



fundraising recap 2011

FUNDRAISING AND WALK/RUN EVENTS

The National MPS Society is honored and proud of families who have found creative ways to raise money over the years for Society programs. Since 2000, our fundraising and walk/run events have raised more than \$4.5 million for research and family assistance programs.

These efforts have provided research grants, medical durable goods, scholarships for conferences and education, regional family gatherings, extraordinary experiences, and support toward the CYCLE program for bereaved families.

We extend our gratitude to our 2011 fundraising and walk/run hosts. Your efforts continue to strengthen the foundation of the National MPS Society. Whether large or small, each fundraising event increased awareness in communities nationwide. These families set out to create change, resulting in accelerated strategic plans for our research and family assistant programs!

THE FOUNDATION OF THE NATIONAL MPS SOCIETY continues to grow each year through members, donors and friends. Since 2000 our walk/run program and our fundraising events have raised more than \$4.5 million for the Society's research and family support programs.

Just as our MPS and related diseases are diverse, our fundraising efforts are unique. Each year families return to host events and new families join the cause. The progress we have made is attributed to each and every member, donor or friend who has championed the Society to find treatments and eventual cures. Through online grant campaigns, social media outreach and superior Web site fundraising tools, the Society is driven to create and support fun and innovative fundraising methods for those dedicated to hope and cures.

Families have set a goal to raise not just the funds necessary for research and family support, but also awareness and, most of all, hope for all our loved ones. Fundraising hosts have made a difference one event at a time.

We take fundraising seriously at the National MPS Society, and because of your trust the Society has received another four-star charity rating from Charity Navigator. We out-perform most charities in America, including much larger charities, in our efforts to operate in the most fiscally responsible way possible. Only 8 percent of charities nationwide receive consecutive four-star ratings.

Thank you to all of our 2011 walk/run and fundraising hosts! You, along with our children and affected adults, are the heroes of the National MPS Society. **Your efforts have made a difference and we will continue fighting strong until each and every disease has a treatment and eventually a cure.** ☺

MaryEllen Pendleton

FUNDRAISING CHAIR

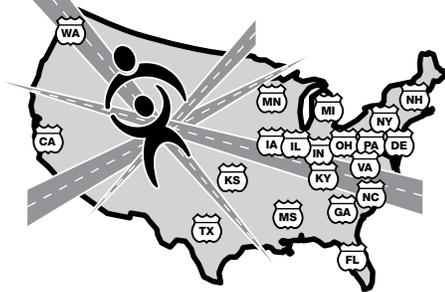


12TH ANNIVERSARY

walk/run program

Raising Awareness, Funding Research and Discovering New Hope

National MPS Society



Support for Families. Research for a Cure.

2011 Walk/Run
www.mppsociety.org


12th Annual Run for Erin

Sept. 24, 2011

Event Coordinator: Stacy Peters

The Peters family, along with 25 volunteers, hosted the 12th Annual Walk/Run for Erin. This year 200 participants ran, walked and raised more than \$13,000 for MPS III research. The event is held in honor of their daughter Erin (MPS III). Since 2000, the event has been held at Woodstock High School, GA, where Erin attended for four years, and has raised more than \$233,000 for research.

The National MPS Society board of directors planned the run and volunteers helped with the raffle, which raised \$1,600. Each year the Peters family finds many rewards in hosting this event as they are able to combine it with a family reunion. Run for Erin also participated in Sponsor A Child For A Cure.



5 for five, Race for a Cure

Sept. 10, 2011

Event Coordinator: Michelle Storm-Butts

The 5 for five second annual walk/run was held in Saratoga Springs, NY, in memory of Louis Butts V (MPS I). The event hosted 55 participants and 20 volunteers on a warm sunny day at the local park.

The event was inspiring for Michelle and her family because many donations were received from the community. 5 for five raised more than \$4,000 and continued a platform of awareness about Louis and his heroic spirit. This walk/run also participated in Sponsor A Child For A Cure with three participants.

Action for Aidan

June 19, 2011

Event Coordinators:

Brooke Carter & Jennifer Carter

The Carter family held their inaugural walk/run in Exeter, NH,



in honor of Aidan who was diagnosed with MPS II. The event hosted 300 participants and 50 volunteers with tremendous support from corporate donors and families.

