

2008 Annual Fund Campaign

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 2009 is \$70,000. Please help us by sending your donation today.

Please accept our sincere thanks to everyone who has already donated to the 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.

Philanthropist

\$1,000 or more

Mel and Millie Anhalt

Wayne Bardsley

Bryson Foundation

Catherine and Doug Coltharp

Ron and Barbara Dengel

Ernie and Debbie Dummann

Dutch's Daughter, Inc.

Tom and Anne Gniazdowski

John and Bonnie Hoegl, in memory of

Bonnie Lynn Hoegl

Kendra and Charles Lesta, in memory of

Christopher Lesta

Robert and Marjorie Lovell, in honor of

Olivia Lovell

Stacey Madison, in honor of Jack Frye

Loy and Susan McKeithen, in honor of

Catherine and Doug Coltharp; Marilyn and John Logan; Phillip, Emily and Allie Green

Joseph and Janice Melnyk, in memory of

Lena Melnyk and in honor of her grandson Nick Melnyk

Mark and Mary Ellen Pendleton

Pennies for Nicoll Foundation

George and Athena Sarantinos

Walter and Elizabeth Smoyer, in honor of

Carolyn Faust

Mick and Louise Ukleja

Klane and Amy White, in memory of

Susannah White

Leader

\$500-\$999

Mary Starr Adams

Frederick and Nancy Andrews

Joseph and Kelley Capone

Rob and Diane Cassil

Cecilton Lions Charities, Inc.

Ralph and Jane Daniels, in honor of

Branden Patterson

Patricia Dickson

Susan and Larry Kirch

Douglas McLeod

John Alexander McRae, in memory of

Joe and Maggie Langford

Rose Family Foundation

Robert and Suzanne Washburn

Volunteer

\$250-\$499

Stuart and Karin Adams

Ruth Bauerle

Richard and Dorothy Bosse

Thomas and Laura Catanzarite

D'Lass Dent Company

Charles and Josephine Ellard

Bart and Sally Finzel

Donald Finzel

Stephen and Kimberly Frye

Lamar Hall

Joel and Lisa Klessens

Glenn Ladd Jr.

Wayne and Paige Lewis, in honor of

Madison Lewis

Roxanne Maffitt and Robert Harvey, in honor of

Davis Barkley

Maria Meconi, in honor of Denise Dengel

Benjamin and Elizabeth Neufeld

One Palos Medical Center

James and Linda Pike

Jeffrey and Shelley Rexroth, in memory of

Mitchell Stump

David and An Tootill

Barbara Wedehase

Tom and Kim Whitecotton

Hubert and Elaine Willman

Friend

\$100–\$249

AG Communications, LLC
 Dean and Kathy Aker
 Stacey and David Aronson
 George and Ellen Aschenbrenner
 Stephen Aselage
 Jane Barker
 Ann Barr
 Mary Catherine Barry
 Jennifer and John Birmingham
 Thomas and Diana Boland
 Joe and Katherine Bonville
 Nancy Burke
 Mark and Stephanie Caldwell
 Donald and Michelle Churchill
 Michael and Margaret Ciacciarelli,
 in memory of Max Ciacciarelli
 Jerrold and Marilyn Cohen
 Claire and Michael Constantine
 Robert and Laura Cowin
 Carlos and Joanie DeAyala
 John and Susan Demchak
 B.H. and Barbara DeVries, in honor
 of Sean and Shaye LaBeth
 Andrew and Rebecca Dopheide
 Denmar and Ellen Dixon
 Carla Ellard
 Pamela Farthing, in honor of
 T.J. Catanzarite
 Gail Finney
 Bonnie and William Finzel
 Rodney and Kathleen Finzel
 Lennie Forkas, in honor of
 Scott Whitecotton
 Donald and Mary Jane Fowler
 Ronald and Sheila Francis
 Roslynn and Timothy Garvin
 Jennifer and Shane Gibson
 Shirley and Vincent Giles
 Jeff and Mary Von Handorf
 Billy and Diane Hardison
 Shelby and Tim Haslett
 Keith Hess
 Steve and Amy Holland
 MR Hopkinson, in memory of
 Mark Bernbaum
 James and Sandra Huff
 Steven and Patricia Irish
 Iron City Constructors
 James and Mary Kalteux
 Henry and Ardis Ketterer
 Kevin and Mary Kimmet
 Fred and Joyce Koehler
 David Lebec
 Mike and Amy Legendre, in honor of
 Holly Legendre
 Ron and Monica Leone
 Katheryn and Hai Leu
 Kay and Joel Levy
 Cheryl and Lloyd LoCascio
 Gene and Cynthia Logan
 Wes and Jill Lovell
 Judith Maas
 George and Barbara Malina,
 in memory of Glen Malina
 Eileen Marchica
 Pamela Eddy and Robert Martineau,
 in memory of Danny Gniazdowski
 Robert and Constance Martineau
 Joseph and Paige Migliozi, in memory
 of Christopher Migliozi
 Bernard and Evelyn Morgan
 Ron and Chris Morrissey, in memory
 of Cade Morrissey
 Rene and Patricia M'Sadoques,
 in memory of Anthony M'Sadoques
 Beth Nolan
 Anne Novak
 P&D Enterprises, Inc., in honor of
 Luke Sarantinos
 Wiley and Elizabeth Peck
 Sharlyn and Thomas Pope, in honor
 of Lauren Pope
 Janet Rafferty
 Sue Rattman, in memory of
 Adam Rattman
 Karen Ratto
 Bernard Ray
 H. Hickman Rowland Jr.
 Sally Rullman
 Sylvester Sanfilippo
 Naureen Sayani
 Calogera Simonaro and
 Edward Schuchman
 Don and Tami Slawson
 James and Sheila Slawson
 Julia Smith, in memory of Scott Day
 Mike and Barbara Smith
 Meghan and Bill Stark
 Susan and Robert Steiner
 Peter and Sarah Storlie, in honor of
 Allison Kirch's birthday
 Paul and Mary Tatsios, in memory of
 Alysse Matus

