

## Joint Fundraising Policy

The Society is fortunate to have families and friends throughout the year contacting us with the excitement of hosting a fundraising event to increase awareness about our cause and to raise funds for the Society. The evolution and creativity of ideas in fundraising have been a pleasure to follow and to see carried out by our dedicated families.

Every so often we have the inquiry about hosting a joint fundraising event, which is an event hosted by one or more coordinators that raises funds for two or more unrelated organizations and their missions. For example, a charity dinner that issues proceeds to both the National MPS Society and the Cancer Society.

As a nonprofit, we act as the intermediary between donors and beneficiaries and have an ethical obligation to ensure proper handling of funds to carry out our mission. Nonprofit fundraising should be conducted according to the highest ethical standards with regard to solicitation, acceptance, recording, reporting and use of funds. Nonprofits should adopt clear policies for fundraising activities to ensure responsible use of funds for designated purposes and open, transparent communication with donors.

The Fundraising Committee at this time is finalizing a Joint Fundraising Policy. There are a number of issues to consider when coordinating a joint event:

- For ease of recordkeeping and reduction of complexities, fundraiser coordinators wishing to raise funds for another organization, in

addition to the Society, are encouraged to conduct separate fundraising events for each organization.

- If extenuating circumstances exist that make separate events impractical, fundraiser coordinators should contact the development director to submit a joint fundraising plan for consideration.
- Events must comply with the Family Fundraiser Reimbursement Policy by keeping thorough records of all monies received, expenses incurred and paid, formal request submissions (using the MPS Society reimbursement form) and all sponsorship funding recognized.
- Upon approval of the fundraising plan by the Fundraising Committee—taking into account such issues as estimated donations expected, clarity to the donors, impact on other Society sponsored events, etc.—the joint fundraising event will be considered a Society sponsored event subject to the corresponding benefits and obligations.

It is our obligation as a 501(c)(3) nonprofit to provide clarity, documentation and to protect our donors.

As the Fundraising Committee finalizes the development of the new Joint Fundraising Policy, we encourage any questions or comments you have, which can be directed to Steve Holland, Fundraising Committee chair, at [steve@mpssociety.org](mailto:steve@mpssociety.org), or Terri Klein, development director, at 919.806.0101.

### Fundraising Committee:

Steve Holland, chair  
Steve Chesser  
Ernie Dummann  
Steven Frye  
Anne Gniazdowski  
Angela Guajardo  
Larry Kirch  
Terri Klein  
MaryEllen Pendleton  
Naureen Sayani  
Laurie Turner  
Barbara Wedehase  
Amy White

## 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.

## Sponsor a Child for a Cure

Each year we have families inquiring how can we do more for our children. How can we make a difference and help raise awareness and funds for MPS and related diseases research? How can we participate in a walk/run event if we are not able to host one ourselves and cannot attend another?

The Society wants to provide an opportunity for each family and their loved one affected by MPS or related disease to participate in a nearby walk/run event, even if they cannot be there in person. We understand how gratifying it is to help raise funds for research and that each dollar truly adds up!

Through *Sponsor a Child for a Cure*, families can participate in a selected walk/run event on behalf of your affected child, young adult or loved one who has passed on by assigning a walk/run participant to attend on behalf of your family. The family, in turn, can raise sponsorship for their loved one before the race begins.

A photograph of your loved one needs to be e-mailed or mailed directly to the Society office. The Society office will provide families

with sponsorship forms. Photographs will be printed and attached to the assigned walk/run participant who will run on your family's behalf. At the end of the race, a photo will be taken of the participant and mailed directly to your family along with a courage award medallion.

This is a new program within the walk/run events for the Society. We are starting this year with two events and will grow this program into all walk/run events next year. The assigned events this year will be:

1. Boone, NC — Terri Klein
2. LaVerne, CA — Tami Slawson

We encourage your family to participate. Register, get sponsors and make a donation! This will be a truly inspiring program and an opportunity for your family to help make a difference and fight for a cure!

*For more information, contact Terri Klein, development director, at [terri@mpssociety.org](mailto:terri@mpssociety.org) or 919.806.0101.*

## 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.



Sean and Cody with their sister Amber and friend at their successful trivia night fundraiser

## Walking for a Decade, and Still Going Strong!

The National MPS Society's annual walk/run events are some of the most successful fundraisers by simultaneously raising funds and awareness. Offering high visibility and tons of fun, these events draw thousands of participants across the country. This year marks the 10th anniversary of the inception of three of the Society's annual walk/runs.

