



Pathways program delivers support to newly diagnosed

In mid 2017, the National MPS Society launched a new family outreach program called Pathways. Pathways offers emotional, spiritual and practical support, as well as education and resources to newly diagnosed families. During the last half of 2017, 17 families received home visits by Family Support Lead Coreen Gray, and six additional families have received visits so far this year. A second staff member, Leslie Urdaneta, recently joined the Pathways team to support more families in the coming months and years. For more information, contact [Coreen Gray](#).



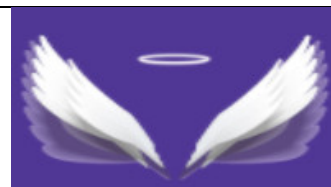
A Pathways Story

Tracy Greenberg's journey to diagnosis was a 40-plus year sojourn of doctor visits and speculation. But what a trip it's been for this 42-year-old singer-songwriter from Cleveland, who has overcome her limitations and enjoys a successful music career in a city known for the Rock n' Roll Hall of Fame.

For Tracy Marie, her stage name, Morquio has been a part of her life and, surprisingly, a guiding force behind her music for many years. Recalling days in school when others picked on her for a limp, Tracy says all that changed when her peers found out she could sing.

"After my classmates heard me sing, they treated me like a rock star," she said. "They said 'I heard you could sing,' and I got some positive feedback."

In her teen years, she started writing songs and working on playing guitar. As she got older, she played a few gigs at coffeehouses and had some major karaoke moments, but her big break came by accident. At a



In Memoriam

We remember those we've lost recently.

Kevin Carter

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Launch of the Bereavement Expense Program

The National MPS Society seeks to provide support to families throughout their MPS and ML journey. As part of this support, the Family Support Committee officially announces the launch of the Bereavement Expense Program. This program will provide financial assistance through a one-time grant up to \$500, issued directly to a

club, a rock band was playing Deee-Lite. The band asked the audience 'who wants to come sing?'

"The guy handed me the microphone, and I just started singing 'Groove is in the Heart,' " she said. After her impromptu performance, the band member sought her out, thinking she was a plant in the audience. He wanted to record the band's version of the song with Tracy on lead vocals.

"My first studio experience was recording that song," she said. She continued her music career, recording albums of songs that ran the musical gamut — everything from rock songs to country ballads. But performances were difficult for her. Standing and playing guitar was difficult. Her hands would ache. And being unable to perform was simply unacceptable.

After years of being told she had skeletal dysplasia, Tracy had her doubts. There were things that didn't add up — eye issues, problems with tooth enamel and six hip replacement surgeries. Tracy asked her doctor to do a workup on her. "I wanted to know what I had," she said.

The diagnosis from Akron Children's Hospital confirmed what Tracy's research and suspicions had indicated — Morquio A. "I was crying. I was happy," she said of the diagnosis. On that same day in October, 2017, Tracy started a [blog](#) on Facebook to help other people in the same situation.

"There's someone else out there who will get diagnosed late in life and need this," she said. And she was right. One woman has been in touch with her through her blog and suspects Morquio. She's currently awaiting the results of her own genetic tests.

And even with the limitations that come with Morquio, Tracy says it isn't something that holds her back.

"A lot of people who have Morquio are creative in artistic ways," she said. "You might feel like 'what can I contribute?' Music is healing, and so is art, and if you're able to contribute or enjoy that, art and music are definitely a medicine."

www.tracymarie.com
[Morquio A Diagnosis blog](#)



funeral home or other professional service provider associated with final expenses.

Please [visit our website](#) or [contact our Family Program Coordinator](#) for more information.



Dates to remember

Feb. 25-26

Advocacy Days on Capitol Hill

Feb. 28

Rare Disease Day

March 17

[Rise Up for MPS](#). Proceeds from the event will benefit the Society's [Jenna Marie Richbourg Endowment](#) and family support programs.

April 29

[MPS Race for the Cure Napa 5K Walk/Run](#)

May 15

MPS Awareness Day

May 20

[Million Dollar Bike Ride](#)

Aug. 2-4

[15th International MPS Symposium](#)

Oct. 8

[Jeff Bardsley Golf Classic](#)

Join Team MPS

Team MPS

spotlight

WORLD Updates – We're Organizing Research on Lysosomal Diseases Symposium 2018

Recently, Society representatives attended the 14th Annual WORLD Symposium, (We're Organizing Research on Lysosomal Diseases) in San Diego, CA. In attendance were our Board Advocates, Stephanie Bozarth, Lisa Todd, Steve Holland and Lynn Hopkins as well as staff members Terri Klein (President and CEO) and Coreen Gray (Family Support Lead). The Symposium hosted almost 2,000 stakeholders, including Patient Advocacy Leaders, Researchers, Clinicians, Industry and most importantly Patients.

