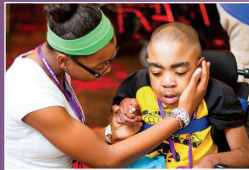
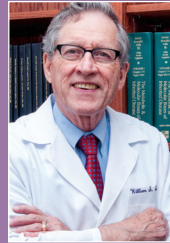


Dedication



Research



Awareness



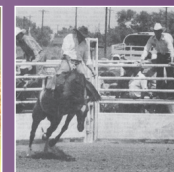
Membership

Fundraising

Legislation

Courage

Advocacy

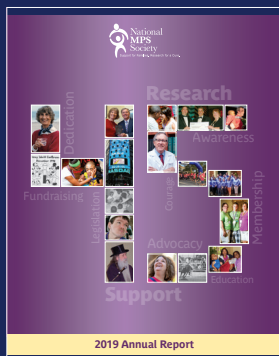


Education

Support



On the Cover...



GLANCE OF OUR PAST

Featured photos of the past 45 years

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!



Table of Contents

- 1** Letter from Chairman and President
- 2** Governance Committee
- 3** Family Support Committee
- 4** Advocacy Committee
- 5** Education and Publicity Committee
- 6** Adult Resource Committee
- 7** Pathways
- 8** Research Committee
- 10** Fundraising Committee
- 13** Financials
- 14** Planned Giving/Annual Fund
- 16** Contributions
- 28** MPS and ML Classifications
- 29** Board of Directors and Staff

OPENING LETTER



Lisa P. Todd, chairman, board of directors



Terri L. Klein, president and CEO

THE NATIONAL MPS SOCIETY'S sustainability and strength come from decades of carefully nurtured growth and strategic change. 2019 was a year of new milestones, expanded programs, and astounding courage. We continue to extend the reach of our excellence throughout the United States and beyond. We are thankful for a record-setting year that illustrates our financial strength and positions us for even greater MPS community impact. We are inspired by our patients, researchers, clinicians, donors, and industry partners. Years of collaboration have contributed to the 2019 historical outcomes we are excited to share with you.

Highlights of this past year include:

- Advocating for Isabel Bueso (MPS VI) as she successfully testified before Congress on a ruling that would deport her family and remove access to her life-saving therapy.
- Awarding more than \$760,000 in research grants to the world's leading researchers.
- Expanding of the Pathways program with visits to almost 60 newly diagnosed families through home and hospital visits.
- Traveling with more than 60 families to Washington, DC, to advocate for key legislation.
- Establishing the first physician's masterclass for training postdocs and junior faculty on MPS diseases.
- Hosting the 33rd Annual Family Conference at Walt Disney World, continuing a 25-year tradition.

The Society also said goodbye to long-time friend Christa Armstrong, a Rising Sun Legacy Circle founding member, who gifted the Society an incredible \$1 million for MPS II research through our Planned Giving program (see page 15).

This level of planned giving provides the capacity to strengthen our programs in a deeper and more meaningful way. The Christa Armstrong legacy gift meant we could implement the MPS II Research Collaborative and fund two \$100,000 research grants focused on newborn screening assays. In addition, the board advanced critical research program strategies by creating the position of chief scientific officer to enhance our staff, a vision that will benefit our patient community. Continued growth of the research program means we are creating new knowledge and producing innovations that will address some of the world's most pressing MPS questions and challenges.

Our donors continue to trust the National MPS Society because we have continually illustrated the ability to achieve key milestones for our community. We received, for the ninth consecutive year, the coveted 4-star (exceptional) rating from Charity Navigator, an independent charity evaluator, making us a national leader among charities and indicating that we operate and perform in the most fiscally responsible way. The Society is among the top 3% of charities nationwide, outperforming most in the United States. This rating illustrates our dedication to program funding and mission commitment.

Another major role of the Society is to bridge advocacy gaps for our families with local and federal government agencies. This includes providing testimony to the U.S. Food and Drug Administration (FDA) and meeting with the National Institutes of Health. In 2019, we met with the FDA to support clinical trial design for alpha-mannosidosis enzyme replacement therapies, and presented at the National Institute of Neurological Disorders and Stroke conference on best practices in patient engagement and data management. The Society is a patient group thought leader and was again sought after for input on new FDA guidelines, patient testimony, and clinical trial designs.

As you review the 2019 Annual Report, we hope you note the accomplishments of our board of directors and committees. We are only able to deliver our mission because of the countless hours our volunteers provide to help our families.

We recognize the challenges that lie ahead and the increased compassion it will require to care for our MPS families. We pledge to provide new levels of support for our rare disease community, now facing a global pandemic, to continue to embrace diversity, and to openly acknowledge how these are interwoven within the underserved populations of our country.

The **Governance Committee** plays a crucial role in the National MPS Society's guidance and direction by reviewing staff and board member resources, identifying gaps in service delivery, and working to improve overall performance. We are methodically building an infrastructure that will allow the Society to enact real results and sustain its longevity for decades to come. This is accomplished through several key initiatives, such as annual compensation and benefit evaluation, board member reviews, and board election oversight.

Fostering Powerful Change and Superior Outcomes

In 2019, the Governance Committee considered staffing and personnel needs of the Society, including compensation recommendations. One requirement was to fill the position of development director. The Governance Committee also oversaw the president and CEO in completing employee evaluations and was available as a resource as needed.

After dividing communication initiatives among the staff for most of 2019, the committee determined an extensive recruiting process would begin for a communications director in the new year. In addition, the committee, along with the full board, evaluated the organization's need and approved the creation of a new position, chief scientific officer.

Also in 2019, the Governance Committee oversaw the annual board of directors election process for the upcoming 2020-2021 term. This consisted of a vigorous vetting of all applicants, including personal interviews, prior to the membership voting. For the 2020-2021 term, two new members were welcomed to the board of directors, along with the incumbents. We look to these outstanding volunteers to help guide the Society through strategic decisions.



Dr. Barbara Burton



Dr. Lorne Clarke and
Dr. Matthew Ellinwood

The Governance Committee exists to ensure that the National MPS Society's board of directors operates in an effective manner. Members of this committee run the election process, train new board members, make certain the board is actively looking for future members, and perform other duties as directed by the president and CEO.

Austin Noll III, Governance Committee chair



Board of Directors and Staff at the WORLD Symposium

Decades of Devotion

The **Family Support Committee** is the cornerstone of our organization. Its purpose is the fundamental reason the Society was created—helping families in every way possible. Whether it's financial aid during a hard time, assistance with the diagnostic odyssey, or help making educational dreams come true, we support families across the nation.

Our agenda continues to evolve and in addition to funding a variety of programs, the family support pipeline assists with obtaining access to humanitarian programs for approved treatments and establishes global connections for referral.

In 2019, we invested more than \$150,000 to improve the lives of 180 families through multiple direct family support initiatives.

2019 HIGHLIGHTS

Family Assistance Program

- Approved nine applications, totaling \$19,848.
- Provided funds for hearing aids, specialized eyewear, seating equipment, vehicle lift, and hot tub.

Medical Travel Assistance Program

- Approved a record 33 applications, totaling \$17,141.

Journey Assistance Program

- Approved 8 applications, totaling \$1,856.
- Funds awarded assisted families with home renovations, computers, iPads, and car seats.

Bereavement Expense Program

- Responded to an unmet need by expanding financial assistance to provide resources for families experiencing the loss of a loved one with MPS or ML.
- Approved 23 applications, totaling \$11,448.

Extraordinary Experiences Program

- Approved three applications, totaling \$2,270.
- Events funded include two school trips and specialized driving lessons.

Conference Scholarships

- Awarded 73 scholarships totaling \$58,515 to the Annual Family Conference, CYCLE Conference, and SPIRIT Conference.

Continuing Education Scholarship Program

- Awarded 22 scholarships, totaling \$21,500.
- Awarded three Jeffrey Bardsley Scholarships totaling \$15,000 (\$5,000 each to individuals with MPS).

Social Gatherings

- Provided funding to support events in Sellersville, PA; Hilliard, OH; and Los Angeles, CA, totaling \$2,025.



CYCLE Conference attendees



The National MPS Society provided a scholarship so that I was able to attend the National Student Leadership Conference where I participated in the Environmental Science and Sustainability Program.

Today, many opportunities are available to me, regardless of my MPS, and others with physical disabilities. My diagnosis has taught me I am special in my own way, and I am grateful for this. Having MPS has helped me to better understand others with rare diseases. It gave me great character and strength. Thank you to the Society for growing as an organization that is forward-thinking and provides educational scholarships.

James Whiteman (MPS VI)

Leveraging Advocacy and Public Policy

Advocacy is a marathon, not a sprint. We are steadily building the substance of our advocacy efforts, while simultaneously being prepared to deploy immediate action to effect change as circumstances shift throughout the legislative landscape. Policy makers, funders, and the public need to understand what is essential for our families, and why. It is crucial that we continually motivate our allies and supporters so that rare disease issues remain relevant. Advocacy is one of the best ways for our rare disease community to share its stories with those who are empowered to make a real difference on a federal level. Federal policies can increase life-saving medical research and access to care for MPS and ML patients.

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.



Dr. Emil Kakkis with
Isabel Bueso (MPS VI),
Rare Voice Award Winners



I came to the United States from Guatemala at age 7 to participate in a clinical trial for MPS VI. After almost 16 years of living legally in this country, I met an unexpected challenge when the administration abruptly ended the deferred action program that enables patients to receive critical care and unique treatments.

Faced with losing life-saving medical treatment, I decided to advocate for patients across the country in a congressional hearing. The policy has been temporarily reversed, and I will continue to work with representatives for a permanent solution. I am grateful for the outpouring of love and support from people who fight with me. This experience taught me that every voice matters and that you can make a difference by speaking up.

Isabel Bueso (MPS VI)

2019 HIGHLIGHTS

- Participated in two trips to Washington, DC, for Rare Disease Day and MPS Awareness Day.
- Facilitated a two-day Capitol Hill visit with 44 advocates meeting with 59 legislators to advocate for newborn screening, Medicare prescription drug price negotiation, and increased NIH funding for MPS and ML diseases through the appropriations bill, as well as recruit rare disease caucus members.
- Created awareness action alerts to support the following legislation:
 - H.R.2507 – Newborn Screening Saves Lives Act
 - H.R.242 and S.377 – Medicare Prescription Drug Price Negotiation Act of 2019; Orphan Drug Resolution
 - H.R.161 and S.90 – A Resolution to mark the last day of February as “Rare Disease Day”
- Provided onsite training in Washington, DC, for our Speaker’s Bureau Program.
- Supported Society member Isabel Bueso whose advocacy efforts gained national media attention, including interviews on MSNBC and features in *People* and *Elle* magazines.
- Hosted two, one-hour advocacy training webinars (*Preparation for Meeting with Your Legislator* and *How to Tell Your Personal Story*) which can be accessed on our website for continuous training.
- Attended the following advocacy and networking conferences: 15th Annual *WORLDSymposium*; COPA; NORD; EveryLife Congress on newborn screening; Global Genes 2019 RARE Patient Advocacy Summit; NORD Patient Summit; NCATS Patient Advocacy Meeting; Taiwan Newborn Screening Meeting for MPS II; University of Minnesota Newborn Screening Updates for MPS I.
- Submitted position statements on increased newborn screening awareness in collaboration with the EveryLife Foundation.

The National MPS Society connects and engages with the MPS and ML community through a variety of communication platforms. We continuously evaluate and expand communications 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.



Effective and Progressive Communication

In 2019, the National MPS Society continued to increase communication efforts by expanding our electronic newsletter, *eCourage*, to a monthly publication, creating an Instagram account, and growing our Facebook and Twitter communities. The Society highlighted its extraordinary 45 years of working to support our families and critical research during MPS Awareness Day and throughout the year. We began updating our core educational resources, including MPS and ML booklets, and republished fact sheets for critical care disease management.



John Thornton (MPS IIIA)



2019 HIGHLIGHTS

- Increased efforts to raise awareness for International MPS Awareness Day, May 15.
- Increased *e-Courage* subscriptions to more than 2,200 members.
- Secured a four-page article in *SciTech Europa Quarterly*, highlighting 45 years of the National MPS Society.
- Participated in the podcast *Mendelspod*, to discuss MPS and educate listeners nationwide.
- Began updating MPS booklets, a primary resource for our members and their networks.
- Completed a comprehensive revision of the fact sheet library for the MPS and ML community.
- Implemented a resource library for adults with MPS and ML, adding specific fact sheets for independent living and care management.
- Continued the second phase of website integration.
- Created new strategies and restructured the committee, which comprises four sub-committees: Content Development, Design Development, MPS Awareness Day, and Strategic Planning.

Our role as the Education & Publicity Committee is to ensure that MPS and ML messages are clearly written, creatively designed, and shared broadly via our website, social media, pamphlets, emails, videos, etc. We make certain our community is informed and stays engaged with the National MPS Society, particularly around MPS Awareness Day. We also assist other committees in getting their messages heard. We especially enjoy focusing on families. Sharing member and caregiver stories so we can all learn from and support each other is our joy and privilege.

Cristol O'Loughlin (MPS II sibling), chair, Education and Publicity Committee



An increasing number of MPS and ML patients are living into adulthood due to the efforts of the National MPS Society, physicians, families, and support systems. Increase in the MPS and ML adult population created a need to discuss unique issues that these adults experience and share. To have a voice within the Society, as well as become actively involved within the MPS adult community, a group of individuals created the **Adult Resource Committee (ARC)**.

Bolstering a Bright Future



“

ARC provides an extension of our strength and individuality. As a patient and research scientist, I was honored to present last year at our family conference on “The Importance of Patient Involvement in the Drug Development Process.” Science will render the answers we need for MPS and ML; while this transpires, I am thankful for the contributions ARC members can bring to our community.

