



2013  
Annual Report



National  
MPS  
Society

Support for Families. Research for a Cure.

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## MISSION STATEMENT

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.

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### **National MPS Society**

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**As you read our 2013 annual report**, you'll notice the common themes of action, hope, power and change. These were not strategic goals for 2013—they are the basic foundations of the mission of the National MPS Society and a focus of our work every day of every year. We have compiled the Society's 2013 highpoints—which are impressive. But who tells a story better than an adult with MPS who received an Extraordinary Experience or a family who has seen the growth of the Society? After reading the following pages you will see what we mean.

Every year the Society offers scholarships to attend our annual conferences and, due to the popularity of this program, preference is given to first-time conference attendees. Michael Whitaker-Russell (MPS II) and Loren McClelland (MPS I) became fast friends because of that opportunity to meet in San Antonio at our 27th Annual Family Conference. See their photo on page 2.

During this conference we had the privilege to celebrate individuals with MPS I who were the first in the world to participate in an MPS clinical trial for enzyme replacement therapy. That celebration encapsulated all the themes of action, hope, power and change! In 2003, Aldurazyme™ was approved by the FDA as the first treatment for individuals with MPS I, and the Society participated in the FDA Advisory Committee Hearing for Aldurazyme. The Society participated in another FDA Advisory Committee Hearing in 2013, this time for VIMIZIM™ for MPS IVA. This treatment was approved in February 2014.

Look through this annual report and reflect on the special moments captured during 2013. See the look of joy on Nick Boyce's (MPS I) face at his college graduation and understand the power and determination that propelled him forward. Appreciate how Jocelyn Wong (MPS IVA) acts on her beliefs and brings hope to patients from other countries. Understand that the Society launched its most diverse disease advocacy effort in Washington, DC, to date with a focus on change. Rejoice that a new company is hoping to change the lives of individuals with MPS IIIB by developing a desperately needed treatment. Appreciate how a father's fraternity developed an action plan to raise money to ultimately cure his son's disease.

These are only a few of the many stories. Every story is special and remarkable because the Society is comprised of many individuals and groups all working for a common mission—to find cures for all MPS and related diseases. Action, hope, power and change will continue to be a part of these stories as we move forward.

Thank you for helping us to achieve our mission.

*Steve Holland*  
President

*Barbara Wedehase*  
Executive Director





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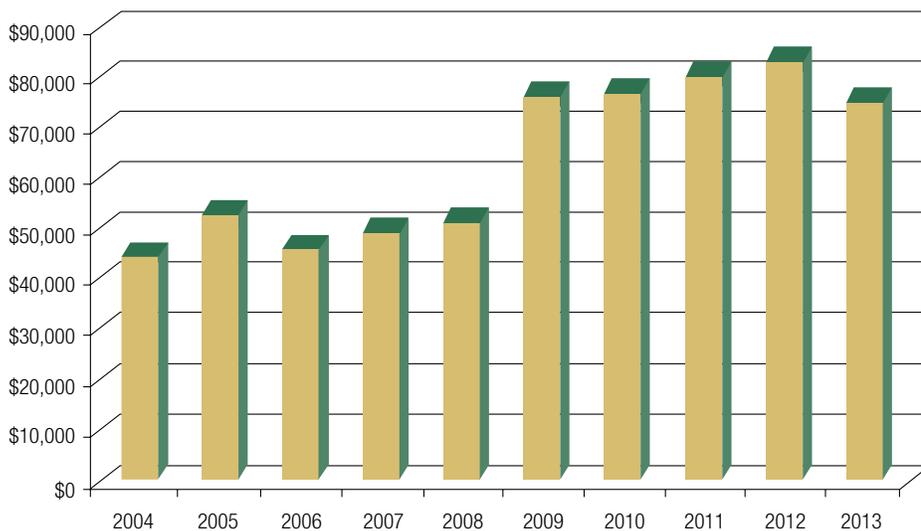
**I would like to thank the National MPS Society for providing a scholarship to the Annual Family Conference in San Antonio, TX. Michael and I created lifelong relationships, but the best part was seeing we are not alone in this. There is an entire MPS family. I want to start a Courage Page to help the Society with fundraising. I want to be a part of making a change because we have hope for our future.**

Monique Whitaker  
*legal guardian of Michael (MPS II)*

# Empowerment Through Support

The **Family Support Committee** is determined to meet the developing needs of individuals and families affected by MPS and related diseases. Since the program's inception, more than \$635,000 has been awarded in direct family assistance, funding medical goods, continuing education and conference scholarships, medical travel assistance and extraordinary experiences. As the program continues to grow, additional support opportunities will be identified for our families.

**Family Assistance Program Dollars**



- Supported 13 families to attend the **28th Annual Family Conference** in San Antonio, TX. These conference scholarships offset the cost of registration, travel and hotel.
- Awarded 28 \$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, to one child of an affected individual and to 19 siblings.
- Funded \$14,650 in **Family Assistance Program grants** to help families obtain durable medical goods. Grants included scooters, car lift, home ramp, WIKE bicycle stroller, sleep safe bed, adaptive car seat and adaptive stroller.
- Assisted 20 families through the **Medical Travel Assistance Program**. In 2013, the program awarded \$8,943 for mileage, airfare and hotel reimbursement to families traveling more than 200 miles (one way) from home for medical appointments.
- Promoted and provided \$2,250 in financial support for three family organized **regional social gatherings** in Illinois, Ohio and Utah.
- Funded five **Extraordinary Experiences** for older children and young adults with MPS. In 2013, the Society awarded \$4,400 for trips to Boston, Japan, London and Paris, and for driving lessons.
- Published the 11th annual *Angels Among Us/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**. Two individuals from each MPS syndrome is honored each quarter, acknowledging their courage, resilience, tenacity and passion for life as they face the challenges of living with MPS.
- Implemented **online application platform** for Family Support Programs.
- Sent the **Award of Courage** signed by MPS Society President Steve Holland to all individuals with MPS and related diseases.

