

2009 Annual Fund Campaign Raises \$45,500 by Oct. 1, 2009

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 2009 is \$70,000. Please help us by sending your donation today.

Please accept our sincere thanks to everyone who has already donated to the 2009 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.

Philanthropist \$1,000 or more

Barbara and Ray Alpert
in honor of Bryce Chesser

Dutch's Daughter Inc.

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in memory of Christopher Lesta

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in honor of Austin Noll IV

Raymond and Barbara Alpert Foundation

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in honor of Jacob and Ali, and in memory of Clinton and Zachary Szemanski

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in memory of Susannah White

Leader \$500–\$999

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Mel and Millie Anhalt

Joel, LeeAnn, and David Bernbaum
in memory of Mark Bernbaum

Elizabeth Karas
in memory of Joseph and Jonathan Karas

Wendell and Karen Keith
in memory of Amanda Keith

Douglas Macleod

Mark and Mary Ellen Pendleton

Robert and Suzanne Washburn
in honor of Erik Fletcher

Volunteer \$250–\$499

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Charles and Josephine Ellard
in honor of Karina Guajardo

Bart and Sally Finzel
in memory of Harold Espinal

Kim and Stephen Frye

John W. Hancock Foundation
in honor of Bryce Chesser

Fred and Joyce Koehler
in memory of Ryan Mask

Lori LeDoux *in honor of Matthew Caldwell*

Sunni and Gary Markowitz
in honor of Connor Anhalt

Maria Meconi *in honor of Denise Dengel*

Alan and Diana Pendley
in honor of Bryce Chesser

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Ken and Barbara Velten
in honor of Bryce Chesser

Barbara Wedehase

Don and Lisa Wells *in honor of Matthew Wells*

Friend \$100–\$249

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in honor of Braden Farrell

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in honor of Davis Barkley

Brad and Cherré Bickham
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in honor of Michael Bodura

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in honor of Matthew Caldwell

Anthony and Donna Cataldi
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Michael and Margaret Ciacciarelli
in memory of Max Ciacciarelli

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in honor of Amanda Crawford

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in honor of Allison Kirch's birthday
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in honor of Lee Matthews
 Lee and Tammy Gottschall
in memory of Danny Gniazdowski
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in memory of Clinton and Zachary Szemanski
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*in honor of Mindy Rennaker and in memory of
 Jill Rennaker*
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 Donald and Rachel Swicker
in memory of Joseph and Jonathan Karas
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in memory of Laura and Michael Sheekey
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in honor of Clay Howard

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in memory of Amanda Keith
 Mildred Ryan
 Paul and Kathleen Rysz
 Ellen Sidman *in memory of Ryan Mask*
 Raymond Young *in memory of Kaylee Kacer*
 Andrew and Louise Zygmuntowicz
in memory of Amanda Keith

The Barnett family raised \$200 for the National MPS Society by asking for donations instead of gifts for Steffany's (MPS III) 14th birthday.



Stephanie Barnett (MPS III)

'Mad Hatter' Tea Party to Benefit MPS IV Research

On Oct. 4, the Bozarth family hosted the 2nd Annual Mad Hatter Tea Party in Alexandria, VA, to benefit MPS IV research and raised more than \$30,000. The special fundraising event was conceived by Stephanie Bozarth, whose daughter, Annabelle, was diagnosed with the disease when she was just 6 months old.

Mad Hatter Tea party guests enjoyed a variety of family entertainment, including a special presentation by MPS researcher Dr. Shunji Tomatsu, face painting, mad hat contest, silent auction, flamingo croquet and energetic dancing with *Mr. Knick Knack!* Special appearances were made by Alice in Wonderland, the Mad Hatter, the White Rabbit and the Queen of Hearts.

This event could not have happened without the outpouring of support from the Bozarth's friends, family and the Alexandria community.