Michael and Veronica Vacca
 Charles Vite
 Anna and Steven Webersen,
 in memory of Edie Burke
 Tom and Theresa Weisenbach
 Lewis Whitaker Jr., in honor of
 Logan Piefer
 Lynn Ann Witt
 Marybelle Yeazel, in memory of
 Danny Gniazdowski
 B.J. Zambrano

Donor

\$26–\$99

Robert and Caryn Ahern
 Lisa Albitz
 Gerald and Susan Anhalt
 Timothy and Michelle Annis,
 in honor of Stephanie Annis
 Barney and Betty Arceneaux
 Marjorie and Robert Austin
 Deborah Ball
 Alberta and Mark Balliet
 Leonard and Barbara Barcoucky
 Donald and Nina Bergquist
 Michael and Grace Bodura
 David and Stephanie Bowser,
 in honor of Maddie Wigglesworth
 Robert Park and Elizabeth Brinkley
 Tammy Brown
 Sharon Browne
 Thomas and Margaret Browne
 Heidi and Keith Caswell
 Anthony and Donna Cataldi
 Katherine and Terence Cavanaugh
 Steve and Karole Chesser
 Steven and Jennifer Clarke
 Tilford and Dorothy Cobb
 Sharon Cochenour
 Ross and Belia Coddington
 Esther Conrad
 Michael Day, in memory of Scott Day
 Barbara Dodane
 Benjamin and Dianne Doughty
 Jeffrey and Mary Dozbaba
 Irene and Wilbur Erhardt,
 in honor of Matthew Wells
 Geraldine Faucett, in honor of
 Michelle Hopkins
 Neil and Ruthie Forman, in honor of
 Jack Frye
 Maria and Steven Foshay
 Dianne Frazier

Lee and Tammy Gottschall
 John and Lynn Griffin
 Charles and Shirley Hagermann
 Steve and Cynthia Hamblen, in honor
 of Kimberly Fowler
 Donna and Rodney Hardy
 Larry and Barbara Hays
 Robert and Michelle Hess
 William and Elizabeth Hooper,
 in memory of Maggie Langford
 John and Janet, in honor of
 Debbie Kappel
 Sally Johnson
 STAMBG Johnson, in memory of
 Edie Burke
 Patricia Jones
 Paul and Leslie Karas
 Susan Ketchum
 Jennifer Landon
 Linda Levin, in honor of
 Sydnee Jensen
 Edward and Suzette Ludloff
 Joseph and Margaret Maher
 Carol Manning
 Toby and Whitie Martin
 Stephen and Marie McClurg
 Judith McKinstry
 Raymond and Amanda McPartlin
 Walter and Barbara Meserve,
 in memory of Adam Rattman
 Michael and Anita Muonio
 Ann Belser Murphy
 Virginia Nall
 Margaret and Sean Offut, in honor of
 Marcus Garvin
 Jeanne Palzer, in honor of
 Brianna Palzer
 Ronda Paullin
 Teresa Peacock
 Leslie Phillips
 Edmund and Stephanie Rabuse,
 in honor of Raimund Kasner's
 80th birthday and in honor of his
 grandson Paul Adams
 Evelyn Rafferty
 Stella Reeve
 Todd and Judy Rock
 A. Kay Rogers
 Thomas and Carolyn Russo,
 in memory of Stephanie DeAngelis
 Donald and Carol Scott

William and Alberta Stanley
 Mark and Kathleen Stone,
 in memory of Jill Rennaker
 William and Margaret Sly
 Noel and Nancy Talcott,
 in memory of Natalie Talcott
 Juanita Todd
 Ruth and Matthew Travis
 Bernard and Donna Vogler
 Shirlee and Ronald Ward
 David and Joan Wenger
 Joan Werner, in memory of
 Mark Bernbaum
 J.M. and E.R. Williams
 Andrew and Louise Zygmuntowicz

