



2014
Annual Report



40 years
1974 – 2014

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.

National MPS Society

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Reading this publication is a reminder of the growth of the Society and our Annual Reports. Our first Annual Report in 2003 was written one Sunday after a board meeting. Larry Kirch, Steve Holland, Laurie Turner and Barbara Wedehase spent the day in the office, each at a computer, cranking out our assigned sections. In 2003, the first FDA-approved treatment for an MPS disease was approved, the Society was in its third year of our “aggressive research (grant) program,” and Family Support offered three programs—complimentary dues for families in need, conference scholarships and funds for regional social gatherings. The few pictures were not in color nor prominently displayed. Contrast that to this beautiful publication, and you can’t help but be amazed at the Society’s achievements and also those of our members, all of whom have strengthened the Society.

The timeline of our 40 Years of Achievements is a testament to the vision of those families in 1974 who wanted a better life for their children with MPS and related diseases. Alice Kalamar, the Society’s first president, shared stories of hope and love when she gave a keynote address at our 40 Years of Achievements Gala in May 2014. Those stories were an inspiration to our many friends who flew to Chapel Hill, NC, for an elegant evening of celebration, a highlight of 2014 for the Society.

The adage “A photo is worth a thousand words” rings true in these pages. Beth Karas, the person who made our videos a reality, attended the gala and highlights the Society’s achievements leading to our growth. MaryEllen Pendleton focused on fundraising during her tenure on our board, and she and her extended family received the fundraising award at the gala. Then there’s Steve Smith, who advocates tirelessly for the Society and all individuals with MPS and related diseases in Washington, DC. These are only a few stories behind the achievements of our members who have strengthened the Society.

Yes, we’re proud of the many achievements, which represent the work of so many dedicated people, but we aren’t resting on those laurels. We look forward to a future of even more growth, with cutting-edge research and increased support to families, because we insist on a better life for our children.

Thank you for your achievements, for helping us with our past achievements and for those achievements yet to be imagined!

Stephanie Bozarth
President

Barbara Wedehase
Executive Director





“

After receiving the devastating news that our son, Ross, had been diagnosed with MPS IIIA, I began researching and found information on the 2014 National MPS Family Conference in Disney World. It was the last day of registration so I made a call to inquire. Laurie informed me we were eligible for a scholarship to attend the conference since we were newly diagnosed.

Two weeks prior to the conference our daughter, Meredith, also was diagnosed with MPS IIIA. At the conference we made instant lifelong connections. It was the first time in our journey that we felt accepted, not judged. We were welcomed with open arms by those who have traveled this journey before us. The conference changed our outlook and the self pity ended. We were the ones chosen for this journey and our extended family grew exponentially that day.

Andrew, Jessica, Ross and Meredith Davis
MPS IIIA family

Meeting a Growing Challenge

The **Family Support Committee** strives to meet the developing needs of individuals and families affected by MPS and related diseases. Since the program's inception, more than \$715,000 has been awarded for funding items such as medical goods, continuing education and conference scholarships, medical travel assistance and extraordinary experiences. As the program continues to grow, additional opportunities of support for our families will become available.

- Supported 24 families to attend the **29th Annual Family Conference in Walt Disney World**. Conference scholarships offset the cost of registration and travel, and provide funding for newly diagnosed families.
- Provided scholarships for families to attend CYCLE, the Society's bereavement conference.
- Provided more than 150 families attending the 29th Annual Family Conference with two complimentary hotel nights at the Walt Disney World conference hotel.
- Awarded 30 \$1,000 **Continuing Education Scholarships** to members continuing their post-high school education. Scholarships were awarded to 12 individuals with MPS and related diseases and to 18 siblings.
- Funded \$22,245 in Family Assistance Program grants to help families obtain durable medical goods. Grants included scooters, stair lift, tumble form deluxe chair, car lift (chair carrier), home ramp, WIKE bicycle stroller and adaptive stroller.
- Provided funding to 14 families through the Medical Travel Assistance Program for mileage, airfare and hotel reimbursement. In 2014, \$6,500 was awarded to families traveling more than 200 miles (one way) from home for medical appointments.
- Promoted and provided funding for two family organized regional social gatherings in Kentucky and Ohio.
- Funded two Extraordinary Experience applications for children (ages 13 and older) and young adults with MPS.
- Published the 12th 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 in *Courage* with Standing Ovation awards. One individual 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.
- Introduced opportunity for the Family Assistance Programs to include applications for iPad funding.
- Sent the Award of Courage, signed by National MPS Society President Steve Holland, to all of our affected individuals with MPS and related diseases.



From our very first conference 21 years ago until today, the Society has provided us with lasting friendships, vital information, supportive programs, pathways to treatment and, above all, a constant hope for the future for all individuals with MPS diseases. When our friends, family and community come together for fundraisers in honor of our children, we are buoyed up beyond the confines of disease, feeling cherished and loved, which sustain us year after year as well as moving the Society ever closer to the cure for all.

Steve, Amy, Maddie and Laynie Holland
MPS I family



Embracing New Technology

The mission of the **Education and Publicity Committee** is to provide 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 our website, introducing an HTML site for mobile devices and utilizing social media, while not losing sight of the essential one-on-one contact with individuals and families affected by MPS.