# Knowledge Is Power

The mission of the **Education and Publicity Committee** is to provide an array of educational materials and health-related communications. 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 site of the essential one-on-one contact with individuals and families touched by MPS.

- Promoted the 7th **International MPS Awareness Day** on May 15.
- Launched 3rd annual **Facebook contest** for MPS Awareness Day.
- **Reached out** to researchers and Scientific Advisory Board on MPS Day.
- Provided **“What is MPS?” cards** to membership via Join the Search program.
- Completed **MPS video revisions** for *Courage at Diagnosis, Living with Courage* and *Journey of Hope*.
- Presented videotaped San Antonio **family conference presentations** through link on Society website.
- Updated **Daily Living booklet**.
- **Updated fact sheets:** *Physical Therapy, Transplant, Air Travel Information* and *Orthopedic Disorders in Children with MPS and Related Diseases*.
- Created the fact sheet ***Your Donation: Your Decision***.
- Published the Society’s **quarterly magazine**, *Courage*, and supplement newsletters.
- Increased and improved **website capabilities**.

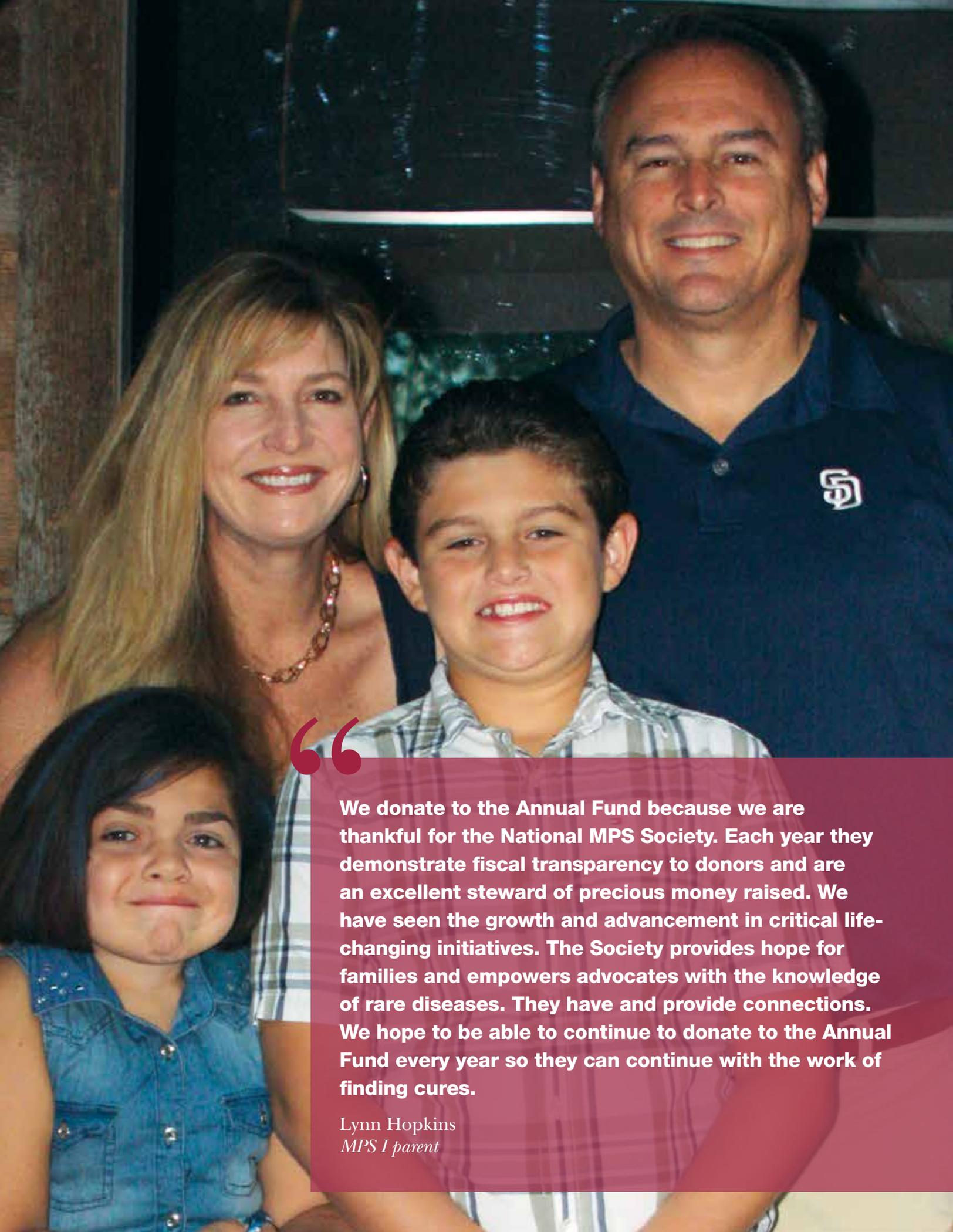


*Pictured above: Celebrating MPS Awareness Day in honor of Jackson Dunn-Kraus (MPS II)  
Pictured at right: Jocelyn Wong (MPS IVA) with Dr. Paul Hartz*

“

I was pleased to be a recipient of an Extraordinary Experiences grant in 2013 and travel to the Taiwan MPS Society meeting. I met with many representatives from many Asian countries. It was emotional for me as I talked with families from other countries struggling through their MPS diagnosis. Still, I was able to share my experience with the clinical trial for MPS IVA and remained optimistic amidst our cultural differences. The community of MPS expands beyond the borders of the United States and I am happy to be part of the bridge into the Asian community. So much has changed over the years with the exchange of information between countries and from the Internet, but nothing compares to meeting families in person.

