

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.

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 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

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.

Kathy Greenberg, special education teacher at Greater Plains Elementary School in Oneonta, NY, and her Basic Life Skills class recently held a walk-a-thon to benefit the National MPS Society. One of Kathy's students, Logan Piefer, has MPS II and the class wanted to do something to help.

"We had a great day, and the teachers and students in the other classes came to encourage us and walk alongside us," said Kathy. "We collected \$927.45 that we are donating to the National MPS Society in Logan's honor. I hope this money helps in your search for a cure and treatments for those afflicted with MPS."



Logan Piefer (MPS II) with Kathy Greenberg

On March 11, 2010, the Wojnarowski family hosted its Annual Piano Recital and Benefit Concert for the National MPS Society in honor of Taylor Geary (MPS III). Seventeen of Rachel Wojnarowski's piano students played their pieces with Taylor's love for music on their minds. Two of the students were Michael and Tristina, Taylor's siblings. In lieu of charging recital fees it was requested that donations be made to the National MPS Society; more than \$700 was raised.



Taylor Geary (MPS III)

Matt and Rachel Wojnarowski also ran the Country Music Half Marathon in Nashville, TN, on April 24. They asked friends to purchase MPS Society's "Someone I Love" T-shirts and wear it on the day of the race.

"We are very excited about this opportunity to celebrate our daughter, Taylor, who is 13 years old," said the Wojnarowskis. "We're calling it 'Celebrating 13 Years in 13 Miles.' God has graciously given Taylor a beautiful life in spite of her diagnosis of MPS."



Rachel and Matt Wojnarowski with fellow marathon runners

We are very happy to report that our first MPS fundraiser, Inspiring Ian's Hope, went very well. Our fundraiser, held on May 15, involved a walk, kid's games and prizes, a live band and a volleyball tournament.

Several teams participated in the walk. We marched around the largest park in Amarillo, with a purple monster truck leading the route! Special thanks to our walk teams, Pro-Step (Candace Hogan), Bulldog Electric (Ginger Lawrence), Wilson Supply (Deanna McLaughlin), and everyone else who participated. I would also like to thank Vernon Adams for bringing out the purple mud truck to help promote our cause. The walk was truly special because Ian (MPS III) made it all the way— $\frac{1}{2}$ mile! Cameron Green also came to walk and show support. He also did very well for his first trip since his battles with MPS II began in October. Our winners of the walk are Josh and Sydne Monden of Borger Texas, siblings who helped coordinate the fundraiser.

After the walk, everyone played games with the children. All of the toys for the children were donated by local fast food restaurants from their kids meal stocks. We also had ice cream tickets from Dairy Queen donated to give out as happy meal prizes.

The volleyball tournament was four, six-man teams, double elimination. The Hereford Texas team won, with Clay Walker sponsoring. Our band, Cy and the Fantastic, was wonderful. This band has an awesome original song, one that I call the star song, that wonderfully commemorates our lost children. For me, it brings back memories of hanging our star at the Give Kids the World Village. The band has agreed to use their music to help promote MPS awareness and in future fundraising endeavors!

Xcel Energy, Ian's father's employer, has taken up a collection from the employees in the form of a cook-off. They will sell hamburgers at lunch to employees, and the company matches all employee donations.

Today, as I am writing this, May 18, I am still selling T-shirts! All in all, we raised a good amount of money for MPS, and we raised a lot of awareness. Next year's fundraiser is already in the works, and I am getting pretty excited about it.

Shelly Maddox, mother of Ian Adams (MPS III)

At the last National MPS Conference in Orlando, Hope and I sat next to Kirsten and Todd Harkins during a presentation on fundraisers. We found out about their very successful Vancouver MPS Cup and Gala and we thought a hockey fundraiser in Minnesota might be a fun event to work on. Todd and Kirsten provided information on how to contact our local NHL alumni. We spoke to Tom Reid, Minnesota NHL alumni president, and Brad Maxwell, celebrity game coordinator, who were immediately on board with our proposal. The date was set for May 1, 2010, for the First Annual Minnesota MPS Cup!

money at Michigan Technological University to help two of the players with their donations.

Although unconventional, the game was played in two halves so that the local St. Croix Hockey Association could play an exhibition game with some lucky mite players with Brad Maxwell and Joe Dziedzic from the NHL Alumni serving between the goal posts as goalies. At half time, spectators were given a chance to win two Minnesota Wild hockey tickets by playing chuck-a-puck.

The game concluded with a lopsided score of 12 to 6 but every player had a huge smile on their face. The ice rink was then stormed by the attending MPS kids—Jessica Moore, Michael Sheridan, Brittney Bjorkman, Fran Madsen and Danny Jenkins—to meet the players and shoot some pictures with the hockey legends.

After the players showered, we reassembled, along with other gala ticket purchasers, at a local event center for an evening of fine dining and entertainment. More than 135 guests, including 22 NHL alumni, joined us for hors d'oeuvres, a silent auction, plated dinner, presentation and music. The silent auction valued more than \$11,000 and included a variety of items such as original artwork, signed Wild jerseys, dining gift certificates, wine tasting and Zamboni goodies.

Terry Klein, MPS Society development director, presented information on the National MPS Society and I gave a personal story of Fran's fight with MPS I. The Johnny Owen Band brought out the dancers in the crowd to round out the evening.