- Developed a **mobile-ready application** for Society members, donors and researchers on an HTML platform.
- Promoted the 8th **International MPS Awareness Day** on May 15.
- Encouraged and thanked our researchers and Scientific Advisory Board on MPS Awareness Day.
- Provided 40 Years of Achievements timeline and awareness pins to membership.
- Produced “*This Fight Is Personal, Advocating with the National MPS Society*,” the final video in a series which focuses on the stories of those affected by MPS and related diseases, and shares the perspective of both families and legislators.
- Completed **MPS video revisions** for *Courage at Diagnosis*, *Living with Courage* and *Journey of Hope*.
- Presented the videotaped Disney **family conference presentations** through link on Society website.
- Updated fact sheets: *Orthopedic Disorders in Children with MPS and Related Diseases*, *A Parents’ Guide Fact Sheet*, *Tracheostomy* and *Otitis Media*.
- Created new fact sheets: **Family Support Programs** and **Mucopolysaccharidoses and Social Security Benefits**.
- Increased social media efforts through **Facebook** and **Twitter**.
- Published the Society’s quarterly magazine, *Courage*, and supplemental newsletters.



National MPS Society

Published by Society May 15, 2014

Today is International MPS Awareness Day! Today we:

- Remember all the children and adults who suffer from MPS and related diseases.
- Thank about the children we have lost.
- Thank about the doctors and scientists who are dedicated to finding a cure for MPS and related diseases
- Appreciate each other and are thankful for the strength and support we both give and receive.

9204 people reached; 634 Likes, 322 shares



National MPS Society

Published by Society December 2, 2014

After years of the promise of gene therapy, we are elated that gene therapy clinical trials for MPS IIIA and MPS IIIB are anticipated to begin in 2015! Thank you for the hard work and collaborative efforts of everyone involved in making this happen!

8008 people reached; 399 Likes, 162 shares



National MPS Society

@MPSSociety – 14 May 2014

Upload your photo in our template logo below and make it your profile pic! Instructions: mpsociety.org/wp-content/uploads/pic.twitter.com/woodflyYUmk

1,066 impressions; 22 engagements, 1 retweet



“
It was exciting and inspiring to attend the 40 Years of Achievements Gala and to observe how the National MPS Society has grown. I've been a member for the past 15 years and am very encouraged to witness the critical strides in research and treatment, the compassionate outreach to families, and the raised awareness of these rare disorders.

I am a sibling of two ML III brothers born in the 1950s when little was known about ML. It is comforting to know that MPS and ML disorders are not so mysterious today, and that the MPS Society plays a critical role in educating families and professionals who come in contact with these precious souls.

Beth Karas
ML III sibling



“

The journey of an MPS diagnosis has had many ups and downs. The love and friendship we have felt these last 18 years from Society members, staff and friends has helped sustain us through tough times. I didn't live with the day-to-day challenges of MPS that my brother's family—Larry, Susan, Helen and Allison—did, but I hope that hosting golf tournaments and serving as a board member for six years in some small way showed them the love and admiration we felt from afar.

The friends I have personally made through the MPS Society have given me the strength to help fight this fight through fundraising. Hosting fundraisers gives you something tangible to do; it helped us not feel helpless. Being able to raise critical funds for research and family support made us feel we are part of a wonderful extended family.

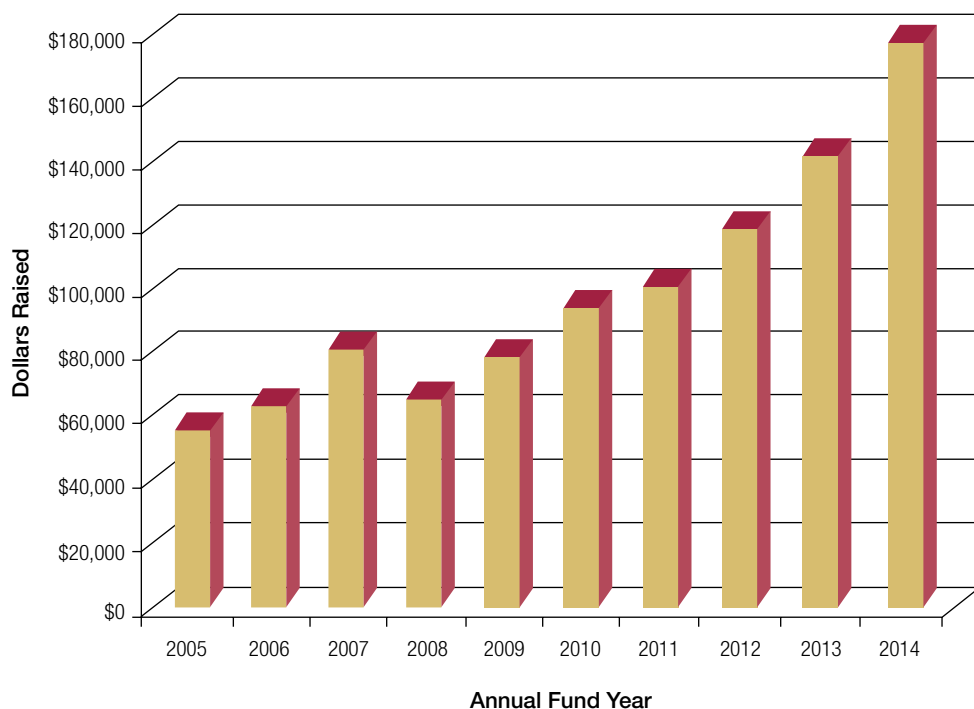
MaryEllen Pendleton
MPS III aunt

Investing with Impact

The National MPS Society recognizes our walk/run and other fundraising organizers by saying **THANK YOU!** Our fundraising program provides essential resources for individuals hosting fundraisers. This past year we increased our efforts with a 40 Years of Achievements Gala, the Annual Fund campaign, visits with major donors and Text to Give, a mobile donation tool.

