



# 2017 ANNUAL REPORT



## MISSION

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

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**MPSSOCIETY.ORG**

Follow us!



PICTURED ON THE COVER: Hudson (MPS II) and Poppy (MPS VII) Roman



**CHAIRMAN OF THE BOARD  
STEPHANIE BOZARTH**

*I continue to be in awe of the progress we are making to cure MPS and ML...*



**PRESIDENT AND CEO  
TERRI KLEIN**

*Our members are a constant source of inspiration for Team MPS and ML on a daily basis...*

**IN RECENT YEARS** there has been a staggering increase of nonprofit communities addressing public needs not overseen by government entities. The larger philanthropic community, around the world, continues to improve efforts in health and education systems. The work, at times, can seem magnanimous. But new methods and models for complex issues are crucial for addressing evolving science, identifying the unmet needs of patient communities and providing organization sustainability.

2017 was a critical year full of change for the National MPS Society. These significant changes included the creation of community data systems; new programs resulting in interconnectedness among all members; and refined communications in research, education and family support programs. Changing systems is never easy, but in order to change outcomes for patients with MPS and ML, we needed to revive our focus and embrace change by working collectively and collaboratively. Critical objectives, including improving access to treatment, advocating for newborn screening, educating our community on frontier science, increasing family support programs and providing information for patient care, are paramount.

Twenty-five years ago, the U.S. Orphan Drug Act stimulated rare disease research. It, combined with the FDA's Rare Pediatric Disease Priority Review Voucher Program, made rare disease research continuously attractive to scientists, as illustrated by the November FDA approval of Mepsevii™ by Ultragenyx Pharmaceutical for MPS VII. Another long-awaited MPS disease celebrates an approved therapy.

Evolving science in gene editing, gene therapy, enzyme replacement therapies and optional delivery mechanisms has led the Society to collaborate with more than 30 global industry partners. Members of our board of directors and team traveled to the WORLD Symposium™ (We Organize Research Lysosomal Diseases) in San Diego in February. With record attendance, MPS and ML science encompassed a significant portion of the program content. We are thrilled to see this level of research focus.

As detailed in the following pages, the Society funded a record \$750,000 in MPS and ML research during 2017. We continue to recognize the uniqueness and diversity of rare diseases, and we foster an international grants funding program. We need researchers who are dedicated to the discovery of treatments and cures,

and researchers need patient participation to ensure the support of their science. Connecting the dots with experts, researchers and clinicians, and championing multinational clinical trials will strengthen research and improve outcomes, ultimately shrinking timelines to approved therapies and cures.

A long-term vision of the Society has been to provide direct services to families at the time of diagnosis. The Pathways Program launched in May (see page 7), allowing our team to begin meeting with families nationwide. This program transforms our ability to fulfill the unmet needs of those beginning this journey.

The 2017 Annual Report highlights key areas the National MPS Society is working in with research, family support and legislative advocacy. It also illustrates how we can achieve what might seem impossible with tireless volunteers, the essential foundation of a successful nonprofit organization. With the efforts of our volunteers and internal team combined with gifts from donors around the world, we move forward reenergized, centering on new programs, new research and new clinical trials—moving steadfastly forward for diseases still in search of a cure.

*“With research, possibilities are limitless”*

SYDNEE JENSEN (MPS I) AND ALLISON RESTEMAYER (MPS I)



# GOVERNANCE COMMITTEE

**THE GOVERNANCE COMMITTEE** continues to play a very important role in the National MPS Society's effective guidance of our organization. Through oversight from the board of directors, this committee helps ensure we continue to properly serve our membership and fulfill our mission.



*THE SPIVEY FAMILY: TYLER, KAITLYN (MPS VI),  
NOAH AND ABEL*



*SHERI WISE (MPS IVA) AND FANNY ZAMBRANO (MPS IVB)*

In 2017, the Governance Committee considered the overall staffing and personnel needs of the Society, including compensation recommendations. One need was to fill a position for the newly created Pathways Program. Others included replacing personnel for both the family support coordinator, and president and CEO positions. All of these important positions were successfully filled with qualified personnel.

Regarding the president and CEO position, the committee began an extensive recruiting process in the fall of 2017. After determining critical external and internal needs of the Society, the committee initiated a national search to find the most qualified individual to lead the Society in the next decade. Through this process, candidates were evaluated and vetted

individually. Upon approval of the Executive Committee of the board, the Society was excited to announce Terri Klein, National MPS Society director of development and operations, as the new president and CEO.

