

## Fundraising in Tough Economic Times: YES, it is possible!

Statistics abound about how difficult things are for nonprofits trying to raise funds. From large organizations to small, it has been a tough year to receive corporate donations. The good news is that individual donors are continuing to give to the groups they hold close to their hearts. Economists feel that people want to give where they know their hard-earned dollars will do the most good.

This is very good news for those of us who are family, friends and advocates for the National MPS Society. We know we have counted on our family and friends to support our very special cause. But we need to become more savvy in our fundraising efforts.

According to [fundraiserhelp.com](http://fundraiserhelp.com), we need to start by thanking our previous donors time and again for their support. We can't thank them too many times. We also need to let them know our previous results. Tell them specifically the amount of money your fundraiser brought in. The amount doesn't have to be large to show how their efforts helped. [Fundrasierhelp.com](http://Fundrasierhelp.com) says that telling your supporters how much you raised and specifically where the money went will allow them to share in your feelings of success. It shows them that you were a good steward of the much-needed dollars.

Marc A. Pitman, author of *Ask Without Fear!*, says fundraisers in this economy need to be positive when asking or recruiting. His theory is to not sound desperate or apologize, but to tell stories about our children and families and their strengths. As passionate advocates we can easily give many examples of how our children inspire us every day. Pitman also asks us to be honest about ways we can cut our costs in fundraising, thus sending the message that we are sensitive to families and businesses facing tough times.

### Getting started

If you have held a successful fundraiser in the past, you don't have to change what has worked for you. If you have been hesitant to have a fundraiser, start small and do something you have an interest in. Our own MPS families have had some wonderful and successful fundraisers. Those include:

Cookie fundraiser, piano recital, trivia night, Silpada jewelry sale, golf fundraiser, California Pizza Kitchen, jeans day at work, Crazy socks, bake sale, Pampered Chef, online auction, Swings and Shots for a Cure, Tupperware fundraiser, Mad Hatters Tea Party, Pumpkin Harvest, cornhole tournament, lemonade stand, bowl-a-thon, dance-a-thon, Macy's Charity Day, wedding fundraiser, Courage Premier Gala and Dress Down Day.

In addition, 21 families held walk/runs in 2009 and raised more than \$285,000.

There also are Web sites that can offer wonderful fundraising ideas. Some Internet ideas are: casino night, cow chip bingo, golf ball drop, 50/50 raffle, grocery bagger for a day, selling flowers for Valentine's day, dog wash...the possibilities are endless!

Let your imagination run and think of creative ideas that may be unique to your area. As previously mentioned but can't be stressed enough, *every dollar raised brings us closer to a cure!*

Experts advise that fundraising in 2010 can be rewarding for all involved if we acknowledge tough times but make our case for funds positive. When asking for donations from friends and stores, don't ask for a specific amount; let them control what they feel they can contribute.

Let our families and children be our inspiration for successful fundraising in 2010!

by *MaryEllen Pendleton*

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## Annual Fund Campaign Raises \$73,500 in 2009

Every year support for the Annual Fund increases. This critical component of the overall funding strategy keeps the organization strong. Through your tremendous support during difficult economic times, you have shown the Society that you understand the need of our families and those affected by MPS and related diseases. Your gift will provide support to families through our Family Assistance Program, provide funding for federal advocacy initiatives within our legislative program, and provide much-needed operating funds.

For all of you who reached into your budgets and donated to the Annual Fund in 2009, the Society gives our sincerest thanks! We can continue working strong within our mission, supporting families and funding research for a cure.

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*in memory of Amanda Keith*

## Dakotah's Day Golf Outing

We lost Dakotah Arthur Smith on April 20, 2006. He passed on the operating table as the doctors were in the process of placing a shunt in his little head.

December of that year, we, Clarence and Peggy Chriss (Dakotah's grandparents) decided to have a fundraiser for the MPS Society to honor our beautiful little grandson. On April 20, 2007, we had the first Dakotah's Day and MPS Society Golf Outing.

