

fundraising news

Inspire to Give

National MPS Society 12th Annual Fund Campaign

Giving to the National MPS Society's 2013 Annual Fund campaign is a partnership opportunity. Your family is making a decision to support the work the National MPS Society does each day to provide support for families. Move forward with the Society, partner with us by giving to the Annual Fund. Together, we can make a difference. Donate through the mail or online!

This year's Annual Fund chair is Stacy Peters, mother to Erin (MPS III). The Peter's family has hosted Run for Erin for 14 years. They share their touching story of how they began a legacy with a pay-it-forward philosophy through their run as they patiently wait for treatments to help their daughter. You can view their story online at www.mpssociety.org.

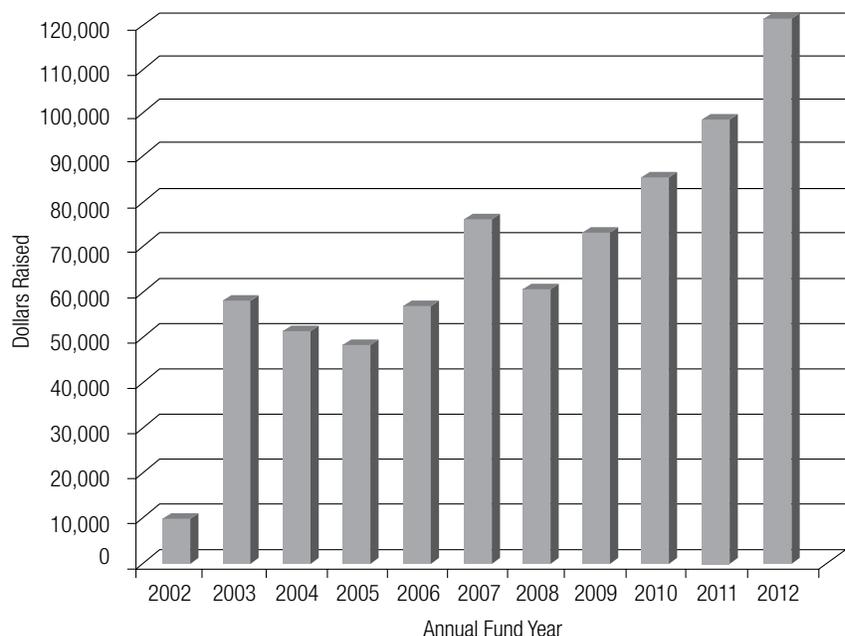
The National MPS Society's Annual Fund:

- was launched in 2002.
- currently is in its 12th year.
- has raised more than \$723,000.
- supports critical program initiatives, such as:
 1. Family Support, continuing education scholarships, medical equipment, conference scholarships
 2. legislative advocacy
 3. member services
 4. educational materials, website and other special projects
- is a mailing campaign sent to Society members, friends and families each summer with a reminder in the fall.
- continues through the end of the year. Make a donation and let us recognize your gift in the Annual Report.

Fundraising Committee:

Jeff Bardsley
 Stephanie Bozarth
 Ernie Dummann
 Lydia Edgal
 Toni Ellard
 Anne Gniazdowski
 Tom Gniazdowski
 Steve Holland
 Larry Kirch
 Terri Klein
 Amy Miller
 Lisa Muller
 MaryEllen Pendleton, *chair*
 Lisa Todd
 Laurie Turner
 Barbara Wedehase

Annual Fund Donations



2013 Annual Fund Campaign Raises \$76,835 by Oct. 18, 2013

The National MPS Society's Annual Fund is a valuable tool that helps to strengthen the vision, purpose and mission of the Society by committing resources to projects that provide direct benefit to members and their families. Your generosity will help fund programs such as conference scholarships, the Family Assistance Program, expanded publications resources and legislative initiatives.

Our goal for 2013 is \$125,000. Please help us reach this historical goal by sending in your donation today. Thank you to everyone who has already donated to the 2013 Annual Fund. With your ongoing support we can continue our very important work, supporting children and adults with MPS and related diseases and their families.

