

# fundraising news

## Donor Pages – A New and Exciting Tool for Fundraising Frenzy!

The National MPS Society continues to bring innovative fundraising tools to its members by launching Donor Pages.

Donor Pages allows you to create a personalized web page under the National MPS Society website. Once created, invite everyone you know via e-mail or social media networking sites, such as Facebook or Twitter, to visit your site and honor your cause. Your Donor Page can tell your story, share a photo and include your fundraising event and/or the goal amount you are trying to raise. You can share a donor recognition list and include additional links for an upcoming event.

Contact Terri Klein at [terri@mpssociety.org](mailto:terri@mpssociety.org) or 919.806.0101 to receive your signup sheet and template to begin building your Donor Page. The Society will input all data and upload photos. We want this to be as easy as possible to spread the word about MPS and related diseases and bring a dynamic, individual approach to raising funds. Whether you have a goal for individual fundraising or event fundraising, Donor Pages is a great companion tool.

### Introducing **DONOR PAGES**



- **New Program 2012**
- Sign up now
- Share your story
- Raise awareness
- Raise money for your cause !
- Each family has their own page
- Share on social media



## How Many FANs Do You Have?

*by Tom and Anne Gniardowski*

If you are not a famous actor, musician or professional athlete, you probably think you don't have any fans—you may have more than you think. Your Family, Friends, And Neighbors are your personal fans and they can help you raise money to find a cure for MPS and related disorders.

The National MPS Society's FAN Program is designed for the family that wants to participate in fundraising but does not have the time to host a major event like a walk/run, golf outing or bowl-a-thon. You can reach out to your network of family, friends and neighbors by using a simple mailer that you create to tell your story about your child. It is an opportunity to educate people about your child, MPS, the work of the Society, and to ask for a donation to support the Society's mission to find a cure for all MPS and related disorders.

Contact Terri Klein at [terri@mpssociety.org](mailto:terri@mpssociety.org) or 919.806.0101 if you are interested in utilizing this easy fundraising tool to reach out to your FANs.

## 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 #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
  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

## Concert for a Cure

On June 24, Jeremy Mask held his 2nd Annual Concert for a Cure for MPS at the Sellersville Firegrove. More than 400 people attended the all-day event, with 11 local bands performing. Local vendors sold goods, a children's area offered face painting, sand art, balloon animals and string art, food was available for purchase and gifts were raffled off from local businesses. For the second year, Haley Miller, sister of Danny (MPS II), baked nearly 650 cupcakes for the event.

The event raised nearly \$5,500 for MPS. Besides raising money and awareness to so many new people, the number of MPS families that showed up was wonderful! The Millers and Langans from PA, the Kapes' from DE, the Taorminos from MD, the O'Connors and Vanderpools from NY, the Rodrigues' from CT and the Espinolas from VA were all there to enjoy the day.



## Sponsor A Child For A Cure 2012— 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 2012.

### 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

The assigned runners are inspired by our heroes of MPS. Together they pave the path of continued hope. The photos and amount raised will be published in an upcoming *Courage* magazine. For more information on the Sponsor A Child For A Cure program, contact Angela Guajardo at [angela@mpssociety.org](mailto:angela@mpssociety.org).

## Inspire to Give

### National MPS Society 11th Annual Fund Campaign

The Annual Fund is a mailing campaign, sent out to members, friends and families each summer with a reminder in the fall. Giving to the National MPS Society's 2012 Annual Fund campaign is a partnership opportunity. By donating, your family is supporting the National MPS Society's work of providing support for families. Donate through the mail or online—together, we can make a difference.

