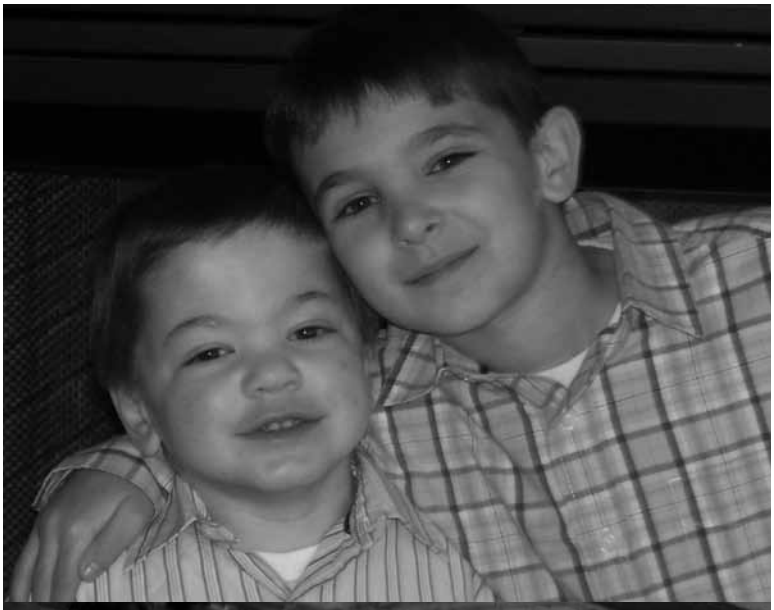
Celebrating 35 Years of Support for Families and Research for a Cure

NATIONAL MPS SOCIETY

2009

ANNUAL REPORT



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 straight-forward, 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 world-wide 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.

Ernest Dummann
PRESIDENT

Barbara Wedehase
EXECUTIVE DIRECTOR

Pictured on the cover: Riley (MPS II) and Donovan Muller; Grey and Blair (MPS III) Chapin

National MPS Society PO Box 14686 Durham, NC 27709-4686 877.MPS.1001 www.mpssociety.org

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)

FUNDRAISING — FUELING RESEARCH

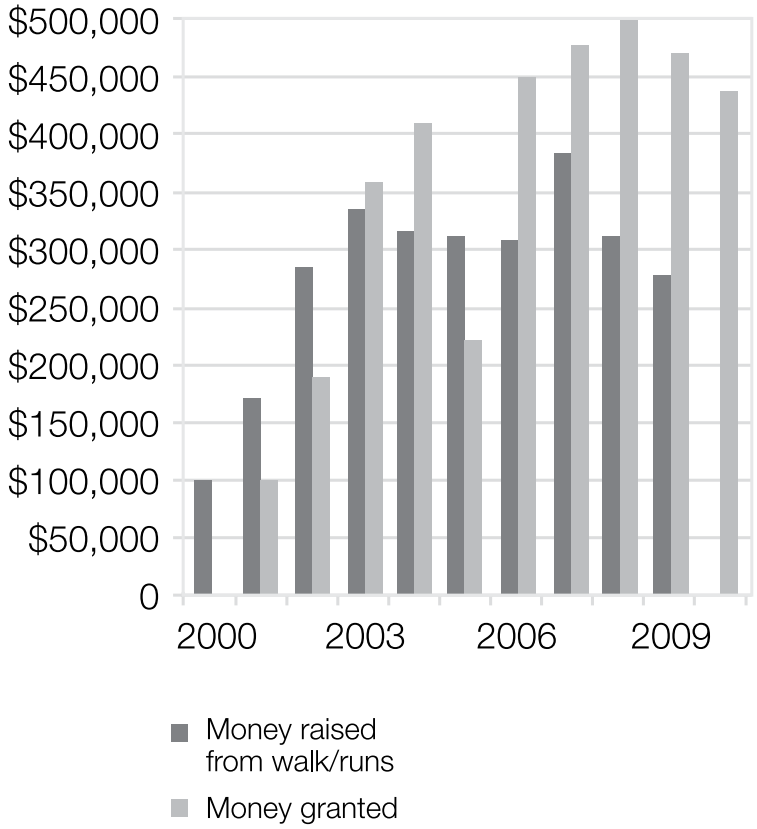
Sean Dummann (MPS III) and his family at the annual Shots for Sean golf tournament in Alaska

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.