### Ryan's Run

Dorothy Mask, with the help of her parents, Fred and Joyce Koehler, has been hosting Ryan's Run every year since 2000. Held at Lenape Park in Sellersville, PA, more than 200 participants attend this annual event. Dorothy has 30–40 volunteers, without whose help the event would not be possible.

In 2000, the National MPS Society began promoting the walk/runs as the key fundraising event for the Society. Dorothy, a good friend of Linda Shine who was president of the Society at the time, admired Linda's dream to have the walk/runs become the major fundraising activity for the Society as a way to get families involved in both raising money for research and raising awareness of MPS across the country. Dorothy decided to host an event of her own in her local community. She received much needed advice from Linda and from her brother, Tom, who likes to participate in runs and marathons. Tom was a big help in getting the first run off the ground.

Every year, Dorothy's mother plays a key role in planning and organizing Ryan's Run. She solicits many of the donations from corporate sponsors. Dorothy's son Jeremy collects donations from his classmates at school, his teachers, friends and neighbors, and from his boy scout troop. Plaques are awarded each year for the highest individual fundraiser and the highest group fundraiser. Jeremy has won the plaque for highest individual fundraiser for the past six years.

One of the things Dorothy enjoys most about hosting Ryan's Run is seeing the same people come back year after year. She has watched many children grow up and change over the years. People from every aspect of Ryan's life come out to support the event. It has meant so much to Dorothy to have them there. Dorothy also loves having the opportunity to educate people about MPS.

For Dorothy, every run is memorable but a few stand out as being especially remarkable. In 2005, the event was rained out. Dorothy and her parents sat at the park watching the rain come

down in buckets. Many avid runners came out even though it was pouring and hoped to run, but the course was flooded and too dangerous. Donations came in any way and more than \$10,000 was raised that year. Another memorable moment was in 2008 when no volunteers were available to lead the singing of the national anthem, so Dorothy's brother Tom offered to do it. He stood up and began singing "My country tis of thee." The crowd was confused but began to sing along. He realized he had messed up but it was too late to stop so he kept on singing. When he was finished he said "Play ball" and left it at that. They still tease him about it today.

Every year, Pennsylvania State Representative Paul Clymer attends Ryan's Run. He always talks about Ryan which makes Dorothy very proud. She loves being able to share stories about Ryan's life. Dorothy's nephew Jonathon, who is like a brother to Ryan and Jeremy, attends Ryan's Run every year.

Dorothy doesn't worry about how much money they raise, what is important to her is having the opportunity to teach people about MPS and to keep alive Ryan's memory. 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 fight to find a cure for this devastating disease.

### Run for Erin

Stacy and Tom Peters have been hosting the annual Run for Erin every year since 2000. The event has been held at the Woodstock High School in Woodstock, GA, for the past nine years. Erin currently attends Woodstock High School. Each year, more than 50 volunteers help with pre-event planning, race day duties and post-event clean up. Approximately 350 participants attend this event. Many of the volunteers are high school students who are classmates of Erin. In the past nine years, Run for Erin has raised more than \$190,000 for MPS research.

Tom and Stacy were avid runners. When they received a letter from the National MPS Society in 2000 announcing the walk/runs as the annual fundraising event for the MPS Society, they decided to host an event of their own. The only problem was they knew nothing about planning and organizing a 5K run. Participating in a 5K run is a lot different from organizing one. But that did not stop them. They attended a few 5K runs in the area to see what takes place and they took a bunch of notes. They went home and began the process of recruiting volunteers to help plan their first event. Their efforts paid off and they raised \$39,000 the first year, an amazing accomplishment for a couple of amateurs.

To help them celebrate the 10-year anniversary of Run for Erin, they will have a reporter from the local CBS news station, CBS Atlanta, as the



Run for Erin

Grand Marshal. They are hoping to get some TV coverage before, during and after their event this year, something they have never had. Run for Erin also will be featured on the local NBC morning news segment "Mugs in the Morning." The morning crew will each use a coffee mug with Run for Erin advertised on it and they will promote Run for Erin during the morning show.

One of the Run for Erin corporate sponsors, Chick-Fil-A based in Atlanta, is donating more than 100 of their stuffed cows to be distributed at Run for Erin this year. One of the cows will have a special coupon around its neck and the person who gets this cow will get a free Chick-Fil-A meal once a week for an entire year.