Jocelyn Wong (MPS IVA)



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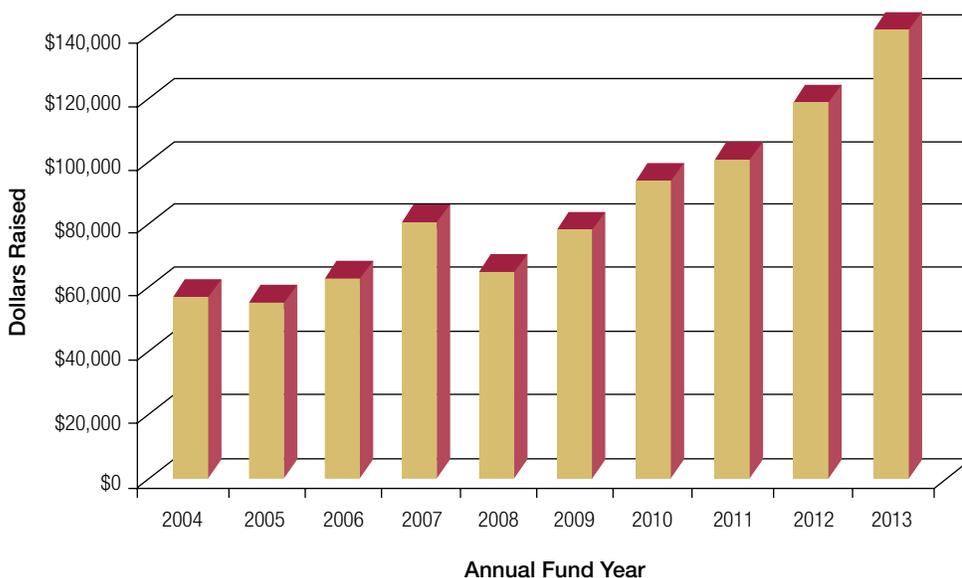
**We donate to the Annual Fund because we are thankful for the National MPS Society. Each year they demonstrate fiscal transparency to donors and are an excellent steward of precious money raised. We have seen the growth and advancement in critical life-changing initiatives. The Society provides hope for families and empowers advocates with the knowledge of rare diseases. They have and provide connections. We hope to be able to continue to donate to the Annual Fund every year so they can continue with the work of finding cures.**

Lynn Hopkins  
*MPS I parent*

# Providing Hope Through Perseverance

The National MPS Society recognizes our 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 increased our efforts with the Annual Fund campaign and Text to Give, a mobile donation tool. The Society continues to embrace the fundraising evolution and provides our donors, membership and fundraisers the essential tools for success. With the increased use of social media, the Society is able to reach donors quickly. The **Fundraising Committee** is dedicated to provide support through the following programs: Walk/run, Family Fundraisers, Annual Fund, Planned Giving, Champion a Cure, Mobile Giving, Courage Pages, Friends and Neighbors, Combined Federal Campaign, United Way and our inaugural platform for online giving, Rally.org.

**Annual Fund Donations**



- Received a **three-star charity rating** from Charity Navigator, representing 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 \$388,000 through **walk/run and fundraising events**.
- Supported **16 walk/run events and 57 fundraising events**, including: Ask Events (two-hour benefit that educates donors and asks for donations), bake sales, bowl-a-thons, concerts, golf tournaments, tea party, jeans day, bingo, auctions and many more.
- Raised more than \$135,000 through our **2013 Annual Fund campaign**.
- Incorporated **mobile pledging** successfully at our annual family conference.
- Hosted **22 Courage Pages** on the Society's website, raising \$35,000. Courage Pages are informative individual family web pages designed to raise awareness and funds for the Society.
- Added a **comprehensive fundraising toolkit** on our website.
- Received **Combined Federal Campaign** application approval.
- Created a **two-minute video** and launched a fundraising effort through rally.org platform.

# Planned Giving, Security for Our Future



- Secured our **largest Planned Gift**, \$94,000, since starting this program.
- Included **Planned Giving articles** in *Courage* magazine.
- Updated **Planned Giving website tools** to help members and friends of the Society become acquainted with Planned Giving and gifts the Society accepts.

**I contributed to Planned Giving because I want to give back to an organization that was and still is a lifeline for me. This is to honor my two sons, Clinton and Zachary, who have passed away from MPS IIIA. I was unable to share with them what I would have wished to during their lives. My planned gift ensures improvement in the lives of those who are still fighting MPS, because even with treatments there are still many battles. I've watched the incredible progress the National MPS Society has made over the years. Part of our family's legacy is to help them fulfill their mission. I am so grateful for its existence, purpose and the lives they touch each day, especially my own.**

Tracy Szemanski  
*MPS IIIA parent*

Although 2013 was only the third year for Planned Giving with the National MPS Society, at year's end we had 11 Planned Giving donors who became part of the Rising Sun Legacy Circle. The Society also received its largest gift to be used for a parents' respite night at our annual conferences and for the Family Support programs.

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.



*Tracy Szemanski with her son Zachary (MPS III), 1987–2004*

# Reinforcing Our Resources

The **Governance Committee** provides for the board's effectiveness and continuing development. The committee recommends board policies and processes designed to provide for effective and efficient governance, including review of bylaws, evaluation of board members, election of board members, and board orientation and education.

- Implemented a new **board of directors review**, self-assessment and peer evaluation process.
- Discussed peer evaluation results and provided **valuable feedback** to each board member in order to improve the effectiveness of both the board of directors and staff.
- Oversaw the **annual board election** process.
- Presented “What makes a dynamic groundbreaking nonprofit board?” as part of the board’s **ongoing education and development**.

