

Gift Planning from the Donor's Perspective and Understanding Revocable vs. Irrevocable Gifts

Planned giving or gift planning with the National MPS Society should be considered a cyclical, long-range strategy for your family. With the ever-changing landscape of research leading to new therapies, the needs of Society members, families and our programs evolve. It is crucial that the Society stays current with a strategic business plan that supports the mission and shares with our members and donors. It is our responsibility to anticipate, listen, strategize and take action.

The Society has many stakeholders and plans to be around for many years to come. How we fund the future, in part, can depend on you and your philanthropic goals. Through our Planned Giving program, we can allow individual donors to support favored causes that support our mission.

We hope to secure your trust and investment over time. The Society hopes to communicate our future nonprofit visions, introduce donors to campaign opportunities, and show our donors how to reach their gift objectives using gift plans and current assets. **We hope to convey that it is not about the money but rather about what will be accomplished with the gift!**

Revocable or Not?

Can you identify the differences between revocable and irrevocable gifts? Here are some important facts:

- ▶ A gift made through your will is not an irrevocable gift. Anyone naming the National MPS Society in his or her will can change the amount and even revoke that gift as long as they are alive. Only at death (when the estate is activated) does that gift become irrevocable.
- ▶ Only irrevocable gifts qualify for a current income tax deduction. To qualify for a tax deduction in a given year, every gift must be completed. Any gift that is revocable will not entitle the donor to a deduction until the gift is actually transferred to a qualified charitable entity.
- ▶ Naming the National MPS Society as a contingent beneficiary in an IRA is a revocable gift. A contingent IRA gift such as "equal shares to A, B and National MPS Society" can be revoked any time during life. In fact, if B does not survive the IRA account owner, upon death A and National MPS Society will be paid their shares by the IRA administrator.
- ▶ A gift that can be recalled before it is completed is revocable. For example, when giving shares of stock the transaction can be reversed if the wrong stock is mistakenly sent out. Only when the shares are correctly sent and accepted by the National MPS Society is the gift complete.
- ▶ Donors without a lot of assets are wise to make revocable gifts first.

What does all of this mean for members and donors?

Whether you are thinking of making an irrevocable or revocable gift to the National MPS Society, the most important consideration is to "expect the unexpected." In other words, we would rather you give thoughtfully and preserve your future personal freedom and financial security.

This is just one reason we recommend that you talk with Terri Klein, development director, who knows about the various options for both irrevocable and revocable gifts. Terri can help you think through the purpose of your gift, the best ways to fund it and the right timing under the circumstances. Contact Terri at 919.806.0101 or terri@mpssociety.org for more information.

National MPS Society 13th Annual Fund Campaign

Inspire to Give. We Need Your Help.

Giving to the National MPS Society's 2014 Annual Fund campaign is a partnership opportunity. Your family is acknowledging that the National MPS Society is working hard each day to provide support for families. Move forward with the Society, partner with us by giving to the Annual Fund. Together, we can make a difference. Donate through the mail or online!

This year our Annual Fund chair is Lynn Hopkins, mother to Michelle (MPS I). The Hopkins family has been members of the Society for many years. They share a touching story of how their daughter has received both enzyme replacement therapy and a life-saving bone marrow transplant. Their story conveys a family seeking a cure for their daughter and the heroic journey they are on. You can view their entire story online at www.mpssociety.org.

The Annual Fund:

- is a mailing campaign sent out to members, friends and families each summer with a reminder in the fall.
- was launched in 2002.
- is in its 13th year.
- has raised more than \$858,000.
- has supported critical program initiatives, including:
 1. family support, continuing education scholarships, medical equipment, conference scholarships
 2. legislative advocacy
 3. member services; and
 4. educational materials, website and other special projects.
- continues through the end of the year. Make a donation and let us recognize your gift in the Annual Report.

“Graceful acceptance of MPS in our lives does not equal complacency. Our acceptance has come with the support of the National MPS Society. By attending conferences and speaking with board members, physicians and families, the Society gave us a road map and connections. The Society is a community that works to find a cure for MPS and supports families. I am honored to share Michelle’s story with you and hope you are inspired to donate to the Annual Fund. Help the Society continue as a beacon of light for families nationwide. Please donate to the 2014 Annual Fund and help the Society continue to serve families.”

Lynn Hopkins

2014 Annual Fund chair



Michelle Hopkins (MPS I) with her brother Christopher

MPS Society Member Denise Crompton Releases New Book

Diagnosis: Rare Disease, the new book by Denise Crompton, is an unexpected journey and impacts the affected individual, family and their community.