"The MPS Society is a big family that gives these precious children a voice, helps make their suffering easier, and works tirelessly for treatments that will help them lead long and productive lives."

Paul Keith
MPS II parent



Kevin Keith (MPS II) at graduation



Kanney family

"Giving to the National MPS Society Annual Fund makes us feel that we are doing all that we can so that Carter, our oldest grandson, and others afflicted with MPS might live long, healthy, happy lives. Our hope is to do our part to help eliminate MPS completely."

Jerry and Pat Kanney
MPS II grandparents

"The funds that have been donated for the Annual Fund have played a large part in creating an awesome support system. Your generous giving helps in so many ways that truly can be seen and appreciated once you have heard how much the Society gives back to its members. A lot of the Annual Fund money is used behind the scenes. Our family witnessed the most amazing results at the conference in renewing friendships with veteran families, supporting families who have just been recently diagnosed and helping families cope with everyday issues. Every single dollar counts and is used wisely in ways to keep families connected, up to date with the most recent medical research, and making it easier to cope with this disease. We are so thankful that we have been able to contribute to this worthwhile cause."

Jan Melnyk
MPS II parent



Melnyk family

2013 Annual Fund Donors

Philanthropist \$1,000 or more

Wayne and Catherine Bardsley
 Joyce Rhodes Barrett
 Austin and Stephanie Bozarth
in honor of Annabelle Bozarth
 Susan and Roger Chapin *in honor of Blair Chapin*
 Joan Cook
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 in honor of Maddie and Laynie Holland*
 Leslie and Marilyn Kelman
 Joe and Jan Melnyk *in honor of Nicholas David Melnyk*
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in memory of Daniel Molinaro
 Austin and Cheryl Noll III *in honor of Austin Noll IV*
 Austin and Dorothy Noll Jr. *in honor of Austin Noll IV*
 Mark and MaryEllen Pendleton
in memory of Allison Kirch
 David and An Tootill *in honor of Shannon Tootill*
 Don and Lisa Wells *in honor of Matt Wells*
 Tom and Kim Whitecotton *in honor of Scotty
 Whitecotton and in memory of Russell Forkas*
 Russell and Alice Witt *in memory of Kevin and Kyle Witt*

Leader \$500–\$999

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 CA Technologies Matching Gifts Program
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 Richard Kernstock
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 Chris Meyerpeter *in honor of Dani Boni*
 Stuart Swiedler and Judy Weiss
 Jerry and Lisa Todd *in honor of Jack Todd*
 Barbara Wedehase

Volunteer \$250–\$499

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in memory of Matthew Caldwell
 Sandra Babel *in honor of Danny Miller and family*
 Carrie Dunn and Melissa Kraus
in honor of Jackson Dunn-Kraus
 Bart and Sally Finzel
 Eugene and Frances Goldfarb *in honor of Jack Todd*
 Kathleen Hillyard *in honor of Austin Noll IV*
 Joel and Lisa Klessens *in memory of Morgan Klessens*
 Lori Caldwell LeDoux *in memory of Matthew Caldwell*
 Charles and Kendra Lesta
in memory of Christopher Lesta

Dr. Elizabeth Neufeld
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 Sam and Nancy Ramsey
 Sheila Slawson *in honor of Sammie and Jake Slawson*
 Jerry and Shirley Todd *in honor of Jack Todd*
 Tom and Theresa Weisenbach
in memory of Megan Weisenbach
 Claude and Roselyn Wells *in honor of Matthew Wells*
 Hubert and Elaine Willman *in honor of Jake Hampton*