“**The review and evaluation process of the Governance Committee was implemented in order to identify gaps and improve performance of our board members. This process creates transparency and adds credibility to board decision making.**

Lisa Todd  
*Governance Committee chair,  
MPS II mother*



*Lisa Todd with her son Jack (MPS II)*



2013  
NATIONAL MPS SOCIETY  
ADVOCACY ACHIEVEMENT  
AWARD  
Presented to  
Senator  
Lindsey Graham  
In grateful appreciation for  
your valuable support of the  
National MPS Society  
National  
MPS  
Society



**I am impressed by the passion and determination of this committee. More than 20 meetings were coordinated and every member was prepared for every meeting they attended. Based on the feedback we received, I believe the advocacy efforts of the National MPS Society continue to be a valuable and important method of awareness, influencing legislation critical to our families.**

Sissi Langford  
*MPS III mom and former chair of Committee on Federal Legislation*

# Collective Action for Collective Change

The **Committee on Federal Legislation** strengthens its strong message each year on Capitol Hill. The voice of the National MPS Society is recognized, and it is the committee's function to be aware and take full advantage of capitalizing on important moments. In 2013, the Society crafted the largest and most diverse disease representative effort that has ever been coordinated for one unified advocacy 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, Food and Drug Administration, Department of Education, Social Security Administration, National Organization for Rare Disorders, and other federal and advocacy agencies occur year round.

- Partnered 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 2014**.
- Advocated for the US Senate to continue passage of the resolution to **recognize May 15, 2013**, as National MPS Awareness Day, as co-signed by Senators Graham (R-SC), Hoeven (R-ND), Begich (D-AK), Whitehouse (D-RI), Heitkamp (D-ND), Murkowski (R-AK) and Boxer (D-CA).
- **Awarded Sen. Lindsey Graham (R-SC)** for his advocacy achievements on behalf of National MPS Awareness Day and NIH funding for grants directed at MPS research.
- Attended the **Rare Disease Caucus** briefing.
- Met with 22 senators and 10 House of Representatives over two days during the **annual Capitol Hill visit**.
- Partnered with other rare disease groups in **Rare Disease Day** activities in Washington, DC.
- Successfully advocated to include rare disease language in the FDA draft guidance on **accelerated approval**. The Society launched several initiatives to help reach the goal of obtaining more than 100 congressional signatures on a letter to the FDA.
- Supported the following **legislative initiatives**: Kids First Research Act of 2013; Life Span Respite Appropriations; Compassionate Allowance within the Social Security Administration; Orphan Drug Tax Credit; Undiagnosed Diseases Research and Collaboration Network; Newborn Screening Save Lives Reauthorization Act; and the Coalition Letter on Healthcare Information Technology framework.
- Supported formal comments to the **Agency for Healthcare Research and Quality** technical brief on enzyme replacement therapy for lysosomal storage diseases.
- Updated the website to include **interactive advocacy** for members and contacted all advocates to thank them personally for advocacy efforts and invite them to join the legislative committee.
- Created **advocacy video** for the annual family conference to promote education and engagement with live action alerts.

# Making the Impossible Possible

## Lachlan Smith, PhD

University of Pennsylvania  
Philadelphia, PA  
*“Mechanisms of Failed Vertebral Bone Formation in Mucopolysaccharidosis VII”*

## Richard Steet, PhD

University of Georgia  
Athens, GA

## Dr. Dwight Koeberl

Duke University  
Durham, NC  
*“Adjunctive Therapy for Hurler Syndrome”*

## Vito Ferro, PhD

University of Queensland  
Brisbane, Queensland, Australia  
*“Development of Pharmacological Chaperone Therapy for MPS II”*

## Jeffrey Esko, PhD

University of California, San Diego  
La Jolla, CA  
*“Delivery of Sulfamidase to the Brain”*

## Adriana Montano, PhD

St. Louis University  
St. Louis, MO

## Raymond Wang, MD

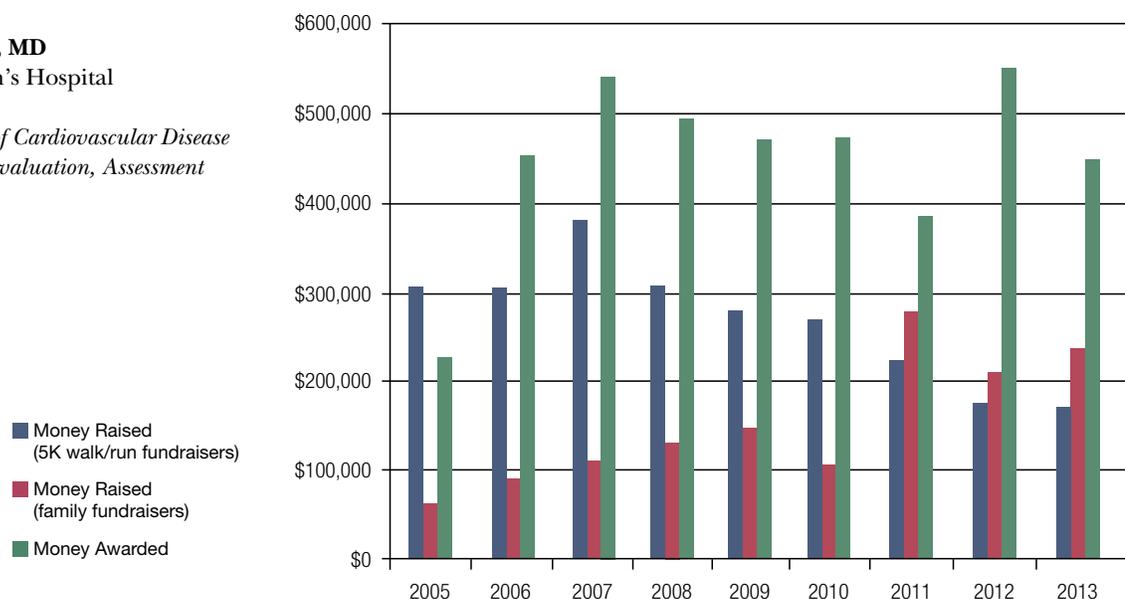
CHOC Children’s Hospital  
Orange, CA  
*“Manifestations of Cardiovascular Disease in Morquio A: Evaluation, Assessment and Therapy”*

The National MPS Society awarded \$530,000 in grant funding for 2013. Funding quality research each year is critical as we move forward with our mission to find the cures. We received 48 letters of intent from researchers around the world for the grants offered.