When the ice was resurfaced at the arena and the tables cleared at the event center we had raised more than \$14,600, in part by tremendous support from Shire and Genzyme as well as the fabulous support of the volunteer team, family and friends. The NHL alumni found the event to be a great time and very moving and are totally on board to do it again next year. Go to www.mpscup.org to learn more.

Dave and Hope Madsen, parents of Fran (MPS I)



To market the event we came up with the slogan, "Putting on the Foil to Fight MPS," fondly borrowed from the movie Slapshot. We then coaxed Brad Maxwell and Joe Dziedzic from the NHL alumni to join some MPS kids (Michael Sheridan, Jessica Moore and Brittney Bjorkman) in a photo shoot for posters and fliers.



Above: Jessica Moore (MPS I) with NHL hockey players

Below: Dave and Hope Madsen

The event was to be in two parts; a hockey game and a gala. The hockey game pitted two teams against each other for a refereed saga. Eighteen participants donated \$300 to play side-by-side with the NHL alumni players, including Brad Maxwell, Joe Dziedzic, Tom Younghans, Jon Rohloff, Gordie Roberts, Dan Mandich, Brian Bonin, Sean Toomey, Shjon Podein, Bob Bergloff and Dave Richter. Fran Madsen's fraternity raised



Walk, run or sponsor your loved one— we need your support!

The 2010 walk/run season is under way! Show support for MPS and related diseases and raise awareness by attending an event near you. Contact Terri Klein (terri@mpssociety.org) to find out how you can be involved in the new *Sponsor a Child for a Cure* program in coordination with a 2010 walk/run.

Inspiring Ian's Hope

5/15/2010
Amarillo, TX
Shelly Maddox
Maddox73@yahoo.com

Strides for Sara

6/12/2010
Fair Haven, NY
Monique Dickerson
mosey@twcny.rr.com

Inaugural 5K MPS Walk/Run

6/13/2010
Wilmington, DE
Carl and Jenifer Kapes
jkapes@swartzcampbell.com

River Run for Ryan

8/14/2010
Guttenberg, IA
Jon and Marie Hunt
mlhunt@alpinecom.net

Kassi's Kause MPS Society Walk/Run

8/28/2010
Travis Air Force Base, CA
Trisha Offenbacher
aadams@bbcgrp.com

Miles for MPS*

9/25/2010
Grand Rapids, MI
Laurel Radius
frazzledblonde@yahoo.com

Beat it for Benny

9/25/2010
Brazil, IN
Emily Durcholz
Annetted3246@yahoo.com

5 for five, Race for a Cure

9/26/2010
Saratoga Springs, NY
Michelle Storm-Butts
Michellestorm23@yahoo.com

BioMarin 5K Walk/Run*

9/26/2010
Novato, CA
Kathie Ward
kward@bmrn.com

11th Annual Run for Erin*

10/2/2010
Woodstock, GA
Stacy Peters
smptra@bellsouth.net

MPS Walk/Run L.A.*

10/3/2010
Buena Vista, CA
Tami Slawson
tslawson@aol.com

Mackenzie's 5K Run/Walk for MPS*

10/9/2010
Poquoson, VA
Jennifer and Steve Clark
clarkies@cox.net

Post Office Café's Annual Fun Run for MPS

10/16/2010
Babylon, NY
Kerri Rose
kerri@lessings.com

MPS Run for Their Lives

10/16/2010
Fort Worth, TX
Steve Holland/Scott Hardin

National MPS Society



Support for Families. Research for a Cure.

2010 Walk/Run
www.mpssociety.org

Congratulations new walk/run events in 2010 and thank you to our returning events.

The National MPS Society walk/run program is the largest funded program for research.

Our members, families and friends should be proud that you are making a difference. Anything less than a cure means we keep working harder!

Want to host an event and raise money for research? Contact the office and let us show you how. You will feel empowered to make a difference.

* Indicates participating *Sponsor a Child for a Cure* events—visit www.mpssociety.org to participate.

The Annual Fund and walk/run season is upon us—it must be fall with the National MPS Society! There are many opportunities for families to contribute to Society programs and we need your help more than ever this season. Take the time to review the list of runs in this edition of *Courage* (see page 19) and think about attending one near you!

2010 is the first year of our Sponsor a Child for a Cure program, which allows families a special opportunity to participate in a walk/run event from afar. A runner will race on behalf of your loved one or angel while you raise sponsorship. We are already receiving photos from around the country from families that want to participate in this heartfelt event.

The 9th Annual Fund campaign is in full swing among our membership and donors. Each year the Society raises significant funding through the Annual Fund for continuing National MPS Society programs. Without your contributions,

our programs would suffer. Please make a donation and recruit friends, family and colleagues to the cause. Start an Annual Fund awareness event and host family and friends for a day or night of fun to raise awareness and funds for an affected individual.

I look forward to meeting many new families and old friends at the upcoming conference in Buena Park, CA. After the conclusion of the conference on Oct. 3, come celebrate the 10th anniversary of the L.A. Walk/Run for MPS, hosted by Tami Slawson. This event is located at the conference venue, Knott's Berry Farm. Contact me for event details or for any fundraising questions and opportunities at 919.806.0101 or terri@mpssociety.org.



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