



NATIONAL MPS SOCIETY | DECEMBER 2018

COURAGE

MPS PATHWAYS

This essential program provides support and resources to families whose children are newly diagnosed.

PAGE 11

FUNDRAISING MILESTONES

Tireless efforts of Society members and supporters continue to raise record-breaking funds to support our mission.

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RESEARCH

The Society will fund \$550,500 in research grants to find cures and develop therapies.

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DID YOU KNOW...?

The National MPS Society offers a wide variety of programs to support our membership

ANNUAL FUND CAMPAIGN

Thank you to everyone who has already donated to the 2018 Annual Fund!

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MEPSEVII APPROVED

Mepsevii™ was approved by the FDA as the first treatment for pediatric and adult patients with MPS VII

FDA MEETING

In October the National MPS Society visited FDA offices to discuss historical and current climate for MPS III

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Welcome to the return of printed *Courage*—this issue is the first to be delivered since Spring of 2016. Looking back, the very first printed edition of *Courage* was sent in 1985, and members received a newsletter four times a year. Two years ago, a strategic decision was made to transition to an emailed electronic version.

Members seem to enjoy the quicker, monthly updates filled with research and fundraising news. But something was lacking. Like a photograph or vinyl record, there is something special about a printed magazine. To fill this void, members will now be getting both!

Twice a year, print editions of *Courage* will hit your mailbox and you will continue to receive the monthly *eCourage*. We hope you enjoy both and find them informative and useful. If you'd like to contribute or share events and life milestones, please reach out to the Society's new communications director, Jacob Desjarlais, at Jacob@mpssociety.org.





TOGETHER WE ARE MAKING HUGE STRIDES!

The National MPS Society is constantly striving to do more, drive change and save lives. Each contribution, big or small, cumulates to create exceptional accomplishments. I am excited to share just a sampling of what was achieved under my chairmanship. Thank you to our team, board of directors, volunteers, stakeholders and, most importantly, families. Our work together is making a difference!

STRATEGICALLY INVESTED \$2,773,000 IN INNOVATIVE RESEARCH SINCE 2014.

The Society has not only increased investment research for the future, but also invested strategically to meet the needs of today. In 2014, we invested seed funding for an MPS III gene therapy clinical trial. In 2015, we awarded the first fundraiser host-directed research grant. In 2017, we invested in a novel approach using an FDA-approved drug to reverse cognitive and motor decline in MPS.

MADE THE MPS PATHWAYS PROGRAM VISION A REALITY.

MPS Pathways provides education and support to families and individuals with MPS and ML. Upon diagnosis, Pathways integrates new members into the Society and directly connects them with services in their community. The program includes in-home visits and provides a comprehensive, compassionate and more meaningful line of support.

SUPPORTED FAMILIES.

The Society has several programs that support annual family conference costs, durable medical goods, medical travel, continuing education and other special requests. Additionally, the Society created the Adult Resource, Siblings

and Bereavement Committees to provide peer-to-peer support and education, which has deepened our personal and community network.

HOSTED SERIOUSLY FUN FUNDRAISING EVENTS.

The Society hosted 11 large walk/run fundraisers across the United States, partnered four times with the UPenn Million Dollar Bike Ride, and hosted two large galas. In 2017, the Society partnered with Markiplier to host our largest social media fundraiser to date, which raised more than \$100,000 in a day.

PARTNERED WITH A PURPOSE.

The Society has partnered with the research community to move two enzyme replacement therapy treatments from clinical trial to FDA approval for MPS IV and VII, along with providing support for more treatments to successfully move through the drug development pipeline. The Society collaborated with the FDA, NIH and others to provide expertise and streamline approval processes. We teamed with the U.K. MPS Society to host Consensus Conference in London for understanding neurological biomarkers. Most recently, the Society hosted the 15th Annual International Symposium on MPS and Related Diseases, which provided a platform for the latest global innovative breakthroughs and discoveries in the field of MPS and ML research.

RECEIVED FIVE CONSECUTIVE YEARS OF 4-STAR CHARITY NAVIGATOR RATINGS.

The Society has reached this exceptional standard for eight of the total 14 years of rating. Charity Navigator's rating system examines two broad areas of a charity's performance-- financial health and accountability and transparency.

AMPLIFIED OUR ADVOCACY VOICE.

There is no better way to tell the complex and urgent needs of the MPS and ML community than by stepping into a legislator's office and speaking with them personally. For the last six years, the Society has provided comprehensive advocacy training to our membership, then brought those advocates to Capitol Hill to speak directly to congressional representatives. This effort started with just a handful of advocates and has grown to more than 50 face-to-face meetings every year. By cultivating these relationships we are able to make an impact on legislation important to our community.

If you are inspired, join us by donating and/or volunteering. Let's keep our momentum going!

With gratitude,

Stephanie Bozarth, MSW, *Chairman, Board of Directors*

IN LATE NOVEMBER, Shire hosted an MPS II expert meeting in Lisbon, Portugal. I was invited to attend with Drs. Joseph Muenzer, Elsa Shapiro and Julie Eisengart. The meeting brought together experts involved in the management of MPS or chronic diseases who have experience with managing cognitive behaviors of children and adults with MPS II. The masterclass included topics not only from a medical but also social point of view. The goal was to define global ways to better understand and serve this patient population. The presentations were both enlightening and fascinating, and left us with more questions and a realization of the many challenges. We'll be sharing more information with you as it becomes available and new possible program ideas.

Before flying to Lisbon, I was invited by Carl Kapes, an MPS IIIA father of Team Sanfilippo, to visit the U.S. Food and Drug Administration (FDA) to discuss clinical trial climates, and expanded access and compassionate allowance for patients in long-term care with Sanfilippo syndrome. The goals of the initiative are to understand access issues and the FDA's role in clinical trial design as well as what role patient advocacy groups can have with the FDA to sponsor the clinical trial design phase. The meeting celebrated the progress made by the FDA's incorporation of a new department devoted to patient advocacy groups.

Early fall provided an opportunity to attend the Global Genes Summit, the National Organization for Rare Disorder's Patient Advocacy Summit, and the EveryLife Foundation's newborn screening meeting roundtable. There is new excitement about the data credibility driven by patient advocacy groups and the collaborative spirit that is the "triangle" approach to successful clinical trials and designs with sponsors, the FDA and groups like the National MPS Society. Today, more than 30 industries are involved in the MPS research and medical field. This has led to astounding science and hope for the unmet need of the syndromes lacking treatment and future optional therapies.

The National MPS Society, along with the expertise of our Scientific Advisory Board, awarded \$515,500 in research for MPS and ML. This is the second largest funding year in

history. We currently have funded more than \$8 million in research since 2001. Read more about selected research on page 38.

We are saying goodbye to retiring board member Kim Whitecotton who served nine years on the board. Kim made significant contributions to our Education and Publicity Committee, and possesses a unique knowledge of our membership. Fortunately, she will remain an active member of the Society and our committees, continuing to positively impact our goals and programs. On Jan. 1 we will welcome our new board members Shelby Lyon, Cristol O'Laughlin and Sherri Wise, plus returning board members Austin and Stephanie Bozarth, Kristine Klenke, Jason Madison and Christine Tippet.

Another change on Jan. 1 is the incoming of a new slate of officers elected in May. Lisa Todd will take over as chairman, Steve Holland will assume vice chair duties, Lynn Hopkins will become treasurer, and Christine Tippet will be secretary. All four have been working with the current officers to ensure a seamless transition.

We continue to cultivate relationships with companies that have developed treatments for MPS diseases so we can collaborate as they move forward to clinical trials. There are several clinical trials being planned for 2019; we will be emailing information when it becomes available, as well as including information on our website and social media.

We continue to develop relationships with companies that are researching treatments for MPS diseases so we can collaborate as they move forward to clinical trials.



Excitement is building at the office for our Disney conference in December 2019, as we finalize the details and prepare registration materials for our membership. We can't wait to see everyone and look forward to another resourceful year!

As you read through this year-end wrap up edition of *Courage*, many stories of research and family support that transpired in 2018 will capture your attention. We are continuing to find new and creative ways to ensure we fulfill our mission of family support, research and advocacy.

Happy Holidays,

Terri Klein, President and CEO



Fundraising remains a building block for the National MPS Society. With the efforts of families and friends around the country we are able to ensure our mission is fulfilled for those with MPS and ML.

This year we hosted national walk/runs in Napa, CA, San Diego, CA, Babylon, NY, and San Antonio, TX. Thousands of participants helped to raise awareness and enjoyed the connection felt by those struggling deeply with rare diseases. Next year's events will be announced in January!