The Society continues to embrace the fundraising evolution and provides our donors, membership and fund raisers 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 providing support through the following programs: walk/run events, family fundraisers, Annual Fund, major gifts, Planned Giving, Mobile Giving, Courage Pages, Crowdfunding, Combined Federal Campaign, United Way, Employee Giving and Corporate Matching Gifts.

Annual Fund Donations



- 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 725 members**.
- Raised approximately \$522,000 through **walk/run and fundraising events**.
- Hosted a 40 Years of Achievements Gala and raised \$164,000.
- Supported 58 fundraising events and 16 walk/run events, which included sports tournaments, Ironman triathlon, Ask Event (two-hour benefit that educates donors and asks for donations), bake sales, bowl-a-thons, concerts, jeans day, bingo, auctions and more.
- Raised more than \$175,000 through the **2014 Annual Fund campaign**, chaired by Lynn Hopkins. A 33% increase from 2013.
- Increased efforts to meet with **major donor and Society friends** nationwide.
- Included **mobile pledging** successfully at the Annual Family Conference, raising \$6,500.
- Hosted 29 **Courage Pages** on the Society's website. These informative individual family web pages raised awareness and \$33,000 for the Society in 2014.
- Updated website for members with a comprehensive fundraising toolkit.
- Received **Combined Federal Campaign** application approval.
- Worked with donors to process more than 200 **Employee Giving Campaign** and **Corporation Matching Gifts**.
- Increased membership to the **Rising Sun Legacy Circle** and processed new **planned gifts** from trusts and wills.

A man with short brown hair and glasses, wearing a dark suit, a blue and white striped shirt, and a blue patterned tie, stands in front of a wooden sign that reads "COMMITTEE ON ENERGY AND COMMERCE". To his left is a portion of the American flag. The background is a plain, light-colored wall.

COMMITTEE ON ENERGY AND COMMERCE

“
It has always been a privilege to help the MPS cause. In 2000, I called on the FDA with Steve Holland and Mark Dant to ask what could be done to further improve successful clinical trial opportunities. Fifteen years later, patient advocates were invited to the FDA Public Workshop for Inborn Errors of Metabolism. Congress initiated the national discussions with key stakeholders—FDA, pharmaceutical companies and rare disease advocates—to transform the clinical trials process. The National MPS Society is recognized by congressional leaders as a key stakeholder. The credibility of the National MPS Society’s voice in legislative efforts is due in large part to the leadership of Stephanie Bozarth and many other MPS parents, who carry on the inspiration of years of advocates before them.

Today, Congress actively seeks our input and our opinion. Draft legislation resulting from these efforts states, ‘Put patients at the center of drug development.’ As a hard-working advocate, this feels good.

Steve Smith
MPS IVA parent

Aiming High to Change Lives

The **Committee on Federal Legislation** magnifies its strong message each year on Capitol Hill. The voice of the National MPS Society is recognized and it is the committee's job to be aware of and capitalize on important moments.

The committee's 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 (NIH), Department of Education, Alliance for a Stronger FDA, National Organization of Rare Disorders (NORD), Social Security Administration and other federal agencies occur year round.

- Met with 41 senators and representatives over two days during the board of directors' **annual Capitol Hill visit**.
- Met with the **Food and Drug Administration** (FDA) key leadership to discuss how we can partner to speed research and develop life-saving drugs for individuals with MPS and related diseases.
- Attended the **FDA Public Meeting on Inborn Errors of Metabolism Patient Focused Drug Development**, and provided several perspectives from MPS advocates and families through testimonials and panel discussions.
- Presented MPS parents' experience and perspectives on enzyme replacement therapy at the **FDA Public Meeting on Immune Responses to Enzyme Replacement Therapies: Role of Immune Tolerance Induction**.
- Submitted formal comments to the FDA on Docket No. FDA-2014-N-1698, **Patient Participation in Medical Product Development and Review**.
- Partnered with rare disease groups to advocate on **Rare Disease Day** in Washington, DC.
- Submitted MPS-related language to the Senate Appropriations Committee Subcommittee on Labor, Health and Human Resources to be included in significant items for 2015. The focus was a directive for the NIH to continue funding MPS research.
- Communicated the critical challenges of those with MPS and related diseases at the NORD Senate Rare Diseases Briefing by Stephanie Bozarth, MPS IVA parent and legislative chair.
- Partnered with **Rare Disease Legislative Advocates**, a clearinghouse for patient advocacy groups to promote common legislative goals; **Global Genes**, a patient advocacy forum to make connections and share resources to positively impact affected patients and families; and **NORD**, an organization committed to identification, treatment and cures for orphan rare diseases.
- Attended three Congressional **Rare Disease Caucus** briefings, co-chaired by Rep. Joseph Crowley (D-NY) or Rep. Leonard Lance (R-NJ).
- Attended House Energy and Commerce Committee **21st Century Cures** roundtable, served as patient advocate partner, and submitted patient perspective comments (available at <http://energycommerce.house.gov/cures>).
- Provided member advocacy training webinars on **Social Media Advocacy** and **How to Tell Your Story**; both webinars available on the Society's website.
- Partnered in the production of the Society call to advocacy action **30-second and six-minute video "This Fight Is Personal!"**
- Supported the following legislative initiatives: Patients Access to Treatment Act (PATA), Achieving a Better Life Experience (ABLE) Act, Tricare Letter to support genetic testing coverage, Orphan Drug Tax Credit Advocacy (ODTC), Newborn Screen Saves Lives Reauthorization Act, Orphan Product Extensions Now, Accelerating Cures & Treatments (OPEN ACT), Gabriella Miller Kid's First Research Act, Accelerating Biomedical Research Act, ACT 4 NIH Campaign, Cure the Process Campaign, and Patient Focused Impact Assessment Act (PFIA).