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in memory of Amanda Keith
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 Millie Anhalt's 50th anniversary*
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in honor of Michael Bodura
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 Dwight and Debbie Barkley *in honor of Davis Barkley*
 Mike and Grace Bodura *in honor of Michael Bodura*
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 Sharon Brack *in honor of Scotty Whitecotton*
 Dale and Myriam Brandt *in honor of Ryan Hunt*
 Marc and Beth Brdar *in honor of Christian Yard*
 Curt and Lou Ann Brooks
 Caroline Butz *in honor of Danny Miller*
 Mark and Stephanie Caldwell
in memory of Matthew Caldwell
 Tony and Shirley Catanzarite
in honor of T.J. Catanzarite's 25th birthday
 Dawn Checrallah *in honor of Nick Boyce*
 Amy Cherrstrom
 Michael, Margaret and Grace Ciacciarelli
in memory of Max Ciacciarelli
 Jerrold and Marilyn Cohen
in honor of Jack Frye and family
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 Billi and Jeremy Crockett
in memory of Mattew and Camden Crockett
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 Susan and John Demchak *in honor of Isabel Jurado*
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 Henry and Barbara DeVries
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 Charles and Josephine Ellard
 Robert and Amy Farrell
in memory of Joe and Maggie Langford
 Phyllis Feibelman *in memory of Petey Feibelman*
 Gail Finney *in memory of Clinton, Zachary and
 Larry Szemanski*
 Rod and Kathy Finzel *in honor of Mitchell Finzel*
 Ronald and Sheila Francis
 Ian and Shelly Fritz
 Thomas and Sylvia Gamache
in honor of Bethany Gamache
 Thomas and Jean Gniazdowski
in memory of Danny Gniazdowski
 Toni Graham and James Graham
in honor of Jacqueline Graham
 Rose Marie Greco
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in honor of Zachary Townsley
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in memory of Brian, Chris and Eric Hardison
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 Kay and Joel Levy *in honor of Conner Anhalt*
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in memory of Glen Malina
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in memory of Dylan McClurg
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in honor of Waverly and Oliver McNeil
 Frank and Jane Middleton
in honor of Scotty Whitecotton
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 and Jason Madison*
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 Zachariah and Noah Muonio*
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 Andrew and Joyce Nielsen
in memory of Joe and Maggie Langford
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 in memory of Zach Durholz*
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 Mark and in honor of Casey Lessing*
 Janet Rafferty *in honor of Shannon Tootill*
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in memory of Jill and Mindy Rennaker
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 Larry and Janice Spadt
in honor of Russell and Alex Browne
 Bob and Barb Taylor *in honor of Aiden Carter*
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 Fern Titus *in honor of Oliver and Waverly McNeil*
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 Eric and Laurie Turner
 Erin Valdez
 Jim and Kathy Ward *in honor of Bryce Chesser*
 Lewis Whitaker Jr. *in honor of Logan Piefer*
 Lynn Ann Witt *in memory of Kevin and Kyle Witt*

Donor \$26–\$99

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in memory of Karlee Rae Classen
 Kevin and Kristina Coen
 David and Maureen Cunningham *in memory of*
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 Pat and Thomas Davitt
in memory of Michael McGuinniss
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 Gracie Day *in memory of Greg and Scott Day*
 Thomas and Judith Diederich
 Patricia DiLuzio
 Denmar and Ellen Dixon *in memory of Edie Burke*
 Douglas, Lori and Katie Dunbar
in memory of Kraig Klenke
 Patricia Dunn *in honor of Dani Boni*
 Lydia Edgal
 Carla Ellard
 Tara and Jack Elston *in honor of Jake Elston*
 Brian Engel *in honor of Erin Peters*
 Clark and Susan Enszt *in honor of Rylie Hays*
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 Kenneth and Ruth Espenshade
in honor of Rachel Dodson
 Steven and Kathryn Espenshade
in honor of Rachel Dodson
 Geraldine Faucett *in honor of Michelle Hopkins*

