

annual 2012 report



National
MPS
Society

Support for Families. Research for a Cure.

NATIONAL 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.

National MPS Society

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TIME MAGAZINE, IN ITS JULY 8–15, 2013, ISSUE on that quintessential topic, “The Pursuit of Happiness,” noted: “Acts of kindness flick the happy switches in our brains: studies have shown that people who volunteer are more satisfied with their lives and are less likely to be depressed. Happier people, in turn, are likelier to help others.”

Although we haven’t studied the many people who volunteer for the National MPS Society, we do have anecdotal comments from them. They tell us how gratified they feel, whether it’s a parent calling a newly diagnosed parent and helping them through the chaos of reactions and appointments, or a family hosting a walk/run for the first time.

“Actions speak louder than words.” This is exemplified by our volunteers who continue their work for the Society year after year.

One person whose actions speak loudly and who has touched many families is Rachel Wojnarowski (page 7). Rachel has hosted a family picnic for 11 years in honor of her daughter, Taylor, who has MPS III. For many families, this is their first time to meet another MPS parent and share information, and for their children to play together.

Tami and Sammi Slawson (page 11) have hosted a walk/run for 13 years. Not only do they volunteer their time and expertise to the Society, but they have trained a huge number of volunteers who help them with their event. Those volunteers subsequently passed on information about our diseases and brought more people to the Slawson run. Talk about a lot of happy people!

Every person has something to give back. Andrew Cochenour’s (MPS II) grandmother, Flossie Pryor, makes bibs for the Society to sell for our kids. Amy White has corporate and other board experience which provides critical expertise for serving on the Society’s committees. And Liam Cavanaugh has amazing technical skills.

Read about all these wonderful people and more in this year’s annual report, which focuses on our volunteers. We wish we could highlight all of you who volunteer, but know that the National MPS Society is stronger because of each of you. And we know—because you’ve told us through your words and actions—that volunteering for the Society and helping to fulfill our mission makes you happy.

Thank you to all our volunteers! You helped make 2012 a banner year.

Steve Holland
PRESIDENT

Barbara Wedehase
EXECUTIVE DIRECTOR



The Gift of Time—Building an Alliance of Extraordinary Support

The FAMILY SUPPORT COMMITTEE strives to meet the developing needs of individuals and families affected by MPS and related diseases. In 2012 the Family Assistance Program expanded to include emergency relief assistance. Since the program's inception, more than \$565,000 has been awarded for funding items such as medical goods, continuing education and conference scholarships. As the program continues to grow additional opportunities of support for our families will become available.

- Supported 16 families to attend the 27th Annual Family Conference in Boston, MA. These conference scholarships offset the cost of registration, travel and hotel.
- Awarded 25 \$1,000 Continuing Education Scholarships to members who are continuing their post-high school education. Scholarships were awarded to 11 individuals with MPS and related diseases and to 14 siblings.
- Funded \$23,969 in Family Assistance Program grants to help families obtain durable medical goods. Grants included hearing aids, glasses, stair glide, Rifton Tryke, Ergo chairs, vehicle modifications and dental work.
- Provided funding for 15 families through the Medical Travel Assistance Program. In 2012, the program awarded \$6,605 for mileage and airfare reimbursement to families traveling more than 200 miles from home for medical appointments.
- Promoted and provided \$2,250 in financial support for three family organized regional social gatherings in Utah, Illinois and Ohio.
- Awarded \$9,908 to 15 families for emergency relief efforts.
- Published the 10th 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.
- Recognized individuals with MPS and related diseases with Standing Ovation awards. One individual from each MPS subtype is honored each quarter, acknowledging their courage, resilience, tenacity and passion for life as they face the challenges of living with MPS.
- Issued Outstanding Siblings, Children and Relatives (OSCAR) Awards, recognizing exceptional family members for their support, dedication, compassion and love as they battle MPS with their affected family member.
- Promoted all Family Support Programs through our website, *Courage* and direct communications with members.
- Funded five Extraordinary Experience applications for children and young adults with MPS. In 2012, the Society awarded \$4,405 for camps, airfares to the International MPS Symposium and a MAC laptop.



After serving six years on the board of directors, I chose to continue my work with the Society by serving on committees. I currently am a member of the Family Support, Education/Publicity and Governance committees. It is gratifying to develop and implement policies and programs that support so many of our families, as well as strengthen the goals of the Society.

