MISSION

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.

In 2009 the National MPS Society celebrated its 35th anniversary. So many significant milestones occurred during this time, but what is most remarkable is the growth of research. In this annual report, Dr. Elizabeth Neufeld writes about her pivotal research before the inception of the Society—research leading to enzyme replacement therapies. Today Dr. Neufeld’s passion is MPS III and research leading to therapies that can cross the blood-brain barrier.

What appeared to be a straightforward, cause-effect problem 35 years ago, now is recognized as significantly more complicated. Replacing the enzyme deficient in MPS and related diseases is only one step to treatment. Researchers worldwide are now focusing on the processes within the central nervous system which can lead to new treatments.

Dr. Calogera Simonaro recently identified the role of inflammation in bones and joints and new biomarkers to monitor disease severity and treatment response, as well as new treatment approaches based on the inflammatory mechanism. National MPS Society research grants to Dr. Simonaro provided funds for her initial research which resulted in a five-year National Institute of Health (NIH) grant.

Collaboration to fund research supplements our research dollars and expands the potential to identify treatments and, ultimately, cures. Our collaborations include MPS family foundations, lysosomal disease advocacy organizations, the NIH, the Lysosomal Disease Network, and our sister MPS organizations within the International MPS Network.

In the last decade, the Society has funded more than $3 million in research. These are funds provided by you—our members, donors and supporters. Because of your generosity the Society has funded cutting-edge research in hematopoietic stem cell transplant, gene therapy, substrate deprivation, animal models of MPS diseases, chaperone therapy and inflammatory responses.

As families testify, this research has impacted the lives of their loved ones with MPS. One mother wrote about enzyme replacement therapy and her unmitigated joy that her son has been given life. What greater gift is there than the gift of life?

Thank you for your support. Together we pledge that every person born with MPS is ensured a life free of the constraints associated with these devastating diseases.
It is the mission of the Family Support Committee to provide financial assistance for families to attend our annual family conferences where they have the opportunity to meet and speak with researchers around the world. Since the inception of the Family Support Program, more than $320,000 has been awarded for funding of medical goods, conference scholarships and continuing education scholarships.

ASSISTING FAMILIES IN NEED

• Supported the membership to attend the 23rd Annual Family Conference at Disney. The Society provided 32 stipends for families to attend and offset the additional cost of travel.

• Issued two Extraordinary Experience awards to affected individuals. These members participated in their very own extraordinary experiences: summer camp and a school-supported trip.

• Awarded 20 $1,000 scholarships through the fifth annual Continuing Education Scholarship Program to three affected individuals, 15 siblings and two parents.

• Funded 11 Family Support grants for medical durable goods. These included hearing aids, wheelchairs, a vehicle lift system and an adaptive tricycle for an average of $1,445 per grant.

• Promoted and supported three family initiated regional social events in Ohio, Illinois and New York for a maximum amount of $750 per event.

• Maintained the White Rose Program and grief booklet series for families whose child passed away during the year.

• Published the seventh annual Angels Among Us/Remembering Our Children memorial tribute.

• Promoted all Family Support programs through the Web site, Courage articles and mailings.

“I am a new member of the Society and feel relief from the support our family has received. We no longer feel alone in our diagnosis. With assistance from the Society’s Family Support Program, we hope to attend the annual MPS conference in California in the fall.”

— Darla Harrison, mother of two MPS IV children

Kianna White (MPS IV) and Justin White (MPS IV)
The National MPS Society’s successful fundraising program is credited to our members, donors, board of directors and staff. The **Fundraising and Membership Committee** provides mentors and marketing tools to help even the novice fundraising host achieve success. The Society recognizes that fundraising creates an opportunity to raise money for research and our programs, and it increases critical awareness among the community.

The Society thanks everyone who has given their time and resources to ensure the success of our mission to find cures for all our supported diseases.

As shown in the graph below, 2009 was a very successful year, with $470,000 raised for research from walk/runs and other fundraising events. More than $3.17 million in research dollars has been raised since 2000.
• Supported an increasing active membership roster of more than 800 members.

• Received the final gift to the Society’s endowment fund from Dr. Emil Kakkis and Dr. Jenny Soriano for a cumulative total gift of $1 million.

• Raised more than $285,000 for research and vast amounts of awareness during the 10-year anniversary of the walk/run events. A total of 21 events were held around the country.

