

fundraising news

Annual Fund Campaign Raises \$96,385 in 2011

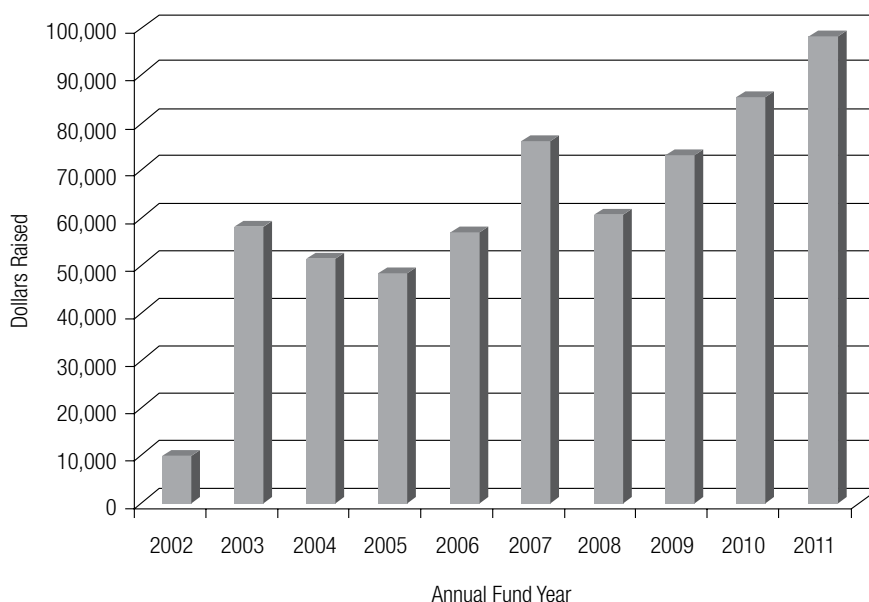
AN AMAZING YEAR FOR THE ANNUAL FUND! We reached a new record of giving in 2011. This critical funding stream within the Society keeps the organization strong. Through your tremendous support during difficult times, you have shown the Society you understand the need of our families and those affected by MPS and related diseases. Your gift provides support to families through the Family Assistance Program, funding for federal advocacy initiatives and necessary operating funds.

This year the board of directors reached out by phoning the Society's families and friends. We are so encouraged by the conversations we had with your families. It was a terrific opportunity to say hello and thank you for supporting our efforts.

For everyone who reached into your wallets once again and donated to the Annual Fund in 2011, the Society gives our sincerest thanks!

A special thanks to our 2011 Annual Fund Chair Beth Karas, correspondent, In Session on truTV (formerly Court TV). Beth shared her story of growing up with two brothers, Joseph and Jonathan, who suffered from ML III, and the hope she has for the future of all children and adults who continue to struggle with MPS and related diseases. She has supported the organization on many levels and her sibling love for her family affirms that our organization's mission must stay strong. ☘

Annual Fund Donations



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

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in memory of Christopher Lesta
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in honor of Ryan and Brayden Kapes
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Sponsor A Child For A Cure 2011

FAMILIES ACROSS THE COUNTRY raised \$23,000 in 2011 for this wonderful and heartfelt program. Each year with renewed hope we reach out to families so they too can make a difference and help raise money for research.

It is easy, and the rewards are tremendous. Thank you to the following families who embraced the challenge. *We HAVE made a difference together and HOPE is stronger than ever before.*

