



Your Donation: Your Decision

The National MPS Society is a 501(c)3 public charity nonprofit organization dedicated to finding cures for MPS and related diseases and supporting affected individuals and their families. Since 1974, the Society has accomplished this mission through research, advocacy and awareness.

It's Your Decision

Individual donors and fundraiser coordinators have the option and flexibility to direct where their donations or fundraising dollars are spent. They may be restricted for research or for family support.

Unrestricted Donations

Donations not restricted for research or for family support are considered unrestricted. As such, they are allocated by the Board of Directors to various areas across the organization where they are needed most. While some is used for general operating expenses, other amounts are used to fund other Society programs and services, including the quarterly newsletter—*Courage*, the Society's website, the many educational booklets and fact sheets, and our legislative advocacy program. The goal of the Society's legislative advocacy is to support federal legislation that impacts our members and to actively support federal funding to the NIH for MPS research. Examples of legislation supported by the Society are: ULTRA/FAST language to improve access to the FDA's Accelerated Approval process for rare disease treatments, and the Rare Disease Caucus which helps to educate legislators about the needs of rare diseases and rare disease patients. Unrestricted donations may also be used to fund programs typically funded by restricted donations, such as research and family support.

Research Donations

The Society funds approximately \$500,000 a year for research. Donors determine where their research dollars are allocated—general research or syndrome specific research (MPS I, II, III, IV, VI or ML). All (100%) of the money donated for research is spent on research grants. A committee comprised of members of the Society's Scientific Advisory board administrates the grant review process, and all grants are peer-reviewed to ensure only the highest quality research is funded.

Family Support Donations

The family support program began with membership assistance, allowing every family to be a member of the Society regardless of their financial situation. Over the years the program has grown to meet the needs of families. The Society now offers grants for medical equipment, education scholarships, medical travel assistance, and grants for individuals with MPS and related diseases to have an Extraordinary Experience. The family support program also provides funding for families to attend the annual family conference and the biannual conferences for bereaved families and for adults with MPS and related diseases. These conferences provide education, support and community for families.

Questions?

For more information about donating, hosting a fundraiser or learning about the Society's many programs, please call the Society's office at 877.MPS.1001.