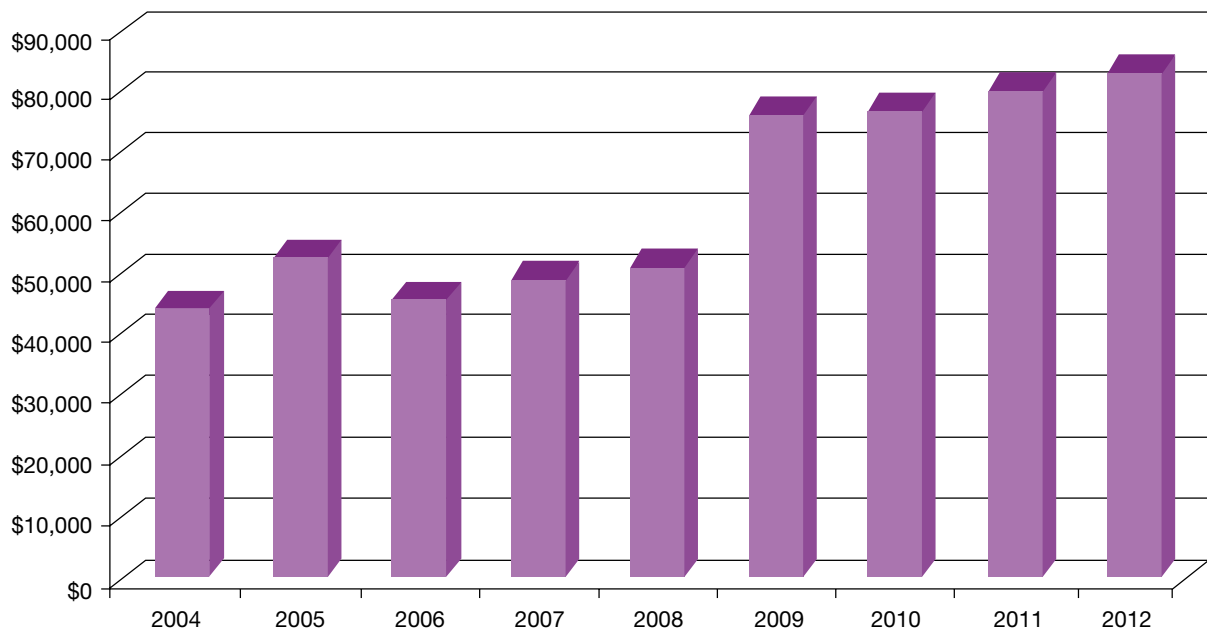
Amy White



It is very important for our family to volunteer whenever we can to raise awareness for the National MPS Society. International MPS Awareness Day is one of those opportunities that we can embrace. Our family wore 'Team John' T-shirts, passed out M&Ms that said 'Help us cure MPS,' and we sent packets of Text to Give information to our family and friends. John's brother plays lacrosse and the entire team devoted a game to our family and wore stickers on their helmets. At John's school, the entire classroom, principal and staff embraced our awareness efforts. We are educating one person or one community at a time.

Sheila Thornton

Family Assistance Program Dollars



04 Perseverance for a Brighter Future— Paving the Way Through Research

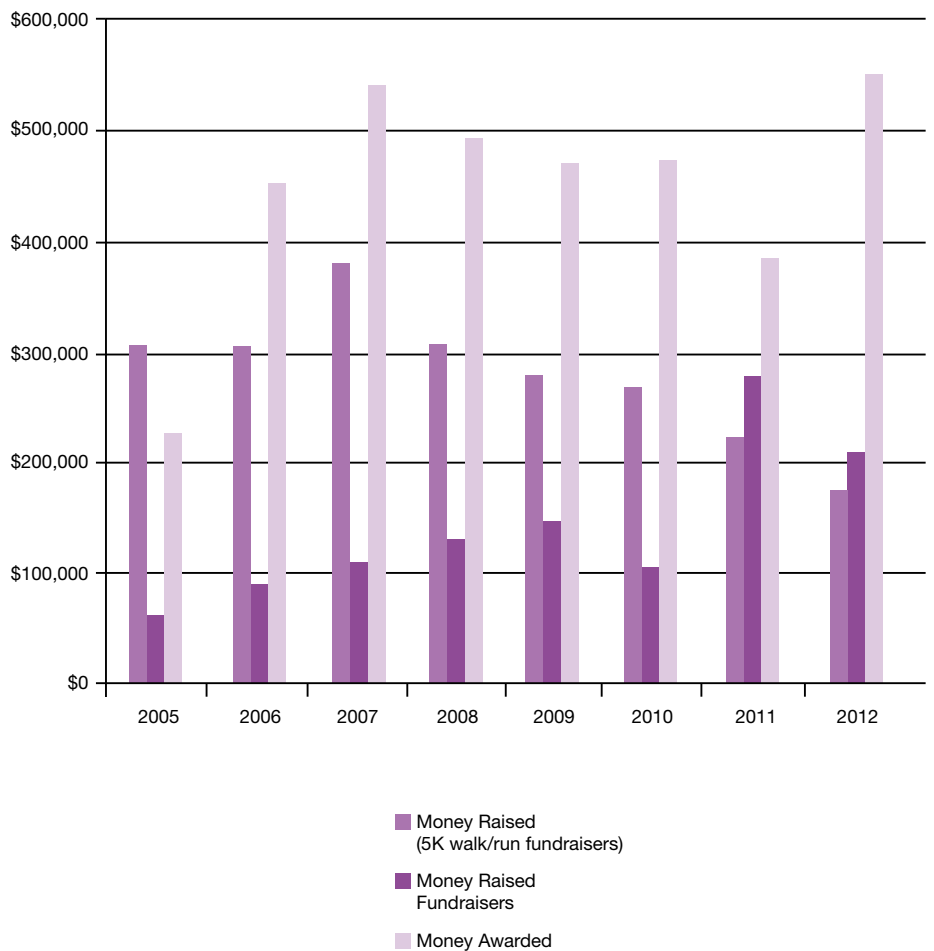
The National MPS Society awarded \$547,000 in grant funding in 2012. The funding the Society provides has been and continues to be critical as we move forward with our mission to find the cures. We received 16 letters of intent from researchers around the world for the three new grants offered.

The Society also funded \$25,000 to support the Lysosomal Disease Network’s National Institutes of Health grant research goals. This funding is designated for the Neuroimaging Core, which benefits four MPS projects. An additional \$15,000 was allocated for a mucopolipidosis partnership grant with the Gandhi Foundation to Dr. Sara Cathey at Greenwood Genetics Center for her study, “PTC 124 for nonsense mutation suppression in ML II and III cultured fibroblasts.” A \$10,000 partnership grant with the Ryan Foundation funded the University of Minnesota project, “Brain Structure and Function in Developmentally Normal Children Ages 4–7.” The Society also provided funding for post-doctoral fellows to attend scientific meetings, such as the American Society of Gene and Cell Therapy.

Gustavo H.B. Maegawa, MD, PhD
 Johns Hopkins School of Medicine,
 Department of Pediatrics
 Baltimore, MD
 “Induced-neuronal (iN) cells as tools
 to study the pathogenesis of neuro-
 logical manifestations in MPS II.”

