

3rd Annual Mad Hatter Tea Party

On June 5, I will “hop down the rabbit hole” to our 3rd Annual Mad Hatter Tea Fundraiser—a bright, cheerful and fun garden party honoring my 4-year-old daughter Annabelle, who has MPS IV. Along with 40 hostess volunteers, we create and plan a 2 ½ hour event to include entertainment for the young and young at heart. Our goals: raise \$40,000 in research funds and a whole lot of MPS awareness!

As the guests stroll down the “paint your roses red” garden lined with silent auction items, the children play flamingo croquet and dance at the “Queen of Hearts court” entertained by the local kid favorite, Mr. Knick Knack. There are plenty of sweets to tempt your tummy and crafts to create a masterpiece hat. The Mad Hatter, White Rabbit, Alice in Wonderland and Queen of Hearts mingle among the guests offering delightful conversation and whimsical treats. The day would not be complete without the entire party wearing their maddest hat attire for all to admire.

Attendance has grown each year for our fundraiser and we are looking forward to even more participation this year. I am very excited, as this event will continue to raise awareness for Morquio syndrome and the MPS Society, and provide generous funds to support MPS research in hopes that it will lead to treatment for all those affected by Morquio syndrome. I believe the key to our success has been to keep it fun, share our story, be inclusive, stay organized, and ask for lots of donations within our community. Not only has the event accomplished our goals for awareness and fundraising, it also has created a community for Annabelle and our family to grow in which people are aware and supportive.

If you have an interest in hosting the same or similar event, I encourage you to get started. I will always be thrilled to share our secrets to fundraising success and creating a fun-filled event. Don't hesitate to contact me at stephbozarth@yahoo.com.

Stephanie Bozarth



Fundraising Committee:

MaryEllen Pendleton, chair
 Stephanie Bozarth
 Jennifer Clarke
 Ernie Dummann
 Anne Gniazdowski
 Tom Gniazdowski
 Angela Guajardo
 Steve Holland
 Larry Kirch
 Terri Klein
 Dave Madsen
 Hope Madsen
 Laurie Turner
 Barbara Wedehase

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.

National MPS Society Receives 4-Star Charity Rating

“On behalf of Charity Navigator, I wish to congratulate the National MPS Society on achieving our coveted 4-star rating for sound fiscal management. As the nonprofit sector continues to grow at an unprecedented pace, savvy donors are demanding more accountability, transparency and quantifiable results from the charities they choose to support with their hard-earned dollars. In this competitive philanthropic marketplace, Charity Navigator, America’s premier charity evaluator, highlights the fine work of efficient charities such as your own, and provides donors with essential information needed to give them greater confidence in the charitable choices they make.

“Based on the most recent financial information available, we have calculated a new rating for your organization. **We are proud to announce the National MPS Society has earned our 4-star rating for its ability to efficiently manage and grow its finances.** Approximately a quarter of the charities we evaluate have received our highest rating, indicating that **the National MPS Society executes its mission in a fiscally responsible way and outperforms most other charities in America.** This “exceptional” designation from Charity Navigator differentiates National MPS Society from its peers and demonstrates to the public it is worthy of their trust.”

Ken Berger, President and Chief Executive Officer, Charity Navigator



Sponsor a Child for a Cure 2011—Don’t get left behind!

If your family has wanted to participate in a walk/run event to raise money for research we have created that opportunity. This program reaches out to families and members of the Society that want to sponsor an affected loved one or a child who has passed away, and help find cures for MPS and related diseases. Walk/runs across the country will be participating in this program in 2011.

All you need to do is:

- Submit a photo of your loved one to the race you wish to participate
- Include the name of your child and address
- Get sponsorship and send to the National MPS Society

In turn, the event will:

- Assign a runner to participate on behalf of your loved one
- Send you a courage medallion and photo with your assigned participant

The assigned runners are inspired by our heroes of MPS. Together they pave the path of continued hope. The photos and amount raised will be published in an upcoming *Courage* magazine.

For more information on the Sponsor a Child for a Cure program, contact Jennifer Clarke at jenniferclarke@mpssociety.org.