Jennifer Klein (ML III), scientist, ARC member

The ARC, although a recent endeavor, quickly established a solid groundwork for increased advocacy and programs for adults in the Society. In 2020, ARC members will have an opportunity to raise awareness, participate in social support sessions, and plan their SPIRIT Conference. This is a tremendous opportunity to take on a greater role in individual care management and mentoring those who will come after.

I have been living with MPS I for 26 years. One of the many ways this disease affects my body is by limiting my vision. Thanks to the National MPS Society's Family Support Program, I recently was able to obtain a new vision device called eSight. This device has allowed me to see things at a distance. I am hopeful that eSight will help me to become more independent and experience the world in a new way.

Jerry Klemm (MPS I)

2019 HIGHLIGHTS

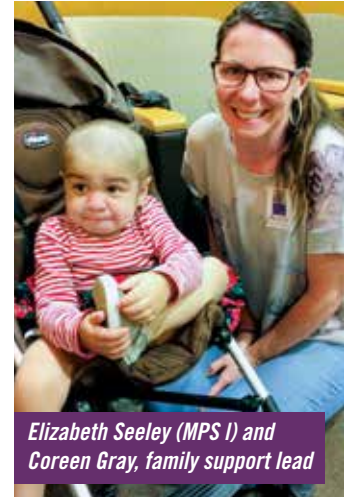
- Released the official “Road Kit” for adults with MPS and ML. This kit provides information and resources for those who are transitioning into adulthood and beyond.
- Hosted the largest attended SPIRIT Conference in Orlando, FL, for more than 45 adults with MPS and ML. Presentations, networking, and social activities provided targeted information regarding care, jobs, and well being. The SPIRIT Conference also offered opportunities for networking with other adults and health professionals, strengthening the patient community.
- Created Project RARE, a fundraising and awareness-cultivating project where merchandise featuring designs created by MPS and ML adults will be sold online. Items will be sold on Café Press. Funds will support ARC initiatives.



Expanding Avenues of Support

MPS families rely on the Society's support, starting with diagnosis. Our long-term vision includes identifying new ways to provide services to families and individuals throughout their journey with MPS or ML. The **Pathways** program executes this forward-thinking approach by deploying skilled social workers who travel the country to meet with newly diagnosed families during this critical time. Home visits maximize the opportunity to provide meaningful, compassionate, and direct assistance.

Pathways provides tools for families and individuals throughout the first year of diagnosis that equip and strengthen them as they move forward. Linking families with local and national services ensures they receive high-quality care and have access to essential resources. The Pathways program has enrolled more than 120 families since its inception three years ago.



*Elizabeth Seeley (MPS I) and
Coreen Gray, family support lead*



Charlie Grace was diagnosed with MPS I through newborn screening. We connected with the National MPS Society immediately and enrolled in the Pathways program. When Charlie Grace was one month old, we had an in-home visit and received support in so many ways for the entire first year after diagnosis. The most important thing I have learned is to accept MPS. This is who Charlie Grace is and she is perfect. The Society is hands down amazing.

Amanda Sinard, mother of Charlie Grace (MPS I)

During the first few months after Aaron's diagnosis, our family was lost. We didn't know who to turn to or where to seek resources and information. We found the National MPS Society through a Google search. They opened their arms to our family, answered questions, and provided us with materials, research, support, and links to pharmaceutical representatives to educate us on enzyme replacement therapy. I attended a gala and met families from across the country. They immediately embraced me and made me feel like the Society was a true family. They assisted us in completing and submitting a scholarship application, and flew Aaron and me to Florida for our very first family conference. My son felt so special and continues to talk about Camp Courage. The administrators, staff, and families made him feel welcome and also provided me with additional information about his disease. I am proud to now serve on the Family Support Committee. It is an honor for our family to be involved.

Ginger Beverly, mother of Aaron (MPS IVA)



2019 HIGHLIGHTS

- Provided services to 66 families in their first year of diagnosis.
- Conducted more than 58 face-to-face visits with families in their homes or at the hospital in 21 states.
- Averaged three to four newly diagnosed family referrals to the program each month.
- Provided services to 13 families through newborn screening. Newborn screening has enhanced the program to reach families sooner.
- Arranged newly diagnosed meetings at the annual family conference.
- Distributed disease-specific information and resources to assist with accessing therapies and clinical trial information.
- Strengthened relationships with industry partners to provide comprehensive support to newly diagnosed families.
- Implemented interpreter services to assist Spanish-speaking families.

Families in the Past Searched for Hope; Families of the Future Will Have a Cure

RESEARCH remains paramount to the National MPS Society's mission—to find cures for all MPS and ML diseases. Grant funding, research partners, and collaboration ensure key efforts toward a better future for all affected.

In 2019, the National MPS Society's research program awarded a historic high level of funding for life-saving and life-changing research.

The Society allocated and invested more than \$760,000 in total grant funding in 2019, which includes second-year funding for grants awarded in 2017; and \$50,000 in partnership with the University of Pennsylvania through the Million Dollar Bike Ride. The Society also committed \$25,000 to the University of Minnesota Lysosomal Disease Network for continued core imaging research with the National Institutes of Health; and \$30,000 was provided to Iowa State University for "Maintaining the Canine MPS Model Research Resource."

The Society awarded an additional \$200,000 for other MPS II research with funding received from the Christa Armstrong legacy gift. The funding the Society provides has been and continues to be critical as we move forward with our mission to find cures.

We received 34 letters of intent from researchers around the world this past year. After reviewing the letters, our Scientific Advisory Board review committee requested full grant proposals from 15 researchers. Projects selected focused on research for syndromes in desperate need of funding.

I am truly grateful to the National MPS Society for its continued support. They have been a tremendous partner in our pursuit of treatments for lysosomal diseases. The funds I have received have enabled me to investigate novel questions, pursue unique therapies, and have provided the seeds for additional funding. The Society's unwavering support has not only financially fueled our research, but also driven our team's passion to find solutions for patients and families. Thank you for being our partner in this fight. We couldn't do the work without you.

Dr. Heather Steet, Greenwood Genetic Center



The funding and encouragement the National MPS Society provides to researchers, especially those in the early stages of their career, have been vital to the development of a new generation of clinical and basic scientists. I am grateful to have received this support in my own career, and honored now to help the Society grow and enrich its research efforts as we drive toward discovering new therapies.

Dr. Richard Steet, Greenwood Genetic Center



RESEARCH GRANTS

This innovative research could not be accomplished without the selfless commitment of our global MPS scientists, who continue to seek answers for our children. Our commitment and dedication to advancing our mission through these partnerships is highlighted in these impressive, carefully chosen, pivotal research projects:

2019 Two-Year Grant Award Recipients

\$90,000 general grant

Dr. Ivan Conte

TIGEM

Pozzuoli, Italy

"Pharmacological pulsatile induction of autophagy as a novel therapeutic strategy for MPS VII"

\$90,000 general grant/ MPS II grant

Dr. Enrico Moro

University of Padova

Padova, Italy

"Characterization of axon guidance defects in experimental in vitro and in vivo MPS II models"

\$90,000 general grant/ MPS III grant

Dr. Nicollina Sorrentina

TIGEM

Pozzuoli, Italy

"Combining autophagy modulation and AAV-mediated gene delivery of lysosomal enzymes for a synergic treatment of CNS and somatic pathology in mucopolysaccharidoses"

\$50,000 MPS IIIC grant

Dr. Liliana Matos

Ricardo Jorge INSA

Porto, Portugal

"Exploring in vivo U1 snRNA splicing modulation as an alternative therapy for MPS IIIC"

\$50,000 MPS IV grant

Dr. Maria Luz Couce

Santiago, IDIS

Santiago de Compostela, Spain

"Development of new lysosomal drug delivery system of elosulfase A for ERT of Morquio A"

2019 One-Year Grant Award Recipients

\$50,000 MPS general grant

Million Dollar Bike Ride

University of Pennsylvania

Philadelphia, PA

\$25,000 multi-syndrome grant

Lysosomal Disease Network

University of Minnesota

Neuroimaging Core NIH Project

\$15,000 ML II/III alpha beta grant

ISMED – partnership grant

United States

2019 MPS II Collaborative Research Award Recipients

\$100,000 MPS II grant

(one year)

Dr. Patricia Dickson

Washington University

St. Louis, MO

"Classification of IDS gene variants using saturation genome editing"

\$100,000 MPS II grant

(two year)

Dr. Richard Steet

Greenwood Genetic Center

Greenwood, SC

"Functional characterization of novel IDS variants in cells and zebrafish"

2017 Second-Year Grant Award Funding

\$45,000 general grant

Dr. Sharon Byers

SA Pathology (WHC site)

Adelaide, Australia

"Can the cell cycle be reset to normal in the MPS growth plate chondrocytes?"

\$25,000 MPS III grant

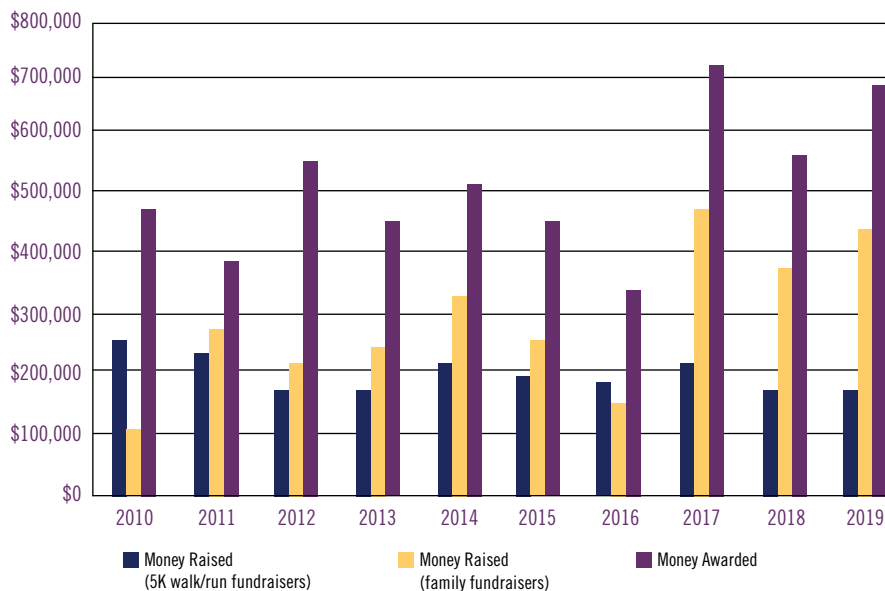
Prof. Elvira De Leonibus

TIGEM

Pozzuoli, Italy

"Disease mechanisms leading to dopaminergic dysfunction underlying behavioral symptoms in MPS IIIA"

MONEY RAISED AND AWARDED FOR RESEARCH



A nonprofit organization is only as strong as the level of support it receives from its members and benefactors. Our donors trust that the Society will employ their ever-increasing generosity to maximize impact on our mission. The **Fundraising Committee** facilitates this through many programs, such as family fundraisers, run/walk events, Annual Fund, major gifts, planned giving, mobile giving, Courage Pages, our Champions Circle, crowd-rising fundraisers, social media campaigns, the Combined Federal Campaign, United Way, employee giving, and matching corporate gifts and grants. The Fundraising Committee strives to increase donations each year and build creative opportunities in 2020.

Turning Trust into Meaningful Purpose



Jammin' for Julia fundraiser

Fundraising highlights of 2019 include Society hosted national events in Napa, CA; Orlando, FL; Raleigh, NC; and Washington, DC. We also teamed up for the sixth year in a row with the University of Pennsylvania for the Million Dollar Bike Ride to raise funds for MPS research. The Dare to Be Different Gala raised more than \$250,000, and more than 650 people attended the Rise Up for MPS Concert, held in memory of Jenna Richbourg.

2019 HIGHLIGHTS

- Maintained the Society's ninth 4-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 2,200 members.
- Raised more than \$600,000 through run/walk and fundraising events.
- Secured more than \$60,000 for MPS and ML research from the University of Pennsylvania through the Million Dollar Bike Ride.
- Hosted four national run/walk events in Babylon, NY; Napa, CA; Orlando, FL; and Raleigh, NC.
- Supported more than 70 family and Facebook fundraisers, including sports tournaments, cycling, bake sales, bowl-a-thons, concerts, bingo, auctions, and school relays.
- Increased grant writing efforts to secure physician and cognitive masterclasses, our newest program to educate physicians about MPS.
- Raised \$245,139 through the 2019 Annual Fund campaign, chaired by Jason Madison (MPS II).
- Continued efforts to meet with major donors and Society friends.
- Received Combined Federal Campaign application approval.
- Hosted 60 Courage Pages (customized, informative family web pages for awareness and fundraising) on the Society's website.
- Worked with donors to process more than 150 Employee Giving Campaign and corporate matching gifts.
- Increased awareness for the Rising Sun Legacy Circle and processed new planned gifts from trusts and wills.
- Fortified the Jenna Marie Richbourg Endowment with funds raised through the second Rise Up for MPS in Waco, TX.

We always knew my nephew was special. When he was diagnosed with MPS IVA I wanted to help in any way possible. I knew I couldn't cure MPS, but I could raise money and awareness for this rare genetic disease. Our family hosted an art auction, and all of the funds we raised went to research to try to find a cure.

This was my first fundraiser for MPS but it certainly won't be my last.