Our 2018 Annual Fund chairs are Steve and Amy Holland. The Hollands have served on the board of directors for 20 years, and helped the Society by fostering, mentoring and advocating tirelessly for MPS and ML. Please consider giving to the Annual Fund. It is the one initiative we champion to maintain our resources. It is an opportunity for you to consider additional gifts for family support and advocacy work.

This past spring the National MPS Society partnered again with the University of Pennsylvania for the Million Dollar Bike Ride. Team MPS raised \$100,000 for research. We have been invited back for the ride in June of 2019—consider joining the fun!

The 2018 International MPS Symposium brought families together from around the world. We have a wonderful photo library on our website that includes the San Diego Superhero 5K. Fundraising for a cause is critical, but having fun can be contagious. Join the movement to help eradicate MPS and ML.

2019 has many spring events that we encourage you to participate in! The 45th anniversary of the National MPS Society will be celebrated at many events, including our “Dare to Be Different Gala” in Washington, DC. Visit mpssociety.org/2019gala for more details on how you can join us in person or donate during our auction from afar.

Rise Up for MPS, with entertainment from Vocal Majority, will be held in Texas this spring. You can enjoy this terrific concert while helping our cause. Visit riseupformps.com for more details.

There are many ways you can help raise funds and awareness for the Society. We are here to encourage and guide you through your initiatives. Our team appreciates your suggestions; please contact me at larry.kirch@mpssociety.org with your ideas.

As we close out 2018, we ask you to include us in your year-end giving. Encourage those in your personal circle—family, friends and colleagues—to also consider giving to the Society this year.

Larry Kirch, Fundraising Chair

FAMILY SUPPORT

In 2018, the National MPS Society accomplished great things in family support, and we are excited to continue this momentum in 2019. If you are interested in serving on the Family Support Committee, please reach out for more information!

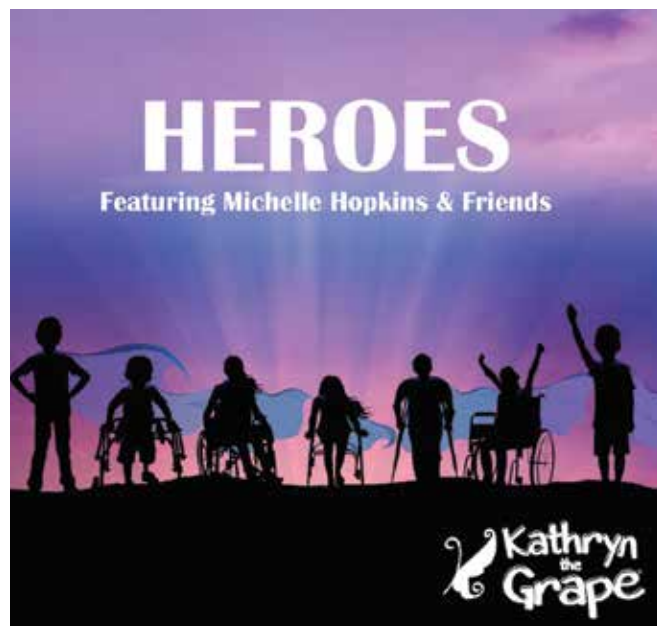
Forty-two scholarships were awarded to families and adults with MPS and ML to attend the 15th International Symposium in San Diego, 31 scholarships were awarded for continuing education, and more than 20 families received support to travel to medical appointments greater than 200 miles from home. Among many other things, we supported a child to get his first pair of hearing aids, an adult to be able to access a wheelchair and travel independently, and provided assistance for siblings to attend a special football event.

As we prepare for 2019, we are looking forward to seeing you and your families throughout the year. In May, we will host the CYCLE conference for bereaved families in Washington, DC and will welcome all of our families to Walt Disney World in December for our annual family conference. This year marks the 45th anniversary of the Society!

Please contact Leslie Urdaneta, Family Program coordinator, if you have a request for something that will help you or your family on your journey with MPS or ML.



CHRISTIANSON
FAMILY



“Heroes” is a song for everyone. We are all heroes. Each of us experiences challenges in life and this song honors the courage, hope, and love that carries us through. Download now at kathrynthegrape.com/heroes and support the National MPS Society!

Heroes was written by Kathryn Cloward and performed by Michelle Hopkins and friends. The video was mostly filmed at the 15th Annual Symposium on MPS and Related Diseases.

FAMILY SUPPORT PROGRAMS

DID
YOU
KNOW
...?

The National MPS Society offers a wide variety of programs to support our membership. Members are eligible to apply for any of the following programs:

- Bereavement Expense Program
- Continuing Education Scholarship Program
- Family Conference Scholarship Program
- Extraordinary Experiences
- Family Assistance Program
- Journey Assistance Program
- Medical Travel Assistance Program
- Regional Social Events

For more information and to apply, visit www.mpssociety.org/support.

SIBLING RESOURCES



GREY AND BLAIR (MPS III) CHAPIN



SIBLING RESOURCE COMMITTEE

The Sibling Resource Committee (SRC) is a network of MPS and ML siblings providing support, friendship and connection and is open to siblings of all ages. The SRC coordinated a carnival for children with MPS and ML at Camp Courage at the 15th International Symposium this year and hosted sessions for both older and younger sibling groups. For more information about the SRC, please send an email to src@mpssociety.org.

The B.L.A.I.R. Connection is a website created by Grey Chapin, whose sister was diagnosed with Sanfilippo syndrome at age 6 and passed away in April of last year. Through Grey's journey as a sibling, she realized that brothers and sisters of terminally ill children are often overlooked. There are not as many (online) support opportunities for kids as there are for parents. The goal of The B.L.A.I.R. Connection is to give every sibling of a terminally ill child a support system of people their age who truly understand what they are going through.

Visit theblairconnection.org for more information and to read sibling blogs. Send an email to grey@theblairconnection.com to submit a blog, photo or video.



JERRY AND FELIX



JERRY AND EMILY YURKINS



NOVAH SHULL WITH FLUTTER-BEE THE CLOWN (AMY RUSAK)



DAUGHTER OF LOURDES ESPINOSA AND PATTY PAGLIERO



FELIX-ANTOINE ABULET



CYCLE CONFERENCE

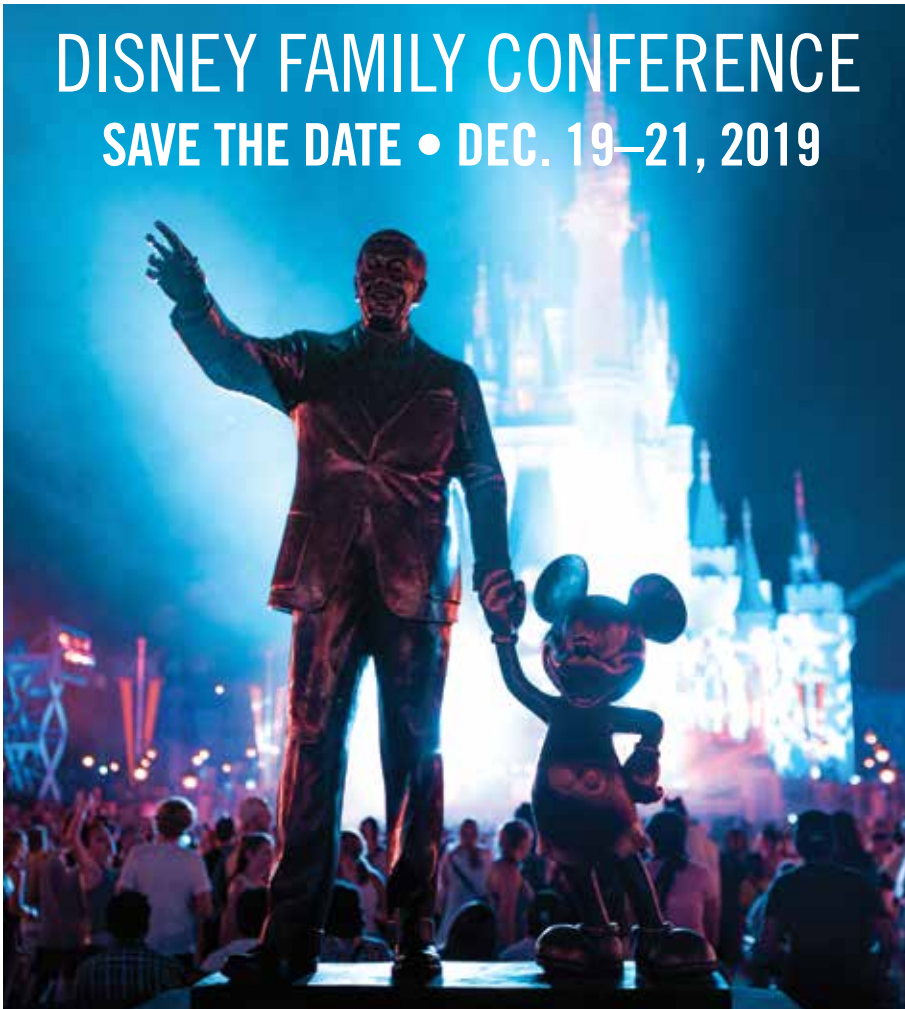
mpssociety.org/2019cycle

CYCLE, Celebrating Your Cherished Life Experiences, is a program supporting families who have lost a loved one to MPS or ML. The National MPS Society will host a CYCLE conference in Washington, DC, May 17-18, 2019. Beginning with a candlelight vigil on Friday evening, the conference will be a time of reflection and remembrance and will feature speakers on a variety of topics throughout the day on Saturday. Conference sessions will include information on talking about loss, sharing your story, finding purpose, managing grief and coping with trauma. Sessions are for adults ages 18 and up. For more information, contact Family Program Coordinator Leslie Urdaneta at leslie@mpssociety.org or 919.806.0101.