We were unsure of the outcome. We were afraid. We have never done a fundraiser before. We did not know the number of golfers who would come. The weather was another big concern. There was talk of a huge nor'easter storm coming through the area. We did not know the number of sponsors we would get or what course would accommodate us. We sent out mailers, placed an ad in the local newspaper and contacted all the people we knew. We prayed and hoped for the best.

With great success, we got sponsors, volunteers, the course, caterers and door prizes. The golfers came and they kept coming. Our broker asked, "Where did all the people come from?" I smiled and said, "God and Dakotah sent them." We had more than 130 golfers. Most importantly the weather that day was great. The sky opened up to a total "Dakotah blue sky" as we like to say. Blue was Dakotah's favorite color. Tears of joy and success were flowing from our eyes. When it came time to send everyone out, I could hardly contain my emotions.

When it was over and everyone returned from the course for dinner, we introduced the committee and the volunteers. We gave out the skill prizes. It was stated by the head of the committee that at that moment we had raised about \$11,000 for the Society. However, that was our first year and we sent all the money to the Society and we never received a donation amount. Since then, we have corrected the way we do things. The following two years we kept an account of what amount was given.

We were pleased to send to the Society a check for \$8,500 from the 2008 golf outing. This year, 2009, we are sending \$4,000. We had a great turnout of golfers, but the sponsors were not there.

The wonderful participants were inquiring about the following year. So we decided to do it again in 2010. We pray that our heavenly Father will shine down upon that day and the ones to follow. We also pray the outcome for future outings will net more funds for the Society. We will give our all to insure that Dakotah's name will always be remembered and the Society will have funds to help a child and their family.

There are so many people we want to thank: Suzette Kostjal, Michele Addams, Michelle Meckley, Linda Melham, Judy Lusk, Kathy Vandenbrugh, Jeannie Jameson, James Priar, Jeffrey Smith, Spike Hensel, Shirley and John Sharpe, Lyn Robinson, Linda Judd, Allen and Vivian Muchmore, Evelyn Kalbfleisch, Linda Cullen, all the participants and sponsors, the Armitage golf course and its staff members, and The Caddy Shack.



Dakotah Arthur Smith (ML II)



Support for Families. Research for a Cure.

**Walk / Run 2009**

[www.mpssociety.org](http://www.mpssociety.org)

# National MPS Society walk/run program celebrated 10th anniversary

*Raising Awareness and Funding Research  
for MPS and Related Diseases*

For a decade, 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. We continue to increase awareness and funds for research by educating one person at a time.

This program continues to be a success year after year. Remarkably, these events have raised more than \$2,806,000 since they began in 2000. In 2009, 21 walk/runs generated approximately \$285,000. Whether large or small, each event was successful at raising awareness, reaching out among the community and involving thousands of people in cities nationwide.

The Society thanks all of the coordinators and many volunteers for their hard work in making each event successful.

### **5K for Katie/Do It for Danny**

Oct. 11, 2009

*Event Coordinators:*

Linda Shine and Amy Miller



Held in Downingtown, PA, the 10th anniversary of the walk/run program is a tribute to Linda Shine in memory of her daughter, Katie. Linda began the walk/run program for the National MPS Society. Amy Miller is the co-coordinator of this annual event in honor of her son, Danny. They raised more than \$20,000 for MPS research. This year the above logo was imprinted on T-shirts with names of all the

children who have succumbed to MPS and related diseases since the first run.

### **10th Annual Run for Erin**

Oct. 3, 2009

*Event Coordinator:* Stacy Peters



The Peter's family, along with more than 50 volunteers, hosted their 10th walk/run. The event is held in honor of their daughter, Erin. Since 2000, the event has been held at Woodstock High School and has raised more than \$200,000 for research. This year participants ran, walked and raised

more than \$17,000. Run for Erin is held annually and has a board of directors. Each year the Peter's family finds many rewards in hosting the event as they are able to combine it with a family reunion.