The Society also funded \$25,000 to support the Lysosomal Disease Network’s National Institutes of Health grant. The funding is designated for the Neuroimaging Core, which benefits four MPS projects. A \$10,000 partnership grant with the Ryan Foundation funded the project of Dr. Elsa Shapiro from the University of Minnesota, “Longitudinal Studies of Brain Structure and Function in MPS Disorders.” The Society also provided funding for post-doctoral fellows to attend the Gordon Conference on lysosomal diseases.

A partnership grant with the International Society for Mannosidosis and Related Diseases was awarded to Heather Flanagan-Steet, PhD, at the University of Georgia for her work, “Investigating the role of cathepsin proteases in ML II cardiac pathology.”

**Money Raised and Awarded for Research**





In 2001, my son Nick became a participant in the clinical trial for Aldurazyme®. We were committed to doing whatever was needed to receive a treatment that could possibly stop the progression of MPS I. Over the years, I watched my son's overall health improve physically and emotionally. I watched him grow into a successful, confident young man. Enzyme replacement therapy empowered him to take on any challenge and succeed at it.

As we celebrate the 10th anniversary of Aldurazyme, I'm thrilled to also be able to celebrate Nick's graduation from Providence College. Aldurazyme changed my son's life and has given him the hope for the future that we all wished for. I'm forever grateful to those who contributed to the creation of Aldurazyme; the impact on the lives it's changing is immeasurable.

Dawn Checraallah  
*MPS I parent*

# Financials

The financial information below has been summarized for the year 2013. The Society is a 501c3 nonprofit public charity. The complete audited financial statements and IRS Form 990 are available on request.

## Financial Position

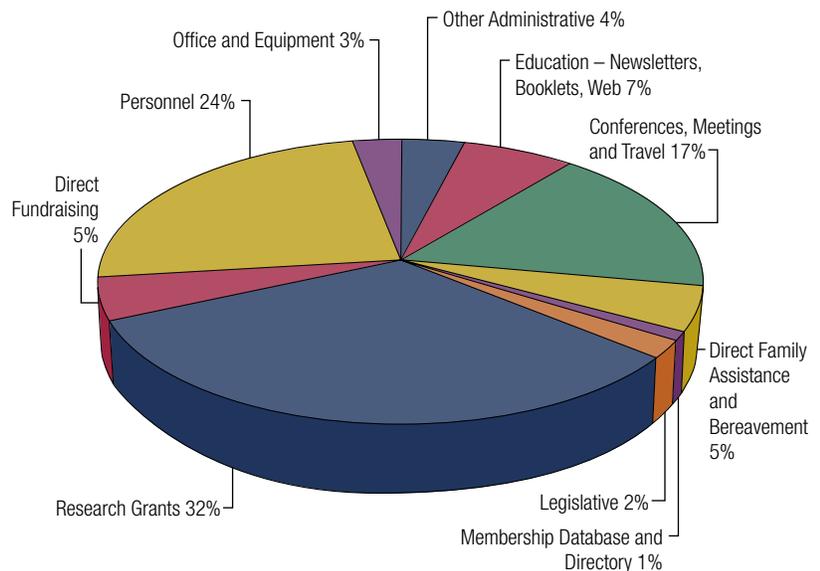
<b>Assets</b>		<b>Liabilities</b>	
Cash	\$ 311,751	Accounts Payable	\$ 20,289
Investments	1,159,509		
Contributions Receivable	15,075	<b>Net Assets</b>	
Prepaid Expenses	16,477	Unrestricted Net Assets	807,394
Property and Equipment	1,183	Temporarily Restricted	676,333
Endowment Investments	1,000,815	Permanently Restricted – Endowment	1,000,794
		<b>Total Net Assets</b>	<b>2,484,521</b>
<b>Total Assets</b>	<b>\$ 2,504,810</b>	<b>Total Liabilities and Net Assets</b>	<b>\$ 2,504,810</b>

## Activities

<b>Support and Revenue</b>		<b>Expenses</b>	
Donations – General	\$ 112,868	Program	\$ 876,173
Donations – Family Assistance	146,971	General and Administrative	190,629
Donations – Research	51,758	Fundraising	125,223
Operating Grant	80,000	<b>Total Expenses</b>	<b>1,192,025</b>
Fundraising	493,651		
Membership Dues	32,135		
Conference Income	130,640		
Sponsored Revenue	38,132		
Investment Income	4,755		
<b>Total Support and Revenue</b>	<b>\$ 1,090,910</b>	<b>Change in Net Assets</b>	<b>\$ (101,115)</b>

## Functional Expenses

Education – Newsletters, Booklets, Web	\$ 86,194
Conferences, Meetings and Travel	206,711
Direct Family Assistance and Bereavement	54,329
Membership Database and Directory	9,145
Legislative	18,757
Research Grants	386,061
Direct Fundraising	60,541
Personnel	279,824
Office and Equipment	41,327
Other Administrative	49,136
<b>Total Functional Expenses</b>	<b>\$ 1,192,025</b>



# 2013 Contributors

...with sincere thanks to our supporters

In 2013, 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 2013. If we received your donation in 2014, you will be recognized in the next Annual Report.