Chance Blakeley, uncle to Keller Blakeley (MPS IVA)



FUNDRAISING COMMITTEE

2019 Fundraising Events

36th District Masonic School PA Fundraising Event, hosted by David Coffman

Art Auction for Keller Blakeley, in honor of Keller Blakeley, hosted by Lori Tolson

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

Cooper Trooper's BBQ, in honor of Cooper Tippet, hosted by Brian and Christine Tippet

Crop for Rachel, in memory of Rachel Dodson, hosted by Michelle Dodson

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

Emily's Dance, in honor of Emily O'Connor, hosted by Kevin and Danielle O'Connor

Halk Fall Festival, in memory of Blake Halk, hosted by Carla Halk Crain

Holland's Hope Fundraiser, in honor of Maddie and Laynie Holland and in memory of Spencer Holland, hosted by Steve and Amy Holland

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

Jammin' for Julia, in honor of Julia Donahue, hosted by Andrea Felton

Kendra Gottsleben Birthday Fundraiser, in honor of Kendra Gottsleben, hosted by Project Organic Life

Kendra Scott Fundraiser, in honor of Michelle Hopkins, hosted by Lynn Hopkins

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

Mackenzie Wynegar Fundraiser, in honor of Mackenzie Wynegar, hosted by Ann Wynegar

Mark's Memorial Drag Race for MPS II, hosted by AMS Performance and Chicago Motor Cars

Noah and Caleb Woodcock Fundraiser, in honor of Noah and Caleb Woodcock, hosted by Cowboy Liquors

Pick Your Charity Golf Tournament, hosted by Mark Janzen

Rise Up for MPS, in memory of Jenna Richbourg, hosted by Keith and Sherri Richbourg

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

Toss for Tony, in memory of Antonio "Tony" Estrada-Willmann, hosted by Katie Willmann

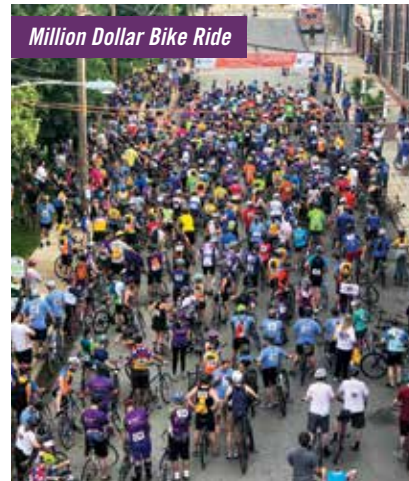
2019 Run/Walk Events

Jingle Bell 5K, hosted by National MPS Society

Napa National Run, hosted by National MPS Society

Post Office Café 5K, hosted by Joan and Mark Lessing

Raleigh Run for Rare, hosted by Terri Klein and Michael Schleiter



Million Dollar Bike Ride

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

2019 Champions Circle

Amy Barkley
Melany Bjorkman
Marc and Beth Brdar
Maria De Granillo
Justin Dickerson
Cindi Dunsworth
Elizabeth and Joshua Eickman
Allison Frazier
Michele Geigle
Brendan Graham
Heinz and Karine Holba

Steve and Amy Holland
Jennifer Hutcheson
Kiran Joshi
Brian and Rebekah Klutz
Lori Lazarescu
Lauren Louison
Donny and Molly Merrill
Greg and Jennifer Mincks
Eric and Amber Mongan
Susan Murphy
Kathy and Josh Nay

Thomas and Peggy O'Malley
Julie Patricia
Mark and Maryellen Pendleton
Linda Perrella
Jared Shelton
Jeremy and Rena Stearns
Jack Swepston
Lorie Tolson
Sarah and Todd Waddell

Courage Pages

The following families have their own website through Courage Pages at 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
Annabelle Bozarth
Tyson Brown
Sam Caswell
Alan Charest

Alex and Nick Cherrstrom
Julia Ann Donahue
Jackson Dunn-Kraus
Kali Gegenheimer
Shane Gibson
Owen Groesch
Karina Guajardo
Mackenzie and Isabella Hardesty
Faith Heard
Jaela Hernandez
Holland family

Michelle Hopkins
Analynn Hughes
Fiona Humphrey
Kathleen Joyce
Carter Kanney
Beth Karas
Eddie Kimminau
Allison Kirch
Jennifer Klein
Kraig Klenke
Drake Lucas
Shane McGoey

Caleb Michalik
Danny Miller
Maura Mongan
Xavier Patton
Analee Perez
Raymond Pinchak
Myles Richardson
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

FUNDRAISING COMMITTEE

2019 Facebook Fundraisers

Jack Abraham
Melany Abrahamsen
Beth Adams
Lee Adams
Rachel Adams
Kathleen Aguilera
Cheyenne Anderson
Emily Ardoin
Gail Armato
Christina Ash
Dianna Ashareef
Steve Bailey
Guillermo Barreneche
Charlotte Barrett-Weber
Rita Basom
Amanda Bayne
Amy Becker
Maurizio Bellassai
Nicole Bennett
Justin Bergstrom
Debra Berry
Rose Berta
Darci Bible
Brooke Biddle
Kerry Bilewski
Jamie Morrison
Blackmon
Brendon Block
Darryl Block
Cenia Blount
Marie Ballard Blumeier
Kellie Bonarski
Jason Boni
Martha Rooks Booth
Squeek Bosch
Lynn Brand
Sara Brannen
Candince Brooklyn
Alicia Brooks
Morgan Brown
Darcy Brunk
Cathy Bryson
Kyle Buffington
Stacie Hembree
Buffington
Gary Bury
Kerry Durham Bynum
Ana Caballero
Brook Carlsen
John Carpenter
Jim R. Case
Anthony Catanzarite
Manahal Ch
Ruth Clancy
Andrea Clark
Melissa Cleroux
Lori Cios
Allison Cochran
Kaitlyn Corwin
Carla Crain
Kelly Crilly
Michelle Crocker
Paula Culet
Jason Cullere
Hannee Curzwiler

Elaine Custer-Kahns
Caroline Dabney
Amanda Dean
Elizabeth Dean
Joanine Dedrick
Leta Deering
Drew Delvaux
Suzanne Depuyt
Kelly Deshaw
Nate Dettmer
Judy Dickerson
Justin Dickerson
Casey Dixon
Katie Dulaney
Alaina Dunwoody
Jacob Ellis
Wayne Eppheimer
Heather Esparza
Ashley Fagerlind
Joyce Favro
Jorge Aiwe Figueiredo
Cristel Figueroa
Megan Fitzgerald
Ann Fountain
Ashley Frix
Elizabeth Fry
Mandy Moore Garrard
Roslynn Offutt Garvin
Laurie Gendreau
Troy Gerard
Ang Germade
Robert Van Ghle
Mary Gipson
Donna Glenn
June Green
Rebecca Green
Brandy Guinn
Tonia Hadley
Jannifer Hafner
Jeanne Jeffreys Hah
Chey Halk
Kelly Fedak Handlovitch
Holly Hanson
Tonia Carr Harvey
Nathaniel Haskins
Jessie Haugen
Linda Stephany Heard
Paul Heard
DeLynn Hedges-Greenfield
Jennifer Higley
Alex Hill
Brandon Hill
Chris Hill
Emma Hill
Mathew Hinkle
Laynie Holland
Debra Hoyopatubbi
Carrie Hubbard
Rita Hubbs
Fidencia Junior
Cisneros III
Riah Jade
Bethany James
Jessie James
JoAnn Jennings

Tammy Jennings
Brook Jewell
Kristi Wood Johnson
Rachael Brady Johnson
Anne Jones
Collin Jones
Kyle Joseph
Kathleen Loomis Joy
Dan Kehoe
Angela Keidel
V. Keith
Brandy Kelley
Jackie Kelly
Sarah Keren
Shelly Kerfoot
Jane Keutzer
Bill Killillay
Brenna King
Susan Kirch
Gloria Klaesges
Terri Klein
Tawnya Kline
Lexi Kramer
Debbie Kruse
Becca Kyle
Ana Mara Lagaro
Debra Laiewski
Tiffany Strickland Lala
Emily Layman
Tammie Lee
Katie Lehive
Michael Lewis
Morgan Lewis
Madison Litchfield
Lena Liu
Mary Katherine
Livingston
Kim Lodge
Angela Lombardi
Megan Love
Jessica Lynn
Shelby Lyon
Danny Lyons
Tiffany Mabry
Sean Macer
Brianna Maddux
Mandy Mae
Liz Tasha Snow Majors
Chad Makuch
Lauren Makuch
Elizabeth Managan
Kelly Mann
Megan Marie
Keke Marshall
Jayme Muskrat Martinez
Stephen Mask
Shaina Runs-For
Matthew
Shannan Rene May
Jim McClelland
Jessyca Rene
McCracken
Jenny McClain-Heinz
Michele Antoinette Mcrae
Liz McWhirt
Bryan McWilliams
Anna Mechem

Anna Medeles
Judy Boudreaux
Mericle
Shane Mericle
Jennifer Midler
Brittany Miller
Glynis Moinet
Sarah Moody
Autumn Mortensen
Richard Mosley
Helen Moss
Gaby Motta
Aaron Mullinax
Janell Murrison
Kathy Nay
Dawn Nelson
Amber Nicole
Lisa Nicole
Jessica Niec
Justin Odagiri
Lindsey Oden
Veronica Evans Oglesby
Kimberly Thrall Olson
John Outten
Janet Owen
Jamie Pace
Nancy Pacl
Liz Paolone
Jessica Parker
Jeff Parks
Ashley Parrish
Jordan Pascucci
Stacey Mericle Pevler
Angelica Prater
Jaclyn Chiorse Pryka
Monica Ptacek
Laurel Radius
Steve Radius
Kaite Ragle
Emily Ramirez
Tammy Rammnes
Kisha Ranika
Bryce Reamer
Danny Reed
Stephanie Renee
Gabrielle Rivas
Tammie Rivere
Roxann Robb
Trisha Robertson-Athy
Dawn Rodriguez
Erika Romo
Lisa Marie Root
Tammy Rose
Emma Rotchell
Alex Rouse
Connie Rowland
Jer Ryan
Samantha Sabbs
Jill Sakuma
Manuel Sanchez
Barbara Santerelli
Lynn Santos
Georgia Schuh
Bonnie Schwab
Jackie Scott
Marilyn Ulrich Scully



*Stephanie Bozarth
and Lisa Todd*

Jordan Sedgwick
Carolynne Seiffert
Cheryl Sena
Taylor Shourds
Trinity Taylor Slagle
Jamie Sliwinski
Phoebe Snow
Judi Wells Sparling
Laura Spencer
Loretta Oaks
Spriesterbach
Amanda Standifer
Dana Stapley
Gerrie Stephens
Marla Stevens
Kimberly Stribling
Tanya Willis Swails
Jessica Swarouth
Randy Tang
Michelle Teng
Daniel Tetreau
Sarah Tharp
Dan Theirl
Donna Theresa
Marissa Theriault
Debbie Thomas
Kathy Thomas
Becky Thomason
Lorie Tolson
Lynne Connor Travers
Marica Garcia Tuckett
Andrew Tuma
Simon Turner
Cliff Tyler
Jennifer Underwood
Katelyn VanGhle
Daisy Vasquex-Vogt
Becky Waibel
Karen Wallace
Linda Wallace
Carrie Warner
Cynthia Waters
Krsiti Owens Watson
Diana Weiler
Stacy Whitley
Em Wighton
Jon Williams
Veronica Wilson
Nick Wiltin
Sheri Wise
Stacy Wood
Ethian Wright
Olivia Yaskus
Julia Bodura Yost
Clayton Yukumoto
Gholamreza Zakeri
Sherry Zwickel

FINANCIALS

The financial information below has been summarized for the year 2019. 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.

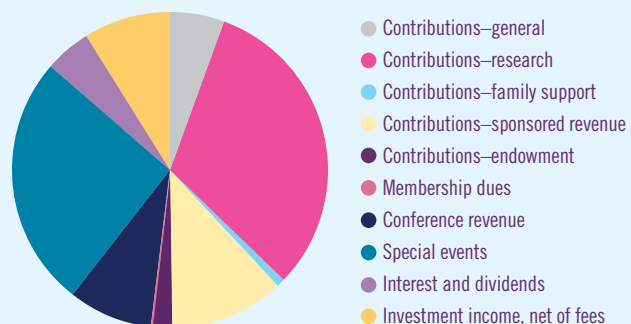
Financial Position

Assets		Liabilities	
Current Assets		Accounts payable	
Cash and cash equivalents	\$ 453,363	Grants payable	\$ 142,469
Investments	3,261,129	Accrued salaries/vacation	140,000
Contributions receivable	22,212	Total Liabilities	306,800
Prepaid expenses	9,242	Net Assets	
Accrued interest	7,612	Without donor restriction	
Property and Equipment, Net	6,501	Undesignated	1,392,003
		Designated	474,850
Other Assets		With donor restrictions	
Deposits	17,582	Purpose restricted	1,743,080
Investments—restricted for purpose	161,252	Time restricted	22,160
Investments—restricted in perpetuity	1,138,568	Perpetual in nature	1,138,568
Total Assets	\$ 5,077,461	Total Net Assets	4,770,661
		Total Liabilities and Net Assets	\$ 5,077,461

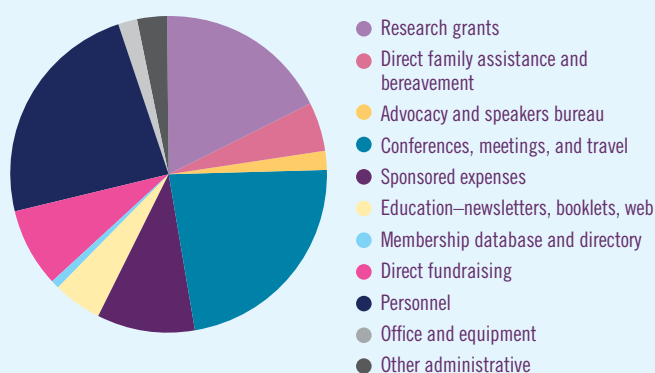
2019 Statement of Activities

Revenue and Support		Functional Expenses	
Contributions		Research grants	\$ 381,487
General	\$ 190,312	Direct family assistance and bereavement	96,124
Research	1,058,492	Advocacy and Speaker's Bureau	35,692
Family support	4,288	Conferences, meetings, and travel	496,615
Sponsored revenue	377,500	Sponsored expenses	204,332
Endowment	13,878	Education—newsletters, booklets, web	104,577
Membership dues	2,300	Membership database and directory	10,032
Conference revenue	278,415	Direct fundraising	174,312
Special events	846,364	Personnel	517,123
Interest and dividends	121,352	Office and equipment	52,216
Investment income, net of fees	277,830	Other administrative	62,928
Total Revenue and Support	\$ 3,170,731	Total Functional Expenses	\$ 2,135,438
		Change in Net Assets	\$ 1,035,293

2019 Revenue and Support



2019 Functional Expenses



2019 was the ninth year for the National MPS Society's **Planned Giving Program**. There are now 29 donors in the Rising Sun Legacy Circle. Planned giving helps donors maximize the personal benefits of charitable giving and allows donors to make gifts they may not have thought possible. Individuals who make these gifts to the National MPS Society, whether through their estates, wills, or other life-income arrangements, share a strong common bond of generosity that will provide security for future generations. Building this community of philanthropy helps our donors achieve their personal vision and fulfills their desire to contribute.