Bryce Chesser (MPS II)

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, benefitting 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 Muller (MPS II) and Donovan Muller

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

The Scientific Advisory Board of the National MPS Society is comprised of 22 leading basic scientists and clinician scientists from the United States, Australia, Canada and Europe. These individuals volunteer their time and expertise, and provide peer review of submitted research grants, offer advice and recommendations on other research and therapy-related issues important to members of the National MPS Society, and present research and clinical updates and reviews when requested by the Society.

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

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.

COMMITMENT TO RESEARCH

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.

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

Waverly McNeil (MPS III) and Oliver McNeil (MPS III)

"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*

Staff from Shire Human Genetic Therapies participated with the Whitecotton family at the 2009 walk/run in North Carolina.

Samantha Slawson (MPS I) and Jacob Slawson (MPS I)

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*

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.

ADVOCATING FOR RESEARCH

- 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.

PUBLICIZING RESEARCH

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.

Marcia and Alena Galan (MPS VI)

- 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.

Sidney "Zach" Zachariah Haggett (ML II/III)

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*

Elizabeth Neufeld, PhD, UCLA
National MPS Society Scientific Advisory Board

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*

Emil Kakkis, MD, PhD,
Kakkis Everyday Life Foundation

FINANCIAL SUMMARY

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.

Financial Position

Assets	
Cash	$ 1,202,079
Certificates of Deposit	214,079
Prepaid Expenses	3,597
Investments	—
Property and Equipment	7,674
Long-Term Investment	1,015,921
Total Assets	**$ 2,443,350**

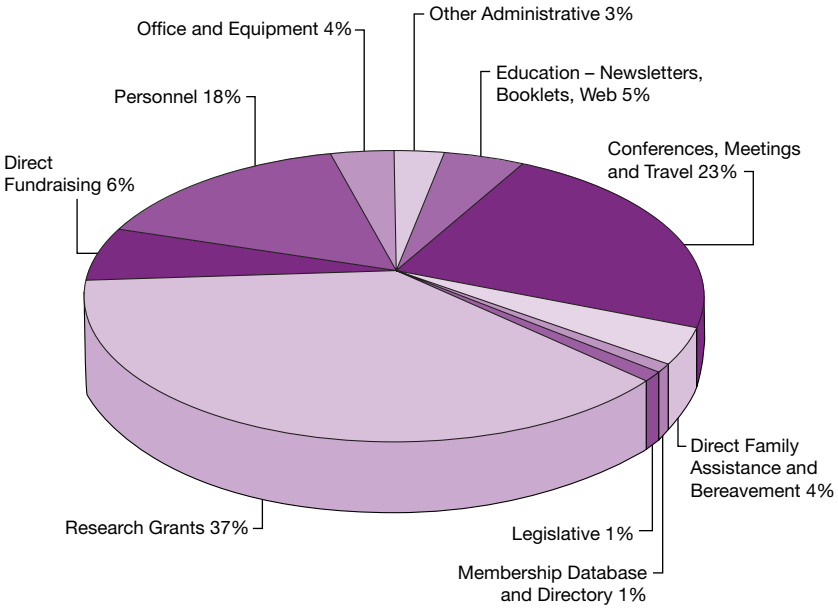
Liabilities	
Accounts Payable	$ 94,288
Net Assets	
Endowments	1,000,794
Unrestricted Net Assets	661,249
Temporarily Restricted	687,019
Total Net Assets	**$ 2,349,062**
Total Liabilities and Net Assets	**$ 2,443,350**

Activities

Support and Revenue	
Donations – General	$ 289,317
Donations – Family Assistance	23,201
Donations – Research	23,246
Donations – Endowment	315,000
Fundraising	550,800
Membership Dues	39,227
Conference Income	178,458
Investment Income	32,492
Total Support and Revenue	**$ 1,451,741**

Expenses	
Program	$ 1,020,663
General and Administrative	154,957
Fundraising	119,517
Total Expenses	**1,295,137**
Change in Net Assets	**$ 156,604**

Functional Expenses	
Education – Newsletters, Booklets, Web	$ 62,628
Conferences, Meetings and Travel	302,066
Direct Family Assistance and Bereavement	49,826
Membership Database and Directory	11,682
Legislative	9,939
Research Grants	478,000
Direct Fundraising	76,490
Personnel	213,998
Office and Equipment	46,398
Other Administrative	44,110
Total Functional Expenses	**$ 1,295,137**



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.