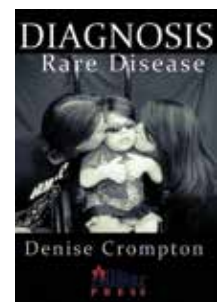
“Denise’s daughter Kelley had ML III, like my daughter Jennifer,” said MPS Society Development Director Terri Klein. “Denise was the very first parent who reached out to me in support. She was persistent though I was months in denial. Denise broke down the walls and showed me and my daughter how to live life with a rare disease.”

Denise is not only a mentor to many families with mucopolysaccharidosis (ML), but also is a second mother to many. Her advice, presentations and availability to converse with families and physicians around the world has brought comfort to many while facing the most difficult decisions. Denise’s inspiration was her beautiful daughter Kelley. Kelley has been an ongoing inspiration to those affected by ML because she lived a full life and was determined to enjoy each day.

Denise wrote her first book, *Kelley’s Journey*, more than 11 years ago while Kelley was still alive. *Diagnosis: Rare Disease* was written after Kelley’s passing. It focuses on a group of families that struggle and still have learned to live a fulfilling life while maneuvering this uncommon journey from the day of diagnosis and beyond.

Denise has showed the world of rare diseases once again that together we are strong! It is through these efforts that families will continue to unite with hope for a treatment and a cure. These will no longer be simply words for our children, but a reality. Denise and her family have always been humble servants—their footprint in the world of ML will forever light our paths.

One hundred percent of the proceeds of the sale of *Diagnosis: Rare Disease* will go to the National MPS Society for ML research.



Mardi Gras in the Park

The annual BioMarin Mardi Gras in the Park 5k Walk/Run was held on Oct. 26 in San Rafael, CA. Proceeds from this event benefit the National MPS Society's research program.



The Robinett family



Team Rachel Adams (MPS III) from the California area

Purple Lemonade Stand

The Wallace family held a Purple Lemonade Stand in conjunction with their neighborhood's fall yard sale. The Wallaces donated the proceeds of the fundraiser, held in honor of Karsyn (MPS III), to the National MPS Society to further MPS III research, and the upcoming clinical trials at Nationwide.



Karsyn Wallace (MPS III)

Ray's Rayce for a Cure

The inaugural Ray's Rayce for a Cure was held Oct. 18 at McDowell Nature Preserve in Charlotte, NC. More than 40 participants enjoyed perfect weather, hugs and high fives from Ray "The Mayor" Pinchak (MPS II). Thanks to Ray's family and friends nearly \$5,000 was raised.



Run for Erin

The Peters family hosted its annual Run for Erin on Oct. 18, raising more than \$1,600 for MPS III research. Thirty participants joined to celebrate 14 years of raising awareness and money for the National MPS Society.



The Peters family with Father Jim Murphy



Erin Peters (MPS III) with her best friend from high school Rebecca Lane

Walker Benefit Concert in honor of Trinity Walker (MPS III)

The 3rd Annual Walker Benefit Concert was hosted by the Walker family in honor of Trinity Walker (MPS III) in Washington.



2014 Annual Fund Campaign Raises \$93,862 by Oct. 24

The National MPS Society's Annual Fund is a valuable tool that helps to strengthen the vision, purpose and mission of the Society by committing resources to projects that provide direct benefit to members and their families. Your generosity will help fund programs such as conference scholarships, the Family Assistance Program, expanded publications resources and legislative initiatives.

Our goal for 2014 is \$135,000. Please help us reach this historical goal by sending in your donation today. Thank you to everyone who has already donated to the 2014 Annual Fund. With your ongoing support we can continue our very important work, supporting children and adults with MPS and related diseases and their families.

Humanitarian \$5,000+

Bryson Foundation, LTD
It Works Gives Back Foundation
in memory of David Radius
Joe and Jan Melnyk *in honor of Nick Melnyk*

Philanthropist \$1,000–\$4,999

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Gordon Wingate *in memory of Jennifer Wingate*
Russell and Alice Witt *in memory of Kevin and Kyle Witt*

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in honor of Branden Patterson
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in honor of Daniel Dobrowolski
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in memory of Danny Gniazdowski
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in memory of Aurora Laorenza
Dana Lieberman *in honor of Gayle Lieberman*
Howard and Jean Madsen *in honor of Fran Madsen*
Loy and Susan McKeithen *in memory of Edie Burke*
Marcia Mederos *in honor of June Ann Murphy*
Rob and Sharon Muller *in honor of Riley Muller*
Sharon O'Connell
Cal Stempel
Stuart Swiedler and Judy Weiss
Susan Taylor *in honor of Olivia Lovell*
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Jerry and Lisa Todd *in honor of Jack Todd*
Melodie and Randolph Watson
in honor of Liam Denneen

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Richard Bosse
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Donald and Romona Finzel
in honor of Mitchell Finzel
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Peggy Holland *in memory of Spencer Holland and in honor of Maddie and Laynie Holland*
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Lori Caldwell LeDoux *in memory of Matthew Caldwell*
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