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

2010 Fundraising Recap

**44 events, one goal:
Make a difference!**

The National MPS Society is honored and proud of families who have found creative ways to raise money for our organization. Since 2004 the Society has raised more than \$1 million for research, family assistance and other Society programs through fundraising events. Those efforts have provided funding for research grants, durable medical goods, scholarships for education and conference registration, regional family gatherings, extraordinary experiences and support toward the CYCLE program for bereaved families.

We extend our gratitude and recognition to our 2010 fundraising hosts. Your efforts strengthen the foundation of the National MPS Society. Whether large or small, each fundraising event succeeded at increasing awareness in communities nationwide. These families set out to make a difference—individually they succeeded, collectively we soared!

1st Annual Corn Hole Toss

Hosted by Hank & Carolyn Hinton



Carolyn Hinton was motivated to fundraise in honor of her son Danny, who has MPS II. Carolyn and her family wanted to make a difference. Together they hosted their first corn hole toss on May 15, MPS Awareness Day.

More than 200 people registered, formed teams and tossed bean bags into corn hole boxes 30 feet away. They raised more than \$3,000. The community, along with other MPS family support, inspired the Hinton family to host another event in 2011.

1st Annual Minnesota MPS Cup

Hosted by Dave & Hope Madsen

Inspired by the Vancouver MPS Cup and Gala, the Madsen family decided they wanted to contribute to the Society. Their daughter Fran has MPS I. With their enjoyment of ice hockey, they spoke with the Minnesota NHL Alumni and other nearby MPS families.

With everyone on board the turnout was spectacular and they raised more than \$26,000 for family assistance. Fans paid to play with NHL Alumni and Brad Maxwell, the celebrity game host.

Afterward, 150 donors, including the alumni, gathered for a charity gala event with a live band and auction.



A Wish for Evan Softball Tournament

Hosted by John & Kristi Abel



The Abel family hosted a weekend softball tournament and spaghetti dinner in Hewitt, TX, in honor of Evan who has MPS III. Teams and the community showed up to support the first A Wish for Evan Softball Tournament.

The event held an auction, issued prizes and raised more than \$10,000.

This also was a unique opportunity for the Abel family to meet and share stories with other MPS families in their area.

Bowl for Caden

Hosted by Chris & Clarissa Bartlett

1st Annual Bowl For Caden

The 1st Annual Bowl for Caden was held in Woodstock, IL, in honor of Caden Mitchell who has MPS II. More than 200 families participated in this team event. Through bowling, raffles, a silent auction and bumper bowling for the kids, this event raised more than \$1,000.

Cameron's Car Show

Hosted by Brian & Julie Mollett



This event was held in honor of Cameron Mollett who has MPS II. The community of Paintsville, KY, got their motors running for a cure and raised approximately \$2,000. Thirty cars entered the competition for a fee. The event presented an overall winner for Best in Show and trophies for other category entries. This event also included a 50/50 raffle and a DJ.

Clara's Courage

Hosted by Shane & Jenifer Gibson

The Gibson family hosted their 2nd annual Clara's Courage hot dog stand in honor of Clara who has MPS III. This event was held outside the local grocery in Wilimington,



OH, and brought the community together for food and awareness. Clara's Courage hot dog stand has raised more than \$4,000. Each year the Gibson family hosts charity dinners and finds creative ways to help fund Society programs.

Chapin's Lemonade Stand

Hosted by Grey Chapin



Grey Chapin, daughter of Roger and Susan Chapin, hosted a lemonade stand in honor of her sister Blair who has MPS III. They event was held on May 16 for MPS Awareness Day with overwhelming support from the community.

Grey's lemonade stand raised more than \$1,500. The lemonade stand was decorated with bright colors and provided beverages, cookies and many other treats.

Delaware Inaugural Walk/Run

Hosted by Carl & Jennifer Kapes



This walk/run was held in honor of Ryan and Brayden Kapes who have MPS III. More than 400 people traveled to the Delaware River to support the Kapes in this extraordinary event that raised more than \$28,000 for MPS III research.

If you would like more information on fundraising, contact Terri Klein at terri@mpssociety.org.

