disease Legislative Advocates' Rare Across America Capitol Hill visits.
- Supported a resolution to recognize National MPS Awareness Day in the U.S. Senate, sponsored by Sen. Michael Bennet, which passed.
- Supported the following legislation:
  - H.R. 4439/S. 4010—**Creating Hope Reauthorization 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 (ARPA-H) Act**
- Provided virtual training for the Speaker's Bureau.
- Attended the 17th Annual *WORLDSymposium*.™
- Presented an overview of the Advocacy Committee's history, goals, and work at the Society's Annual Family Conference.
- Engaged the patient community to participate in the Economic Burden of Rare Diseases Study, through the EveryLife Foundation.
- Participated in quarterly newborn screening and diagnostic meetings held by the EveryLife Foundation.
- Supported the following rare disease legislative response:
  - Include in COVID-19 legislations a provision to let patients receive Medicare-covered Part B infused medications from qualified practitioners in the safety of their homes.
  - Deliver letters and signatures for support for the Speeding Therapy Access Today (STAT) Act of 2021.
  - Add House members who support increase in RUSP funding for program management.
  - Reach out to legislators for support of the Helping Experts Accelerate Rare Treatment (HEART) Act.



**17th**

Annual WorldSymposium™  
was attended



Rita Basom and Christine Tippet



**4**

rare disease legislative  
responses supported



## FUNDRAISING



# Advancing Fundraising

STRATEGIES SUCCESSFULLY

Concert for the Cure

Once again, our wonderful supporters buoyed our fund development efforts by seeing us through our second year of virtual events.

A nonprofit organization is only as strong as the level of support it receives from its members and benefactors. Our supporters and team worked tirelessly to create engaging virtual events for precious mission dollars. We recognized in 2021 that postponing events was not an option—because decreased funds would limit our ability to deliver services in subsequent years. The **Fundraising Committee** and board of directors guided supporters and volunteers in raising attendance at virtual events through social media outlets. Additional phone calls with major donors again secured extraordinary gifts. The Pennies for Nicoll Foundation assisted Family Support programs for the second year with its legacy gift.

With all the changes in 2021 and the emergence of slowly planning to restore in-person events, the unwavering commitment from our donors saw us through an incredibly challenging year. The Annual Fund reached more than \$340,000, with 184 new donors to the campaign. We received the donor's message loud and clear—we will sustain you.



**2,500+**  
active members of the  
National MPS Society



**4-star**  
exceptional rating from  
Charity Navigator



**Our family chose to fundraise for the National MPS Society not only to help find a cure for precious Kierean and all of the amazingly strong MPS/ML children, but to support families who need assistance. Each and every one of them deserves a long life without suffering.**

*Kimberly Jessie (mother of Kierean McKelton, MPS I)*



We were honored to take part in several fundraisers this year, not only to help our family but every family affected by MPS. They say “It takes a village,” and our family is always there to support Meekel and the Society. We couldn’t do this without them.

*Dixie Stevens (mother of Meekel Stevens, MPS VI)*



Since our son Graylon was diagnosed with MPS II, finding a cure has become our mission. Because MPS is such a rare disease, fundraising for research and awareness is vital in order to find a cure.

*Kelsey Posey (mother of Graylon Posey, MPS II)*

## 2021 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 2,500 members.
- Raised approximately \$507,755 through virtual walk/run and other fundraising events.
- Raised more than \$42,500 for MPS and ML research through the University of Pennsylvania’s Million Dollar Bike Ride.
- Hosted two successful national virtual walk/run events, raising more than \$160,000 with more than 200 participants.
- Supported more than 210 family and Facebook fundraisers, including cycling events, golf tournaments, lemonade stands, scrapbooking events, bake sales, and clothing and jewelry sales.
- Raised \$343,802 through the 2021 Annual Fund campaign, chaired by National MPS Society board member and MPS IVA mother Stephanie Bozarth.
- Received \$37,000 in legacy gifts through the Planned Giving program.
- Hosted 62 Courage Pages (customized, informative family web pages for awareness and fundraising) on the Society’s website.
- Received Combined Federal Campaign application approval.
- Worked with donors to process more than 260 Employee Giving Campaign and corporation matching gifts.
- Increased awareness for the Rising Sun Legacy Circle and processed new planned gifts from trusts and wills.
- Hosted the National MPS Society’s second annual Big Bake for MPS and ML, raising more than \$17,000.
- Celebrated MPS Awareness Day with the “A Night Off Broadway” virtual gala, raising more than \$203,000 to support the mission of the Society.