• Supported 43 family fundraising/awareness raising events, including golf tournaments, dinner events, bowl-a-thons, casual/crazy dress events, cornhole tournaments and many others. These events raised more than $186,000 for research and family support programs, an increase of 40 percent from 2008.

• Raised approximately $73,500 from the seventh Annual Fund campaign, benefiting family support programs, legislative initiatives and general operating needs.

• Formalized the Fundraiser Reimbursement Policy restricting fundraising event costs to a maximum of 25 percent of amounts raised, in accordance with national responsible fundraising practices.

• Received a three-star Charity Navigator rating indicating that we “exceed or meet industry standards and perform as well as or better than most charities in its cause.”

• Formalized the Joint Fundraiser and T-Shirt Policies for special event and walk/run fundraising.

• Initiated the Sponsor a Child for a Cure program in California and North Carolina. This program provides an opportunity for families to raise money for a walk/run regardless of their location within the United States.

• Updated Event Guides to enable our membership success in their awareness and fundraising endeavours.

Riley was diagnosed with MPS II on Oct. 13, 2008, when he was only 3 1/2. Though neither of us had heard of MPS, we learned about treatment options through the National MPS Society. Having weekly treatments of Elaprase® provided hope for our family and Riley’s future. Riley’s enzyme replacement therapy has become part of our weekly routine. We have seen subtle changes in Riley and we look forward to what continued research has in store.

We believe in the MPS Society and the programs they support; we try to do all we can to help. At first, the thought of fundraising was intimidating. We started small and then held a successful larger event in 2009. We know that money raised will support research all over the world to help further treatments and hopefully, one day, find a cure for all MPS and related diseases. It is such an honor for my family to be part of something bigger, and we thank all of the courageous families who came before us and raised the money to fund research that has brought hope to our son.

— Lisa and Robb Muller
CommIt MeNt
To ReSEarCh

Each year the National MPS Society is committed to funding researchers who are dedicated to developing cures. For many years the Society has awarded fellowships to aspiring researchers. Thanks to the generosity of our donors, the Society funded $432,000 for critical research in 2009. We received 33 letters of intent from researchers around the world and awarded five new two-year grants for $80,000 each.

The Society is proud of our continued involvement and collaboration through Research Partnership Grants with organizations and family foundations. This program stretches our research dollars and provides researchers with additional funds to advance their projects. In 2009, $7,000 for mucolipidosis research was provided as a Partnership Grant to the International Society for Mannosidosis and Related Diseases. In support of the Lysosomal Disease Network’s National Institute of Health grant research goals, the Society funded $25,000 for the Neuroimaging Core which will benefit four MPS projects.

The Society is unique among rare disease support groups in that we support many diseases, each of which is defined by a specific enzyme deficiency.

My lab over the years has focused on pathogenic mechanisms responsible for brain dysfunction in lysosomal diseases (including the mucopolysaccharidoses, as well as others), with current work focused on the consequences of disruption of normal lysosomal processing on neuron and glial cell function. We pioneered the development of two specific therapies for lysosomal diseases, established efficacy for using bone marrow transplantation for correction of the brain disease in alpha-mannosidosis and developed a use of substrate reduction therapy for treatment of Niemann-Pick disease type C.

— Steve Walkley, DVM, PhD, Albert Einstein School of Medicine, Chairman, National MPS Society Scientific Advisory Board
I have been involved with the National MPS Society for more than 25 years and currently serve on their Scientific Advisory Board. In the last nine years the Society has made great advances, cultivating relationships with global researchers, clinicians and pharmaceutical companies that develop treatments for MPS disorders. The Society disseminates information about research and clinical trials to its members, including work I conduct at the University of North Carolina.

The National MPS Society is well respected by all stakeholders as an international leader in providing accurate and up-to-date information about these complex disorders and is a referral source to the many specialists involved in the lives of individuals with these diseases.