### **Andrew's Walk 'n Roll for MPS**

Aug. 29, 2009

*Event Coordinators:* Sharon Cochenour and Barbara Pryor



Held in Clarksburg, OH, this seventh annual event raised more than \$3,500 in honor of Andrew Cochenour. The event includes a family picnic for attendees.

*continued*



### **BioMarin/MPS "Run for Your Life"**

Sept. 27, 2009

*Event Coordinator:* Kathie Ward

BioMarin hosted its seventh annual run/walk in Novato, CA. The event hosted 111 participants and 15 volunteers with tremendous support from corporate donors and families. The event raised more than \$49,000.

### **Evan Reed Family Fun Run**

Oct. 24, 2009

*Event Coordinator:* Laura Hiler

The 4th Annual Evan Reed Family Fun Run, held in Mountain Grove, MO, raised more than \$1,000. The event hosted 73 participants and was a brisk 41 degrees.

### **Heartland Run for MPS**

Sept. 19, 2009

*Event Coordinator:* Emmy Hogue

Organized by Iowa State University students in honor of MPS research completed by Dr. Matthew Ellinwood, this Ames, IA, event raised more than \$1,300 for research.

### **Kassi's Kause**

May 30, 2009

*Event Coordinators:* Trisha Offenbacher and Amy Adams

Kassi's Kause was a first-year event held at Travis Air Force Base in California. This event had children's activities, food vendors, a silent auction and brought many MPS families together from the area. The event had more than 200 participants and 50 volunteers, and raised more than \$6,000 for research.

### **Krusade for Khunsha**

Sept. 19, 2009

*Event Coordinators:* Khunsha Numan and Vicky Mansfield

This first-time walk/run was held in Pittsburgh, PA, and was hosted by high school senior Khunsha Numan, (MPS IV). The event had wonderful school support, 58 participants and raised \$3,000.

### **Jack's Run for MPS**

Sept. 19, 2009

*Event Coordinator:* Heather Alden Pope

The 4th Annual Jack's Run for MPS was held in Eden Prairie, MN. More than 275 participants joined 50 volunteers for race events, a silent auction and lunch. The event was covered by TV KARE 11 and raised more than \$17,500.

### **Laps for Lucas**

Aug. 30, 2009

*Event Coordinators:* Stacey and Lew Montgomery



Families joined the Montgomery's for the 4th Annual Laps for Lucas in Cedar Rapids, IA. This year's walk/run raised more than \$4,500. The Montgomery family has raised more than \$78,000 for MPS research in the past three years.

### **MacKenzie's Run for MPS**

Oct. 11, 2009

*Event Coordinators:* Steven and Jennifer Clarke



More than 300 participants in Poquoson, VA, and surrounding communities came out in support of the 7th Annual Mackenzie's 5K Run/Walk for MPS. The cloudy skies and rain didn't dampen the spirits of the crowd. Family and friends helped as well as volunteers from the Poquoson Kiwanis club. The high school was well represented by runners, walkers and volunteers. Mackenzie's amazing team lined the streets with posters, bringing awareness to MPS. Everyone enjoyed home-baked goodies. The event raised more than \$12,500.

### **Miles for MPS**

Sept. 12, 2009

*Event Coordinator:* Laurel Radius



Miles for MPS celebrated its eighth annual walk/run in Grand Rapids, MI. This event is in honor of brothers Chip and David Radius with MPS II and raised more than \$6,000 for research.

### **MPS and Mito Walk/Run 2009**

Sept. 19, 2009

*Event Coordinator:* Kristin Myking

In Apple Valley, MN, families gathered for the fourth annual walk/run to raise approximately \$1,100 for research. They have enjoyed raising awareness among the community and hope to raise funds for research in 2010 with a charity dinner.

