

Sponsor a Child for a Cure

Fall 2010 went forth with a burst and the 2nd annual Sponsor a Child for a Cure program exceeded our expectations! Five runs participated:

- BioMarin “Run for Your Life 5K,” *Kathy Ward, race coordinator*
- Mackenzie’s 5K for MPS, *Steven and Jennifer Clarke, race coordinators*
- National MPS Society Walk/Run LA, *Tami Slawson, race coordinator*
- Miles for MPS, *Laurel Radius, race coordinator*
- 11th Annual Run for Erin, *Stacy Peters, race coordinator*

Thirty families signed up to be included in these events and raised thousands of dollars for research. After the events were finished, families were sent a letter, photograph and medallion of courage in honor or in memory of their loved one affected by MPS or related disease.

Our goal is to have families participate from every state. It is an opportunity to reach out to members who wish they could do something more that contributes to awareness and research but are not able to attend an event themselves.

There is a way your family can help and provide hope for the future. Contact Terri Klein at terri@mpsociety.org for details on 2011 Sponsor a Child for a Cure.

Fundraising Committee:

Steve Holland, chair
 Ernie Dummann
 Steven Frye
 Jenifer Gibson
 Shane Gibson
 Anne Gniadzowski
 Tom Gniadzowski
 Angela Guajardo
 Larry Kirch
 Terri Klein
 MaryEllen Pendleton
 Laurie Turner
 Barbara Wedehase



Amy West, a student in Poquoson, VA, finished the race with a time of 26:10 and ran for Taylor Geary (MPS III) of Hilliard, OH. Amy participated in the Mackenzie 5K Run for MPS.

“Thank you for this new program! How precious to receive a picture of Amy West from Virginia.”

Rachel Wojnarowski, mom to Taylor Geary (MPS III), who participated in the 11th Annual Run for Erin



Runners gathered from across the Los Angeles region at Knott’s Berry Farms to participate in Sponsor A Child for A Cure at the 10th Annual Walk/Run LA.

“The Sponsor a Child for a Cure program lets John’s presence be felt at runs when he cannot be there in person. There is power in numbers; the more people see those afflicted with MPS the more powerful the message is that we need help to find a cure. A runner wearing a picture of John is the next best thing to John being there in person.”

Sheila Thornton, mom to John (MPS III), who participated in the 10th National MPS Society Walk/Run LA



Klane White, MD, runs for Peter Wehrle (MPS II) of Issaquah, WA. Dr. White finished in 25th place overall with a finish time of 24:39 at the 10th Anniversary of the National MPS Society Walk/Run LA at Knott's Berry Farms.

“Russell and Dougie Kennedy were sponsored at the National MPS Society Walk/Run at Knott’s Berry Farms. Dougie was 11 when he died in 1990; Russell was 13 and died in 1991. They both had MPS II. My son, Chuck Kennedy, their father, would like to walk for them and has already raised \$2,000.”

Millicent Kennedy, grandmother of Russell and Dougie Kennedy

It’s amazing who you meet. While attendance to Buena Park was not possible for my family, we made sure to take full advantage of the fund-raising opportunity. And unexpectedly we made a friend.

I took this opportunity to participate in the Sponsor a Child for a Cure program by posting fliers at work, where I received an overwhelming response to the donation request. Not only did this flyer help educate those who were not aware of my son’s condition, it helped me speak openly about our situation and MPS in general. This was quite a relief as since December 2009, when Owen was diagnosed with MPS II, I only shared our situation with a select few individuals. I wanted to scream out loud about Owen, but until the fundraiser I never had the appropriate venue.

Here’s what really blew me away: A gracious gentleman by the name of Scott Mangini of Benicia, CA, took the flyer home to share with his family. His oldest son, Tony, said, “Dad, I would like to do something to help.” Tony, as it turns out, happens to be a very successful semi-pro Legends car racer. Tony decided to raise awareness for MPS. He asked if we minded if he put Owen’s picture on his race car, along with the MPS Society’s logo. The MPS Society gave their blessing. Owen loved the idea. Tony easily could have had a paying sponsor taking up this precious space on his car. During the last few months Tony has received many questions about MPS and he is doing all he can to educate people.

Tony will continue his mission to raise awareness for MPS next season. If you happen to live in Northern California, please come out and show your support for Mangini Racing.

