

participating in natural history studies or clinical trials. The audience was grateful to hear Steve



Young adults at the banquet

Holland, Melissa Hogan and Jill McDermott share the benefits and tribulations associated with the commitment to be a part of a study or clinical trial.

Soon the banquet ended, the awards were given and participants were inspired by the talk by Mercedes Johnson about “Second Chance Living” and her triumphant road of hope, love and faith. Hugs and kisses were shared with promises about when we’ll meet again. If not before Boston next July, at least we’ll keep in touch on Facebook, through our personal blogs, e-mail or even a phone call. Friendships made and renewed will sustain us throughout the year.

Creative Fundraising in a Challenging Climate

Mary Ellen Pendleton, chair of the Fundraising Committee, opened this session by highlighting the many fundraising events held in 2010. There were a total of 64 fundraising events that raised in excess of \$480,000. She spoke of the importance of every fundraising event, large or small. Every dollar raised puts us closer to a cure. Small fundraisers bundled together can support a research grant, a scholarship opportunity or a family assistance item. The Society also is using social media such as Facebook and First Giving for additional fundraising opportunities.

Terri Klein, development director, National MPS Society, discussed the need families have to make a difference once they have dealt with a diagnosis. MPS families are eager to raise funds with a variety of strategies. Terri spoke of two new fundraising opportunities: The Planned Giving program which enables families to plan long-term gifts to the National MPS Society, and the Sponsor a Child for a Cure program which enables families that are unable to attend a walk/run event to raise money in honor of a child affected with an MPS disorder.

Our MPS children are our inspiration, but our unsung heroes are the siblings who want to raise awareness and find a cure. The highlight of the fundraising session was hearing from three siblings of MPS children. Their stories were heartfelt and inspirational.

Emily Durcholz hosted a walk/run event in honor of her brother Ben and in memory of her brother Zach. Her event was a lot of hard work but

she received tremendous support from her family and the community. Her advice was to tell yourself that YOU CAN DO IT, to ask for help, to be pushy and to use the pity card if necessary!

Jeremy Mask hosted a fundraising event in memory of his brother Ryan. He has been active

in the fundraising world for quite some time through Ryan’s Run and other MPS walk/run events. He was inspired to host a charity concert because of his brother’s love of music. His dream is to have all the youth start a fundraiser. “The good feeling you get is the best reward,” said Jeremy.

Chelsey Montgomery spoke about her strong family unit as the foundation for a successful fundraising event. Her brother Lucas is her

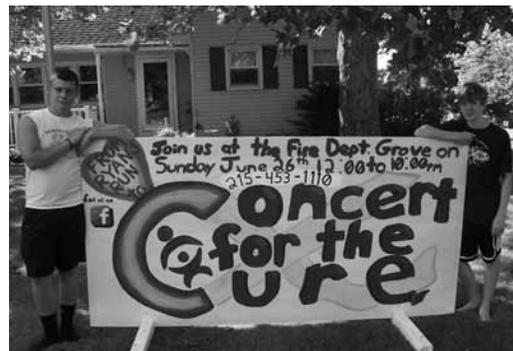
...our unsung heroes are the siblings who want to raise awareness and find a cure...

inspiration. Each family member takes the lead on one charity event every year. Her focus is on awareness and advocacy. The key to her fundraising success is to step out and do something fun. She did this by organizing an MPS dance-a-thon. Her motivation is very simple; she loves Lucas and loves to see Lucas in the spotlight.



Jeremy Mask, Emily Durcholz and Chelsey Montgomery pictured with Terri Klein.

The 1st Annual Concert for the Cure for MPS was held on June 26, 2011, in Sellersville, PA, at the Sellersville Fire Grove. This all-day event, organized by Jeremy Mask whose brother, Ryan, had MPS III, featured 11 local bands that donated their time to raise awareness and money for the National MPS Society. More than 350 people attended.



Vendors sold jewelry, woodcarvings and custom-designed clothing; they donated 10 percent of their sales that day to the Society.

Food and drink were sold, including 400 purple ribbon “courage” cupcakes baked by Haley Miller, sister of Danny Miller (MPS II). In addition, more than 40 raffle items were given away. In total, more than \$4,000 was raised.