Anderson family, Nathan Roma, MPS VI

Boni family, Danica, MPS I

Caswell family, Sam, MPS I

Cavanagh family, Scott, MPS IV

Fowler family, Jack, MPS II

Gibson family, Clara, MPS III

Kemp family, Zain Semones, MPS II

Kirkpatrick family, Wendy and Kaylee, MPS I

Laorenza family, Aurora, MPS III

Migliozzi family, Christopher Joseph, MPS I

Podesky family, Adam and Benjamin, MPS I

Rice family, Amelia, MPS III

Robson family, Jaeda, MPS III

Szemanski family, Clinton and Zachary, MPS III

Waddell family, Ethan, MPS I

Yard family, Christian, MPS II



Action for Aidan, Exeter, NH

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 Earns 4-Star Rating

The National MPS Society has received four out of a possible four stars from Charity Navigator, America's premier charity evaluator. The four-star rating indicates that the Society adheres to good governance and other best practices that minimize the chance of unethical activities and consistently executes its mission in a fiscally responsible way. Approximately one quarter of the charities evaluated by Charity Navigator have received the four-star, or highest rating, indicating that the National MPS Society outperforms most other charities in America. This exceptional designation differentiates the Society from its peers and demonstrates to the public it is worthy of their trust.



National MPS Society



Run With Us in 2012 —We Need You!

Have you ever wanted to host a walk/run event? Our walk/run program strictly funds research dollars and we need your help. Our goal is to host races across the country and let everyone know we will not rest until there are cures for MPS and related diseases. Get on board, have fun and raise awareness in your community.

Children around the country will thank you.

E-mail Terri Klein at terri@mpssociety.org or call 919.806.0101 to request a fundraising packet, which includes all of the tools necessary to host a successful event! You also can visit the Web site at www.mpssociety.org.

Walk/Run Program Celebrates 12th Anniversary

*Raising Awareness and Funding Research
Discovering New Hope*

FOR 12 YEARS NATIONAL MPS SOCIETY members, families and friends have committed to walk/run fundraisers throughout the country. Each of these events has brought us one step closer to finding treatments and cures for MPS and related diseases. This past year families raised money for both the general research program and syndrome-specific research.

This program continues to be a success year after year. Remarkably, these events have raised almost \$4 million since they began in 2000. In 2011, 14 events generated approximately \$200,000. One additional event, Action for Aidan, raised another \$100,000 for MPS II research. Whether large or small, each event was successful at raising awareness, reaching out among communities and involving thousands of people in cities nationwide.

The Society thanks all of the coordinators and many volunteers for their hard work at these successful events. ☘



12th Annual Run for Erin ☘

Sept. 24, 2011
Event Coordinator: Stacy Peters

The Peters family, along with 25 volunteers, hosted the 12th Annual Walk/Run for Erin. This year 200 participants ran, walked and raised more than \$13,000 for MPS III research. The event is held in honor of their daughter Erin (MPS III). Since 2000, the event has been held at Woodstock High School, GA, where Erin attended for four years, and has raised more than \$233,000 for research.

The board of directors planned the run and volunteers helped with the raffle, which raised \$1,600. Each year the Peters family finds many rewards in hosting the event as they are able to combine it with a

family reunion. Run for Erin also participated in Sponsor A Child For A Cure.

5 for five, Race for a Cure ☘

Sept. 10, 2011
Event Coordinator: Michelle Storm-Butts

The 5 for five second annual walk/run was held in Saratoga Springs, NY, in memory of Louis Butts V (MPS I). The event hosted 55 participants and 20 volunteers on a warm sunny day at the local park.

The event was inspiring for Michelle and her family because many donations were received from the community. 5 for five raised more than \$4,000 and continued a platform of awareness about Louis and his heroic spirit. This walk/run also participated in Sponsor A Child For A Cure with three participants.





Action for Aidan 🌀

June 19, 2011

Event Coordinators:
Brooke Carter & Jennifer Carter

The Carter family held their inaugural walk/run in Exeter, NH, in honor of Aidan who was diagnosed with MPS II. The event hosted 300 participants and 50 volunteers with tremendous support from corporate donors and families.

The day was sunny, warm and filled with many fun activities. There was an auction, barbecue, balloons, entertainment and crafts for children.

The Carters worked for more than a year planning this extraordinary event and the support was tremendous. They used both the National MPS Society Web site and Firstgiving to raise more than \$100,000 from across the country for MPS II research.