DISNEY FAMILY CONFERENCE

SAVE THE DATE • DEC. 19–21, 2019



MAY 15, 2018

MPS AWARENESS DAY



NEW MEMBERS

Mariel Abreu, adult with MPS VI, NY

Kim and Ben Amos, parents of Liam and Oliver Amos, MPS IIIA, MA

Brad and Tara Anderson, parents of Isabel Anderson, MPS I, MN

Gail Armato, mother of Graham McDonough, MPS I, CA

Ashton Baird, mother of Gabriel Clark, MPS IIIA, OH

John and Shantell Barbour, parents of Tanner Andrew Barbour, MPS II, OK

Jason Colbert, adult with MPS I, OH

Lisa Compton, mother of Taylor Jones, MPS IIIB, VA

Angela Cook, mother of Taheisha Turner, MPS IIIA, VA

Candace Eastman, mother of Owen Eastman, MPS I, MN

Dee Ann Gaston, mother of Connal Gaston, MPS II, TX

Allicia and Randall Gibbs, parents of Jamea Gibbs, MPS IIIA, KA

Jenny and Travis Greer, parents of Trenton Greer, MPS IIIA, FL

Bethany Hampton, mother of Ara Gullede, MPS I, MN

Josh Harden, father of Rebel Harden, MPS I, TN

Linda and Jacob Heard, parents of Faith Heard, MPS I, MN

Jennifer Hens, mother of Liberty Hens, MPS I, NY

Jason Huang, father of Jonathan Huang, MPS II, CA

Jessica Huggett, mother to Matty, MPS III, MA

Robert and Christina Hyman, parents of Cameron, MPS IIIA, NJ

Jeanne Johnston, great aunt, MPS I, NJ

Natalie Anaya Luna and Bruno Marie Bordes, parents of Juliette Marie Anaya, MPS I, Puerto Rico

Randy and Shelby Lyon, parents of Owen Groesch, MPS IIIA, IL

Henry Madison, father of Jason Madison, MPS II, PA

Diane May, mother of Matthew May, MPS IV, Cape Town, South Africa

Melissa Mckee, mother of Nevaeh Thompson, MPS III, TX

Sarah Mertens, mother of Luke Mertens, CO

Katie Miner, mother of Kiera Miner, MPS VI, OH

Melissa Moore and Jeremy Snell, parents of Eleanor Snell, MPS I, IL

Macey Necochea, mother of Kaeden Necochea, MPS I, CA

Amy Newell, aunt of Savannah Timbrook, MPS VI, TX

Udit Rastogi, parent of Eira Rastogi, ML, WA

Kristin Reyes, mother of Jamea Gibbs, MPS IIIA, KA

Cinthia Rivas, mother of Melina Rivas, MPS I, AZ

Tracy and Thomas Rose, parents of Maggie Rose, MPS I, NC

Vanessa Ruiz, sister of Kristen Ruiz, MPS IIIA, TX

Samantha Sanchez, mother of Jayce Carrillo, MPS IV, TX

Jill Schindler and Darren Lucas, parents of Drake Lucas, MPS I, IL

Tyler Seabrook, adult with MPS I, PA

Katharine Sink, mother of Declan Sink, MPS IIIB, TX

Kayla Stanford, parent of Kennedy Stanford, MPS I, TN

Cynthia Summers, mother of Caleb Summers, MPS II, KY

Cara Thomas, mother of Griffin Thomas, MPS I, GA

Alex and DeAnna Timbrook, parents of Savannah Timbrook, MPS VI, TX

Clair and Jon Trappe, parents of Jett Trappe, MPS I, CA

Doyle Walker Jr., adult with MPS II, TX

Crystal Watson, mother of Alexander Watson, MPS II, OR

Jenna Watson, adult with MPS I, CA

Mariah Williams, mother of Knoah Williams, MPS I, TX

Katie Willmann, mother of Antonio Estrada-Willman, MPS II, MO

Jessica and Tyler Wintringham, parents of Tyler Wintringham, MPS IIIA, VA

Perrian Wood, parents to Reyna Nieto, MPS III, CA

Bereavement

We remember and acknowledge the losses of children and adults with MPS and ML and understand that grief and memories remain over time. Our website includes a bereavement section with links to resources and an online application for a Bereavement Expense Program grant. Please reach out to our Family Program coordinator, Leslie Urdaneta (leslie@mpssociety.org or 919.806.0101), if you need more information on any of our bereavement programs or for grief and loss support.

REMEMBRANCE PAGES: To share your story with others, we invite you to create a Remembrance Page through our website and to visit and sign the guestbooks of those who have shared their own.

ANGELS AMONG US: We produce a yearly electronic publication to remember and honor loved ones. If you would like to submit a letter, picture or other submission, we will collect these with membership renewals in January 2019.

BEREAVEMENT EXPENSE PROGRAM: This program began in early 2018 to provide financial assistance to support families with final expenses. This is a one-time grant offering up to \$500 per individual.

REMEMBRANCE COMMITTEE: A group of parents volunteer their time for monthly committee meetings to provide input on our bereavement programs and provide support to other families as needed. We appreciate their support and drive to demonstrate how crucial these programs are to the Society and how we seek to honor the memory of the loved ones in our community.

WHITE ROSE PROGRAM: When an individual with MPS or ML passes away, the National MPS Society provides support through the White Rose Program, sending flowers, cards and booklets and having a flag flown at our nation's Capitol in memory of the lost loved one.

Beginning in 2019, the Society will reach out to families who have lost a loved one from MPS or ML with card sentiments. Our goal will be to include future opportunities for families to engage beyond our CYCLE conferences if they choose.



TOP PHOTO: AVERY PIEFER

MIDDLE PHOTO: JASON MADISON (MPS II) WITH MOTHER SHARON

BOTTOM PHOTO: WHITE ROSE PROGRAM

PATHWAYS

It has been a long-standing dream of the National MPS Society's board of directors to provide support and resources to families whose children are newly diagnosed.

For so many, the heart-wrenching news that their precious child has MPS or ML leaves them feeling bewildered, hopeless and not knowing where to turn. In those moments, one desperately needs a reliable source for answers and reassurance that they will find their way through, and although life may never be the same, it can still be just as beautiful. The Pathways program is the National MPS Society's response to that critical unmet need. Pathways provides families with education and comprehensive support throughout the first year of diagnosis. Through innovative ways, we connect members with services, both locally and collectively. We equip and strengthen families to manage care and establish resources needed for the MPS and ML journey.



TRAVELING THE JOURNEY TOGETHER

The program began in 2017 when Coreen Gray, MSW, joined the Society staff as family support lead to implement the vision for Pathways. She began developing the program, reaching out and working with families whose children were newly diagnosed. In the beginning of 2018, the program was expanded to include Leslie Urdaneta, family support coordinator, to develop and formalize services offered. This year marks the first full year we have provided Pathways services to every family or individual in our membership experiencing a new diagnosis of MPS or ML. We have connected personally with 85 families all over the country through home or hospital visitation since the inception of Pathways. It has been an honor to join these families at such a tender and critical time and to be an ambassador of hope, a source of strength and ultimately to bring these families into the wider support of the entire MPS community. Pathways exists because we know this journey is so much better together.



LILAH MUELLER



SAWYER LAGARDE

THE BARBOUR FAMILY

After a long struggle with infertility, doctors informed John and Shantell Barbour that they had a one in five billion chance of ever conceiving, let alone carrying to full term. Brokenhearted, the couple let go of their precious dreams of family and tried to embrace a new vision. It was a complete shock when, seven years later, Shantell became pregnant. The couple was surprised and delighted, as was their extended family.