In addition, the committee oversaw the 2017 annual board of directors election process for the upcoming 2018–2019 term. This consisted of a vigorous vetting process of all applicants, including personal interviews, prior to the membership voting. For the 2018–2019 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 in the months and years to come.

# FAMILY SUPPORT COMMITTEE

**FAMILIES ARE THE LINCHPIN OF THE MPS AND ML COMMUNITY**, and the National MPS Society continues to work to assist families in every way possible. Whether it's financial assistance during a hard time, a special treat for an affected family member or to help make education dreams come true, we support families across the nation. In 2017, two additional committees were formed (Remembrance and Sibling Resources) to address the unmet needs of our membership.

Our family support initiatives include financial grants for our family assistance program (providing medical durable goods denied by insurance), medical travel assistance program, scholarships to attend the annual family conference, continuing education scholarships, extraordinary experiences for individuals with MPS or ML, regional social gatherings, and MPS journey assistance for specific needs of an MPS patient.

**In 2017, we invested more than \$120,000 in the following family support initiatives:**

## Family Assistance Program

- Approved 13 applications totaling \$17,559.
- Allocated funds for dentures, evacuation chairs, glasses, hearing aids, therapeutic tricycle, wheelchairs, wheelchair ramps and wheelchair modifications.

## Medical Travel Assistance Program

- Approved 16 applications totaling \$7,070.
- Approved increased travel eligibility to \$700 per applicant.

## Conference Scholarships

- Awarded \$42,000 in scholarships to the Annual Family Conference in Minneapolis, MN.
- Approved increased scholarship eligibility up to \$1,100 per applicant.

## Continuing Education Scholarship (CED)

- Awarded 30 \$1,000 full-time scholarships and one \$500 part-time scholarship.
- Introduced the Jeff Bardsley Scholarship and awarded one \$5,000 scholarship to an individual with MPS.
- Implemented a lifetime cap on the CED program of \$5,000, (not including the Jeff Bardsley Scholarship award).

## Extraordinary Experience Program

- Awarded three extraordinary experience applications, including a summer camp.

## Social Gatherings

- Funded three events, held in Kentucky, Ohio and New York.

## Journey Assistance Program

- Approved 10 applications for assistance.
- Authorized recipients to receive up to \$500 per individual with MPS or ML, annually.
- Awarded funds for bereavement expenses, iPads and a recliner.



*My life has been greatly impacted because of having MPS II. I have gained an appreciation for modern medicine and for the impact it has on everyday life. As a recipient of the National MPS Society's **Jeff Bardsley Continuing Education Scholarship**, I am able to pursue my goal of higher education at the university level. I want to continue my education in the engineering sciences field and make a difference for those in need. My career goal is to work in a lab or for a company in the medical field producing new medicine and engineering new technology to shape a better world.*

**NICHOLAS DI TOMMASO, MPS II**

# LEGISLATIVE COMMITTEE

**ADVOCACY IS THE BEST WAY** for the MPS and ML community to share rare disease stories with lawmakers and policy influencers who can help make a difference on a federal level.

Federal policies can increase life-saving medical research and access to care for MPS patients. The Legislative Committee focuses on a number of goals throughout the year, including regular calls to action on rare disease legislation, disseminating carefully crafted appropriations language to spread our message to new members, collaborating with the rare disease community as a whole, conducting advocacy training webinars, and growing and fostering relationships with key decision makers.

## In 2017, the Legislative Committee:

- Facilitated 31 MPS and ML advocates meeting with 43 legislators over two days to advocate for the OPEN Act, Affordable Care Act and increased NIH funding for MPS diseases.
- Presented Jeff Denham (R-CA), with the MPS Advocacy Award.
- Provided onsite training in Washington, DC, for our Speaker's Bureau Program.
- Created action alert for Missouri Newborn Screening Act for inclusion of MPS I and spinal muscular atrophy, and a membership alert on community advocacy.
- Partnered with the National Organization for Rare Disorders (NORD) for education of healthcare reform.
- Increased newborn screening awareness opportunities with collaborations led by EveryLife Foundation and patient advocacy within individual states.
- Drafted sign-on letters for ending the FDA/NIH hiring freeze, FDA User Fee Agreements Coalition, RACE for Children Act, request for Lifespan Respite and the National Family Caregiver Support Program, NORD letter on enhancing patient engagement efforts across FDA, NORD letter to protect the Orphan Drug Tax Credit, and proposed adaptation of the ICER value framework for the assessment of treatments for ultrarare conditions.
- Attended advocacy and networking conferences, including World Lysosomal Disease Conference, World Orphan Drug Conference, Global Genes and the Rare Voice Awards.
- Continued member education and engagement efforts with webinars and conference calls on social media strategies, expanded access vs. right to try legislation, and grassroots targeted advocacy.