Taking Action Today for Future Generations

Moin Vera, MD, PhD

Los Angeles Biomedical Research
Institute at Harbor-UCLA Medical
Center, Torrance, CA

R. Scott McIvor, PhD

University of Minnesota
Minneapolis, MN

*"AAV mediated gene transfer to the CNS
for MPS II"*

Beverly Davidson, PhD

The Children's Hospital of Philadelphia
Philadelphia, PA

Calogera Simonaro, PhD

Icahn School of Medicine at
Mount Sinai, New York, NY

The National MPS Society allocated \$509,500 in grant funding for 2014. Funding the Society provides has been and continues to be critical as we move forward with our mission to find the cures. We received 38 letters of intent from researchers globally for the grants offered.

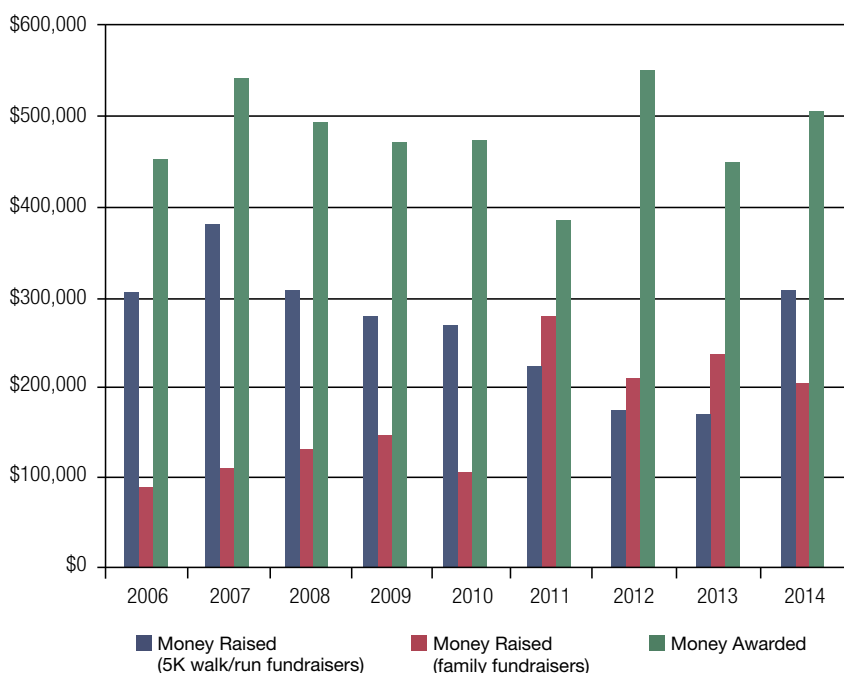
The board of directors allocated \$117,000 to Abeona Therapeutics which has licensed MPS IIIA and MPS IIIB gene therapy technology from Nationwide Children's Hospital.

The Society also provided \$25,000 to support the Lysosomal Disease Network's NIH grant research goals. The funding is designated for the Neuroimaging Core, which will benefit the four MPS projects. A \$10,000 MPS I partnership grant with the Ryan Foundation funds the University of Minnesota project "Longitudinal Studies of Brain Structure and Function in MPS Disorders." The Society provided funding for post-doctoral fellows to attend the American Society and Gene and Cell Therapy conference.

From the time of the pivotal FDA Advisory Committee meeting in 2003 where MPS families spoke on behalf of treatments needed, we have seen so much more being done for MPS patients. It is never enough or too soon, but there currently are four approved enzyme therapies, and a fifth coming. There are gene therapies and ERT in development for Sanfilippo syndromes, finally getting the attention they desperately deserve. After 20 years since our first ERT experiments, it's an exciting and new world for kids with MPS.

Dr. Emil Kakkis, *Ultragenyx*

Money Raised and Awarded for Research



Drawing on Experience to Elevate Our Goals

The National MPS Society's **Governance Committee** is dedicated to empowering their board of directors. The committee provides an ongoing review of effectiveness, knowledge and leadership to ensure the highest quality board. This committee initiated an extensive planning process related to the 2015 retirement of current Executive Director, Barbara Wedehase. They, along with the board of directors, govern the Society by determining direction, desired outcomes, understanding why the direction and outcomes are beneficial, and determining deadlines while, at the same time, refraining from managing the Society. The Governance Committee helps ensure the Society properly serves its membership and fulfills our mission.

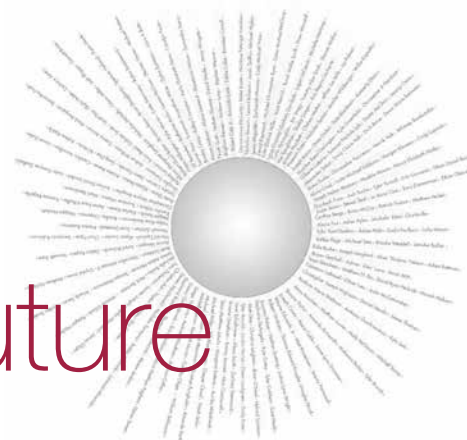
- Completed the second board of directors review and evaluation process. This process is used to identify gaps, improve board performance, and illustrate transparency and credibility of the board.
- Managed individual board evaluation self-assessments.
- Discussed evaluation results and provided valuable feedback with each board member to make process improvements with both the board of directors and staff.
- Engaged in a thoughtful planning process for an executive director replacement in 2015 that included stakeholder surveys, job analysis and detailed review of the Society's future.
- Completed the 2014 annual board of directors election process.