The day was sunny, warm and filled with many fun activities. There was an auction, barbecue, balloons, entertainment and crafts for children.

The Carters worked for more than a year planning this extraordinary event and the support was tremendous. They used both the National MPS Society Web site and Firstgiving to raise more than \$100,000 from across the country for MPS II research.



Beat MPS 5K Walk/Run Delaware

June 12, 2011

Event Coordinators: Carl & Jennifer Kapes

This second annual walk/run was held in Wilmington, DE, in honor of Ryan and Brayden Kapes who have MPS III. Hundreds of participants and volunteers attended.

Families traveled from across the country to support the Kapes, and raised more than \$22,000 for MPS III research.



BioMarin MPS Run for Your Life

Oct. 2, 2011
Event Coordinator: Kathie Ward

This 9th annual walk/run was held in sunny Novato, CA, with 110 participants and 20 volunteers. This motivating group raised more than \$36,000. Altogether supporters have raised almost \$350,000 for research.

This walk/run also participated in Sponsor A Child For A Cure with eight participants. BioMarin continues to support our families from coast to coast.

Cameron's 5K Walk/Run for Cures

May 14, 2011
Event Coordinator: Julie Mollett

Friends and family gathered in Ashland, KY, for the inaugural Cameron's 5K Walk/Run. The Mollett family has held fundraising events in the past but wanted to join the walk/run program.

More than 100 participants supported Cameron and raised more than \$3,000. Community spirit, friends and donors encouraged the Mollett family to host again in 2012!



Kenton's Cause

April 17, 2011
Event Coordinator: Amanda Fults

This first walk/run was held on a beautiful day in Lincoln, IL, in memory of Kenton Fults who lost his struggle with MPS I.

The event had more than 100 participants and volunteers. Together this inspiring group raised more than \$9,000 with donations from friends and family throughout the community.



It Works 1st Annual MPS 5K Run

Oct. 29, 2011
Event Coordinator: Kate Martin

Almost 75 participants weathered the rain and wind in Bradenton, FL, for this inaugural walk/run. It Works hosted the 5K in honor of the Radius family who has relocated to the area.

Together they raised \$5,000 and had tremendous support from their employees. It Works introduced awareness about MPS and related diseases to the community of Bradenton and more importantly embraced the Radius family with a heartfelt welcome!

It Works also participated in Sponsor A Child For A Cure with four participants.



Laps for Lucas

Sept. 18, 2011
Event Coordinators:
Lew & Stacey Montgomery

The Montgomery family hosted their 5th Annual Laps for Lucas in honor of their son Lucas (MPS III).

Family and friends raised more than \$3,500 for MPS III research. Laps for Lucas altogether has raised more than \$63,000.



Miles for MPS

Sept. 17, 2011
Event Coordinators:
Steve & Laurel Radius

Miles for MPS celebrated its 10th anniversary walk/run in honor of David (MPS II) and in memory of Chip (MPS II). On this beautiful day family and friends came out to embrace the Radius family while they were relocating to Florida and hosting this extraordinary event.

The event raised nearly \$5,000 and altogether has raised more than \$63,000.



MPS Run For Their Lives

Oct. 22, 2011
Event Coordinators:
Scott Hardin & Steve Holland

MPS Run For Their Lives celebrated its 10th anniversary in Fort Worth, TX. This event is held in honor of Maddie and Laynie Holland (MPS I) and in memory of Spencer Holland (MPS I).

A total of 242 participants ran or walked and raised more than \$7,500. Altogether MPS Run For Their Lives has raised almost \$55,000 for research.



MPS Society Walk/Run LA

Oct. 22, 2011
Event Coordinator: Tami Slawson

Held in southern California, the MPS Society Walk/Run LA celebrated its 11th anniversary and has graciously retired after years of extraordinary efforts!

The event had more than 200 participants and 20 volunteers. Again this year the event hosted a post-race speaker and picnic for families.

This event has grown within the community and among families. They have raised nearly \$30,000 and altogether have raised more than \$360,000 for research. This event has truly been inspiring for all of our walk/run coordinators across the country.