The 2nd Annual Minnesota MPS Cup Hockey Game and Gala was held April 16, 2011, raising more than \$37,500 for the National MPS Society.

The starting lineup for the Minnesota MPS Cup event consisted of returning veterans Dave and Hope Madsen, Colleen and Jason Moore, and Bruce and Michelle Bjorkman. They welcomed new MPS Cup rookies to the team: Sally and Bart Finzel, and Elizabeth and Chris Hoff.

Teams consisted of 14 Minnesota NHL alumni players, including Minnesota North Star players Brad Maxwell and Don Beapre, and Buffalo Sabres player Phil Housley. Joining them were 19 donor participants who were inspired and touched by MPS families. The game ended in a 10-10 tie.

A gala was held following the game at the Grand Banquet Hall in Stillwater, MN, where the teams celebrated their accomplishments. Special speakers included Dr. Paul Orchard, medical director of Inherited Metabolic and Storage Disease Bone Marrow Transplantation Program at the University of Minnesota, and Colleen Moore, parent of Jessica (MPS I). Together they presented their personal story on the success of bone marrow transplant and their new challenges with a plea for more research dollars. The rest of the evening was a rousing bash led by rock band The Dweebs.

“MPS is a lonely disease,” said MPS Cup organizers Dave and Hope Madsen. “Fundraising by yourself can be overwhelming, but with the strength and support of members of the National MPS Society, we can accomplish much.”

Please consider sponsoring a Minnesota MPS Cup team next year. Teaming up with a hockey player is a fun and creative way for you to participate even if you cannot join the MPS Cup celebration in Minnesota.

For more information, contact:

Dave and Hope Madsen

651.331.9625

hope.madsen@comcast.net

www.mpscup.org

www.facebook.com/home.php#!/MinnesotaMPS Cup



Jessica Moore (MPS I) singing with The Dweebs



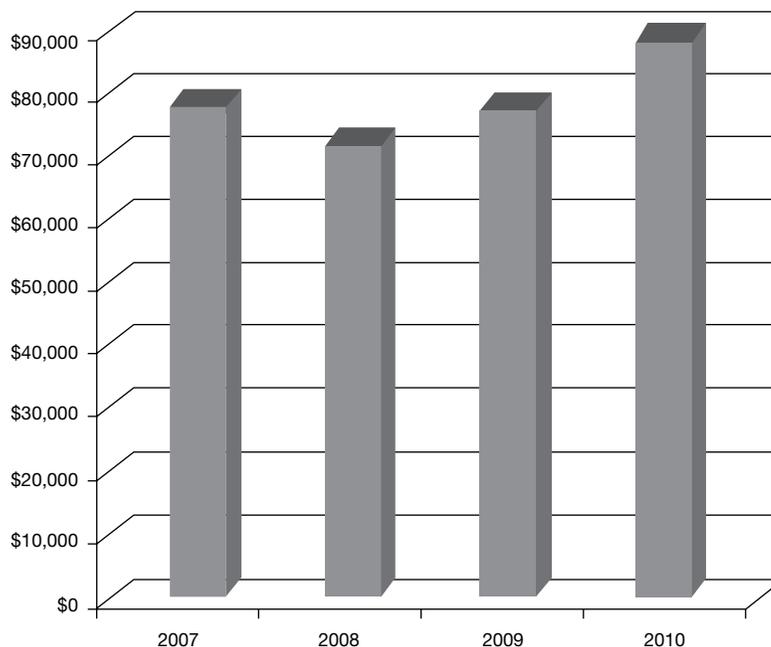
Willow Hoff (MPS IV) with NHL alumni Gord Hampson

National MPS Society 10th Annual Fund Campaign Happening Now!

Giving to the National MPS Society's 2011 Annual Fund campaign is a partnership opportunity. Your family is making a decision to support the National MPS Society, which is working hard each day to provide support for families and research for cures. 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!