“**When Madison was diagnosed with Mucopolipidosis, we wanted to do anything we could to help find a treatment and raise awareness. We decided to run for the board of directors. Working with the Governance Committee through the board interview process confirmed the level of commitment the Society has for our families in this next decade and beyond.**

Aaron and Holly Thompson
ML III parents

Planned Giving, Security for Our Future



- Secured a large stock gift and remaining trust estates.
- Included Planned Giving articles in *Courage* publications.
- Worked to create a strategic plan for stewardship with donors.
- Acknowledged five future gifts to the Society.
- Updated Planned Giving website tools to help members and friends of the Society become acquainted with Planned Giving and gifts the Society accepts.

Rising Sun Legacy Members Include:

Emil Kakkis and Jenny Soriano, 2011

Becky Clarke, 2011

Christa Armstrong, 2011

Mary Starr Adams, 2012

Terri Klein, 2012

Tracy Szymanski, 2012

Barbara Wedehase, 2013

Brian and Kris Klenke, 2013

Steve and Amy Holland, 2013

Carol Elwell*, 2014

Steve McDonnell*, 2014

Randy McDonnell*, 2014

Austin and Stephanie Bozarth, 2014

** Indicates gift has been received.*

Some members wish to remain anonymous.

2014 was the fourth year for Planned Giving with the National MPS Society. At year's end we had 20 Planned Giving donors who became part of the Rising Sun Legacy Circle. The Society also continued planning for our parents' respite night at our annual conferences and for the Family Support Programs from a gift bestowed in 2013.

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 these gifts to the National MPS Society, whether through their estates, wills 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.



National MPS Society founding president Alice Kalamar (far right), with her husband, Joe, and Marlene Schatz.



Being at the 40th Anniversary Gala was such an honor. I felt an overwhelming sense of gratitude and pride for what a small group of parents started at a conference room table 40 years ago. It was a tremendous effort to recognize achievements and raise funds for a mission we fully support. It was a night I will always treasure.

Alice Kalamar, founding member, past president

Financials

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The financial information below has been summarized for the year 2014. The Society is a 501c3 nonprofit public charity. The complete audited financial statements and IRS Form 990 are available on request.

Financial Position

Assets

Cash	\$ 489,046
Investments	1,428,572
Contributions Receivable	4,975
Prepaid Expenses	8,236
Endowment Investments	1,001,143

Total Assets \$ 2,931,972

Liabilities

Accounts Payable	\$ 219,764
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Net Assets

Unrestricted Net Assets	880,376
Temporarily Restricted	831,038
Permanently Restricted – Endowment	1,000,794
Total Net Assets	2,712,208

Total Liabilities and Net Assets \$ 2,931,972

Activities

Support and Revenue

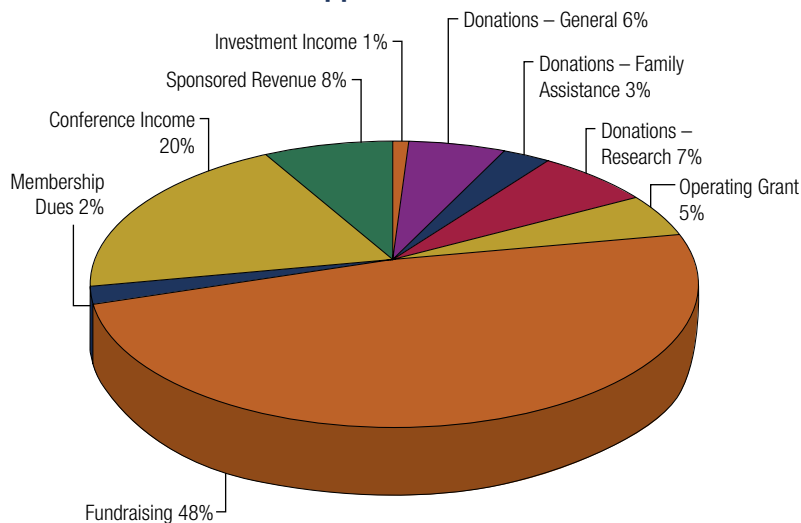
Donations – General	\$ 94,853
Donations – Family Assistance	41,940
Donations – Research	103,007
Operating Grant	75,000
Fundraising	730,104
Membership Dues	31,740
Conference Income	303,245
Sponsored Revenue	121,162
Investment Income	18,175
Total Support and Revenue	\$ 1,519,226

Functional Expenses

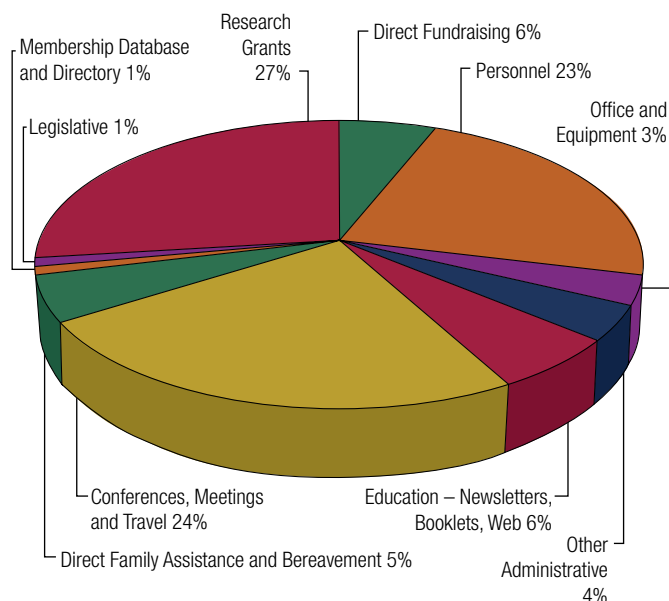
Education – Newsletters, Booklets, Web	\$ 80,297
Conferences, Meetings and Travel	315,041
Direct Family Assistance and Bereavement	61,659
Membership Database and Directory	10,296
Legislative	17,850
Research Grants*	341,525
Direct Fundraising	79,004
Personnel	290,359
Office and Equipment	43,598
Other Administrative	51,910
Total Functional Expenses	\$ 1,291,539

Change in Net Assets \$ 227,687

Support and Revenue



Functional Expenses



* Please note an additional \$112,500 was spent on research in 2014 but was classified as an investment due to the nature of the transaction.

