MISSION STATEMENT
The National MPS Society exists to find cures for MPS and related diseases. We provide hope and support for affected individuals and their families through research, advocacy and awareness of these devastating diseases.
As you read our 2013 annual report, you’ll notice the common themes of action, hope, power and change. These were not strategic goals for 2013—they are the basic foundations of the mission of the National MPS Society and a focus of our work every day of every year. We have compiled the Society’s 2013 highpoints—which are impressive. But who tells a story better than an adult with MPS who received an Extraordinary Experience or a family who has seen the growth of the Society? After reading the following pages you will see what we mean.

Every year the Society offers scholarships to attend our annual conferences and, due to the popularity of this program, preference is given to first-time conference attendees. Michael Whitaker-Russell (MPS II) and Loren McClelland (MPS I) became fast friends because of that opportunity to meet in San Antonio at our 27th Annual Family Conference. See their photo on page 2.

During this conference we had the privilege to celebrate individuals with MPS I who were the first in the world to participate in an MPS clinical trial for enzyme replacement therapy. That celebration encapsulated all the themes of action, hope, power and change! In 2003, Aldurazyme™ was approved by the FDA as the first treatment for individuals with MPS I, and the Society participated in the FDA Advisory Committee Hearing for Aldurazyme. The Society participated in another FDA Advisory Committee Hearing in 2013, this time for VIMIZIM™ for MPS IVA. This treatment was approved in February 2014.

Look through this annual report and reflect on the special moments captured during 2013. See the look of joy on Nick Boyce’s (MPS I) face at his college graduation and understand the power and determination that propelled him forward. Appreciate how Jocelyn Wong (MPS IVA) acts on her beliefs and brings hope to patients from other countries. Understand that the Society launched its most diverse disease advocacy effort in Washington, DC, to date with a focus on change. Rejoice that a new company is hoping to change the lives of individuals with MPS IIIB by developing a desperately needed treatment. Appreciate how a father’s fraternity developed an action plan to raise money to ultimately cure his son’s disease.

These are only a few of the many stories. Every story is special and remarkable because the Society is comprised of many individuals and groups all working for a common mission—to find cures for all MPS and related diseases. Action, hope, power and change will continue to be a part of these stories as we move forward.

Thank you for helping us to achieve our mission.

Steve Holland  
President

Barbara Wedehase  
Executive Director
I would like to thank the National MPS Society for providing a scholarship to the Annual Family Conference in San Antonio, TX. Michael and I created lifelong relationships, but the best part was seeing we are not alone in this. There is an entire MPS family. I want to start a Courage Page to help the Society with fundraising. I want to be a part of making a change because we have hope for our future.

Monique Whitaker
legal guardian of Michael (MPS II)
Empowerment Through Support

The Family Support Committee is determined to meet the developing needs of individuals and families affected by MPS and related diseases. Since the program’s inception, more than $635,000 has been awarded in direct family assistance, funding medical goods, continuing education and conference scholarships, medical travel assistance and extraordinary experiences. As the program continues to grow, additional support opportunities will be identified for our families.

- Supported 13 families to attend the 28th Annual Family Conference in San Antonio, TX. These conference scholarships offset the cost of registration, travel and hotel.
- Awarded 28 $1,000 Continuing Education Scholarships to members who are continuing their post-high school education. Scholarships were awarded to eight individuals with MPS and related diseases, to one child of an affected individual and to 19 siblings.
- Funded $14,650 in Family Assistance Program grants to help families obtain durable medical goods. Grants included scooters, car lift, home ramp, WIKE bicycle stroller, sleep safe bed, adaptive car seat and adaptive stroller.
- Assisted 20 families through the Medical Travel Assistance Program. In 2013, the program awarded $8,943 for mileage, airfare and hotel reimbursement to families traveling more than 200 miles (one way) from home for medical appointments.
- Promoted and provided $2,250 in financial support for three family organized regional social gatherings in Illinois, Ohio and Utah.
- Funded five Extraordinary Experiences for older children and young adults with MPS. In 2013, the Society awarded $4,400 for trips to Boston, Japan, London and Paris, and for driving lessons.
- Published the 11th annual Angels Among Us/Our Special Children memorial publication.
- Continued the White Rose Program and grief booklet series for families whose child passed away during the year.
- Recognized individuals with MPS and related diseases with Standing Ovation awards. Two individuals from each MPS syndrome is honored each quarter, acknowledging their courage, resilience, tenacity and passion for life as they face the challenges of living with MPS.
- Implemented online application platform for Family Support Programs.
- Sent the Award of Courage signed by MPS Society President Steve Holland to all individuals with MPS and related diseases.