*REP. JEFF DENHAM (R-CA) RECEIVES THE MPS ADVOCACY AWARD, PRESENTED BY THE MPS BOARD, ADVOCATES AND TEAM IN WASHINGTON, DC*



# EDUCATION & PUBLICITY COMMITTEE

**THE NATIONAL MPS SOCIETY CONNECTS AND ENGAGES** with the MPS and ML community through education and publicity efforts. Whether via social media campaigns, MPS Awareness Day activities, education fact sheets or promotional materials, we are always looking for new ways to reach our target audiences.

With our communications director, the team has expanded our reach even further through enhanced social media, email marketing, and digital and print publications. Our social media channels, with focus on increased member and donor engagement, have been well received. The National MPS Society's website, [www.mppsociety.org](http://www.mppsociety.org), was redesigned in 2017 with a fresh, new appearance. Our website provides clear pathways for members, researchers, physicians and the public to access a multitude of resources.



TAYABBA BEG (MPS III PARENT) AND TERRI KLEIN EDUCATING THOMAS JEFFERSON MIDDLE SCHOOL STUDENTS ON MPS

*Raising awareness for MPS and educating communities nationwide is very important. When Thomas Jefferson Middle School, asked me to come share MPS Day to honor one of our families, there was only one answer—yes. These young philanthropists raised funds and awareness throughout New Jersey and spent the afternoon learning about MPS. I'm so proud of our upcoming generation. They have embraced a difficult disease that has impacted one of our families three times over. Their efforts created real change.*

**TERRI KLEIN**

## In 2017, the Education and Publicity Committee:

- Created International MPS Awareness Day materials to share with members and donors around the country. Items included: MPS Day trifold mailer, Forget Me Not flower seed packets, two-week action awareness calendar and directions for Take to the Skies campaign website, hosted by Shire.
- Continued the National MPS Society thank you card campaign mailing to researchers around the country.
- Increased social media outreach efforts with Facebook (7,000 followers) and Twitter (2,000 followers), in 12 months.
- Increased *e-Courage* bi-monthly newsletter subscriptions. *e-Courage* now reaches more than 1,200 members and is also available on our website.
- Launched the redesign of [www.mppsociety.org](http://www.mppsociety.org) to provide ease of access to resources for members, physicians and researchers.
- Developed the MPS VII Resource Guide, in collaboration with patients, professionals and physicians.
- Continued updating essential fact sheets and syndrome booklets.
- Revised tactical plans to align with the National MPS Society's new strategic plan.

# ADULT RESOURCE COMMITTEE

**THE ADULT RESOURCE COMMITTEE (ARC)** is comprised of adults with MPS or ML. Because of successful therapies and trials, some patients with these disorders are living longer, higher quality lives. ARC has been created to address and fulfill the unique needs of adult patients living with MPS or ML.

The goals of ARC are to increase resources and involvement of adult patients within and outside of the National MPS Society. Their platform provides increased engagement opportunities with membership, legislators, scientists and the general public. In addition, ARC creates key networking opportunities that are essential to these deserving individuals.



*ADULTS WITH MPS OR ML*

## **In 2017, ARC:**

- Developed the “Road Kit” to provide information and resources for those who are transitioning into or have entered adulthood.
- Participated in the planning for adult breakout sessions and discussions at National MPS Society conferences and gatherings by the adult community.
- Formed a committee focused on advocating for adults with MPS or ML syndromes.
- Increased both membership and public awareness of these syndromes through stories of encouragement, hope and successes obtained by adults with MPS or ML.



# PATHWAYS COMMITTEE

**THE NATIONAL MPS SOCIETY'S LONG-TERM VISION** has been to provide direct services to families in need. It has been our hope to be forward thinking and provide skilled services, something beyond a phone call, that would transcend the MPS journey for newly diagnosed families. In 2017, this program, Pathways, became a reality with support from BioMarin and the board of directors.

