

# annual

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2011

# report



## NATIONAL MPS SOCIETY **MISSION**

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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.

## MPS **CLASSIFICATIONS**

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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.

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

### **National MPS Society**

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# collaboration

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WHEN WE THINK ABOUT COLLABORATION, the focus of this year's Annual Report, we visualize the National MPS Society as the hub of a large wheel with the spokes our many stakeholders. Over the years we have developed and nurtured relationships with individuals, companies and organizations—our many stakeholders. Through the support of this large community we have grown and developed many successful programs.

Our earliest collaborators were the pharmaceutical companies that developed treatments critical to the long-term health of individuals with MPS. Thanks to the generosity of BioMarin, Genzyme and Shire HGT the Society added staff which enabled the growth of our educational, awareness and family support programs. Our collaboration with the companies provide access to our members for patient surveys and advisory boards, patient education materials, and our ongoing Join the Search awareness program.

Other collaborators include family foundations and other rare disease organizations that allow our research dollars to extend further through partnership grants. Recipients of a partnership grant appreciate that the Society is working together with foundations and organizations, because it

shows joint commitment to our goal to cure MPS and related diseases. We are grateful to our research funding collaborations with the International Society for Mannosidosis and Related Diseases, the Ryan Foundation, the Caterina Marcus Foundation, Insieme per Gabriel, Ben's Dream Foundation and the Children's Medical Research Foundation. The Society led the development of the Lysosomal Storage Disease Research Consortium, a research initiative between lysosomal disease advocacy groups and the National Institutes of Health (NIH), to fund translational research. In recent years we have been an active participant in the Lysosomal Disease Network, including providing research support to complement their NIH funding.

Additional collaborations developed by both our Legislative Committee and our individual members with legislative staffers have led to awareness about the National MPS Society among our elected officials in Washington, DC. The work of the Society in Washington has resulted in increased funding to the NIH, support of policies affecting our members, and recognition of our annual MPS Awareness Day.

The Society is a leader among the International MPS Network, bringing together our sister MPS organizations. Sharing research

updates, in addition to mentoring new MPS organizations, provides equality of knowledge globally among individuals with MPS.

We are grateful for these many and varied collaborations, but are also mindful of the collaborations with our members and donors through fundraisers, family support programs and our new Planned Giving program. The stories you will read in this Annual Report about their interaction with the National MPS Society are uplifting and reinforce their commitment to follow our mission.

Thank you for your support and collaboration with the Society. ☘

*Steve Holland*  
**PRESIDENT**

*Barbara Wedehase*  
**EXECUTIVE DIRECTOR**

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## PICTURED ON THE COVER

*Texas MPS Regional Gathering, Annabelle Bozarth (MPS IV) and Aidan Carter (MPS II)*

# supporting *courageous families*

*“My son, Nick, received scholarship funding from the Family Assistance Program. This has helped lessen the burden of having to pay for college. The scholarship is just another example of how the Society assists our children in all phases of their lives.*

*We are grateful for the family support programs and their overall mission to improve the quality of life for our children.”*

*Dawn Checrallah*

**MOTHER OF NICK BOYCE (MPS I)**



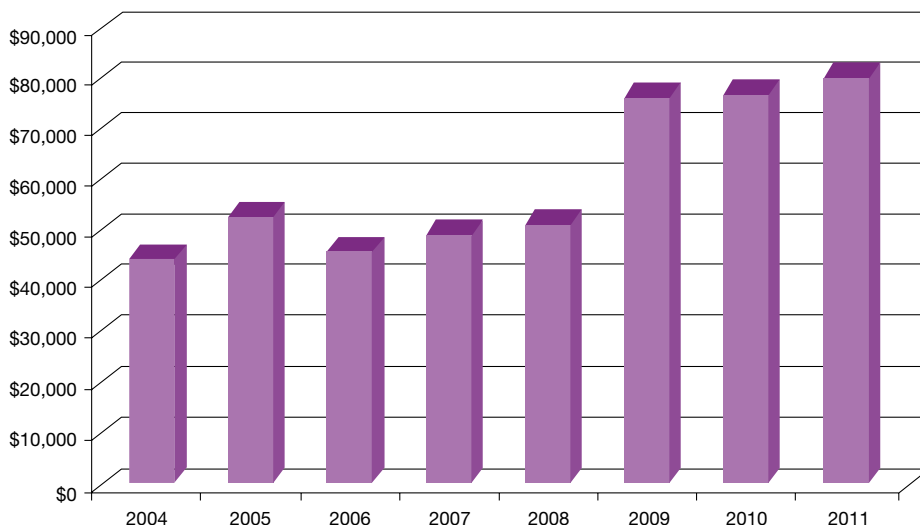
*Nicholas Boyce (MPS I)*

The **Family Support Committee** strives to meet the developing needs of individuals and families affected by MPS and related diseases. In 2011 the Family Assistance Program expanded. Since the program’s inception more than \$485,000 has been awarded for funding such items as medical goods, continuing education and conference scholarships. As the program continues to grow additional opportunities of support for our families becomes available.