## 2021 Fundraisers

**A Night Off Broadway Virtual Gala**, hosted by the National MPS Society and the Gala Committee

**American Legion Fundraiser**, in memory of Liam Johnson

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

**Cincinnati Country Day School Fundraiser**, in honor of Logan Beaudoin, hosted by Cincinnati Country Day School

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

**Egging for MPS**, in honor of Lilah Mueller, hosted by Kimber Heiling

**Easter Egg Hunt for MPS**, in honor of Meekel Stevens, hosted by Dixie and Jobi Stevens

**Freedom Fighter Filson's Rainbow Connection Tour**, in honor of Filson Newman, hosted by Brian and Ashley Newman

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

**Holland Sharing and Caring Fundraiser**, in honor of the Holland family, hosted by the Holland family

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

**Humbert Road Dentistry Fundraiser**, hosted by Humbert Road Dentistry

**Jack "The Beast" Bennett 1st Annual Memorial Ride**, in memory of Jack Bennett, hosted by Kimberly and Jerry Bennett

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

**Joyce Family Pampered Chef Party**, in honor of Bridget Joyce, hosted by Kathleen and Sean Joyce

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

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

**Memorial Ride**, in memory of Angelina Khoshaba and Jack Bennett, Weasels NE/NL

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

**Mitchell Family Pampered Chef Party**, in memory of Dylan Poole, hosted by Jackie Mitchell

**MPS Awareness Day Fundraiser**, in honor of Grady Yenzi, hosted by Julie and Corey Yenzi

**MPS Awareness Day T-Shirt Fundraiser**, in honor of Jacob Bohley, hosted by Alicia Bohley

**MPS Awareness Signs Campaign**, in honor of Gabriel Reese, hosted by Autumn Reese

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

**Nathan Grant Book Publishing Fundraiser**

**Pearl City Popcorn Fundraiser**, hosted by Wayne and Joan Eppehimer

**Post Office Café 5K Run and 1K Fun Run**, in memory of Mark and Casey Lessing, hosted by the Lessing family



*Lilah's Lemonade Stand  
(Lilah Mueller, MPS VI)*

**Purple Pumpkin Smash**, in honor of Christopher Hohn, hosted by Emily Viti and Darryl Hohn

**Raleigh Run for Rare**, hosted by National MPS Society

**RGX 4 Good ONEHOPE Wine Fundraiser**

**Sarantinos Family Drive-by Birthday Celebration**, in honor of Luke Sarantinos, hosted by Dr. George and Athena Sarantinos

**Scentsy Fundraiser**, in honor of Clara Gibson, hosted by Jennifer Jones

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

**When Life Gives You Lemons Lemonade Stand**, in honor of Jacob Bohley, hosted by Mia Bohley

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

## Courage Pages

The following families have their own website through Courage Pages at [mpssociety.org](http://mpssociety.org). Whether hosting an event or raising awareness for MPS or ML, these custom pages are an effective way to reach donors and help enhance fundraising efforts with no expense. These inspirational sites can be found under the "Give" section of the Society's website.

Evan Abel  
Ashley Allen  
Aaron Athy  
Hunter Beam  
Ryder Belisle  
Colin Berning  
Keller Blakeley  
Jacob Bohley  
Annabell Bozarth  
Tyson Brown  
Sam Caswell  
Alan Charest

Alex and Nick Cherrstrom  
Julia Ann Donahue  
Jackson Dunn-Kraus  
Colin Dwyer  
Kali Gagenheimer  
Owen Groesch  
Karina Guajardo  
Makenzie and Isabella Hardesty  
Faith Heard  
Fletcher Henry  
Jaela Hernandez  
Holland family

Michelle Hopkins  
Analynn Hughes  
Fiona Humphrey  
Kathleen Joyce  
Carter Kannev  
Beth Karas  
Eddie Kimminua  
Allison Kirch  
Jennifer Klein  
Kraig Klenke  
Drake Lucas  
Shane McGoey  
Caleb Michalik

Danny Miller  
Maura Mongan  
C.J. Pace  
Xavier Patton  
Analee Perez  
Raymond Pinchak  
Myles Richardson  
Gage Robles  
Hudson Roman  
Christopher Sanchez  
Elijah Story  
Katie Swanson  
Madison Thompson

Cooper Tippet  
Jack Todd  
Easton Walker  
Trinity Walker  
Michael Whitaker Russell  
Scotty Whitecotton  
Antonio Estrada  
Willmann  
Carter Worthen  
Christian Yard  
Emily Yurkins  
Roy Zeighami



# 2021 Champions Circle

Members of the MPS Champions Circle generously support the Society by making a monthly recurring donation.