Seven months went by and everything seemed to be going wonderfully until the results of genetic testing came in—positive for Hunter syndrome. Shantell knew she was a carrier. She had a brother, Bradley, who was severely affected by MPS II and passed away at age 13. After so deeply desiring a child, thinking it would never happen and then having the delightful surprise pregnancy, the whole family was crushed to think that the fate of this unborn son would follow the same course as Shantell's brother.

Because all of the information they had was from the 1980s, John scoured the Internet for answers and hope, which is how he connected with the National MPS Society and the Pathways program. Their first conversation in January 2018 was a huge game changer for the Barbours. They felt hope for the first time since having received the terrible news of their son's diagnosis. They learned that the outcome for their son was likely to be much different than that of his uncle because of the medical advances, such as enzyme replacement therapy (ERT) with Elaprase®. The Society worked with John and Shantell to find a hospital near them with a genetics department and arranged for their son to begin treatment as soon as possible upon his birth.

Tanner Andrew Barbour soon arrived, and began ERT at OU Children's Hospital (Oklahoma City, OK) at age 3 months. The genetics doctor then referred the Barbours to consult with the bone marrow transplant (BMT) unit, where they met Dr. David Crawford, who felt strongly that he could improve the outcome for Tanner by doing a hematopoietic stem cell transplant. Data from a study in Japan, a good

donor match, a family history of neurological aspect of the disease, and the fact that their son would be receiving the intervention so young were all factors that influenced the Barbour's decision to move forward with the treatment. The process went very smoothly, and Tanner is now 100% engrafted and has hit the 100 day out from transplant milestone. His parents couldn't be more thrilled. John reports that even the medical professionals at OU Children's have been amazed by the positive results, and there is much hope that Tanner's long-term outcome has been greatly improved by this course of action. The Barbours know the fight isn't over and are in it for the long haul.

John and Shantell hope that their family's story can help someone else who is struggling with a recent diagnosis of their child and feeling overwhelmed with decisions to make. They want to be a sounding board for any parent out there, especially in the Midwest. John and Shantell are hopeful a cure will be found and feel that the BMT was the short-term treatment to help prolong Tanner's life until a cure is found.

**The National MPS Society
congratulates the Barbour family
on the birth of their beautiful baby
boy and hopes that their 2018 will
be the first of many wonderful
years together!**

By the time she was 3, Alexia Jade Rodriguez had very few words. A neighbor, who had a child with autism, suggested Alexia's parents, Dave and Janet, take her to see a pediatric developmental specialist. The developmental specialist referred Alexia to a pediatric neurologist. Without mentioning it aloud, the neurologist wrote in his report (which Janet didn't receive or read until much later) that he suspected Sanfilippo syndrome. Several indicators were cited, including results from an MRI and the fact that Alexia did not look like her brother. The family was referred to a geneticist who stated that Alexia didn't have the appearance of a child with Sanfilippo syndrome and diagnosed Alexia with autism. They continued seeing the developmental specialist and eventually started receiving occupational and speech therapy.

THE RODRIGUEZ FAMILY

Life moved along. Alexia started school and had some developmental gains, but still very few words. She loved to run and play with the other children. In second grade, Alexia began to regress and over the course of the next few years, her family noticed more and more issues that were not explained by autism. When Alexia's walking and balance became unstable, special boots were prescribed to help but caused terrible bruising. Her wrists were twisted up, making it difficult for her to use her hands. The little girl who had once loved puzzles now struggled to figure out where the pieces should go. Potty training was still an issue. One night, Janet went into Alexia's room to discover that she was having a mild seizure. Again, they sought help from a neurologist. This time a very extensive study was done that took many months. During multiple exams, the family was told Alexia would never talk again. This pronouncement broke their hearts and left them wondering, why? They were told of several conditions that Alexia didn't have.

After nine months, they received a call from a genetic counselor who told them that Alexia had Sanfilippo syndrome. Though the word "Sanfilippo" had plagued her mind over the years, Janet's response was denial due to the negative assessment of the disease when she was 3. The counselor explained that testing had actually never taken place at that time. Still, Janet needed something



more than a phone call. This news was unbelievable. Finally, she found a doctor in Boston who had seen other patients with Sanfilippo. More months went by until May of 2017 when, at the age of 10, the diagnosis of MPS IIIA was confirmed.

While it was a relief to finally understand what was causing Alexia's issues, the answer wasn't what the family had hoped for. In fact, that answer left them with an even bigger question—what could be done to help their precious daughter? The family still awaits an answer to that question. Shock, sadness, anger; they have been through every stage of the grieving process trying to come to terms with this diagnosis. Of course, they treasure each day with their precious angel of a daughter. She brings them immeasurable joy. One of Janet's most treasured memories happened when the family took a road trip to Myrtle Beach. Alexia knew it was a special time and ran and jumped on the hotel bed with such excitement. Alexia loves Dora the Explorer, riding in the

car, being outside, going on walks, to be read stories, back scratches, bear hugs and to play "rough" with her big brother David.

Janet says Alexia has been the best teacher she has ever had. Through Alexia, she has learned patience, awareness of differences and empathy. She has learned to understand her daughter without words. Dance class and equine therapy have been very special experiences for Alexia. She is somewhat of a celebrity in the small mountain town of New York where the family resides. Inspired in part by Alexia, a few family members are currently pursuing education in the medical field and may one day go on to make a difference in the world for children like Alexia. The Rodriguez family prays for a cure to be found in time for Alexia. They hope the pharmaceutical companies that are working on this will have mercy for older children and allow for compassionate use of the therapies that are showing positive results in clinical trials right now. Janet says, *"My daughter deserves a chance!"*



FUNDRAISING

Dare to be Different

NATIONAL MPS SOCIETY CELEBRATES

45th
ANNIVERSARY

Join us on May 18, 2019

THE MANSION ON O STREET

2020 O ST NW, WASHINGTON, DC 20036

6:00–11:00 PM

MPSSOCIETY.ORG/2019GALA





RISE UP FOR MPS

The Rise Up for MPS concert performed by Vocal Majority was held at the Midway Performing Arts Center in Hewitt, TX, this past April. The event was held in memory of Jenna Marie Richbourg, a beautiful young lady who suffered from MPS I, to raise funds for the Society's Family Support programs. The event had many touching moments during the performance. The song, "The Lord Bless You and Keep You" left the audience in tears. More than 700 people attended, including several MPS families.



2018 ANNUAL FUND CAMPAIGN

RAISES \$126,855 BY OCT. 30, 2018

The National MPS Society's Annual Fund is a valuable tool that helps to strengthen the vision, purpose and mission of the Society by committing resources to projects that provide direct benefit to members and their families. Your generosity will help fund programs such as conference scholarships, the Family Assistance Program, expanded publications resources and legislative initiatives.

Our Annual Fund chairs for 2018 are Steve and Amy Holland and our goal is \$210,000. Please help us reach this historical goal by sending in your donation today. Thank you to everyone who has already donated to the 2018 Annual Fund. With your ongoing support we can continue our very important work, supporting children and adults with MPS and ML and their families.

HUMANITARIAN \$5,000+

Wayne and Catherine Bardsley in memory of Jeff Bardsley

Marsha and Robert Bozarth in honor of Annabelle Bozarth

Bryson Foundation, Ltd.

Joe and Jan Melnyk in honor of Nick Melnyk

Sam and Nancy Ramsey

The James and Pamela Rogers Family Fund

PHILANTHROPIST \$1,000–\$4,999

Helen Allison in honor of Michelle Hopkins and the Holland family

Bill and Mary Andrews in honor of the Holland family

Dr. Mel and Millie Anhalt in memory of Connor Anhalt

Stephanie and Austin Bozarth in honor of Annabelle Bozarth

Chris Brodmerkel

Dwain Camp

Liam and Mary Cavanagh in honor of Scott Cavanagh

Steve and Amy Holland in honor of Maddie and Laynie Holland and in memory of Spencer Holland

Wendell and Karen Keith in memory of Amanda Keith

Kainani and Walter Kraut in memory of Jake Elston

Sandra Miller in honor of Jason Madison and Wayne Eppenhimer

John Nay in memory of Bernice Nay

Austin and Cheryl Noll in memory of Austin Noll IV

Austin and Dorothy Noll in memory of Austin Noll IV

George and Athena Sarantinos in honor of Luke Sarantinos

Adam Shaywitz

William and Margaret Sly

Steven Teitelbaum in honor of Michelle Hopkins

Herbert Tilsner in memory of Max Tilsner

Stuart and Judy Weiss

Russell Witt

Teresa and Alan Wulff in honor of Carter Korth

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Mary Starr Adams in memory of Paul Adams

