NATIONAL 2010 MPS SOCIETY



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.

MOST Of US view philanthropy as the act of giving money to a cause near and dear to our hearts—and we thank all of you for whom the National MPS Society remains near and dear to your hearts. Because of your generosity you will read in this year's Annual Report how we prospered in 2010, allowing for the continuation of our very important programs such as legislative advocacy and education, and growth of the critical research and family support programs.

Simply stated, philanthropy can be anything you do to make the world around you a better place. In addition to the giving of money, philanthropy includes people giving of themselves—their time, expertise and help to causes they care about.

We are dedicating the 2010 Annual Report to our young philanthropists. Leslie Phillips is a young woman who exemplifies a young philanthropist. Her interest in MPS while in high school transformed into not just volunteering for the Society but developing close relationships with MPS families around the country. As Leslie writes, "Philanthropy is what you do when you love someone in pain or in need. Philanthropy is spreading awareness and sharing your story."

Steve Holland 2011 PRESIDENT

Barbara Wedehase EXECUTIVE DIRECTOR Jeff Bardsley, who has MPS II, has an interest and expertise with our legislative process. Jeff is giving of his time, not just during our trips to Washington, DC, to meet with our elected officials, but throughout the year as a member of our board of directors. Fran Madsen not only inspired her sorority sisters to join her family in their annual MPS Cup fundraiser, but also educated them about her MPS I.

The stories you will read about our super siblings, those individuals whose brothers and sisters struggle daily with the complications of MPS or related diseases, will leave you in awe of the strength and determination of these young philanthropists. They had no choice of the family they were born to, but they did have a choice of how they dealt with the many challenges. How they inspire us to do more!

We thank each of you for your philanthropy to the National MPS Society in 2010!

Pictured on the cover: Jeremy Mask with Kevin Thompson Carter (MPS III) and Leslie Phillips with Kraig Klenke (MPS II)

The Family Support Committee strives to meet the developing needs of individuals and families affected by MPS and related diseases. Since the program's inception, more than \$410,000 has been awarded to individuals and families for medical goods, continuing education and conference scholarships. In 2010 the Family Assistance Program expanded to add the first conference for adults with MPS and related diseases.

MOTIVATED TO MAKE A CHANGE

- Supported the membership to attend the 25th Annual Conference at Knott's Berry Farm in Buena Park, CA. The Society provided 19 stipends for families to attend and offset the additional cost of travel.
- Implemented the first adult conference: SPIRIT (Finding our Strength, Purpose, Independence, Resilience and Initiative Together).
- Issued three Extraordinary Experiences to individuals with MPS and related diseases. These members participated in their very own extraordinary experience, such as summer camps, school-supported trips or educational conferences.
- Awarded 20 \$1,000 scholarships through the sixth annual Continuing Education Scholarship Program to six individuals with MPS and related diseases, 11 siblings, two parents and one child of an affected adult.
- Funded 12 Family Assistance grants for medical durable goods. These included hearing aids, wheelchairs, a vehicle lift system, mattress, aqua therapy and more for an average of \$1,651 per grant.
- Promoted and financially sponsored three family initiated regional social events in the amount of \$750 per event.
- Maintained the White Rose Program, Honorary Flag flown over State Capitol and grief booklet series for families whose child passed away during the year.
- Published the eighth annual *Angels Among Us/Remembering Our Children* memorial tribute.
- Promoted all Family Support programs through the Web site, *Courage* articles and mailings.



Fran Madsen (MPS I, pictured top right) with her sorority during the 1st Annual MPS Cup

"Last year my parents held a fundraiser called the Minnesota MPS Cup—a charity hockey game and gala benefiting the Society's Family Support Program. While away at Michigan Technological University, I spoke to some of my sorority sisters about sponsoring a hockey player for the event.

"At the time I was the philanthropy coordinator for our chapter. It was the first time I had truly opened up about having MPS. Everyone was excited to have the opportunity to support a charity and a sister.

"We decided to host a soda can drive. With flyers in hand and speaking with fellow students, we coordinated an event that raised enough money to sponsor a hockey player.

"Four of my sorority sisters came to Minnesota to support the event. I don't think our fundraising would have been possible without the love of my sisters and the support of the Greek community at Michigan Tech. I feel more comfortable in my own skin after sharing this experience with my peers and family."