Jodi Adams	William English	Brian and Rebekah Klutz	Calvin Nelson	Jack Sweptston
Colleen and Shawn Arni	Terry Epps	Patricia Kruse	Ann Palmer	Leslie and Alex Urdaneta
Carole and John Barnhardt	Teresa Everett	Theresa Leggett	Thomas and Vickie Patterson	Todd Waddell and Sarah Aaserude
Ronnie and Jaye Beck	Gary Flores	Lauren Louison	Linda Perrella	Ricker and Dawn Williams
Melany Bjorkman	Allison Frazier	Wynona Maxwell	Lynda Polgreen, MD	Leonel and Edith Yoque
Marc and Beth Brdar	Denise Glatzmaier	Anthony Menendez	Edward and Evelyn Schultz	
Victoria Calzada	Steve and Amy Holland	Donny and Molly Merrill	Riddhi Shah	
Michael Clawar	Jennifer and Bryan Hutcheson	Greg and Jennifer Mincks	Jared Shelton	
Maria De Granillo	John and Yvette Iannelli	Susan Murphy	Jeremy and Rena Stearns	
Elizabeth and Joshua Eickman	Mirna Juarez	Kathy and Josh Nay		

## Facebook Fundraisers

Beth Adams	Fidencia Junior Cisneros III	Teri Hankel	Kathy McDaniels	 <p><i>Napa Race for a Cure, Team Patricia (Patricia Espinal, MPS VI)</i></p>
Lee Ann Adams	Tela Clancy	Kimber Heiling	Annie McGraw	
Cadan Alexus	Amber Clark	Ryan Hicks	Taurean Mckelton	
Gail Armato	Diane Cloutier	Jennifer Higley	Anna Zakas McManus	
Shaun Bach-Haynes	Allison Cochran	Alex Hill	Rose Merrell	
Page Bales	Carrie Condon	Chris Hill	Eric and Vicki Merril	
Rachel Barclay	Kalya Cotkin	Edward Hinkelman	Lexi Michelle	
Rita Basom	Tamara Cullere	Alice Hinton	Liz Miljas	
Debbie Bateman	Keena Davis	Rosamond Hoerr	Gabby Miyoshi	
Amy Becker	Dianne Davis-Jones	Judy Denney Hollington	Michael Morris	
Lana Becker	Cassie Dearman	Renee Homer	Eileen Murphy	Donie Shiels
Mandy Bellassai	Jennifer Dearman	Brandon Hool	Hannah Rose Murphy	Niki Simpson
Nicole Bennett	Ashlee Deitcher-Keeler	Brianna Hope	Nazaret Navarro	Joseph Sloan
Kimberly Bergstrom	Amy Diaz	Colleen James	Alyssa Rose Neil	Tatyana Sloan
Nichole Bickerton	Judy Dickerson	Jeanne Jeffreys Hahn	Megan Nicole	Ashley Smith
John Biddle	Wilma Dickerson	Amanda Johnson	Shaun Noble	Shannon Smith
Anne Marie Bisner	Alexis Didon	Kristi Wood Johnson	Tommy O'Brien	Michael Spring
Keith Bisner	Stephanie DiDonato	Rachael Brady Johnson	Liz Paolone	Marla Stevens
Feleica Black	Nicole DiMicelli	Sherrie Clinton Johnson	Rhonda Pare	Aaron Stewart
Cory Blain	Annie Djukic	Becky Jordan	Susan Pauline	Mary Woolfolk Stoner
Darryl Block	Kate Dreihobl	Alejandro Juarez	Bailey Pevler	Charlene Swanson
Melanie Block	Mike Dwyer	Jeremy Judd	Kim Phillips	Charlotte Tate
Alicia Bohley	Karen Doss Edwards	Dianne Kelley	Gianfranco Pizzillo	Dena Taylor
Cenia Blount	Wayne Eppheimer	Helen King	Darren Proulx	Jennifer Toby
Christine Bohley	Joanne Evans	Shari Kinsman	Melissa Rachunek-Zielonka	Christina Urdaneta
Michell Farrell Bohley	Mark Farrell	Andra Koblitiz Tidwell	Brynne-Lei Radcliff	Neil Valentine
Tori Boothby	Melissa Fay	Debbie Kruse	Emily Ramirez	Katelyn VanGhle
Rachael Bosch	Megan Fitzgerald	Jim LaRue	Lacey Reardon	Daisy Vasquez-Vogt
Bre Bowen	Christopher Fleming	Haylee Lauren	Amanda Reuter	Allie Walls
Austin Bozarth	Amy Francek	Jennifer Leighton	Marie Sanchez Salas	Wendy Way
Drew Brodie	Ann Franzi	Caroline Lewandowski	Keeley Sanchez	Sherly Wharton-Hughes
Ella Brown	Ashley Frix	Reema Macer	Mike Sanson	Sierra Whitaker
Samantha Brownfield	Elizabeth Fry	Dakota Marie	Michelle Schichtel	Carley Wienkes
Barbara Bush	Julie Garrison	Julie Marie	Christina Sciammas	Chelsea Bohley Wilkins
Sue Byers	Amy Gioletti	Kristina Marie	Jackie Scott	Debbie Williams
Anastasia Caldwell	Kirsten Goins	Tracy Marie	Carolynne Seiffert	Tara Williams
Lisa Caporal	Rebecca Green	Stefan Matties	Lisa Serang	Julie Willoughby
Kelly Caram	Tim Guilfoyle	Nona Maxwell	Shel Shampine	Samantha Wilson
Steve Cardwell	Carla Halk Crain	Erin McBride	Linda Cebon Shenk	Sheri Wise
Heidi Caswell	Chey Halk	Jessica McCue		Mayra Zelaya-Olivo