One of Stacy and Tom's most memorable moments was in 2006 when they came up with a way to allow Erin to actually participate in the 5K walk/run. It became known as "Push for Erin." Volunteer "pushers" pushed Erin in her wheelchair the entire 5K course to clapping,

cheering and applause from participants and onlookers as she completed the race course. Another special moment was when they hung a medallion around the neck of Tom and Stacy's 9-year-old daughter, Kelly, who won her age group the very first year of Run for Erin. They also did the same for Stacy's father and Tom's mother who won their respective age groups.

One of the greatest joys of hosting Run for Erin is that it brings their entire family together every year. It is like a family reunion. Family members come from Ohio and Tennessee the weekend of the run.

A Run for Erin board of directors has been created and is made up of Gene and Laurie Sanders, Jana and Randy Clift, Virginia Richards, Ginny Hardwick, and John and Donna Richardson. Each of these members takes on a responsibility and makes sure everything gets done. There would not be a Run for Erin without them.

Many other MPS families have attended Run for Erin over the years including the Frix family, the Shumantine family and the Prince family.

Stacy and Tom have received many rewards through hosting Run for Erin. Organizing the run allows them to actively participate in the fight to find a cure for all MPS disorders, even though there remains no treatment or cure for MPS III B. Erin knows the event is all about her. She sees people from all aspects of her life including family, schoolmates, teachers, friends and neighbors. She greets them all with her joyous expressions and giant hugs.

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

Linda and Mike Shine are proud to be among the first of the 5K runs beginning in 1999. The event has been held at the Log House Pavilion Kerr Park in Downingtown, PA, for the past 10 years. Initially it was just Linda and Mike along with some friends and family members. Fortunately, many people pitched in to help, some who were directly impacted by family members who had MPS, including Sue Wanstall, Les Sheaffer and Sue Rattman; others were people who wanted to do more to help with the cause. The effort of raising money for research for a cure is a very compelling argument for anyone. So, with a needed cause and a great deal of enthusiasm, the first 5K for Katie took place in October of 1999.

Mike has been a runner for many years so he had some knowledge of what was needed, but Linda did most of the work in lining up parks, police and EMT needs. What started somewhat simple grew very rapidly. However, the unconditional love that Katie and the other children who had their lives impacted by MPS brought out many people who wanted to help. Katie's siblings, John and Mackenzie, are now working with Linda on the event as well.

Katie unfortunately only attended the first two events before she succumbed to the disease in August 2002, just months before the third run. The run has always been held on the second Sunday in October. Linda and Mike will never forget Katie's spirit and determination in fighting the disease. Many of the volunteers were caregivers and friends of the family. While it has been 10 years, many of the same people join in the fundraising effort every year—rain or shine.

After the second year, the Miller family—Amy, Ray, Danny (MPS II) and Haley—joined Linda and Mike in hosting the run. Amy and Ray brought a great deal of determination to the run and helped expand the effort to raise money for research. Linda and Mike were very glad to have the added help in expanding the fundraising efforts.

Over the years there have been many different hands helping to raise awareness of the struggle the families impacted by MPS face every day. The fact that so many organizations offer gifts and contribute in so many ways has made the efforts very worthwhile. The runners who turn out, from high school teams to senior communities, makes the hard work seem easier—once the run is finished and the park is cleaned up!

Many different events take place in conjunction with the run—from pony riders to a cheerleading competition. The Shine and Miller families have been fortunate to have had almost perfect weather each day of the run. One of the more dicey situations was when they had rain in the days before the run. There were flood warnings, strong winds and severe weather warnings for the area. They were all very anxious but reported to the park at 5:30 a.m. as always, but watching the creek in the park and all eyes were on the sky. The run was to start at 8:30; at 8:00 the sun came out and the winds stopped. The race went off



5K for Katie/Do it for Danny



5K for Katie/Do it for Danny

with the usual suspects—more than 250 runners that year, one of the lesser attended events. After the last runners finished and the awards were presented the sky grew dark and the rain started again.

Everyone scurried to their cars, their eyes were as wet as their faces knowing their guardian angels had worked their magic with the weather to allow the run to take place. They realize that those who attend are but a few of the many who work “behind the scenes” to help make it happen.