- Supported the membership to attend the 25th Annual Family Conference in St. Louis, MO. The Society provided 17 stipends for families to attend and offset the cost of travel and hotel.
- Awarded twenty five \$1,000 Continuing Education Scholarships to members who are continuing their post high school education. Scholarships were awarded to eight individuals with MPS and related diseases, 15 siblings, one parent and one child.
- Funded \$23,060 in Family Assistance Program grants to help families obtain durable medical goods. Grants included scooters, hearing aids, an adaptive tricycle and an enclosed bed.
- The Medical Travel Assistance Program, in its inaugural year, provided funding for 13 families. Awards included \$5,809 for mileage and airfare reimbursement to families traveling more than 200 miles from home for medical appointments.

*continued >>*

**Family Assistance Program Dollars**



- >> • Promoted and provided \$1,271 in financial support for two family-organized, regional social gatherings.
- Published the 9th annual *Angels Among Us, Remembering Our Special Children* memorial publication.
- Continued the White Rose Program and grief booklet series for families whose child passed away during the year. Families also received U.S. flags flown over the capitol in Washington, DC, in honor of their child.
- Promoted all Family Support Programs through the website, *Courage* and direct communications with members.
- Presented Standing Ovation awards to individuals with MPS and related diseases. One individual from each MPS subtype is honored each quarter in *Courage* magazine for their courage, resilience, tenacity and passion for life as they face the challenges of having MPS.
- Issued Outstanding Siblings, Children and Relatives (OSCAR) awards, recognizing exceptional family members for support, dedication, compassion and love provided as they battle MPS with their family member. These individuals are recognized in *Courage*.

*“A regional event is a great way for local families to meet and get to know other MPS families. We still remember the first event we attended when Karina was first diagnosed with MPS. The Hodgkins’ family hosted a regional picnic at a park designed for special needs kids in Katy, TX. As a newly diagnosed family, it was so nice to be able to spend time with other families that were going through similar things with their kids.*”

*The last two years, we’ve hosted Texas MPS day at Morgan’s Wonderland in San Antonio, TX. It is a great theme park created for people with disabilities.*

*Both years, I applied for the Society’s grant, however, the second year I did not need to use it because of other sponsorships. Families had a wonderful time visiting with each other and enjoying the park.*

*It is vital for families to connect with each other; we need the support of other families going through similar issues. MPS is not an easy disorder to live with, but what makes it bearable are the people we have supporting us. The National MPS Society is committed to assisting families. With their support we were able to host our regional family gathering and continue to build and maintain a strong Texas MPS community!”*

*The Guajardo family*



*Angela and Karina (MPS III) Guajardo*



*The Hogan family at the St. Louis family conference*

*“We were incredibly grateful to receive a scholarship to attend the 2011 National MPS Society Family Conference. Trying to attend with three children can be extremely challenging, both logistically and financially, but the scholarship helped ease that burden so we could fully enjoy the conference. Our older boys also were blessed by meeting so many siblings and affected kids. They, as well as us, came away with a much greater appreciation of our MPS community as a family that we will embrace our entire lives.”*

*James and  
Melissa Hogan*

**MPS II PARENTS**

# paving a road to a cure



Vaughn and Nancy Bryson, Bryson Foundation

*“We are long-term donors to the National MPS Society through our family foundation. Although we are interested in helping families, our recent focus is research. We’ve followed the growth of the Society’s research program which is now awarding many grants each year, with a focus on young researchers. Our son benefits from this research and the treatments developed, and we’re pleased to see the Society building relationships with not just researchers, but also pharmaceutical companies.”*

*Vaughn and Nancy Bryson*

**BRYSON FOUNDATION**

Thanks to the generosity of our donors, the Society funded \$432,000 for critical research in 2011. We received 33 letters of intent from researchers around the world and awarded five new, two-year grants for \$70,000 each. The funding the Society provides has been and continues to be crucial as we move forward with our mission to find the cures.

The Society funded \$25,000 to support the Lysosomal Disease Network’s National Institutes of Health grant research goals. The funding is designated for the Neuroimaging Core, which benefits the four MPS projects. An \$8,000 MPS I Partnership Grant with the Ryan Foundation funded the University of MN project “Longitudinal Studies of Brain Structure and Function: The Effects of Genetic Mutations.” We are honored to again collaborate with the Ryan Foundation on a Partnership Grant.