Stuart and Karin Adams in memory of Paul Adams

Robert and Marjorie Austin in memory of Matthew Caldwell

Mark and Stephanie Caldwell in memory of Matthew Caldwell

Carey and Mary Crumling in honor of Christian Yard

Kathy and Paul Dobrowolski

Bart Finzel in honor of Mitchell Finzel

Joseph Gramble

Kevin and Susan Hanley in honor of Maria Ratto

Dr. Paul Harmatz

Larry and Susan Kirch in memory of Allison Kirch

Terri Klein and Michael Schleter in honor of Jenny Klein

Gene and Cynthia Logan

Marcia Mederos

Chris and Diane Meyerpeter

Sharon O'Connell

James Olson, DDS

David and Rose Pelton in honor of the Radius family

Annette and Larry Pung in memory of Austin Noll IV

Linda Quinlivan in memory of Austin Noll IV

Lynn Ann Sembach in memory of Kevin and Kyle Witt

Sheila and Michael Thornton in honor of John Thornton

Tanya and Gordy Wahl in memory of Zachary Wahl

Tom and Kim Whitecotton in honor of Scotty Whitecotton and in memory of Russell Forkas

Kevin and Peggy Yard in honor of Christian Yard

Kelly and Patricia Young in memory of Miles Young

VOLUNTEER \$250–\$499

Amy Barkley in honor of Davis Barkley

Dwight and Debbie Barkley in honor of Davis Barkley

Joel and Leeann Bernbaum in memory of Mark Bernbaum

Ross and Hilary Berning in honor of Colin Berning

Cheryl Bien in memory of Cecilia Rose Bien

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Dawn Brewer-Reilly in honor of Jack Todd

Kevin Cassil in memory of Matthew Cassil

Betsy Drew Imagine and Ken Imagine in honor of Kendra Gottsleben

Carla Ellard in honor of Karina Guajardo

Christine Ho in memory of Susannah White

Bob and Ginger Kell in honor of John Kell

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Benjamin and Elizabeth Neufeld

Brad Plantiko in honor of Lynn Hopkins

Antonietta and William Spacciapoli in memory of Christian Lon

Becky and Robert Tanamachi

Susan Taylor in memory of Olivia Lovell

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Joseph Vieira in memory of Kelley Crompton

Hubert and Elaine Willman

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 Sheldon and Jacqueline Friedman in honor of Spencer Friedman
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 Kevin Gates in honor of Spencer Gates
 Jayne Gershkovitz in honor of the Holland family and Barbara Wedahase
 John and Lynn Gladysz in memory of Danny Gniazdowski
 Betty Glock in honor of Travis Glock
 Melissa Green
 Natasha Hargrove in honor of the Holland family
 Johanna Harmeier in honor of Michelle Hopkins

Jeni Hasselbrack in honor of Erin Peters
 Andrea Haynes in honor of Erin Peters
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 Ardis Ketterer
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 Fred Koehler in memory of Ryan Mask
 Carol and Thomas Kuhn in honor of Michelle Hopkins
 David Lebec in honor of Michael Bodura
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 Lorraine MacMillan in honor of Zachary Haggett
 Jason Madison
 Barbara and George Malina in memory of Glen Malina
 Carolyn and Michael Managan in honor of Richy Hodgkins
 Clayton and Iva Martin in memory of Audrey Lawson

continued

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 William and Karen McNeil in memory of Waverly McNeil
 Mary Messick in memory of Russell and Alexandria Browne
 Edwina Meyers
 Charles Miller in memory of Austin Noll IV
 Eric and Amber Mongan in honor of Maura Mongan
 Judith Morales in memory of Melissa Santos
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 Cindy Preuss
 Sue Rattman in memory of Paul Rattman
 Bernard Ray
 Celeste and Stephen Raydo in honor of Christian Yard
 James and Janis Raynak
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 Chad Resner
 Carol Reynolds in honor of Michelle Hopkins
 Richard and Carol Riazzi in honor of Christian Yard
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 Stephen and Sara Smith in memory of William Peterson
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 Lewis and Pamela Waber
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 Joanna Janssen in honor of Olivia Lawson
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 Dorothy and Ralph Ostella in honor of Lucas Ostella
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 Teresa Peacock in honor of Lynn Peacock
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 Michael and Laurie Sparkman in honor of the Holland family
 Terri and Allen Thomalla in honor of Patrick James Hyland
 Brian and Chris Tippet in honor of Cooper Tippet
 Arleen Trioo in memory of J.R. Block
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 Gregory and Kristina Williams
 John and Gail Williams in honor of Allison Williams
 Charlotte Wilson in memory of Nathan Bivens
 Jan Wimberley in honor of Dr. Jerral Wimberley, D.C. and in memory of Jimmy Wimberley
 Bob and Kate Zimmerman in honor of Aidan Jack Carter

2018 FUNDRAISING EVENTS



AUSTIN NOLL AND TERRI KLEIN

QUARTER 1

The Knights of Pennsylvania Rotary Club Pig Roast in memory of Ryan Mask

Traveling Through Memories scrapbooking event, hosted by Michelle Dodson in memory of Rachel Dodson



KIMBER HEILING AND LILAH

QUARTER 2

Karina's Birthday Fundraiser hosted by Luis and Angela Guajardo in honor of Karina Guajardo

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

Case Junior High School's MPS Day Fundraiser in honor of Benjamin and Adam Podesky

Shirley and Peter Cino's Anniversary Fundraiser in honor of Jonathan Cino

Fort Recovery Elementary School's MPS Day Fundraiser in honor of Ava Kremer

Junior Woman's Club of Hilton Village annual fundraiser for Family Support programs

The Klenke Bowl, hosted by Kris and Brian Klenke in memory of Kraig Klenke, for Family Support programs

The Million Dollar Bike Ride at the University of Pennsylvania, for research

The Napa National Walk/Run hosted by the National MPS Society

Lisa Radcliff's classroom fundraiser in honor of Taylor Wojnarowski



Keith and Sherri Richbourg's Pizza Fundraiser in memory of Jenna Richbourg for Family Support programs

Rolling Meadows School's Volleyball Fundraiser in honor of Molly Birmingham

St. Paul's United Church Fundraiser in memory of Ryan Mask for MPS III research

Virginia Charity Tennis Tournament Fundraiser in honor of Annabelle Bozarth

Toss for Tony washer tournament hosted by Katie Willmann in memory of Tony Willmann

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

Volleyball Tournament and MPS Awareness Day Fundraiser hosted by Molly Birmingham

The 36th Masonic District of Pennsylvania Fundraiser hosted by Josh Nay in honor of Miriam Nay

Mel and Millie Anhalt's Anniversary Fundraiser in memory of Connor Anhalt and in honor of the Anhalt's anniversary

Sarah Van Orden's Fundraiser in honor of her 21st birthday

Houston's Kendra Scott Fundraiser, hosted by Trisha Jensen in honor of Sydnee Jensen

Annabelle Bozarth's Birthday Fundraiser hosted by Stephanie Bozarth in honor of Annabelle's special day, for MPS IV research

Cooper's Troopers BBQ Fundraiser hosted by Christine Tippet in honor of Cooper Tippet, for MPS IV research

QUARTER 3

San Diego National 5K Run and One-Mile Walk hosted in conjunction with the International MPS Symposium



LUKE DEVOLDER AND JACK BENNETT

QUARTER 4

Post Office Café Run hosted by Michael Lessing in memory of Mark and Casey Lessing, for MPS III research

Do it Fore Dan Golf Tournament hosted by Ray and Amy Miller in memory of Dan Miller, for MPS II research

Halk Fall Festival hosted by Carla Halk Crain in honor of Blake and Paige Halk

CaBi Clothing Fundraiser hosted by Lynn Hopkins in honor of Michelle Hopkins, for MPS I research

Sharing and Caring fundraiser hosted by the Holland family

Alamo Battle for MPS 5k

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2018 was an incredible year for MPS Society national walk/run events. More than 5,000 participants raised more than \$170,000.

ONCE UPON A TIME



“There is something so special about being able to be with each other in person. It’s something you just can’t get on Facebook.”

Rachel Wojnarowski

ANNUAL OHIO FAMILY GATHERING

Matt and Rachel Wojnarowski have been hosting regional events in Ohio for almost two decades. They started organizing this annual event before the advent of social media, when the only chance to meet and connect with other families was in person at these rare and precious gatherings. This event drew families from far and wide.

It was in 2003 when the Society’s president and CEO attended this gathering and, for the very first time, met other families affected by MPS and ML. Little did she know she was meeting the community she would spend the next decade and a half so fervently serving. This year’s event, “Once Upon a Time,” had a fairytale theme, boasted delicious food and included interactive games everyone could participate in. Several families in attendance had young adult children with MPS and have been attending this event yearly since the beginning. The National MPS Society is grateful for the efforts made by the Wojnarowskis and their team of volunteers to provide this special time for our families year after year.