Most years names of the sponsors are printed on the shirts. This year they will have the names of the many children who have succumbed to MPS since they started the race imprinted on the shirts. Each represents a family and a child whose life has been altered due to a very rare genetic disease. While we all question why it happens, it happens.

We realize that much has been done and there is always more to do. The money raised by 5K for Katie/Do it for Danny and the many other events have made a difference in the lives of those who come to run, to walk or to lend a helping hand... for that we are forever grateful.

## **MPS Family Helps Raise a “Lot of Dough”!**

Greg and Sarah Fletcher have been members of the MPS Society since 2002 shortly after their youngest son, Erik, was diagnosed with MPS I. Their family raised more than \$1,600 for MPS with the assistance of their local California Pizza Kitchen (CPK) restaurant. This type of fundraiser is available throughout the country and if you are interested in hosting one of these events, we encourage you to contact your local CPK.

### **Philanthropizza!**

Several months ago we tried to come up with an idea for a fundraiser for MPS here in Southern California. A friend suggested contacting restaurants in the area that have experience working with charities. After looking around, we found that our local CPK has a program in place at all of their locations called “Philanthropizza” which fits the bill perfectly. When guests visiting the restaurant on a specific night bring with them a special flyer, 20 percent of their bill will be donated to the MPS Society. The flyer can be used for lunch, dinner or even take-out. The challenge is to distribute the flyers as widely as possible in order to draw the largest number of guests to the restaurant.

### **What We Did**

We approached the two local schools our children attend with the idea of supporting the event by distributing the “Philanthropizza” flyers to all staff and families who attend each school. We received full support from the administration. The flyers were distributed both in paper form to every student and electronically via school e-mail blasts.

Our whole family pitched in to help print flyers, organize them for distribution, make signs, purchase purple balloons and distribute purple courage wristbands to key supporters at each school. We also worked with our community association to pass flyers around throughout our neighborhood, in addition to e-mailing family and friends about the event.

### **Great Results**

The result was an outstanding success! When we showed up for dinner at the restaurant, it was packed with people supporting MPS! The manager at CPK mentioned that fundraisers of this type are usually able to generate between \$200 and \$500 for the charity since, as a family restaurant, the average bill per person is between \$15–\$20. When the totals were calculated at closing time the manager e-mailed us with the wonderful news that the MPS fundraiser generated more than \$1,000 that day! Some families who could not attend sent us checks made out to the Society, which raised an additional \$600 for a total of more than \$1,600!

### **You Can Do It Too!**

We believe strongly that this type of fundraiser could be organized by many other MPS families with a CPK (or other restaurant) in their area. This is perfect for families like ours who want to raise money for MPS but are unable to devote the time necessary for larger events like walk/runs. This type of fundraiser will certainly take time and effort, but with an experienced partner like CPK it is not too difficult. We have set aside the materials we used to organize and promote MPS with CPK and our local schools.

### **Why CPK is a Good Partner**

This type of event is much easier with a restaurant that has a program already in place. Basically, CPK is already set up to take care of the paperwork necessary so you can simply concentrate on getting people to visit the restaurant. With locations in 33 states, CPK is a great family-friendly restaurant that is perfect for this type of event. CPK’s program is designed to help you raise as much money as possible by including money from lunch and especially take-out orders. They also offer the opportunity to host the event over multiple days.

In these tough economic times, we believe this type of event is a definite “win-win.” Many people can support MPS while also enjoying a nice evening out with their family and friends. You can draw on

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the support of your local schools and organizations in a way that leaves everyone feeling very good about participating. Our local CPK is excited about doing this event again with us soon and we are going to plan it as a two-day event. We hope other MPS families will consider this fundraiser as well. Who knows, maybe one day we could see a nationwide event with CPK—now that would really be a “whole lot of dough”!

Because of the devastating flood of 2008 in Cedar Rapids, IA, with many companies and corporations forced to reduce staff, tightly managing budgets and cutting back on donations toward nonprofit events, we were hit with many challenges in the planning of our 2009 Links for Lucas MPS Golf Outing campaign. Not knowing what to expect, we were successful at attracting more than 30 teams to the Saddleback Golf Course in Solon, IA, for a four-man best shot outing on June 26, 2009. Our attendance was stellar with 30–40 additional family, friends and spectators who came out to support our kids. We were honored to have two other MPS families, the McDermott and Valdez families, participate and take part in the joy of the day’s activities.

