

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.

On Aug. 20, the Leider family hosted a fundraising event for their “Let Them Be Little” foundation, honoring their sons Jason and Justin who were diagnosed with MPS II last year.

The all-day event began with a service followed by a walk in downtown Rochelle Park, NJ. Later, the community gathered at the Knights of Columbus for a barbecue, music and activities for the children.

The turnout was tremendous. The Leiders met the Beg family, who are local to the area and have three girls with MPS III. In addition, Terri Klein, development director for the National MPS Society, attended and helped the Leiders understand that their road is not traveled alone, and was able to educate them about the research and family support programs offered by the Society.



The event raised \$5,000 for the Society for MPS II research.

Ways to Give

Help make a difference

- Renew your membership or sponsor another family
- Gifts in honor or 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 (visit our Web site for more information):
 1. wills or bequests
 2. charitable remainder trust or charitable gift annuity
 3. charitable lead trust
 4. life insurance policy or 401(k) retirement funds
 5. gift of appreciated assets (stocks, mutual funds, bonds)
- Gifts may be applied to the Society’s general operating purposes or restricted to one of our research, family support or legislative programs.

CONTACT:

terri@mpssociety.org or call 919.806.0101.

Fundraising Committee:

- MaryEllen Pendleton, chair
- Stephanie Bozarth
- Jennifer Clarke
- Ernie Dummann
- Anne Gniazdowski
- Tom Gniazdowski
- Angela Guajardo
- Steve Holland
- Larry Kirch
- Terri Klein
- Dave Madsen
- Hope Madsen
- Laurie Turner
- Barbara Wedehase

Sponsor A Child For A Cure

The 2011 Sponsor A Child For A Cure (SACFAC) program included families and friends from around the country, raising more than \$23,000 to help fund research. This year five walk/run events and 20 families took on the challenge. Each child or their family received a courage medallion and a photo of the runner who ran on their behalf.

We understand how much it means for families to help the Society raise money for research and be included in an awarding experience. We hope that SACFAC has touched your hearts as it does ours and that others will consider participating next year. This program continues to grow each year and reach new heights of awareness among communities nationwide.

2011 Sponsor A Child For A Cure events:

- fiVe for V, in memory of Louis Butts V, New York—*hosted by Michelle Storm-Butts*
- 12th Annual Run for Erin, Georgia—*hosted by Stacy Peters*
- Run for Your Life 5K, California—*hosted by Kathie Ward, BioMarin*
- Run for Their Lives, Texas—*hosted by Scott Hardin and the Holland family*
- It Works 5K for MPS, Florida—*hosted by Kate Martin, It Works*

2011 Sponsor A Child For A Cure Participants

Danica Boni
 Sam Caswell
 Scott Cavanagh
 Jack Fowler
 Clara Gibson
 Kaylee Kirkpatrick
 Wendy Kirkpatrick
 Family of Aurora
 Laorenza
 Family of Christopher
 Joseph Migliozi
 Adam Podesky
 Benjamin Podesky
 Amelia Rice
 Jaeda Robson
 Nathan Roma
 Zain Semones
 Family of Clinton and
 Zachary Szemanski
 Ethan Waddell
 Christian Yard



Ed Ross ran in the 9th Annual BioMarin Run for Your Life 5K in California. He ran in honor of Jaeda Robson (MPS III), age 8, from St. Paul, MN.



Sherri Richbourg ran in the 10th Annual Run for Their Lives in Fort Worth, TX. She ran in honor of Nathan Roma (MPS VI) who is 15 years old from Virginia Beach, VA.



Nick Angalet ran in the 12th Annual Run for Erin in Woodstock, GA. He ran in honor of Amelia Rice (MPS III) who is 6 years old from Tucson, AZ.



Jim, Amy, Ella and Christian (MPS II) Yard ran for a SACFAC event in Pittsburgh, PA. They rallied family and friends for support of their extraordinary efforts!

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.

5K for Christian — a Sponsor A Child For A Cure event

Our son Christian was diagnosed with MPS II this spring at the age of 3. With the dramatic change to our lives and with adjusting to the countless doctor visits, therapists and treatments, we decided to start small when it came to the amount of time we had available to begin our fundraising efforts for MPS.

We contacted the Society in July and found we could Sponsor A Child For A Cure (that child being Christian). Needless to say, what started as a small idea to get involved in the support for a cure soon turned into a big event in our lives. On Sept. 25, we ran a 5K race for Christian. The little man, his sister, his papa and grandma Carol were all awaiting us at the finish line. It made for a day our family will never forget.

The response to our outreach was amazing. Every afternoon when the mail came we were overwhelmed with unexpected contributions. Friends told friends who told friends, family told friends of the family who told friends of the family, and co-workers told co-workers who told co-workers. Much to our surprise, we raised more than \$20,000 and have now become addicted to the thought of continuing our efforts with future events.