POST OFFICE 5K

The Post Office Cafe raised a record \$38,000 for the National MPS Society on Oct. 20 in Babylon, NY. The amazing Lessing family raised money directly for the MPS Society in memory of Mark Jr. and Casey Lessing, both diagnosed with MPS IIIA.

MPS RACE FOR A CURE

The National MPS Society hosted its third annual MPS Race for a Cure 5K Run and One-Mile Memorial Walk on Sunday, April 29, in Napa, CA. The race was extremely well attended with more than 600 participants. Families and friends had a great time raising funds for the Society and catching up while enjoying the beautiful grounds of the Veterans Home of California.

This event continues to be a success year after year due to the generous time and support our race committee members provide. This year was no exception; families and local businesses organized an outstanding auction and raised more than \$60,000! A nice time was had by all with entertainment for the kids, live music and a post-run lunch.

More than 100 representatives from pharmaceutical industry sponsors made it a priority to attend the event this year; we are astonished by their dedication to the fight against MPS and ML. Because of their support, we have been able to consistently raise tens of thousands of dollars each year to fund research and family support programs.



SAN DIEGO SUPERHERO 5K

The San Diego Superhero 5K was held on Aug. 5 in San Diego, CA. This event included more than 350 attendees of the International Symposium, as well as supporters from the surrounding community. The weather was perfect, especially along the water at the Spanish Landing embankment. Superheroes, puppies and music created a fun and festive atmosphere, raising more than \$60,000 for research.



MORGANS WONDERLAND



TEXAS FAMILY GATHERING

Ten families, from long-time members to newly diagnosed, came together recently for a weekend of fun in Texas. They enjoyed a fun day at Morgan's Wonderland, an accessible park with rides for all ages and abilities. Lunch was provided with discounts and gift cards from Firehouse Subs, HEB and Costco, and park expenses were covered by the National MPS Society's regional social gathering grant.

The first annual Alamo Battle for MPS 5k was held the following day. There was a beautiful show of support from many families. Jason Munoz was remembered with 25 family members forming the Jason's Running Clowns team. Newly diagnosed with MPS III, Naveah Thompson had much support with her team, Naveah's Angels. Her team raised the most money and many family members traveled to support her, including her father who came all the way from Georgia! Anyssa Guajardo brought many friends to show support for her sister's team, Karina's Krew. In addition, family members attended in honor of Ricky Hodgkins, Cate Wong, and the late Alex Luna.

The route of the run included a circular drive that served as a memorial walk, so participants passed by photos and remembered individuals who have lost the fight to MPS and ML. Despite the cold weather—it was a fun, family event! Thanks to our sponsors: BioMarin, Sangamo, Sanofi-Genzyme, Shire, Strike; HEB, State Farm Agent Darren Featherstone, Costco and Bird Bakery.



TOP PHOTO: GUAJARDO AND WONG FAMILIES

MIDDLE PHOTO: ANGELA AND LUIS GUAJARDO AND DAWN RODRIGUEZ

BOTTOM PHOTO: CATE WONG AND ELLIE

MILLION DOLLAR BIKE RIDE



MIRIAM AND JOSH NAY

Once again, the National MPS Society was invited to participate in the Million Dollar Bike Ride in Philadelphia, PA. More than 20 riders joined Team MPS to support research for rare diseases with a large number in attendance from REGENXBIO, which provided a generous \$10,000 donation.

Through your support, we met the fundraising goal of \$100,000! The Penn Medicine Orphan Disease Center provided a \$50,000 match on top of the funds raised by members of the Society. Funds go directly to funding research to find treatments and cures for MPS and ML. Over the past four years, the Million Dollar Bike Ride has raised more than \$400,000.

We are thrilled to announce that Team MPS has been invited back to participate in 2019! Be on the lookout for more information and ways you can support research through this event. Visit www.MillionDollarBikeRide.org for more information.



DO IT FORE DAN

Amy and Ray Miller have been hosting events for the National MPS Society for almost 19 years. Their son Dan (MPS II) fought an incredible battle and touched many lives before he passed in January 2016. The Miller's started raising money for the National MPS Society with a run and have been hosting the Do It Fore Dan Golf Tournament for the last nine years. This year the event was held at the beautiful Moccasin Run Golf Course in Atglen, PA, on Oct. 5 and raised a record \$17,702.

Upon meeting the Millers, you are immediately part of the family—no handshakes, just hugs. From the estimated 100 golfers to the dozens of volunteers, everyone has a hand in making this a successful, fun day. Ray's work team, all of whom have been with him for more than 20 years, is invested in raising funds for the National MPS Society and our mission and wouldn't miss this event. In addition to golf, the event includes a raffle auction of themed baskets, which are stuffed with incredible treats donated by schools, companies and friends. The golf tournament concludes with a banquet of delicious food and desserts. This community of friends and family come together with incredible love for the Miller's to fight for a cure.



MPS SHARING & CARING



The Holland family and friends hosted their annual MPS Sharing & Caring fundraiser the weekend before Thanksgiving raising an incredible \$22,000. Every year, more than 50 high-end specialty baked goods are donated for silent and live auctions and beautifully wrapped by a team of volunteers to make ready for holiday entertaining. Cook Children's Home Health sponsors a complimentary meal from Panera Bread to share with about 150 family and friends as they bid on auction items, obtain holiday ornaments created by Madison and Laynie Holland, purchase handcrafted centerpieces, participate in a cake walk for kids, or just share their love with the Holland family.

"Hosting a fundraiser is our way of giving back to the Society, an organization that has supported our family during every step of our MPS journey. Each year, our fundraiser is just what our hearts need. Every MPS family should experience the feeling of having a room full of family, friends, and community members rain down love and support. We consider this to be an amazing blessing and a visible display of God's goodness and love working in others. We have hosted annual fundraisers for the last 18 years, first as walk/runs and now as holiday events, and have already started planning next year's event!"

Steve and Amy Holland



VOLUNTEER OPPORTUNITIES

The National MPS Society is seeking volunteers to help facilitate events in 2019. We are primarily looking for volunteers to assist with the following:

- national walk/runs
- family fundraisers
- Washington, DC gala
- serving on an established committee
- Disney conference
 - childcare
 - general conference volunteers

If you are interested in volunteering at an event or joining a committee, email Katelyn Blackman at katelyn@mpsociety.org.

2018 FACEBOOK FUNDRAISERS

Dwaa Al	Tela Clancy	Dewayne Green	Brenna King	Kathryn Murphy	Julien Tom Simo
Bob Allen	Vicki Clayton	Monica Green	Zach Kramer	Aysia Nguyen	Julie Simpson
Mitch Andreotta	Alayna Coates	Andrea Gribble	Susan Elizabeth	Ursula Nicole	Niki Dale Simpson
Betty Arceneaux	Carla Halk Crain	Holliman	Ladewig	Roslynn Offutt Garvin	Melissa Skelton
Emma Armato	Ashely Crist	Cate Griffith	Tiffany Strickland Lala	Katie Orr	Dana Stapley
Aleta Bart	Jason Cullere	Megan Griffiths	Matthew Lemke	Stacey Pevler	Dianne Stefanic
Maurizio Bellassi	Karen Cutrer	Bethany Hampton	Michael Lewis	Angelica Prater	Williams
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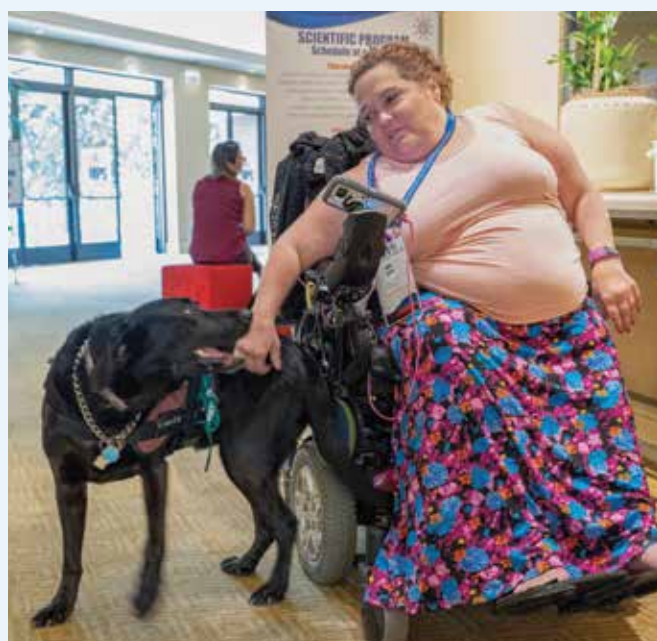
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For information on the upcoming 2019 CYCLE conference in Orlando, visit <https://mpssociety.org/2019cycle>

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SINCERE THANKS



Kim Whitecotton, vice chair, board of directors, ends her term serving the National MPS Society this year. For nine years Kim's leadership has guided the Society to improve greatly, and by chairing the Education and Publicity Committee, she drove key initiatives that personally encouraged and supported families and industry partners.