Planned Giving—Rising Sun Legacy Circle

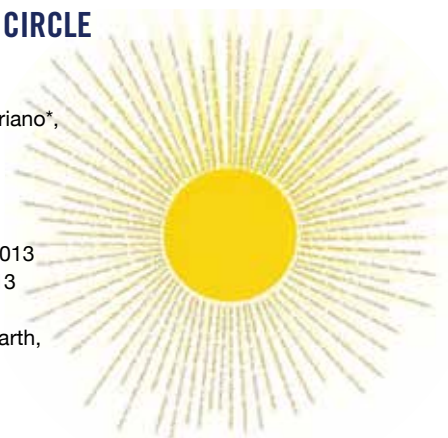
Unexpected Benefits from a Decade-Long Program

2019 HIGHLIGHTS

- Received a \$1 million estate gift.
- Established a new MPS II Research Collaborative Network.
- Included planned giving articles in *e-Courage*.
- Continued stewardship with donors.
- Informed of two new planned gifts to be received by the Society in 2020.
- Maintained a Planned Giving website to help members and friends of the Society become acquainted with planned giving and gifts the Society accepts.

RISING SUN LEGACY CIRCLE

Christa Armstrong*, 2011
 Becky Clarke, 2011
 Emil Kakkis and Jenny Soriano*, 2011
 Mary Starr Adams, 2012
 Terri Klein, 2012
 Tracy Szymanski, 2012
 Steve and Amy Holland, 2013
 Brian and Kris Klenke, 2013
 Barbara Wedehase, 2013
 Austin and Stephanie Bozarth, 2014
 Carol Elwell*, 2014
 Randy McDonnell*, 2014
 Steve McDonnell*, 2014
 Ron and Barbara Crecco*, 2015
 Cheryl Sorter*, 2015
 Pamela M. Daoust, 2016
 Gordon R. Case Trust, 2017
 Glenn F. Leiter, 2019
 Darlene Sweeney, 2019



* Indicates gift has been received. Some members wish to remain anonymous.

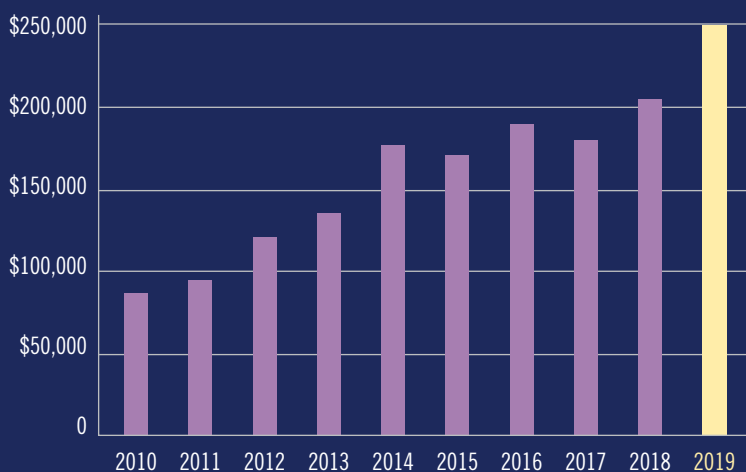
Annual Fund Donations



As an adult with MPS II, it was an honor to chair the 2019 Annual Fund. We raised a historic level of funding for our research and family support programs.

This important contribution is an example of how giving can provide key assets for the Adult Resource Committee.

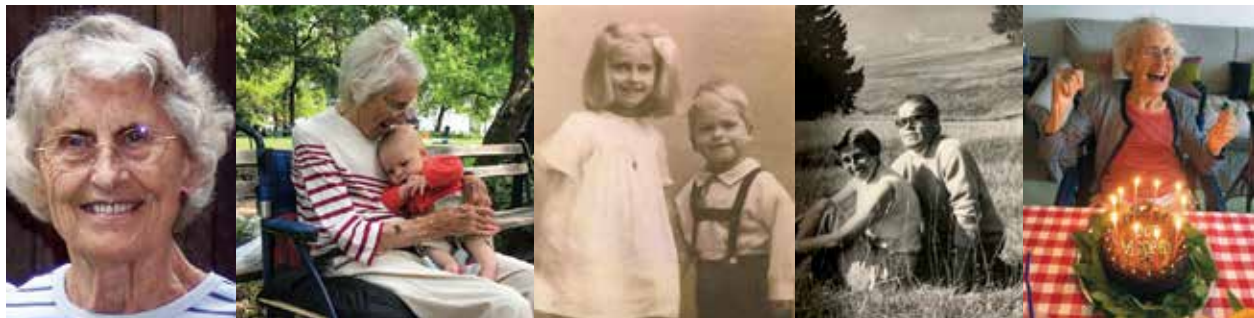
Jason Madison (MPS II), chair, 2019 Annual Fund



Christa Armstrong—Journalist, Photographer, and Author—Gifts the Society for MPS II Research

This past fall, the National MPS Society lost a long-time friend, Christa Armstrong, who passed away at age 101. Christa became a member of the Society in the early 2000s and stayed in constant contact ever since. Her brother, Ulrich von Tippelskirch, had MPS II and passed away in 1964.

In 2011, Christa became one of the first members of the Rising Sun Legacy Circle. These individuals have pledged a legacy, or planned gift, with the Society—one of the highest and most meaningful contributions an organization can receive. After Christa's passing last year, the Society was notified of her legacy gift: **an astonishing \$1 million**.



Christa's memoir, "Heiligengrabe or Speaking in the Third Person," describes her life during World War II in Berlin where several of her friends belonged to a group plotting to assassinate Hitler. She courageously supported imprisoned members of the resistance and protected a Jewish friend, whom she hid in her apartment. Christa escaped shortly before the Russians took Berlin. In 1948, she immigrated to the United States and married Hamilton Fish Armstrong, founding editor of *Foreign Affairs*. Together they traveled the world's conflict zones of the 1950s and 60s, and her articles and photos were published in several countries. After her husband's passing, Christa traveled to South Africa and across Europe researching the history of her family, who followed a religious guru in the early 1800s to Cape Town, South Africa. Her findings were the basis for her second book, "God's Errant Children."

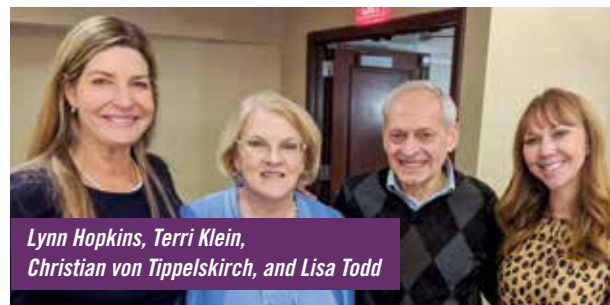
We had the privilege of meeting Christa and her family in person, and over the years the Society enjoyed sending her *Courage* publications and keeping her informed on MPS research, especially the approval in 2006 of Elaprase, the enzyme replacement therapy developed to treat MPS II.

MPS II research was a focus for Christa and her family, and through this incredibly generous legacy gift, the Society will be able to continue to fund critical research pathways.

"I'm so glad that Christa's bequest will help future scientific research into MPS II," said Christa's nephew, Christian von Tippelskirch. "Christa had high standards, self-discipline, and felt responsibility for others. She was the most wonderful and reliable friend who cherished giving to others."

At the 33rd Annual Family Conference, the Society presented Christian, along with Christa's niece, Dorothea von Tippelskirch-Eissing, the esteemed Visionary Award.

"Christa observed our family experience Hunter syndrome for decades," said Christian. "You can imagine how much it means to us that her vision has been fulfilled by her contribution to establish the first MPS Syndrome Collaboration Network for MPS II Research, and to be a part of supporting new global research into the illness."



Lynn Hopkins, Terri Klein,
Christian von Tippelskirch, and Lisa Todd

2019 Contributors

with sincere thanks to our supporters...

In 2019, 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 2019. If your name is not listed, we apologize and ask that you contact us. If we received your donation in 2020, you will be recognized in the next Annual Report.

Humanitarian (\$50,000+)

BioMarin
Christa Armstrong
Revocable Trust
Genzyme Corporation
JCR Pharmaceuticals
REGENXBIO, Inc.
Sanofi Genzyme
Shire Human Genetic
Therapies
Streblow Family
Foundation
Ultragenyx
Pharmaceutical

Visionary (\$10,000 to \$49,999)

Abeona Therapeutics
Amicus Therapeutics, Inc.
Wayne and Catherine
Bardsley
Bryson Foundation, Ltd.
Royce Bunce and
Elizabeth Sherwood
Gene Spotlight, Inc.
Kercheville Foundation
Lysogene
Sangamo Therapeutics,
Inc.

Philanthropist (\$5,000 to \$9,999)

Bluebirdbio, Inc.
Stephanie and Austin
Bozarth
Marsha Bozarth
Rob Burkholder
Barbara and Ron Crecco
Denali Therapeutics, Inc.
Marie and Ralph
Edwards

GB & Charlotte Saunders
Foundation, Inc.
Scott and Lynn Hopkins
Immusoft
Michael Schleter and
Terri Klein
Kori Ogrosky
Orchard Therapeutics
Sam and Nancy Ramsey
Horace Richbourg
James and Pamela
Rogers
Seelos Therapeutics, Inc.
Marla and Randy
Stevens
United Bank
Dr. Klane and Mrs. Amy
White

Champion (\$1,000 to \$4,999)

AbbVie
Affordable Care, LLC
Allievex Corporation
Helen Allison
Amazon Smile
Automotosports, Inc.
Backpack Health
Margaret Barry
Mike Beard
Clinton and Lindsey
Blakeley
Richard and Mignon
Bosse
Brandy and Beau Bozarth
Brackeen Power
Solutions
Jeffrey Bridge
Sean Burr
Dwain Camp
Casa de Fruta
Rob and Diane Cassil

Kevin Cassil
Brendan Clark
Comprehensive Health
Management
Gary and Linda Corbett
Cowboy Liquors
Lisa Crabtree
Anthony Del Monaco
Jeff and Anne Denneen
Seth and Amy Downen
du Alaska Incorporated
Duke Energy
Kathleen Dull
Dutch's Daughter, Inc.
Mark Egan
Robert Farrior
Megan Fass
Carl Felten
Fifth Generation, Inc.
Marilyn and Gary Figlar
Stan Fink
Susan Fitzgerald
Betsy and Steve Fowler
James Gosdin
Angela and Luis
Guajardo
Elisabeth Harding
Harris & Associates
Kim Hillis
David and Susan Holder
Steve and Amy Holland
Jeffery House
John Hunnicutt
IDI Logistics, LLC
Invitae
Mark Janszen
Julie and William
Johnson
Kajima Foundation
Wendell and Karen Keith
Kendra Scott, LLC



Danny Latham (MPS I)

Mark and Dana Kinslow
Lawrence and Susan
Kirch
Tom and Linda Kirch
Jenny Klein
Carl and Deborah Kruse
Linwood Lacy Jr.
Dawn and Philip
Laorenza
Leger Strategies, LLC
Lawrence and Peg
Lessing
Wayne and Sharon Lewis
Wes and Jill Lovell
D. and G.R. Lowry
Margot Shriver Fund
Matz Family Foundation
Matt and Stephanie
Mays
Cooky and Howard Mays
Joseph and Mary
McCafferty
Joseph and Jan Melnyk
Ray and Amy Miller

Tim Miller
Michael Milone
David and Jamie Moon
Sarah and David Moore
Ted and Kathy Nace
Austin and Cheryl Noll III
Austin and Dorothy Noll Jr.
Cristol Barrett O'Loughlin
and James O'Loughlin
Pacific Gas and Electric
Mary Jo Page
Jason and Mandy Pate
Stephanie Peebles
David and Rose Pelton
Mark and Maryellen
Pendleton
Justin Perran
Janelle Perry
Matthew and Claudia
Peterson
Project Organic Life, LLC
Paul and Katie Rector
Royalton Village
The Rusnak family

2019 CONTRIBUTORS

Sam and Hope Saadat
Dr. George and
Mrs. Athena Sarantinos
Adam Shaywitz
Eric Shero
William and Margaret
Sly, MD
Maureen Snider
Glenn Snyder
Julie Snyder
Jack and Barbara Sorter
David and Pamela
Sowder
Sheri and Bryan
Springston
Bob and Susan Steiner
Stuart Swiedler and Judy
Weiss
The Matthew Evangelista
Foundation, Inc.
Herbert Tilsner
Timothy Schaffer Roofing
and Siding, Inc.
Christine and Brian
Tippett
Jerry and Lisa Todd
Lorie Tolson
Dawn Watkins
Amy and Brent White
Tom and Kim
Whitcotton
Fred Williams
Katie Willmann
Russell and Alice Witt
Jared Wolff
Woodstock Power
Company