## Platinum

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

BioMarin  
Bryson Foundation, LTD  
Daniel Molinaro Foundation  
David and Kiersten Lowe  
Fund of the Goldman Sachs  
Philanthropy Fund  
Fidelity Charitable Gift Fund  
Genzyme Corporation  
Kercheville Foundation  
Orsini Pharmaceutical  
Services, Inc.  
Shire Human Genetic Therapies

## Gold

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

AIG Matching Grants Program  
Alpha Chi Rho Educational  
Foundation, Inc.  
Angel's Hands Foundation, Inc.  
Baltimore Community Foundation  
Bank of America Corporation  
Ross and Hilary Berning  
Marsha and Robert Bozarth  
duAlaska, Inc.  
KPMG, LLP  
Matt and Stephanie Mays  
Joe and Jan Melnyk  
Morgan Stanley Smith Barney  
Global Impact Funding  
Trust, Inc.  
Donald Myers  
Austin and Dorothy Noll Jr.  
Premier Source, LLC  
Progress Energy Foundation  
PSHS Softball Booster Club  
R.A. Bryan Foundation  
Sam and Nancy Ramsey  
Streblov Family Foundation  
Vitaquest International, LLC

## Silver

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

AbbVie, Inc. Employee Giving  
Campaign  
Amicus Therapeutics, Inc.  
Dr. and Mrs. Mel and  
Millie Anhalt  
Anne Lamkin Kinder Foundation  
AT&T United Way/Employee  
Giving Campaign  
Keith and Debra Banks  
Wayne and Catherine Bardsley  
Joyce Rhodes Barrett  
Birnham Oaks Foundation  
Fund of the San Antonio Area  
Foundation  
Bishop-McCann  
Richard and Mignon Bosse  
Brandy and Beau Bozarth  
Stephanie and Austin Bozarth  
Chris Brodmerkel  
CA Technologies Matching  
Gifts Program  
Rob and Diane Cassil  
Susan and Roger Chapin  
Amy and Dan Cherrstrom  
Chiesi Pharmaceuticals, Inc.  
Michelle and Don Churchill  
Joan Cook  
Caroline Dabney  
Ron and Barbara Dengel  
Justin and Gina Develin  
John and Beth Devoe  
John Downing  
Ernie and Debbie Dummman  
Pat and Kathy Dunn  
Carrie Dunn and Melissa Kraus  
Dutch's Daughter, Inc.  
Betsy and Steve Fowler  
Genworth Foundation  
Sharon Glasscock  
Greencross Corporation  
Luis and Angela Guajardo  
Hamilton County Firefighters  
Local 4416  
Sabrina Hanitz  
Helping Hands Ministries

John and Bonnie Hoegl  
David and Susan Holder  
Steve and Amy Holland  
Darlene Holliday  
Honeywell International Charity  
Matching  
Scott and Lynn Hopkins  
Laura Hudson  
Wayne and Lori Hummel  
IBM Employee Services Center  
William and Michelle Iglesias  
Issaquah Swedish Cancer  
Institute  
Kajima Foundation  
Jeffrey and Stephanie Kell  
Legacy Wealth  
Brenda Lacombe  
John and Helen Lancaster  
Lawrence and Peg Lessing  
Lessing's, Inc.  
Jeff and Caroline Lewandowski  
Matthew and Shannon McNeil  
Microsoft Matching Gifts Program  
Ray and Amy Miller  
Heath and Kimberly Monesmith  
Mark and Angie Morris  
Wayne and Pam Morris  
Jim and June Murphy  
Austin and Cheryl Noll III  
Travis Parigi  
Jo Anne Paterniti  
Bill and Betsy Pelham  
Mark and MaryEllen Pendleton  
Linda and Dave Perry  
Pershing  
Thomas and Stacy Peters  
PG&E Corporation  
Ryan Pierce  
Barbara Pryor  
Paul and Katie Rector  
Robert and Elizabeth Rigney  
James and Courtney Robertson  
George and Athena Sarantinos  
Mr. and Mrs. Arthur Schechter  
Siemens Caring Hands  
Campaign  
Slumberland  
Jack and Barbara Sorter



*Edward Kimminau (MPS IV)*

David and Pamela Sowder  
Synageva BioPharma Corporation  
Jerry and Lisa Todd  
Tracy Szemanski  
The Inner Circle  
The Meyer Foundation, Inc.  
Thomson Reuters  
Herbert Tilsner  
David and An Tootill  
Ultragenyx Pharmaceutical  
Mary Ellen Vernon  
Dawn Watkins  
Mr. and Mrs. Don and Lisa Wells  
Wells Fargo Advisors, LLC  
Wells Fargo Bank, N.A.  
Harold and Janet Whartnaby  
Amy and Klane White  
Tom and Kim Whitecotton  
Gordon Wingate  
Russell and Alice Witt  
James and Carol Yard  
Jim and Amy Yard

## Leader

**\$500 to \$999**

John Abernathy  
Mary Starr Adams  
America's Charities  
Armored School District No. 9  
Artisan Home Resorts  
Robert and Marjorie Austin Jr.  
Automotive Booster Club B-20  
Brenda Baker and Steve Baum  
Mr. David Beatty  
Michael Beiting  
Elliot and Lindsey Berke  
Lee Bloemendal, MD  
Myrna Borman  
Richard Bosse  
Burnside First Church of God, Inc.  
Gregory and Therese Calvelo  
George Gary Card  
Liam and Mary Cavanagh  
John and Lisa Cenicerros  
Citigroup Payment Services  
Clare Rose, Inc.  
Walter and Gretchen Clayton

>> ClearView Healthcare Partners  
on Washington Street  
Christine Clettenberg  
Sharon Cochenour  
Cynthia Cochran  
Country Road Park  
David Crotty  
Lynn Crumling  
Ralph and Jane Daniels  
Patrick and Debi Dee  
Deloitte Services, LP  
Thomas and Kimberly Dickson  
Kathy and Paul Dobrowolski  
Jani Domire  
Julie Dopheide  
Thomas and Judith Downs  
Nancy Dunn  
Kara Echols  
Joseph and Janeen Eisler  
EP Energy  
Elia Margoth Espinola  
Kayla Foltz  
Lennie Forkas  
Joseph Gamble  
Greg Givens  
Gregory Glyman  
Tom and Anne Gniazdowski  
Eugene and Frances Goldfarb  
Greater Houston Community  
Foundation  
Greenwood Building Company  
Pam and Richard Gross  
Wallis and Monica Hampton  
Adam and Jodi Harrington  
Jason and Rebecca Harrington  
Harris and Associates, Inc.  
Mark Haskins, DVM, PhD  
Joe and Beverly Herndon  
Cara Hillyard  
Dr. Christine Ho  
Kevin Hogan  
Sloane Hurst  
Julie and William Johnson  
Gary and Paula Kacer  
Paul and Nga Keith  
Mr. and Mrs. Wendell and  
Karen Keith  
Bob and Ginger Kell  
Kelly King Insurance Services  
Richard Kernstock  
Larry and Susan Kirch  
Tom Kirch

