



fundraising recap 2012

FUNDRAISING AND WALK/RUN EVENTS

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 877.MPS.1001 or send an e-mail to Terri Klein, development director, at terri@mpsociety.org. For more information, visit www.mpsociety.org/fundraising.

Ways of giving include:

Annual Fund
Company matching gifts
Courage Pages
Gifts in honor or in memory of a special person
Host a fundraiser or walk/run
Major gift
Planned gift
Give through the Combined Federal Campaign or United Way

TO ALL OF YOU, our fundraisers, cherished families, treasured friends and awesome supporters, we thank you sincerely for all of your efforts in 2012 to support the mission of the National MPS Society.

Dollars raised by National MPS fundraising hosts can be designated toward research (general or syndrome specific), family programs or wherever it is most needed. One hundred percent of the money raised for research goes to research. Many organizations say this, but not all actually do this. Because of your dedication the MPS Society is able to provide funding of \$450,000 in new grants for MPS research. In addition, \$65,000 will be committed to existing and partnerships grants.

Your hard work last year also allowed newly diagnosed families to attend our annual conference, families to obtain assistance to attend an annual conference, and families to receive medical supplies not covered by their insurance or other sources. These efforts continue our mission of support for families. Our scholarship program, Extraordinary Experience and bereavement support programs also benefit from funds raised by you, our dedicated members and friends.

Your fundraising efforts have made the National MPS Society the dynamic force we are today in furthering research and supporting our affected adults and families. The following pages detail fundraising events held in 2012. Please consider joining this hardworking group by hosting a fundraiser. Large or small, from a lemonade stand to a gala event, together we can all make a difference! ☘

MaryEllen Pendleton

FUNDRAISING CHAIR



13TH ANNIVERSARY

walk/run program

Raising Awareness, Funding Research and Discovering New Hope

National MPS Society



Novato, CA, with 100 participants and 40 volunteers, and raised more than \$31,000. In total, this annual event has raised more than \$380,000 for general research.

began with the local Boy Scouts leading the pledge of allegiance. This event also raised awareness by launching an event website (www.mpsride.com).

2nd Annual Cameron's 5K Walk/Run for a Cure ♡

Event Coordinators: Brian & Julie Mollett
May 12, 2012

The Mollett family brought the community of Ashland, KY, together in honor of Cameron who was diagnosed with MPS II. The event had more than 80 participants and 29 volunteers and was recognized by the local newspaper. The event raised more than \$4,000 for research.



Big Nate's Hope 5K Fun Run ♡

Event Coordinator: Ester Gonzalez
April 21, 2012

This event, held in memory of Nathan Vasquez (MPS III), was held in Uvalde, TX, and had 74 participants and 15 volunteers. The event raised more than \$4,000.



BioMarin MPS 5K Run for Your Life ♡

Event Coordinator: Kathie Ward
Sept. 23, 2012

BioMarin celebrated its 10th anniversary walk/run in sunny



1st Annual Charity Motorcycle Poker Run & Family Fun Day ♡

Event Coordinators: Jerry Bennett & Kimberly Frye
Oct. 27, 2012

Held in honor of Jack Frye (MPS II), the Charity Motorcycle and Poker Run brought the community of Thousand Oaks, CA, together on a beautiful sunny day. The event raised more than \$19,000 and



13th Annual Run for Erin ♡

Event Coordinator: Stacy Peters
Sept. 29, 2012

Parents, grandparents and friends gathered to support the Peters family for the 13th Annual Run for Erin. More than 200 participants and 50 volunteers gathered in the community of Woodstock, GA, to raise more than \$18,000 for MPS III research. Since its inception, this event has raised more than \$251,000.



5 for five, Race for a Cure ♡

Event Coordinator: Michelle Storm-Butts
Sept. 1, 2012

This third annual walk/run was held in Saratoga Springs, NY, in memory of LB (Louis Butts V, MPS I). The event had 130 participants and 20 volunteers. Hosting this

>> event gives Louis' parents, Michelle and Lou, a sense of comfort three years after losing their baby. The event raised more than \$4,000 and continued a platform of awareness about Louis and his heroic spirit.

Henry's Walk n' Roll

Event Coordinator: Melissa Koker-Kent
Sept. 15, 2012

Friends gathered in McPherson, KS, for the inaugural Henry's Walk n' Roll. This inspiring event raised more than \$1,700 for research, and included a bake sale, raffle, face painting and music.



HHS NHS Funfest for MPS

Event Coordinator: Evan Wilson
May 12, 2012

The National Honor Society at Hampton High School in Allison Park, PA, hosted this walk/run in honor of former employee Amy Yard whose son, Christian (MPS II), was diagnosed last year. The school and community enjoyed a beautiful day with a funfest following the walk/run. The event had 200 participants and 50 volunteers and raised more than \$12,000 for research.