— Fran Madsen, MPS I

INSPIRED TO MAKE A DIFFERENCE

The National MPS Society extends our gratitude and recognition to walk/run and other fundraising organizers in 2010. Many events were organized and hosted by young philanthropists who set out to make a difference and were inspired by their personal connection with MPS or related diseases. Today, tools for fundraising have evolved through social media networks such as Facebook, YouTube, Firstgiving and e-mail. The **Fundraising Committee** embraces the fresh perspective our young philanthropists offer. Individually they succeeded; collectively we soared!



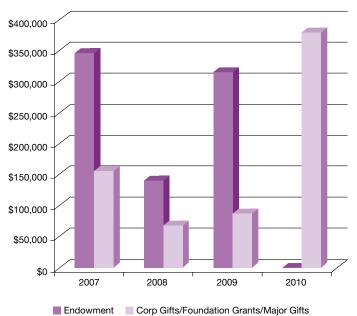
Robert Lukondi and his stepson, Michael Fisher, trained and ran their first 5K.
Robert and Michael completed the event in honor of Allison and Lacey Lukondi who have MPS III D and raised \$250.
Michael trained for months while working through his autism in this inspiring tribute for his cousins.

- Received a four-star charity rating from Charity Navigator, representing
 excellent performance that exceeds industry standards and performs better
 than most charities.
- Supported an active membership roster of more than 800 members.
- Raised approximately \$250,000 in funds for research and vast amounts of awareness through the 11th anniversary of the walk/run program. A total of 13 events were held around the country.
- Supported 44 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 approximately \$150,000 for research and Family Support programs.
- Raised more than \$85,000 from the eighth Annual Fund campaign, benefiting Family Support programs, legislative initiatives and general operating needs. The 2010 Annual Fund was the most successful in eight years!
- Continued the Sponsor a Child for a Cure program with five walk/runs in 2010, raising more than \$10,000. This program raised awareness and provided an opportunity for families to support the Society regardless of their location within the United States.
- Updated Event Guides to enable our membership success in their awareness and fundraising endeavors.
- Continued working with the Combined Federal Campaign and United Way to raise funds.
- Launched a fundraising booth at the annual conference.

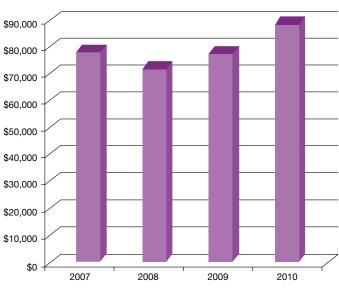
The National MPS Society is grateful to our many donors. Through strategic planning we are committed to working creatively increase revenue and to fulfill our mission. With diversified sources of revenue we are determined to support families and find treatments and a cure for MPS and related diseases. 2010 has seen increases in the Annual Fund, grant funding and major gifts. Other sources of revenue include: family fundraisers and walk/run events, membership, the Combined Federal Campaign, United Way, tributes and individual donations. We are encouraged as we move forward through 2011 and appreciate your continued support.

SOURCE OF REVENUE

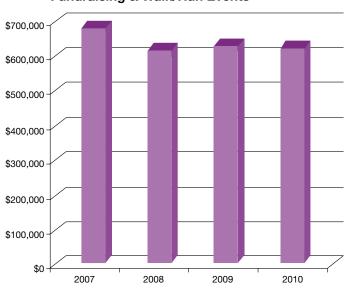
Corp Gifts/Foundation Grants/ Major Gifts/Endowment



Annual Fund



Fundraising & Walk/Run Events



The Society funded \$471,000 for critical research in 2010 through walk/run and other fundraising events. We received 45 letters of intent from researchers around the world and awarded seven new, two-year grants for \$60,000 each. The funding the Society provides has been and continues to be crucial as we move forward with our mission to find the cures.

DRIVEN TO EXPLORE INNOVATIVE IDEAS

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 2010 we received \$60,000 from the Caterina Marcus Foundation (www.caterinamarcusfoundation.org) to fund a general research grant, and \$52,000 from Insieme per Gabriel, an ML family foundation in Graglia, Italy, for an ML Partnership Grant. We are honored that both foundations selected the National MPS Society as partners to fund this very important research.

In support of the Lysosomal Disease Network's National Institute of Health grant research goals, the Society again funded \$25,000 for the Neuroimaging Core which will benefit the 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.



Thomas Howard, vice president of Fraternity Pi Betta Kappa, presents a check to MPS Society Development Director Terri Klein during a 440-mile bike-a-thon from Rockport, SC, to the National MPS Society office in Durham, NC. More than 15 fraternity members participated in this exhilarating effort as each shared in the joy of raising funds and awareness for MPS.