Lucas (MPS III) was on hand to enjoy his event and attention from all of the pretty ladies (always his favorite). Other families and friends made the event worth every minute spent planning, organizing and asking for donations. Stacey and I worked to ensure logistically we had things in place and that participants would enjoy themselves as we remained focused on our awareness cause. One participant commented when asked if they planned to participate again next year:

“This was our first time coming to a MPS event. We have heard about other MPS events in the community and we have seen Lucas and the Montgomery’s on the local news. My wife and I were moved by their story but we never knew quite how or where we could get involved. Our

neighbor invited us to play in this year’s Links for Lucas outing and seeing them (Lew and Stacey) in action and what they are doing for their son and others like him is unbelievable. We had never heard of MPS until now. You can tell they love their children. You can count on us every year.”

In addition to the participation we were fortunate to receive generous donations from the JM Swank Company and several local retailers who provided gift certificates, golf balls, coupons, golf attire and giveaways. In addition to meeting our immediate goals, awareness and fun, we anticipate more donations will be directed to the Society in the upcoming months as word of mouth continues to spread. We ask that other families who are considering taking on an awareness event to just do it! Our kids will reap the overall award.

*Lew Montgomery*



Jill and Lucas (MPS III) Valdez and Lew and Lucas (MPS III) Montgomery

## 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

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- 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

In addition to being a career firefighter at Wright Patterson AFB, OH, Captain Harold "Sparky" Sparks was a benevolent man who helped many children through his volunteerism and compassion. He would do this annually for an organization that helped children with special needs. Every year he would volunteer a week of his time at a camp for children and would take them fishing. This past October 2008, my son Aiden Spaeth was diagnosed with MPS II. When my fellow firefighters received word of Aiden's new fight they went into action organizing and fundraising. In the forefront of this



Aiden Spaeth (MPS II) and his mother Kristin

effort was Sparky, as always, when someone was in need he was there to help in any way he could. He was supportive from the start reaching out to my family with his big heart and helping with our every need. Sparky assisted in ensuring that more than 3,000 International Association of Firefighters locals were notified of Aiden's story by spending hours addressing envelopes. Sparky passed away suddenly this past January and will be truly missed by many. To our surprise, his wife and family were so impressed with Sparky's desire and effort to help in Aiden's fight they determined that in lieu of flowers, donations were to be made to Aiden. Their generosity has overwhelmed us and many of those who have touched our lives over the last seven months. Aiden is blessed to be surrounded by kind and caring people. In celebration of such a wonderful, compassionate man's life we send this donation to the National MPS Society.

The International Association of Firefighters has collectively raised awareness for Hunter syndrome and MPS either by wearing a purple courage bracelet or by educating family and friends. The support continued through a union-sponsored golf outing with more than 100 golfers and their families in attendance. There are many people responsible for making this happen. The fire department is most certainly a brotherhood and for us our family. In recognition of the IAFF Local F-88 and all of Wright Patterson AFB Fire Department I request you accept this donation for the Society.

*Jared and Kristin Spaeth*

## On Your Mark, Get Set, GO!

The 2009 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 a new program this year, *Sponsor a Child for a Cure*, in coordination with a 2009 walk/run. See page 22 for more information.