*continued >>*



>> The Society also provided funding for post-doctoral fellows to attend scientific meetings, such as the American Society of Gene and Cell Therapy. In a letter to the Society from the American Society of Gene and Cell Therapy, Executive Director Mary Dean wrote, “The continued progress in gene and cell therapy to cure MPS and related diseases depends on support of students and trainees just beginning their own independent research. We are incredibly grateful for your support of these students.”

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.

**Vito Ferro, PhD**

University of Queensland  
Brisbane, Australia  
“Small molecule chaperones for ERT for MPS II”

**Alberto Auricchio, MD**

Fondazione Telethon  
Naples, Italy  
“Gene therapy of MPS VI”

**Patricia Dickson, MD**

Los Angeles Biomedical Research Institute at Harbor-UCLA  
Torrance, CA  
“Choroid plexus-directed gene therapy as a source of intraventricular NAGLU-IGF2 for MPS III B”

**Adriana Montano, PhD**

St. Louis University  
St. Louis, MO  
“Role of inflammation in pathogenesis of MPS IV A”

**Richard Steet, PhD**

University of Georgia  
Athens, GA  
“Blockade of cathepsin activity and TGF-beta signaling as a therapeutic approach for LSDs”



*2nd Annual Minnestoa MPS Cup*

# influencing supporters on capitol hill

*“The Mad Hatter Tea Fundraiser is an event our family hosts every other year. We are thrilled that the event continues to draw more new friends, raises more money and simply becomes more exciting! It started with just an idea to have a fun family fundraiser to raise money for MPS research in honor of Annabelle.*

*I was startled at the outpouring of time, commitment, donations and creativity that was generously shared from my community to make it a smashing success. At each event our friends, family and community have returned and many times brought new friends and family with them.*

*Watching our event grow each year is my confirmation that we have tapped into something everyone enjoys. I also have learned that we are not alone in this struggle to find treatments and a cure for MPS. The bonuses from the hard work, time and money have multiple levels of payoff that I treasure. Through philanthropy for MPS, I have developed relationships in my community that give us a solid foundation and a sense of confidence to forge courageously ahead.”*

*Stephanie Bozarth*

**MOTHER OF ANNABELLE (MPS IV)**

The **Committee on Federal Legislation** expands their strong message each year on Capitol Hill. The voice of the National MPS Society is recognized and respected on the Hill, and it is the committee’s job to be aware and take full advantage of capturing important moments while attending their annual Washington, DC, visits.

Legislative Committee platforms include medical, research, health services, special education and disability policies. Regular correspondence and personal visits with policy makers at the National Institutes of Health, Department of Education, Alliance for a Stronger FDA, National Organization of Rare Diseases, Social Security Administration and other federal agencies occur year round.

*continued >>*



*Kaitlyn O'Donnell (MPS IV) at the Mad Hatter Tea Party*





Ernie Dummann, Legislative Correspondent Dennis W. Sendros, Stephanie Bozarth, Jeff Bardsley and Debbie Dummann

*“I am not a doctor, chemist or any other medical professional, simply a daddy who is fighting to save his two little boys. My two sons, Jason and Justin, were diagnosed with MPS II.*

*The National MPS Society has been our source of strength, understanding and hope. A society we never wanted to be members of but are so grateful to have in our lives. The Society provides us the forum to meet with other MPS families. We learn about different medical challenges, progressive and innovative treatments to help our children, and how to develop the emotional strength an MPS family needs. The Society also gives MPS and each of our children a voice, a voice that deserves to be heard.*

*Through our foundation, Let Them Be Little, we are proud to partner with the National MPS Society to raise money to provide funding for important Society programs. We shouldn't have to struggle to educate the population of this unknown disease if we work together as a community.”*

*Jeff Leider*

**MPS II PARENT**



Jeff and Deena Leider with Terri Klein, National MPS Society development director

- >> • Presented the National MPS Public Policy Document given to Congressional members.
- Continued partnering with Rare Disease Legislative Advocates, a clearing house for patient advocacy groups to promote common legislative issues.
- Submitted language to the Senate Appropriations Subcommittee on Labor Health and Human Services included in the Significant Item Report for 2011.
- Continued the Policy with Partners program.
- Advocated for the U.S. Senate to once again pass the resolution to recognize May 15, 2011, as National MPS Awareness Day and received special acknowledgement from the House of Representatives.
- Introduced MPS and related diseases to the Rare Disease Caucus during a visit to Washington, DC.
- Provided educational webinar training to committee members on “How Advocacy Moves Government.”
- Continued to advocate for additional updates within the Compassionate Allowances Program by the Social Security Administration to include all MPS and related diseases.
- Initiated interviews with several consulting firms to aid the Society with its legislative advocacy efforts.
- Supported the following legislative changes in 2011: funding for the New Division of Biochemical and Genetic Diseases with the Office of New Drugs under the FDA; increased funding of the Lifespan Respite Care Act; legislation for the Creating Hope Act for Rare Pediatric Diseases; Medical Foods Equity Act; unlocking Lifesaving Treatments for Rare Diseases Act; reauthorization of the Prescription Drug User Fee Act.