40 years of Achievements

1974-2014

1974-1976

- Parents for MPS formed (1974)
- The MPS Society was incorporated (1975)
- First seminar held and attended by 33 people (1975)
- Membership of 34 families (1976)

1980

- Brochure explaining MPS/ML published
- First bone marrow transplant performed on 9-month-old boy with MPS I

1983-1984

- Dr. Haskins reports to BOD research with MPS I and MPS VI cats & MPS VII dog (1983)
- Amniotic membrane transplantation in MPS I, MPS II, MPS IIIA&B announced (1983)
- Annual fundraiser money used to fund research student (1984)

1986



- First major national family conference held
- Brochures, logo wear and a membership directory are created
- Membership of 300 families and mailing list of 600

1988



- Hosted 1st International Congress on MPS and related diseases, Minnesota

1991

- National MPS Society meeting – UCLA includes scientific, family and joint meeting
- Syndrome-specific booklets published



1974

1977-1979

- Society headquarters moved from Washington, DC, to New York (1977)
- Dr. Neufeld summarizes MPS/ML research for newsletter (1978)
- First annual fundraiser—a raffle raising almost \$1,000 (1979)

1981-1982

- \$2,557.03 reported in treasury (1981)
- First conference devoted to MPS/ML diseases at North Shore University Hospital, NY (1982)

1985

- Society refiled for incorporation as the National MPS Society, Inc. in New York
- Newsletter renamed *Courage*

1987



- President Marie Capobianco testifies before Congress
- Ballot nominations for board member appears for the first time in *Courage*

1989

- 1st Disney family conference

- Two student researchers selected by the SAB for summer research fellowships

1992



- *Ethan's Feeling Switch* published

2003

- Aldurazyme®, the first ERT for MPS I, approved by FDA; Society members testified before FDA as part of the approval process
- MPS II phase III ERT clinical trial began
- MPS VI phase III ERT clinical trial began
- First Society video produced
- National MPS Awareness Day established as Feb. 25
- Bereavement and regional family picnic programs implemented



2006

- Elaprase®, ERT for MPS II, approved by FDA
- Launched Join the Search campaign
- Participated in the NASDAQ closing ceremonies—ringing the bell
- Received a four-star charity rating and raised \$423,000 through fundraising events
- Published *Daily Living with MPS and Related Diseases* in conjunction with Canadian MPS Society
- Held the inaugural CYCLE (Celebrating Your Child's Life Experience) conference for bereaved families



2007

- Provided testimony to the Social Security Administration
- Awarded \$459,000 in research grants
- Moved the National MPS Society to Durham, NC
- Global MPS advocacy organizations adopt MPS Awareness Day. The day is changed to May 15 and is officially called International MPS Awareness Day.



2004



- \$1 million budget
- \$410,000 awarded in research grants
- Hired part-time development director
- Membership of 800, mailing list of 3,500
- Society leases first paid office space in Bangor, ME

2005

- Naglazyme®, ERT for MPS VI, approved by FDA
- Received a \$1 million endowment from Drs. Emil Kakkis and Jenny Soriano
- U.S. Senate unanimously passed the resolution marking Feb. 25 National MPS Awareness Day
- Celebrated MPS Awareness Day with NASDAQ—ringing opening bell
- Created Continuing Education Scholarship program—\$1,000 grants
- Launched new branding for the National MPS Society with current logo and tagline



2008

- Awarded \$528,000 in research grants
- Updated all syndrome-specific booklets, and developed and distributed comprehensive MPS II and MPS III resource guides
- Provided 37 stipends for member families to attend the 10th International Symposium on MPS and Related Diseases in Canada
- Membership of 800, mailing list of 6,000



1994

- Dr. Neufeld presented National Medal of Science award by President Clinton for her MPS research
- Budget increases to \$106,450

1995

- Calendar and note cards created for fundraising

1997-1998

- MPS I phase I/II ERT clinical trial began (1997)
- 1st clinical trial of gene therapy on a human conducted on adults with milder MPS II (1998)
- Creation of the Society's Committee on Federal Legislation (1998)
- Steve and Amy Holland elected to board of directors (1998)



2000

- MPS VI phase I/II ERT clinical trial began
- Co-hosted international MPS and related disease conference in Minnesota
- National MPS Society 5K walk/run program launches with seven events, raising \$100,000 for research
- The Society completed its first strategic planning process
- Barbara Wedehase becomes executive director



1993



- Mark Dant family begin a large fundraising campaign in Texas to fund Dr. Kakkis' lab and the 1994 Disney family conference
- Board votes to waive conference fees for affected individuals

1996

- National MPS Society website launched
- MPS Day held in Chapel Hill, NC, with UNC hospital



1999

- BioMarin/Genzyme provided first operational grant to Society allowing hiring of first employee
- Bylaws of Society amended and restated for first time