Pictured: Michael Whitaker-Russell (MPS II) and Loren McClelland (MPS I)
The mission of the Education and Publicity Committee is to provide an array of educational materials and health-related communications. Our commitment is to provide the most current information about MPS and related diseases through multiple resource channels. The National MPS Society embraces forward-moving technology by maintaining a new website, funding video materials and utilizing social media, while not losing site of the essential one-on-one contact with individuals and families touched by MPS.

- Promoted the 7th International MPS Awareness Day on May 15.
- Launched 3rd annual Facebook contest for MPS Awareness Day.
- Reached out to researchers and Scientific Advisory Board on MPS Day.
- Provided “What is MPS?” cards to membership via Join the Search program.

- Completed MPS video revisions for Courage at Diagnosis, Living with Courage and Journey of Hope.
- Presented videotaped San Antonio family conference presentations through link on Society website.
- Updated Daily Living booklet.
- Updated fact sheets: Physical Therapy, Transplant, Air Travel Information and Orthopedic Disorders in Children with MPS and Related Diseases.
- Created the fact sheet Your Donation: Your Decision.
- Published the Society’s quarterly magazine, Courage, and supplement newsletters.
- Increased and improved website capabilities.

Pictured above: Celebrating MPS Awareness Day in honor of Jackson Dunn-Kraus (MPS II)
Pictured at right: Jocelyn Wong (MPS IVA) with Dr. Paul Harmatz
I was pleased to be a recipient of an Extraordinary Experiences grant in 2013 and travel to the Taiwan MPS Society meeting. I met with many representatives from many Asian countries. It was emotional for me as I talked with families from other countries struggling through their MPS diagnosis. Still, I was able to share my experience with the clinical trial for MPS IVA and remained optimistic amidst our cultural differences. The community of MPS expands beyond the borders of the United States and I am happy to be part of the bridge into the Asian community. So much has changed over the years with the exchange of information between countries and from the Internet, but nothing compares to meeting families in person.

Jocelyn Wong (MPS IVA)
We donate to the Annual Fund because we are thankful for the National MPS Society. Each year they demonstrate fiscal transparency to donors and are an excellent steward of precious money raised. We have seen the growth and advancement in critical life-changing initiatives. The Society provides hope for families and empowers advocates with the knowledge of rare diseases. They have and provide connections. We hope to be able to continue to donate to the Annual Fund every year so they can continue with the work of finding cures.

Lynn Hopkins
MPS I parent
Providing Hope Through Perseverance

The National MPS Society recognizes our walk/run and other fundraising organizers with a big THANK YOU! Our fundraising program provides essential resources for individuals hosting fundraisers. This past year we increased our efforts with the Annual Fund campaign and Text to Give, a mobile donation tool. The Society continues to embrace the fundraising evolution and provides our donors, membership and fundraisers the essential tools for success. With the increased use of social media, the Society is able to reach donors quickly. The Fundraising Committee is dedicated to provide support through the following programs: Walk/run, Family Fundraisers, Annual Fund, Planned Giving, Champion a Cure, Mobile Giving, Courage Pages, Friends and Neighbors, Combined Federal Campaign, United Way and our inaugural platform for online giving, Rally.org.