Dopheide "Oklahoma" Fundraiser

Hosted by Emma Dopheide



Emma Dopheide, along with her middle school, presented "Oklahoma" for their school play. The school selected the proceeds to benefit the National MPS Society in honor of Emma's sister, Julia, who has MPS III. This wonderful gift and charming invitation was then followed with a matching gift from the Sanfilippo Syndrome Medical Research Foundation. Together the event raised approximately \$6,000 for MPS III research.

Fowler Family Charity Dinners

Hosted by Jason & Jamie Fowler



Each year the Fowler family gathers around their home in Colorado or with family in Arizona. They raised more than \$1,500 through charity dinners in honor of their son Jack, who has MPS II.

Klenke Bowl, 12th Anniversary

Hosted by the Klenke family

The Klenke family hosted its 12th Annual Bowl-a-Thon in Edwardsville, IL, in memory of their son Kraig who had MPS II. Family, friends and the community came together to bowl a game for Kraig and help raise more than \$10,000 for the Family Assistance Program.

This event included a raffle, food and prizes for the bowlers. Each year they develop a theme for participant T-shirts.

Everyone celebrated the end of this event with a special cake.



Links for Lucas

Hosted by Lew & Stacey Montgomery



Every year the Montgomery family hosts an event to raise money in honor of their son Lucas, who has MPS III. Links for Lucas was a terrific golf tournament that brought family, friends and the community together. The event raised more than \$10,000. The Montgomery family has hosted other events such as walk/runs and charity dinners, and even Lucas' sisters have been involved with hosting a dance-a-thon.

Lukondi Fisher Walk/Run 5K

Hosted by Rob Lukondi



Robert Lukondi and his stepson, Michael Fisher, who is autistic, trained for and ran their first 5K.

Robert and Michael completed their event in honor of Allison and Lacey Lukondi, who have MPS III, and raised \$250. Michael trained for months while working through his autism in this inspiring tribute for his cousins.

Muller Family Fundraisers

Hosted by Robb & Lisa Muller



For the second year in a row the Muller family hosted the Riley Corn Hole Tournament. More than 60 teams participated in the event to honor Riley Muller who has MPS II.

The Muller family had special boards made for the event with purple ribbons painted on each of them. Teams registered and participated on this sunny day. They raised more than \$5,000 in the past two years. Along with this event the Muller family likes to host fun charity dinners throughout their hometown of Marysville, OH.

Play for Taylor

Hosted by the Wojnarowski family



For many years the Wojnarowski family has hosted Play for Taylor, a musical recital in honor of Taylor, who has MPS III. The family hosted a number of other events throughout the year and raised more than \$900. In 2010 they held a T-shirt sale for Run 13 Miles for 13 Years and included family in the 2010 Annual Fund drive.

Post Office Café Charity Events

Hosted by Mark Lessing & Kerri Rose



The Lessing family hosts charity events at their Post Office Café each year to benefit Society programs. Events are held in honor of Casey Lessing and in memory of Mark Lessing Jr., both with MPS III.

The Post Office Café hosted the Great Case Race and raised \$600 while extending hospitality to patrons and raising awareness for MPS and related diseases. In 2010 the Post Office Café also celebrated their fifth walk/run event for MPS.

Shots for Sean

Hosted by Ernie & Debbie Dummann



Shots for Sean is an annual golf tournament hosted by the Dummann family. In 2010, this event was held in memory of their son Sean who had MPS III.

The event was held in Anchorage, AK, and brought family, friends and colleagues out to swing for Sean.

The Dummanns included a raffle, prizes, plaques and giveaway bags for the participants and food as part of the registration fee. Shots for Sean raised more than \$11,000 in 2010.

Wynn & Dorian Birthday Fundraiser

Hosted by Chris & Mercedes Johnson



The Johnson family held their second birthday bash in honor of twin sons Wynn and Dorian who have ML II.

The family combines Wynn and Dorian's birthday with a Halloween theme and invites family and friends. They have raised more than \$7,000 for ML research.