Pathways is designed to provide education and support to families and individuals with MPS and ML. Upon diagnosis, Pathways directly connects members with services in their community and integrates members into the Society for support. The program includes in-home visits with families, something never achieved before, and provides a comprehensive, compassionate and more meaningful line of support. This program provides continued navigation and resources to ensure a family can obtain the best quality of care for their loved one.

## In 2017, Pathways:

- Established a committee and hired its first family support lead, with social work skills and education.
- Created a training and educational environment for the Pathways team to triage the variability of MPS and ML syndromes.
- Implemented new processes to ensure newly diagnosed families receive immediate services.
- Provided services to 50 families and visited 16 families in person. Each syndrome was represented in services provided nationwide.
- Hired a second part-time Pathways position in the fourth quarter and began to build program assets required for consistent programming.
- Launched a new contact management system to foster the Pathways Program and help to integrate members into all programs at the Society.

*CHRISTENSEN FAMILY*



*AUSTIN (MPS IIIA) AND CHERYL NOLL AND COREEN GRAY*



# RESEARCH GRANTS

**RESEARCH REMAINS PARAMOUNT** to the National MPS Society's mission—to find cures for MPS and ML. Grant funding, research partners and collaboration ensure significant progress toward a better future for all affected individuals.

In 2017, the National MPS Society subsidized or invested historical levels of funding—the largest annual amount invested in our research program history. More than \$750,000 was invested in total grant funding for 2017, which includes second-year funding for grants awarded in 2016, and \$110,000 in partnership with The Ryan Foundation and University of Pennsylvania through the Million Dollar Bike Ride. Funding research is critical to find cures. The funding process begins with our receiving many letters of intent from researchers from around the world outlining their research proposals. After reviewing those letters, our Scientific Advisory Board review committee requests full grant proposals for evaluation and recommended funding.

The Society also committed \$30,000, in partnership with the International Society for Mannosidosis and Related Diseases, to Dr. Steven Gray for ML research; \$50,000 to the University of North Carolina, Dr. Mathew Hirsch, for MPS I corneal gene therapy research; \$25,000 to the University of Minnesota for continued core imaging research with the National Institutes of Health; and reinvested funds into Abeona Therapeutics for MPS III studies.

MATTHEW EVANGELISTA (MPS VII)



*Obtaining a research grant from the Society permitted a collaborative study involving researchers in Italy, New Zealand and Australia. This research was significant because it 'scaled up' the evaluation of a potential therapy for MPS IIIA from mice to dogs.*

DR. KIM HEMSLEY

COOPER TIPPETT (MPS IVA)



**We are thankful for the commitment of global MPS researchers. Our profound devotion through collaboration and partnerships is highlighted in these pivotal research projects:**

### 2017 Two-Year Grant Award Recipients

**Dr. Sharon Byers – \$90,000 general grant (over two years)**  
SA Pathology (WHC site)  
Adelaide, Australia  
*“Can the cell cycle be reset to normal in the MPS growth plate chondrocytes?”*

**Prof. Elvira De Leonibus – \$50,000 MPS III (over two years)**  
Telethon Institute of Genetics and Medicine  
Pozzuoli, Italy  
*“Disease mechanisms leading to dopaminergic dysfunction underlying behavioral symptoms in MPS IIIA”*

**Dr. Charbel Moussa – \$120,000 MPS IIIA**  
Georgetown University  
Washington, DC  
*“The effects of tyrosine kinase inhibition on MPS IIIA mice”*

**Dr. Chet Whitley – \$50,000 MPS IV (over two years)**  
University of Minnesota  
Minneapolis, MN  
*“Neurocognitive and neuroimaging of Morquio syndrome – MPS IV”*

### 2017 One-Year Grant Award Recipients

**Dr. Igor Nestrail – \$60,000 MPS I**  
Department of Pediatrics,  
University of Minnesota  
Minneapolis, MN  
*“Probing oxidative stress and neuroinflammation as potential therapeutic targets in MPS I”*

**Dr. Thomas M. Stulnig – \$50,000 MPS II**  
Clinical Division of Endocrinology and Metabolism, Medical University of Vienna, Vienna, Austria  
*“Metabolic, microstructural and functional hallmarks of brain alteration in Mucopolysaccharidosis type II”*

### 2016 Second-Year Grant Funding

**Dr. Lachlin Smith – \$40,000 MPS VII**  
University of Pennsylvania  
Philadelphia, PA  
*“Therapeutic targeting of Wnt/BCatenin signaling to improve bone formation in MPS VII”*