Post Office Café 5K Walk/Run for Mark and Casey Lessing

Oct. 15, 2011
Event Coordinators:
Kerri Rose & Mark Lessing

Held in Babylon, NY, this 6th annual event raised more than \$12,000 in honor of Casey Lessing and in memory of Mark Lessing Jr. for MPS III research.

The event hosted 600 participants and 40 volunteers and continues to grow each year as the community comes together to support the Lessing's children. Altogether, the Post Office Café has raised almost \$115,000.



River Run for Ryan

Aug. 13, 2011
Event Coordinators:
Jonathon & Marie Hunt

This 4th year event held in Guttenberg, IA, raised more than \$12,000 for research with 190 participants and 20 volunteers. The event is held in honor of Ryan Hunt (MPS II) and grows each and every year. The Hunt family receives donations from as far away as Canada. Altogether they have raised \$61,000 for research.



Strides for Sara

June 11, 2011
Event Coordinator: Monique Dickerson

The 4th annual Strides for Sara was held in Fair Haven, NY. Hundreds of participants and 35 volunteers raised more than \$5,000 and had tremendous support from the community.

The event included raffles and food. The Dickersons are thankful for the community support and look forward to next year's event. Altogether they have raised more than \$16,000.



50 fundraising events

Hope for Families, Treatments and Cures



1st Annual Concert for MPS VI

Hosted by: Marla Stevens

Marla Stevens was motivated to fundraise in honor of her granddaughter, Meekel, who has MPS VI. Her family reached out to the community and shared their story.

More than 200 people attended the concert that included an auction. They raised \$21,000. The community, along with other MPS families, inspired Meekel's family to host another event in 2012!

Concert for a Cure

Hosted by: Jeremy Mask

The Mask family hosted their first Concert for a Cure in memory of Ryan Mask (MPS III). The Mask family has hosted many walk/runs in the past and wanted to reach a



new audience to raise awareness about MPS and related diseases.

This event brought 11 bands and the community out for a day of celebration. Vendors donated directly to the Society.

The event charged for admission and offered beverages and a bake sale. Hailey Miller, sister to Danny Miller, MPS II, baked 400 cupcakes (*see page 7*)! Together they raised more than \$4,500 and the Masks are excited to plan an event again in 2012.



Third Annual Mad Hatter Tea Party

Hosted by: Stephanie Bozarth

The 3rd Mad Hatter Tea Party was filled with guests from around the country. The Bozarth family hosts this event to raise funds for MPS IV research in honor of Annabelle.

Each year the event grows and includes The Mad Hatter, White Rabbit, Alice in Wonderland and the Queen of Hearts. Everyone comes dressed in their maddest hat!

A supportive community has embraced Annabelle and her family. This year the event raised more than \$75,000.

A Wish for Evan

Hosted by:

John & Kristi Abel

The Abel family hosted a spaghetti dinner in honor of their son, Evan (MPS III), in Hewitt, TX. The community showed up to support the second annual Wish for Evan and raised more than \$7,000.

This event held an auction and a raffle for a large screen TV. This was another great opportunity for the Abel family to meet and share their MPS story with others. Friends shared thousands of photos and they are having a book made of the event.



Cabi Clothing Party

Hosted by: Lynn Hopkins

The Hopkins family hosted their 2nd annual Cabi Clothing Party with friends. This event was held in Long Beach, CA, and was inspired as a way to share Michelle's MPS I story while friends shopped for a cause. They raised \$625 for MPS I research.



Johnson Halloween Bash

Hosted by: Chris & Mercedes Johnson

The Johnson family hosted their 3rd annual Halloween Bash and birthday party in honor of their sons, Wynn and Dorian, with ML II. Each year family and friends come out for a terrific evening of fun and food.

The Johnson family raised more than \$11,000 in the last three years for ML research. They combine their event with a silent auction and have food donated from various restaurants in the Lewisville, TX, area.



Lukondi Gift Basket Drawing

Hosted by: Elena Lukondi

Elena Lukondi, grandmother of Allison and Lacey Lukondi, MPS III, set up a raffle for a re-giftable gift basket as a fundraiser with proceeds to benefit research. The basket included various gift cards, candy, wine, ornaments, Pittsburgh Penguins tickets and more. Each person paid \$2 per ticket. The drawing raised \$1,000 for Sanfilippo research.