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in memory of Clinton and Zachary Szemanski
 Maria and Steven Foshay *in memory of Katie Foshay*
 Donald and Mary Jane Fowler
in honor of Kimberly Fowler
 Anna Funkhouser
 Tricia and Andy Gates *in honor of Brea Gates*
 Lee and Tammy Gottschall
in memory of Danny Gniadzowski
 Jackie Gull *in honor of Ryan Hunt*
 Mick and Shirley Hagermann
in memory of Tom Hagermann
 Rodney and Donna Hardy *in memory of Adam Hardy*
 David Hoeffert *in honor of Tyler and Ethan Sowden*
 Jennifer Houser *in honor of Cecilia Bien*
 Rose Marie Houser *in honor of Cecilia Bien*
 Connie Howe *in honor of Carter Kanney*
 Bernadette Iannelli
 George and Linda Johnson
in honor of Amanda Crawford
 Sally Jones *in honor of Aiden Carter*
 Heidi Kanealy *in honor of Matthew Allen*
 Rick and Beth Kania *in memory of Allison Kirch*
 Sheri Kee *in honor of Shelby George*
 Ardis and Henry Ketterer *in memory of Peg Ketterer*
 Alan and Kathleen Kimura
 Allen and Mary Jane Koehler
in honor of Joyce Koehler's 80th birthday and
in memory of Ryan Mask
 Louise and Ed Kotron *in honor of the Peters family*
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in honor of Amanda Crawford
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 Clayton and Iva Martin *in memory of Audrey Lawson*
 John and Cynthia McCabe *in honor of Jenny Klein*
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 Judy McKinstry *in honor of Adam Hale*
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Alexandra Browne
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 Paul Miltgen *in memory of Alexander Sobie*
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 Tom Mulkerin *in honor of Austin Mulkerin*
 Raymond and Julia O'Hara
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 Eileen and Larry O'Steen *in memory of Ryan O'Steen*
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in memory of Sally Rowland
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 Anna Spriggs *in honor of Cameron Mollett*
 Jeannie Stover *in honor of Erin Peters*
 Nancy Stringham *in honor of Declan Mitchell*
 Pauline Stukus *in honor of Sarah Mallia*
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 Daren Sweeney
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 James and Bonnie Tully *in memory of Paul Adams*
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 Linda Burt *in honor of Sasha Segal*
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 Jan Conrad
 Cathryn Cavanagh and Peter Coppola
in memory of Gabriela Giannone
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 Dena Dutille *in memory of Blake and Lance Dutille*
 Martin and Ann Elliott *in memory of Marty Elliott Jr.*
 Wilbur and Irene Erhardt *in honor of Matthew Wells*
 Lucille Fernandez *in honor of Karina Guajardo*
 Donna Finnegan
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in memory of Clinton and Zach Szemanski
 Barb Fisher *in memory of Allison Kirch*
 Cynthia Foster *in memory of Edie Burke*
 Paul and Susan Gauthier
in honor of Adam and Benjamin Podesky
 Jill and Elmer Haley *in honor of Sasha Segal*
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 Joann and David Holder
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 Wayne Howser *in memory of Jenny Wingate*
 Mary Hughes *in memory of Kristofer Arnold*
 Michael and Patricia Hydanus
in honor of Erin Peters
 Janet Johnson

Deborah and Donnie King
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Brian Krase

Larry and Jennifer Latham *in honor of Ben Durcholz*

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Bill and Eileen Manthe *in memory of Rebecca Manthe*

Michaelle and Wolfgang Mauch

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James and Eleanor McCaffrey

Madeline and Merritt Moseley

in memory of Edie Burke

Bernadine Nardin *in memory of Daniel Nardin*

Eugene and Elizabeth O'Shea

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Mary Page *in memory of Danny Gniazdowski*

Shirley Pelletier *in memory of Amanda Keith*

Ambrose and Patricia Perreault

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Douglas and Mary Pica

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Tom and Carrie Porzel *in memory of Bobby Alvarado*

Donald and Marie Reising

in honor of Mark and MaryEllen Pendleton

Donna Ricca

George and Carol Rice

in honor of Serrina and Autumn Cooper

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Sally and Charles Roberts

in honor of Dr. Mel Anhalt's birthday

John and Isabella Rodrigues

Joan Seward *in honor of Andrew Eisler*

Joel Bloom and Jody Shapiro

in memory of Maggie and Joe Langford

Larry and Diane Suhr *in honor of Rachel Dodson*

David and Catherine Thurston

in memory of Allison Kirch

John Trainor

Carol Treutlein *in memory of Stephanie DeAngelis*

Thomas Uebelacker *in memory of Brendan Carter*

Michael and Amy White

in honor of Jennifer and Savannah Prince

Rick and Rebecca Wildman

in honor of Matthew Wells

Patrick Wyers *in honor of Shawn Wallace*

Andrew and Louise Zygmuntowicz

in memory of Amanda Keith

Is Your Family Prepared? Do You Have a Will?