Leader (\$500 to \$999)

Stuart and Karin Adams
Jack Allen
Dr. Mel and Mrs. Millie
Anhalt
Maryanne Baier
David Beatty
Roshan Bhakta
Bruce Bjorkman
Susan and Dennis Burke
Liam and Mary
Cavanagh
Ryan Caya
Rene and Kristine Chaze
Clare Rose, Inc.
Clark Capital
Management Group
Coventry Corners, Inc.
Gerald Cox

David and Kathryn
Croson
Jennifer Crosswell
Carey and Mary Crumling
John Dallas
Paul and Cara David
Maria De Granillo
Deere & Co.
Steven and Sarah
Deutser
Kathy and Paul
Dobrowolski
Jim and Michelle Dodson
Jani Domire
Julie Dopheide
Vidmantas and Cecilia
Duda
Shannon Durrant
Eco-Safe Wastewater
Technologies
Christopher Edwards
Nancy and David Edwards
Michael Elgin
Carla Ellard
Carole Ellis
David Esposito
Elizabeth Feldman
Bart and Sally Finzel
Rod and Kathy Finzel
Framingham High School
National Honor Society
Baxter and Michele
Fullerton
Roslynn and Timothy
Garvin
Richard Gelber
Brendan Graham
Sandra and Mark
Greenberg
Pam and Richard Gross
Wallis and Monica
Hampton
Kevin and Susan Hanley
Deanna and Eldon Hardy
Eric Hargrove
Paul Harmatz, MD
James and Kelly Hart
Joanne Hayo
Lyle and Jade Hays
Tracy Higgins
Kathleen Hillyard
Matthew Hirsch
Carole Ho
Christine Ho
Heinz and Karine Holba
Peggy Holland
Zhanzhi Hu and Pei Wang
Jennifer Hutcheson

Mollie Ifshin
International Association
of Machinists District
No.1
Moe Jafari
Jordan Park Mission
1st Fund
Scott Keaton
Steven Keene
Bob and Ginger Kell
Anna and Dave Kidwell
Jason Kulas
Rebecca Lahren
Daniel LaPointe
Steven and Elizabeth Law
Chris and Anna
Leatherow
Daniel and Kelsey Lee
Grant and Kimberly Lee
Mike and Amy Legendre
James Leitner
Donald and Karen Loudon
David and Kiersten Lowe
Salvador and Adriana
Maciel
Daniel and Barbara
Maher
William Massa Jr.
Mark and Kim McCall
Marcia Mederos
MedLogix
Communications
Chris and Diane
Meyerpeter
Bertha Minnihan
Mongrel Industries
Cunneen
Michael and Amy Murrell
Dennis and Martha Noll



Jingle Bell Memorial Walk

Thomas and Peggy
O'Malley
One Source Staffing, Inc.
Ram Palanki
Thomas and Vickie
Patterson
Linda Pittman
Brad Plantiko
Premier Healthcare
Solutions, Inc.
Annette and Larry Pung
Readington Middle
School
Keith and Sherri
Richbourg
Gregory Rick
Adam Rupright
Ed Schmidt
Rahilla Shatto
Ryan Sheffield
Mahesh Shrestha
Margot Shriver
Priscilla Slaven
Tami and Don Slawson
Mike and Barbara Smith
Scott Smith

Marilyn and Willard Sniffin
Sports Gallery
Authenticated
Stefanie Stayin
Lisa and Josh Stevens
Nicole Swain
Lawrence Sweeney
Tracy Szemanski
Susan Taylor
Michele and Anthony
Teoli
The Alfred & Adel Davis
Academy
The Perk South Perkasio
Hotel, Inc.
Denise Thomas
Sheila and Michael
Thornton
Daniel and Eleanor Tobin
Jerry and Shirley Todd
David and An Tootill
Hugo and Marylyn
Van der Moer
W. Promotions
Tanya and Gordy Wahl
Richard Waldman

continued...



Maura Mongan (MPS I)

2019 CONTRIBUTORS



Bob Ward
Wardlaw Claims Service
Larry and Karen Watkins
Trent and Ilsa Weaver
Hubert and Elaine
Willman
Jim and Kim Wilsford
Kevin and Peggy Yard
Kelly and Patricia Young

Volunteer

(\$250 to \$499)

Ryon and Caroline Acey
Mary Starr Adams
Jeff Alves
Ralph and Martha
Anderson
Randall Anhalt
Joseph and Kristina
Ashton
Steven Ausband
Lewis and Marie Babel
Joe and Susan Babic
Ethere and Pauline Baird
Amy Barkley
Elizabeth Barnhill
Heather Barr
Rita and Mike Basom
Ruth Bauerle
Mary Beiting and Jeff
Von Handorf
Monika and Jack Berg
Joel and Leeann
Bernbaum
Cheryl Bien
John Bird
Melany Bjorkman
Sharon Brack

Dawn Brewer-Reilly
Daniel and Debra
Brockman
Tracy Burger
Dennis Burns
Christina Cain
Paul and Abby Calabro
Mike Capri
Stevens Carey
Scott and Connie Carney
Heidi and Keith Caswell
Tom and Laura
Catanzarite
Central Electric
Membership Corporation
Anne Chau
Amy and Dan Cherrstrom
Amy and Corey Christie
Nicole Churchill
David Coffman
Collaborations
Pharmaceuticals, Inc.
Sanmar Corporation
Gary and Judith Cox
Michael Cox
Bradley Davids
Martin Davis
Linda and Dan Day
Baadal Deliwala
Amit Desai
Sabine Detweiler
Jerry and Sue Deutser
Doug and Diane Diehle
Heather and Shane
Doucet
Ernie and Debbie
Dummann
Cindi Dunsworth
Bruce Eden

Catherine Familathe
Vivian Fernandez
Tim Finnegan
Steve Foltz
Janet Forde
Tim and Tish Foster
Robert and Melanie
Franko
Erin Frey
Marice Furlong
Katherine Gamao
Robert Genau
Sharon Glasscock
Tom and Anne
Gniazdowski
Gene Grabinski
Catherine Griffis
Michael Guldin
Rob Hagelin
Carla Halk Crain
Alexa Hansen
Diana and Michael
Hanson
Laurel Harry
Robert Harvey and
Roxanne Maffitt
Susan Hayes
Brandon Herder
Susan Hess
Allison Hill
Sean Hoffman
Melissa Hogan
Thomas Holder
Jill Holloman
Robin Honeywell
Todd and Jennifer
Howard
Richard Hurley
W. Andrew and Luran
Jack
Justin Jessee
Kris Johnson
Terry Jones
Joseph H. Brensinger
School
Jimmy and Leslie Jurado
Christopher Kenworthy
Tom and Julie Kirch
Donna Kleinert
Brian and Kris Klenke
Ralph Kytte
Debbie Lacey
Glenn Lackey
Eric Lefkof
Monica Leone and family
Gib and Sandra Lewis

Kathryn and Hai Lieu
Gregory and Susan Lock
Jenice Long
Lauren Louison
Robert Malone
Keith and Jennifer
Marshall
David Massa
Deidre Maull
Monica Maynez
Caitlin McIntire
Midway Independent
School District
Midwest Home Exteriors
Jeff and Chris Miller
Greg and Jennifer Mincks
Becky Mingo
Eric and Amber Mongan
Mitchell and Cherylynn
Moore
Neetu Multani
Stefani Murrell
Laura Navarre
Roberta Nelson
Richard Nelson
Benjamin and Elizabeth
Neufeld, PhD
Kevin and Danielle
O'Connor
Granya O'Neil
Michael Pando
Colin Partridge
Melvaree Pate
Jo Anne Paterniti
Alan and Diana Pendley
Pension Corporation of
America of Cincinnati
Margaret Perrin
Kent and Nina Peter
Megan Pickard
Alan and Kathy Portnoy
Randal Pruitt
Purchasing Solutions
International, Inc.
Holly Reason
Shannon Resetich
Mark Reynolds
Bonnie Rose
Glenn Rosenbluth
Jason Ruben
Stacy Sadler
Donald Saunders
Toby Schiel
Sheila and Richard
Schlesinger
Jim and Judy Schneider
Dave Selman

Lynn Ann Sembach
Anna Shermeyer
Brian Shingle
Bonnie Singh
Pamela Smith
William Smith
Spengel-Boulanger
Funeral Home
Sarah Steele
Yolanda Su
Becky and Robert
Tanamachi
The O Street Museum
Foundation
The Vocal Majority Dallas
Metropolitan Chapter
Cara Thomas
Dave and Hiromi Tilsner
Jennifer Trainor
Uwharrie Regional
Pediatrics, PA
Sagar Vaidya
Joseph Vieira
Sarah and Todd Waddell
John Waples
Tom and Theresa
Weisenbach
Gregory Wimmer
Jason Wintz
Harold Wood
Gilda Youdeem
Christine Young
George Zimmerman
Benjamin Zuffi

Friend

(\$100 to \$249)

Kay Anne and Peter
Abbott
Lee Ann Adams
Johnda Adkins
Dean and Katherine Aker
Virginia Allen
Robert Allen
Marc Alu
Catalina Anderson
George and Gail
Anderson
Bill and Mary Andrews
Cindy and Mark Andrews
David Andrews
Gerald and Susan Anhalt
Elena and Philip
Anischenko
Betty and Barney
Arceneaux
Phillip Armato

2019 CONTRIBUTORS

Sharon and David
Armendariz
Colleen and Shawn Arni
David and Stacey
Aronson
Sherry Asbell
AT&T
B & M Trailers, Inc.
B.E. Warfield Contracting
Kimberly Back
Rena Baek
Jeff Bahm
Rebecca and Robert
Bailey
Bair's Tree and Lawn
Service
James and Mary Baker
Darlene Baker
Ava Baldwin
George and Kathleen
Baldwin
Mark and Alberta Balliet
Joseph and Jacqueline
Balukin
Alan Barbell
Delaine Barr
Sandra Barstow
Jeter Basden
Andy and Angela
Basinger
Eileen Basquill
Charlie and Danielle
Bateman
Mary and Don Beaudin
Janet Bek
Dick Belf
Patrick and Susan Bell
Maurizio Bellassai
Rose and Jolee Benden
Brandie Bennett
John and Maria
Bereschak
Melanie Berkmen
Andrew and Carol Bertke

Kathryn Bickham
Linda Biondi
John and Jenny
Birmingham
Susan Bissett
Adele and John Blasiak
Blueyte Solutions, LLC
Jim Blum
Jeffery Boas
Jeffrey Bodnar
Robert and Anne
Boggiano
Kristin Bolton
Michele Bonistalli
Dave Bortz
Blair Bost
Thomas and Joyce Boster
Robert Bouck
Nancy and Leister
Bowling
Christopher Bowser
James Bradley
Ann Braff
Gretchen Brainard
Dale and Myriam Brandt
Pamela Brantly
Rick Braun
John and Alida Braz
Marc and Beth Brdar
Pam Brendel
Tom and Suzanne
Brennan
Cynthia Brockman
Thomas Broderick
Shelley Brooks
John and Judie Brooks
Cornelius Brown
Bruart Collision
Bill Bryson
Bubba's Burrito Bar
Nancy Bucher
Eileen Buckley
Rosemary Bueger

Leslie Burchett
Tim and Keena Burnet
Mary Burns
Maura Byrnes
Barbara Cabello
Richard and Sue Cadena
Michael and Karen
Calhoun
Cathleen Caliguire
Corbin Caliguire
Thomas and Kristine
Cantwell
David Carey
Craig Carlson
Patricia Carver
Juanita Cassell
Fred Cataldo
Franklin and Carol
Catalfamo
Gregory and Angela
Cathey
Bradley Causee
Diana Cavenagh
Susan and Roger Chapin
Steve and Sandy
Chapman
Steve and Karole
Chesser
Rob Christiansen
Michelle and Don
Churchill
Rodney Ciafre
Pete and Lisa Cino
Scott and Shirley Circle
City of Seattle
CJV Consultants, Inc.
Carol Clanton
Donald and Susie Clark
Bina Clark
Craig Clarkson
Rod Clement
Tony Clines
Gary Cobb
Ross and Belia
Coddington
Margaret Cohen
Linda Cohen
Heather Coker
James and Martha Colby
Peggy Cole
Brendan Coleman
Catherine Collette
Taylor Collins
Jeff and Julia Conner
Carol Conti
William and Peggy Cook
Molly and Timothy
Corcoran



Justin Gentile (MPS II)

Chris Costello
Angela Cowan
Billi and Jeremy Crockett
Andy Crowson
Sarah and Mario Cua
Adam Cummis
Caroline Dabney
Melissa Dalburgs
Bill and Laura Dapper
Kathryn and Tim
Davidson
Elizabeth Davis
Michael Davis
Daniel Davis, DDS
Victor and Mary Davis
Monique De Ville
Charles Deale
Louis Debarberie
John and Amelia
Defilippis
Linda Delp
Delta Construction
Sandra Demello
Avedis Demirdijan
Paul and Joann
Desrosiers
Justin Dickerson
Patti Dickson
Alice Dixon
John and Linda Dobbyn
Brian and Jennifer Dolan
Jonathan and Lisa Dols
Ginny Dubose
Duckies Grill & Bar, Inc.
Phillip and Donna Dudley
Peter D'Urso
William and Carolyn
Eames
Vanessa Egle
Elizabeth and Joshua
Eickman
Charles and Josie Ellard
Matthew Norman
Ellinwood, DVM, PhD

Tara and Jack Elston
Michele Elvander
Grant and Mieke Embry
David and Judy
Engelbert
Edna and William English
Nancy Esper
Jane Fang
Robert and Amy Farrell
Geraldine Faucett
Phyllis Feibelman
Margaret Ference
Nancy Ferguson
Hildegard and Joseph
Filebark
Brenda Fillman
Molly Finnegan
Ruth Fitzsimmons
Lynn Flanagan
Greg and Sarah Fletcher
Kay and George Follett
Maria and Steven Foshay
Ronald and Sheila Francis
Greg Frank
Elizabeth Franker
Diane Fritz
Gail Froberg
Lee Ann Fulmer
Fuzzy's Taco Shop
G & F Carpet, Inc.
Stephen Gagola Jr.
Heather Gaillard
Thomas and Sylvia
Gamache
Chris and Linsey Garcia
Garretson Insurance
Agency
Phillip Garvin
Morton Garyhoward
Kevin Gates
Richard and Ronni Gates
Veronica Gates
Peggy Gaudi

continued...