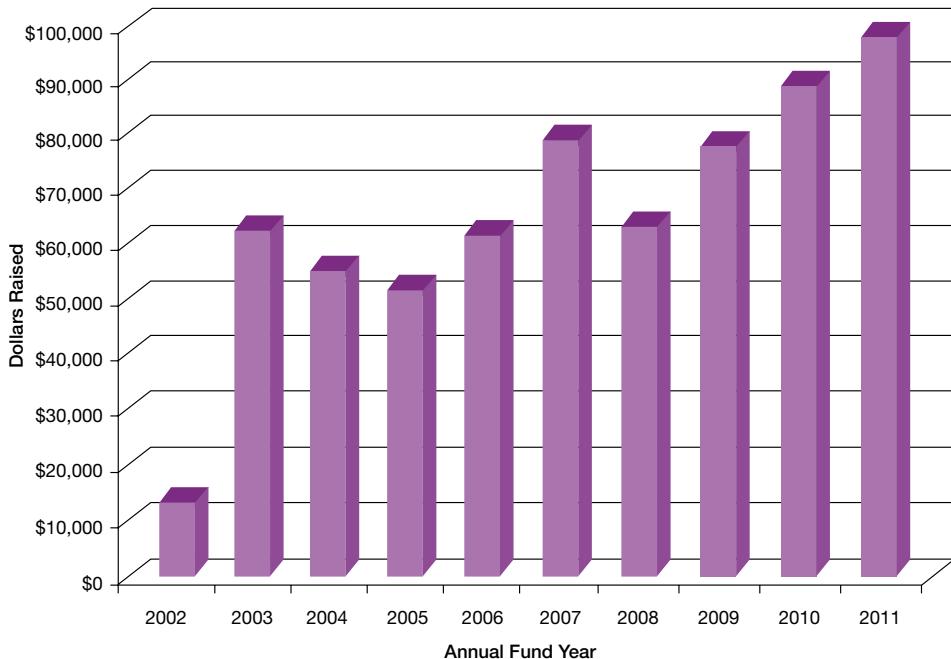
This year's Annual Fund chairs are Kim Whitecotton, a current board member of the National MPS Society, and her mother Lennie Forkas. Their touching and extraordinary experience with MPS has transcended generations within their family.

Since its inception, the Annual Fund has raised more than \$615,000 and supports critical programs such as:

- family support
- continuing education scholarships
- medical equipment
- conference scholarships
- legislative advocacy
- member services
- educational materials
- website
- special projects

The Annual Fund continues through the end of the year. Make a donation and let us recognize your gift in our Annual Report.

#### Annual Fund Donations



## 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 website for more information or to post your event.
- For free MPS Society brochures and donor envelopes, or to submit information for the website or *Courage*, send an e-mail to Terri Klein at [terri@mpssociety.org](mailto: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.

**Consider hosting your own fundraising event. Whether large or small, the rewards are endless.**

#### Fundraising Committee:

Stephanie Bozarth  
 Ernie Dummann  
 Toni Ellard  
 Anne Gniazdowski  
 Tom Gniazdowski  
 Steve Holland  
 Larry Kirch  
 Terri Klein  
 Austin Noll  
 MaryEllen Pendleton, *chair*  
 Kelly Rose  
 Lisa Todd  
 Laurie Turner  
 Barbara Wedehase



Anne Schnare, grandmother to Logan Piefer (MPS II), with the Piefer family

## Upcoming Walk/Run Events

### **It Works 2nd Annual MPS 5K & Family Fun Walk**

Hosted by Kate Martin  
Bradenton, FL  
Sept. 15

### **Henry's Walk and Roll for a Cure**

Hosted by Melissa Koker  
McPherson, KS  
Sept. 15

### **BioMarin MPS 5K Run For Your Life**

Hosted by Kathie Ward  
Novato, CA  
Sept. 23

### **6th Annual Laps for Lucas**

Hosted by Lew and Stacey Montgomery  
Cedar Rapids, IA  
Sept. 23

### **13th Annual Run for Erin**

Hosted by Stacy Peters  
Woodstock, GA  
Sept. 29

### **Post Office Café 21st Annual**

**5K Run & 1K Fun Run**  
Hosted by Kerri Rose  
Babylon, NY  
Oct. 20

### **11th Annual MPS Run for Their Lives 5K**

Hosted by Steve Holland  
Fort Worth, TX  
Oct. 27

## From One Generation to the Next

Logan Piefer (MPS II) has tremendous support behind his fight with MPS. His family have been fundraising and raising awareness for MPS since 2005.