**Dr. Ainslie Derrick-Roberts – \$60,000 MPS IVA**  
Central Adelaide Local Health Network, Adelaide, Australia  
*“Creating new tools for understanding skeletal disease in MPS IVA”*

**Dr. Kazuki Sawamoto and Dr. Shunji Tomatsu – \$35,000 MPS IVA**  
Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE  
*“Pathogenesis and management of life-threatening tracheal obstruction in Morquio A syndrome”*

In addition, the following research grants were funded in collaboration with our research partners:

**ISMRD – Dr. Steven Gray and Dr. Charles Vite – \$30,000 ML II/III (over two years)**  
University of North Carolina and University of Pennsylvania  
*“Evaluation of adeno-associated virus gene therapy in the feline model of Mucopolipidosis II”*

**Matthew L. Hirsch – \$50,000 MPS I (2016 Million Dollar Bike Ride Matching Funds)**  
University of North Carolina  
*“MPS I corneal clouding AAV gene therapy project”*

**Lysosomal Disease Network – \$25,000 multi-syndrome**  
University of Minnesota  
Neuroimaging Core NIH Project

TEAM MPS AT THE MILLION DOLLAR BIKE RIDE, PHILADELPHIA, PA



# FUNDRAISING COMMITTEE

**COMMUNITY SUPPORT WILL ALWAYS BE THE KEY** to raising funds, and we are thankful for everyone who helped support our walk/run and other fundraising events. Significant national fundraising endeavors this year included national walk/run events in Minneapolis, MN, Napa, CA, and Raleigh, NC; the Annual Fund campaign; major donor visits; Million Dollar Bike Ride for MPS with a match from University of Pennsylvania; and our grants program.

We continue to embrace the fundraising evolution. With increased use of social media, we are now able to reach donors quickly with just a click.

The Fundraising Committee is dedicated to supporting our mission through the following comprehensive list of fundraising programs: family fundraisers, walk/runs, Annual Fund, major gifts, planned giving, mobile giving, Courage Pages, Champions Circle, Crowd Rising fundraisers, Combined Federal Campaign, United Way and employee giving, and corporate matching gifts and grants.

## In 2017, the Fundraising Committee:

- Received our seventh four-star charity rating from Charity Navigator, representing sound fiscal management and commitment to accountability and transparency. This “exceptional” designation differentiates the Society from its peers and demonstrates to the public it is worthy of their trust.
- Supported an active membership roster of more than 1,700 members.
- Raised approximately \$655,000 through walk/run and fundraising events.
- Hosted the Boston Gala with nearly 200 attendees, raising more than \$150,000 for research and family support programs.
- Participated in the Society’s largest social media fundraiser through Markiplier online, raising more than \$100,000 in one day.
- Secured more than \$110,000 for MPS research in partnership with The Ryan Foundation and University of Pennsylvania through the Million Dollar Bike Ride.
- Hosted three national walk/run events in Columbus, OH, Napa, CA, and Raleigh, NC.
- Successfully implemented mobile pledging at the Annual Family Conference.
- Supported more than 50 family fundraisers, including: sports tournaments, cycling, bake sales, bowl-a-thons, concerts, jeans day, bingo, auctions, school relays and more.
- Increased grant writing efforts to secure new sources of funding for critical research, family support and our newest programs: Pathways and the Speakers Bureau.
- Raised \$176,000 through the 2017 Annual Fund campaign, chaired by Luis, Angela and Anyssa Guajardo.
- Continued efforts to meet with major donors and Society friends.
- Hosted 50 Courage Pages (customized, informative family web pages for awareness and fundraising) on the Society’s website.
- Received Combined Federal Campaign application approval.
- Worked with donors to process more than 250 Employee Giving Campaign and corporation matching gifts.
- Increased awareness for the Rising Sun Legacy Circle and processed new planned gifts from trusts and wills.