Shunji Tomatsu, MD, PhD
 Nemours Children’s Clinic – Delaware
 Valley of the Nemours Foundation
 Wilmington, DE
 “Development of Long Circulating
 Enzyme Replacement Therapy for
 MPS IV A.”

Brian Bigger, PhD
 Stem Cell & Neurotherapies Group
 Manchester, UK
 “Evaluation of high-dose genistein
 aglycone in the treatment of
 mucopolysaccharide disease
 types III A, B and C.”



The Volunteer Effect— Making an Impact on Capitol Hill

The COMMITTEE ON FEDERAL LEGISLATION expands their strong message each year on Capitol Hill. The voice of the National MPS Society is now recognized and it is the committee's job to be aware and take full advantage of capitalizing on 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 partnering with Rare Disease Legislative Advocates, a clearing house for patient advocacy groups to promote common legislative issues.
- Provided an educational webinar for members available online through our legislative toolkit, "In District Legislative Advocacy."
- Submitted language to the Senate Appropriations Subcommittee on Labor, Health and Human Services included in the Significant Item Report for 2012.
- Advocated for the U.S. Senate for the continued passage of the resolution to recognize May 15, 2012, as National MPS Awareness Day, presented by Sen. Lindsey Graham (R-SC).
- Attended the Rare Disease Caucus briefing and Rare Voices Gala.
- Participated in the annual Capitol Hill visit to meet with 21 senators' offices representing 18 states.
- Supported the following legislative efforts: legislation for the Creating Hope Act for Rare Pediatric Diseases; Transforming the Regulatory Environment to Accelerate Access to Treatments Act; and Fast Access to Specialized Treatments. Each was a component of the Safety and Innovation Act signed into law in 2012.
- Participated in Rare Disease Day activities in Washington, DC.
- Submitted formal comments to the Agency for Healthcare Research and Quality technical brief on enzyme replacement therapy for lysosomal storage diseases.
- Increased timely e-mail alerts to members for click-and-send action alerts to senators and congressmen.



When our grandson, Conner, was diagnosed with MPS II, we had no previous knowledge of this disease. Our family quickly found the National MPS Society. They provided the answers and support which helped us to understand and deal with this diagnosis. Since then, the Society has been there for all of us in times of frustration, pain and even joy. The funding provided by the Society has helped to make possible research by dedicated physicians and scientists who work to provide vital needed treatments for our children. The camaraderie and support among our families helps to make living with this disease tolerable. The dedicated staff guides us through the development and hopes for the future of the organization. In short, the Society provides the support, hope and courage for families which would not otherwise exist.

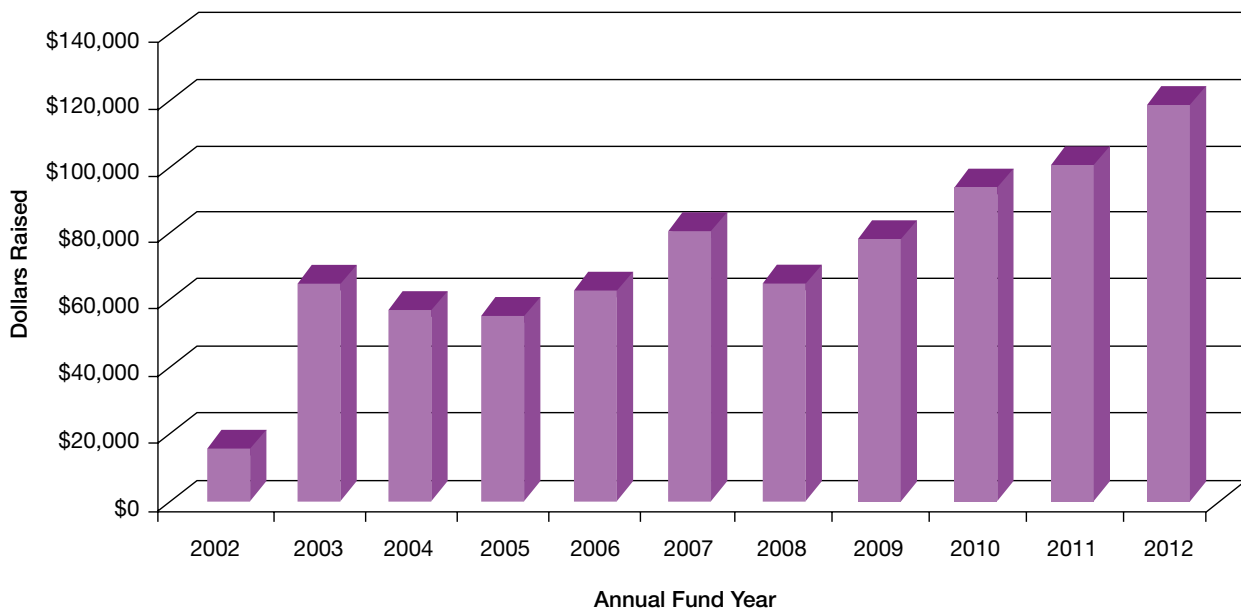
Mel and Millie Anhalt

06 The Value of Volunteering— Inspiring Donors Through Action

The National MPS Society recognizes our 2012 walk/run and other fundraising organizers with a big THANK YOU! Our fundraising program provides essential resources for individuals hosting fundraisers. This past year we incorporated Text to Give, a mobile donation tool, as an additional resource for fundraising events, allowing supporters to donate in 60 seconds. Whether large or small, every event makes a difference. The Society continues to embrace the fundraising evolution and provides our donors, membership and fundraisers with cutting-edge tools for success. The FUNDRAISING COMMITTEE is dedicated to providing support through the following programs: walk/run events, fundraisers, Champion a Cure, Annual Fund, Planned Giving, Friends and Neighbors, Combined Federal Campaign, United Way and our inaugural programs of Mobile Giving and Courage Pages.