McDermott Bake Sale and Birthday Party Fundraiser

Hosted by: Friends of Jill McDermott

In honor of Blake and Morgan McDermott, MPS III, two school-aged students held separate fundraisers for the National MPS Society. Jeff, a 6th grader, combined a bake sale with a community service project. Petyon, an elementary school student, asked for donations in lieu of birthday presents. The birthday group wore MPS T-shirts to the party.

Friends of the McDermott family raised more than \$700 along with other lemonade stands and birthday gifts for MPS III research.



2nd Minnesota MPS Cup

Hosted by: Dave & Hope Madsen

The Madsen family hosted the 2nd annual MPS Cup in the Minneapolis area. The Moore family helped with support of the silent auction during the charity dinner. This event combines a pay-to-play hockey game with NHL alumni, as well as a charity dinner and auction.

Money raised at this event benefits family support programs and MPS I research. It was a terrific turnout, raising more than \$37,000.



Pi Kappa Alpha Bike-A-Thon

Hosted by: Thomas Howard

The fraternity Pi Kappa Alpha completed a 440 mile roundtrip bike-a-thon from Rock Hill, SC, to the National MPS Society's office in Durham, NC! Each year the group chooses a worthy cause.

The Society was recommended by the Isabel Juardo Foundation. After warming up and presenting a check, the group jumped back on their bikes to refresh with some banquet food for the second leg of the trip, their ride home.

The fraternity videotaped MPS Development Director Terri Klein sharing the MPS story of research and hope with the group. They raised \$7,000 for research.



Muller Family Fundraisers

Hosted by: Robb & Lisa Muller

For the third year in a row the Muller family hosted the Riley Corn Hole Tournament. More than 50 teams participated in the event to honor Riley Muller, who has MPS II.

continued >>



>> The Muller family had special boards made for the event with purple ribbons painted on each of them. Teams registered and participated on this sunny day. They raised more than \$11,000 in the past three years. Along with this event, the Muller family hosts other fun charity dinners in their hometown of Marysville, OH.



Rockland Boulders, Eisler Event

Hosted by: Janeen Eisler

Janeen and Joseph Eisler decided to raise awareness and funds for MPS II research in honor of Andrew Eisler. They teamed up with the Rockland Boulders in New York to set up a display at game time. The day was slightly dampened by the hurricane that ripped across the East Coast.

Before they closed the booth they had raised \$470. They enjoyed sharing their story about Andrew and MPS II with everyone. The Eisler family plans on hosting this event again in 2012!

Shots for Sean

Hosted by: Ernie & Debbie Dummann

Shots for Sean is a memorial golf tournament hosted by the Dummann family in memory of their son Sean who had MPS III.



The event was held in beautiful Anchorage, AK, and brought family, friends and colleagues out to swing for Sean. They included a raffle, prizes, plaques and giveaway bags for the participants, along with food as part of the registration fees. Shots for Sean raised almost \$8,000 in 2011.

Studebaker Middle School Fundraiser

Hosted by: Studebaker Schools

The students of Studebaker Middle School, along with their teacher Elaine Stewart, held a fundraising event for MPS IV research.

The class had just completed reading the book, "Freak the Mighty" and wanted to help in some way. The class raised more than \$200 for MPS IV research.

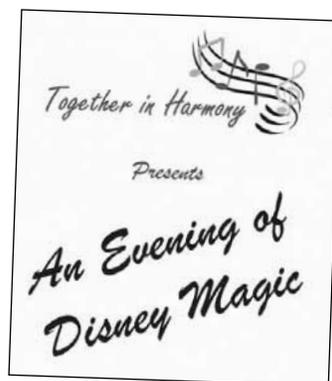


Together In Harmony Concert

Hosted by: G. Lora Grooms

The Elm Street Cultural Arts Village hosted An Evening of Disney Magic in support of Erin Peters, MPS III, in Woodstock, GA.

They hosted the concert on three dates in December and all the proceeds were donated for MPS III research.



Inspired by the fun and success of last year's fundraising events?