STEVE HOLLAND AT BOSTON GALA



MINNEAPOLIS MADNESS WALK/RUN

RAY MILLER AND MARK DANT,  
MILLION DOLLAR BIKE RIDE



*While we have seen great progress in treatments, there are still no cures and many forms of MPS still do not even have treatments. Through our fundraising efforts, we hope to continue to raise awareness of MPS, and fund research so that one day there will be treatments and cures and other parents will not have to see their child suffer with this terrible disease.*

**RAY MILLER** (host of Do It For Dan fundraiser)

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

**2017 Champions Circle**

- Jennifer Bishop
- Melany Bjorkman
- Toni Bowen
- Marc and Beth Brdar
- Lola Gindrat
- Steve and Amy Holland
- Jennifer Hutcheson
- Charles and Roberta Kachel
- Lori Lazarescu
- Lauren Louison
- Donny and Molly Merrill
- Eric and Amber Mongan
- Susan Murphy
- Rev. Ted and Kathy Nace
- Linda Perrella
- Adam and Jennifer Schepis
- Sarah Aaserude and Todd Waddell

**Courage Pages [www.mpsociety.org](http://www.mpsociety.org)**

The following families have their own website through Courage Pages at the National MPS Society. 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 home page.

- Evan Abel
- Ashley Allen
- Aaron Athy
- Hunter Beam
- Ryder Belisle
- Colin Berning
- Annabelle Bozarth
- Tyson Brown
- Sam Caswell
- Alan Charest
- Alex and Nick Cherrstrom
- Julia Donahue
- Jackson Dunn-Kraus
- Kali Gegenheimer
- Shane Gibson
- Karina Guajardo
- Makenzie and Isabella Hardesty

- Faith Heard
- Holland family
- Michelle Hopkins
- Analynn Hughes
- Fiona Humphrey
- Kathleen Joyce
- Carter Kanney
- Beth Karas
- Eddie Kimminau
- Allison Kirch
- Jennifer Klein
- Kraig Klenke
- Shane McGoey
- Caleb Michalik
- Danny Miller
- Maura Mongan
- Xavier Patton

- Analee Perez
- Raymond Pinchak
- Hudson Roman
- Christopher Sanchez
- Elijah Story
- Katie Swanson
- Madison Thompson
- Cooper Tippet
- Jack Todd
- Trinity Walker
- Michael Whitaker Russell
- Scotty Whitecotton
- Antonio Estrada Willmann
- Christian Yard
- Emily Yurkins
- Roy Zeighami

# FUNDRAISING, *continued*

## 2017 Fundraising Events

**Action for Aidan**, hosted by Brooke Carter

**Belisle Fundraiser for MPS III**, hosted by Taci Belisle

**CaBi Fundraiser**, hosted by Lynn Hopkins

**Cards for a Cause**, hosted by Amber Mongan

**Cooper's Troopers BBQ**, hosted by Christine Tippett

**Courage for Kristofer**, hosted by Jennifer Christianson

**Cross Creek Charity Golf Tournament**, hosted by William Bagwell

**Do It Fore Dan Golf Tournament**, hosted by Amy and Ray Miller

**Donations in honor of Karina's birthday**, hosted by Angela and Luis Guajardo

**Ella Praise Fundraiser**, hosted by Kris Klenke

**Emily's Dance**, hosted by Danielle O'Connor

**Facebook Birthday Fundraiser**, hosted by Adele Kary, Amy Jo Bruno, Casey and Jason Hurst, Kendra Gottsleben and Shaun Bach-Haynes

**Facebook Giving Tuesday Fundraiser**, hosted by Brittany Laine Mason and Stacy Buchanan

**Facebook Fundraiser**, hosted by Andrea Souza, Autumn, Brian and Taundra Mortensen, Bailey Deal Lamb, Bobby Morrison, Darryl Block, Kimberly O'Kane, Kristine Klenke, Leslie Urdaneta, Matthew Gibson, Matthew Lemke, Shannon Smith, Shelly Maddox and Tracy Marie Greenberg