National MPS Society Funded Research Projects

Mark J. Osborn, PhD

University of Minnesota

Minneapolis, MN

Gene therapy for the central nervous system

 $pathology\ of\ MPS\ I$

Brett E. Crawford, PhD

Zacharon Pharmaceuticals, Inc.

La Jolla, CA

 $Gly cosamin og ly can\ in hibitors\ as\ substrate$

reduction therapies for MPS II

Elizabeth F. Neufeld, PhD

UCLA

Los Angeles, CA

Making a minigene suitable for gene therapy

for MPS III B

Calogera M. Simonaro, PhD, associate professor

Mount Sinai School of Medicine

New York, NY

A novel approach for the growth and expansion of bone marrow-derived mesenchymal stem cells in mucopolysaccharidoses type IV

and other mucopolysaccharidoses

Katrin Kollmann, PhD

Partnership Grant with

Insieme per Gabriele

University Medical Center

Hamburg-Eppendorf

Hamburg, Germany

Skeletal abnormalities in mucolipidosis II

 $alpha/beta\ pathomechanisms\ and\ the rapeut ic$

strategies

Andrea Ballabio, MD, PhD

Caterina Marcus Foundation Grant

Telethon Institute of

Genetics & Medicine

Naples, Italy

Modulating lysosomal function to treat

mucopolys accharidoses

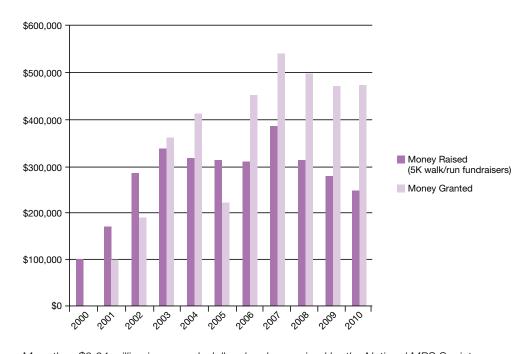
Alisdair B. Boraston, PhD

University of Victoria

Victoria, BC, Canada

Discovery and assessment of inhibitor-based chemical chaperones as potential agents for the

treatment of mucopolysaccharidosis III B



More than \$3.64 million in research dollars has been raised by the National MPS Society since 2000.



National MPS Society Legislative Committee visits with Congressional staff

Throughout the year, the **Committee on Federal Legislation** is determined to move forward with a strong voice on Capitol Hill. It is a large task to be initially heard; it is monumental to maintain strength and focus on significant legislation that will make a difference in the life of an individual with MPS or related disease.

The 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, Department of Education, Alliance for a Stronger FDA, National Organization of Rare Diseases, Social Security Administration and other federal agencies occur year round.

DETERMINED TO KEEP OUR VOICE STRONG

"The MPS Society is fortunate to have a growing body of young philanthropists who will be able to lead and inspire future generations. I ran for the board with the interest in helping establish a foundation in which young philanthropists can join the Society and contribute toward finding a cure for MPS and related diseases. The Legislative Committee was particularly appealing since I have been a life-long Washington, DC-area, resident, and I appreciate the impact advocacy and public policy efforts can have on furthering nonprofit organizations, such as the National MPS Society."

—Jeff Bardsley



Jeff Bardsley (MPS II), MPS Society board member and Legislative Committee member