Beat MPS 5K Walk/Run Delaware 🌀🌀

June 12, 2011

Event Coordinators: Carl & Jennifer Kapes

This second annual walk/run was held in Wilmington, DE, in honor of Ryan and Brayden Kapes who have MPS III. Hundreds of participants and volunteers attended.

Families traveled from different states to support the Kapes and they raised more than \$22,000 for MPS III research.



BioMarin MPS Run for Your Life 🌀

Oct. 2, 2011

Event Coordinator: Kathie Ward

This 9th annual walk/run was held in sunny Novato, CA, with 110 participants and 20 volunteers. This motivating group raised more than \$36,000. Altogether supporters have raised almost \$350,000 for research.

This walk/run also participated in Sponsor A Child For A Cure and had eight participants. BioMarin continues to support our families from coast to coast.

Cameron's 5K Walk/Run for Cures 🌀

May 14, 2011

Event Coordinator: Julie Mollett

Friends and family gathered in Ashland, KY, for the inaugural Cameron's 5K walk/run. The Mollett family has held fundraising events in the past but wanted to join the walk/run program.

More than 100 participants supported Cameron and raised more than \$3,000. Community spirit, friends and donors encouraged the Mollett family to host again in 2012!



Kenton's Cause 🌀

April 17, 2011

Event Coordinator: Amanda Fults

This first walk/run was held on a beautiful day in Lincoln, IL, in memory of Kenton Fults who lost his struggle with MPS I.

The event had more than 100 participants and volunteers.

Together this inspiring group raised more than \$9,000 with donations from friends and family throughout the community.





MPS 5K Run ↻

Oct. 29, 2011
Event Coordinator: Kate Martin

Almost 75 participants weathered the rain and wind in Bradenton, FL, for this inaugural walk/run. It Works hosted the 5K in honor of the Radius family who has relocated to the area.

Together they raised \$5,000 and had tremendous support from their employees. It Works introduced awareness about MPS and related diseases to the community of Bradenton and more importantly embraced the Radius family with a heartfelt welcome!

It Works also participated in Sponsor A Child For A Cure and had four participants.



Laps for Lucas ↻

Sept. 18, 2011
Event Coordinators:
Lew & Stacey Montgomery

The Montgomery family hosted their 5th Annual Laps for Lucas in honor of their son Lucas (MPS III).

Family and friends raised more than \$3,500 for MPS III research. Laps For Lucas altogether has raised more than \$63,000.

Miles for MPS ↻

Sept. 17, 2011
Event Coordinators:
Steve & Laurel Radius

Miles for MPS celebrated its 10th anniversary walk/run in honor of David (MPS II) and in memory Chip (MPS II). On this beautiful day family and friends came out to embrace the Radius family while they were relocating to Florida and hosting this extraordinary event.

The event raised nearly \$5,000 and altogether has raised more than \$63,000.



A total of 242 participants ran or walked and raised more than \$7,500. Altogether MPS Run For Their Lives has raised almost \$55,000 for research.



MPS Society Walk/Run LA ↻

Oct. 22, 2011
Event Coordinator: Tami Slawson

Held in southern California, the MPS Society walk/run LA celebrated its 11th anniversary and has graciously retired after years of extraordinary efforts!

The event had more than 200 participants and 20 volunteers. Again this year the event hosted a post-race speaker and picnic for families.

This event has grown within the community and among families. They have raised nearly \$30,000 and altogether have raised more than \$360,000 for research. This event has truly been inspiring for all of our walk/run coordinators across the country.

MPS Run For Their Lives ↻

Oct. 22, 2011
Event Coordinators:
Scott Hardin & Steve Holland

MPS Run For Their Lives celebrated its 10th anniversary in Fort Worth, TX. This event is held in honor of Maddie and Laynie Holland and in memory of Spencer Holland.





Post Office Café 5K Walk/Run for Mark and Casey Lessing ↻

Oct. 15, 2011

Event Coordinators:
Kerri Rose & Mark Lessing

Held in Babylon, NY, this 6th annual event raised more than \$12,000 in honor of Casey Lessing and in memory of Mark Lessing Jr. for MPS III research.

