

A GUIDE TO THE NATIONAL MPS SOCIETY

# Planned Giving Program



*What will be your legacy?  
The impact of your life can be felt  
and remembered for generations.*



National  
**MPS**  
Society

Support for Families. Research for a Cure.

The National MPS Society is a 501(c)(3) nonprofit organization dedicated to fulfilling its mission to support families and individuals affected by MPS and related diseases and fund research for treatments and cures. Since 1974 the Society has accomplished this through awareness and advocacy.

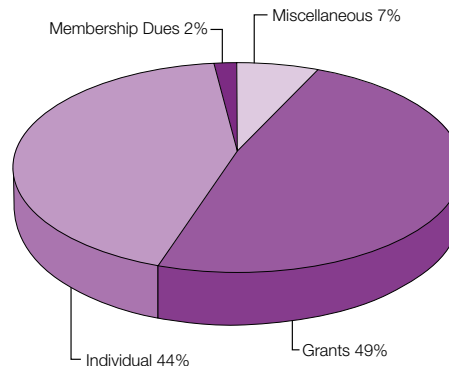
Respected for its ability to bring families together nationally, and researchers and physicians globally, the National MPS Society not only delivers compassion through support of families but has funded more than \$4 million toward research.

Over the years the Society has reached out beyond its community of members to spread its research and family support efforts through its Web site ([www.mpssociety.org](http://www.mpssociety.org)), legislative advocacy in Washington, DC, and attendance at international conferences.

In recent years the Society has succeeded in delivering enzyme replacement treatments for some of the MPS diseases through research dollars and strong partnerships with pharmaceutical companies. Still the Society has increasing need from families for program services, and some diseases do not have treatment.

The National MPS Society earns the majority of its revenue through foundation grants and the generosity of individual donors, without which the Society could not sustain.

### Society Revenue



*Careful financial planning can provide peace for you and your family. A legacy gift will provide support for future generations of individuals suffering from MPS and related diseases.*

# Planned Gifts Can Help Preserve this Vital Organization

There are many ways you can leave a legacy and help sustain the National MPS Society while providing significant tax benefits for your family and heirs. In addition to outright, tax-deductible cash gifts, there are other creative ways to support our mission:

- a bequest in your will or living trust
  - a beneficiary designation on a life insurance policy, 401(k) plan or IRA
  - an endowment
  - gifts of stock or other assets
  - life estate gifts or bargain sale gifts
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*Emil Kakkis, Jenny Soriano and their family*

Our goal in creating an endowment was to provide a gift that would help ensure the longevity and stability of the National MPS Society so it can continue to support and advocate for patients and their families. The Society provides essential functions that help patients get treatments as well as support them in their daily lives. Even with treatments, the needs are not all satisfied and there is always more the Society must do. They advocate on a national level, fundraise to support student fellowships and research projects, raise awareness, and support individuals and families with both emotional and financial assistance.

***We encourage others to join us in supporting the National MPS Society. Your gift will help the Society make meaningful change in the lives of those affected by MPS.***

# Strategies for Planned Giving

	<b>Outright Gift</b>	<b>Bequest through Living Trust</b>	<b>Bequest through Will</b>
<b>What is it?</b>	A donation of cash, securities, real estate or property.	A gift you make by naming the Society to receive a gift through your living trust.	A gift you make by naming the Society to receive a gift through your will.
<b>What are the tax benefits?</b>	Charitable deduction for the value of the gift, plus no capital gains tax due on appreciated property.	No charitable deduction but may be used to reduce liability for estate taxes.	No charitable deduction but may be used to reduce liability for estate taxes.
<b>What are some other benefits?</b>	Can be tailored for immediate or future needs of the Society.	Can be kept confidential. Terms of living trust can be changed. Gift is made when you no longer need it.	Can be changed at any time. Gift transfers to the Society at a time when you no longer need it.

## *Estate Gifts and Additional Beneficiary Ideas*

Most people leave some sort of estate when they die. An estate may be complex and large or simple and small. An estate is any property, money or personal belongings you own at the time of your death. Anyone can arrange to leave a charitable gift from his or her estate.

Other types of planned gifts include: charitable lead trusts, charitable remainder trusts, pooled income funds and charitable gift annuities.