Many families are so involved with the care of loved ones suffering from MPS and related diseases, inundated with day-to-day work schedules and tasks, that the last thing on their mind is a will. Many of us fail to plan, put off important decisions and don't talk with a qualified attorney.

Ten important reasons to have a will:

1. Names who will care for your children.
2. Determines how your estate will be distributed.
3. Avoids a lengthy probate process.
4. Designates an executor of your estate.
5. Minimizes estate taxes.
6. Can disinherit individuals who otherwise stand to inherit.
7. Designate gifts and donations in your will.
8. The will is subject to change as your life circumstances change.
9. Important decisions will be expressed by you and not left to others.
10. Finally, because tomorrow is not promised.

Don't wait until you are faced with unforeseen tragedy to prepare your will or living trust. For more information about wills or planned giving, contact Terri Klein at terri@mpssociety.org or call 919.806.0101.

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

Von Handorf Cross-Country Bicycle Trip

Jeff Von Handorf and his brothers decided to take a cross-country bicycle trip during the summer of 2013. As the trip began to take shape, Jeff began to see it as an opportunity to do something he had always wanted to do: raise money for the National MPS Society. Jeff's daughter, Aly, has MPS III and his family had benefited from being members of the Society. Here was a chance to give back. The Von Handorfs organized the fundraiser using Courage Pages, and did some publicity through business cards, e-mails, flyers and newspapers.

Jeff, his two brothers and sister-in-law left Astoria, OR, on June 8 and traveled along the TransAmerica Bike Trail, ending at the finish in Yorktown, VA, on July 31. They surpassed their goal of raising \$5,000 and, even better, raised awareness for families and children suffering from MPS.

"Traveling across the country, we met hundreds of people, and I never passed up a chance to talk about the organization and MPS," said Jeff. "There were times when we didn't know if we could make it, but all the people who contributed provided the incentive to keep pedaling, as well as the thought of all the kids and families who cope with MPS diseases each and every day. What I was doing was easy compared to what MPS families face. I had the greatest time on the bicycle trip and the satisfaction of what we accomplished for the MPS Society made it even more worthwhile and satisfying. Thanks to everybody who supported our efforts."



Jeff Von Handorf and friends.



Alyson Von Handorf (MPS III) and family.

Fundraising Made Simple—the Phantom Event

Fundraising and "friendraising" in our MPS community have seen many exciting variations, from debutant balls to bake sales. It is amazing what wonderful ideas our membership thinks of to support the noble effort to raise money for research and raise awareness for MPS and related diseases. Once you get started, your fundraising project can grow from a little idea to something very special.

Here is a good fundraising idea that is simple and easy: host a "phantom event"! Your contact list can simply be your family, friends and co-workers. This is a clever way of asking for donations in a novel and humorous manner. This event will never actually happen—other than on paper. You send invitations to supporters and potential supporters for a spectacular event with scrumptious food, exciting entertainment and a glamorous guest of honor. The sky's the limit since the event won't actually occur. Let your imagination run wild! Create an event where participants "don't play" the Harlem Globetrotters or Green Bay Packers, or "don't debate" between someone in your organization and the president, a movie star, athlete or other famous person on a silly topic.

Why in the world would you do this? Because it's a good way to raise funds and have some fun at the same time. Your only costs are the printing of the invitations, thank you notes and postage. If you can get some of this donated, that's even better.



Jack Todd raised nearly \$50 for the National MPS Society by selling water at a family garage sale.

Ninth grade students at Prairie Point Academy presented checks to Lew Montgomery in honor of his son Lucas (MPS III). The students hosted a magazine sale and donated a portion of their sales to the National MPS Society.



Pictured from l. to r.: Taylor Fisher, Matt Mims, Annah Waldron, and Lucas (MPS III) and Lew Montgomery.