— Joseph Muenzer, MD, PhD, University of North Carolina, National MPS Society Scientific Advisory Board

Maria Pia Cosma, PhD
Telethon Institute of Genetics and Medicine
Naples, Italy
AAV2/5CMV-IDS therapy in MPS II mice; correction of CNS defects through IDS delivery across the blood-brain barrier

Jeffrey Esko, PhD
University of California
San Diego, CA
Substrate reduction strategy for MPS III A

Alessandro Fraldi, PhD
Telethon Institute of Genetics and Medicine
Naples, Italy
Developing a systemic AAV-mediated gene therapy to cross the blood-brain barrier and treat brain pathology in MPS III A

Katherine Ponder, MD
Washington University
St. Louis, MO
The role of cathepsin K in cardiac valve in disease in MPS

Dr. Calogera Simonaro, PhD
Mount Sinai School of Medicine
New York, NY
Novel anti-inflammatory therapies for the mucopolysaccharidoses

“...The morning of Nathan’s North Carolina Walk/Run was far from the bright, crisp, autumn-in-the-mountains vision I had of how race day was going to be; it was damp, chilly and rainy. Although I was very excited by the opportunity I was given to participate in this race, I awoke feeling a bit less enthused about leaving my warm hotel room to run 3.1 miles in the cold rain. That all changed when I was asked to run on behalf of Madison Dula. When I saw the picture of that beautiful, smiling little girl, I knew I could do it. Madison and I were a team and we were going to run together, no matter how gloomy the weather was! The best part of the whole experience was after I finished the race when I was able to meet Madison and her family. Race day may have been a bit gloomy, but my memories will always be bright and cheery!”

— Lauren Hartman, Shire Human Genetic Therapies, Lexington, MA
The Committee on Federal Legislation advocates throughout the year with a voice on Capitol Hill. Their focus is identifying and supporting significant legislation that will enhance the life of an individual with MPS or related disease through awareness and research funding. The platform focuses on medical research, health services, special education and disability policies. Correspondence and personal visits with policy makers at the National Institutes of Health (NIH), Department of Education, Alliance for a Stronger FDA, National Organization of Rare Diseases, Social Security Administration and other federal agencies occur year round. With your support the committee has a voice to ensure the best quality of life for individuals suffering from MPS.

In 2001, my children Jacob and Samantha were diagnosed with MPS I. At this time there was no treatment for any type of MPS or related disease. A clinical trial became available, which led to an approved treatment in 2003. As wonderful as this day was for our family, the sad truth was so many children were still dying waiting for a treatment. My children had been given hope, not because of anything I did, but because of the parents, researchers and many heroes of MPS who came before us.

We began hosting the National MPS Society Walk/Run L.A. to raise money for research. Now, 10 years later, my children are thriving and living the life I was told they would never see. Sadly though, many children are still waiting for this same wonderful gift—the gift of life and hope. As long as we have hope, I will continue with my family and the National MPS Society to fundraise. We will make a difference, there will be treatments and we will say the word “cure.” Until then, we walk, we run and we raise money for research.

— Tami Slawson, board member, National MPS Society

Obtained partial funding for the Lifespan Respite Care Act of 2006.

Worked with Senate supporters to pass the fifth consecutive National MPS Awareness Day.

Visited Capitol Hill throughout the year to raise awareness and advocate for individuals with MPS and related diseases.

Launched a new initiative, Policy with Partners, which focuses on advocacy for public policies.

Visited with members of the House of Representatives to seek support and cosponsors for H.R. 1441, the Ryan Dant Healthcare Opportunity Act of 2009.

Worked with directors of the NIH, National Institute of Neurological Disorders and Stroke, National Institute of Diabetes and Digestive and Kidney Diseases, National Center for Research Resources and Office of Rare Diseases to increase support of research funding for effective treatments.

Met with Nancy Schoenberg of the Social Security Administration Compassionate Allowance Program requesting the addition of MPS and all lysosomal diseases in this program.

Implemented the new flag program requesting Congress fly a U.S. flag over the Capitol in memory of individuals with MPS. The flags are sent to families in memory of the loss of their loved one.

Attended a constituents’ meeting with the NIH and newly appointed NIH Director Francis S. Collins. The meeting focused on plans for the future of the NIH, and an open discussion platform included leaders from scientific organizations, nonprofit voluntary and advocacy groups.

Partnered with the Kakkis Everyday Life Foundation and the Cure the Process campaign, which focuses on rare disease access to an accelerated approval pathway in clinical trials and with the FDA. This will potentially provide orphaned treatments a seat on the fast track for treatments and cures.

Eric and Vicki Merrell are active members of the Legislative Committee and traveled to Washington, DC, to meet with senators in 2009.