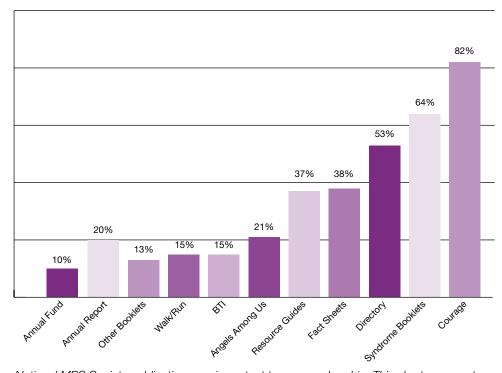
- Submitted language to the Senate Appropriations Subcommittee on Labor Health and Human Services included in the Significant Item Report for 2010.
- Advocated for the U.S. Senate to pass once again the resolution recognizing May 15, 2010, as National MPS Awareness Day.
- Collaborated with Social Security Compassionate Allowance personnel to broaden the definitions for MPS I, MPS II and MPS III.
- Supported insurance and healthcare legislative changes including: elimination of lifetime insurance caps; increased dependent coverage of children to 26 years of age; elimination of retroactive insurance cancellations; advocacy for funding of the Lifetime Respite Care Act; Cures Acceleration Network and Access to Clinical Trials Act for MPS patients.
- Advocated for a New Division of Biochemical and Genetic Diseases within the Office of New Drugs under the U.S. Food and Drug Administration (FDA).
- Provided public testimony to the FDA, "Why Clinical Study Designs are Needed for Treatment Development."
- Assisted with the formation of the Rare & Neglected Disease Caucus, Kakkis Everylife Foundation and the Cure the Process campaign.
- Supported the following new laws: Brownback/Brown Amendment and Keeping All Students Safe Act (an elimination of restraints in school).
- Joined the Rare Disease Legislative Advocates comprised of more than 170 rare disease patient organizations.
- Presented the National MPS Public Policy document to Congressional members.
- Expanded the Policy with Partners program through recruitment during the 25th Annual Family Conference in Buena Park, CA.
- Advocated Society positions with the National Institutes of Health and members of Congress.

EAGER TO INFORM

The mission of the **Education and Publicity Committee** is to provide an array of educational materials to our families and health-related communities. Our commitment is to provide the most current information about MPS and related diseases through multiple resource channels. Increasing awareness of these diseases is generated by embracing the forward movement of technology, such as social media, while not losing site of the essential one-on-one contact with individuals and families affected by MPS. This unique and comprehensive approach of disseminating accurate information allows us to better meet the needs of our members.

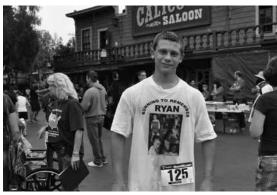
- Promoted the 4th International MPS Awareness Day on May 15, 2010.
- Designed and obtained results from the 2010 membership survey.
- Launched the new Web site.
- Obtained and profiled physician and specialist information from membership.
- Established the Outstanding Children Siblings and Relatives (OSCAR) award featured in *Courage*.
- Published fact sheets on *Special Education & IEP Tips*, *Feeding Issues* and *Uses of Developmental Testing*.
- Published the Society's quarterly magazine, *Courage*, and supplemental newsletters.

Publications Found Most Helpful



National MPS Society publications are important to our membership. This chart represents which publications are found to be most helpful in education, family support or facilitating collaboration with others.

"Fundraising isn't just about raising money, it is also about raising awareness. My family has spent more than 10 years raising awareness for MPS by hosting Ryan's Run in Pennsylvania in memory of my brother who had MPS III. This year I decided to start my own fundraiser.



Jeremy Mask running in memory of his brother Ryan (MPS III) at the MPS Walk/Run L.A.

I began by selling Ryan's Ribbon pins, and I hosted our first annual 'Concert for the Cure, Remembering our Angels.' The response from bands that want to participate was wonderful. I believe if you are dedicated and never give up, you can make a difference. You do not have to follow the current path—go instead where there is no path and leave a trail. Youth have so many opportunities in today's world. We are the next generation of philanthropists and it is up to us to assist in funding therapies and cures for MPS and related diseases. Choose to be a LEADER, not a follower; I have learned this from my family."

— **Jeremy Mask**, 17 (brother of Ryan, MPS III)

PHILANTHROPHY IS

When I opened the e-mail asking me to share my story as a "young philanthropist" for the National MPS Society, I was honored. A philanthropist is more than someone with millions of dollars, giving freely to an organization for which he or she feels passionate. With reflection, I realize that money does not limit philanthropy. Rather, it is defined by deeper offerings that I can freely give; a drive and dedication to a cause and a willingness to step out and act in ways to spread that cause's message.

With reflection, I realize that money does not limit philanthropy.

I became involved with MPS through my homework for a cancer research paper. I stumbled on a story of a child with MPS. As I presented my findings to my class, I realized the facts could not convey the feelings and heartache of families struggling with the disease. I longed to meet children with these diseases and to love them as much as possible.

I continued my education with MPS and related diseases by attending conferences and fundraisers, and helped to facilitate a family picnic. I grew very close with Kraig Klenke (MPS II) and his family and fell in love, over and over again, with every child I met. I soon was enjoying more frequent visits with Kraig and had the opportunity to accompany him to a special needs camp. My determination to educate others about MPS and related diseases continued through college. I took opportunities to share freely stories of these heroic children with a rare disease.