Kim's "jump in and get things done" attitude provided extensive support during our hectic and exciting family conferences, national walk/runs and regional family gatherings. Her time advocating on Capitol Hill and championing for rare disease advocacy has been a priceless addition to our community.

Kim fostered a key relationship with Congressman Denham and helped him understand the priorities of the MPS community. Denham's support was not only critical for Kim's son Scotty, but also incredibly important for the Society and its members. These accomplishments were only a few of the reasons why Kim was recognized with the Outstanding Membership Award during her tenure.

Out of all the amazing achievements during her time with the Society, by far the most meaningful was watching Kim engage with families at all of our events. Her warm and inviting charisma made it easy to see her priorities were always with Scotty and the rest of our MPS families. Thank you Kim! And thank you Tom and Scotty for sharing your wife and mother with us for so many years.



MPSSOCIETY.ORG/SHOP

There are many ways to support the National MPS Society. From walk/runs, to donations, to auctions, there are many ways to advocate for families and find a cure. By purchasing and wearing logo gear from **MPSSociety.org/shop** you not only support the mission, but also spread awareness. Stay tuned in 2019 as we expand our selection of products.



RESEARCH



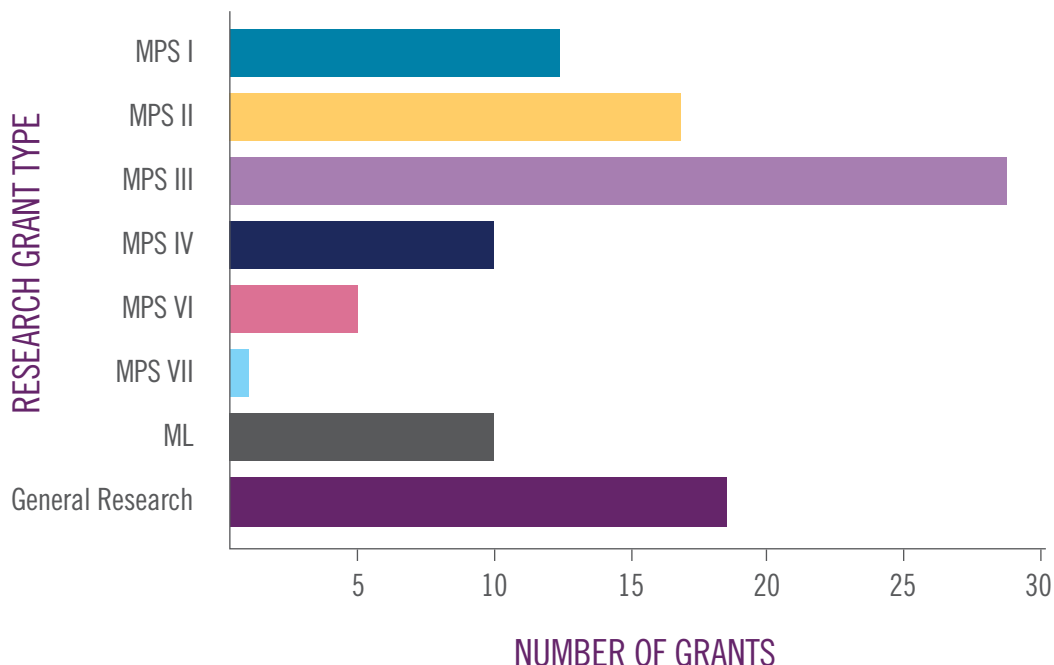
Thank You TO OUR SCIENTIFIC ADVISORY BOARD

In 2018, we awarded \$550,500 through our research grants program. The Scientific Advisory Board (SAB) works with the National MPS Society to ensure that peer-reviewed research is a component of our final decisions. The SAB provides valuable contributions for our program and our families; its research accomplishments have greatly improved the quality of life for all.

In addition, in 2018, Dr. Patricia Dickson dedicated many hours as one of our scientific chairs, along with Dr. Lorne Clarke and Dr. Brian Bigger, at the 2018 International MPS Symposium. Their generous gifts of time and advice for the National MPS Society and presence at the symposium illustrate their dedication to the world of MPS and ML.

Thank you to the members of the SAB for your continued support of finding therapies and cures for our children suffering from these diseases.

NUMBER OF RESEARCH GRANTS ISSUED SINCE 2001



2018 RESEARCH GRANTS

Thanks to your hard work and support, the National MPS Society is thrilled to announce the investment of \$450,000 in new research grants through its annual research program. **This year, the Society will fund a total of \$550,500, which includes grants for both 2018 and the second-year distribution of 2017 grants.** Therapies and cures will be discovered because of research programs like this.

In April, the board of directors announced the availability of grants for MPS I, MPS III, MPS IV and general research (open for all MPS and ML syndromes). Following a review of 32 letters of intent, our Scientific Advisory Board reviewed requested proposals and recommended funding the following projects as the best research presented in each category.

Research selected includes syndromes in desperate need of funding. In 2018, Sanfilippo research will receive \$320,000 and Mucopolidosis will receive \$90,000. In addition, gene therapy discoveries will highlight MPS IV, and critical safety studies for MPS I cornea gene therapy will occur.

The National MPS Society's professionally run and peer-reviewed research program continues to be recognized as a major global funder of research, a supporter of young researchers and a collaborative effort with the National Institutes of Health, family foundations, research institutions and charities in the United States and globally.

We extend a huge THANK YOU to our contributors and all the researchers who continue to fight for our children. We look forward to soon announcing research projects funded by the \$100,000 raised in partnership with the University of Pennsylvania through the Million Dollar Bike Ride.

TWO-YEAR GRANTS

\$90,000 general grant

Dr. Heather Flanagan-Steet
**Greenwood Genetic Center
Greenwood, SC**

"Cysteine Cathepsins as Therapeutic Targets in Mucopolidosis II"

\$90,000 general grant

Dr. Kim Hemsley
**SAHMRI
Adelaide, Australia**

"A Window to the Sanfillipo Brain: Visualizing Experience-Dependent Plasticity in MPS IIIA Mice"

\$75,000 MPS IV grant

Dr. Kazuki Sawamoto
**Nemours Biomedical Research,
Alfred I. duPont Hospital
Wilmington, DE**

"Substrate Degradation Enzyme Therapy for MPS IVA"

\$60,000 MPS III grant

Dr. Laura Hewson
**University of Australia
Adelaide, Australia**
"Purine Metabolic Enzymes as Therapeutic Targets in Sanfillippo Syndrome"

ONE-YEAR GRANTS

\$30,000 MPS I grant

Dr. Timothy Wood
**Greenwood Genetic Center
Greenwood, SC**

"Functional Analyses of IDUA Sequence Variants – MPS I"

\$30,000 MPS I grant

Dr. Brian Gilger
**NC State University
Raleigh, NC**
"Safety Studies for Corneal AAV-IDUA Gene Therapy to Reverse Corneal Blindness in MPS I"

\$25,000 Multi-syndrome

**Lysosomal Disease Network
University of Minnesota**
Neuroimaging Core NIH Project

Mepsevii Approved as FIRST MPS VII TREATMENT

Mepsevii™ was approved by the FDA as the first treatment for pediatric and adult patients with MPS VII in November of 2017. Prior to the approval, patients with MPS VII did not have viable therapies. It is another milestone for MPS families as Ultragenyx has successfully brought Mepsevii to our patient community.



HOLLAND FAMILY WITH DR. PAUL HARMATZ AND TERRI KLEIN



RYAN DANT, SILVIA RAMIREZ, MADDIE AND LAYNIE HOLLAND

The FDA granted Fast Track designation for Mepsevii, which facilitates the development and expedites the review of drugs to treat serious conditions to fill an unmet medical need. Ultragenyx also received Orphan Drug designation for Mepsevii, which provides incentives to assist and encourage the development of drugs for rare diseases. In addition, they received a Rare Pediatric Disease Priority Review Voucher under a program intended to encourage development of new drugs and biologics for the prevention and treatment of rare diseases. This was the 12th rare pediatric disease priority voucher issued by the FDA since the program started.

MPS VII is an inherited, rare genetic condition that impacts less than 150 patients worldwide. The features of MPS VII vary widely from patient to patient, but most patients have various skeletal abnormalities that become more pronounced with age, including short stature. Affected

individuals also can develop heart valve abnormalities, enlarged liver and spleen and narrowed airways, which can lead to lung infections and trouble breathing. The life expectancy of individuals with MPS VII depends on the severity of symptoms. Some affected individuals do not survive infancy, while others may live into adolescence or adulthood. Heart disease and airway obstruction are major causes of death in people with MPS VII. Affected individuals may have developmental delay and progressive intellectual disability.