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Every year the National MPS Society walk/run T-shirts have the names of the sponsors printed on them. In 2009 they had the names of the many children who have succumbed to MPS since the walk/run program began 10 years ago. Each represents a family and a child whose life has been altered due to a very rare genetic disease. While we all question why it happens, it happens.

If we look at how far we have come as an organization over the same time span, we realize that much has been done and there is always more to do.

— Linda K. Shine, president emerita, who implemented the walk/run program in 2000

Through increased awareness of MPS, funding for research will increase. It is the mission of the Education and Publicity Committee to provide an array of educational materials that will assist our families and their communities, researchers and physicians in the journey of MPS. Our commitment to fund programs and awareness materials cultivates a powerful community of global communication.

• Promoted the 3rd International MPS Awareness Day on May 15. The Society mailed embossed logo luggage tags to Society members.
• Introduced the first “How Did You Celebrate MPS Awareness Day?” drawing to our membership.
• Began National MPS Society Web site redesign.
• Updated and published syndrome-specific booklet on ML II/III.
• Began the development of the 2010 membership survey.
• Published fact sheets on Uses of Behavioral Medication, Pain Management, Traveling, Spica Cast Care, Seizures and Conservatorship.
• Published the Society's quarterly magazine, Courage, and newsletters.
• Added “A Warm Welcome” section to Courage to introduce new Society members.
• Added “Standing Ovation” section to Courage to honor members in our MPS family.
I started working on MPS in 1967, eight years before the National MPS Society was formed. I went to meetings at Johns Hopkins Hospital with MPS parents, genetic counselors, physicians and researchers; I have always thought of that group as a forerunner of the current Society. Those eight years were busy and productive. Studying cells derived from MPS patients in culture, my associates and I were able to show that the MPS diseases were disorders of mucopolysaccharide degradation, which could be corrected by “factors” specific to the disorder. Each factor proved to be the missing enzyme, but with something in addition—a chemical signal that allowed the enzyme to be taken up and targeted to lysosomes. By the mid-70s, I knew the signal was a carbohydrate, but was beaten to the punch by Bill Sly (of Washington University) who identified it as mannose 6-phosphate. These findings opened up a new field of cell biology and raised the hope (or rather, the expectation) that if patients’ cells could be corrected in a Petri dish, then patients themselves could be treated in the same way.

It took two more decades to turn this expectation into the reality of enzyme replacement. What took so long? In part, it was to understand the basic science underlying the diseases; but mostly it was to become familiar with the tools of molecular biology, then a new science, which made it possible to produce human enzyme in cells of the Chinese hamster, in quantities sufficient to treat patients for years on end. It also was necessary to find or make animal models on which the enzyme could be tested. The National MPS Society knows well the investigators most closely associated with the development of enzyme replacement: Drs. Joe Muenzer and Emil Kakkis. Both had been trainees in my laboratory, and I am most proud of their achievements.

For the past 10 years, I have worked on MPS III, Sanfilippo syndrome, for which there is still no therapy. The problem is complicated by the fact that the disease affects primarily the brain, and that therapeutic enzyme can’t get into cells of the brain because of the blood-brain barrier. I have been investigating what accumulates in the brain (we made an MPS III B mouse for that purpose), and have been surprised to find compounds similar to those found in Alzheimer disease, but limited to a very small yet very important area that is involved in memory. I hope this may lead to some novel therapies.

This has been a very long journey, filled with an equal mix of excitement and frustration. Many wonderful post-doctoral trainees joined me on that trip, and some continue to work on MPS or related diseases in their own laboratories and are training a new generation of MPS researchers. The MPS field is in good hands.

—Elizabeth Neufeld, PhD, UCLA
I began my work in MPS enzyme therapy with a stimulating and boisterous National MPS Society meeting hosted by Dr. Elizabeth Neufeld at UCLA in June of 1991. It was an awakening as I saw activist parents press for treatment for their kids and be fed the watered-down “parent version” of current research. At that meeting I learned that parents want their kids treated and want to be able to make the decision about what is right for them. It was both humbling as a physician but energizing to see proactive parents press for their kids.

In a few years following that meeting, I was able to make the enzyme missing in MPS I patients, treat dogs with the enzyme and show that it could work as a treatment. Scientists were concerned about not treating the brain, and the Society, at the time, had begun to be more concerned about the repeated failings of research to deliver anything useful at all, and had focused on making life better for families. This is always a struggle within any group or any family. How much do we enjoy today, and how much do we fight against our presumed fate? As we were trying to get set to treat a patient or two, we obtained funding from the Ryan Foundation and a substantial boost of a start-up company, BioMarin, which provided us the funding to build a team of dedicated people and leap to the clinic to treat 10 patients.