- Received a three-star charity rating from Charity Navigator, representing good performance that exceeds or meets industry standards and performs as well as or better than most charities in its cause.
- Supported an active membership roster of more than 700 members.
- Raised approximately $388,000 through walk/run and fundraising events.
- Supported 16 walk/run events and 57 fundraising events, including: Ask Events (two-hour benefit that educates donors and asks for donations), bake sales, bowl-a-thons, concerts, golf tournaments, tea party, jeans day, bingo, auctions and many more.
- Raised more than $135,000 through our 2013 Annual Fund campaign.
- Incorporated mobile pledging successfully at our annual family conference.
- Hosted 22 Courage Pages on the Society’s website, raising $35,000. Courage Pages are informative individual family web pages designed to raise awareness and funds for the Society.
- Added a comprehensive fundraising toolkit on our website.
- Received Combined Federal Campaign application approval.
- Created a two-minute video and launched a fundraising effort through rally.org platform.

Annual Fund Donations

![Annual Fund Donations Graph](image-url)

Pictured: Hopkins family
Planned Giving, Security for Our Future

Although 2013 was only the third year for Planned Giving with the National MPS Society, at year’s end we had 11 Planned Giving donors who became part of the Rising Sun Legacy Circle. The Society also received its largest gift to be used for a parents’ respite night at our annual conferences and for the Family Support programs.

Planned Giving helps donors maximize the personal benefits of charitable giving and allows donors to make gifts they may not have thought possible. Individuals who make planned gifts to the National MPS Society, whether through their estates or other life-income arrangements, share a strong common bond of generosity that will provide security for future generations. Building this community of philanthropy helps our donors achieve their personal vision and desire to give.

I contributed to Planned Giving because I want to give back to an organization that was and still is a lifeline for me. This is to honor my two sons, Clinton and Zachary, who have passed away from MPS IIIA. I was unable to share with them what I would have wished to during their lives. My planned gift ensures improvement in the lives of those who are still fighting MPS, because even with treatments there are still many battles. I’ve watched the incredible progress the National MPS Society has made over the years. Part of our family’s legacy is to help them fulfill their mission. I am so grateful for its existence, purpose and the lives they touch each day, especially my own.

—Tracy Szemanski
MPS IIIA parent

Tracy Szemanski with her son Zachery (MPS III), 1987–2004
Reinforcing Our Resources

The Governance Committee provides for the board’s effectiveness and continuing development. The committee recommends board policies and processes designed to provide for effective and efficient governance, including review of bylaws, evaluation of board members, election of board members, and board orientation and education.

- Implemented a new board of directors review, self-assessment and peer evaluation process.
- Discussed peer evaluation results and provided valuable feedback to each board member in order to improve the effectiveness of both the board of directors and staff.
- Oversaw the annual board election process.
- Presented “What makes a dynamic groundbreaking nonprofit board?” as part of the board’s ongoing education and development.

The review and evaluation process of the Governance Committee was implemented in order to identify gaps and improve performance of our board members. This process creates transparency and adds credibility to board decision making.

Lisa Todd
Governance Committee chair,
MPS II mother

Lisa Todd with her son Jack (MPS II)
I am impressed by the passion and determination of this committee. More than 20 meetings were coordinated and every member was prepared for every meeting they attended. Based on the feedback we received, I believe the advocacy efforts of the National MPS Society continue to be a valuable and important method of awareness, influencing legislation critical to our families.

Sissi Langford
MPS III mom and former chair of Committee on Federal Legislation
Collective Action for Collective Change

The Committee on Federal Legislation strengthens its strong message each year on Capitol Hill. The voice of the National MPS Society is recognized, and it is the committee’s function to be aware and take full advantage of capitalizing on important moments. In 2013, the Society crafted the largest and most diverse disease representative effort that has ever been coordinated for one unified advocacy while attending their annual Washington, DC visits. Legislative Committee platforms include: medical, research, health services, special education and disability policies. Regular correspondence and personal visits with policy makers at the National Institutes of Health, Food and Drug Administration, Department of Education, Social Security Administration, National Organization for Rare Disorders, and other federal and advocacy agencies occur year round.