MAKING THE PROMISE OF

# Improved Therapies and Cures

A REALITY FOR ALL

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

In 2021, the National MPS Society's research program fully implemented an exciting program of three annual defined grant submission cycles (Cycles I–III). This provides flexibility to researchers, a rapid turnaround of improved resubmissions of research proposals, and provides the researchers and reviewers a consistent calendar with which to optimally plan future research efforts. We also have defined levels of funding (Tier I, \$100,000; Tier II, \$50,000), including fellow-initiated research proposals (\$50,000), to provide consistency and flexibility so researchers can choose both the level and duration (one or two years) of funding that best meets their research needs. The grants initiative, in an effort to ensure research achieves its full promise, has begun a program allowing for a grant to be awarded a one-time competitive renewal of funding. Finally, the Society, with the aid of a Guidance Committee comprised of a selection of the Scientific Advisory Board, has defined in an ongoing manner areas of need and emphasis that help focus and encourage research.

This inaugural year of our new approach has been met with great success. First, in 2021 we hit an all-time high of distributing more than \$1 million in

funding of life-saving and life-changing research. This sum includes allocations for new competitive research awards of \$605,000, with the balance going to continued funding for previously awarded multi-year grants. This total 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. The Society also committed to continue ongoing research resource support of \$25,000 to the University of Minnesota Lysosomal Disease Network for core imaging research with the National Institutes of Health. Notable again this year was the continued support for MPS II and relevant research, totaling \$275,000 in new and ongoing research commitments, provided from the Christa Armstrong legacy gift.

Grants that addressed initiatives of the new grant program structure include the award of a fellow-initiated research proposal to Dr. Brianna Yund (now faculty) at the University of Minnesota, an award for an improved MPS IVA model to Dr. Brunetti-Pierri, and the utilization of the competitive one-time renewal process [Dr. Moro (Padova) and Smith (ISU)].



*C.J. Pace (MPS I)*

## \$1 million+

distributed to fund life-saving and life-changing research

*Jim, Kelly, and Kaitlyn (MPS IIIA) Hart*



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

### 2021 Competitive Program in Innovative Research

#### 2021 CYCLE I GRANTS (award date Aug. 1, 2021)

##### Tier I: \$100,000 for a two-year general MPS/MPS III award to Dr. 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*

##### Tier II: \$50,000 for a one-year general MPS award to Dr. Michelina Iacovino

Lundquist Institute for Biomedical Innovation at Harbor-UCLA Medical Center, Torrance, CA, USA  
*Role of Autoimmune Disease in MPS Pathology*