In April of 2018, Ultragenyx hosted the “From Possibility to Reality” approval party for key stakeholders. Families, researchers and patient advocacy groups attended this significant event, marking this milestone for patients with MPS VII.

LEGISLATIVE

Speakers Bureau

In February, the National MPS Society had the opportunity to host families and individuals with MPS and ML through our Speakers Bureau program. Fourteen families participated, along with the board of directors and staff. Participants received training on telling their stories and sharing information and learned about the advocacy efforts of the Society, readying them for visits on Capitol Hill. On Feb. 26 and 27, participants met with representatives and senators from across the United States to share their personal experiences and to advocate for legislation to support MPS and ML. Key topics for the 2018 legislative sessions were:

- requesting support for the OPEN ACT (Orphan Product Extensions Now Accelerating Cures and Treatments)
- including MPS and ML specific appropriations language in funding requests
- invitations to join the Rare Diseases Congressional Caucus

Feedback from Speakers Bureau participants was positive and visits were well-received to kick off a successful week of advocacy for Rare Disease Week!

"I am very appreciative of the training provided by the National Organization for Rare Disorders and the MPS Society Advocacy Committee before my meetings. It made me familiar with the content of our asks and confident in telling my personal story. It empowered me and made for successful conversations with my legislators. I feel like I'm making a difference for our MPS families."

Speakers Bureau participant



GROUP PHOTO: WASHINGTON, DC SPEAKERS BUREAU
OTHER PHOTOS (CLOCKWISE FROM TOP LEFT): CHRISTOPHER HOHN;
FLORA HOLM; ALLISON WILLIAMS AND SAM CASWELL; LAYNIE AND AMY
HOLLAND; ANGELA GUAJARDO, CHRIS TIPPETT, LYNN HOPKINS, LUIS
GUAJARDO; KRIS AND CHELSEY KLENKE



FDA MEETING

In October, the National MPS Society visited the FDA offices of Patient Affairs Staff, Center for Biologics Evaluation and Research and Center for Drug Evaluation and Research, to discuss historical and current climate for MPS III and Sanfilippo syndrome U.S. patient population demographics. Building bridges and proactive networks is critical for rare disease research. MPS Society President and CEO Terri Klein; Mark Dant, chair of the EveryLife Foundation and The Ryan Foundation; and Carl Kapes, Team Sanfilippo, discussed Sanfilippo syndrome and pending efforts in our country regarding research and expanded access as it relates to rare diseases.

The meeting addressed clinical trial climates in the United States, expanded access, clinical trial endpoints, quality of life impact for rare diseases and clinical trial escalation timelines. We are proud to partner with dedicated parents, patients and foundations to realize necessary change.



2018 LEGISLATIVE WEBINARS

- MPS Advocacy—Preparation for Meeting with Your Legislator
- How to Tell Your Personal Story
- Letters to the Editor and Social Media Advocacy
- Finding, Meeting and Cultivating a Relationship with Your Lawmaker
- Influence and Access: Understanding the Legislative Process as an Advocate

Stay tuned for webinars that will be held in 2019.



INTERNATIONAL MPS NETWORK

The International MPS Network met in San Diego, CA, during the 15th International Symposium on MPS and Related Diseases. For two days the network discussed global issues addressing patients and various countries. At the end of the meeting, the network decided to create the first board of directors.

Co-chairs include Terri Klein, president and CEO of the National MPS Society, and Bob Stephens, group executive of the U.K. MPS Society. The new board will have a total of seven members.



TERRI KLEIN WITH THE YASH GHANTI FOUNDATION AT GLOBAL GENES



TERRI KLEIN ATTENDED THE PATIENT ADVOCACY SUMMIT PRESENTED BY NORD IN WASHINGTON, DC

RESOURCES

Sanofi Genzyme Support Services for Patients and Families through CareConnectPSS™ Program

www.careconnectpss.com

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

Frank Mobility Systems

www.FrankMobility.com

Wheelchairs differ in many ways. Some are made for persons in need of intensive care, some are designed for very active persons using the wheelchair all day long. In order to cover the individual needs of wheelchair occupants, Frank Mobility Systems, Inc. offers a variety of add-on drives and portable wheelchair motors that enhance the benefits of a manual wheelchair. All of these power add-on drives can be retrofitted to an existing wheelchair with a special bracket. The wheelchair does not need to be modified and maintains its characteristics such as portability.

Frank Mobility also offers solutions for climbing stairs without renovations being made to the home, and recreational products such as the Duet Wheelchair Bicycle Tandem.

College Resources for Students with Disabilities

www.bestcolleges.com/resources/disabled-students

Prospective college students with disabilities find that many campuses are equipped with offices and services that address accessibility, accommodation and assistive technology for a diverse range of needs. Student services offices and disability coordinators at many colleges work to make campuses inclusive environments through specialized advocacy, support and academic services.

The increased visibility of these resources makes college a very compelling option for people with disabilities. In addition to campus-based resources, students with disabilities also are protected by state, federal and local laws prohibiting discrimination and requiring equal levels of access to academic services, environments and resources. This guide explains the legal rights of students with disabilities—both physical and learning—and the campus resources that can provide assistive services and tools. Additionally, a number of sites, apps and software resources are listed that are designed to aid students with specific types of disabilities, be they physical impairments or learning disabilities.

Wrightslaw

www.wrightslaw.com

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

Shire OnePath®

www.onepath.com

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

Ultragenyx UltraCare Program

www.ultracaresupport.com

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

SHELBY LYON AND OWEN GROESCH



RESOURCES

MPS I Website

www.MPSIdisease.com

This website developed by Genzyme provides parents and patients with information and resources on MPS I. This site provides valuable information on the disease, diagnosis, on-going clinical trials, and other references and services available to patients.

Access to information is critical for providing the best care for patients with MPS I. However, information on the disease is limited because of its rarity. A resource developed by Genzyme is now available for physicians and healthcare professionals that is dedicated to improving the understanding of MPS I. With the MPS I Registry, your physician can access your data and compare it to aggregate data from around the world. Ask your physician to call 1.800.745.4447, ext. 17021. Additional information also is available at MPSIdisease.com.

Aldurazyme® Website

www.Aldurazyme.com

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

National Family Caregivers Association

www.caregiveraction.org

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

Hearing Aid Funding Assistance

www.sertoma.org

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

www.starkeyhearingfoundation.org

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

Legal and Assistive Technology Funding Assistance

www.nls.org

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



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

Electric Scooters for Little People

<http://adaptiveliving.com>

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

Transitioning to Adulthood

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

For more information, check out these transition resources:

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

HealthTalker—An MPS II Online Community

www.HunterPatients.com

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



RESOURCES



FELIX AND HIS DAD

MPS IVA Websites

www.morquiosity.com

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

morquioanswers.com

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

NAGLAZYME.com

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

Resources for Siblings

<http://siblingleadership.org>

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

www.siblingsupport.org

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

www.theblairconnection.org

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

www.siblingswithamission.org

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

Furniture for Little People

www.lpbigdesign.com

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

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

Parent Educational Advocacy Training Center

www.peatc.org

The Parent Educational Advocacy Training Center (PEATC) serves families and professionals of children with disabilities in the Commonwealth of Virginia. PEATC promotes respectful, collaborative partnerships between parents, schools, professionals and the community that increase the possibilities of success for children with disabilities.

PEATC's mission is to build positive futures for Virginia's children by working collaboratively with families, schools and communities in order to improve opportunities for excellence in education and success in school and community life.

A Workbook for Youth with Disabilities

www.ncwd-youth.info/publications/the-411-on-disability-disclosure-a-workbook-for-youth-with-disabilities/

A Workbook for Youth with Disabilities is designed for youth and adults to learn about disability disclosure. This workbook helps young people make informed decisions about whether or not to disclose their disability and understand how the decision may impact their education, employment and social lives. Based on the premise that disclosure is a very personal decision, the workbook helps young people think about and practice disclosing their disability.

Bereavement Resources

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

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

<https://courageousparentsnetwork.org> was created for and by parents, and provides support, information, and knowledge bases around issues of parenting and caring for children with illnesses, as well as bereavement and loss support.

NeedyMeds

www.needymeds.com

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

Miracle Flights

<http://miracleflights.org>

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



TERRI AND JENNI KLEIN AND SHERRI WISE WITH A QUILT FOR AUCTION CREATED BY MPS AND ML ADULTS

MPS CLASSIFICATIONS

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

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

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

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