Other 2010 Fundraising Events

- Allison and Ashley's fundraising event, hosted by Ashley Restemayer*
- Anderson harvest fundraiser, hosted by Dave and Cynthia Anderson*
- Angel Aurora Laurenza's birthday event, hosted by Providence Schools*
- Bluegrass concert for MPS, hosted by Sharon Gilham*
- Booster Arbonne fundraiser in honor of Rebekah, hosted by Dawn Booster*
- Bosch garage sale neighborhood fundraiser, in honor of Daniel "Squeek" Bosch*
- Bozarth soccer camp fundraiser, hosted by Stephanie Bozarth*
- Camelot Preschool MPS Day, in honor of Oliver McNeil*
- Cavanaugh bracelet show, hosted by the Cavanaugh family in honor of Allison Kirch*
- Chesser lemonade stand, hosted by Bryn Chesser*
- Cirolì jewelry show, hosted by Lisa Muller in honor of Riley Muller*
- Holmes Elementary bake sale, in honor of Clara Gibson*
- Ice Cream Corner fundraiser, hosted by the Restemayer family in honor of Allison Restemayer*
- Jean for Genes, hosted by BioMarin*
- Kassi's Kause charity dinners, hosted by the Offenbacher family*
- Life Skills walk-a-thon, hosted by Kathy Greenberg in honor of Logan Piefer*
- Lee dance-a-thon, hosted by Griffen Lee*
- Malone garage sale, hosted by James and Joan Malone in memory of Louis Butts V*
- NH Eye Associates fundraiser, in honor of Sasha Segal*
- Sowden's Walk for a Cure, hosted by Josh and Sheri Sowden*
- St. Anne's bake sale and craft show, hosted by St. Anne's school in honor of the Sarantinos family*
- Tricky Tray fundraiser, hosted by St. Andrews Church in memory of Rishi Garg*
- Williams' bicycle race, hosted by Adam Williams in honor of Riley Muller*

Inspired by the fun and success of last year's fundraising events? Consider hosting your own!

The National MPS Society provides a comprehensive how-to packet with checklists and details for hosting events, including instructions for securing donations, building a volunteer team, obtaining liability releases, gathering sponsorships, publicity and much more. To receive your packet, contact the Society at 919.806.0101 or send an e-mail to Terri Klein, development director, at terri@mpssociety.org.



Summer is here and we are gearing up for the walk/run season and preparing for the annual conference in St. Louis, MO. The Fundraising Committee has been preparing for the launch of our newest program—Planned Giving. This program will be unveiled during the annual conference and information will be available on our Web site under “Fundraising.”

This will be the third year for our Sponsor a Child for a Cure program. Last year 30 children, young adults and families participated. Together they raised more than \$11,000. We hope this year more families will be able to participate in the joy of raising awareness and money for research. This program is embraced by runners nationwide

and we are thrilled that families unable to attend a walk/run in person can still make a difference. Take a moment and read through the wonderful fundraising events of 2010 on page 16. We are thankful to everyone who contacts the Society with creative and worthwhile fundraising events. Our strength is gained from those who reach beyond their expectations in honor or in memory of a loved one and raise awareness to help eradicate these diseases.

When you have time, visit the National MPS Society Facebook page or follow us on Twitter! For more information about Planned Giving, Sponsor a Child for a Cure or any other fundraising programs, please contact me at terri@mpssociety.org. Happy summer everyone!



The last few months have been a whirlwind of activity. I have had the opportunity to speak with a lot of our members and even had the privilege to spend time with some of you. I spent International MPS Day at Shire HGT with the Noll family. They shared their story of little Austin and his journey with MPS III with the Shire employees, and I was able to inform them of the Society and our programs. It was a lovely afternoon, made better by some hugs from little Austin! In June I attended Action for Aiden—a walk fundraiser in Exeter, NH. Yes, this is the first time in almost 10 years that we have had an event in New England. Thank you Carter family. It was wonderful to be able to participate in this event!

I am very excited to see many of you in St. Louis.

Conferences are always the highlight of the year for me; it reminds me of the reasons I love my work with the Society. Being able to spend time with those of you I speak with on a regular basis, being able to finally put a face to the voice and, best of all, having the opportunity to spend time with your children. The families I serve are the best; I am amazed by your courage, strength, love, passion and determination. You inspire me daily, and for that I thank you.

I am pleased to be able to let you know that the Family Support Committee approved travel scholarships to help 18 families attend the conference. For 12 of these families and affected individuals this will be their first conference! We hope your family also will be able to attend this wonderful event!