We have already planned our next fundraiser for the spring of 2012. Additionally, several community organizations have volunteered support. For example, the National Honor Society for a local high school is fundraising this school year exclusively for MPS. We also received a call this October from our local fire department to notify us that Christian was chosen as the child this year to ride with Santa in our annual community Light Up Night. He is so excited to ride in the fire truck, and with Santa to top it off!



Times are tough, no question about that, but it is moments like these that we now cherish!

Jim and Amy Yard, parents of Christian Yard (MPS II)

Meekel's Music for MPS VI

Meekel's Music for MPS VI was held Oct. 8, in Gheens, LA, in honor of Meekel Stevens (MPS VI). This was our first annual event and it was a huge success, raising more than \$21,000. Six wonderful bands donated their time and talent.

A variety of food and beverages were served, including chicken and sausage jambalaya and alligator sauce picante (this is how we do it in Louisiana!). We charged admission and sold tickets for a half and half raffle and we also had a live auction. Gordon Wingate, board member for the National MPS Society, and Barry Fauchaux, Meekel's nurse, were guest speakers. They both did a fantastic job speaking about the importance of raising money for research and family support.

I also have to give credit to a young gentleman by the name of Jeremy Mask, whose brother Ryan had MPS III. When I read his philanthropy story in *Courage* I was inspired to also do a concert.

My heart is overjoyed at the response from the community here in southern Louisiana. Everyone here has fallen in love with my granddaughter. She has touched so many lives. We are fortunate to have a large support system and prayer circle. May God continue to bless her and may He also bless the National MPS Society with finding a cure for all of our children with MPS and related diseases. I cannot wait to start planning for 2012!

Marla Stevens, grandmother to Meekel (MPS VI)



Raising money for research, family support and support of the National MPS Society overall has become more creative than ever before! As our year draws to an end, I reflect back on these past 12 months and all of the wonderful conversations I have had with families, corporations, vendors and donors with a smile

and gratitude for recognizing and honoring our mission.

Again this year we were inundated with news stories about our economy and the woes and burdens of financial markets. Still, families and donors opened their wallets to help those less fortunate. They have shown that treatments and cures for MPS and related diseases are still a high priority.

This year we hosted 13 walk/run events, concerts, hockey and golf tournaments, a tea party, bake sales, charity dinners, carnivals, birthday donations, Annual Fund parties, Halloween parties, comedy shows, Dress Down Days and a roller derby—the list goes on and on! No one is slowing down, and the commitment to find cures is stronger than ever before.

Sponsor A Child For A Cure finished its third season and raised more than \$25,000. You can learn more about this remarkable program by reading

the article on page 20. Families and runners experienced pride and joy in their participation. Everyone worked hard at sponsorship for their loved ones, knowing the funds were for research.

The 2011 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 critical for continued operation, family support and legislative funding of the National MPS Society.

As I glance back over the past year, one family's story is near to my heart. Marla Stevens contacted the office after her granddaughter Meekel (MPS VI) was recently diagnosed. She was inspired to host a concert from articles she read in the Annual Report and *Courage* about Jeremy Mask, brother to Ryan Mask who had MPS III. You can read more about Marla and Meekel and their amazing event on page 21.

We are very thankful to our families and donors who see the importance of supporting the Society's mission. 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. We have launched our new Web site and many of our fundraising tools for a successful event are now available online to assist you.

Have a wonderful holiday season.



As I speak with many families each and every week, I am constantly inspired by the amazing connections you as parents and families have with one another. Other parents, parents who have already walked the journey of receiving diagnosis and parenting a child with MPS or related disease, become the lifeline for the newly

diagnosed. When I ask a family to connect with a new family, I know a lasting relationship will begin. I recently was reminded of this lifeline, the important relationships, the hope, the knowledge, the support, the inspiration and the courage you are able to share with others, when Jeanette, mom of Dominic (MPS II), shared the following with me:

"This past week has been incredible for me. First, the devastating news that Dominic might have MPS. Initially, this seemed like the end of the world, and my world seemed dark and sad. I've never been very religious, but I have always believed things happen for

a reason. I started to question, Why? Why me? Why my son? I don't have concrete answers—I never will. But I started to learn more about the MPS journey and started talking to families, and most important I learned in a very short time about the LOVE AND HAPPINESS they all share. They are a family. Most of the darkness and sadness has started to go away and it's been replaced by happiness, love and HOPE!"

Thank you for being there for other families. With technology and social media, it is possible to instantly reach out to many other families. Thank you for responding to these families. No matter where you are along the journey, it is important to know you are not alone, important to know that another family who understands is there for you. Let's all take time this holiday season to reach out to those in your extended MPS family. A member once said, "The only good thing about our MPS journey is the people we have met along the way." I have to agree; I am convinced that my MPS families are the best! Thank you for being there to help me help other families.