**Framingham High School Charity Volleyball Tournament**, hosted by Framingham High School National Honor Society

**Halk Fall Festival**, hosted by Carla Crain Halk

**Jammin' for Julia**, hosted by Andrea Felten

**Jamming for MPS**, hosted by Julie Sykes

**Josh's Birthday Party**, hosted by Ruth Murphy

**Kendra Scott Party Fairfax**, hosted by Stephanie Bozarth

**Kendra Scott Party Fashion Island**, hosted by Lynn Hopkins

**Kendra Scott Party Houston**, hosted by Trisha Jensen

**Kendra Scott Party Raleigh**, hosted by National MPS Society Staff

**LuLaRoe Fundraiser for MPS Society**, hosted by Heather Palmer

**Markiplier Charity of the Month**, hosted by Markiplier on YouTube

**Mask Concert for a Cure**, hosted by Dorothy Mask

**Michelle's Scrapbooking Event**, hosted by Jim and Michelle Dodson

**Million Dollar Bike Ride**, hosted by Penn Medicine Orphan Disease Center

**Moore Family Bingo Event**, hosted by Spencer Moore

**MPS Chili Cook-Off for a Cure**, hosted by Beth Kramer

**MPS Purple Sock Fundraiser**, hosted by Emily Viti and Darren Hohn

**Neighborhood Lemonade Stand for Cooper's Troopers**, hosted by Laura Navarre

**Olivia's Senior Project**, hosted by Olivia Yaskus

**Perry Elementary School Fundraiser**, hosted by Perry Elementary School

**Scotty Whitecotton Birthday Fundraiser**, hosted by Kim Whitecotton

**Team Eddie T-Shirt and Bracelet Fundraiser**, hosted by Park View Middle School

**T-shirt Fundraiser**, hosted by Christine Tippett

**Thomas Jefferson Activists**, hosted by Thomas Jefferson Middle School

**White Castle Fundraiser**, hosted by Kim Huskey

**Williams Greeting Card Fundraiser**, hosted by Allison Williams

*Fundraising to me isn't just raising money for a cause, but coming together as a group to help spread awareness. Our cause obviously is to spread awareness for MPS. This is important to us as our 4-year-old daughter was diagnosed with MPS IV last year. We have been so blessed with all the support and love we have received from family and friends. We are glad to be able to help others with our fundraiser, Jammin' for Julia. We look forward to another amazing day at our next event.*

**ANDREA FELTEN** (host of Jammin' for Julia)

## 2017 Walk/Run Events

**Benny Strong 5K**, hosted by Northview High School

**Jingle Bell Run**, hosted by Betsy Fowler

**Napa National Walk/Run**, hosted by National MPS Society

**Minneapolis National Run**, hosted by National MPS Society

**North Carolina National Walk/Run**, hosted by National MPS Society

**Post Office Café Walk/Run in memory of Mark and Casey Lessing**, hosted by Michael Lessing Jr.

NATHAN JAMES (MPS IIIA)



# FINANCIALS

The financial information below has been summarized for the year 2017. The Society is a 501(c)(3) nonprofit public charity. Complete audited financial statements and IRS Form 990 are available on request.

## Financial Position

### Assets

Cash and cash equivalents	\$ 1,078,619
Investments	2,026,563
Contributions receivable	25,000
Property & equipment, net	9,823
Endowment investments	1,130,652

**Total Assets** \$ 4,270,657

### Liabilities

Accounts payable \$ 11,068

### Net Assets

Unrestricted net assets	1,441,883
Temporarily restricted	1,752,202
Permanently restricted endowment	1,065,504
<b>Total Net Assets</b>	<b>4,259,589</b>

**Total Liabilities and Net Assets** \$ 4,270,657

## Activities

### Support and Revenue

Donations - general	\$ 101,749
Donations - family assistance	37,060
Donations - research	133,031
Donations - endowment	64,710
Operating grant	637,971
Fundraising	786,762
Membership dues	3,178
Conference income	571,264
Investment income	764,128

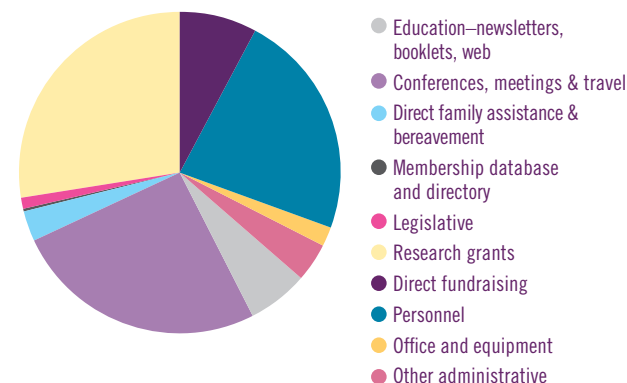
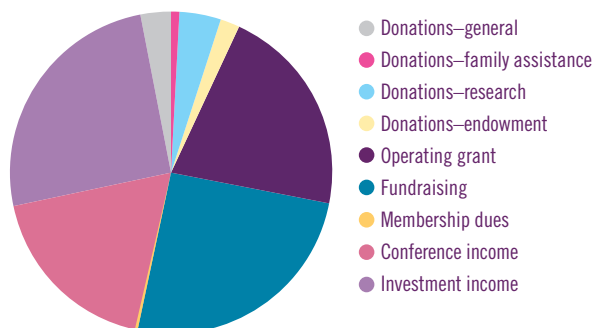
**Total Support and Revenue** \$ 3,099,853