It Works! Charity 5K & Family Fun Walk

Event Coordinator: Kate Martin
Sept. 15, 2012

It Works! hosted its second annual event in honor of the Radius family and Miles for MPS. This is the 12th year the family has been involved in hosting an event for research.

The community of Bradenton, FL, came together on a beautiful sunny day with 110 participants and 25 volunteers and raised more than \$5,000 for research.

Kilometers for Karina

Event Coordinator: Anyssa Guajardo
Nov. 3, 2012

This past fall Anyssa Guajardo contacted the Society and wanted to host a walk/run in honor of her sister, Karina, who suffers from MPS III. The Guajardo family embraced the idea and with the help of friends and the community of Edinburg, TX, they raised more than \$4,000 for research. Sixty-five participants and 15 volunteers came out to honor Karina and learn about MPS.



Laps for Lucas

Event Coordinators:
Lew & Stacy Montgomery
Sept. 12, 2012

The Montgomery family gathered with friends in Cedar Rapids, IA, to host their sixth annual event in honor of Lucas (MPS III).

This year they raised more than \$2,000 that will benefit Sanfilippo research.

The event had 67 participants and 12 volunteers. The local TV station broadcasted a heartfelt story sharing Lucas' struggles with MPS. Altogether Laps for Lucas has raised more than \$65,000 for research.



MPS Run For Their Lives

Event Coordinator: Steve Holland
Oct. 27, 2012

MPS Run For Their Lives celebrated its 11th anniversary in Fort Worth, TX. This event is held in honor of Maddie and Laynie Holland and in memory of Spencer Holland. Though Maddie was hospitalized during the event, about 200 participants ran or walked raising more than \$6,000. Altogether MPS Run For Their Lives has raised almost \$61,000 for general MPS research.



North Carolina National MPS Society 5K Run for MPS & ML ↗

Event Coordinators:
Mike Schleiter & Leslie Phillips
May 19, 2012

The community of Raleigh-Durham, NC, gathered last spring to support this inaugural event, which raised almost \$15,000. The North Carolina National MPS Society 5K Run will benefit research for both MPS and ML diseases. Mike Schleiter, stepfather to Jennifer Klein (ML III), wanted to initiate community awareness about these diseases and is determined to host an event each year.

Nearly 320 participants joined with 28 volunteers at Bond Park for a challenging 5K course and a one-mile fun walk. A family picnic was held after with face painting and music.



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

Event Coordinator: Kerri Rose
Oct. 20, 2012

Held in Babylon, NY, this seventh annual event raised more than \$13,000 in honor of Casey Lessing

and in memory of Mark Lessing Jr. for MPS III research.

The event hosted almost 700 participants and 40 volunteers, and continues to grow each year as the community comes out to support the Lessing family. It is the largest walk/run the Society sponsored last year; altogether they have raised \$128,000 for research.



Strides for Sara ↗

Event Coordinator: Monique Dickerson
June 9, 2012

Everyone had a wonderful time at the 5th Annual Strides for Sara in Fairhaven, NY, last summer. More than 200 participants and 55 volunteers came out in memory of Sara and raised almost \$5,000 for research.

The event also included a number of donated items for a raffle and a picnic hosted by the local car club. Each year the event continues to grow and altogether has raised more than \$21,000 for research.

The Society also sponsored the following walk/run events in 2012:

Memorial Walk for Kyle Witt

hosted by Cynthia Zea

Andrew's Rock n' Roll

hosted by Pioneer High School

COMMUNITIES NATIONWIDE

fundraising events

Hope for Families, Treatments and Cures

Alena Galan Fundraising Event ☺

hosted by Marcia Galan
Winter 2012

The middle and high schools in Alena's district hosted various events in honor of Alena (MPS VI). They raised almost \$500 around her January birthday in addition to events in February. Students marched into the auditorium while Alena showcased her talent singing "The Climb," which has become her signature song. Everyone linked arms creating a human chain that surrounded the schools. The community and student support was very inspirational!



Logan's Heros ☺

hosted by Ann Schnare
Spring 2012

Ann ran her seventh Vermont City Marathon in honor of her grandson, Logan Piefer (MPS II). Ann says that when she looks at



Logan and all he has had to endure over the years, she is determined to keep running until a cure is found. Logan has now lost the ability to speak, eat and play. Since 2005 Anne and her supporters have raised more than \$22,000.



Dancing with Dominic ☺

hosted by Jeanette Espinola & Fredy Henriquez
Spring 2012

This inaugural event was hosted in honor of Dominic Henriquez (MPS II). The family wishes to increase community awareness for Hunter syndrome and celebrated with a semi-formal event. They had music, dancing, a dinner buffet, kid's activities and door prizes. It was a terrific event (with Dominic dancing everywhere) that raised almost \$15,000 for MPS II research.