Not only did the Buena Park event raise money for research, but it helped my family open up about our situation. And, most strikingly, the MPS Society and our family gained an advocate and friend in Tony.

Jason McKee, father of Owen (MPS II)



Diedra Walker of Grand Rapids, MI, walked in the Miles for MPS Run in Grand Rapids, MI, in memory of Cade Morrissey (MPS I).



Tom Lester ran the BioMarin 5K in a finish time of 19:12. Tom ran for Rachel Adams (MPS III) of Napa, CA.



Bobby Singer of Woodstock, GA, ran in honor of Nathan Bivens (MPS II) of Banner Elk, NC, at the 11th Annual Run for Erin. Bobby ran with a finish time of 23:50.

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
- Publish everyone and all the money raised in an upcoming *Courage* magazine

The assigned runners are inspired by our heroes of MPS. Together they pave the path of continued hope.

For more information on the Sponsor a Child for a Cure program, contact National MPS Society Development Director Terri Klein at 919.806.0101 or terri@mpssociety.org.

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.

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 #0845
- 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

Bryn Chesser, sister of Bryce (MPS II), and Renee Congdon have formed the B&R Baking Company and sold their homemade cookies to raise funds for the MPS Society. They collected \$75.



A friend of the Muller family, Adam Williams, road races with a bicycle team every year. This year he decided to donate his winnings to the National MPS Society in Riley Muller's (MPS II) name. Adam wrapped the handles of his bike with purple tape to show his support and raised awareness with his teammates. Next year he hopes to get the whole team to race for MPS awareness.

Fundraising: road to a cure. This has been our theme throughout last year. Each event, large and small, set its GPS to CURE. Whether the road was smooth at high speeds or bumpy moving a bit slower, fundraising in 2010 has once again been successful. Our families truly embraced the challenges of hosting events throughout the year, determined to make a difference on behalf of a loved one or friend affected by MPS or ML. How exhilarating it has been to watch our families set goals and reach them.

In 2010 fundraising and walk/run events included school plays, lemonade stands, hot dog stands, auctions, jewelry parties, golf tournaments, baseball scrambles, cornhole tournaments, charity dinners, inaugural events, Sponsor a Child for a Cure and much more! Highlights from some events hosted this year can be found in the fundraising section of *Courage* (page 22). Please take a moment to read about these extraordinary families and their efforts.

On behalf of the Fundraising Committee, thank you donors for contributions to the 2010 Annual Fund Campaign. The Annual Fund focuses directly on National MPS Society programs and

our operational budget. This campaign provides funds to meet the goals of our mission, support for families and research for a cure.

Each and every event set its GPS on a course for the road to a cure. Still, we need your help. Last year we had fewer events that celebrated the 11th annual walk/runs for research; we need to increase our efforts. These events support our general research funding. For more details on hosting an event, corporate gift matching programs, the United Way, combined federal campaign or planned giving, please contact me directly at terri@mpssociety.org.

Be sure to visit our Web site (www.mpssociety.org) frequently for upcoming events and our Giving pages. There are many helpful ideas and tools available for you to help the Society now and in the future.

Happy New Year!




Wow, what an amazing conference in California! It is always energizing and refreshing to be able to spend time with all of you. It is wonderful to visit with old friends and get to know so many new friends. As we move into 2011, we are getting excited for the St. Louis conference, and I hope that its central location will allow many of you to attend; it promises to be a fantastic conference.

Our first SPIRIT conference for adults affected with MPS and related disease was an amazing experience and we are looking forward to hosting this adult-only conference again in 2012. We also held a CYCLE conference for those families who have lost a child to MPS; once again this conference allowed for families to share memories and provides strength to help move forward.

I also would like to thank our retiring board of directors. Thank you for your countless hours, unending dedication and expertise in helping the Society continue to move forward. I am looking forward to working with our new board of directors in 2011!

Thank you for the well wishes on baby Amelia's arrival, and thanks to Barb and Terri for taking over my duties during my maternity leave.

You will notice a new section in this issue of *Courage*, OSCAR awards. This section honors outstanding siblings and children in our amazing MPS families. We have honored our super siblings for many years, and thanks to Dorothy Mask these individuals will now be formally recognized. If you wish to nominate someone in your family, please see page 11 for more information.

We would love to hear how your family is doing—send us an update, let us know what is happening and don't forget we love photos!