Anthony Stahl and Lilah Mueller (MPS VI)

2019 CONTRIBUTORS



Mary Mitchell Stewart (MPS IIIA)

George and Jaja Gawartin
Thomas and Debra Gebbia
Michele Geigle
George Bartram - Paul Sand Lodge No. 298
Jayne Gershkowitz
Earnie Giles
Dennis Gilfoyle
John and Lynn Gladysz
Patricia and Thomas Glatthaar
Andrew and Stephanie Glock
Betty Glock
Sarah Gniazdowski
Michael Gogel
Jonathan and Melissa Golightly
Drake Gonzales
Christopher Goodnow
Richard and Shirley Goolsby
Kendra Gottsleben
Kathleen Graham
Lindsay Grand-Zabbia
Laura Gray
Rose Greco
Katherine Greene
Fran and Rob Greenstein
James Greenwell
Matthew Greer
Julianne Grundfest
Francisco and Yvonne Guajardo
Juan and Sylvia Guajardo
Stanton and Jean Gunnells
Carla Gustafson
Cheryl and William Guthman
Rita Haan

JoAnn and Michael Hageman
Laura Hahn
Kalpana Hall
Nicole and Toby Hall
Jane Hamberg
Hamberg Capital Management, LLC
Paul Hammann
Mona Hand
Sharon Hankins
August Harder
Rodney and Donna Hardy
Kimberly and Frank Harker
Jason and Rebecca Harrington
Dan and Jeannie Harrington
Mark and Keely Harris
Lisa Harrison
Bernard and Betty Harvilla
Jeni Hasselbrack
Kristen Hatmaker
Donna Hatmaker
William Hauselt
Mark and Jane Hauser
Richard Havens
Kathryn Hawkins
Andrea Haynes
William Haynes
Paul Heard
Judy Heitman
Trish Hejazi
Megan Henderson
Greg Hendry
Austin Henry
Sharon Henson
Mark and Darlene Hesprich

Robert and Michelle Hess
Kathleen and Michael Heymans
Gwendolyn Heys
Sheila Hicks
Chloe Hill
Brady and Emily Hoak
Robbin and Anita Hodgkins
Anne Hoffman
Beth Hoffman
Katey and Andrew Hoffman
Amanda Hoffman
Diedrich Hohn
Andrew Holder
Carolyn Holland
Travis and Alyssa Holland
Noel Holmberg
Tom and Jackie Holt
Joe and Tina Hopkins
Shelley Houx
Paul and Laurie Howard
Jason Huang
William and Margaret Hughes
William Hughes
Catriona and Randy Humphrey
John and Yvette Iannelli
Nicholas Imbo
Rebecca Intfen
J & Z, Inc.
Richard and Carol Janis
Daniel and Mary Lou Jaszka
Larry and Joy Jeffers
Dean and Stephanie Johnson
John Johnson
Kevin Joseph and Beth Johnson
Jen Jones
Jennifer Jorgensen
Sandra Jungck
Junior Women's Club of Hilton Village, Inc.
Anthony Justice
Joe and Alice Kalamar
James and Mary Kalteux
Ramalakshmi Kandasamy
Jerry and Pat Kanney
James and Tabitha Kappel
John and Janet Kappel
Joseph and Michelle Karl

Karen Karns
Raimund and Inge Kasner
George Kavulich
Daniel Kehoe
Kelley Keller
Sherry and Michael Kelley
Bob Kelly
Kris Kelly
Ronnie and Flo Kennedy
Ardis Ketterer
Karen Kiker
Jay Kim
Sharon Kimmell
Shashi Kini
Robert and Mary Kirch
Sheri and Chad Kizer
Jerry and Katherine Klemm
Brian and Rebekah Klutz
Linda Knight
Michael Knudsen
Ivan and Leann Koblitz
Barbara and Richard Kochanski
Anne and Nathan Krick
Karen Krizan
Keith and Colleen Kruse
Margaret Kruse
Mary Kruse
Stella Kruse
Ernest and Agnes Kuebler
Carol and Thomas Kuhn
Dan Kulbieda
Janelle Kunellis
Debbi Kvietkus

Steven La France
Brenda Lacombe
Noni Langford
Steven and Cam Lanier
Stephen Laorenza
Suzanne Lappas-Schubeck
Helen Lau
David Lauser
Stephanie Lawrence
Judy Lawson
Robert and Katie Lawson
David Lebec
Doug and Angela Lee
Kevin and Robyn Lee
Lorraine Lee
Robert Lee
Ron and Naomi Lee
Danny and Sally Leinen
Alicia Leonard
Douglas and Linda Lepeirs
Douglas and Grace Lessing
Joan and Mark Lessing
Lawrence Lessing
Peter and Gerilyn Lessing
Charles and Kendra Lesta
Kathryn Leu
Kimberly Leveaux
Janine Levitch
Michael and Karen Lewandowski



Dr. Klane and Amy White

2019 CONTRIBUTORS

Constance Lilly
Mark and Mary
Linenbroker
Ann Lippka
Banba Lipton
Donna and David Littrell
John and Millette
Litzinger
Sharon Lockhart
Koen and Pat Loeven
Gene and Cynthia Logan
Kara Long
Katie and Timothy Long
Michael Longo
Sara Lowe
Chuck and Nancy Lukondi
Jim and Doris Lupardo
Melinda and Jose Lynam
Courtenay Lyons
Rhandi Mackey
Donald MacMillan
Jason Madison
Sharyn Madison
Dave and Hope Madsen
Jeff Magee
Barbara and George
Malina
Eileen Malle
Marilyn Maloney
Lyle and Susanne
Malotky
Carolyn and Michael
Managan
Jason Manalili
Gary and Lana Marble
Andre and Melissa
Marcotte
Peter Margolis
Debbie Marsh
David Marshall Jr.
Corbett and Brooke
Martin
Michael and Lori Martin
Pamela and Robert
Martineau
Elizabeth Martinelli
Dorothy Mask
Bill and Laurie Matchneer
Jeffrey Matthews
Carol and Darren May
Jeffrey and Karen Mays
Dennis McAllen
Paul McBride
Sean McCabe
Brian McCann
Anne McClelland
Scott and Evelyn
McClelland

Corey McClure
Stephen and Marie
McClurg
Janet and James
McColgan
Cheryl McGregor
Michael and Kim McGurk
Rachel McIntosh
Joanna McNamara
William and Karen
McNeil
Meghan McNicholas
Ami Mehta
Kathleen Meyer
Sandra Miler
Beverly Miller
Cindy and Kent Miller
Eric and Megan Miller
Karen Miller
John and Rosalind Miller
Patrick Milligan
Vikki Minor
Patricia Mioduch
Margaret Moeder
Brian and Julie Mollett
Jessica Monford
Kevin Mongan
Monroe Housing
Commission
Irene Moon
Donovan and Allison
Moore
Jason and Colleen Moore
Wes and Kimberly Morgan
Ron and Chris Morrissey
Rene and Patricia
M'Sadoques
Amanda Mu
Philip and Marita
Mulholland
Michael and Anita
Muonio
Brian and Virginia
Murphy
Maryrose Murphy
Christina Murphy
Susan Murphy
Pat Murray
David and Cathy
Musselman
Susan Narducci
Sivakumar Natarajan
Nautilus Family Fitness
Kathy and Josh Nay
Ross and Shawna Nelle
Aywon and Krystal
Nguyen
Vu Nguyen
Madison Noll



Michael and Amy
Noonan Jr.
Bijan Noori
David Notley
Anne Novak
Jessica Novosel
Rita Nunag
Daniel and Pamela
O'Brien
Bernard O'Hara
Mary Oliger
Rosemary Oliveira
Kate O'Loughlin
Mary and James Olson
Glenn and Cara O'Neill
Jason and Christi
Ormeroid
James and Mary
O'Rourke
Ian O'Ryan
Eileen and Larry O'Steen
James Owens
Beth Palma
Jeanne and Bruce Palzer
Andrea Papa
Jae Park
Shana Parker
Susanne Partridge
PASCO
Tim and Sheila Patton
Nora Perez
Linda Perrella
Linda and Dave Perry
Sara Perry
Stuart and Pam Perry
Thomas and Stacy
Peters

Nancy Peterson
Tracy Pharis
Kim and Keith Phillips
Patty Phillips
Vernon and Patricia
Phillips
Kesha Phyfer
Dennis and Robyn
Piasecki
Sarah Pick
Michelle Pierce
Holly Piper
Neal Pitts
Beth Pletcher, MD
David Polgreen
William Powell
Susan Powers
Frank Price
Braden Pritchett
Barbara and Keith
Pushsee
Lesa Quick
Christina Rademakers
Heather and Darius Rafii
Kevin and Carolyn
Raleigh
Bill Ramer
Ralph and Marva
Ramsey
David and Bette Rattan
Sue Rattman
John and Deborah Ratto
Tina Ratto
Dorothy Rawlinson
Bernard Ray
Celeste and Stephen
Raydo

Walter Raynaud
Elaine Reed
Kiley Reed
Devin Reich
Thomas and Cynthia
Reinhardt
Bonnie and Ralph
Rennaker
Michael Rephlo
Jim and Jennifer
Restemayer
Carol Reynolds
April Rhea
Richard and Carol Riazzi
William and Lynette Rice
Douglas Richmond
Judith Ries
Patricia and Jim Rigby
Rick Rineer
Ron Rineer
Theresa Ring
James and Mary Risbon
Jenn Robart
Dan and Rita Robertson
Rusty and Alison Rochelle
Kristine Rodden
Michael Rodriguez
Stephen Roeder
Nina Rogers
Nancy Rogers
Sherrie and Tony Roman
Kelly Romeo
Carl and Donna Rose
Tracy and Thomas Rose
Jeremy and Lisa-Marie
Ross

continued...

2019 CONTRIBUTORS

Lauren Rothman
Linda Rotondaro
Maggie Rousseau
Adam Rowe
Brian and Stephanie Rubinstein
Silvia Ruiz
Roger and Cheryl Ryan
Sarah Ryan
Gregory Rydberg
Deborah Saeger
Marco Sagliocca
Randy Saitta
Mary Jean Salcido
Lysa Saltzman
Harold Samuels
Victor Santoro
Jay Saul
Joseph Scalice
Larry and June Schultz
Mark Schwab
Ira Schwartz
Bruce Scott
Carole Scott
David and Diane Scotting
Roberta Scoville
Matthew and Christine Seabrook

Dennis Shelly
Kevin and Kathy Sheridan
Mary and Thomas Shine
Patricia Shore
Rosemary and Michael Shourds
Raj Shukla
Rodney Shute
Stuart and Jennifer Siedman
Marc Silber
David and Rebecca Silkey
Edward Simcox II
Bruce and Sherrie Simpson
John Simpson
Michael Singer
Suzanne Skasik
Burt and Leenie Skolnik
Robert and Cheryl Slowey
Timothy and Amy Small
Elaine and Mark Smith
Scott Smith
Stephen and Sara Smith
Betty Snow
Elsie Snyder

Daniel Soliday
John Solomn
Michelle Sorensen
Anthony and Pamela Sosinski
Robert Soule
Mary Speights
Marcus Spencer
St. Catherine Philoptochos Society
Annette Starks
Max Statum
Jeremy and Rena Stearns
Kenneth Stewart
Jay Stickles
Louis and Mildred Stielper
Elizabeth Stoltz
Benita Stone
Ayumi Stubbs
Christine and Troy Stultz
Kevin Sullivan
Suntrust Banks, Inc.
Kathy and Vic Surma
Kim and Bill Swartz
Jack Swepston
Noel and Nancy Talcott
Kathy Taylor
TCG, LLC
Pamela and Dana Teich
Daniel and Valerie Teitsma
Timothy and Gretchen Tierney
Billy Tilotta
Holly Tinkey
Lindsey Tolson
Jon and Ellie Totz
Maureen and Sean Tribby
James and Bonnie Tully
Pam and Dave Umstead
Kathy Urbanek
K. Neil Van Dine
Helen and Bill Vespe
Joseph and Lois Vinci
Barbara Viti
Keith Vogt
Jerry and Sue Von Handorf
Frank Von Turkovich
Beverly Waddell
Marty and Sandy Wagner
John and Shirley Wake
Fred Walters
Barbara and James Ward
Kenneth and Victoria Warner
Steven Waters

Eric and Michelle Weinstein
Dr. Cara Weismann
Daniel Weiss
Don and Lisa Wells
Stephen and Jane Wendel
Tracey Whaley
Heather White
David Whiteman
Barbara and David Wiedman
Thomas and Blanca Wier
Ron and Kim Wiest
Lisa Wilds
Donald and Marla Williams
James Williams and Rosie Oakley
W. Williams
Katherine Willis
Ann Willis
Joseph Winkler
Steven Winkler
Matthew and Rachel Wojnarowski
Women of the Moose
Kirk Wondra
Jimmy and Susan Workman
Gilda Worsham
Laura Wuerth
Justan and Ann Wynegar
James and Carol Yard
James Yates
Stanley and Nancy Yukevich
Richard Zachariason
Joe and Jennifer Zamboni
Cynthia and Kenneth Zawacki
Jocelyn Zeng
Evelyn Zohlen
Andrew and Louise Zygmuntowicz