The goal of the WORLD Symposium is to provide an interdisciplinary forum to explore and discuss specific research and clinical applicability related to lysosomal diseases. Each year, WORLD hosts a scientific meeting, designed to help researchers and clinicians better manage and understand diagnostic options for patients with lysosomal diseases; identify areas requiring additional basic and clinical research, public policy and regulatory attention; and identify the latest findings in the natural history of the lysosomal diseases.



Along with presenting the latest information from basic science, translational research, and clinical trials for lysosomal diseases, WORLD has two additional meetings COPA (Council of Patient Advocates) and CORE (Council of Research Experts). COPA provides a platform for patient advocacy groups in lysosomal diseases to participate in round table discussions and carve out unmet needs in the rare disease landscape. The end goal is to determine if a research grant is possible. Topics included newborn screening barriers, patient advocacy roles in clinical trial designs surrounding endpoints, triaging psychological issues with progressive diseases and more. This provides an opportunity for patient advocacy groups to network on a global level and have input into the LDN grant submitted in the coming months.

The National MPS Society was invited to participate in CORE this year. CORE provides an opportunity for Researchers to pitch their research projects in front of participants in CORE for the LDN (Lysosomal Disease Network). Leaders in the Lysosomal Diseases review the grants and disseminate feedback back to private investigators on the overall proposal. Eventually five grants will be included in the LDN submission.



Ride with Team MPS at the Million Dollar Bike Ride

Team MPS will be participating in the Million Dollar Bike Ride hosted by Penn Medicine Orphan Disease Center. This event is critical for funding research for MPS and ML, and we need your support. Whether you come to Philadelphia and ride as part of the team or make a donation towards our \$50,000 goal, we are counting on you!

Every dollar we raise is matched up to \$50,000! Please help us double our donations by spreading this exciting opportunity to your friends and family on Facebook and Twitter.

@milliondollarbikeride @MDBRide4Rare

Sunday, May 20, 2018

Philadelphia, PA

www.milliondollarbikeride.org

Help us reach our goal!

WORLD provides one of the best opportunities for the Society to meet with many of our stakeholders discussing the current drug emerging trends for drug development, clinical trials and therapies and discuss future initiatives we can partner in the upcoming year.

The 2019 WORLD symposium will be held in Orlando, Florida on February 4-8, 2019. Everyone is encouraged to make plans to attend.



Sobi MPS III drug gets Fast Track status with FDA

The U.S. Food and Drug Administration has accepted Sobi's investigational new drug (IND) application for the drug candidate SOBI003. In addition, SOBI003 was granted Fast Track status by the FDA. SOBI003 is a chemically modified human recombinant sulfamidase for the treatment of MPS IIIA. [More information](#)

ArmaGen to start Phase III clinical trial for MPS I drug

ArmaGen's recent Phase 2 proof-of-concept study results will lead to a controlled phase 3 clinical trial to examine long term impact in cognition in MPS I patients with CNS involvement. The results show that the drug can provide therapeutic benefit to patients and suggest that AGT-181 stabilized the neurocognitive development quotient (DQ) in patients with severe cases of the lysosomal storage disorder.

[More information](#)

BioMarin study reports on MPS IIIB data

BioMarin has completed the first part of a study into BMN 250, an ERT for MPS IIIB. The company has completed dose escalation portion of the study – three patients received escalating doses (30mg, 100mg, 300mg) of BMN 250 over 9-12 months. This determined drug efficacy and safety. Part 2 will roll over patients from an observational study and administer the 300mg dose to them.

[More information](#)

Lysogene moves forward on MPS IIIA study; looks to clinical trials

Lysogene received a positive opinion from the Pediatric Committee (PDCO) of the European Medicines Agency (EMA) for LYS-SAF302, an MPS IIIA drug. Regulations require a positive opinion before new drugs can be sold, and the approval confirms the appropriate design of Lysogene's phase 3, single



Scientific abstracts due

Abstracts for the 15th International Symposium on MPS and Related Diseases are now being accepted until March 4. To submit your abstract, please [click here](#). To encourage presentation of new data, all abstracts will be compiled into a conference proceedings abstract book but will not be published. The submitting author will be notified of the outcome by April 11 via email. For more information, visit www.MPS2018.com, or email [Chantal Smith](#).