### Functional Expenses

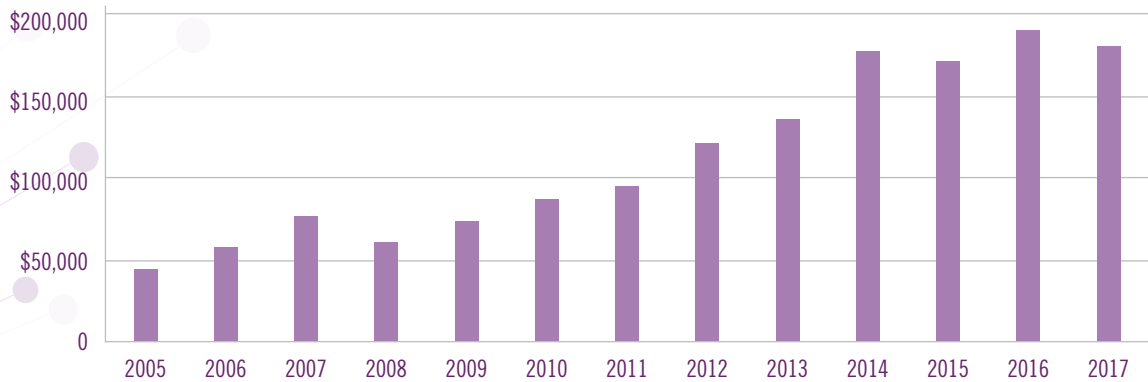
Education - newsletters, booklets, web	\$ 139,952
Conferences, meetings & travel	551,210
Direct family assistance & bereavement	69,206
Membership database and directory	9,933
Legislative	22,697
Research grants	579,413
Direct fundraising	167,201
Personnel	487,558
Office and equipment	51,813
Other administrative	80,886

**Total Functional Expenses** \$ 2,159,869

**Change in Net Assets** \$ 939,984



# ANNUAL FUND DONATIONS



*We were honored and humbled to be chosen as co-chairs for the 2017 Annual Fund. We have witnessed the growth of the Annual Fund over the years and know how significant it has become to the National MPS Society's fundraising efforts. We fully support the Society because we believe in all of its main objectives: to fund research to find a cure, to support families through scholarships and grants, and to advocate for the MPS and ML community. The Society is a remarkable organization that inspires us to continue giving, fundraising and sharing our story.*

**THE GUAJARDO FAMILY**

## PLANNED GIVING

### Rising Sun Legacy Circle

2017 was the seventh year for Planned Giving with the National MPS Society. At year's end, 27 Planned Giving donors had joined 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 desire to give.

#### In 2017, the Planned Giving committee:

- Secured a large stock gift.
- Included Planned Giving articles in *e-Courage*.
- Continued stewardship with donors.
- Acknowledged two future gifts to the Society.
- Maintained a Planned Giving website to help members and friends of the Society become acquainted with Planned Giving and gifts the Society accepts.

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



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In 2017, 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 *e-Courage* and this Annual Report. The following list represents all donations received in calendar year 2017. If your name is not listed, we apologize and ask that you contact us. If we received your donation in 2018, you will be recognized in the next Annual Report.

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(\$10,000 to \$1,000,000)

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# MPS AND ML

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

## MPS I

MPS I H Hurler  
MPS I S Scheie  
MPS I H-S Hurler-Scheie  
Enzyme / $\alpha$ -L-Iduronidase

## MPS II

MPS II Hunter  
Enzyme /Iduronate sulfatase

## MPS III

MPS III A Sanfilippo A  
Enzyme / Heparan N-sulfatase  
MPS III B Sanfilippo B  
Enzyme /  $\alpha$ -N-Acetylglucosaminidase  
MPS III C Sanfilippo C  
Enzyme / Acetyl CoA:  
 $\alpha$ -glycosaminide acetyltransferase  
MPS III D Sanfilippo D  
Enzyme / N-Acetylglucosamine  
6-sulfatase

## MPS IV

MPS IV A Morquio A  
Enzyme/ Galactose 6-sulfatase  
MPS IV B Morquio B  
Enzyme /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 Pseudo-Hurler polydystrophy  
Enzyme / N-acetylglucosamine-1-  
phosphotransferase

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