Philanthropy is doing everything you can to help people put a face on an unpronounceable disorder. Philanthropy is what you do when you love someone in pain or in need. Philanthropy is spreading awareness and sharing your story.

Several months ago, I stood in front of Kraig's casket to present the eulogy at his funeral. As I spoke about his life, I felt a renewed desire to tell others of the joy he brought to my life and the importance of continuing the fight. This cause is not one we can afford to let lose its momentum. We desperately need to continue research for treatments, and to support programs that help families as they redefine their lives to include MPS. Philanthropy is more than news stories showing your face as you present a large check to an organization. Philanthropy is doing everything you can to help people put a face on an unpronounceable disorder. Philanthropy is what you do when you love someone in pain or in need. Philanthropy is spreading awareness and sharing your story. Share your story, again and again, people will listen.



Leslie Phillips, friend and donor of the Society, with Kraig Klenke (MPS II)

DOING EVERYTHING YOU CAN TO HELP

In our life we are faced with many obstacles. Having determintaion and being inspired by loved ones can help carve a path for your future, regardless of life's obstacles. My younger brother, Lucas, has MPS III.

He has been an inspiration in my life because he struggles and endures; all the while his smile shines. He is driven to overcome his obstacles.

My parents have taught me to value hope and to create positive experiences from difficult situations. They have showed me that there are always opportunities to raise awareness. I was inspired to host my first dance-a-thon and participate in awareness presentations throughout the year. My ongoing philanthropy for MPS will continue through sibling forum support, fundraising and helping others while hoping someday a treatment exists for Lucas.

My life's epiphany has been my brother's determination with MPS. In my eyes he's just like any brother—he pulls my hair, wipes slobber on my face and rips my homework, but in my heart I know it is just his way of saying, 'Hey sis, I love you.' I know he means it when I look at him and see his big, shiny brown eyes, cute bushy eyebrows and see him always trying to smile or laugh. He is the greatest gift God could have given me. Lucas has taught me to appreciate each day, because tomorrow isn't promised to anyone.

— Chelsey Montgomery

My brother, Ben, is a fun-filled, charismatic little 8 year old. He loves watching truck movies, playing ball and spending time with the family. Although he sounds like a happy, normal 8 year old, he is hardly that. Ben suffers from MPS III just as my older brother Zach did (he passed away in 1997).

I began working with the National MPS Society to host a walk/run called 'Beat it for Benny.' I was inspired by Ben to reach out to our community and help fund research.

I was in charge of the initial planning at first, but as winter turned to spring and the event grew, so did the help! My family realized how determined I was when we surpassed our first financial goal and the event gained momentum. After securing the Colts cheerleaders and Indy race cars we knew this was going to be very special for Ben.

I realized at 18 years old I had become a young philanthropist. Even though I had many hats to wear I learned about raising awareness, volunteering and raising money to help a cause. Our efforts raised \$15,000 which will help fund a research grant. This walk/run changed my life in a way most people wouldn't understand. It taught me unbelievable leadership, teamwork, empathy and how one person can make a difference. Ben is determined to live his life to the fullest. I was inspired to become a philanthropist by his tremendous courage.



Chelsey Montgomery with her brother Lucas (MPS III)



Emily Durcholz with her brother Ben (MPS III) at the Beat It for Benny walk/run



The financial information below has been summarized for the year 2010. The Society is a 501c3 nonprofit public charity. The complete audited financial statements and IRS Form 990 are available on request.

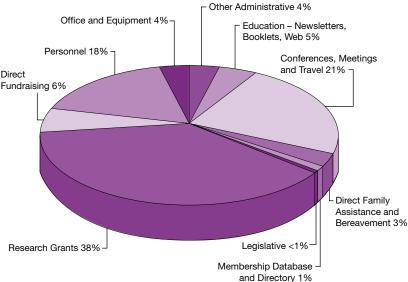
Financial Position

Assets		Liabilities	
Cash	\$ 792,844	Accounts Payable	\$ 14,357
Certificates of Deposits	1,008,000		
Prepaid Expenses	5,067	Net Assets	
Property and Equipment	5,889	Endowment	1,000,794
Long-Term Investment	1,035,651	Unrestricted Net Assets	1,245,079
		Temporarily Restricted	587,221
		Total Net Assets	2,833,094
Total Assets	\$ 2,847,451	Total Liabilities and Net Assets	\$ 2,847,451