- Received a three-star charity rating from Charity Navigator, representing a good performance that exceeds or meets industry standards and performs as well as or better than most charities in its cause.
- Supported an active membership roster of more than 700 members.
- Raised approximately \$380,000 through walk/run and fundraising events.
- Supported 17 walk/run events and 57 fundraising events that included: Ask Events (two-hour benefit that educates donors and asks for donations), bake sales, bowl-a-thons, concerts, golf tournaments, recitals, trunk shows and many others.
- Raised more than \$118,000 through the 2012 Annual Fund campaign.
- Introduced Mobile Pledging, raising almost \$10,000 with this new technology platform.
- Launched Courage Pages on the Society’s website, informative, individual family web pages designed to raise awareness and funds for the Society.
- Updated our website with new planned giving information, Courage Pages and current event guides.
- Received Combined Federal Campaign application approval for the eighth consecutive year.
- Continued working with donors to receive funds through the Combined Federal Campaign and United Way.
- Produced the National MPS Society video series, which includes “Journey of Hope,” compassionate family stories about MPS and inspiring fundraising efforts.

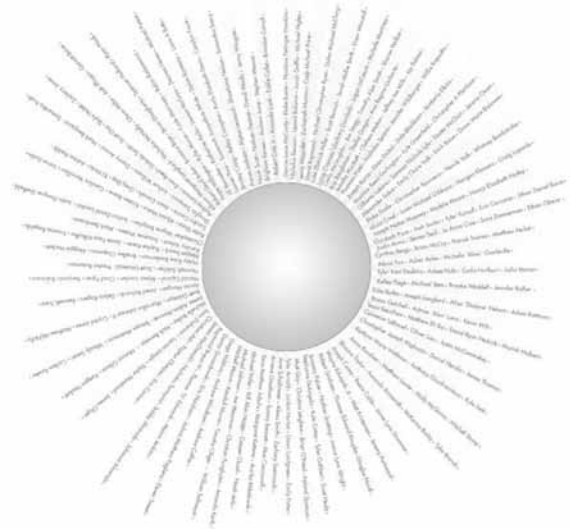
Annual Fund Donations



Planned Giving— Security for Our Future

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

- Formed the Planned Giving Committee that met semi-annually, which includes members, board and staff.
- Launched Planned Giving website tools to help members and friends of the Society become acquainted with Planned Giving and gifts the Society accepts.
- Introduced Planned Giving through *Courage*, on membership renewal forms and through the Annual Fund drive.



Purplicious Regional Family Gathering

Our family has volunteered to host the Ohio family picnic for 11 years. We are inspired to do this in honor of our daughter, Taylor, who has MPS III. This past summer we had a catered lunch, gift bags for attending families, carnival games, prizes, root beer floats and cotton candy. A professional photographer volunteered her time to take a family photo of each family, as well as a group photo. It was truly a day of encouragement and fun. We are thankful for the grant provided by the National MPS Society to assist in the cost of this monumental day.

Rachel Wojnarowski

Communication Is Key—Connecting Through Education and Technology

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 vibrant website, developing video materials and utilizing social media, while not losing site of the essential one-on-one contact with individuals and families affected by MPS.

After seeing the positive impact the National MPS Society has made for so many families, I knew this was an organization I wanted to get involved with. I also wanted to look beyond the traditional volunteer roles and leverage my technical background. Because the Society uses technology in so many areas, such as education, research grants, scholarships, fundraising and helping to facilitate communication between families affected by MPS and related diseases, I learned that there were many areas where I could help. After working with the Society this past year, I have come to appreciate even more all they are doing for families. I look forward to continuing to play a small part in my volunteer efforts. I would encourage others to ask themselves if their own unique skills also could be used to help the Society.

Liam Cavanaugh



- Promoted the sixth International MPS Awareness Day on May 15, 2012.
- Launched the second annual membership contest for MPS Awareness Day, called the “Self Expression Artwork Facebook Contest.”
- Developed online video sessions from the Annual Family Conference, held in Boston. Presentations were made available to our families through the National MPS Society YouTube channel.
- Introduced a Social Media Policy.
- Published fact sheets on “Wishes” for our children.
- Produced “Journey of Hope,” the first in a new MPS Society video series which focuses on the stories of those affected by MPS and related diseases and shares the perspective of both families and researchers.
- Completed additional website enhancements and introduced an online legislative toolkit for members.
- Created teleconferencing opportunities at the Boston family conference.
- Introduced the Presidential Proclamation of Courage, honoring children with MPS and related diseases for their accomplishments.
- Published the Society’s quarterly magazine, *Courage*, and supplemental newsletters throughout the year.
- Introduced two new features in *Courage*. Volunteer Spotlight and Congratulations to Our Graduates.

The financial information below has been summarized for the year 2012. The Society is a 501c3 nonprofit public charity. The complete audited financial statements and IRS Form 990 are available on request.