Platinum
$10,000 and higher

BioMarin
Bryson Foundation
Genzyme Corporation
Emil Kakkis and Jenny Soriano
David and Kiersten Lowe
Donald Myers
Shire Human Genetic Therapies
The Caterina Marcus Foundation, Inc.

Gold
$3,000 to $9,999

Angel's Hands Foundation, Inc.
Bemis Company Foundation
Employees Community Fund of Boeing California
Marsha and Robert Bozarth
John and Beth Brooks
Ernest and Debbie Dummann
Emerson Network Power
Jewish Communal Fund
Kercheville Foundation
KPMG, LLP
Joe and Jan Melnyk
Daniel Molinaro Foundation
Novo Construction
Premier Source
Mark Rasmussen
Jack and Barbara Sorter

Silver
$1,000 to $2,999

Bridget Aboel-Nil
Access TCA, Inc.
Amicus Therapeutics, Inc.
Bill and Mary Andrews
Dr. and Mrs. Mel and Millie Anhalt
Christa Armstrong
Balfour Beatty Construction
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Kajima Foundation
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Charles and Kendra Lesta
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Douglas Macleod
Margot K. Shriver Rev. Trust
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William and Karen McNeil
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Merck Partnership for Giving
Morgan Keegan & Company, Inc.
Glen and Karen Mowers
Jim and June Murphy
Austin and Cheryl Noll
Paul, Hastings, Janofsky & Walker, LLP
Mark and MaryEllen Pendleton
Pentacrest
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Barbara Pryor
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Saylor and Hill Co.
SC Johnson
Servant Christian Community Foundation
Siemens Caring Hands Foundation
Simpson Healthcare Executives
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Squire Sanders
William and Ann Stark
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Statewide Roofing
Darlene Sweeney
Tracy Szemanski
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Universal City Development Partners
UPS Foundation, Inc.
Wachovia Securities
Jason Waldrop
Walmart Foundation
Kathie Ward
Robert and Suzanne Washburn
Wells Fargo of California Ins. Svcs., Inc.
Amy and Klane White
Whitney Young Children's Foundation

Leader
$500 to $999

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Ann Alden
Alliant Energy Foundation, Inc.
America's Charities
Frederick and Nancy Andrews
Robert and Marjorie Austin
Vicki Ayers
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Kurt Bauerle
Joel and LeeAnn Bernbaum
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Center Elementary PTA
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Connemara Corp.
David and Kathryn Croson
Gerald and Lisa Curtin
Ralph and Jane Daniels
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Deloitte Services LP
Bill and Peggy Deremer
John and Beth Devoe
Diana Holdings, Inc.
Julie Dopheide
Sean Dummann
ECH Enterprises
Charles Evers
Federated Church Shepard Fund
Kim Fellows-Peake
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Janet Forde
Betsy and Steve Fowler
Fudge Family Foundation
Jean Gardner
Gregory Glyman
Jennifer and Micheal Goodwin
Gordon Hospital
Steve Guidry
John and Laura Guitar
Kjersti Hagen
Jason and Keri Hammen
Becky and Jeff Hardman
Jeffrey Hargett
Todd and Kirsten Harkins
Harris & Associates
Shawn Healy
Robert Hewitt
Hewlett-Packard
Steve and Amy Holland
Jonathan and Marie Hunt
Illinois Tool Works Foundation
Insulators and Allied Worker Local 45 Entertainment and Charity Fund
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JPMorgan Chase & Co.
Tanya Juarez
Elizabeth Karas
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Larry and Susan Kirch
Knabe for Supervisor
Fred and Joyce Koehler
Mary and Jaime Lambea
Lori Caldwell LeDoux
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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 Rileys' 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 Cochenour and Barbara Pryor*
BioMarin, Run for Your Life, *hosted by Kathie Ward*
Evan Reed Family Fun Run, *hosted by Laura Hiler*
Heartland 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 Jonathon 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*

Sowden family Walk for a Cure 2009

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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	*N*-acetylglucosamine-1-phosphotransferase