Activities

Support and Revenue		Expenses	
Donations – General	\$ 480,670	Program	\$ 831,708
Donations – Family Assistance	37,371	General and Administrative	311,103
Donations – Research	77,539	Fundraising	75,676
Operating Grant	100,000	Total Expenses	1,218,486
Fundraising	493,903		
Membership Dues	33,830		
Conference Income	136,328	Change in Net Assets	\$ 484,033
Sponsored Revenue	298,000		
Investment Income	44,878		
Total Support and Revenue	\$ 1,702,519		
		Office and Equipment 40/	- Other Administrative 4%

Office and Equipment 4% **Functional Expenses** Personnel 18% Education - Newsletters, Booklets, Web 64,187 Conferences, Meetings, and Travel 256,289 Direct Fundraising 6% **Direct Family Assistance** and Bereavement 37,099 Membership Database and Directory 10.646 Legislative 5,986 Research Grants 457,500 **Direct Fundraising** 75,676 Personnel 220,789 Office and Equipment 43,016 Research Grants 38% -Other Administrative 47,298 **Total Functional Expenses** \$ 1,218,486



with sincere thanks to our supporters

In 2010, 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 2010. If we received your donation in 2011, you will be recognized in the next Annual Report.

Platinum

\$10,000 and higher
Pat and Janice Barrett
Bill and Ann Bresnan
Foundation, Inc.
BioMarin
R.A. Bryan Foundation
Genzyme Corporation
Insieme per Gabriel
David and Kiersten Lowe
Stacy Madison
Shire Human Genetic Therapies

Gold

\$3,000 to \$9,999

Angel's Hands Foundation, Inc.
Barney & Barney, LLC

Vaughn and Nancy Bryson
duAlaska, Inc.
KPMG, LLP
Mack Trucks, Inc.
Howard and Jean Madsen
McGraw-Hill Companies
Employee Giving Campaign
Joe and Jan Melnyk
Premier Source
Joshua and Sheri Sowden
Specialized Contraction Services Inc.

The Paul and Phyllis Fireman Charitable Foundation Wells Fargo Insurance Svcs. USA, Inc.

Silver

St. Andrew's Philoptochos Society

\$1,000 to \$2,999 Access TCA, Inc. Bill and Mary Andrews Dr. and Mrs. Mel and Millie Anhalt Christa Armstrong Automotive Booster Club B20 Bank of America Matching Gifts Wayne and Catherine Bardsley David Bernbaum Joseph and Kelley Capone CAS Associates Conagra Food Ingredients Co. Joan Cook Corporation Service Company Robert and Kathleen DeNight George Diehl

Dome Construction Corporation John Downing Carl Dummann Ernie and Debbie Dummann Dutch's Daughter, Inc. **Emerson Network Power** John Exner Betsy and Steve Fowler Stephen and Kimberly Frye Global Impact Gordon Hospital Robert and Monica Green Harris & Associates Scott and Lynn Honkins Wayne and Lori Hummel IBM Employee Services Center Independant Order of Foresters Courts No. 1279 The Inner Circle It Works Marketing, Inc. Jones Day Kajima Foundation Brian and Kristine Klenke Kohl's Lee Mount Vernon Sports Club Lawrence and Margaret Lessing Lessing's, Inc. Kevin and Tracey Litwin Robert and Marjorie Lovell Marshall, Gerstein, & Borun LLP MediResource, Inc. Jim and June Murphy Austin and Cheryl Noll Novo Construction Nutter, McClennen & Fish, LLP Jo Anne Paterniti Paul, Hastings, Janofsky & Walker, LLP Mark and MaryEllen Pendleton PG&E Corporation Chris and Timi Pieretti Pioneer Bank Crystal Polis Pool Tool, Inc. Progress Energy Service Company, LLC Quest Diagnostics Sam and Nancy Ramsey Raymond and Barbara Alpert Foundation

George and Athena Sarantinos

Servant Christian Community

Foundation

Siemens Caring Hands Foundation Squire Sanders William and Ann Stark Tracy Szemanski The Sanfilippo Syndrome Medical Research Foundation, Inc. Timothy's of Delaware, LLC UBS Financial Services, Inc. Valero Energy Wells Fargo Advisors, LLC WFB Ohio - Foundation Amy and Klane White Tom and Kim Whitecotton Wilmington Blue Rocks, LP Phyllis Wilson Carrie and Doug Yates