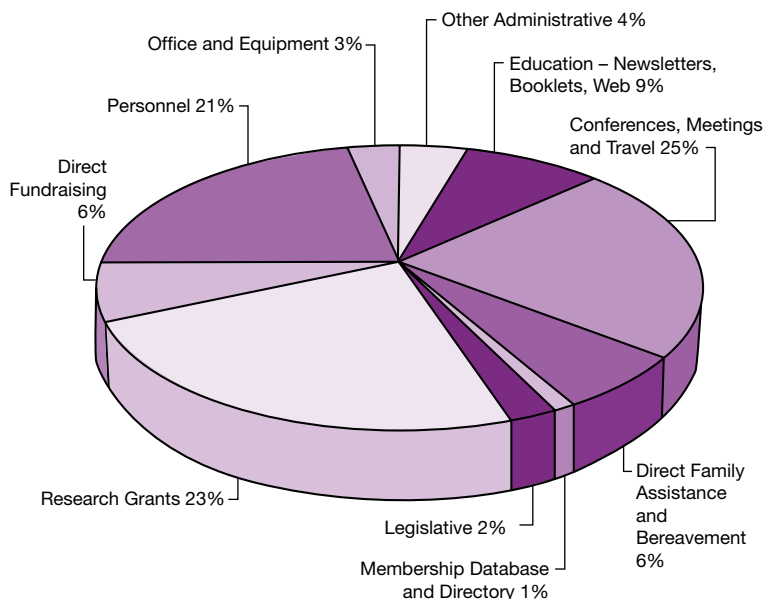
Financial Position

| | | | |
|--------------------------|---------------------|---|---------------------|
| Assets | | Liabilities | |
| Cash | \$ 343,885 | Accounts Payable | \$ 13,680 |
| Investments | 1,192,354 | | |
| Contributions Receivable | 24,800 | Net Assets | |
| Prepaid Expenses | 9,625 | Unrestricted Net Assets | 908,383 |
| Property and Equipment | 3,070 | Temporarily Restricted | 676,459 |
| Endowment Investments | 1,025,582 | Permanently Restricted – Endowment | 1,000,794 |
| | | Total Net Assets | 2,585,636 |
| Total Assets | \$ 2,599,316 | Total Liabilities and Net Assets | \$ 2,599,316 |

Activities

| | | | |
|----------------------------------|---------------------|-----------------------------|---------------------|
| Support and Revenue | | Expenses | |
| Donations – General | \$ 114,791 | Program | \$ 952,190 |
| Donations – Family Assistance | 46,857 | General and Administrative | 187,431 |
| Donations – Research | 86,216 | Fundraising | 135,794 |
| Operating Grant | 20,000 | Total Expenses | 1,275,415 |
| Fundraising | 510,895 | | |
| Membership Dues | 30,717 | | |
| Conference Income | 200,200 | | |
| Sponsored Revenue | 50,000 | | |
| Investment Income | 46,345 | | |
| Total Support and Revenue | \$ 1,106,021 | Change in Net Assets | \$ (169,394) |

| | |
|---|---------------------|
| Functional Expenses | |
| Education – Newsletters, Booklets, Web Conferences, Meetings and Travel | \$ 319,981 |
| Direct Family Assistance and Bereavement | 73,915 |
| Membership Database and Directory | 8,948 |
| Legislative | 32,236 |
| Research Grants | 291,064 |
| Direct Fundraising | 73,601 |
| Personnel | 267,149 |
| Office and Equipment | 44,094 |
| Other Administrative | 51,821 |
| Total Functional Expenses | \$ 1,275,415 |





I became involved with the National MPS Society in 2010 when I was asked by Kimberly Frye, mother of one of my students in my BMod Fitness program (Jack, MPS II), if I would be interested in

providing childcare services for the annual family conference at Knots Berry Farm. Helping with quality onsite childcare is what got me there for day one, but it was the amazing smiles and personalities of the children I met who have brought me back to each conference since. Recently I choose to become involved in a fundraising effort to help the Society. In collaboration with the Frye family, we developed a joint Poker Run and Poker Walk and raised \$19,000. We plan to host this event again in 2013.

I am honored to have become a part of the MPS family. This experience has renewed my desire to give as much of myself as I can to help all those affected by MPS and related diseases.

Jerry Bennett

I recently served as Genzyme's patient advocacy volunteer coordinator for Camp Courage at the National MPS Society family conference. I had 30 employees respond, expressing a desire to make a more personal contribution to the communities we serve. Our 'day jobs' can feel fairly removed from the people our products help, and Camp Courage offered us a way to meet some of the children and families whose lives are positively impacted by the treatments we make.

Our roles as volunteers were simple—have fun with the kids and maintain a safe environment. This was such a tremendous opportunity to interact with the children and gain a better appreciation of the challenges some families face.

Lisa O'Donnell, Genzyme



Genzyme volunteer at Camp Courage



Soon after Andrew was diagnosed with MPS II, I became a member of the National MPS Society and attended my first conference. Our family really enjoys giving back. My daughter has hosted Andrew's Rock 'n Roll in Ohio, and I have made bibs for many of our MPS children to wear. One of the highlights of the family conference in 2009 was walking into the banquet and seeing bibs on children everywhere! Volunteering for the MPS Society does not have to involve a lot of time or money; small things mean a lot too.

Flossie Pryor



Haley Miller with Austin Noll III (MPS III A)



Annabelle Bozarth (MPS IV A)



As I got to know my stepdaughter, Jennifer (ML III), and her friends, I began to ask myself, ‘What can I do to help the National MPS Society?’ Though I am not a great speaker, I share the Society’s story with people in my network.

I also live near the Society’s office in Durham, and run errands and do some heavy lifting for the small and hard-working staff.

By attending conferences, it has been rewarding to chaperone the young adults on offsite activities during their SPIRIT conference. When I volunteer, I take away more than I give.

As a volunteer, you do not have to be an expert at any one thing, or have a lot of money or time. Be helpful to others. Make an effort to make a difference. The rewards will be yours.

Michael Schleiter

Before I joined the National MPS Society when my children were diagnosed, I observed that Society volunteers were hard working and dedicated to finding a cure for these horrid diseases. Our volunteers continue to be motivated, thanks to the progress we have made. Volunteers are the building block of support while we strive for treatments. When we reflect back on hosting 13 years of the National MPS Society Walk/Run LA, we realize our success was achieved and milestones were reached because of our volunteers. I gladly volunteer for the Society where I can, whether committee work or through other fundraising efforts. As my daughter Sammie says, ‘Volunteer today with the National MPS Society to save a child’s life!’

