

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 2010—Don’t get left behind!

We are excited to launch the **Sponsor a Child for a Cure** program nationally! 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. The event coordinators are ready for your calls!

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 Sponsor a Child for a Cure program ran a pilot in 2009 in both the Los Angeles and Boone, NC, walk/run events. This was very successful and exciting for the families who participated. The assigned runners were inspired by our heroes of MPS. Together they paved the path of continued hope. We hope the following stories from a few of our participants inspire you.

continued

Fundraising Committee:

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

"I am not a regular runner like I was in my younger days. I knew I would be attending the walk/run in Boone, NC, but was unsure which I would do, walk or run. The Society asked me if I would carry a photo of one of our MPS children as I raced, as they could not attend, and of course the answer was yes! The inspiration of putting out effort for someone else, though I had not met them, made my decision clear: I would run as hard as my body would allow. The inspiration was needed at the half-mile, as my legs suggested I quit. Knowing what my running buddy must go through on a day-to-day basis, quitting was not an option. The race was finished, mission accomplished! Thanks to my new buddy for giving me the push. I wish I could return the favor."

Mike Schleiter, Minneapolis, MN



Mike Schleiter, who ran for Connor David Vanderveen (MPS II), from Alberta, Canada, finished in third place in the age 40-45 5K.



Lauren Hartman, Shire Pharmaceutical in Lexington, MA, finished in third place in the age 30-39 5K.

"The morning of Nathan's North Carolina Walk/Run was far from the bright, crisp, autumn-in-the-mountains vision I had of how race day was going to be; it was damp, chilly and rainy. Although I was very excited by the opportunity I was given to participate in this race, I awoke feeling a bit less enthused about leaving my warm hotel room to run 3.1 miles in the cold rain. That all changed when I was asked to run on behalf of Madison Dula. When I saw the picture of that beautiful, smiling little girl, I knew I could do it. Madison and I were a team and we were going to run together, no matter how gloomy the weather was! The best part of the whole experience was after I finished the race when I was able to meet Madison and her family. Race day may have been a bit gloomy, but my memories will always be bright and cheery!"

Lauren Hartman



Tonya Price and her daughter Madison Dula (MPS III), age 8.



Jack Burke ran for his sister, Edie Burke (MPS I), who gained her angel wings at the age of 9. Jack finished in ninth place overall and first place in the age 13-19 5K event in Boone, NC.

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

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.



Soon we will be together at the conference at Knott's Berry Farm. We are excited to be hosting our Celebrating Your Child's Life Experience (CYCLE) conference, and also the first ever adult-only conference, "Finding Our SPIRIT" (Strength, Purpose, Independence, Resilience and Initiative Together) along with our

family conference. This will be a great conference year, and we hope your family can be a part of the excitement!

The Family Support Committee (FSC) has been busy awarding 2010 Continuing Education Scholarships. Once again, we are proud to be able to help 20 individuals obtain their educational

goals. We will have more information on the scholarship recipients in the next issue of *Courage*. The FSC also has been busy awarding conference travel scholarship grants to help families attend the conference in September.

I hope you are able to attend one of the upcoming regional social events being held this summer, or one of the local walk/runs. It is always energizing to be with your extended MPS family. If there is not an event near you, please consider hosting a picnic yourself. This is a great way to get to know other MPS families in your area, and also allows for a chance to renew old friendships. Please contact me if you are interested in hosting your own event. I hope to see you in September!

A handwritten signature in cursive script that reads "Laurie J. Turner".



Springtime brings outdoor fun! Our National MPS Society families and friends have been inspiring this spring with fundraising and awareness campaigns to help our children. We have spoken with new families and families who have been Society members for many years. Each conversation escalates the efforts of our mission.

Cornhole tournaments, school plays, marathon races, charity dinners, preschool purple day and the first annual MPS cup with NHL alumni. The Society takes their hats off to those who have found the time to help raise money and awareness for these diseases. Our children have courage, and MPS Society families and friends are courageous in their efforts.

Remember, whether hosting a small or large event, every opportunity you educate your family, friends, colleagues and corporations about MPS and related diseases is another step toward finding

cures. All of us have a bit of courage; many of us live each day with the most courageous children. It takes courage to speak up for our diseases and our children deserve the opportunity to be heard.

It is time for walk/run preparations! Sponsor a Child for a Cure is a program that will be offered at events across the country. If you are unable to attend an event but would like to participate with your family in honor or in memory of a loved one please contact the office. A runner will be assigned for your child and you will have an opportunity to raise sponsorship. The money raised is for research and your family will be given a photo of your assigned runner with a courage medallion.

The Society needs your help, your creative spirit and your courage to help us make a difference and find cures. If you would like additional information, have a great idea, or need a little help, please give me a call or send me an e-mail.

A handwritten signature in cursive script that reads "Julie L. Klein".