##### Tier II: \$50,000 for a one-year MPS II Christa Armstrong legacy award to Dr. Igor Nestrasil

The University of Minnesota, Minneapolis, MN, USA  
*MPS II Brain Phenotypes*

##### Tier I: \$100,000 for a two-year MPS IVA/ML award to Dr. Heather Flanagan-Steet

Greenwood Genetic Center, Greenwood, SC, USA  
*Comparative Analysis of Mechanisms Driving Skeletal Dysplasia*

##### Fellow-Initiated Research: \$50,000 for a one-year MPS VI award to Dr. Brianna Yund (mentor: Dr. Julie Eisengart)

The University of Minnesota, Minneapolis, MN, USA  
*Uncovering Neuronopathic Features of Non-Neuronopathic MPS*

#### 2021 CYCLE II GRANTS (award date Dec. 1, 2021)

##### Tier II: \$50,000 for a one-year competitive renewal MPS II Christa Armstrong legacy award to Dr. Enrico Moro

The University of Padova, Padova, Italy  
*Investigation of the Retinotectal and Neurobehavioral Defects in a Zebrafish Model of Hunter Syndrome*

##### Tier II: \$50,000 for a one-year competitive renewal MPS III award to Dr. Jodi Smith

Iowa State University of Science and Technology, Ames, Iowa, USA  
*Efficacy of Gene Therapy and Pentosan Polysulfate in a Large Animal Model for MPS IIIB*

##### Tier II: \$50,000 for a one-year MPS IVA award to Dr. Nicola Brunetti-Pierri

The Telethon Institute of Genetics and Medicine, Pozzuoli (Naples), Italy  
*A Clinically Relevant MPS IVA Animal Model for Investigation of New Therapies*

##### Tier II: \$50,000 for a one-year general MPS award to Dr. Elvira de Leonibus

The Telethon Institute of Genetics and Medicine, Pozzuoli (Naples), Italy  
*Role of Polyamines in Disease Progression in Mucopolysaccharidosis IIIA*

#### Second-Year Grant Award Funding Disbursed in 2021

##### \$45,000 general MPS/ML research award to Dr. Carmine Settembre

The Telethon Institute of Genetics and Medicine, Pozzuoli (Naples), Italy  
*Dissecting the Role of Selective Autophagy Dysfunction in MPS Pathogenesis*

##### \$45,000 general MPS/ML research award to Dr. Allison Bradbury

The Abigail Wexner Research Institute at Nationwide Children's Hospital, Columbus, OH, USA  
*ML Cardiac Disease: Paving a Road to Therapy*

##### \$37,500 MPS I award to Drs. Brian Bigger and Tereza Andreou

The University of Manchester, Manchester, UK  
*Bone, Brain, and Cardiac-Targeted Lentiviral Haematopoietic Stem Cell Gene Therapy for MPS I (Hurler)*

##### \$50,000 MPS II Christa Armstrong legacy award to Dr. Richard Steet

Greenwood Genetic Center, Greenwood, SC, USA  
*Functional Characterization of Novel IDS Variants in Cells and Zebrafish*

##### \$25,000 MPS III award to Dr. Lilliana Matos

National Health Institute (INSA), Porto, Portugal  
*Exploring In Vivo U1 snRNA Splicing Modulation as an Alternative Therapy for MPS IIIC*

#### 2021 Research Resource Award

##### \$25,000 multi-syndrome general MPS award

Lysosomal Disease Network, University of Minnesota, Minneapolis, MN, USA  
*The Neuroimaging Core NIH Project*

#### 2021 Partnership Award

##### The Orphan Disease Center

##### \$64,015 (Million Dollar Bike Ride & \$30,000 from National MPS Society funding) to Dr. Brian Bigger

University of Manchester, Manchester, UK  
*Understanding the Role of Inflammation in MPS IIIA Disease to Identify Therapeutic Approaches for Older Patients Without Treatment Options*



# Elevating Communication,

## NEW FRONTIERS

The National MPS Society connects and engages with the MPS and ML communities through a variety of communication platforms. We continuously evaluate and expand communication vehicles to ensure efficient message delivery to our members. Through social media, educational materials, printed publications, email, and promotional materials, the **Education and Publicity Committee** actively seeks new and innovative ways to involve our members and increase public awareness.

In 2021, the National MPS Society forged ahead through the pandemic to deliver a higher level of communication. We increased publications through peer-review research, submitted our first poster at the *WORLDSymposium™*, collaborated with other foundations to publish inequities surrounding therapeutic needs for special needs children, and began implementation of our inaugural podcast, *Our Voices*. We worked up front and behind the scenes providing key materials to the Centers for Disease Control to address MPS and ML diseases. This past year also provided an opportunity to update many of our written publications.