# educating families

## *and health-related communities*

*“I did not realize when selected to intern with the National MPS Society how impactful this experience would be. I got off the plane in St. Louis for the family conference barely able to pronounce ‘mucopolysaccharidosis,’ but eager to learn as much as possible. I have learned that, while MPS invades many facets of your lives, it does not define you or your children. The conference provided me an opportunity to preview presentations and special sessions. I was touched by the three presentations given by siblings about fundraising, and realized it creates unbreakable family ties and allows one another to move forward. I listened to your questions during the clinical trial lectures and I, too, was desperately wishing there would be a promising trial for every one of your children. I cried with the MPS community as you remembered those who have lost their fight during the memorial ceremony. The National MPS Society was instrumental in a life-changing experience and because of this I have changed my Capstone Project to include MPS.”*

*Julie Jesiolowski, MS*

GENETIC COUNSELOR

The mission of the **Education and Publicity Committee** is to provide an array of educational materials that will benefit our members and health-related communities. Our commitment is to provide the most current information about MPS and related diseases through multiple resource channels. The National MPS Society embraces forward-moving technology by maintaining a new website, funding video materials and utilizing social media, while not losing sight of the essential one-on-one contact with individuals and families affected by MPS.

- Promoted the fifth International MPS Awareness Day on May 15.
- Completed website transfer launch.
- Published fact sheets on *Special Education, Hydrocephalus, G-Tube Feeding and ML Feeding*.
- Launched inaugural Facebook contest for MPS Awareness Day.
- Published the Society’s quarterly magazine, *Courage*, and supplemental newsletters.



*Through the National MPS Society, Julie Jesiolowski completed an internship while working on her master’s degree in genetic counseling from UNC Greensboro.*

# increasing awareness *in communities nationwide*

The National MPS Society extends our gratitude and recognition to walk/run and fundraising coordinators in 2011. Our fundraising program is an essential resource for supporting Society programs. Road to a Cure was the theme at many of our events, and the fundraising coordinators were very creative designing their events. Whether large or small, fundraising was successful at raising awareness about MPS and related diseases in communities nationwide. The Society embraces the fundraising evolution and provides our membership, donors and fundraisers the essential tools for success. Through online grant campaigns, social media outreach and superior website fundraising tools, the Society is driven to create and support fun and innovative fundraising initiatives.

- 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 700 members.
- Raised approximately \$520,000 for research and family support programs.

*continued >>*



*The Yard family during a Sponsor A Child For A Cure walk/run event*

*“Our son, Christian, was diagnosed with MPS II in 2011 at the age of 3. We decided to start small when it came to the amount of time we had available to begin our fundraising efforts for MPS.*

*By contacting the National MPS Society we found out about Sponsor A Child For A Cure. What started out as a small idea, to get involved in a support for a cure, soon turned into a big event. In September we ran a 5K race for Christian. The response to our outreach was amazing. Friends told friends, family told friends of family and coworkers spread the word. We raised \$20,000 and have become addicted to the thought of continuing our efforts with future events.*

*We have already planned our next fundraiser and have several community organizations that have offered to volunteer their support. Times are tough, but it is moments like these that we now cherish!”*

*Jim and Amy Yard*

**PARENTS OF CHRISTIAN YARD (MPS II)**



Luke Chambers (MPS I)