Leader \$500 to \$999

Abbott Laboratories Employee Giving Campaign Judith and Art Ackerman ADL Associates Alliant Energy Foundation, Inc. Stephen and Elizabeth Andress Frederick and Nancy Andrews Robert and Mariorie Austin Brenda Baker Balfour Beatty Construction Shawn Barkley Joel and LeeAnn Bernbaum Lorraine and Frank Bien Bruce and Michelle Bjorkman Boening Bros., Inc. Richard Bosse Julia Bradley Brazelton Investments, LLC Susan and Dennis Burke Cadent Medical Communications William and Jennifer Carter Rob and Diane Cassil Cedar Rapids Janitorial Service Central Assembly of God Church Clare Rose, Inc. Larry and Margaret Cohen Stacie Contreras Crandic Railway Co. Crossfire Consulting Corp. Ralph and Jane Daniels Deloitte Services, LP

Bill and Peggy Deremer

Kathy and Paul Dobrowolski

Charles and Josephine Ellard Thomas Engellenner Exeter Hospital, Inc. Janet Forde Forest Park School Lynn Gasaway Kevin and Andrea Gates Sharon Glasscock Jeffrey and Elizabeth Goodwin Kathleen Greenberg Greenwood Building Company Barbara Haas Wallis, Monica, Natalie and Nicole Hampton Susan Hanley Mark and Elizabeth Hanson Hewlett-Packard John and Bonnie Hoed Peggy and Stephen Holland Steve and Amy Holland Mark Hopkinson Chris and Mercedes Johnson Mr. and Mrs. Wendell and Karen Keith Larry and Susan Kirch Joel and Lisa Klessens John and Esther Kregel Lori Caldwell LeDoux Judith Leger Levelthree Solutions Yvonne Luu-BioMarin Douglas Macleod Daniel and Barbara Maher Joseph McCarthy Meeting Expectations, Inc. Microsoft Matching Gifts Program Mighty Docs Troy and Dianne Mitchell Todd Montigney Thomas and Colleen Moore Motorola Foundation Austin and Dorothy Noll John and Jeanette O'Brien Lewis Oliver Carlos Otero Norma and Lawrence Pack Mary Jo Page Joseph and Josephine Paterniti Thomas and Vickie Patterson Roche Diagnostics Corporation

Nina Rogers

Julie Dopheide

Rebecca and Michael Rover Sacred Heart Schools Atherton Tami Slawson Mike and Barbara Smith Gilbert Rider, Daniel Prybski and Erik Snyder Jack and Barbara Sorter State Farm Companies Foundation Dr. and Mrs. Larry and Mary Sweeney Gary and Jackie Tanghe Terra Properties, Inc. The Burt Family Foundation The Cleveland Foundation Thomson Reuters Truist Altruism, Connected Antoinette and Anthony Ventura Dawn Watkins Don and Lisa Wells Wells Fargo Bank, N.A. Adam and Michelle Williams Gordon Wingate Shoii Yano

Volunteer \$250 to \$499 Kevyn and Stacey Adams Mary Starr Adams Michael and Stephanee Adams Cynthia and Randy Anhalt Mr. and Mrs. Gerald and Susan Anhalt Sandra Babel Baird and Baird, PSC Peter and Jackie Bates Mark Beasom David Beatty Bethel United Methodist Church Dr. and Mrs. B.L. Bickham Cheryl Bien Blue Bee Designs Blueprint PM, LLC Michael Blum BMG Enterprises, LTD Nancy Bode Jill Bollwerk, Ryan and Tartlow Marie Bonville