Kiwanis Club of Poquoson  
Donna Kleinert  
Brian and Kristine Klenke  
Clint and Nikki Kremer  
John and Helen Lancaster  
Michael Lange  
Victoria Lange  
John and Stephanie Leavelle  
Dawn and Ross Lipenta  
Gene and Cynthia Logan  
Howard and Jean Madsen  
Daniel and Barbara Maher  
Esther McDougal  
Chris Meyerpeter  
Midland Township Fire Dept.  
Rob and Sharon Muller  
Ted and Kathy Nace  
Susan Narducci  
Sharon O'Connell  
Fred and Ronda O'Donnell  
Christopher and Lynda Papoi  
Thomas and Vickie Patterson  
Principal Combined Fund  
Organization  
Don C. Pung  
Ben Ramsey  
Randall's Home  
Improvement, LLC  
Kenneth Ray Raysteel Inc.  
Lonnie Rodrigue  
James and Pamela Rogers  
Stacy Sadler  
Leonard and Ann Sanchez  
Sanofi Foundation for  
North America  
Michael Schleiter and Terri Klein  
Alex Sinaiko  
Mike and Barbara Smith  
Thea Stuedli  
Dr. and Mrs. Larry and  
Mary Sweeney  
Stuart Swiedler and Judy Weiss  
Alan Taylor  
Teamsters Local 959  
The Triumphant Fellowship  
Church  
Timothy Schaffer, Inc. Roofing  
and Siding  
Albert and Betty Tully  
United Way of the National  
Capital Area

Upper Moreland Township  
School District  
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## 2013 Fundraising Events

Abel family A Wish for Evan, hosted by John and Kristi Abel	Bozarth family Dress Down Jeans Day for MPS Day, hosted by Austin and Stephanie Bozarth	Halk Fall Festival, hosted by Carla Halk	Kenton Fult's Dress Down Day, hosted by Kroger employees	Providence Schools Dress Down Day in memory of Aurora, hosted by Diana Renzi
2nd Annual Walker benefit concert, hosted by Ken and Courtney Walker	Bozarth Houston Ask Event - Annabelle's Journey, hosted by Austin and Stephanie Bozarth	Hike NH in honor of Liam, hosted by Alissa Marzetti	LB Foster Denim Day, hosted by LB Foster employees	Push Up Challenge, hosted by Alpha Chi Rho Educational Foundation
3rd Annual Concert for A Cure, hosted by Dorothy and Ryan Mask	Bozarth wedding gift event, hosted by Beau and Brandy Bozarth	Hope for Hunter Gala, hosted by Michelle Hoffman	Lemon Drops fundraising event, hosted by Glenn and Kathy Miller	Rockland Boulders fundraiser, hosted by Janeen Eisle
Alves Ironman Arizona for the Pagliero family, hosted by Jeff Alves	Carving a Decoy auction fundraiser, hosted by Sandra and Lonnie Rodrigue	Hopkins family annual CaBl clothing party, hosted by Lynn Hopkins	Logan County Bank Jeans Friday, hosted by Logan County Bank employees	Ryan's birthday open house, hosted by Johnathon and Marie Hunt
Amorel Key Club MPS Awareness Day fundraiser, hosted by Kristina Lee	Charity Bakers for Nolan Ramsey, hosted by Jacksonville Schools Charity Bakers	Hughes' 60th wedding anniversary fundraiser, hosted by Donna Weaver	Logan's Heroes, hosted by Anne Schnare	Sarah's sweet 16 birthday party, hosted by Thomas and Ruthann Van Orden
Automotive Booster charity golf tournament, hosted by Harry Wilson	Charles Schwab bake sale and employee gift day, hosted by Diane Russell	Ice Cream Corner 4th annual Awareness and Bridge Club, hosted by Janelle Kunellis	Mad Hatter Tea Party, hosted by Stephanie and Austin Bozarth	Scotty's 16th Birthday Bash, hosted by Tom and Kim Whitecotton
Bake sale in honor of Julia Dolpheide, hosted by Allie Rosenberg	Coach Bag Bingo, hosted by Gerald Hall	Italian Festival, hosted by Caroline and Jeff Lewandowski	Maura's Awareness Day T-shirt fundraiser, hosted by Amber and Eric Mongan	Shots for Sean Memorial Golf Tournament, hosted by Ernie and Debbie Dummann
Birthday donations in memory of Allison Kirch, hosted by the Kirch family	Cross Creek charity golf tournament, hosted by William Bagwell	Jackson and Sydney's birthday fundraiser, hosted by Carrie Dunn and Melissa Kraus	Max & Erma's fundraiser for Riley, hosted by Robb and Lisa Muller	Sowden annual golf outing, hosted by Josh and Sheri Sowden
Bowl for Kristofer, hosted by Jennifer and Chris Christiansen	Do It Fore Dan golf tournament, hosted by Ray and Amy Miller	Jacksonville Elementary School Jumpathon, hosted by Jennie Springer	MPS Awareness Day ribbon fundraiser, hosted by Ryan and Cassandra Reamer	Sowden Bank Jeans Day, hosted by Josh and Sheri Sowden
Bowling for A Bear Bowl-a-Thon, hosted by Upper Moreland High School Key Club	Donuts for Dominic, hosted by Nancy Hutzell	Johnson family Spooktacular fundraiser, hosted by Chris and Mercedes Johnson	Noah Mehling trivia night, hosted by the Hamilton County Firefighters 4416	Todd lemonade stand, hosted by Jack Todd
		Karima's MPS 50/50 raffle fundraiser, hosted by Carol Rucker	Post Office Café events, hosted by Kerri Rose and Mark Lessing	Von Handorf Bike Across the Country, hosted by Jeff and Mary Von Handorf
			Prairie Point fundraiser, hosted by Prairie Point Schools	