Courage for Kristofer

The inaugural Courage for Kristofer MPS Bowl was held July 28, 2013, by the Christianson family of Vancouver, WA. They raised more than \$2,000 with 70 people in attendance. The event included an auction and raffle to build the excitement.



Kristofer Christianson (MPS II) with an MPS Bowl participant.

>> Phantom Event, *continued from page 13*

Send the invitations to as many people as you want—overcrowding will not be a problem. In addition to your regular supporters, be sure to include local political leaders, businessmen and media personnel. You should also send press releases to media outlets in your area. They are always looking for humorous current event items.

Include information on how to purchase a ticket. Why would anyone buy a ticket to a non-existent fundraising event? Because there are a lot of very busy people who are willing to support a good cause but don't have the time, energy and/or interest to go to one more rubber-chicken dinner. Purchasing a ticket to a phantom event lets them support a worthy cause while relaxing at home. Plus, they will appreciate your ingenuity.

Make your invitations classy, printed on good quality paper. After all, the invitation is all potential supporters will receive for their ticket purchase. Create it just like an invitation to any formal affair. You can use a standard good quality thank you card. Be sure the invitations and thank you cards are hand addressed to make them more personal. Include a notice with their thank you card that their donation is fully tax deductible.

Lastly, don't forget to be informative about your loved one with MPS when asking for donations from corporations or from those who do not know you well. Give a brief summary about MPS diseases and why your special loved one deserves a cure. Be very specific on what MPS is and that money raised will go to the National MPS Society for a specific program (medical research, family support, etc.) Be humorous. Have fun. Make money!

Let's Get Started.

1. Pick the dream event you feel most comfortable with, such as a phantom run, phantom ball, phantom dinner party or some other humorous event.
2. Pick the date for the event that will give you plenty of time to get organized and distribute invitations.
3. Create a list of family, friends and corporate sponsors who should attend your event.
4. Create the event invitation, letter, brochure or sign-up sheet for distribution.
5. Create the invitation letters. One for family and friends and one for corporate sponsors.
6. Mail out the invitation. It is beneficial to include a stamped return envelope to help make participating in your event very simple. Then wait for the dollars to roll in!
7. After the event date remember it's most important to send out a timely thank you to all who participated.

After having done this several times, Debbie and Ernie Dumann promise it will be a great success in increasing awareness about MPS diseases and raising money. To learn more about their Phantom Run for Sean and to view their Power Point presentation online, log into the Members Only section of the website and click "Fundraising Tools."



The National MPS Society continues to bring innovative fundraising tools to its members by launching Courage Pages. Courage 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 Courage Page can tell your story, share a photo and include your fundraising event and/or the goal amount you are trying to raise. This page can be for fundraising, or in honor or in memory of someone with MPS or related disease. You can share a donor recognition list and include additional links for an upcoming event.

Courage Pages can be viewed at www.mpssociety.org; click on Courage Pages on the right side of the screen. If you would like to take part in this opportunity go to <http://mps.onlineapplications.net>. Once you log in you will be able to submit your Courage Page request.

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, Courage Pages is a great companion tool.

For more information contact Terri Klein at terri@mpssociety.org or call 919.806.0101.

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.

Keep in mind—the Annual 5K Walk/Run and the Annual Fund are great ways to raise money for the National MPS Society.

National MPS Society Receives Three-Star Charity Rating

Having received the prestigious four-star Charity Navigator rating for the last few years, the National MPS Society learned in December 2012 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 enough points to regain the four-star rating.

WAYS TO GIVE AND INSPIRE HOPE IN 2013

- Gifts in honor or 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 will process the gift!
- Courage Pages—*brand new!* Share your family story with your own web page to raise awareness and funds.
- 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).
- Give to 2013 Annual Fund.
- Major gift (usually 10 times that of your Annual Fund gift).
- Planned gift (visit our website and search Planned Giving).
 1. wills or bequests
 2. charitable remainder trust or charitable gift annuity
 3. charitable lead trust
 4. life insurance policy or 401(k) retirement funds
 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 research, family support or legislative programs.

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