Tami and Sammie Slawson



2012 Contributors— With Sincere Thanks to Our Supporters

In 2012, 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 2012. If we received your donation in 2013, you will be recognized in the next Annual Report.

platinum

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

BioMarin
Bryson Foundation
David and Kiersten Lowe Fund
Genzyme Corporation
Jareds Foundation
Kerchville Foundation
Shire Human Genetic Therapies
Team Sanfilippo

gold

\$3,000 to \$9,999

Angel's Hands Foundation, Inc.
Barney & Barney, LLC
John Downing
duAlaska, Inc.
Hampton Township School District
Innogive Foundation
It Works Marketing, Inc.
Larry and Susan Kirch
KPMG, LLP
Matthew and Shannon McNeil
Joe and Jan Melnyk
Donald Myers
Orsini Pharmaceutical Services, Inc.
Premier Source
Sam and Nancy Ramsey
Paul and Katie Rector
Streblo Family Foundation
Carole Vogler
Wells Fargo Bank, N.A.

silver

\$1,000 to \$2,999

Raymond and Barbara Alpert
Bill and Mary Andrews
Dr. and Mrs. Mel and Millie Anhalt
Christa Armstrong
Automotive Booster Club B20
Baltimore Community Foundation
Wayne and Catherine Bardsley
Glenn Barquet, MD, PA
Karen and Wilbert Bateman
Mr. and Mrs. Ronnie and
Jaye Beck
Ross and Hilary Berning
Bishop-McCann
Marsha and Robert Bozarth
Stephanie and Austin Bozarth
R.A. Bryan Foundation

CAS Associates
Christian Lon Foundation for
MPS Children
Community Foundation of
Greater Memphis
Joan Cook
Cooper Industries Foundation
Craftworks Restaurants
Lynn Crumling
Shawn Donnelly
Patrick Dunn
Dutch's Daughter, Inc.
Elia Margoth Espinola
Five Star Painting Services
Betsy and Steve Fowler
Luis and Angela Guajardo
Hamilton County Firefighters
Local 4416

Harris & Associates
Christopher and Catherine Heffron
Steve and Amy Holland
Darlene Holliday
Robert Holliday
IBM Employee Services Center
The Inner Circle
Dave and Gerry Johnson
Kajima Foundation
Lawrence and Margaret Lessing
Kevin and Tracey Litwin
Dorothy Mask
McCormick and Co, Inc.
Microsoft Matching Gifts Program
Heath and Kimberly Monesmith
Monsanto Fund
Mark and Angie Morris
Wayne and Pam Morris
Jim and June Murphy
New York Knights of the Grip,
Nassau, Inc.
Austin and Cheryl Noll
John and Sandy Owen
Mary Jo Page
Deborah Pascualano
Jo Anne Paterniti
Mark and MaryEllen Pendleton
Linda and Dave Perry
PG&E Corporation
Don Phillips
Presbyterian Healthcare Services
Craig and Rosalie Rogers
George and Athena Sarantinos

SCS Specialized Contracting
Services
Siemens Caring Hands
Foundation
Jack and Barbara Sorter
St. Paul's United Church
William and Ann Stark
The Charles and Ann Foundation
The Isabel Jurado Foundation
Herbert Tilsner
Towers Watson
True Speed Enterprises
UBS Financial Services, Inc.
US Bank
Mr. and Mrs. Don and Lisa Wells
Wells Fargo Advisors, LLC
Amy and Klane White
Tom and Kim Whitecotton
Jim and Amy Yard
Young Family Foundation

leader

\$500 to \$999

Mary Starr Adams
Rosita Adams
Thomas Adams Jr.
AIG Matching Grants Program
Alaska Mill and Feed Co.
America's Charities
Frederick and Nancy Andrews
Cynthia and Randy Anhalt
Stephen Aselage
Robert and Marjorie Austin Jr.
Brenda Baker
Keith and Debra Banks
Rita Basom
Joel and LeeAnn Bernbaum
Bruce and Michelle Bjorkman
Boeing Brothers, Inc.
Richard Bosse
Mark and Sandy Byrd
C&M Construction
Cambridge Biomarketing
Rob and Diane Cassil
Juan and Lisa Cenicerros
Clare Rose Inc.
Walter and Gretchen Clayton
Sharon Cochenour
Margaret Cohen
Crossfire Consulting Corp.
Gerald and Lisa Curtin

Ralph and Jane Daniels
Patrick and Debi Dee
Jerry and Sue Deutser
Kathy and Paul Dobrowski
Jani Domire
Julie Dopheide
Ernie and Debbie Dummann
Elegity, Inc.
Steven and Deborah Estes
Layne Fess
Floyd A. Boyd Co.
Lennie Forkas
Ian and Shelly Fritz
Joseph Gamble
GenR Media
Global Impact
Tom and Anne Gniazdowski
Gordon Hospital
Karen Graven
Greater Houston Community
Foundation
Greenwood Building Company
Pam Gross
Trista Hannan
Adam and Jodi Harrington
Larry Harrison
Seamus Hayes
Hewlett-Packard/YourCause
Wayne and Lori Hummel
Idem Translations, Inc.
Julie and William Johnson
Joy Communications
Scott Keaton
Wendell and Karen Keith
Patrick and Stephanie Kinser
Kevin Kirkpatrick
Michael Schleter and Terri Klein
Kroger, Inc.
E. Paul and Marcelle Kunst
Dawn and Phillip Laorenza
Lori Caldwell LeDoux
Judith Leger
Howard and Jean Madsen
Menasha Corporation Foundation
Mike's Septic Service, Inc.
Morrison & Foerster Foundation
Network for Good
Austin and Dorothy Noll
Fred O'Donnell
Bernie O'Hara
Lewis Oliver, Jr.