"After Annabelle's diagnosis, our friends and family came together to support us through the initial shock of diagnosis," said Stephanie. "Now they are taking it a step further by helping us to raise money and awareness for MPS IV research."

The Mad Hatter Tea and MPS IV awareness was publicized in more than 100 online newsletters this past summer. Annabelle also was spotlighted in a community newsletter about what it is like to be a 3-year-old with MPS IV. For more information about Annabelle and the Bozarth's fundraising, visit www.morquio.org or www.caringbridge.org/visit/belle.



Annabelle Bozarth (MPS IV) and Dr. Tomatsu



Riley's Toss for MPS, a cornhole tournament to raise money for the National MPS Society in honor of Riley Muller (MPS II), was held on Sept. 19, 2009. Thirty six teams came to play, and more than 30 people arrived just show their support. Local businesses donated items for raffles, and nearly \$5,000 was raised.

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

Having received the prestigious four-star Charity Navigator rating for the last three years, the National MPS Society learned in December 2008 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—Casual Dress for MPS, the Annual 5K Walk/Run and the Annual Fund are great ways to raise money for the National MPS Society.



It is hard to believe 2009 will soon be over. The 2009 conference held at Disney was a fantastic event. It was wonderful to see so many families together enjoying one another's company. It was heartwarming to see families from all phases of life with MPS come together as one. We had families whose child was diagnosed in the

last several months, to families whose children passed away more than 20 years ago. Conferences are always energizing for me, time spent with families, and sneaking into childcare to visit with the children, it reminds me of why I truly enjoy my position with the Society. My families I work with—you are the heart of the Society. You are our inspiration each and every day. You are amazing, and I am honored to be a part of your lives.

The Family Support Committee has had another wonderfully successful year. We funded 10 families

through the Family Assistance Program, for a total of almost \$23,000. In addition, we funded \$20,000 in Continuing Education Scholarships, and another \$20,000 helped families attend the Disney conference. This would not be possible without your support. Thank you for the fundraisers you organize for the Family Support Committee, and for the personal donations.

I am looking forward to 2010 and the continued growth of the Society. Please make sure to renew your membership in January, or if you are experiencing financial difficulties please let me know—we want to ensure that everyone is able to renew membership.

Continuing Education Scholarship applications will be available in January. Don't forget to save the date for the 2010 conference to be held in Los Angeles at Knott's Berry Farm Resort, Sept. 30–Oct. 2. We hope to see you there!



Measurable downward effects of the economy are rippling across the country within many business sectors. A nonprofit is no exception to these effects. A nonprofit does have one distinct difference: a fundamental drive of mission or cause.

The National MPS Society's mission is to find cures for MPS and related diseases. We are more vulnerable during economic downturns—but this fuels the board and the staff to work harder than ever to support and advocate for our families and members of the Society.

With corporate funding down in 2009 we rely on our creativity, hard work and hope from families in collaborating fundraising events that will help assist the Society with its mission. From a tea party, golf tournament, dance-a-thon, Tupperware sales, lemonade stand, walk/runs, restaurant dinners, Pampered Chef, jewelry sales, public speaking, piano recital, trivia night, dress down days at work to cornhole tournaments—our families have been creative and worked hard to raise funds

for the Society in 2009 to aid in research, family assistance programs and operations.

With our new program, *Sponsor a Child for a Cure*, the staff was able to participate directly with families and runners with pride and joy as each racer paced in hope for a cure of a sponsored child. Our families worked hard at sponsorship for their loved ones—knowing the funds were for research.

The 2009 Annual Fund is still in full swing, if you have not yet made a contribution, please consider this before the end of the year. The Annual Fund is a critical funding staple in the budget for the MPS Society that is used where designated by our members.

As we glance back over the past year, we are very thankful to our families and the many donors who see the importance of support to the Society, especially during financially difficult times. If you have any ideas or would like to host a fundraising event please call me directly at the office. I am happy to give you a helping hand.