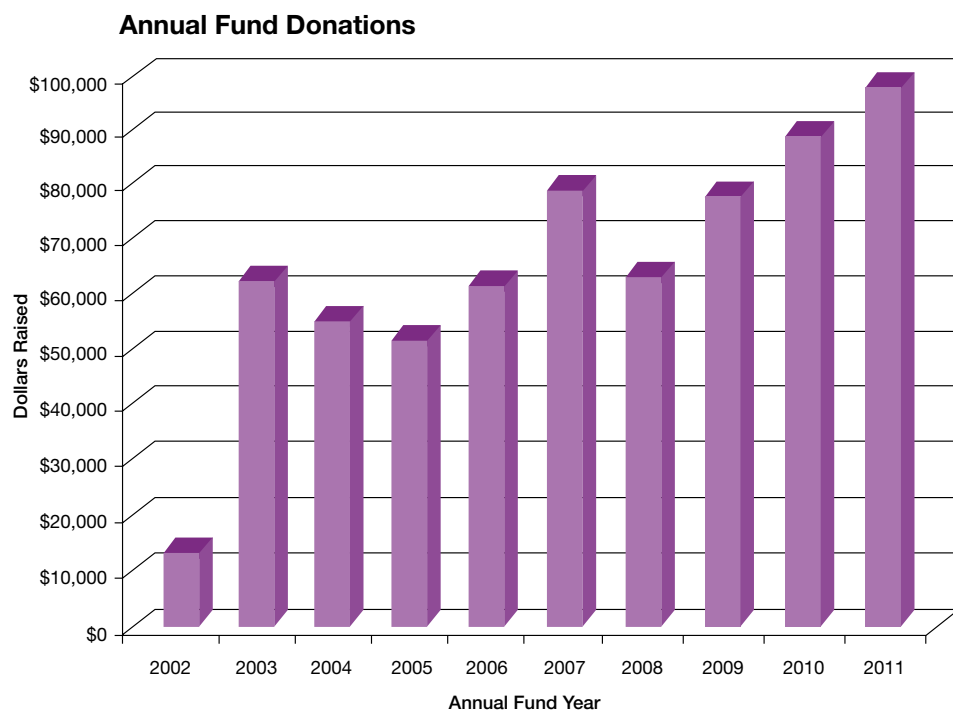
*“Our son, Luke, was diagnosed with MPS I in June 2006. We immediately became members of the MPS Society, but all along we wanted to become more involved. With the busy life that MPS brings, we felt that we didn’t have the time to make a difference. Then I read an issue of Courage that included information for the Friends and Neighbors (FAN) fundraising program. THIS WE CAN DO!*

*It was important for our family to do more for Luke, for all those affected by MPS, and the National MPS Society. We embraced this program because it was easy and did not consume a lot of time or planning. We shared our personal story along with a letter of appeal and e-mailed everyone in our e-mail address book and asked to please forward it to everyone in their address book. We also mailed more than 100 copies and addressed them to every friend, coworker, family member and healthcare provider we have. We had terrific success with the FAN program and, more importantly, raised awareness among our community.”*

*Bethany and  
Chet Chambers*

**PARENTS OF LUKE CHAMBERS (MPS I)**

- >> • Supported 13 walk/run events and 52 family fundraising events across the country.
- Raised more than \$95,000 in the ninth Annual Fund campaign, benefiting family support programs, legislative initiatives and general operating needs. The 2011 Annual Fund was the most successful to date.
- Continued the Sponsor A Child for A Cure (SACFAC) program with five walk/runs in 2011. In addition to raising more than \$25,000, SACFAC increased awareness and provided an opportunity for families to help the Society. This program allows families to raise money for a walk/run regardless of 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 new website with online fundraising tools.
- Implemented a new Planned Giving Program and the Rising Sun Legacy Circle for Society donors.



## PLANNED GIVING, SECURITY FOR OUR FUTURE

Planned Giving with the National MPS Society launched in 2011. Along with providing our first Guide to Planned Giving in our Inaugural year, five donors became part of the *Rising Sun Legacy Circle* with their planned gifts to the Society. Planned Giving helps donors maximize the personal benefits of charitable giving and allows the donor to make gifts they may not have thought possible. Individuals who make planned gifts to the National MPS Society, whether through their estates or other life-income arrangements, share a strong common bond of generosity that is promoting the Society's mission and providing security for future generations. Building this community of philanthropy helps our donors achieve their personal vision and desire to give.

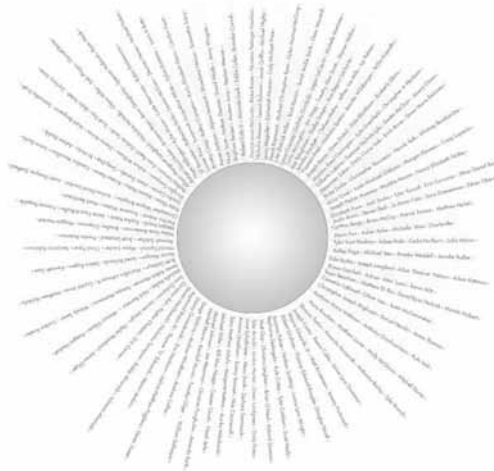
### Rising Sun Legacy Circle – 2011

Mary Starr Adams

Christa Armstrong

Becky Clarke

Emil Kakkis and Jenny Soriano



Steven and Jennifer Clarke and family during the Mackenzie 5K Run

*“I have been a member of the National MPS Society for 13 years, and made the decision to include the Society in my estate planning to recognize its important efforts and contributions, and to honor my brother who had MPS II.”*