No one knew what would happen once we treated the first patients with MPS I, but at the first dose the team celebrated the chance to find out. Without taking those chances and pressing forward, there is no opportunity to do better. We were successful and the transformation on all of us was profound. The Society suddenly had something positive from research, something possible for more MPS patients, and began supporting more research. Companies got involved and invested, particularly BioMarin, Genzyme and what was then TKT, and now Shire HGT. With the burgeoning investment, the work progressed. At BioMarin, I followed on with MPS VI; the rarity of this disorder constantly challenged the business prospects for enzyme replacement therapy (ERT). We had only six patients in the United States identified at one time. The Societies in the United States, United Kingdom and elsewhere were instrumental in publicizing the work and locating patients to support the case that new therapies should be developed.

With MPS VI ERT and MPS II ERT by Shire, research had now achieved a substantial shift in the diseases, the families, the companies and the Society. We had more optimism despite the shortcomings of ERT, and renewed hope for better therapies. With the final work most recently on MPS IV A (Morquio A), bucking the establishment of how ERT works, we had another step forward in helping MPS patients. I was happy to have been involved in resurrecting the program at BioMarin and applying our insights from MPS VI in understanding how ERT really helps patients. There is still more to do, as patients with MPS III, MPS VII, Mucolipidosis II and Mucolipidosis III are still without therapy. Today, I have more hope that everything is possible. Hard work, good ideas, and close collaboration with families, companies, scientists and the National MPS Society will get us there.

— Emil Kakkis, MD, PhD, Kakkis Everyday Life Foundation
**Financial Position**

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**Support and Revenue**

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**Functional Expenses**

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<td>$ 9,999</td>
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*The financial information below has been summarized for the year 2009. The Society is a 501c3 nonprofit public charity. The complete audited financial statements and IRS Form 990 are available on request.*
2009 CONTRIBUTORS

with sincere thanks to our supporters

In 2009, 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 2009. If we received your donation in 2010, you will be recognized in the next Annual Report.
2009 CONTRIBUTORS

Neil and Terri Korte
Elizabeth and Jayson Kramer
Clint and Nikki Kremer
Doug Kreul
Mary Kroohn
Ben and Kathleen Kruthoff
Carol Kuhn
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Cori Lagao
Fred and Jennifer Landon
Donna Kay Langon
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Doug and Kirsten Laraby
Renee Lasilla
Darren and Patty Latham
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LAVLPA
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William Parkerson
Ronda Paulinn
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Janice and James Petit de Mange
Darrell and Stacy Pevler
Leslie Phillips
Jay and Lori Podesky
Lynda Polgreen
Frank and Nita Porter
Carolyn Leor Porzial
Richard and Linda Post
Diana Potts
Erika Poulos
Allan Dula and Tonya Price
Bob Prince
Christine Protass
Brian Publicover
Michele and Michael Rabasco
Stephanie and Edmund Rabuse
Chris Rabinowitz
Steve and Laurel Radius
Jennifer Radkte
Priscilla and Jay Rattery
Tammy and Dan Ragonese
Michelle Rasich
Sue Rattman
Debbie and Ron Reagan
Carol Redmond
Randy and Jan Ann Reed
Marriane Reid
Bonnie and Ralph Remnaker
Jim and Jennifer Restemeyer
Fred and Donna Reyes
Charles and Donna Rice
George and Carol Rice
Tania Ridley
Christi Riedel
Pete and Shannon Rieg
Gary and Bonita Ritondaro
Joseph and Catherine Rizzo
Nichole Robinson
Robert Robinson
Ralph Rodak
Dawn Michelle Rodrigue
Richard and Darline Rome
Robert and Corin Middle School
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2009 FAMILY FUNDRAISERS

