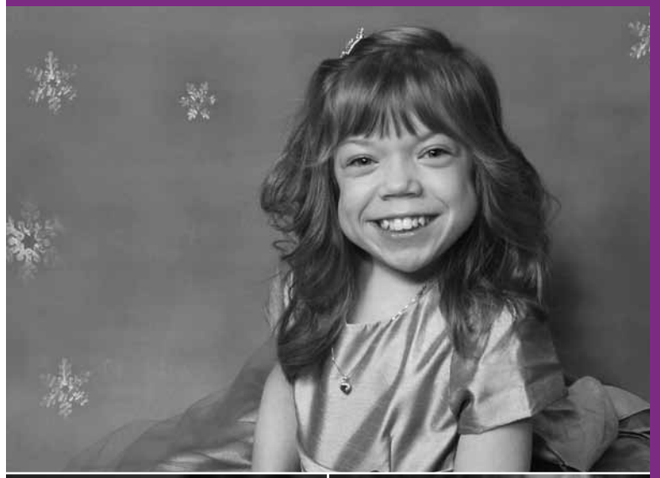
Mucopolysaccharidoses (MPS) and related diseases are genetic lysosomal storage diseases (LSD) caused by the body's inability to produce specific enzymes. Normally, the body uses enzymes to break down and recycle materials in cells. In individuals with MPS and related diseases, the missing or insufficient 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	Eponym	Enzyme Deficiency
MPS I	Hurler, Scheie, Hurler-Scheie	α-L-Iduronidase
MPS II	Hunter	Iduronate sulfatase
MPS III A	Sanfilippo A	Heparan *N*-sulfatase
MPS III B	Sanfilippo B	α-*N*-Acetylglucosaminidase
MPS III C	Sanfilippo C	Acetyl CoA: α-glycosaminide acetyltransferase
MPS III D	Sanfilippo D	*N*-Acetylglucosamine 6-sulfatase
MPS IV A	Morquio A	Galactose 6-sulfatase
MPS IV B	Morquio B	β Galactosidase
MPS VI	Maroteaux-Lamy	*N*-Acetylgalactosamine 4-sulfatase (arylsulfatase B)
MPS VII	Sly	β-Glucuronidase
MPS IX		Hyaluronidase
ML II/III	I-Cell, Pseudo-Hurler polydystrophy	*N*-acetylglucosamine-1-phosphotransferase

National MPS Society
PO Box 14686 | Durham, NC | 27709-4686
t: 877.MPS.1001 | **p:** 919.806.0101 | **f:** 919.806.2055

National MPS Society is a tax exempt, non-profit organization under IRS Section 501(c)3, dedicated to individuals affected with MPS and related diseases.



National MPS Society
Support for Families. Research for a Cure.

mpssociety.org

National MPS Society

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.

Since 1974 the Society has supported individuals and families affected with MPS and related diseases. We are governed by a member-elected volunteer Board of Directors, many of whom are parents of children with MPS. We also benefit from the expertise of a Scientific Advisory Board, comprised of world-class physicians, researchers and medical professionals throughout the world.

How Can You Help?

We need your support to help us educate others about our mission and to raise the money we need to support medical research — the key to longer, happier lives with MPS and related diseases.

Please join us in our efforts to fight these diseases.

Become a **Donor.**

Your donation helps us fulfill our mission to find cures for MPS and related diseases and to support our families. Thank you for your support.

Name _____

Address _____

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State, ZIP _____

Telephone _____

E-mail _____

This gift is: ☐ In memory of ☐ In honor of

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Please send acknowledgement card to:

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Please make checks payable to National MPS Society

☐ Payment online: www.mpssociety.org

Mail to: National MPS Society, PO Box 14686, Durham, NC 27709-4686

Donations are tax deductible. Tax ID number is 11-2734849

Please join us in our efforts to fight these diseases.

Become a **Member.**

Your donation helps us fulfill our mission to find cures for MPS and related diseases and to support our families. Thank you for your support.