2001-2002



- MPS II phase I/II ERT clinical trial began
- 2nd year of 5K walk/run program raises \$170,000 for research with 11 events (2001)
- Awarded \$100,000 in grants for research (2001)
- Participated in the formation of Global Organization for Lysosomal Diseases (GOLD) (2002)
- Annual Fund program established, raising \$12,600 (2002)
- Hired Laurie Turner as part-time office assistant (2002)

2010

- MPS I, MPS II and MPS III are added to the Compassionate Allowance Program under the Social Security Administration
- Held first affected adult conference, SPIRIT, in California
- Created the Governance Committee
- Celebrated 10 year walk/run anniversary
- Created National MPS Society Facebook page



2012

- Awarded \$547,000 in research grants
- Provided \$114,000 in family support and scholarship grants
- Began three-part video series for fundraising and awareness with Beth Karas, TV correspondent
- Introduced Mobile Pledging and Family Courage Pages for fundraising



2014

- Vimizim™, ERT for MPS IVA, approved by FDA
- MPS III genestein clinical trial began
- Society holds its first fundraising gala honoring its 40th anniversary



2014

2009

- Met with Social Security Administration about adding MPS to the Compassionate Allowance Program
- Provided a record \$72,500 through the family support programs
- Annual Fund raised \$73,500
- Raised \$470,000 through fundraising events
- Hired Terri Klein as development director



2011

- Provided first training webinar for Federal Legislative Committee and Society members, "How Advocacy Moves Government"
- Launched Planned Giving program and the Rising Sun Legacy Circle
- Launched improved website with increased membership interaction
- Received four-star charity rating from Charity Navigator



2013

- Families testified before FDA on patient results in clinical trials for MPS IVA; FDA recommends approval
- Board travels to Washington, DC, for large advocacy effort; Sissi Langford presents Sen. Graham with Legislative Achievement award
- Award of Courage signed by President Steve Holland given to all of our affected individuals with MPS and related diseases
- Annual Fund raised \$135,000
- MPS VII phase I/II ERT clinical trial began



2014 Contributors

...with sincere thanks to our supporters

In 2014, 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 2014. If we received your donation in 2015, you will be recognized in the next Annual Report.

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 Wes and Missy Morgan
 Corinne Morici
 Sheila and Tom Morley
 Elizabeth Morris
 Zachary and Dawn Morrison
 Steacy Morrissey

Mark Mortimer
 Carmen Mosley
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 Sugden and Sarah Murphy Jr.
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 Erin and Jason Nickleby
 Raymond Niemczura
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 Randi Osterhoudt
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 Kim and John Outten
 Orhan and Laura Ozkan
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 Alexis Palefsky
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 Jeanne Paolini
 Rhonda Pare
 Kim Parks
 Michael and Margaret Pashen
 Beth Patrick
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 Carmen Moser-Payne and
 Cliff Payne

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Matthew and Mary Pincombe	David Rollins	Rozann Sheppard	Larry and Diane Suhr	Jill Underwood
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 Rachel Caddell
 Marguerite Caldwell



MPS I parent Dawn Checraallah (front center) with the Genzyme Group at the 40 Years of Achievements gala.

Felicia Calhoun
 Debbie Campbell
 Jerry and Charlotte Campbell
 Stephanie Cancilla
 Brenda Carbon
 Holly Carpenter
 Patrick and Kelly Anne Carroll
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 Jessica Cotturone
 Angela and John Coughenour
 Marie Cromwell and
 Lucius Cromwell III
 Edward and Ann Cumiskey
 Jamey Dagenhart
 Christine Dahlk
 David and Mary D'Amour
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 Robert Daniels II
 Joel and Jane Dapkus
 Nibha Dash
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 Susan Ketchum
 Faina Khrizman
 Jenniferann Kightlinger
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 Thomas and Darcy Kobinsky
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 Joan Kroll
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 Michael and Margaret Lamson
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 Michaelle and Wolfgang Mauch
 Marie Mauro
 Amelia Mavrikis
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 Christina McGoran
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 Amelia McHugh
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 Meuser Lumber Company
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Biomarin Group at the 40 Years of Achievements gala.

Donald and Linda Nelson
 Mary Ann Nestheide
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 Tara Nicholas
 Steven Niewald
 David North
 Kate North
 Khunsha Numan
 Thomas Nuzzalo
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 Miguel and Sarah O'Campo
 Teresa Ocotl
 Ann Ohl
 Kenichi Okamoto
 Margaret O'Neal
 Dickie and Mary Jane Orgeron
 Joseph McCarthy and Ann O'Rourke
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 Mary Page
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 Patsy Palmer
 Salvatore Palumbo
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 Positive Waves
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 Sandy Proksch
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John Snarey
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 Kerri Vivathana
 Sung Vivathana
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 Dennis and Michele Walker
 Richard and Rosemarie Walker
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Brian Waters
Courtney Weaver
Laura Webber
Sara Wells
Michael Wenzel

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Shannon Yarbrough
Rebecca and Angel Zambrano
Heather Zehringer
Ronald Zike

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Joseph M. Ziomek
Angela and Roger Zylstra

2014 Fundraising Events

3 V 3 Basketball Tournament
hosted by Destin Porche
3rd Annual Walker Benefit
Concert hosted by the Walker
family
4th Annual Concert for a Cure
hosted by Jeremy and Dorothy
Mask
Dustin's Poker Tournament
hosted by Lee Ann Adams
American Bible Challenge
hosted by the Wojnarowski
family
Annual Diamondhead Bridge
Club Fundraiser for MPS
hosted by Janelle Kunellis
Aurora's Elementary Dress
Down Fridays hosted by Asa
Messer Elementary School
BBQ for Conner hosted by Carl
and Deborah Kruse
Bowl for Kristofer hosted by
Chris and Jenifer Christianson
Carter Family Ask Event hosted
by Brooke Carter
Cato Balloon Release
Fundraiser hosted by Armored
School District Key Club