*Christa Armstrong*

SISTER OF ULRICH (MPS II, 1919–1964)

*“I was so excited when my first granddaughter was born. I was looking forward to having a little girl to play with and take shopping to buy pretty dresses and beautiful dolls. After having two sons and two grandsons, I could now buy something other than planes, trains and automobiles. At age 2, Mackenzie was diagnosed with MPS III. I have designated in my will that each of my grandchildren will receive a sum of money. Mackenzie’s share will go to the National MPS Society in support of research. Mackenzie has given me many gifts; this is my gift back to her.”*

*Becky Clarke*

GRANDMOTHER OF  
MACKENZIE (MPS III)

# financial summary

The financial information below has been summarized for the year 2011. The Society is a 501c3 nonprofit public charity. Complete audited financial statements and IRS Form 990 are available upon request.

## Financial Position

Assets		Liabilities	
Cash	\$ 247,077	Accounts Payable	\$ 11,696
Investments	1,474,455		
Prepaid Expenses	4,077	Net Assets	
Property and Equipment	6,854	Endowment	1,000,794
Investment Restricted for Endowment	1,034,260	Unrestricted Net Assets	1,124,760
		Temporarily Restricted	629,473
		Total Net Assets	<b>2,755,027</b>
Total Assets	<b>\$ 2,766,723</b>	Total Liabilities and Net Assets	<b>\$ 2,766,723</b>

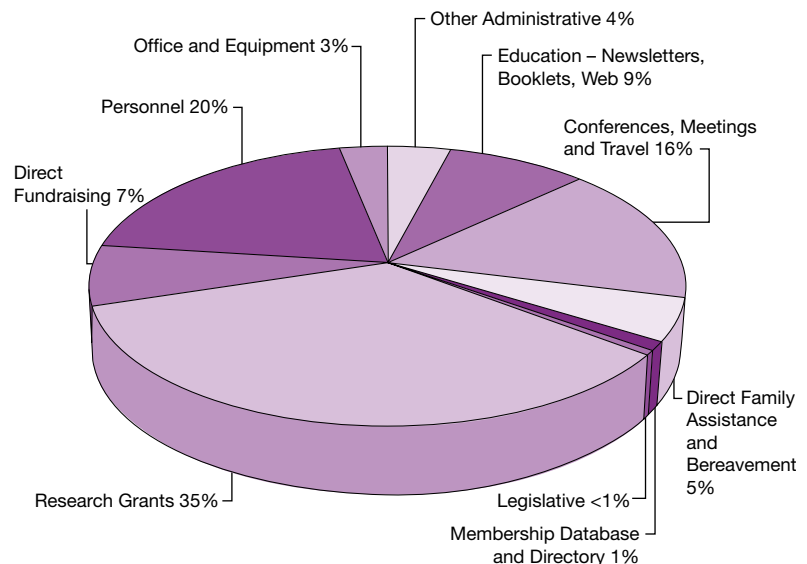
## Activities

Support and Revenue		Expenses	
Donations – General	\$ 87,511	Program	\$ 907,607
Donations – Family Assistance	82,165	General and Administrative	167,710
Donations – Research	61,622	Fundraising	136,157
Operating Grant	25,000	Total Expenses	<b>1,211,474</b>
Fundraising	623,422		
Membership Dues	34,065		
Conference Income	51,445		
Sponsored Revenue	93,872		
Investment Income	74,303		
Total Support and Revenue	<b>\$ 1,133,405</b>		

## Functional Expenses

Education – Newsletters, Booklets, Web	\$ 111,569
Conferences, Meetings and Travel	195,796
Direct Family Assistance and Bereavement	62,460
Membership Database and Directory	9,212
Legislative	4,999
Research Grants	419,200
Direct Fundraising	77,785
Personnel	238,518
Office and Equipment	40,655
Other Administrative	51,280
Total Functional Expenses	<b>\$ 1,211,474</b>

Change in Net Assets \$ (78,069)



## 2011 CONTRIBUTORS

### WITH SINCERE THANKS TO OUR SUPPORTERS

In 2011, 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 2011. If we received your donation in 2012, you will be recognized in the next Annual Report.