MPS Boot Camp & Halloween Spooktacular ☺

hosted by Chris & Mercedes Johnson
Spring/Fall 2012



In 2012 the Johnson family once again hosted two events in honor of Dorian (ML II) and Wynn (ML II). These events included a boot camp/exercise fundraiser and an annual Halloween Spooktacular that honors the twins' birthdays. The events also included food and auction items, and raised \$7,000 exclusively for ML research.



Keep Hope Alive ☺

hosted by Lisa & Jerry Todd
Summer 2012

This inaugural "Ask Event" was hosted in honor of Jack Todd (MPS II). Among a beautiful setting in Albuquerque, NM, the Todd family hosted more than 150 family and friends. It was an afternoon of delicious food and an opportunity to learn about the children and families of the National MPS Society. The event shared a visionary session and presentations from board members. They raised more than \$23,000 in 2012 and have pledges for additional funding in the next two years.



Concert for a Cure ♡

hosted by Dorothy & Jeremy Mask
Summer 2012

Each year the Mask family hosts an event in memory of Ryan Mask (MPS III). This event brought bands and the community out for a day of celebration. The event charged for admission and offered beverages and a bake sale. Families from the Midwest and East Coast raised more than \$4,500 and the Masks are excited to plan an event again in 2013.



Gamache Family Chinese Auction & Dinner ♡

hosted by the Gamache family
Summer 2012

The Gamache family hosted their first Chinese auction and dinner at the Cebars Madison Tavern in their community. This type of event combines both hosting a raffle and an auction all in one! The event was hosted in honor of Bethany (MPS III). The family sold tickets for \$10 per person, had more than 30 auction items and many door prizes. They had wonderful support and raised more than \$3,000 for MPS III research.

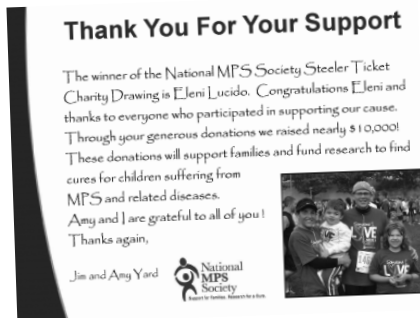


Shots for Sean Memorial Golf Tournament ♡

hosted by Debbie & Ernie Dummann
Summer 2012

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

The annual 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 participants, and food as part of the registration fees. Despite the bad weather, Shots for Sean raised almost \$14,000 in 2012!



Pittsburgh Steelers Ticket Raffle ♡

Hosted by Jim & Amy Yard
Summer 2012

The Yard family hosted a very creative event by donating season tickets to the 2012 Pittsburgh Steelers home games. Family, friends and the community went viral to raise awareness in honor of their son Christian (MPS II). The Yard family ran the raffle in conjunction with the numbers drawn from the Pennsylvania Big 4 daily lottery. Many friends and family supported their efforts and they raised almost \$9,000 for MPS II research.

Walker Benefit Concert ♡

hosted by Ken & Courtney Walker
Summer 2012

Soon after the diagnosis of their daughter, Trinity, the Walker family decided to raise money for MPS III research. It was important for the family to share their story. Together with a local band and the community, they gathered for a fun night of food and music. The family hosted a raffle, auctioned gift baskets and played the National MPS Society video "Journey to a Cure." Their efforts raised more than \$1,500 and they look forward to the 2013 event!



Halk Fall Festival Fundraiser ♡

hosted by Carla Halk
Fall 2012

The Halk family hosted their first Fall Festival in Texas in honor of Blake (MPS I) and Paige (MPS I). The event included a pumpkin prize patch, haunted house, face painting, cake walk, auction, coloring contest, raffles and more. The community raised almost \$3,000 for the Society.





Bike for Brooke ♡

hosted by Tracy & Olivia Martin
Fall 2012

Dedicated cousins hosted their first bike-a-thon in memory of Brooke Weddell (ML II). Brooke passed away at the age of 4 and her cousins wanted to put together a community event in her memory. They had shirts designed and posted banners throughout the town. More than 100 people gathered on a beautiful fall day and raised more than \$2,000 for ML research. Holly, Brooke's mother, is very touched that Brooke is still in the hearts of her family and neighborhood.



Klenke Family Bowl-a-Thon ♡

hosted by Brian, Kris & Chelsey Klenke
and Kelli Boni
Fall 2012

The Klenke family, along with their community, hosted the 12th Annual Klenke Bowl-a-Thon in memory of Kraig (MPS II). The family sells tickets for \$25 which includes shoes, a shirt and two games of bowling, in addition to a silent auction, bake sale and prizes. Everyone gathers for an afternoon

of sharing memories of Kraig along with a day of celebration with friends and loved ones. This event raised more than \$4,000 for family assistance programs that benefit Society members.