Anderson Harvest fundraiser, in memory of David Ryan Hedrick
Ascension Health Jeans Day
Barnett birthday fundraiser, honoring Steffany Barnett
Bastounis wedding fundraiser
Bowen Walmart fundraiser
Bozarth Mad Hatter Tea Party, honoring Annabelle and all MPS IV patients
Burke cookie fundraiser, in memory of Eliza Burke
Chapin golf fundraiser, hosted by Roger and Susan Chapin
Chesser lemonade stand, honoring Bryce Chesser
Chris family golf tournament, in memory of Dakotah Smith
Clarke family MPS Day event, honoring Mackenzie Clarke
Clarke family golf tournament, honoring Mackenzie Clarke
Columbus Metro Federal Credit Union Dress Down Day, honoring Riley Hunter
Dummann Shot's for Sean Alaska golf tournament, honoring Sean Dummann
Fletcher family CPK fundraising dinner, honoring Erik Fletcher
Formica Courage Premier Gala, honoring the family of Sharon Brown
Fowler Many Putts and Swings for a Cure, honoring Jack Fowler
Gibson family and Clara’s Courage hot dog stand, honoring Clara Gibson
Hays family Riley's Runners fundraiser, honoring Rylie Hays
Hill family balloon release
Hubert family Macy’s Shop for a Cause fundraiser, honoring Livia Grace Hubert
Johnson Halloween fundraiser, honoring Dorian and Wynn Johnson
Karina’s Krazy Sock fundraiser, honoring Karina Guajardo
Klenke bowl-a-thon, honoring Kraig Klenke’s 18th birthday
Klenke jewelry sale, honoring Kraig Klenke
Lane family Memorial Day fundraiser
Merrell family trivia night, honoring Cody and Sean Merrell
Miller classroom presentation, honoring Rachel Longston
Montgomery Links for Lucas, honoring Lucas Montgomery
Montgomery MPS Day event, honoring Lucas Montgomery
Montgomery MPS Dance Fest, hosted by Chelsea Montgomery
Muller 1st Annual Cornhole Tournament, honoring Riley Muller
Muller MPS Dress Down Day, honoring Riley Muller
Podesky Pampered Chef fundraiser, honoring Benjamin and Adam Podesky
Salcher online auction, in memory of Hannah Salcher
Schnare run event, Logan’s Heros
Spaeth golf fundraiser, honoring Aiden Spaeth
St. John’s Reformed Church fundraiser, honoring Austin Nace
St. Patrick Church Dress Out of Uniform Day
Valdez golf tournament, Lukie’s Legacy, honoring Luke Valdez
Vespe holiday gathering, honoring Caitlin Vespe
Wingate Tupperware fundraiser, in memory of Jennifer Wingate
Wojnarowski piano recital, in honor of Taylor Wojnarowski

2009 NATIONAL MPS SOCIETY WALK/RUN EVENTS

*5K for Katie/Do It for Danny, hosted by Linda K. Shine and Amy Miller
*10th Annual Run for Erin, hosted by Stacy Peters
Andrew’s Walk n’ Roll, hosted by Sharon Cachenour and Barbara Pryor
BioMarin, Run for Your Life, hosted by Katie Ward
Evans Reed Family Fun Run, hosted by Laura Hiler
Heardland Run, hosted by students of ISU
Jack’s Run for MPS, hosted by Heather Alden Pope
Kassi’s Kause, hosted by Trisha Offenbacher
Khunsha’s Krusade, hosted by Khunsha Numan
Laps for Lucas, hosted by Lew and Stacey Montgomery
Mackenzie’s 5K Run/Walk for MPS, hosted by Steve and Jennifer Clarke
Miles for MPS, hosted by Laurel Radius

MPS and Mito Run, hosted by Kristin Myking
MPS Run for Their Lives 5K, hosted by Scott Hardin and Steve Holland
MPS Society Walk/Run LA, hosted by Tami Slawson
Nathan’s North Carolina Walk/Run for MPS, hosted by Terri Klein and Emily Trivette
Post Office Café Run for MPS, hosted by Keri Rose
River Run for Ryan, hosted by Jonathan and Marie Hunt
Ryan’s Run, hosted by Dorothy Mask
Sowden family Walk for a Cure, hosted by Josh and Sheri Sowden
Strides for Sara, hosted by Monique Dickerson

* Represents 10-year anniversary walk/run event
WHAT ARE MPS AND RELATED DISEASES?

Mucopolysaccharidoses (MPS) and related diseases 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 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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<tr>
<th>SYNDROME</th>
<th>ENZYME DEFICIENCY</th>
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<tr>
<td>MPS I</td>
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<td>MPS II</td>
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<td>ML II/III</td>
<td>I-Cell, Pseudo-Hurler polydystrophy</td>
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