#### *platinum*

**\$10,000 to \$1,000,000**

BioMarin  
Bryson Foundation  
David and Kiersten Lowe Fund  
Will Ferrell  
Genzyme Corporation  
J.P. Morgan Chase & Company  
Kercheville Foundation  
Val and Marlene Salcher  
Shire Human Genetic Therapies  
Wilbur M. Havens Charitable Fund

#### *gold*

**\$3,000 to \$9,999**

Angel's Hands Foundation, Inc.  
Baltimore Community Foundation  
Barney & Barney, LLC  
Marsha and Robert Bozarth  
duAlaska, Inc.  
Employees Community Fund of Boeing California  
Fidelity Charitable Gift Fund  
Fred and Joyce Koehler  
KPMG, LLP  
Let Them Be Little Fund  
Howard and Jean Madsen  
Joe and Jan Melnyk  
Donald Myers  
Pi Kappa Alpha  
Premier Source  
Schneider Downs & Company, Inc.  
Irene Streblov  
U.S. Raceworks, Inc.

#### *silver*

**\$1,000 to \$2,999**

Access Sports Medicine and Orthopaedics  
AIG Matching Grants Program  
Airway Oxygen, Inc.  
Raymond and Barbara Alpert  
Bill and Mary Andrews  
Dr. and Mrs. Mel and Millie Anhalt  
Annie's Angels Memorial Fund  
Apache  
Automotive Booster Club B20  
Wayne and Catherine Bardsley  
Joan and Howard Beaufait  
Jon Berg  
Bishop-McCann

Joseph Boulos  
Stephanie and Austin Bozarth  
Broadband Capital Management, LLC  
R.A. Bryan Foundation  
Joseph and Kelley Capone  
Brooke Carter  
Drs. William and Jennifer Carter  
William P. and Judith Carter  
CAS Associates  
Rob and Diane Cassil  
Cynthia Cochran  
Kathleen Coolidge  
Cooper Industries Foundation  
Crossfire Consulting Corporation  
John Culver  
Rosemary and David Deahl  
Delmarva Power  
Ron and Barbara Dengel  
Shawn Donnelly  
Patrick Dunn  
Dutch's Daughter, Inc.  
Empire Merchants, LLC  
EZCorp Foundation  
Fairview Health Services  
Jon and Joya Favreau  
Andy Fickman  
Betsy and Steve Fowler  
Mr. and Mrs. Noelle and Jonathan Frye  
Stephen and Kimberly Frye  
Michael Hardin  
Harris and Associates, Inc.  
Coy Heldermon  
Scott and Lynn Hopkins  
Jonathan and Marie Hunt  
The Inner Circle  
ISI Alaska Section  
It Works Marketing, Inc.  
Bradenton  
John N. Kelly Ranglely  
Kajima Foundation  
Jennifer and Carl Kapes  
John Kelly  
Kids Under Construction  
Kiwanis Club of Poquoson  
Margaret Kramer  
Dawn and Philip Laurenza  
Lawrence and Margaret Lessing  
Lessing's, Inc.  
Kevin and Tracey Litwin  
Chuck and Nancy Lukondi  
Dave and Hope Madsen  
Allan and Sally Martin

Stephanie Mays  
Howard W. Mays Jr., P.C.  
MediResource, Inc.  
Chris Meyerpeter  
Microsoft Matching Gifts Program  
Miller Foundation  
Heath and Kimberly Monesmith  
Jim and June Murphy  
Kevin Newsom  
Austin and Cheryl Noll  
Michael O'Malley  
One Sky Community Services, Inc.  
Mary Jo Page  
Deborah Pascualano  
Jo Anne Paterniti  
Mark and MaryEllen Pendleton  
Pershing  
Thomas and Stacy Peters  
PG&E Corporation  
Charles and Judith Pitman  
Pool Tool Incorporated  
Portland Community Charitable Corporation  
Portsmith Regional Hospital  
Suzanne Priebsatsch  
Progress Energy Service Company, LLC  
Sam Raimi  
Sam and Nancy Ramsey  
Paul Rector  
Karen Rosenfelt  
George and Athena Sarantinos  
Katherine and George Schwander  
Ira Schwartz  
Elliot and Jacquie Segal  
Stebbing & Stebbing  
Marla Stevens  
Steve Sunenblick  
Tracy Szemanski  
The Burt Family Foundation  
The Hubbard Broadcasting Foundation  
Truist Altruism, Connected  
Ron Trujillo  
UBS Financial Services, Inc.  
Unitarian Universalist  
Congregation of Atlanta  
US Bancorp Foundation  
Employee Matching Gift Program  
Valero Energy  
Johanna Vespe  
Wells Fargo Bank, N.A.