Long Drive II Survive for MPS II
hosted by Dan and Amy
Cherrstrom
Cooper's Birthday Fundraising
Event hosted by Brian and
Christine Tippet
Cross Creek Charity Golf
Tournament hosted by William
Bagwell
Crossfit Fundraiser hosted by
Sherri Richbourg
Do It Fore Danny Golf
Tournament hosted by Ray
and Amy Miller
Dorian and Wynn's Birthday and
Annual Halloween
Spooktacular hosted by Chris
and Mercedes Johnson
Volley for Support for Jackson
hosted by Cherry Hill School
District
Eisler Rockland Boulders
Fundraiser hosted by Janeen
Eisler
Graven Fundraiser for MPS II
Research hosted by Karen
Graven
Halk Fall Festival hosted by
Carla Halk

Christian's Dress Down Friday
hosted by Hampton High School
MPS Sharing and Caring hosted
by Steve and Amy Holland
Hope for Maura hosted by
Amber Mongan
CaBI Clothing Party for Michelle
hosted by Lynn Hopkins
Alves Ironman Arizona for the
Palgriego family hosted by Jeff
Alves
Poker Tournament for ML
hosted by Chris and Mercedes
Johnson
Carter's Concert and Raffle
for MPS II hosted by Dan and
Natalie Kanney
Keep Hope Alive - Ask Event,
Final Pledge Drive hosted by
Jerry and Lisa Todd
Kendra's 30th Birthday
hosted by Kendra Gottsleben
Klenke Bowl-a-Thon in memory
of Kraig Klenke hosted by
Brian, Kris and Chelsey Klenke
BBQ for Cooper hosted by Carl
and Deborah Kruse
LB Foster Company Denim Day
hosted by the Employees of LB
Foster Company

Lemonade Stand for Oliver and
Waverly hosted by Mark and
Breanne Melikan
Hats On Day for MPS hosted by
Lincoln Elementary School
Lindsey Efrid's Sweet 16
Birthday hosted by Karen Efrid
Livewire Fitness Charity
Bootcamp hosted by Yen and
Paul Reid
Lockport Casual for Causes
Day hosted by the Faculty of
Lockport High School
Loren's 16th Birthday hosted by
Kimberly McClelland
Milz T-shirt Fundraiser hosted
by Sheila Ford and Kelly, Jill
and Miles Young
MPS Bunco Bash hosted by
Carolyn Kanney
MPS Day Fundraiser for Meekel
hosted by Marla Stevens
National MPS Society 40 Years
of Achievements Gala hosted
by the National MPS Society
Old National Bank
Fundraiser hosted by Loretta
Priestersbach
Rachel's 15th Birthday
hosted by Andrea Longston

Reamer Awareness Day
Bracelet Sale hosted by
Cassandra Reamer
Run for Erin - Meet and Greet
hosted by Stacy Peterson
Slide-a-Thon for Max hosted by
Milo and Ann Goodell
Swinging Fore MPS Angels
hosted by Jon and Teresa
Mussleman
UGI Blue Jeans Fundraiser
hosted by the employees of
UGI Energy Services
Hinton Family Mary Kay
Fundraiser hosted by Amy
VanCleave
Wedding Dollar Dance for Lucas
hosted by Anna Marcotte-
Herdina
Woodsville High School
Fundraiser hosted by Lori
MacPherson
Hugo Desouza Fundraising
Event hosted by Bernard
Xavier
Yoga Class Fundraiser in
memory of Tejada hosted by
Levy Solomon

2014 Walk/Run Events

Clara's Courage Walk/Run
hosted by Shane Gibson
12th Annual BioMarin Run
hosted by SuYvonne Bell
Action for Aidan 5K hosted
by Jennifer Carter and
Brooke Carter

Bike and Walk for Brooke
hosted by Holly Zollman
Cameron's Run for a Cure
hosted by Julie Mollett
Holden's Hope Hero Run
hosted by Juliana Hughes

Hope 4 Hunter hosted by
Michelle Hoffman
Marshall Academy 5K hosted
by Marshall School and
Oaklawn Hospital
Post Office Café Run hosted by
Kerri Rose and Mark Lessing

Rays of Hope Family Fun Walk
hosted by Jennifer Fair and
Stephanie Kell
Rays Rayce for a Cure hosted
by Meredith Pinchak
River Run for Ryan hosted by
Johnathan and Maria Hunt

Sauk Trail Walk-a-Thon for
Austin hosted by Carol
Pincombe
Scrambled Legs Walk/Run
for Hannah hosted by Holly
McIlwaine

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 are a terrific way to reach donors and help enhance your fundraising efforts. **Consider building your Courage Page, there is no expense!** To view these inspirational sites click Courage Pages on the right margin of our homepage www.mpssociety.org. Thank you to the following families:

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Cooper Tippet
Jack Todd

Alyson Von Handorf
Trinity Walker
Scotty Whitecotton
Michael Whitaker-Russell
Christian Yard
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

α -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

α -*N*-Acetylglucosaminidase

SYNDROME

MPS IIIC

EPONYM

Sanfilippo C

ENZYME DEFICIENCY

Acetyl CoA: α -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

β Galactosidase

SYNDROME

MPS VI

EPONYM

Maroteaux-Lamy

ENZYME DEFICIENCY

N-Acetylgalactosamine 4-sulfatase (arylsulfatase B)

SYNDROME

MPS VII

EPONYM

Sly

ENZYME DEFICIENCY

β -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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