*continued*

**MPS Run for Their Lives**

Oct. 17, 2009

*Event Coordinators:* Scott Hardin and Steve Holland

MPS Run for Their Lives was held in Fort Worth, TX, for the eighth consecutive year. More than 290 participants and 40 volunteers came out on a beautiful day to raise awareness and funds for MPS. A western theme was incorporated into the event. Courage medallions were provided to the many children who came to the event, which raised more than \$9,500.

**MPS Walk/Run LA**

Oct. 17, 2009

*Event Coordinator:* Tami Slawson

On a hot day in October many families and friends came out in support of the 9th Annual MPS Walk/Run LA. 450 participants with many volunteers raised more than \$34,000. The annual event hosts many MPS families from around California and is followed by a regional picnic and family meeting.

**Nathan's North Carolina Walk/Run**

Sept. 26, 2009

*Event Coordinators:*

Emily Trivette and Terri Klein



This event was held in Boone, NC, in honor of Nathan Bivens with MPS II. The families worked very hard throughout the community raising awareness and funds for MPS. On the day of the event 100 participants and many volunteers raised more than \$12,000 for research. The event included a silent auction and luncheon for families and friends of the Bivens. The coordinators are very thankful to all media

formats that contributed their time to spreading awareness throughout the community.

**Post Office Café Annual 5K Run/1K Fun Run for MPS**

Oct. 17, 2009

*Event Coordinator:* Kerri Rose

Held in Babylon, NY, this event raised more than \$16,000 in honor of Mark and Casey Lessing for research.

**River Run for Ryan**

Sept. 5, 2009

*Event Coordinators:*

Jonathon and Marie Hunt

This second-year event held in Guttenberg, IA, raised more than \$13,000. The event is held in honor of Ryan Hunt and had more than 200 participants and 30 volunteers on a beautiful sunny day.

**Ryan's 10th Annual Run for MPS**

Oct. 10, 2009

*Event Coordinators:* Dorothy Mask, and Fred and Joyce Koehler

This year was the 10th anniversary for Ryan's Run for MPS. The event is held each year in Sellersville, PA. There were 85 participants and 20 volunteers who came out on a rainy day to raise awareness for MPS and \$7,000 for research. Dorothy does not worry about how much money they raise or about how many people show up each year. What is important to her is having the opportunity to teach people about MPS. Dorothy continues to do fundraising for the MPS Society because it helps release the feeling of helplessness. It allows

her to focus her energy on something positive and it gives her a great deal of satisfaction to know that she is doing something to find a cure for this devastating disease.

**Sowden Family & Friends Walk for a Cure**

Sept. 13, 2009

*Event Coordinators:*

Josh and Sheri Sowden

On a beautiful sunny day in Auburn, MI, the Sowden family hosted their second annual Walk/Run for MPS research. The Sowden family also hosted a golf tournament to raise awareness for their Walk/Run event. They had 185 participants and 15 volunteers. The event is held in honor of their sons, Ethan and Tyler, and raised more than \$24,000.

**Strides for Sara**

June 6, 2009

*Event Coordinator:*

Monique Dickerson



The 2nd Annual Strides for Sara was held in Fair Haven, NY, on a beautiful summer day. There were 229 participants and 33 volunteers. The event, which raised more than \$3,900, included a raffle, and hotdogs and beverages at the finish line. The Dickerson's are thankful for the community support and look forward to next year's event!

## 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](mailto:terri@mpssociety.org) or 877.MPS.1001

## National MPS Society Receives Three-Star Charity Rating

Having received the prestigious four-star Charity Navigator rating for the last three years, the National MPS Society learned in December 2008 that we were awarded a three-star rating, indicating that we “exceed or meet industry standards and perform as well or better than most charities in its cause.” The board of directors has reviewed Charity Navigator's detailed ratings table and scoring system in order to identify ways to earn a few more points to regain the four-star rating.

### 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](mailto: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.