Mike and Traci Bosch

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2010 FAMILY FUNDRAISERS

1st Annual Hinton Corn Hole Toss, hosted by Hank and Carolyn Hinton 1st Annual MPS Cup, hosted by Dave and Hope Madsen 2nd Annual Corn Hole Tournament, hosted by Rob and Lisa Muller Abel softball tournament, hosted by Kristi Abel Allison and Ashlev's fundraising event. hosted by Ashlev Restemaver Anderson harvest fundraiser, hosted by Dave and Cynthia Anderson Angel Aurora Laorenza's birthday event, hosted by Providence Schools Bluegrass Concert for MPS, hosted by Sharon Gilham Booster Arbonne fundraising event, hosted by Dawn Booster Bosch garage sale, hosted by the Bosch family Bowl for Caden. hosted by Troy and Dianne Mitchell Bozarth soccer camp fundraiser, hosted by Stephanie Bozarth Camelot Preschool MPS Day, hosted by Nancy Hutzell and the McNeil family Cameron's Car Show, hosted by Brian and Julie Mollett Cavanaugh bracelet show for Allison Kirch. hosted by Kathy Cavanaugh Chapin's lemonade stand for Blair, hosted by Grey Chapin Chesser lemonade stand, hosted by Bryn Chesser Ciroli jewelry show for Riley Muller, hosted by Jennifer Ciroli Clara's Courage hotdog stand, hosted by Jennifer and Shane Gibson Coin Drive for MPS. hosted by Cindy Miller Delaware Inaugural Walk/Run for MPS III, hosted by Carl and Jennifer Kapes Dopheide "Oklahoma" middle school performance, hosted by Emily Dopheide Fowler family charity dinners, hosted by the Fowler family

Ice Cream Corner fundraising event for Allison, hosted by John and Janelle Kunellis Jeans for Genes, hosted by BioMarin Johnson birthday celebration for Dorian and Wynn, hosted by the Johnson family Klenke 10th Annual Bowl-a-thon in memory of Kraig, hosted by the Klenke family Lee dance-a-thon, hosted by Griffen Lee Life Skills walk-a-thon for Logan Piefer, hosted by Kathy Greenberg Links for Lucas, hosted by Lew and Stacey Montgomery Logan's Heros, hosted by Ann Schnare Lukondi-Fisher walk/run 5K, hosted by Robert Lukondi Malone garage sale in memory of Louis Butts V. hosted by James and Joan Malone Muller family charity dinners, hosted by the Muller family NH Eye Associates fundraiser for Sasha, hosted by Linda Burtt Offenbacker charity dinners, hosted by the Offenbacker family Play for Taylor. hosted by the Woinarowski family Post Office Café Charities, hosted by Mark Lessing Race for Someone I Love, hosted by the Wojnarowski family Shots for Sean, hosted by Ernie and Debbie Dummann St. Anne's bake sale and craft fundraising event, hosted by St. Anne's School Tricky Tray fundraiser in memory of Risha. hosted by Elenie Constantinides William's Bicycle Race for Riley, hosted by Adam Williams

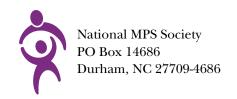
Holmes Elementary bake sale for Claria, hosted by Holmes Elementary School

2010 NATIONAL MPS SOCIETY WALK/RUN EVENTS

5 for FiVe memory run for Louis V, hosted by Michelle Storm-Butts
11th Annual Run for Erin, hosted by Stacy Peters
Beat it for Benny, hosted by Emily Durcholz
BioMarin MPS Run For Your Life, hosted by Kathy Ward
Inspiring lan's Hope, hosted by Shelly Maddox
Kassi's Cause, hosted by Trisha Offenbacker and Amy Adams
Mackenzie's Run for MPS, hosted by Steven and Jennifer Clarke

Miles for MPS, hosted by Laurel Radius
MPS Run for Their Lives, hosted by Scott Hardin and Steve Holland
MPS Walk/Run LA, hosted by Tami Slawson
Post Office Café Annual 5K/1M Run for MPS
River Run for Ryan, hosted by Jonathon and Marie Hunt
Strides for Sara, hosted by Monique Dickerson

Wojnarowski Annual Fund event, hosted by Sharon Glasscock



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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.

SYNDROME		ENZYME DEFICIENCY
MPS I	Hurler, Scheie, Hurler-Scheie	α-L-Iduronidase
MPS II	Hunter	Iduronate sulfatase
MPS III A	Sanfilippo A	Heparan N-sulfatase
MPS III B	Sanfilippo B	α- N -Acetylglucosaminidase
MPS III C	Sanfilippo C	Acetyl CoA: α-glycosaminide acetyltransferase
MPS III D	Sanfilippo D	N-Acetylglucosamine 6-sulfatase
MPS IV A	Morquio A	Galactose 6-sulfatase
MPS IV B	Morquio B	β Galactosidase
MPS VI	Maroteaux-Lamy	N-Acetylgalactosamine 4-sulfatase (arylsulfatase B)
MPS VII	Sly	β-Glucuronidase
MPS IX		Hyaluronidase
ML II/III	I-Cell, Pseudo-Hurler polydystrophy	<i>N</i> -acetylglucosamine-1- phosphotransferase