Thomas and Vickie Patterson
Penn Liberty Bank Tricia Lefkof
Principal Combined Fund
Organization
Pro-Spect Technical Services
Progress Energy Service
Company, LLC
Barbara Pryor
Kenneth Ray
Sherrie and Tony Roman
Tami Slawson
Mike and Barbara Smith
Kathleen Stark
Michael and Suzanne Stevens
Dr. and Mrs. Larry and
Mary Sweeney
Stuart Swiedler and Judy Weiss
Tracy Szemanski
The Burt Family Foundation
The Chemist Shoppe, Ltd.
Sheila and Michael Thornton
Timothy Schaffer, Inc.
Charles Vite, DVM, PhD
Dorsey and Brenda Walker
Watercraft Irrigation, Inc.
Dawn Watkins
Barbara Wedehase
Claude and Roselyn Wells
David and Nannette Wheelis
Gordon Wingate
John and Brenda Winkler
Eric and Linda Wright
Roy and Zezee Zeighami

volunteer

\$250 to \$499

Abbott Laboratories Employee
Giving Campaign
Stuart and Karin Adams
AG Communications, LLC
Allstate Giving Campaign
Patrick and Patricia Althoff
Kayla Argumedo
Robert Atkinson
Axa Foundation
Sandra Babel
Baird and Baird, PSC
Michael and Sally Bartlett
Ruth Bauerle
David Beatty

>> David Beauchesne
 John Beem
 Bill and Kay Bemis
 Cheryl Bien
 Steve and LaVonne Blechinger
 D'Lass Dent Company
 Mike and Grace Bodura
 Katherine and Joe Bonville
 Marie Bonville
 Robert and Molly Boyle
 Sharon Brack
 Dawn Brewer-Reilly
 Briarcliff Manor UFSD
 Jane Brickner
 Susan and Dennis Burke
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 Susan Byers
 CA Technologies Matching
 Gifts Program
 Mark and Stephanie Caldwell
 CAS, LLC
 Rudy Cassellati
 Cecilton Lions Charities
 Amy Cherrstrom
 Cherry Hill Company
 Ciao Pizza Italian Restaurant
 City of Seattle
 Ruth Clarke
 Jane Schramka-Cohen and
 Michael Cohen
 College Community School
 District
 Michael and Martha Collins
 Charles and Marianne Connolly
 Sharon and William Cook
 Dr. and Mrs. William and
 Peggy Cook
 David and Kathryn Croson
 Allen Crowder
 Jasmine and Emmanuel Cuffee
 Dex Imaging, Inc.
 Bonnie and William Doster
 Kari Dunn
 Durand Wayland
 Easterly Enterprises
 Carla Ellard
 Empire Merchants, LLC
 Barry Fauchaux
 Pam and Ben Feldman
 Bill Ferris
 Hildegard Penhallurick and
 Joseph Filebark
 Bart and Sally Finzel
 Donald and Romona Finzel
 Tim and Tish Foster
 Gerald and Luella Gabriel
 Thomas and Sylvia Gamache
 Ozlem Goker-Alpan
 Eugene and Francis Goldfarb
 Georgia Goss
 Steve and Mary Jo Graphenteen
 Adam and Regina Gushard
 Christopher and Patricia Guyre
 Hacienda Ford
 Jacob and Audrey Hall
 Lillie Hall
 Sheryl and Gerald Hall
 Timothy and Betty Hammer
 Wallis and Monica Hampton
 Paul Harmatz, MD
 Mark Haskins, DVM, PhD
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Ace One for Allison golf scramble, hosted by the Kirch family
 Alena Galan fundraising events, hosted by Marcia Galan
 3rd Annual Clara's Courage Hotdog Stand, hosted by the Gibson family
 3rd Annual A Wish for Evan, hosted by John and Kristi Abel
 Allison's book signing, "Hi, my name is Allison," hosted by Allison Restemayer
 Ben Bridge Jewelers Dress Down Day, hosted by Stephanie Woods
 Bernstein birthday party, hosted by Jen Bernstein
 Bike for Brooke, hosted by Tracy and Olivia Martin
 CaBi clothing party, hosted by Lynn Hopkins
 Carmichael jewelry party, hosted by Karli Carmichael
 Carson-Green Song and Dance for MPS III, hosted by Harley and Pacey Carson
 Charles Schwab Product & Platform bake sale, hosted by employees at Charles Schwab
 Christian Lon Charity Paintball Tournament, hosted by Maureen and Tony Lon
 Collins Ernst & Young jean day, Team Alexandra, hosted by Melissa Harkey
 Concert for a Cure, hosted by Dorothy and Jeremy Mask
 Dancing with Dominic, hosted by Jeanette Espinola and Fredy Henriquez
 Danny's 16th birthday party, hosted by Ray and Amy Miller
 Do It "Fore" Danny golf tournament, hosted by Ray and Amy Miller
 Dr. William Sly birthday fundraising event, hosted by Dept. of Biochemistry & Molecular Biology at Saint Louis University
 Dress Down Friday, hosted by Dianne Renzi and the Providence School District
 Edinburg School Team Karina MPS Day event, hosted by Anyssa Guajardo
 Eisler Rockland Boulders fundraiser, hosted by Janeen Eisler
 Gamache family Chinese auction and dinner, hosted by the Gamache family
 Gold Party for MPS, hosted by Elizabeth Tuck
 Halk Fall Festival, hosted by Carla Halk
 Homecoming Trunk Show for Nathan, hosted by Michelle McPherson
 Hudsonville Schools popsicle fundraiser, hosted by Bill Ross
 Ice Cream Corner 3rd Year Awareness and Bridge Club, hosted by Janelle Kunellis
 Keep Hope Alive, hosted by Lisa and Jerry Todd
 Klenke family bowl-a-thon, hosted by the Klenke family and Kelli Boni
 Krewson Terrace lemonade stand, hosted by Dawn Lipenta
 Kroger's of Lincoln, IL, Dress Down Day, hosted by Kroger staff
 Lacrosse game in memory of Mark Lessing Jr., hosted by Kevin Connolly
 Lemonade Stand for MPS, hosted by Tracy Leonard
 Logan County Bank Jeans Friday, hosted by staff at Logan County Bank
 Logan's Heros, hosted by Ann Schnare
 Mackenzie's 5K Run/Walk, hosted by the Poquoson Kiwanis Club
 Madison's birthday, hosted by Wayne and Paige Lewis
 Mallia birthday fundraising event, hosted by John and Jeanne Mallia
 Meekel's Music for MPS VI, hosted by Marla Stevens
 Mission Slimpossible, hosted by MPS moms
 MPS Awareness Day auction at Bethel School, hosted by Jason and Michelle Moore
 MPS Awareness Day checkout fundraiser, hosted by Rhiannon and Marcus Woodcock
 MPS Awareness Week, Thompson High School, hosted by Shelby Key
 MPS Boot Camp and Halloween Spooktacular
 Piefer fundraising event, hosted by Avery Piefer
 Pittsburgh Steelers ticket raffle, hosted by Jim and Amy Yard
 Play for Taylor, hosted by Matt and Rachel Wojnarowski
 Post Office Café events, hosted by Kerri Rose
 Purple Lemonade Stand, hosted by Laura Thorsrud
 Roll Over for MPS and ML, hosted by Mackenzie Kasper
 Rosenberg bake sale, hosted by Allie Rosenberg
 Scrapbooking fundraiser, hosted by Michelle Dodson
 Shots for Sean Memorial Golf Tournament, hosted by Debbie and Ernie Dummann
 Tag sale in memory of Kris Roman, hosted by Sherri and Anthony Roman
 Trivia Night for Noah Mehling, hosted by Hamilton County Firefighters, Local 4416
 Valentine's Day for Cures, hosted by Tami Slawson and the National MPS Society
 Walk 4 Josh, hosted by Karen and Wilbert Bateman
 Walker benefit concert, hosted by Ken and Courtney Walker