Developing new strategies to communicate with our families remains a high priority for the Education and Publicity Committee.

## 2021 Highlights

- Wrote and published new MPS III resource booklet.
- Terri Klein authored “Lasting Lessons from the Pandemic: Advancing the Understanding of Special Education and Therapeutic Needs of Children with Neurodegenerative Disorders” with Cure Sanfilippo, Project Alive, and the University of Minnesota.
- Submitted poster at the 16th Annual *WORLDSymposium™* in Barcelona, Spain, titled, “Increased Clinical Trial Readiness Through a Master Class in Neurocognitive and Neurobehavioral Measurement in MPS.” Co-authored by Elsa Shapiro, PhD, Julie Eisengart, PhD, Terri Klein, and Jennifer Greenburg.
- Initiated the new podcast, *Our Voices*, a monthly broadcast that launched in 2022.
- Increased efforts to raise awareness for International MPS Awareness Day, May 15.



- Increased *eCourage*, the Society’s monthly electronic newsletter, subscriptions to more than 2,500 members.
- Developed a webcast, “COVID-19 Pandemic: Impact on Mucopolysaccharidosis,” with Dr. Heather Lau.
- Continued updating the Society’s website.
- Increased presence on Facebook and Instagram.

# Summary Financial Report

The financial information below has been summarized for the year 2021. 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	\$ 830,753
Investments	2,898,478
Contributions receivable	27,277
Prepaid expenses	7,220
Accrued interest	0

**Property and Equipment, Net** 7,055

#### Other Assets

Deposits	52,747
Investments—restricted for purpose	397,941
Investments—restricted in perpetuity	1,138,568

**Total Assets** \$ 5,360,039

### Liabilities

Accounts payable	\$ 9,664
Grants payable	25,000
Accrued salaries/vacation	31,315
<b>Total Liabilities</b>	<u>65,979</u>

### Net Assets

Without donor restriction	
Undesignated	2,328,587
Designated	420,651

### With donor restrictions

Purpose restricted	1,384,117
Time restricted	22,137
Perpetual in nature	1,138,568

**Total Net Assets** 5,294,060

**Total Liabilities and Net Assets** \$ 5,360,039

## 2021 Statement of Activities

### Revenue and Support

Contributions	
Planned Giving	\$ 37,098
General	320,832
Research	207,228
Family support	28,280
Sponsored revenue	8,000
Membership dues	3,300
Conference revenue	167,400
Special events	851,755
Interest and dividends	108,120
Investment income, net of fees	280,867
Paycheck Protection Program SBA grant	101,103

**Total Revenue and Support** \$ 2,113,983

### Functional Expenses

Research grants	\$ 1,026,446
Direct family assistance and bereavement	103,131
Advocacy and Speaker's Bureau	29,000
Conferences, meetings, and travel	67,825
Sponsored expenses	2,605
Education—newsletters, booklets, web	102,965
Membership database and directory	43,694
Direct fundraising	64,639
Personnel	585,606
Office and equipment	58,769
Other administrative	47,745

**Total Functional Expenses** \$ 2,132,425

**Change in Net Assets** \$ (18,442)



# 2021 CONTRIBUTORS

## 2021 Contributors with sincere thanks to our supporters

In 2021, the National MPS Society was able to provide support to families and funding for research because of the generosity of the following individuals, families, foundations, companies, groups, and fundraising events. The board of directors and the Fundraising Committee thank you for your dedication. The Society makes every effort to recognize our supporters through *eCourage* and this Annual Report. The following list represents all donations received in calendar year 2021. If your name is not listed, we apologize and ask that you contact us. If we received your donation in 2022, you will be recognized in the next Annual Report.

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## MPS & ML Classifications

Mucopolysaccharidoses (MPS) and Mucopolipidosis (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 /  $\alpha$ -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 /  $\alpha$ -*N*-Acetylglucosaminidase  
MPS III C Sanfilippo C  
Enzyme / Acetyl CoA:  $\alpha$ -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 /  $\beta$ -Galactosidase

### MPS VI

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

### MPS VII

MPS VII Sly  
Enzyme /  $\beta$ -Glucuronidase

### MPS IX

Enzyme / Hyaluronidase

### ML II/III

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