[Submit Abstracts](#)

Conference scholarships available

National MPS Society members can [apply for scholarships](#) to attend the International Symposium in San Diego, CA. These scholarships can assist with travel and hotel reimbursement for parents and families of children with MPS or ML or for an adult diagnosed with MPS or ML and a caregiver. Preference is given to families attending a conference for the first time, but everyone interested is encouraged to apply.

arm clinical trial in children with MPS IIIA. In a completed Phase 1-2 clinical trial in children with MPS IIIA, Lysogene's first generation gene therapy, LYS-SAF301, exhibited a favorable safety profile over five years, and encouraging efficacy data. [More information](#)

Abeona reports on MPS IIIB gene therapy clinical trial

Abeona Therapeutics announced that the first patient treated with ABO-101, a therapy for MPS IIIB, has demonstrated that the AAV gene transfer is well-tolerated. Abeona plans to enroll a total of three patients in cohort 1 before dose-escalating to the cohort 2 dose.

[More information](#)



Cooper is very active 5-year-old with MPS IVA from Littleton, CO. who thoroughly enjoys watching and cheering on the Denver Broncos, Colorado Avalanche, Colorado Rockies and the University of Denver Men's hockey teams. He brings footballs, baseball mitts and even hockey equipment to infusion days at the hospital to help pass the time. The Child Life staff at Children's Hospital Colorado chose Cooper to be the recipient of Denver Broncos tickets that were anonymously donated in December. Cooper was thrilled to bring his family to the December 31st game against the Kansas City Chiefs - Cooper's 1st Broncos game! Reportedly, it was the 5th coldest game to be held at Mile High, with game time temperatures hovering around 11 degrees. But

This year, we are able to offer some exciting new activities and programs, including:

- Trip to the San Diego Zoo
- Entertainment opportunities at Camp Courage
- Adults with MPS and ML cruise

The deadline to apply for conference scholarships is March 22, 2018. Contact Family Program Coordinator Leslie Urdaneta at leslie@mpssociety.org or 919-806-0101.

[Apply Now](#)

Register now for #MPS2018!

The 15th International Symposium on MPS and Related Diseases in San Diego, CA will also serve as our annual family conference featuring everything from workshops geared toward best practices in MPS care to the latest advances in research from around the globe. The symposium will feature scientific and family focused tracks to meet the needs of all attendees. Click [here](#) to visit the symposium website, register to attend or submit a scientific abstract.

[Register](#)

you wouldn't have known it, judging from the look on Cooper's face, and his constant cheering. Local Children's Hospitals around the country are more than happy to accept in-kind donations such as event tickets, sports memorabilia and legos. The staff will gift the items to a child in need, and make their day!



Annual Fund Campaign Raises \$175,482

2017 has been a terrific year for the 16th Annual Fund! We reached another new record of total donors from our families and friends giving to the National MPS Society. This critical funding stream keeps the organization strong so that we can continue serving you. Through your tremendous support, you have shown you understand the needs of our families and those affected by MPS and ML. Your gift will provide necessary operating funds, support to families through the family assistance program and crucial funding for federal advocacy initiatives.



Once again the board of directors reached out to steward our Society membership and friends with phone calls. We are so encouraged by the conversations we had with all of you. It was a terrific opportunity to say hello and thank you for supporting our efforts over the years.

A special thanks to our 2017 Annual Fund co-chairs Luis and Angela Guajardo with their daughter Anyssa. They shared their family story of coping with the diagnosis of MPS IIIA as Karina, their daughter and sister, has celebrated her 26th birthday and still teaches them lessons every day. They shared how they found the strength to care for Karina, in part, by the support of the National MPS Society.

We want to thank you for keeping the National MPS Society as a part of your giving priorities. For everyone who believed in our



We are grateful to our donors. Thank you to all who made contributions!

[Donor List](#)

Patient Day in California

Ultragenyx is holding Patient Day to honor patients with rare diseases. The event will include a "Super Hero" themed day of live music, food, games, and refreshments with opportunities to meet people dedicated to working on rare disease treatments. Children are encouraged to attend with their parents!