A donor also can make the Society the beneficiary of a bank account, certificate of deposit or brokerage account.

# The Gift that Lasts Forever

	Life Insurance Gift	Retirement Planned Gift	Life Estate Gift	Gift through Bargain Sale
<b>What is it?</b>	The donation of the policy itself or naming the Society as the death beneficiary.	All or a portion of a tax-deferred retirement plan such as a 401(k) or an IRA can be designated to the Society.	A gift of a personal residence or farmland in which the donor reserves lifetime occupancy or use of the property. (Some real estate, such as an office building, business property or vacant lot, does not qualify.	Property sold to the Society at much less than appraised. Most often used for real or personal property.
<b>What are the tax benefits?</b>	Fair market value of policy or donor's cost basis, whichever is less, when policy is transferred to the Society. No deduction if named charity.	Since these assets have not been taxed, leaving them in your family can be costly. Careful planning of distribution can avoid adverse tax results.	Income tax deduction for the charitable portion of the gift.	Can receive charitable tax deduction for difference between the appraised value and the selling price.
<b>What are some other benefits?</b>	May enable a significant gift with little expenditure to the donor. A meaningful use for a policy which is no longer needed.	Can leave more of your estate to your heirs and to the Society. This is an area where tax rules are changing.	Allows donor the ability to retain use of the property for life or for a period of time.	An effective gift strategy for a donor who wishes to make a gift but needs some income from the property to complete a payment.

## *Must I have a will to leave a gift?*

Surprisingly, most people do not have a will. Not leaving a will can create complications for your heirs. To ensure the National MPS Society will receive your gift, you should create a will and state your intention in your will or trust. Without a will, you lose control over your belongings after death, and your property and finances are distributed according to state laws, regardless of your wishes. However, a gift of a life insurance policy or a retirement plan account may be made without a will by designating the Society as the beneficiary of the policy or account.

# Our Lives Have Been Enriched by the National MPS Society

The Society impacts its members through family support programs, research for treatments and cures, voices in Washington, DC, hope through conferences and support for bereaved families. Those of us familiar with the National MPS Society have been recipients of hope and support throughout our journey with MPS.

These are rare diseases, and families have few places to turn for continued support year after year. The National MPS Society guarantees their accessibility.

We have an obligation and opportunity to create a legacy that will benefit children who have suffered enough. With successful research, the Society will grow to meet the changing population of those affected by MPS and related diseases. New programs for affected adults and support services will be established.

*Planned gifts offer many advantages to help you meet your financial goals and help the National MPS Society in its long-term financial planning. Your legacy can provide opportunities for the Society to increase the strength and support of our many programs.*



# How to Name Us in Your Will or Trust

*If you choose to name the Society in your will or other estate planning, please include the following information:*

National MPS Society, a nonprofit corporation, organized and existing under the laws of the State of New York and with the principal address of P.O. Box 14686, Durham, NC 27709.

Tax identification number: 11-2734849

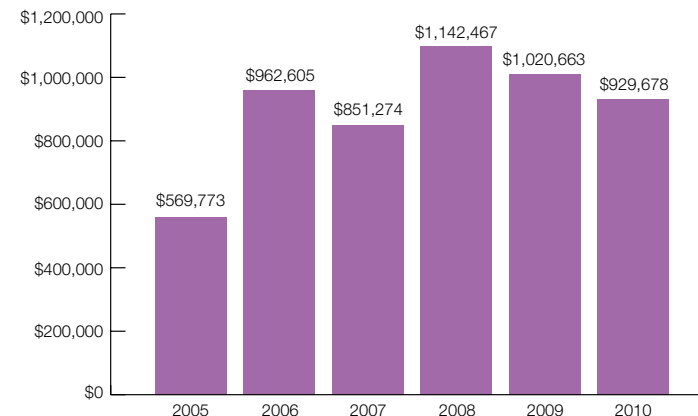
*Designation language example:*

“I give to the National MPS Society, a tax-exempt corporation, with its principal business office at P.O. Box 14686, Durham, NC 27709 (insert written amount of gift, percentage of estate or residuary of estate or description of property) to be used for the mission of the Society.”