Westlake Hills Presbyterian Church  
WFB Ohio - Foundation  
Amy and Klane White  
Crow White  
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## 2011 FAMILY AND FRIENDS FUNDRAISING EVENTS

### 1st Annual Concert for MPS VI,

hosted by Marla Stevens

**1st Annual Timmy's Toss,** hosted by Amy White

**2nd Minnesota MPS Cup,** hosted by Dave and Hope Madsen

**3rd Annual Clara's Courage hotdog stand,** hosted by Shane and Jennifer Gibson

**3rd Annual Mad Hatter Tea Party,** hosted by Stephanie Bozarth

**A Wish for Evan,** hosted by John and Kristi Abel

**Allenwood School May carnival,** hosted by Judy Harms

**Allison Kirch's birthday event,** hosted by Abigail Cohen

**Bastrop School fundraiser,** hosted by Ms. Pogue

**Breakfast with Santa,** hosted by Kids Under Construction

**CABi clothing fundraiser,** hosted by Lynn Hopkins

**Cadyn's Car Wash,** hosted by Rita Luna

**Cayden's birthday fundraiser,** hosted by Cayden Duncan

### Caring Hands employee fundraiser,

hosted by Siemens Healthcare

**Caswell MPS Awareness Day,** hosted by Heidi Caswell

**Celebration Day for Rare Diseases,** hosted by BioMarin

**Channel car wash,** hosted by Kandy Channel

**Concert for a Cure,** hosted by Jeremy Mask

**Cook candle fundraiser,** hosted by Angie Cook

**Deer Creek Walk-a-thon,** hosted by Lake Forest Middle School

**Dress Down Friday, Providence Schools,** hosted by Dianne Renzi

**FAN program,** Chet and Bethany Chambers

**Fowler charity dinners,** hosted by Jamie Fowler

**Gillis half marathon walk,** hosted by Mary Gillis

**Ice Cream Corner and Bridge Club,** hosted by Janelle Kunellis

**Jeans Day at USF-Holland,** hosted by Mark and Tina Mulder

**Johnson Halloween Bash,** hosted by Chris and Mercedes Johnson

**Kelly family wedding fundraiser,** hosted by Ryan and Kelly Curry

**Laff-a-thon,** hosted by Stacey Montgomery

**Lemon Drops grand opening,** hosted by Glenn and Kathleen Miller

**Lukondi gift basket auction,** hosted by Elena Lukondi

**McDermott bake sale and birthday party fundraiser,** hosted by friends of Jill McDermott

**McCreary Dress Down Day,** hosted by Laura McCreary

**Muller family fundraisers,** hosted by Robb and Lisa Muller

**Olivia's 9th birthday bash,** hosted by Wes and Jill Lovell

**Palm Pointe Student Council event,** hosted by Palm Pointe Schools

**Piefer lemonade stand,** hosted by the Piefer family

**Play for Taylor,** hosted by Matt and Rachel Wojnarowski

### Post Office Café fundraising events,

hosted by the Lessing family

**Rockland Boulders,** hosted by Janeen Eisler

**Roller Derby for MPS,** hosted by Shelly Maddox

**Rylie's Runners,** hosted by Lyle and Jade Hays

**Shots for Sean memorial golf tournament,** hosted by Ernie and Debbie Dummman

**SF Giants fundraising event with Keenan Cahill,** hosted by BioMarin

**Silge lemonade stand,** hosted by Emily and Allie Silge

**Studebaker Middle School fundraiser,** hosted by the students of Studebaker Middle School

**Sowden Walk for a Cure,** hosted by Josh and Sheri Sowden

**Together in Harmony,** hosted by G. Lora Grooms

**Vespe wedding donations,** Anthony Aulisa and Johanna Vespe

**Yard family Sponsor A Child For A Cure event,** hosted by Jim and Amy Yard

## 2011 NATIONAL MPS SOCIETY WALK/RUN EVENTS

**12th Annual Run for Erin,** hosted by Stacy Peters

**5 for fiVe, Race for a Cure,** hosted by Michelle Storm-Butts

**Action for Aidan,** hosted by Brooke and Jennifer Carter

**Beat MPS 5K Walk/Run Delaware,** hosted by Carl and Jennifer Kapes

**BioMarin MPS Run for Your Life,** hosted by Kathie Ward

**Cameron's 5K Walk/Run for Cures,** hosted by Julie Mollett

**Kenton's Cause,** hosted by Amanda Fults

**It Works 1st Annual MPS 5K Run,** hosted by Kate Martin

**Laps for Lucas,** hosted by Lew and Stacey Montgomery

**Miles for MPS,** hosted by Steve and Laurel Radius

**MPS Run for Their Lives,** hosted by Scott Hardin and Steve Holland

**MPS Society Walk/Run LA,** hosted by Tami Slawson

**Post Office Café 5K Walk/Run for Mark and Casey Lessing,** hosted by Kerri Rose and Mark Lessing

**River Run for Ryan,** hosted by Jonathon and Marie Hunt

**Strides for Sara,** hosted by Monique Dickerson



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