- 2002 was the launch of the 1st Annual Fund
- This is the 9th year of the Annual Fund
- The Annual Fund has raised more than \$520,000
- The Annual Fund has supported critical program initiatives:
 1. Family Support, continuing education scholarships, medical equipment, conference scholarships
 2. legislative advocacy
 3. member services
 4. educational materials, Web site and other special projects
- Previous campaign chairpersons have included:
 1. Beth Karas, *2011 Annual Fund chair, True TV correspondent and sister of two ML III brothers who have passed*
 2. Denise Dengel, *2010 Annual Fund chair, adult with MPS I*
 3. Susan McKeithen, *previous board director and MPS I grandparent*
 4. Larry Kirch, *previous board director and MPS III parent*
 5. Tom and Anne Gniazdowski, *current board directors and MPS II parents*
 6. Dr. Mark Sands, *Research and Scientific Advisory Board with Bryce Chesser, MPS II*
 7. Terri Klein, *development director and parent of Jenny Klein, ML III*
- The Annual Fund is a mailing campaign sent out to our members, friends and families each summer with a reminder in the fall.
- The Annual Fund continues through the end of the year; make a donation and let us recognize your gift in our Annual Report.

Annual Fund Campaign



Ways to GIVE

- Renew your membership or sponsor another family
- Gifts in honor of a special person
- Gifts in memory of a special person
- Matching gifts through your employer (check with your human resource office)
 1. Request a matching gift form from your employer
 2. Complete the employee section of the form
 3. Mail to the Society and we'll do the rest
- Contribute through the Combined Federal Campaign if you are employed by the federal government — CFC #10943
- Designate the Society as a member of your local United Way. You will need to supply them with the Society's name, address and Federal ID number (FEIN #11-2734849)
- Annual Fund donation
- Major gift (usually 10 times that of your Annual Fund gift)
- Planned gift
 1. Bequest in your will
 2. Charitable remainder trust or charitable gift annuity
 3. Charitable lead trust
 4. Life insurance policy
 5. Gift of appreciated assets (stocks, mutual funds and bonds)
- Gifts may be applied to the Society's general operating purposes or restricted to one of our designated programs.

CONTACT:

terri@mpssociety.org or 877.MPS.1001

National MPS Society Receives Three-Star Charity Rating

The National MPS Society learned in spring 2011 that we were awarded a three-star rating, indicating that we “exceed or meet industry standards and perform as well or better than most charities in its cause.” The board of directors has reviewed Charity Navigator's detailed ratings table and scoring system in order to identify ways to earn a few more points to regain the four-star rating.

Fundraising Reminders

- Don't forget to submit a brief article for *Courage* about your fundraising success stories and suggestions—they are terrific resources for other families planning events.
- Check out the fundraising section on the Web site for more information or to post your event.
- For free MPS Society brochures and donor envelopes, or to submit information for the Web site or *Courage*, send an e-mail to Terri Klein at terri@mpssociety.org.

Keep in mind—the Annual 5K Walk/Run and the Annual Fund are great ways to raise money for the National MPS Society.

What will be your legacy?

The impact of your life can be felt and remembered for generations

For 36 years the National MPS Society has embraced new and challenging ideas that raise awareness and funds for our mission: *Support for Families. Research for a Cure.* The Society and its fundraising efforts have evolved through a range of economic climates.

Our newest program, *Planned Giving*, illustrates why it is essential to be forward thinking with our fundraising efforts. Through sound fiscal responsibility the Society has developed into an organization that is able to collaborate with others on advancement of research and groom programs to meet the needs of those affected by MPS and related diseases. In order to sustain and protect our future research and family programs, the time is now for the Society to reach out to members, donors and friends and introduce planned giving.

During the past few years there has been an increased movement toward donor-centered philanthropy, where charities focus on the interests of the donor. Through our development of planned giving we can continue to help meet this donor interest movement and develop critical funds for the Society's mission.

What is Planned Giving?