## 2013 Walk/Run Events

3rd Annual It Works Family Fun Run, hosted by Kate Martin	14th Annual Run for Erin, hosted by Stacy Peters	Clara's Courage Walk/Run, hosted by Shane Gibson	Memorial Walk for Kyle Witt, hosted by the Witt family	Post Office Café Run for Mark and Casey Lessing, hosted by Kerri Rose
3rd Annual Walk/Run for Cameron, hosted by Brian and Julie Mollett	Andrew's Walk n' Roll, hosted by Sharon Cochenour	Hop for Hunter, hosted by Michelle Hoffman	MPS Run For Their Lives, hosted by Steve Holland and Scott Hardin	Rays of Hope Family Fun Walk, hosted by Jennifer Fair and Stephanie Kell
6th Annual Strides for Sara, hosted by the Dickerson family	Annual NC Run for MPS and ML, hosted by Mike Schleiter and Terri Klein	Kassie's Kause, hosted by Mike and Trisha Offenbacher	North Carolina 5K Run for MPS/ML hosted by Mike Schleiter and Terri Klein	
11th Annual BioMarin Run, hosted by Suyvonne Bell	Bike for Brooke and Fun Walk, hosted by Holly Zimmerman	Marshall Academy 5K Run, hosted by Marshall School		

## 2013 Adopt a Runner, Champion a Cure Participants

Families across the country have raised more than \$55,000 through Adopt a Runner, Champion a Cure. 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 while not hosting or even attending an event. It is easy and the rewards are tremendous. Thank you to the following families who embraced the 2013 challenge.

Bennett family, Hunter, Ciara and in memory of Tommy (MPS IIIA)	Gibson family, Clara (MPS IIIA)	Kirch family, in memory of Allison (MPS IIIA)	Klenke family, in memory of Kraig (MPS II)	Szemanski family, in memory of Clinton and Zachary (MPS IIIA)
Caswell family, Sam (MPS I)	Dunn-Kraus family, Jackson (MPS II)	Klein-Schleiter family, Jennifer (ML III)	Marine family, Austin (ML II/III)	Tootill family, Shannon (MPS IIIA)
	Espinola family, Dominic (MPS II)		Robson family, Jaeda (MPS IIIA)	Yard family, Christian (MPS II)

## Courage Pages at [www.mpssociety.org](http://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 are a terrific way to reach donors and help enhance your fundraising efforts. Consider having us build your family's custom website for free. To view these inspirational sites, click "Courage Pages" on the right margin of our homepage ([www.mpssociety.org](http://www.mpssociety.org)). Thank you to the following families:

Evan Abel	Alan Charest	Allison Kirch (in memory of)	Maura Mongan	Trinity Walker
Hunter Beam	Kali Gegenheimer	Kraig Klenke (in memory of)	Michael Whitaker-Russell	Scotty Whitecotton
Annabelle Bozarth	Mackenzie and Isabella	Jennifer Klein	Jack Todd	Christian Yard
Sam Caswell	Hardesty	Danny Miller	Alyson Von Handorf	Reed Zeighami

# Classifications

Mucopolysaccharidoses (MPS) and related diseases are genetic lysosomal storage diseases caused by the body's inability to produce specific enzymes.

## **SYNDROME**

### MPS I

#### **EPONYM**

Hurler, Scheie, Hurler-Scheie

#### **ENZYME DEFICIENCY**

$\alpha$ -L-Iduronidase

## **SYNDROME**

### MPS II

#### **EPONYM**

Hunter

#### **ENZYME DEFICIENCY**

Iduronate sulfatase

## **SYNDROME**

### MPS IIIA

#### **EPONYM**

Sanfilippo A

#### **ENZYME DEFICIENCY**

Heparan *N*-sulfatase

## **SYNDROME**

### MPS IIIB

#### **EPONYM**

Sanfilippo B

#### **ENZYME DEFICIENCY**

$\alpha$ -*N*-Acetylglucosaminidase

## **SYNDROME**

### MPS IIIC

#### **EPONYM**

Sanfilippo C

#### **ENZYME DEFICIENCY**

Acetyl CoA:  $\alpha$ -glycosaminide acetyltransferase

## **SYNDROME**

### MPS IIID

#### **EPONYM**

Sanfilippo D

#### **ENZYME DEFICIENCY**

*N*-Acetylglucosamine 6-sulfatase

## **SYNDROME**

### MPS IVA

#### **EPONYM**

Morquio A

#### **ENZYME DEFICIENCY**

Galactose 6-sulfatase

## **SYNDROME**

### MPS IVB

#### **EPONYM**

Morquio B

#### **ENZYME DEFICIENCY**

$\beta$  Galactosidase

## **SYNDROME**

### MPS VI

#### **EPONYM**

Maroteaux-Lamy

#### **ENZYME DEFICIENCY**

*N*-Acetylgalactosamine 4-sulfatase (arylsulfatase B)

## **SYNDROME**

### MPS VII

#### **EPONYM**

Sly

#### **ENZYME DEFICIENCY**

$\beta$ -Glucuronidase

## **SYNDROME**

### MPS IX

#### **ENZYME DEFICIENCY**

Hyaluronidase

## **SYNDROME**

### ML II/III

#### **EPONYM**

I-Cell, Pseudo-Hurler polydystrophy

#### **ENZYME DEFICIENCY**

*N*-acetylglucosamine-1-phosphotransferase

Normally, the body uses enzymes to break down and recycle materials in cells. In individuals with MPS and related diseases, the missing or insufficient enzyme prevents the proper recycling process, resulting in the storage of materials in virtually every cell of the body. As a result, cells do not perform properly and may cause progressive damage throughout the body, including the heart, bones, joints, respiratory system and central nervous system. While the disease may not be apparent at birth, signs and symptoms develop with age as more cells become damaged by the accumulation of cell materials. ☼

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