- Partnered with Rare Disease Legislative Advocates, a clearing house for patient advocacy groups to promote common legislative issues.
- Submitted language to the Senate Appropriations Subcommittee on Labor, Health and Human Services included in the Significant Item Report for 2014.
- Advocated for the US Senate to continue passage of the resolution to recognize May 15, 2013, as National MPS Awareness Day, as co-signed by Senators Graham (R-SC), Hoeven (R-ND), Begich (D-AK), Whitehouse (D-RI), Heitkamp (D-ND), Murkowski (R-AK) and Boxer (D-CA).
- Awarded Sen. Lindsey Graham (R-SC) for his advocacy achievements on behalf of National MPS Awareness Day and NIH funding for grants directed at MPS research.
- Attended the Rare Disease Caucus briefing.
- Met with 22 senators and 10 House of Representatives over two days during the annual Capitol Hill visit.
- Partnered with other rare disease groups in Rare Disease Day activities in Washington, DC.
- Successfully advocated to include rare disease language in the FDA draft guidance on accelerated approval. The Society launched several initiatives to help reach the goal of obtaining more than 100 congressional signatures on a letter to the FDA.
- Supported the following legislative initiatives: Kids First Research Act of 2013; Life Span Respite Appropriations; Compassionate Allowance within the Social Security Administration; Orphan Drug Tax Credit; Undiagnosed Diseases Research and Collaboration Network; Newborn Screening Save Lives Reauthorization Act; and the Coalition Letter on Healthcare Information Technology framework.
- Supported formal comments to the Agency for Healthcare Research and Quality technical brief on enzyme replacement therapy for lysosomal storage diseases.
- Updated the website to include interactive advocacy for members and contacted all advocates to thank them personally for advocacy efforts and invite them to join the legislative committee.
- Created advocacy video for the annual family conference to promote education and engagement with live action alerts.

Pictured: Sissi Langford with Sen. Graham (R-SC)
The National MPS Society awarded $530,000 in grant funding for 2013. Funding quality research each year is critical as we move forward with our mission to find the cures. We received 48 letters of intent from researchers around the world for the grants offered. The Society also funded $25,000 to support the Lysosomal Disease Network’s National Institutes of Health grant. The funding is designated for the Neuroimaging Core, which benefits four MPS projects. A $10,000 partnership grant with the Ryan Foundation funded the project of Dr. Elsa Shapiro from the University of Minnesota, “Longitudinal Studies of Brain Structure and Function in MPS Disorders.” The Society also provided funding for post-doctoral fellows to attend the Gordon Conference on lysosomal diseases.

A partnership grant with the International Society for Mannosidosis and Related Diseases was awarded to Heather Flanagan-Steet, PhD, at the University of Georgia for her work, “Investigating the role of cathepsin proteases in ML II cardiac pathology.”

Lachlan Smith, PhD
University of Pennsylvania
Philadelphia, PA
“Mechanisms of Failed Vertebral Bone Formation in Mucopolysaccharidosis VII”

Richard Steet, PhD
University of Georgia
Athens, GA

Dr. Dwight Koeberl
Duke University
Durham, NC
“Adjunctive Therapy for Hurler Syndrome”

Vito Ferro, PhD
University of Queensland
Brisbane, Queensland, Australia
“Development of Pharmacological Chaperone Therapy for MPS II”

Jeffrey Esko, PhD
University of California, San Diego
La Jolla, CA
“Delivery of Sulfamidase to the Brain”

Adriana Montano, PhD
St. Louis University
St. Louis, MO

Raymond Wang, MD
CHOC Children’s Hospital
Orange, CA
“Manifestations of Cardiovascular Disease in Morquio A: Evaluation, Assessment and Therapy”

![Money Raised and Awarded for Research](chart)

Money Raised (5K walk/run fundraisers)
Money Raised (family fundraisers)
Money Awarded

Pictured: Nick Boyce (MPS I)
In 2001, my son Nick became a participant in the clinical trial for Aldurazyme®. We were committed to doing whatever was needed to receive a treatment that could possibly stop the progression of MPS I. Over the years, I watched my son’s overall health improve physically and emotionally. I watched him grow into a successful, confident young man. Enzyme replacement therapy empowered him to take on any challenge and succeed at it.