Andrew's Walk n' Roll, hosted by Sharon Cochenour
 1st Annual Charity Motorcycle Poker Run and Family Fun Day, hosted by Jerry Bennett and Kimberly Frye
 2nd Annual Cameron's 5K Walk/Run for a Cure, hosted by Brian and Julie Mollett
 5 for fiVe, Race for a Cure, hosted by Michelle Storm-Butts
 13th Annual Run for Erin, hosted by Stacy Peters
 Big Nate's Hope 5K Fun Run
 BioMarin MPS 5K Run for Your Life, hosted by Kathie Ward
 Henry's Walk n' Roll, hosted by Melissa Koker-Kent
 HHS NHS Funfest for MPS, hosted by Evan Wilson
 It Works, Charity 5K & Family Fun Walk, hosted by Kate Martin
 Kilometers for Karina, hosted by Anyssa Guajardo
 Laps for Lucas, hosted by Lew and Stacey Montgomery
 MPS Run for Their Lives, hosted by Steve Holland
 Memorial walk for Kyle Witt, hosted by the Witt family
 North Carolina National MPS Society 5K Run for MPS & ML, hosted by Mike Schleiter and Leslie Phillips
 Post Office Café 5K Walk/Run for Mark and Casey Lessing, hosted by Kerri Rose
 Strides for Sara, hosted by Monique Dickerson

2012 CHAMPION A CURE PARTICIPANTS

Families across the country have raised more than \$45,000 through Champion a Cure. This heartfelt program needs your help, too! Each year with renewed hope we reach out to families and share that they too can make a difference and help raise money for research. It is easy and the rewards are tremendous. Thank you to the following families who embraced the 2012 challenge. Participants LOVED running for these families.

Boyce family, Jayden and Brooklyn, MPS III A
 Caswell family, Sam, MPS I
 Klein-Schleiter family, Jennifer, ML III
 Phillips family, Alex and Anna, MPS II
 Szemanski family, Clinton and Zachary, MPS III A

COURAGE PAGES AT WWW.MPSSOCIETY.ORG

The following families have their own website in Courage Pages through the National MPS Society. Whether you are hosting an event or raising awareness for MPS and related diseases, these custom pages have been a hit with donors and can help enhance your fundraising efforts. Consider having us build your family's custom website—there is no expense! To view these inspirational sites, go to www.mpsociety.org and click "Courage Pages" on the right margin. Thank you to the following families:

| | |
|------------------------------|--------------------|
| Evan Abel | Jennifer Klein |
| Hunter Beam | Danny Miller |
| Annabelle Bozarth | Jack Todd |
| Sam Caswell | Trinity Walker |
| Alan Charest | Scotty Whitecotton |
| Allison Kirch (in memory of) | |
| Kraig Klenke (in memory of) | |



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MPS CLASSIFICATIONS

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

| | |
|-----------|-------------------------------|
| MPS I | Hurler, Scheie, Hurler-Scheie |
| MPS II | Hunter |
| MPS III A | Sanfilippo A |
| MPS III B | Sanfilippo B |
| MPS III C | Sanfilippo C |
| MPS III D | Sanfilippo D |
| MPS IV A | Morquio A |
| MPS IV B | Morquio B |
| MPS VI | Maroteaux-Lamy |
| MPS VII | Sly |
| MPS IX | |
| ML II/III | I-Cell, Pseudo-Hurler |

Enzyme Deficiency

| |
|--|
| α -L-Iduronidase |
| Iduronate sulfatase |
| Heparan N-sulfatase |
| α -N-Acetylglucosaminidase |
| Acetyl CoA: α -glycosaminide acetyltransferase |
| N-Acetylglucosamine 6-sulfatase |
| Galactose 6-sulfatase |
| β Galactosidase |
| N-Acetylgalactosamine 4-sulfatase (arylsulfatase B) |
| β -Glucuronidase |
| Hyaluronidase |
| N-acetylglucosamine-1-polydystrophy phosphotransferase |