Anne Schnare, Logan's grandmother, has been running marathons to raise awareness about MPS for seven years! This year she participated in the Vermont City Marathon in Burlington, VT, and raised \$2,230. Since 2005 total contributions received from the community have been more than \$22,750.

"When I look at Logan and see all he has had to endure over the years and think of all he still has to face, I am determined to keep running until a cure is found," said Anne. "Logan is almost 9 and has lost the ability to talk, eat and play, but still has his sweet smile and disposition. We are thankful for him every day."

Logan's sister, Avery, made bracelets and sold them with her friends at a fundraising event at school last year. Together they raised more than \$400 in honor of her brother.

The love for Logan as well as making a difference for MPS awareness has passed from generation to the next.

The Gamache family of Geneva, OH, hosted their first fundraising event in honor of their daughter Bethany (MPS III). Inspired to help fund research, the family held a fun-filled auction with gift baskets, food and music. Several MPS families from across the area attended, raising more than \$3,000.



## 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.



## North Carolina 5K Walk/Run for MPS & ML

After a year of planning we hosted our first walk/run event in our new home of North Carolina! Leslie Phillips, along with my family and a number of volunteers, worked hard to make this event a success. I have attended events in the past and watched as my wife hosted events in the Ann Arbor area, but I really wanted to do something to help my step-daughter, Jennifer Klein (ML III), and raise awareness for MPS and ML.

It is heartbreaking for me to watch this superb young woman struggle throughout different points of her day with the disease that gives such physical pain. She is truly inspiring and has shown me these past five years that “No isn’t an option.” I needed to do something to help raise money for research to help Jennifer. She and all the other children deserve a treatment.

This past May we hosted the North Carolina 5K Walk/Run for MPS & ML. We created a website ([www.mpsrunnc.com](http://www.mpsrunnc.com)) with the help of Jessica Wellman and Wellman Designs. Friends and coworkers volunteered and more than 320 people were at the start line.

It is incredible to witness a community coming together to help our family fight for research and a treatment. The staff, volunteers and sponsors were amazing. Together we raised \$15,000 for research and, more importantly, we made new friends throughout the Raleigh area. Following the event, we shared lunch and a balloon release. One of our local families provided music, and it was a great opportunity to get people together to share stories, spend time together and spread awareness. We look forward to the next event on May 18, 2013. Mark your calendars and come join us.

*Mike Schleter*



*Mike Schleter with volunteer Chris McEachen at the North Carolina 5K Walk/Run for MPS & ML*



## Text to Give Embraced in Boston

During the 26th Annual Family Conference in Boston, the Fundraising Committee surprised banquet attendees with a fun and creative way to give to Society programs. The committee has signed on with Mobile Causes to increase giving opportunities and brought the live link functionality to the conference dinner.

A \$5,000 dollar goal was set, however members and friends were determined to top that and did so successfully with a total raised of more than \$6,000. There were many positive comments and in those brief few hours families and friends worked as a team to reach a goal and fund needed program services.

Contact Terri Klein at [terri@mpssociety.org](mailto:terri@mpssociety.org) to find out how to bring this interactive tool to your next fundraising event.

There is no amount too small or too large. Donate today by texting “COURAGE” to 41444 on your mobile device. You will be notified by phone by Mobile Causes how to provide your credit card information.

Or quickly donate \$10\* by texting “CUREMPS” to 80888. Your phone bill will be charged this amount.

\*A one-time donation of \$10 will be added to your mobile phone bill or be deducted from your prepaid balance. Message and data rates may apply. All charges are billed by and payable to your mobile service provider. Service is available on Verizon Wireless, AT&T, Sprint and T-Mobile. All purchases must be authorized by account holder. By participating you certify that you are 18 years or older and/or have parental permission. Donations are collected for the benefit of MPS Society by Innogive Foundation and subject to the terms found at [igfn.org/t](http://igfn.org/t). Privacy policy: [igfn.org/p](http://igfn.org/p). Text STOP to 80888 to stop; Text HELP to 80888 for help.