As we celebrate the 10th anniversary of Aldurazyme, I’m thrilled to also be able to celebrate Nick’s graduation from Providence College. Aldurazyme changed my son’s life and has given him the hope for the future that we all wished for. I’m forever grateful to those who contributed to the creation of Aldurazyme; the impact on the lives it’s changing is immeasurable.

Dawn Checrallah
MPS I parent
The financial information below has been summarized for the year 2013. The Society is a 501c3 nonprofit public charity. The complete audited financial statements and IRS Form 990 are available on request.

**Financial Position**

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**Support and Revenue**

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<td><strong>Total Expenses</strong></td>
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<td>$ (101,115)</td>
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**Activities**

- Education – Newsletters, Booklets, Web: $ 86,194
- Conferences, Meetings and Travel: 206,711
- Direct Family Assistance and Bereavement: 54,329
- Membership Database and Directory: 9,145
- Legislative: 18,757
- Research Grants: 386,061
- Direct Fundraising: 60,541
- Personnel: 279,824
- Office and Equipment: 41,327
- Other Administrative: 49,136

**Total Functional Expenses**

- $ 1,192,025
2013 Contributors

...with sincere thanks to our supporters

In 2013, the National MPS Society was able to provide support to families and funding for research because of the generosity of the following individuals, families, foundations, companies, groups and fundraising events. The board of directors and the Fundraising Committee thank you for your dedication and efforts.

The Society makes every effort to recognize our supporters through Courage and this Annual Report. If your name is not listed, we apologize and ask that you contact us. The following list represents all donations received in calendar year 2013. If we received your donation in 2014, you will be recognized in the next Annual Report.

Platinum
$10,000 to $1,000,000

AbbVie, Inc.
John and Bonnie Hoegl
Steve and Amy Holland
Darlene Holliday
Honeywell International Charity Matching
Scott and Lynn Hopkins
Laura Hudson
Wayne and Lori Hummel
IBM Employee Services Center
William and Michelle Iglesias
Issaquah Swedish Cancer Institute
Kajima Foundation
Jeffrey and Stephanie Kell
Legacy Wealth
Brenda Lacombe
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Lessing’s, Inc.
Jeff and Caroline Lewandowski
Matthew and Shannon Mcknight
Microsoft Matching Gifts Program
Ray and Amy Miller
Heath and Kimberly Moneysmith
Mark and Angie Morris
Wayne and Pam Morris
Jim and June Murphy
Ameritech
Cheryl Noll III
Travis Parigi
JoAnne Paterniti
Bill and Betsy Pelham
Mary and MaryEllen Pendleton
Linda and Dave Perry
Pershing
Thomas and Stacy Peters
PGE Corporation
Ryan Pierce
Barbara Pryor
Paul and Katie Rector
Robert and Elizabeth Rigney
James and Courtney Robertson
George and Athena Sarantinos
Mr. and Mrs. Arthur Schechter
Siemens Caring Hands
Campaign
Slumberland
Jack and Barbara Sorter

Silver
$1,000 to $2,999

AbbVie, Inc.
Employee Giving Campaign
Amicus Therapeutics, Inc.
Dr. and Mrs. Mel and Millie Anhalt
Anne Lammot Kinder Foundation
AT&T United Way/Employee Giving Campaign
Keith and Debra Banks
Wayne and Catherine Bartley
Joyce Rhodes Barrett
Birnam Oaks Foundation
Fund of the San Antonio Area Foundation
Bishop-McCarr
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Brandy and Beau Bozarth
Stephanie and Austin Bozarth
Chris Brodmerkel
CA Technologies Matching Gifts Program
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Susan and Roger Chapin
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Joan Cook
Caroline Dabney
Ron and Barbara Dengel
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John and Beth Devoe
John Downing
Ernie and Debbie Dummann
Pat and Kathy Dunn
Carrie Dunn and Melissa Kraus
Dutch’s Daughter, Inc.
Betsy and Steve Fowler
Genworth Foundation
Sharon Glasscock
Greencross Corporation
Luis and Angela Guajardo
Hamilton County Firefighters Local 4416
Sabrina Hanitz
Helping Hands Ministries