### Andrew's Walk/Roll for MPS

8/29/09  
Clarksburg, OH  
Sharon Cochenour  
scochenour@hotmail.com

### Laps for Lucas

8/30/09  
Cedar Rapids, IA  
Stacey Montgomery  
lewnstacey@yahoo.com

### River Run for Ryan

9/5/2009  
Guttenberg, IA  
Jonathon and Marie Hunt  
mlhunt@alpinecom.net

### Miles for MPS

9/12/09  
Grand Rapids, MI  
Laurel Radius  
frazzledblonde@yahoo.com

### Sowden Family & Friends Walk for a Cure

9/13/09  
Auburn, MI  
Josh and Sheri Sowden  
jasowden@scj.com

### Jack's Run for MPS

9/19/09  
Eden Prairie, MN  
Dara Persson  
jedanddara@aol.com

### The Heartland Run for MPS

9/19/09  
Ames, IA  
Alyssa Hajek-Jones  
alyssah@iastate.edu

### Krusade for Khunsha & MPS

9/19/09  
Allison Park, PA  
Khunsha Numan  
mps.walk@gmail.com

### MPS & Mito Walk/Run

9/19/09  
Eagen, MN  
Krysten Myking  
Deebo5@aol.com

### Nathan's North Carolina Walk/Run for MPS

9/26/09  
Boone, NC  
Terri Klein  
terri@mpssociety.org

### BioMarin 5K Walk/Run

9/27/09  
Novato, CA  
Kathie Ward  
kward@bmrn.com

### 10th Annual Run for Erin

10/3/09  
Woodstock, GA  
Stacey Peters  
smptrs@bellsouth.net

### Ryan's Run

10/10/09  
Sellersville, PA  
Maria Mask  
rjmom@verizon.net

### MacKenzie's 5K Walk/Run

10/10/09  
Poquoson, VA  
Jennifer and Steve Clark  
clarkies@cox.net

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

10/11/09  
Downingtown, PA  
Linda Shine  
lshine@comcast.net

### MPS Run for Their Lives 5K

10/12/09  
Fort Worth, TX  
Scott Hardin  
scotthardin777@gmail.com

### MPS Walk/Run L.A.

10/17/09  
LaVerne, CA  
Tami Slawson  
tislawson@aol.com

### Post Office Café's Annual Fun Run for MPS

10/17/09  
Babylon, NY  
Kerri Rose  
kerri@lessings.com

### Evan Reed Family Fun Run

10/24/09  
Mountain Grove, MO  
Laura Hiler  
lhiler@aol.com

*Thank you to the following walk/runs already held in 2009:*

**Kassi's Kause**, Travis Air Force Base, CA, May 2009

**Strides for Sara**, Fair Haven, NY, June 2009

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For more information or to register for an event, go to [www.mpssociety.org](http://www.mpssociety.org)

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The Family Support Committee has awarded more than \$303,000 to families since 2004. This money has helped families purchase durable medical goods, provided scholarships for post high school education, waived membership dues for families experiencing financial difficulties, funded regional social events and assisted

families to attend our conferences through travel scholarships.

In the first half of 2009, we awarded \$45,000 to families.

The Family Assistance Program (FAP) can provide grants of up to \$3,000 for durable medical goods that have been denied by insurance. Families have been able to purchase hearing aids, hot tubs, adaptive trikes and power seats for the family vehicle, just to mention a few of the items.

Extraordinary Experiences (EE) is our newest program, designed specifically for individuals ages 14–24 with MPS and related disease to have an extraordinary experience. We are helping a young lady with ML attend band camp this summer.

At this time, funding is still available for both the FAP and EE. If your family is interested in applying, please contact me at 207.843.7040 or laurie@mpssociety.org.

The FSC awarded \$20,000 to families attending the Annual Family Conference to be held at Disney World in December. We received 45 applications, with families eligible for a maximum of \$750 each. In addition, each family also qualified for the complimentary guest room for two nights at the Coronado Springs Resort. We are funding 29 families who have never attended one of our conferences and three families who have previously attended a conference.

The FSC also has funded 20 \$1,000 Continuing Education Scholarships. Scholarships were awarded to three individuals with MPS, 15 siblings and two parents.

Applications for all our Family Support programs are available at [www.mpssociety.org/content/4141/Family\\_Support\\_Program/](http://www.mpssociety.org/content/4141/Family_Support_Program/).

We hope your family will be able to attend the Disney conference with us. While we have awarded all of our scholarship money, there may be funding available within your community or state. We have heard from several families who have received funding from state programs and local civic organizations. It never hurts to ask, and you may receive good news that funds are available to you!



Walk/run into fall with the National MPS Society during our 10th anniversary of these events! It's that time of year again and race coordinators and the Society are working hard to get the word out about MPS and related diseases. Raising awareness and funds is critical for eventual therapies to treat all of our supported diseases.

Though we have lost a few events this year, we have gained others! This is an opportunity to say thank you to all of our families for their past years of hard work and dedication to raising funds for research. The number of research grants supported by your efforts is significant.

This year the walk/run events in North Carolina and L.A. will be launching a new program to

coincide with their events, *Sponsor a Child for a Cure*. See page 22 to read about how your family can be part of this wonderful experience if you are unable to attend a walk/run in 2009. Every child and their family can experience the satisfaction of raising funds and participate in these events from afar.

Each month the Society is fortunate for the phone calls received from families and friends across the country asking what they can do to help raise funds and awareness for MPS and related diseases. The creativity of our members is commended! If you are interested in organizing your own event next year, please give me a call and we can talk through the process. A new event guide has been updated for 2009–2010.