Carson-Green Song & Dance for MPS III ♡

hosted by Harley & Pacey Carson
Fall 2012

The cousins of Trinity Walker (MPS III) put their talents together to host the first Carson-Green Song & Dance in their community to benefit MPS III research. The girls gathered the community to a local church and performed a beautiful dance program. They raised almost \$3,000 for research and awareness throughout the community.

Sponsor A Child For A Cure 2012

Families across the country have raised more than \$45,000 through Sponsor A Child For A Cure. This heartfelt program needs your help too! 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 2012 challenge.

Boyce family, Jayden and Brooklyn (MPS III)

Caswell family, Sam (MPS I)

Klein-Schleter family, Jennifer (ML III)

Phillips family, Alex (MPS II) and Anna (MPS II)

Szemanski family, Clinton (MPS III) and Zachary (MPS III)

Courage Pages

The following families have their own websites in Courage Pages through the National MPS Society. Whether you are hosting an event or raising awareness for MPS and related diseases, these custom pages have been a hit with donors and can help enhance your fundraising efforts. ***Consider having us build your family's custom website—there is no expense!*** To view these inspirational sites, go to www.mppsociety.org and click on "Courage Pages" on the right margin.

Evan Abel

Hunter Beam

Annabelle Bozarth

Sam Caswell

Alan Charest

Allison Kirch, in memory of

Kraig Klenke, in memory of

Jennifer Klein

Danny Miller

Jack Todd

Trinity Walker

Scotty Whitecotton



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Additional 2012 Fundraising Events

3rd Annual Clara's Courage Hotdog Stand, hosted by the Gibson family

3rd Annual A Wish for Evan, hosted by John and Kristi Abel

Ace One for Allison Golf Scramble, hosted by the Kirch family

Allison's book signing, "Hi My Name Is Allison," hosted by Allison Restemayer

Ben Bridge Jewelers dress down day, hosted by Stephanie Woods

Bernstein birthday party, hosted by Jen Bernstein

CaBi clothing party, hosted by Lynn Hopkins

Carmichael jewelry party, hosted by Karli Carmichael

Charles Schwab Product & Platform bake sale, hosted by employees at Charles Schwab

Christian Lon Charity Paintball Tournament, hosted by Maureen and Tony Lon

Collins Ernst & Young jean day, Team Alexandra, hosted by Melissa Harkey

Danny's 16th birthday party, hosted by Ray and Amy Miller

Do It "Fore" Danny golf tournament, hosted by Ray and Amy Miller

Dress Down Friday, hosted by Dianne Renzi and the Providence School District

Edinburg School Team Karina MPS Day event, hosted by Anyssa Guajardo

Eisler Rockland Boulders fundraiser, hosted by Janeen Eisler

Gold Party for MPS, hosted by Elizabeth Tuck

Homecoming Trunk Show for Nathan, hosted by Michelle McPherson

Hudsonville Schools popsicle fundraiser, hosted by Bill Ross

Ice Cream Corner 3rd Year Awareness and Bridge Club, hosted by Janelle Kunellis

Krewson Terrace lemonade stand, hosted by Dawn Lipenta

Kroger's of Lincoln, IL, Dress Down Day, hosted by Kroger Grocery staff

Lacrosse game in memory of Mark Lessing Jr., hosted by Kevin Connolly

Lemonade Stand for MPS, hosted by Tracy Leonard

Logan County Bank Jeans Friday, hosted by staff at Logan County Bank

Madison's birthday, hosted by Wayne and Paige Lewis

Mallia birthday fundraising event, hosted by John and Jeanne Mallia

Meekel's Music for MPS VI, hosted by Marla Stevens

Mission Slimpossible, hosted by MPS moms

MPS Awareness Day auction at Bethel School, hosted by Jason and Michelle Moore

MPS Awareness Day checkout fundraiser, hosted by Rhiannon and Marcus Woodcock

MPS Awareness Week, Thompson High School, hosted by Shelby Key

Piefer fundraising event, hosted by Avery Piefer

Play for Taylor, hosted by Matt and Rachel Wojnarowski

Post Office Café events, hosted by Kerri Rose

Purple lemonade stand, hosted by Laura Thorsrud

Roll Over for MPS and ML, hosted by Mackenzie Kasper

Rosenberg bake sale, hosted by Allie Rosenberg

Scrapbooking fundraiser, hosted by Michelle Dodson

Tag sale in memory of Kris Roman, hosted by Sherri and Anthony Roman

Trivia night for Noah Mehling, hosted by Hamilton County Firefighters, Local 4416

Valentine's Day for Cures, hosted by Tami Slawson and National MPS Society

Walk 4 Josh, hosted by Karen and Wilbert Bateman