Name _____

Address _____

City _____

State, ZIP _____

Telephone _____

E-mail _____

Child's Name _____

Date of Birth _____

Diagnosis _____

Relationship _____

Publications:

Would you like to receive our newsletter? ☐ Yes ☐ No

Would you like our publication in ☐ electronic (emailed) or ☐ hard copy (mailed) form

Would you like your name to appear in our Directory? ☐ Yes ☐ No

Yearly Membership Dues:

☐ Families $50 ☐ Professionals $75 ☐ Foreign $80

☐ Corporate $1,000 ☐ Additional Donation $_____

Total Amount Enclosed $ _____

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Mail to: National MPS Society, PO Box 14686, Durham, NC 27709-4686

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What are the Major Characteristics of MPS and Related Diseases?

While the symptoms of the diseases may vary from one syndrome to another, there are many similarities. Affected individuals often have mental retardation, cloudy corneas, short stature, stiff joints, incontinence, speech and hearing impairment, chronic runny nose, hernia, heart disease, hyperactivity, depression, pain and a dramatically shortened life span.

How Are These Diseases Inherited?

MPS diseases are hereditary. In nearly all cases a child receives a recessive gene from each parent. MPS II is the only exception where the gene may be passed from a mother to her male children. A couple's chance of having another child with one of these diseases is 1 in 4 with each pregnancy. Unaffected siblings may be carriers of the disease. The occurrence of MPS in the general population is thought to be one in 25,000 births.

Is Prenatal Diagnosis or Carrier Detection Testing Available?

For most MPS and related diseases, amniocentesis can be performed between 14 and 17 weeks gestation to determine if the unborn child is affected. Alternatively, chorionic villus sampling (CVS) can be performed between eight and ten weeks pregnancy. Tests also are available to determine whether individuals are carriers of an MPS gene. To learn more about these tests, contact your doctor, nearest genetic center or the Society.

Is Research Helping Today's Families?

Although there is currently no cure for MPS, research is making great strides. Carrier detection, the development of replacement enzymes and the possibility of gene therapy are among today's research themes and treatment options. Bone marrow and cord blood transplantation can be successful, though relatively few individuals qualify for this highrisk procedure. We've made major advancements in research thanks to the fundraising efforts of the Society and its members.

Our Purpose

To support research the Society and our members raise money to provide student fellowships and fund research projects at a number of prestigious university centers. Contributions may be designated for general or syndrome-specific research. Technical conferences are periodically held allowing researchers to collaborate and discuss their findings. The Society collaborates with other LSD patient support groups and family research foundations to fund research. Although great strides have been made in research, sponsors are urgently needed to accelerate the encouraging research that is bringing therapies — and ultimately the cures — to children and adults with MPS and related diseases.

To support families the Society works in many ways. We publish an ever-growing series of resource guides dealing with the specific syndromes and treatments. Our newsletter, *Courage*, is commonly referred to as a lifeline for families, physicians and professional care providers. *Courage* contains letters and photos submitted by families, reports on the breakthroughs in research and information on disease management and improvements in therapies. We hold conferences every year in different parts of the country enabling families to meet and learn more about their disease. Leadership families have been identified both by region and by syndrome to serve as valuable points of contact for newly diagnosed families. In addition, a fund has been designated to assist families to attend our conferences, to obtain medical products that will improve their quality of life and to provide continuing education scholarships. We also provide much needed emotional support to all those affected by the tragedies of MPS.

To increase public and professional awareness the Society sponsors public events, issues press releases, publishes syndrome and treatment materials and maintains a website. The Society's website, www.mpssociety.org, provides updates on research, legislative activities, family support and upcoming events. Our committee on federal legislation advocates enhanced research in the pursuit of treatments for our diseases. We cultivate working relationships with congressional offices and government agencies and advocate for enhancements to federal programs, such as SSI, Medicaid and others important to our families. The Society participates in international symposiums with a global contingent of medical and scientific professionals and networks with a growing number of international sister organizations.