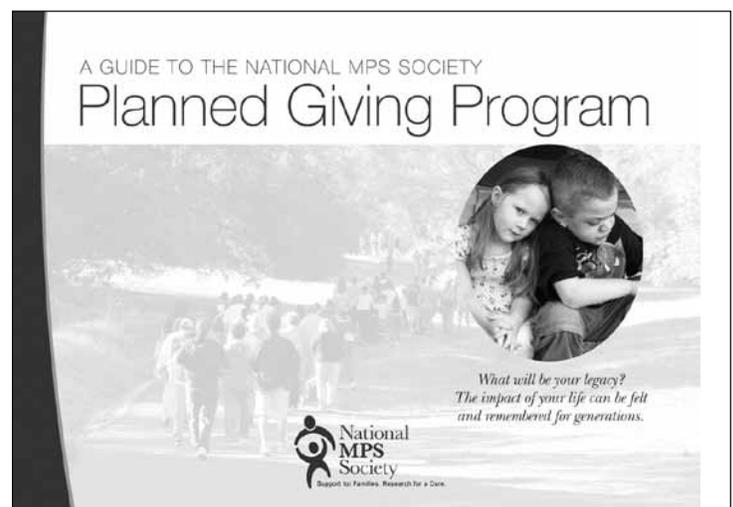
Historically planned giving was a process of asking loyal supporters to provide for a charity through a will or gift annuity. The process of planned giving focused primarily on circulating tax materials, understanding tax benefits and the best method to implement the gift.

Today, planned gifts embrace these historical philosophies but have a donor-centered approach. Charitable planned gifts for the National MPS Society can be successful by integrating donors' philanthropic goals with their overall tax and financial planning needs. With donors embracing this forward program of giving they will be able to create a more meaningful and lasting legacy.

Planned gifts can help sustain and protect the mission of the National MPS Society while providing significant tax benefits for your family and heirs. Types of gifts include:

- outright tax-deductable cash gifts
- 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 such as real estate
- life estate gifts

You do not have to be wealthy or elderly to consider a planned gift! These gifts can be provided to the Society today or in the future. For more information and to receive "*A Guide To Planned Giving*," contact Terri Klein, development director, at terri@mpssociety.org or 919.806.0101.



On Your Mark, Get Set, GO!

The 2011 walk/run season is under way! Show support for MPS and related diseases and raise awareness by attending an event near you. Contact Terri Klein (terri@mpssociety.org) to find out how you can be involved in a new program this year: *Sponsor a Child for a Cure* in coordination with a 2011 walk/run.

12th Annual Run for Erin*

9/24/11
Woodstock, GA
Coordinator: Stacey Peters
smptrs@bellsouth.net

4th Annual River Run for Ryan

8/13/11
Guttenberg, IA
Coordinators:
Jonathon & Marie Hunt
mlhunt@alpinecom.net

5 for FiVe, Memory Run for Louis Butts V

9/10/11
Saratoga Springs, NY
Coordinator: Michelle Storm-Butts
michellestorm23@yahoo.com

BioMarin 5K Walk/Run*

10/2/11
Novato, CA
Coordinator: Kathie Ward
kward@bmrn.com

It Works, Run for MPS*

10/29/11
Bradenton, FL
Coordinator: Kate Martin
katem@itworksglobal.net

We are already lining up walk/run events for 2012! Contact Terri Klein for details (terri@mpssociety.org) to help you organize your upcoming event.

Laps for Lucas

9/18/11
Cedar Rapids, IA
Coordinator: Stacey Montgomery
lewnstacey@yahoo.com

Miles for MPS

9/17/11
Grand Rapids, MI
Coordinator: Laurel Radius
frazzledblonde@yahoo.com

MPS Run for Their Lives 5K*

10/11
Fort Worth, TX
Coordinator: Scott Hardin
scotthardin777@gmail.com

Post Office Café's Annual* Fun Run for MPS

10/17/11
Babylon, NY
Coordinator: Kerri Rose
kerri@lessings.com

Thank you to the following walk/runs already held in 2011:

Action for Aidan

Exeter, NH
June 2011
Coordinators:
Brooke Carter and Jennifer Carter

2nd Annual Beat MPS

Wilmington, DE
June 2011
Coordinators:
Jennifer and Carl Capes

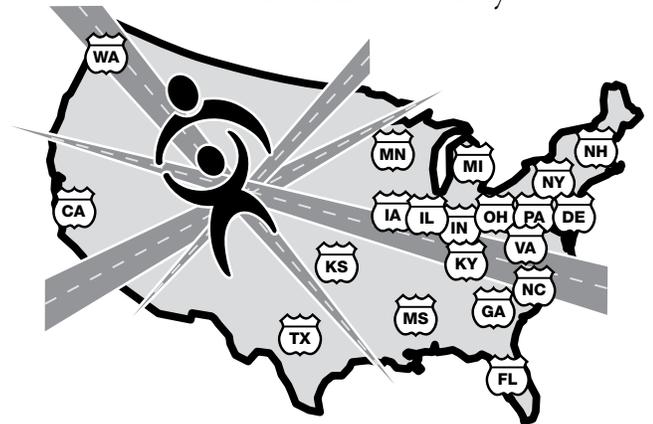
4th Annual Strides for Sara

Fair Haven, NY
June 2011
Coordinator: Monique Dickerson

Cameron's Race for a Cure

Ashland, KY
May 2011
Coordinators:
Brian and Julie Mollette

National MPS Society



Support for Families. Research for a Cure.

2011 Walk/Run
www.mpssociety.org

** These events are participating in Sponsor a Child for a Cure.*



During our 2011 family conference fundraising workshop we were honored by three young philanthropists—Emily Durcholz, Jeremy Mask and Chelsey Montgomery—as they spoke with attendees and shared their stories about inspirational fundraising. Little did any of us know just how much we would be touched by their active role in fundraising and the lives of their affected brothers. After the session ended and throughout the remainder of the conference, I was told by member after member how much these stories impacted their families and how they wanted to make a difference too.

Members and friends of the Society recognize that while others raise awareness for our cause, we have those who have the ability to raise money for research, family support and move the mission forward for treatments and cures. We are always trying to find creative ways to spotlight our affected loved ones and raise money to eradicate these diseases.

Currently we are in our 12th walk/run season. Please review a list of this year's events (page 22) and become part of Sponsor a Child for a Cure. There are many opportunities for families to contribute to Society programs and we need your help now more than ever this season.

The 10th Annual Fund campaign is under way; you should have received information regarding this in the mail. The ability for the Society to continue valuable programs would suffer without your contributions. Please make a donation and recruit friends, family and colleagues for our cause. Start an Annual Fund awareness event and host family and friends for a day or night of fun!

The Fundraising Committee also is pleased to offer *A Guide to Planned Giving* (page 21). Are you familiar with the concept of planned giving? This is a term used to describe any number of ways you can support the National MPS Society in the future by making arrangements today. The simplest way would be to provide for the Society in your will. There also are planned gift opportunities that would provide income now to the Society. Establishing this program insures the Society will be able to continue to support research and meet the evolving needs during a family's MPS journey.

If you would like more information about this or other fundraising opportunities, contact me at terri@mpssociety.org, visit www.mpssociety.org or call 919.806.0101.

I'd like to share this inspirational quote: **"Try and fail, but don't fail to try."** – Stephen Kaggwa

Happy fall!



It is one of those times when I have been fortunate to be able to talk with many of you on the phone. The phone calls tend to come in waves—more at one time, less in others. I enjoy being able to speak with you, get to know you and your family, answer any questions you may have and connect you with other parents. I hope I am able

to help your family wherever you happen to be along the MPS journey. I am so fortunate to be able to learn and grow as I connect with all of you on a daily basis.

The calls vary in subject—sometimes just someone needing a helpful trick or the Web site to purchase a new chewy toy, sometimes, more involved—helping to find a medical specialist for a troublesome issue. Other times, just simply listening and allowing you the time to talk. Please know we are all here to help your family along

your journey. It also is helpful for me to talk with you, after all **you are the experts**. While a new item or symptom may not seem that big of a deal, it may be just the information needed by another family to help ease their current struggle. I am able to share your wealth of knowledge with other families facing the same battle.

Thank you for sharing with us.

Just a friendly reminder that we still have funds available for the 2011 Medical Travel Assistance, Extraordinary Experiences and Family Assistance programs. Let me know if you have any questions about these programs. Submissions also are needed for the OSCAR awards. If you would like to honor the brother, sister or other relative of a child with MPS or related disease in an upcoming issue of *Courage* please let me know.

Give me a call or send me an e-mail, I would love to hear how your family is doing.