Gold
$3,000 to $9,999

AbbVie, Inc.
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Helping Hands Ministries

Silver
$1,000 to $2,999

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James and Courtney Robertson
George and Athena Sarantinos
Mr. and Mrs. Arthur Schechter
Siemens Caring Hands
Campaign
Slumberland
Jack and Barbara Sorter

Edward Kimminbau (MPS IV)

Leader
$500 to $999

John Abernathy
Mary Starr Adams
America’s Charities
Armored School District No. 9
Artisan Home Resorts
Robert and Marjorie Austin Jr.
Automotive Booster Club B-20
Brenda Baker and Steve Baum
Mr. David Beaty
Michael Belling
Elliot and Lindsey Berke
Lee Bloomenthal, MD
Myrna Borman
Richard Bosse
Burnside First Church of God, Inc.
Gregory and Therese Calvelo
George Gary Card
Liam and Mary Cavanaugh
John and Lisa Conceros
Citigroup Payment Services
Clare Rose, Inc.
Walter and Gretchen Clayton

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Syngenta MPS IIIB Patient Advisory Board

Volunteer
$250 to $499
Abbott Fund

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Toys and Shirley Catanzarite
Cecilton Lions Charities, Inc.
Century Carpet, Inc.
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Tori Eiland
Empire Merchants, LLC
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Kristine Fair
Hildegard Penhallurick and
Joseph Filebark
Bart and Sally Finzel
Donald and Romona Finzel
Red and Kathy Finzel
Pamela Floyd
Janet Forde
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Georgia Gampe
Ken Gardner
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Fredric Gilde
Andrew and Jennifer Graser
Phil Haddad
Matthew Hamlin
Lisa Hansen

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K. and V. Hartz
Jennifer Hemingway
Samuel and Keri Henderson
Jim Hensler
Hewlett-Packard / YourCause
Kathleen Hillyard
Horizon Lines of Alaska, LLC
Jennifer Hutcheson
John and Yvette Iannelli
W. Andrew and Lauran G. Jack
Jacksonville Elementary School
Jewish Communal Fund
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Dawn and Philip Lorenz
Lori Caldwell LeDoux
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Joan and Mark Lessing
Charles and Kendra LeSta
Timothy Lethin DDS APC
Levelthree Solutions
Kathryn and Hai Lieu
Jenn and Jamie Lipscomb
Donald and Karen Louden
Chuck and Nancy Lukodi
Barbara Lyons
Jane Mabbett
Stockton and Danielle MacInnes
Mariana MacMillan
Robert Harvey and
 Roxanne Maffett
Kathryn and Kevin Maher
Marantha Bible Church
Gary and Sunni Markowitz
Josephine Marzetti

continued >>
Karen Graven
Karen Graven
Rose Marie Greco
Paul Greely
Peggy and James Greenbaum
Sydney Greenblatt
Agnes Greene
Richard Greene
Leonard and Phyllis Greenstein
Greg Kroka Woodcarving, Inc.
Ted Gregory
Mrs. Julienne Grundfest
Guardian Security Systems, Inc.
Tesa Guveul
Stanton and Jean Gannels
Christopher and Patricia Guye
Rita Haan
William Hagerman
Mick and Shirley Hagermann
Christy Stephens and Jerry Hall
Sheryl and Gerald Hall
Alan and Lori Halvorsen
Tanya Hammel
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2013 Fundraising Events