[Register here](#)

mission and donated to the Annual Fund in 2017, we give our sincerest thanks!

We are so grateful to our 2017 Annual Fund donors for their generosity.

[2017 Annual Fund Donors.](#)

Donate



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We want to hear from you!

Please let us know what stories and information you'd like to see in future editions of Courage. Click [here](#) to send story ideas or submissions.

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Cross Creek Charity Golf Tournament, hosted by William Bagwell, in honor of Julia Casey Gray – MPS III Research.

Do it for Dan Golf Tournament, hosted by Ray and Amy Miller, in memory of Dan Miller – MPS II Research.

Greeting Card Fundraiser, hosted by Allison Williams – General Research.

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

Jingle Bell Run, in memory of Kimberly Fowler.

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

National MPS Society Walk/Run in Raleigh, NC

Pig Roast, hosted by the Knights of PA Rotary Club, in memory of Ryan Mask.

Post Office Café Run, hosted by Mark Lessing, in memory of Casey Lessing and Mark Lessing Jr – MPS III Research.

Scotty Whitecotton's Birthday Fundraiser, hosted by Tom and Kim Whitecotton, in honor of Scotty Whitecotton – MPS II Research.

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Raymond and Julia O'Hara in memory of Kristofer Arnold	Maurice and Christina Sciammas in memory of Shannon Tootill	Daniel Weiss in honor of Bethany Gamache
Mary Anne Oliger	Seymour Pediatrics	Joan Werner in memory of Mark Bernbaum
Steve O'Malley and Paula Manor in memory of Allison Kirch	Greg Sharrits in memory of Edie Burke	Sue Wharton in honor of Analynn Hughes
Sylvia Opsahl in honor of Cooper Tippet	Sean Shockley in honor of Michelle Hopkins	Sara and Thomas White in honor of Liam Denneen
Eileen and Larry O'Steen in memory of Ryan P. O'Steen	Anne Marie Siudzinski in honor of Michael Lewandowski	Michael and Amy White in honor of Jennifer and Savannah Prince
Dorothy and Ralph Ostella in honor of	Jackie and Joan Skinner in memory of Tucker Lanier	

Jack and Betty Willer in honor of
Taylor Wojnarowski

Cory and Janice Williams in honor of
Alex Fair

Sheila Wilson

John H. Wolfe

Jimmy and Susan Workman

Dennis and Mary Worwa in honor of
John Kell

Judy and Mansour Yamin in memory
of Logan Locascio

Ray and Priscilla Zechender in
memory of Michael Zechender

Marilyn Zeidner in honor of Tracy
Marie Greenberg

Andrew and Louise Zygmuntowicz in
memory of Amanda Keith

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Auguste Areizaga in memory of
Frederika Graf

Corazon Barcelona

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Kirch

Sheryl Bates in honor of Michael
Lewandowski

Rose Ann and Dominic Bencivenga

Kathy and James Birmingham in
honor of Molly Birmingham

Kathleen Brady in memory of Logan
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Linda Burt in honor of Sasha Segal

Tony and Claudia Busse in honor of
Erica Thiel

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B.I. Camp in honor of Laynie and
Madison Holland and in memory of
Spencer Holland

Brenda Carbon in memory of Dan
Miller

Shirley Catanzarite in memory of TJ
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honor of Nicholas and Christopher
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Douglas, Lori and Katie Dunbar in
memory of Kraig Klenke

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Geri Lynn Edwards in memory of Dan
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Sherri Fleming in honor of Scotty
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Cynthia Foster in memory of Edie
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Michael and Marcia Geller in memory
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Amy L. Hennessey in honor of Josie
Mae Williams

Juan and Susan Heredia in memory of
Zach Townsley

Marlys Herring

Elizabeth Hoffman in honor of Sam
Caswell

Joann and David Holder in honor of
Laynie and Madison Holland and in
memory of Spencer Holland

Jane Johnston in memory of Gwen
Olita

Catherine Jones in memory of Chloe
Key

JudesKids in honor of Aidan Carter

Shih-Hsin Kan

Kathleen Kapes in honor of Ryan and
Braydon Kapes

Gail Katz in memory of David Katz

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A.L. and Angela Sarantinos in honor of Luke Sarantinos
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Don and Lisa Wells in honor of Matthew Wells
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Bob and Kate Zimmerman in honor of Aidan Carter