Donor
(\$26 to \$99)
Jeremy Albright
Edward Allen
Laura Anderson
Alice Andrus
Timothy and Michelle Annis
ARG Construction, Inc.
Stephanie Aripotch
Gail Armato
Uzma Atif

Francis Ayotte
Greg Bachman
Len and Barbara Barcousky
Keith Baron
Eileen and Tom Barreca
Mary Barringer
Jim and Maureen Basting
Patricia Bates
Alice and Ron Beam
Tim Beck
Lauren Bedard
Rolland Bek
Bonnie Belanger
Raymond Bell
John and Alicia Bennett
Eileen Bensten
Daniel and Christine Bergin
Angela Bergmann
Linda Bergquist
Tony Bertauski
Jennifer Bielefeldt
Jenni Biggs
Katelyn Blackman
Margaret Blakely
Richard Blanchard
Ellen Bland
John and Joanne Blasiak
Richard Blasiak
Alison Blue
Helen Bollinjer
Linda Boone
Boston Society of Architects
Ray and Barb Bowman
Lisa Boyce
James Bozarth
Bradley Elementary District No. 61 Activity Fund
Bill and Ginny Brady
Greg Brennan
Brian Bachman Electric Company
Kenneth and Joann Brinker
Reuel Brockman
Darlene Brogdon
David and Barbara Brooks
Jeanne Broussard
Kathleen Broussard
Delbert and Jody Brownfield
Sue Broyles
Kathy Buckley
Kiley Buckner



Hailee Makuch (MPS IVA)

2019 CONTRIBUTORS

Dr. Tim Wood, Dr. Paul Harmatz, and Terri Klein with Chiesi Pharmaceuticals



Larry and Myrl Burdett
Clive Burger
Debra Burkeen
Patti Burr
Shirley Burt
Linda Burt
Bushay's, LLC
Susan Byers
Tim and Valerie Byers
Mary Byman
Arthur Cabral
Tammy Calandro
Victoria Calderone
Patty Camerone
Charlotte Campbell
Jona and Jeff Cantrell
Michael Capone
Elizabeth and Joseph Caponi
Kathy Carlson
Donald Carpenter
Timothy and Cynthia Carris
Jennifer Carroll
Kevin and Kathryn Casey
Marjorie Cassady
Maria Castillo
Mark Castillo
Jennifer Chabus
Lewis and Ann Chapman
Andrew Charest
James and Joan Charters
Loretta and Salvatore Chillemi
Jonathan Christian
William Clarke

Kent and Karlene Classen
Heather Claypool
Terry Clayton
Doug Cobb
Maida Cohen
Rick Cole
Sally Combs
Angela Cook
Ryan Cook
Sharon and William Cook
Ron and Cheryl Cooley
Katherine Copeland
Michael and Janet Corrado
George and Sharon Costa
Kristin Costigan
Bob and Denise Crompton
Conrad Culberston
Jason and Tamara Cullere
Marie Cundiff
Brendan Cunningham
Mary and Ann Cunningham
Steve Cuomo
Marisol Curtiss
Stacey Curtiss
Shannon Daly
Bobby and Kelly Daquara
Royce Daugherty
Darin and Lisa Davis
Pat and Thomas Davitt
Elizabeth Day
Roderick and Liza De Leon
Pamela and Robert Dean
Deborah Delano

Dawn Derrick
James Desiderio
Robert Desnick, MD
Andrea Detamore
Rachel Diana
Jill Dickey
Ellen and Gerald Dimbat
Daniel DiNardo
Denmar and Ellen Dixon
Daniel and Dolores Doman
Jeanne and Maurice Drew
Marilyn and Gary Drew
Mark and Jill Dry
Henry Durham
Julie and Bryan Durnen
Awd Dwa
Justin Lischak Earley
Candace and Ben Eastman
Daryl and Marjorie Eck
Ruth Edwards
Joe and Ruby Efird
Antionietta Ellard
Lianne Elliott
Darla Elswick
David and Sylvia Enciso
Brian Engel
Wayne and Joan Eppehimer
Terry Ermnoian
Douglas and Mary Erwin
Kenneth and Ruth Espenshade
Steven and Kathryn Espenshade
Karl Eurenium
Fairbank Equipment, Inc.

Curt and Sandy Faith
Patrick Fenton
Lucille Fernandez
Amy Fisher, MS, CGC
Jennifer and Chris Fitzgerald
Mary and Jeff Fleming
Richard and Cheryl Fletcher
Mark and Billie Flint
Andrew and Joan Flynn
Laverne and Peggy Foess
Cynthia Forrest
Karen and Timothy Foster
Cathy Foutz
Laura Fox
Hazel Francis

Paul and Martha Frank
Donald and Betsey Frankel
Frederick Freitag
Terry Fremuth
Julia Fritze
Mark and Marie Frost
Tanya Fulkerson
Maria and Frances Gallo
Nancy Garces
Kelly Garcia
Felice Gebhardt
Kathleen Gee
Cheri Gey
Laura Giardino
Dennis and Sharon Gillham
Katie Gillies
Lola Gindrat
Eileen and Bob Gittins
Royce Goforth
Ryan Goodwin
David and Marsha Gorewitz
Lee and Tammy Gottschall
Toni and James Graham
Douglas and Michele Graham
Mary Gralen
Joy Grandi
Joanne Gratiot
Frank Greco
Lorne and Tamara Green
Coyte and Jilian Greer
George Grierson
David and Laureen Groves

continued...



Dr. Joseph Muenzer, physician's masterclass

2019 CONTRIBUTORS



The Stewart and Holder families (MPS IIIA)

Kevin and Jackie Gull
Nena Gunn
David Gutierrez
Christopher and Patricia Guyre
Carol Hack
Susan and Michael Hagen
Sheryl and Gerald Hall
Kelly and Shawn Hallowell
Hamel Seed & Farm Supply, Inc.
David and Cathy Hamm
Renee Hammond
John Hanley
Claudia Harder
Natasha Hargrove
Joseph Harne
Kim and William Harper
Lyndon Hart
Alisa Hartsell
Marty Harvill
Mark Haskins, VDM, PhD
Dennis and Debbie Haskins
Emily Hasse
Leilani Havens
Karen Hayes
Steve and Michelle Hayes
Larry and Barbara Hays
Rich Hebner
Ruth Heemsoth
Eloise and Fred Henry

Mary Heredos
Marlys Herring
Edgar and Sherry Hess
Gabriel Hickey
Nicole Hirsch
Christopher and Lauren Holbrook
Cris Holcomb
Darlene Holliday
Ashley and Cody Holm
Mark Hopkinson
Ronald Hornung
Carol Howard
Lois Howard
Laura Howley
Joel and Barbara Huber
Frank and Carolyn Hudak
Beth and Jeremy Hudson
Elaine Hughes
Jesse and Sheryl Hughes
Kaye Hughes
Richard and Kim Hutchings
Robert and Marguerite Iannaccone
Annie Ippolito
Dan Iriwn
Kathy James
Mary Ann Janszen
Tona Jebbia
Sally Jochimsen
Richard Johnson
Anna Johnson
Elaine and Mark Johnson

Chris and Lisa Jones
Shionta Jones
Stacy Juehrs
Elaine Kahns
Shih-Hsin Kan
Kristi Kane
Matt and Deanna Karlson
Drew and Ryan Keagy
Julie Keefer
Sean and Elizabeth Keely
Robert Kelley
Karen Kelly
Maria Kelly
Shannon Kennedy
Anita and William Kennelly
Dawn Killough
Bill King
Randall King
Stacy King
James and Donna Kirby
Seyma Kirca
Berta Kittner
Theresa Kleine
Robert and Ruth Klenke
Bryan Klimt
Jennifer Kloczek
Pat and Talmadge Knight
Helga Knode
Mindy Koenig
Louise and Edward Kofron
Neil and Terri Korte
Teresa Korth

Maria Kostka
Melissa Kraus
Kelly Kroeger
Laura Kunka
Kathleen Lacy
Thomas Lacy
Diane Laforges
Geoffrey Lamb
Jennifer Lambert
Rachel Lane
Julie Lange
Louise Langley
Karen Larson
Michael Lawrence
Lori Lazarescu
Kenneth and Sandra Ledford
John and Linda Lejeune
Tom and Martha Lemieux
Charles Lesch
John and Laura Lessing
Robert and Maribeth Letourneau
Vincent Lettieri
Kay and Joel Levy
Jeff and Caroline Lewandowski
Barry and Barbara Lewis
Paige Lewis
Scott and Gabriella Lich
Lynn Lilore
Jenn and Jamie Lipscomb
Peter Lombardi
Beth and Nick Lombardo
Sandra Long
Long Island Boat & Motor Works, Inc.
Valerie Lopez
Loughridge, Inc.
Alayne and William Lowenberger
Jasmine Lucas
Mary Lucignani
Allison Lynch
Holly Lynch
Matthew Lynch
Judy MacKay
Bonnie Mackey
Linda and Robert Maddox
Patricia Madeux
Peter and Therese Manninen
Don and Carol Manning
Salvatore Marinello
Bob Marion

Rachel Markworth
Peter and Janine Marques
Gregory Marsh
Marilyn and Paul Massaro
Janelle Maxwell
Jim Maxwell
Michael Maxwell
Emily Maynez
Stephen and Veronica McCarthy
Peter McGloin
Barbara McHale
Amelia McHugh
Laura McKeithen
Nathan and Jessica McMichael
Jenelle Mehlhaff
Louis Meier
Samantha Mejia
Billy and Ernestine Mercer
Donny and Molly Merrill
Miami Corporation
Middlesex Volunteer Fire Department
Cynthia Miller
Donald and Joan Miller
June Miller
Jack Mitchell
Angela Moeller
Lynn Moffett
Jaime Moll
Gary and Carol Moll
Harry and Carolyn Montgomery
Tricia and Greg Moriates
Sheila and Tom Morley
Patricia and Scott Morris
Tim Mulroy
Sharon and Thomas Murphy
Christine and William Muzio
Paul and Gail Myers
N & N Automotive, Inc.
Lisa Nadal
Jen Nevenhoven
Amanda Newman
Brenda Newman
Tessa Nichols
Tony Nickoloff
Donna Noesi
Karen Noles
Roy and Martie Oates
Julia O'Hara
Debbie Orlando

2019 CONTRIBUTORS

Kaitlin, Jennifer, and Richard Gallo (MPS II)



James O'Rourke
Robert and Barbara Osgood
Eugene and Elizabeth O'Shea
John and Patty Pagliero
Warren Palzer
Glee Papczynski
Christopher and Lynda Papoi
Noreen and Craig Parsons
Julie Patricia
Mat Patricia
Elena Paxton
Toni Pederson
Teresa Peecook
Maria and Bill Pence
Edward Perron
Perry Elementary School
Charles Perschetz
Christine Pertusi
Robert and Nancy Peterson
Joan Phalen
Diana Pickup
Glenda and Donnie Pierce
Daniel Pietroske
Sharon and Robert Pinkston
Katherine Ponder, MD
Tom and Carrie Porzel
Diane Powers
Preschool 101
Amy Prewett
John and Kathleen Price
Janice Prutch
Dennis and Carole Przywara
Selma Pyles
Felicidad Quilo

Stephanie and Edmund Rabuse
Katie Ragle
Bridget Raleigh
Bradley Randall
Marcia Rebrovich
Floyd and Sharon Reed
Randy and Jean Reed
Tom Reedy
Kristi Reesman
Julie and Hank Reichert
Paul Rendich
Randy and Julie Reneer
Mindy Renner
Diana Rhoades
Diane Richter
Becky Ritz
Joseph and Catherine Rizzo
James Roberts
Heather Robinson
Rebecca Robinson
Kenneth Rodriguez
Dave and Janet Roessner
Brandon and Corinne Roig
Richard and Darlene Rome
Susan Rooth
Ellen Rose
Maggie Rose
Toranong Ruenprom
Kenneth Rush
Candice Rutherford
Paul and Kathy Rysz
Karen Sackett
Ruth Sammuell
Monica Sanchez
Rodger Sanders
Michelle Sanders
Harpreet Sandhu

Jeanne Scanlan
James and Elaine Schaefer Jr.
Paul and Lisa Scharr
Beverly Schneider
Janet Schneider
Catherine and Peter Schreiber
Paul and Rita Schulz
Thomas Scully
Valarie Seger
Seymour Pediatrics
Shades of Health
Mark Shaffer
Kerry and Josephine Shamaly
Lorna Shannon
Greg Sharrits
Teri and Les Sheaffer
Jared Shelton
Nancy and Kent Shelton
Robert Sheridan
John Shultz
Pam Shurmantine
Aaron Siegel
Faith Siewers
Mary Sigler
Ben Sims
Mary and Gregory Siragusa
Anne Siudzinski
Haldri Ann Sjovold
Constance Skidmore
Juliet and Dean Skuldt
Kevin Slayden
Peter and Jennifer Smaildone
Clara Smith
Delores Smith

Elizabeth Smith
J. Smith
R.J. and M. Pamela Smith
Joyce Ann Solomon
Michael and Laurie Sparkman
Anna Spriggs
Norma Staats
Anndrea Stamey
Jessica Stankard
Stanley's Bakery, LLC
Alexander Stanross
Bob and Ginny Stark
Myrna Stelman
John Stio
Beverly and James Stolhand
Shawn and Vicki Stone
Tracie Stone
Isaac and Brooke Story
Nancy Stringham
Pauline Stukus
Sara Stutes
Larry and Diane Suhr
William and Jannette Swafford
Bill and Lisa Sweeney
Daren Sweeney
John and Diane Szuchy
Jeffrey Tall
Sean Tamney
Michelle Tanenbaum
TD Technologies
Dennis Teachworth
Feven Teckie
The Carle Collection
The Trust Company of Tennessee

Eric Theiss
Lou Thompson
Nancy Thomson
Courtney Thorpe
Greg and Cheryl Thurman
Andra Tidwell
Richard and Caroline Tilley
Nancy Timmons
Juanita Todd
Linda Townsend
John Trainor
Carol Treutlein
Michelle Trout
Katie Tuttle
Daniel Tyminski
Edward and Lauren Underwood
Leslie and Alex Urdaneta
Debi Urschel
Rich and Debbie Vanderpool
Esther Varga
Lauren Vecchione
Danielle Vedder
Kristy Vetter
Gloria Vinson
Theresa and Joseph Vitale
Ray and Kelly Waddell
Chad and Kathleen Wallace
Linda Wallace
Nancy Ward
Ronald and Shirlee Ward
Steve and Martha Waters

continued...