The event hosted 600 participants and 40 volunteers and continues to grow each year as the community comes to support the Lessing's children. Altogether, the Post Office Café has raised almost \$115,000.

River Run for Ryan ↻

Aug. 13, 2011

Event Coordinators:
Jonathon & Marie Hunt

This 4th year event held in Guttenberg, IA, raised more than \$12,000 for research with 190 participants and 20 volunteers. The event is held in honor of Ryan Hunt (MPS II) and grows each and every year. The Hunt family receives donations from as far away as Canada. Altogether they have raised \$61,000 for research.



Strides for Sara ↻

June 11, 2011

Event Coordinator: Monique Dickerson

The 4th annual Strides for Sara was held in Fair Haven, NY. Hundreds of participants and 35 volunteers raised more than \$5,000 and had tremendous support from the community.

The event included raffles and food. The Dickersons are thankful for the community support and look forward to next year's event. Altogether they have raised more than \$16,000.



LETTER FROM THE **DEVELOPMENT DIRECTOR**

04

SPRING IS IN THE AIR, and with reflection on 2011 accomplishments the National MPS Society says thank you! In 2011, our fundraising and walk/run programs raised more than \$500,000 for research and family assistance; the Sponsor A Child For A Cure program raised more than \$23,000! Whether you hosted a large or small event, each one made a difference. We are honored that you continue to work on behalf of our families to raise awareness and funds.

In this issue of *Courage* are program highlights from the successful 2011 Annual Fund and the 2011 walk/run program which funds both general and syndrome-specific research. A fundraising *Between the*



Issues will soon be mailed to our members—we hope you enjoy reading this wonderful publication and perhaps be encouraged to host an event yourself.

The Web site has been updated with all the information and tools you could possibly need to support a fundraising or walk/run event. We also have been updating materials to mail out directly. Please contact me

if you are ready to get on board—we need everyone to make a difference!

We are always looking for creative ideas for our fundraising efforts. If you have any suggestions or are interested in serving on the Fundraising Committee with our board members, please contact me directly at terri@mpssociety.org. We look forward to a successful 2012 fundraising year.

For all of our families and friends hosting gatherings and fundraisers in awareness of International MPS Day on May 15, we send our best for strong efforts and renewed hope! ☘

Terri Klein

LETTER FROM THE **PROGRAM DIRECTOR**

THIS IS THE TIME OF YEAR I enjoy the most—membership renewals, college scholarships, conference registrations and new programs starting. This is when I get to talk with you all the most! You might be calling to ask how to fill out a form, or to question a program, but we also are able to share and learn from each other. For some of you, it allows me to catch up on what has happened over the last year since our last chat, for others, it may have been even longer. Yet still, for some of you, we talk a lot more and the updates are on a weekly or even daily basis. I love to catch up and hear the family news and to share in the laughter and the tears.

The Family Support Committee was honored to accept a generous anonymous donation allowing us to create the Emergency Relief



Program, which will help member families facing a financial crisis. Funding includes, but is not limited to, utility bills, home and car repairs, rent and mortgage payments, and bereavement expenses. We hope this program will be able to help our members by providing short-term financial assistance in a crisis situation. Thank you to the amazing family who made this program possible. Please contact me directly if you have questions about the program or how to apply.

We also have made some minor changes to the Medical Travel

Assistance Program (MTAP). Families will now be able to apply for one hotel night stipend up to \$100 per eligible MTAP trip. Please see the Family Support section of the Web site for the MTAP application.

Don't forget about our other Family Support Programs: The Continuing Education Scholarship deadline is March 15; the Conference Travel Scholarship deadline is April 1; Extraordinary Experiences is open to individuals with MPS and related disease ages 14 and up; and the Family Assistance Program which provides financial grants up to \$3,000 for durable medical goods denied by insurance.

Please call or e-mail me—I would love to see how we can help your family and to hear how everyone is doing! ☘

Laurie Turner