Abel family A Wish for Evan, hosted by John and Kristi Abel
2nd Annual Walker benefit concert, hosted by Ken and Courtney Walker
3rd Annual Concert for A Cure, hosted by Dorothy and Ryan Mask
Alves Ironman Arizona for the Pagliero family, hosted by Jeff Alves
Armored Key Club MPS Awareness Day fundraiser, hosted by Kristina Lee
Automotive Booster charity golf tournament, hosted by Harry Wilson
Bake sale in honor of Julia Delphi, hosted by Allie Rosenburg
Birthday donations in memory of Allison Kirch, hosted by the Kirch family
Bowl for Kristofer, hosted by Jennifer and Chris Christiansen
Bowling for A Bear Bowl-a-thon, hosted by Upper Moreland High School Key Club
Bozarth family Dress Down Jeans Day for MPS Day, hosted by Austin and Stephanie Bozarth
Bozarth Houston Ask Event - Annabelle’s Journey, hosted by Austin and Stephanie Bozarth
Bozarth wedding gift event, hosted by Beau and Brandy Bozarth
Carving a Decoy auction fundraiser, hosted by Sandra and Lonnie Rodriguez
Charity Bakers for Nolan Ramsey, hosted by Jacksonville Schools Charity Bakers
Charles Schwab bake sale and employee gift day, hosted by Diane Russell
Coach Bag Bingo, hosted by Gerald Hall
Cross Creek charity golf tournament, hosted by William Bagwell
Cure for Gavin, hosted by Kimberly Legg
Do It Fore Dan golf tournament, hosted by Ray and Amy Miller
Donuts for Dominic, hosted by Nancy Hutzell
Halk Fall Festival, hosted by Carla Halk
Hike NH in honor of Liam, hosted by Alessa Marzetti
Hope for Hunter Gala, hosted by Michelle Hoffman
Hopkins family annual Cabl clothing party, hosted by Lynn Hopkins
Hughes’ 60th wedding anniversary fundraiser, hosted by Donna Weaver
Ice Cream Corner 4th annual Awareness and Bridge Club, hosted by Janelle Kunells
Italian Festival, hosted by Caroline and Jeff Lewandowski
Jackson and Sydney’s birthday fundraiser, hosted by Carrie Dunn and Melissa Kraus
Jacksonville Elementary School Jumblethon, hosted by Jennie Springer
Johnsonfamily Spooktacular fundraiser, hosted by Chris and Mercedes Johnson
Karima’s MPS 50/50 raffle fundraiser, hosted by Carol Rucker
Kenton Full’s Dress Down Day, hosted by Kroger employees
LB Foster Denim Day, hosted by LB Foster employees
Lemon Drops fundraising event, hosted by Glenn and Kathy Miller
Logan County Bank Jeans Friday, hosted by Logan County Bank employees
Logan’s Heroes, hosted by Anne Schnare
Mad Hatter Tea Party, hosted by Stephanie and Austin Bozarth
Maura’s Awareness Day T-shirt fundraiser, hosted by Amber and Eric Morgan
Max & Erna’s fundraiser for Riley, hosted by Robb and Lisa Muller
MPS Awareness Day ribbon fundraiser, hosted by Ryan and Cassandra Reamer
MPS Bowlathon, hosted by Ryan and Cassandra REamer
Noah Mehling trivia night, hosted by the Hamilton County Firefighters 4416
Post Office Café events, hosted by Kerri Rose and Mark Lesing
Prairie Point fundraiser, hosted by Prairie Point Schools
Providence Schools Dress Down Day, hosted by Clay and Terri Klein
Push Up Challenge, hosted by Alpha Chi Rho Educational Foundation
Rockland Boulders fundraiser, hosted by Janeen Eisle
Ryan’s birthday open house, hosted by Johnathon and Marie Hunt
Sarah’s sweet 16 birthday party, hosted by Thomas and Ruthann Van Orten
Scotty’s 16th Birthday Bash, hosted by Tom and Kim Whitecotton
Shots for Sean Memorial Golf Tournament, hosted by Ernie and Debbie Dummman
Sowden annual golf outing, hosted by Josh and Sheri Sowden
Sowden Bank Jeans Day, hosted by Josh and Sheri Sowden
Todd lemonade stand, hosted by Jack Todd
Von Handorf Bike Across the Country, hosted by Jeff and Mary Von Handorf