NORD conference with the Sanofi Genzyme team

2019 CONTRIBUTORS

Tracy Waters
Michelle Watson
Deirdre and Gregg Watson
Linda Weaver
Cathy Werley
Joan Werner
Chris Whisenand
Michael and Amy White
Raymond and Samantha Whittaker
Dale and Karen Whittle
Jessica Wilds
Rockford Willet
Torman William
Joseph and Jacqueline Williams
Love Williams
Timothy Williams
Julie Willoughby
Jan Wimberley
Wylene Wingate
Susan Woodward
Clint Woodward
Chen-Han Wu
Janet Wunder

Marcus and Angela Young
Anthony and Gladys Zeller
Bob and Kate Zimmerman
Raymond Zizzo

Patron (\$5 to \$25)

Rachel Adams
Kenneth and Donna Ahles
Ibrahim Al' Abri
Donald and Julie Ames
Auguste Areizaga
James and Barbara Barker
Lorraine Baron
Rhonda Bartel
John Bartlett
Sheryl Bates
Andrea Bell
Rose and Dominic Bencivenga
Jessica Benesh
Kara and Christopher Benneche

Eirwyn Beres
Katie Bernhard
Pat Bissinger
Amanda Blayne
Darryl and Melanie Block
Stephanie Boesche
Karen Bohl
Kathleen Brady
Brian and Janice Nelson Trust
Rebecca Browning
Lavern Bruce
Robert and Marianne Brulhardt
Brian and Emily Buechler
Justine Bush
Claudia Caceres
Joshua Call
B.I. Camp
Vania and William Campbell
Keith and Jennifer Cantin
Donna Cantrell
Tracye Caple
Monika Carbochova
Brenda Carbon
J.P. Carlin
Patrick and Kelly Carroll
Stefanie Castelli
Shirley Catanzarite
Joshua Chalfant
Michael and Margaret Ciacciarelli
Helma Clavin
Jo Coan
Richard and Blanche Cochran
Bruce and Karma Colbert
Brian Coleman
Elaine Coleman
Content Distributors, LLC
Shane Cook
Ivette Cordero
Kayla Cotkin
Dan and Lisa Cremeans
Linda Cross
Edward and Ann Cumiskey
Cami Cuomo
Susan Curry
Raymond Cushmore
Susan Danielson
Stacy Davidson
Jerry Davis
Gaye Decker
Sharon Decker
Shelly Decker



Chris Harmon, Takeda

Patricia Delaney
Todd Delano
Stephanie Denton
Amy Diaz
Linda and Daryl Diesen
Patricia Diluzio
Alice Dobrowolski
Donna Dodson
Barbara Donnellan
David Douglas
Barbara Dunbar
Ronald and Karen Duncan
William Dunn
Deniz Durmusoglu
Geri Edwards
Megan Eggleston
Rachel Eichler
Mike Eisenman
Jackie Epps-Hardy
Erin Erickson
John and Geraldine Euliano
Samantha Eva
Margaret Evans
Helen Fallon
Norcalith Feliciano
Shelley Felicilda
John and Wendy Ferguson
Emily Fields
Gary and Carolyne Filsinger
Patricia Finch
Lois Finney
Karen and Larry Fischer
Barb Fisher
Bertie Fisher
Gayanna Fisher
Daniel Flynn
Teresa Flynn

Cynthia Foster
Mary Kate Fountaine
Kellie Fox
Kimberly Fransen
Allison Frazier
Lawrence and Stacey Froehlich
Tiffany and Jason Fujioka
Douglas and Linda Fussinger
Jordan and Shawn Garvin
Barbara Gedney
Nivert Ghattas
Arthur and Joan Giammarino
Christina Giannopoulos
Sandy Gibbons
Jennifer Gibson
Marcia and Bernard Girard
Brigitte Glatter
Dana Glazer
Eugene Goldfarb
H. Granberry
Cliff and Debbie Greenbaum
Richard Gregory
June Greisemer
Jack and Lynn Griffin
Michael Gross
Lawrence and Debra Groth
Tim and Jenny Guilfoyle
Martha Gunn
John and Cheryl Hackett
Craig Haller
Suzanne and John Hamilton
Barbara Hamlet
Tracy Hancock
Addie Hanebury



Loren McClelland (MPS I)

2019 CONTRIBUTORS

Yvonne Harman	Kristen Leone	Michael O'Keeffe	Kari Singleterry	Justin Vento
Chris Harmon	Kory and Karen Leppo	Michael and Evelyn Ostella	Allison Smith	Helen Vice
Jeffrey and Barbara Harrell	Stefan Lerow	Dorothy and Ralph Ostella	Joan Smith	Elizabeth Vielhauer
Julia Hejduk	John Paul Linner	Michael and Veronica Parisi	Keenan Smith	Michael Von Handorf
Kenneth and Sheryl Hencke	Alice and Dennis Locy	R. Michael and Margaret Pashen	Thomas and Janie Smith	June Von Neumann
Lisa and Ted Henry	Gene and Barbara Lotter	Harold and Suzanne Pate	Mohankumar Somasundaram	Theresa Waggoner
Julie Hicks	Janet Loughnot	Mary Lou Paul	Roger and Diane Soulagnet	Bill and Kathy Wardlaw
Chris Hill	Sharon Luciano	Katie Payne	Nancy Sprosty	Greg and Crystal Watson
Betsy Hoffman	James Lunz	Erin Pearsall	David Sprott	Michael Weathers
Glenda Hollabaugh	Michael Magers	Catherine Perry	Darlene and Philp Stalion	Shawn Wells
Dave and Pat Holman	Chelsea Magro	Pete Peters	Trula and Michael Stevens	Francesca Westerfeld
Janice and Willard Houck	Gloria and James Manigrassi	Ruth Pias	Jeffrey and Margaret Stroehlein	Kerrie and Darren Whetstone
Connie Howe	Denise Marcotte	Douglas and Mary Pica	Joann Tassone-Dost	Sarah and James White
Patricia Huff	Samantha and Gerard Martinez	Rhonda Pietsch	Erica Thiel	Sharon Whitley
Christie Hussa	Laura Mason	Carrie Pitt	Kate Tighe	Rick and Rebecca Wildman
Janet Huston	Michaelle and Wolfgang Mauch	Aletha Poe	Alex and DeAnna Timbrook	Debra and Daniel Williams
Sheila Hykel	Jessica McCall	Linda Post	Hilary Topper	Dennis Williams
Janice Inman	Marty McCann	Billy and Sharon Prince	Jillian Turk	Erin Williams
Steve and Melanie Irish	Lauren McCarthy	Melissa Pritchard	Isabel Van Deventer	John and Gail Williams
Kelli and Scott Jablonski	Elise Mccuiston	Kerry Protain	Michael Vanchieri	Leslye Winslow
Mildred Jackson	Lena Mcdonald	Rebecca Pursell	Carol Vansplinter	Anne Witt
Joanna Janssen	Jennifer McGivern	Irene Quigley	Debra Varela	David and Clarice Wojnarowski
Sharon Jeffries	Erica and Kirk McKenzie	Patrick and Brittani Ray	Patty and Russ Veit	Perriann Wood
Summer Jewell	Kasey McKnight	Gayla Reed	David Velasco	Judy and Mansour Yamin
Edward Johnson	Kevin McQuillan	Resident Council of the Landing		Angela and Roger Zylstra
Emily Johnson	John and Maria McSweeney	Julie Romig		
Jennifer Johnson	Joe Meadows	Peter and Rosemary Rotelli		
Jane Johnston	Paula Medina	Katherine Rowan		
Kelli Jones	Jason Migne	Carol and Karima Rucker		
Kiran Joshi	Jeff and Yvonne Miller	Tommy Rudibaugh		
Kathleen Kapes	Joy Mingle	Sushil Sagarwala		
James Keane	Shawntell Mitchell	Mose and Robin Salters		
Lori Kemp	Christeen Moburg	Michelle Sanchez		
Meggan Kent	Nicolette Moinet	Gerald and Catherine Sanderson		
Shelly Kerfoot	Shawna Mondry	Ruslan Sarmurzakov		
Jessica Kevins	Robert and Joy Monte	Joan Scalamandre		
Phillip Kim	Dolores Moreno	Megan Schlegel		
Lori and Roger Klenke	Susan Morgan	Charles and Mary Schmidt		
Richard and Joyce Koenig	Madeline and Merritt Moseley	Donald and Janet Schmidt		
John and Nancy Kolich	Ken and Jackie Mueller	April Schoolcraft		
Chelsey Kramer	James Murphy	Michael and Joan Schwern		
Elizabeth and Jayson Kramer	Juliana Myers	Allison Scoville		
Rosemary Kruse-Hefti	Howard and Sallie Namkin	Nicole Scully		
Richard Kulka	Emily Nichols and Xan Weaver	David Seaman		
Jerry and Delores Kunz	Ken and Helen Noble	Bob and Carmel Seifert		
Gene Laforges	Liam Norkett	Brian Service		
Janine Lalia	David and Mona Noyes	Robyn Sherer		
Cheryl Lamm-McLendon	NSA Civilian Welfare Fund	Dana Siegfried		
Harry Lampert	Molly O'Connor			
Gavin Lane				
Stacey Lapine				
Lori Caldwell Ledoux				



Terri Klein, Barbara Wedehase, and Kendra Gottsleben (MPS VI) at the 2019 PPALS Conference

MPS & ML

Mucopolysaccharidoses (MPS) and Mucopolidosis (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 / B-Galactosidase

MPS VI

MPS VI Maroteaux-Lamy

Enzyme / (arylsulfatase B)
N-Acetylgalac-tosamine 4-sulfatase

MPS VII

MPS VII Sly

Enzyme / B-Glucuronidase

MPS IX

Enzyme / Hyaluronidase

ML II/III

ML II I-Cell

ML III Psuedo-Hurler polydystrophy

Enzyme / N-acetylglucosamine-1-
phosphotransferase

SPiRiT Conference attendees



2019 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 Tippet
MPS IV parent
Littleton, CO
christine.tippet@mpssociety.org

Austin Bozarth

MPS IV parent
McLean, VA
austin.bozarth@mpssociety.org

Stephanie Bozarth

MPS IV parent
Alexandria, VA
stephanie.bozarth@mpssociety.org

Caroline Dabney

(through March 1)
New York, NY

Amy Holland

MPS I parent
River Oaks, TX
amy.holland@mpssociety.org

Scott Hopkins

MPS I parent
Long Beach, CA
scott.hopkins@mpssociety.org

Larry Kirch

MPS III parent
Scottsdale, AZ
larry.kirch@mpssociety.org

Kris Klenke

MPS II parent
Worden, IL
kris.klenke@mpssociety.org

Shelby Lyon

(through September)
MPS III parent
Aledo, IL

Jason Madison

MPS II adult
Allentown, PA
jason.madison@mpssociety.org

Amber Mongan

MPS I parent
Eugene, OR
amber.mongan@mpssociety.org

Austin Noll

MPS III parent
Middleton, WI
austin.noll@mpssociety.org

Cristol Barrett O'Loughlin

(through September)
MPS II sibling
San Anselmo, CA

Sheri Wise

MPS IVA adult
Del City, OK
sheri.wise@mpssociety.org

Current Staff

President and CEO

Terri L. Klein
terri@mpssociety.org

Communications Director

Jason Papagan
jason@mpssociety.org

Family Program Director

Leslie Urdaneta
leslie@mpssociety.org

Family Support Lead

Coreen Gray
coreen@mpssociety.org

Special Events and Program Coordinator

Katelyn Blackman
katelyn@mpssociety.org

Administrative Support Associate

Rebecca Schranz
rebecca@mpssociety.org

Controller

Angela Guajardo
angela@mpssociety.org

Chairman of the Board Emerita

Mary Majure Couture
Alice Kalamar
Marie Capobianco
Linda Shine
Steve Holland
Ernie Dummann
Stephanie Bozarth

2019 Scientific Advisory Board

Matthew Ellinwood, DVM, PhD,

Committee Chairman

Lorne Clarke, MD
Alessandra D'Azzo, PhD
Robert Desnick, MD, PhD
Patricia Dickson, MD
Julie Eisengart, PhD
Paul Harmatz, MD
Mark Haskins, PhD, VMD
Kim Hemsley, PhD

John Hopwood, PhD

William G. Mackenzie, MD
Joseph Muenzer, MD, PhD
Elizabeth Neufeld, PhD
Matthew Pendleton, PhD
Beth A. Pletcher, MD
Lynda Polgreen, MD, MS
Kathy Ponder, MD
Mark Sands, PhD
Edward H. Schuchman, PhD

Calogera Simonaro, PhD
William S. Sly, MD
Richard Steet, PhD
Charles H. Vite, DVM, PhD
Steve Walkley, DVM, PhD
David Wenger, PhD
Klane White, MD
Chester Whitley, PhD, MD
John H. Wolfe, VMD, PhD



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

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

Dare to Be Different Gala