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## National MPS Society Funded Programs

- Research Grants
- Durable Medical Goods
- Scholarships for Education
- Scholarships for Conferences
- Legislative Initiatives
- Medical Travel Assistance Program
- Regional Family Gatherings
- Celebrating Your Child's Life Experience bereavement program





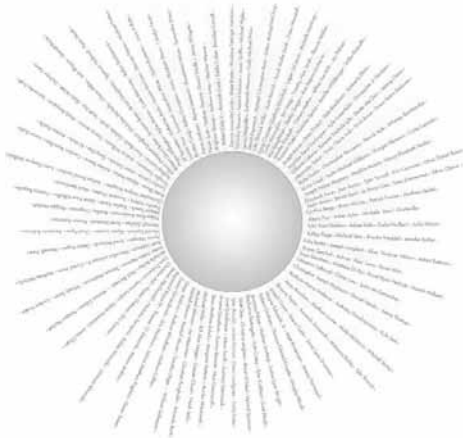


## Remember the Children, a Memorial Legacy

A memorial gift is a wonderful way to perpetuate the values and ideals of loved ones. These gifts can be included in your will or trust. Gifts for specific causes such as scholarships, programs or services also can be arranged. Inform the financial advisor and/or attorney you are working with about what you have in mind.

## Do I Tell the National MPS Society I've Left a Gift?

This is completely up to you. If the National MPS Society knows of the gift it can show its appreciation. We also can inform you about specific opportunities for giving. In addition, prior knowledge of the gift helps the Society plan for its best use.



## Rising Sun Legacy Circle

If you are planning to include or have already included the National MPS Society in your estate planning, please let us know. We would like to thank you for your generosity and welcome you to the Rising Sun Legacy Circle. This is a group of forward-thinking individuals who have demonstrated their love of and concern for the future of the National MPS Society by supporting the Society through planned giving.



# The Next Step

☐ I have included the National MPS Society in my will or trust.

I would like more information on:

- ☐ planned giving
- ☐ wills and trusts
- ☐ Rising Star Legacy Circle
- ☐ naming gift opportunities

Enclosed is my gift of:

☐ \$25   ☐ \$50   ☐ \$75   ☐ \$100   ☐ Other \$ \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

City, State, ZIP \_\_\_\_\_

Phone \_\_\_\_\_

E-mail \_\_\_\_\_

☐ Enclosed is a check, made payable to **National MPS Society**.

☐ Please charge my credit card:   ☐ VISA   ☐ MasterCard   ☐ Discover

Name as it appears on card \_\_\_\_\_

Card number \_\_\_\_\_ Exp. date \_\_\_\_\_

Signature \_\_\_\_\_

If you would like assistance planning and directing your gift to the National MPS Society, please contact:

National MPS Society  
P.O. Box 14686  
Durham, NC 27709  
919.806.0101  
E-mail: [gifts@mpssociety.org](mailto:gifts@mpssociety.org)



**Thank you for your interest in leaving a legacy to help sustain the mission of the National MPS Society.  
Your legacy will enrich the lives of those affected today and provide hope for cures in the future.**

# An Ordinary Gift Can Make an Extraordinary Impact

“I wish I could do more” are words we often hear from the thoughtful people who support the National MPS Society’s mission. In truth, you can do more for our future—through carefully planned gifts.

At the heart of planned giving is the ordinary will. Making a provision in your will to support the National MPS Society is a thoughtful way you can make an extraordinary impact on the individuals with MPS and related diseases and the families we serve.

## *Examples of Additional Bequests:*

A residual bequest may be made for a percentage or all of the estate remaining after payment of debts, taxes and expenses.

*I devise and bequeath the rest, residue of my estate to the National MPS Society to their (specific endowment or program named).*

*I devise and bequeath \_\_\_\_\_ percent of the residue of my estate to the National MPS Society for general use and purposes.*

A general bequest may be made for a specific dollar amount:

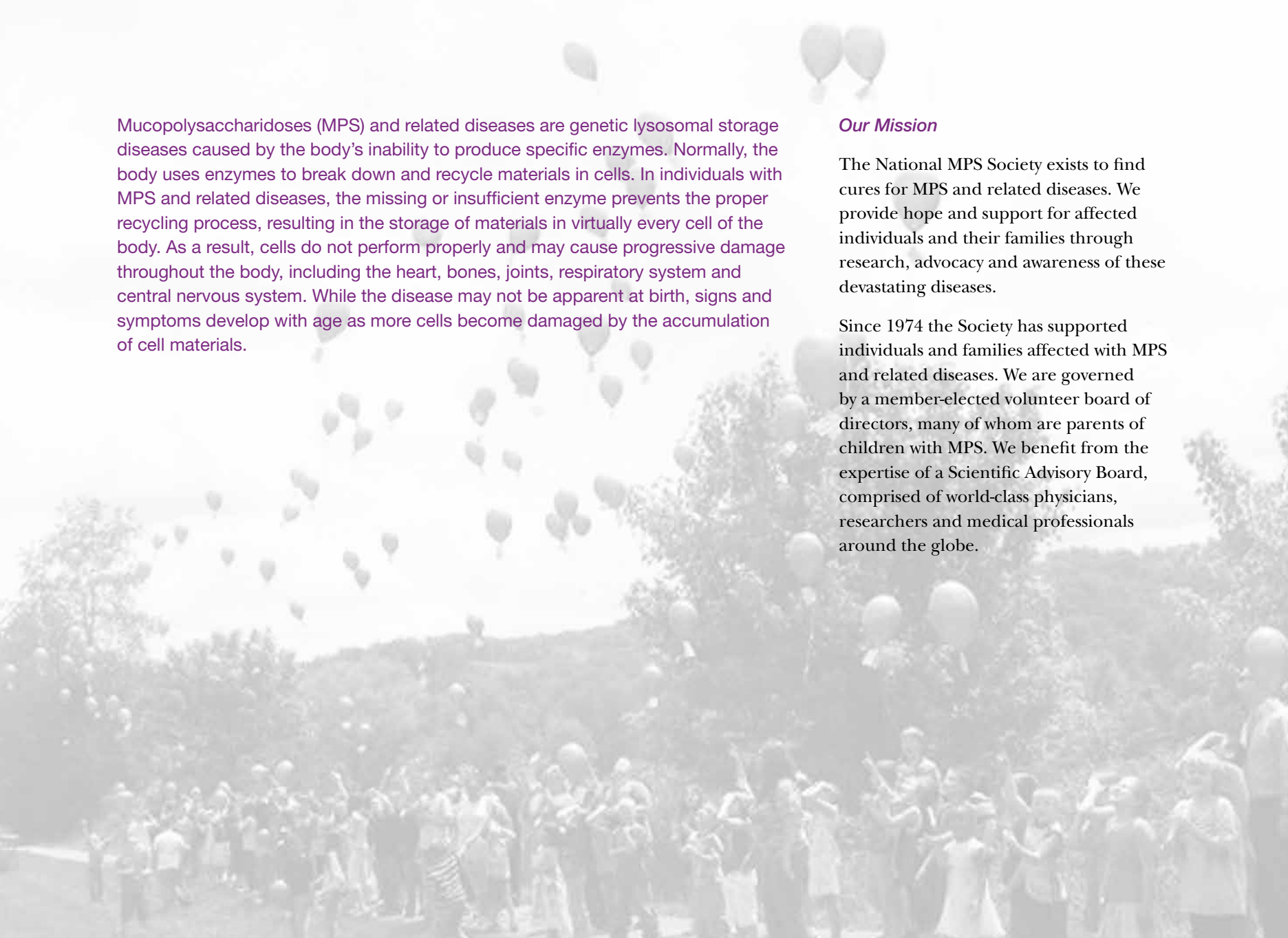
*I bequeath the sum of \$\_\_\_\_\_ to the National MPS Society for general use and purposes.*

A specific bequest may be made for a specific piece of property:

*I bequeath (insert description of property) to the National MPS Society for general use and purposes.*

*The National MPS Society recommends you always consult with a financial advisor and/or an attorney with the preparation of your planned gift.*





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

### ***Our Mission***

The National MPS Society exists to find cures for MPS and related diseases. We provide hope and support for affected individuals and their families through research, advocacy and awareness of these devastating diseases.

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 benefit from the expertise of a Scientific Advisory Board, comprised of world-class physicians, researchers and medical professionals around the globe.