2013 Walk/Run Events

3rd Annual It Works Families Fun Run, hosted by Kate Martin
3rd Annual Walk/Run for Cameron, hosted by Brian and Julie Moller
6th Annual Strides for Sara, hosted by the Dickerson family
11th Annual BioMarin Run, hosted by Suyonene Bell
14th Annual Run for Erin, hosted by Stacy Peters
Andrew’s Walk n’ Roll, hosted by Sharon Cocheron
Annual NC Run for MPS and ML, hosted by Mike Schletter and Terri Klein
Bike for Brooke and Fun Walk, hosted by Holly Zimmerman
Clara’s Courage Walk/Run, hosted by Shane Gibson
Hop for Hunter, hosted by Michelle Hoffman
Kaiir’s Kause, hosted by Mike and Trisha Offerbacker
Marshall Academy 5K Run, hosted by Marshall School
Memorial Walk for Kyle Witt, hosted by the Witt family
MPS Run For Their Lives, hosted by Steve Holland and Scott Hardin
North Carolina 5K Run for MPS/ML, hosted by Mike Schletter and Terri Klein
Post Office Café Run for Mark and Casey Lesing, hosted by Kerri Rose
Rays of Hope Family Fun Walk, hosted by Fair and Stephanie Kell

2013 Adopt a Runner, Champion a Cure Participants

Families across the country have raised more than $55,000 through Adopt a Runner, Champion a Cure. Each year with renewed hope, we reach out to families and share that they too can make a difference and help raise money for research while not hosting or even attending an event. It is easy and the rewards are tremendous. Thank you to the following families who embraced the 2013 challenge.

Bennett family, Hunter, Clara and in memory of Tommy (MPS II)
Caswell family, Sam (MPS I)
Gibson family, Clara (MPS IIIA)
Dunn-Kraus family, Jackson (MPS II)
Espinola family, Dominic (MPS II)
Kirch family, in memory of Allison (MPS IIIA)
Klein-Schlie family, Jennifer (ML III)
Klenke family, in memory of Kraig (MPS II)
Marine family, Austin (ML II/III)
Robson family, Jaeda (MPS II)
Szemanski family, in memory of Clinton and Zachary (MPS IIA)
Tooth family, Shannon (MPS II)
Yard family, Christian (MPS II)

Courage Pages at www.mpssociety.org

The following families have their own website in Courage Pages through the National MPS Society. Whether you are hosting an event or raising awareness for MPS and related diseases, these custom pages are a terrific way to reach donors and help enhance your fundraising efforts. Consider having us build your family’s custom website for free. To view these inspirational sites, click “Courage Pages” on the right margin of our homepage (www.mpssociety.org). Thank you to the following families:

Evan Abel
Hunter Beam
Annabelle Bozarth
Sam Caswell
Alan Charest
Kali Gegenheimer
Mackenzie and Isabella Hardesty
Allison Kirch (in memory of)
Kraig Klenke (in memory of)
Jennifer Klein
Danny Miller
Maura Morgan
Michael Whitaker-Russell
Jack Todd
Alyson Von Handorf
Trinity Walker
Scotty Whitecotton
Christian Yard
Reed Zeigami
Classifications

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

<table>
<thead>
<tr>
<th>SYNDROME</th>
<th>MPS I</th>
<th>SYNDROME</th>
<th>MPS IVA</th>
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<tr>
<td>EPONYM</td>
<td>Hurler, Scheie, Hurler-Scheie</td>
<td>EPONYM</td>
<td>Morquio A</td>
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<td>ENZYME DEFICIENCY</td>
<td>Galactose 6-sulfatase</td>
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<th>SYNDROME</th>
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<td>Morquio B</td>
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<td>ENZYME DEFICIENCY</td>
<td>β Galactosidase</td>
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<td>EPONYM</td>
<td>Maroteaux-Lamy</td>
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<td>Heparan N-sulfatase</td>
<td>ENZYME DEFICIENCY</td>
<td>N-Acetylgalactosamine 4-sulfatase (arylsulfatase B)</td>
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<td>Sly</td>
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<td>ENZYME DEFICIENCY</td>
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<td>EPONYM</td>
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<td>ENZYME DEFICIENCY</td>
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</tbody>
</table>

Normally, the body uses enzymes to break down and recycle materials in cells. In individuals with MPS and related diseases, 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.
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