Consider hosting your own! The National MPS Society provides a comprehensive how-to packet with checklists and details for hosting events, including instructions for securing donations, building a volunteer team, obtaining liability releases, gathering sponsorships, publicity and much more. To receive your organization packet, contact the Society at 919.806.0101 or send an e-mail to Terri Klein, development director, at terri@mpssociety.org.



Yard Sponsor A Child For A Cure

Hosted by: Jim & Amy Yard

Jim and Amy Yard participated in the Sponsor A Child For A Cure program and also ran themselves in a nearby event in Pennsylvania. They mailed letters and information about their fundraising efforts. Family and friends came out to support their run in honor of their son Christian, who has MPS II.

The Yard family raised more than \$20,000 for MPS II research and shared their story with the entire community.



Hailey Miller baked 400 cupcakes and formed a "ribbon of courage" for the Concert for a Cure fundraiser hosted by the Mask family.



National MPS Society
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Additional 2011 Fundraising Events

1st Annual Timmy's Toss, hosted by Amy White
3rd Annual Clara's Courage Hotdog Stand, hosted by Shane and Jennifer Gibson
Allenwood School May Carnival, hosted by Judy Harms
Allison Kirch's birthday event, hosted by Abigail Cohen
Bastrop School fundraising event, hosted by Ms. Pogue
Breakfast with Santa, hosted by Kids Under Construction
Cadyn's Car Wash, hosted by Rita Luna
Cayden's birthday fundraiser, hosted by Cayden Duncan
Caring Hands employee fundraiser, hosted by Siemens Healthcare
Caswell MPS Awareness Day fundraiser, hosted by Heidi Caswell
Celebration Day for Rare Diseases, hosted by BioMarin
Channel car wash, hosted by Kandy Channel
Cook candle fundraiser, hosted by Angie Cook
Deer Creek Walk-a-Thon, hosted by Lake Forest Middle School
Dress Down Friday, Providence Schools, hosted Dianne Renzi
FAN Program, hosted by Chet and Bethany Chambers
Fowler charity dinners, hosted by Jaimie Fowler
Gillis half marathon walk, hosted by Mary Gillis
Ice Cream Corner and Bridge Club, hosted by Janelle Kunellis
Jeans Day at USF, Holland, hosted by Mark and Tina Mulder
Laff-a-Thon, hosted by Stacey Montgomery
Lemon Drops Grand Opening, hosted by Glenn and Kathleen Miller
McCreary Dress Down Day, hosted by Laura McCreary
Olivia's 9th Birthday Bash, hosted by Wes and Jill Lovell
Palm Pointe Student Council Event, hosted by Palm Pointe Schools
Piefer lemonade stand, hosted by the Piefer family
Play for Taylor, hosted by Matt and Rachel Wojnarowski
Post Office Café fundraising events, hosted by the Lessing family
Roller Derby for MPS, hosted by Shelly Maddox
Rylie's Runners, hosted by Lyle and Jade Hays
SF Giants fundraising event with Keenan Cahill, hosted by BioMarin
Silge lemonade stand, hosted by Emily and Allie Silge
Sowden Walk for a Cure, hosted by Josh and Sheri Sowden
Vespe wedding donations, hosted by Anthony Aulisa and Johanna Vespe
Kelly family wedding donations, hosted by Ryan and Kelly Curry

Sponsor A Child For A Cure 2011

Families across the country raised \$23,000 in 2011 for this wonderful and heartfelt program. Each year with renewed hope we reach out to families and share that they too can make a difference and help raise money for research.

It is easy, and the rewards are tremendous. Thank you to the following families who embraced the challenge. We HAVE made a difference together and HOPE is stronger than ever before.

Anderson family, Nathan Roma MPS VI
Boni family, Danica MPS I
Caswell family, Sam MPS I
Cavanagh family, Scott MPS IV
Fowler family, Jack MPS II
Gibson family, Clara MPS III
Kemp family, Zain Semones, MPS II
Kirkpatrick family, Wendy & Kaylee, MPS I
Laorenza family, Aurora, MPS III
Migliozzi family, Christopher Joseph
Podesky family, Adam & Benjamin, MPS I
Rice family, Amelia, MPS III
Robson family, Jaeda, MPS III
Szemanski family, Clinton & Zachary, MPS III
Waddell family, Ethan, MPS I
Yard family, Christian, MPS II