Patron

\$5-\$25

Frank and Nancy Aiello
 Auguste Areizaga
 Wade Baise
 Valerie Barnett
 Rose and Dominic Bencivenga,
 in memory of Stephanie DeAngelis
 Todd and Nicole Blancheri
 Kevin and Kim Burke
 Helen and James Carr
 John and Barbara Casino
 Kent and Karlene Classen
 Stephanie and Joseph Duffy
 Joseph and Ruby Efird, in honor of
 Lindsey Efird
 Ann and Martin Elliott
 Brian Engel
 Peter and Elena Fairchild
 Benjamin and Pamela Feldman,
 in honor of Amy and Davis Barkley
 Lois Finney, in memory of
 Clinton and Zachary Szemanski
 Barbara Fisher
 Nancy and William Fountos
 Susan Gilbert and Nic McPhee
 Freda Goodyk
 James and Toni Graham
 Michael and Susie Hamilton
 Walter and Judi Hauck
 Roy and Goldie Hedrick
 Susan and Scott Hoffmann,
 in honor of Allison Kirch
 Herbert Kirch
 Brian and Kristine Klenke

Victor and Pamela Kovach
 Carol and Thomas Kuhn
 Patricia Langin
 Darren and Patty Latham
 Kasey and Ted McCannon
 Merritt and Madeline Moseley
 Caroline Masur, in honor of Mel,
 Millie and Connor Anhalt
 Bernadine Nardine
 Trish and Michael Offenbacher
 Eugene and Elizabeth O'Shea
 Eileen and Lawrence O'Steen
 Mary Page
 James and Jenifer Pappasergi
 Linda Parsons, in memory of
 Scott Day
 Thomas and Stacy Peters
 Donald and Janey Schmidt
 Douglas and Lauren Sanford
 Richard and Ellen Sidman
 Allen and Jackie Theriot
 Earl and Elinor Tracey
 Eric and Laurie Turner
 Jean Jacobsen and
 Richard Underwood
 F.L. and M.A. Wick, in honor of
 Clay Howard
 Richard and Rebecca Wildman
 William and Frances Woody
 D.H. Young, in memory of
 Maggie Langford
 Robyn and Paul Young
 David Zimmerman

The Fundraising Committee would like to thank all those who conducted a fundraiser this year. Equally important are all the other ways people give to the Society, including the Annual Fund, and gifts in honor of and in memory of special people in our lives. The Fundraising Committee and the entire board of directors can never thank you enough. Please support these efforts by attending an event in your area or hosting your own event. The work and mission of the Society are totally dependent on the generosity of our members, families, friends, scientists and companies. It takes all of us to make the difference in the lives of family and friends.

Family Fundraisers

In 2008 there were 17 events for a total raised of \$168,000. The committee truly appreciates the efforts of these families. The proceeds from these events may be designated toward research, the Society's Family Assistance Program or to support general operation of the Society. There are all sorts of ideas for fundraisers, such as bowl-a-thons, golf outings, walks, Pampered Chef events, and even dancing with the bride to benefit the National MPS Society. If you are interested in doing any type of fundraiser, the Society has a "how-to" guide to help you, or you can contact any of the great folks listed here for their advice, support and enthusiasm!

- **Jill and Christopher Valdez:** Lukie's Legacy— A Walk for A Cure, second year
- **Stacey and Lew Montgomery:** Links for Lucas golf tournament
- **Andrea Longston:** Pampered Chef fundraiser
- **Rachel Wojnarowski:** Piano recital
- **Kris Klenke:** bowl-a-thon
- **Trisha and Robb Jensen:** family fundraiser
- **Carlton Hardy:** weight loss challenge
- **Kathy Cavanaugh:** Great Escape ticket sales
- **Patricia Latham:** Kool-aid stand
- **Tom Weisenbach:** Megan's Mulligans golf fundraiser
- **Steve Chesser:** Friends Helping Friends
- **Cindy Clarke:** golf tournament
- **Dan and Jenna Freeman:** dollar a dance with the bride
- **Pam Faust:** fundraiser in honor of Carolyn Faust
- **Katie Hedrick:** Hedrick marathon
- **Matthew Allen:** Matthew Allen fundraiser
- **Lori Podesky and Dawn Checralah:** Pampered Chef fundraiser

Walk/Runs

In 2008 there were 18 walk/run events that raised a total of \$310,000. These are very time-consuming yet inspirational events, so please support the efforts of your hard-working members. This is the ninth year the Society has sponsored the walk/runs and they are critical for funding the Society's research program. Listed below are last year's events and the main contact persons, but we know there are many others who equally contribute to the success of each event. Thank you all for your hard work!

- **Kathie Ward:** BioMarin/MPS 5K Run/Walk
- **Sharon Cochenour and Barbara Pryor:** Andrew's Walk and Roll for MPS
- **Mark Lessing:** Post Office Café 17th Annual 5K Run/1K Fun Run for MPS
- **Laura Hiler:** Evan Reed Family Fun Run
- **Tami Slawson:** MPS Walk & Run LA
- **Linda Shine:** 5K for Katie/Do it for Danny
- **Jennifer and Steven Clarke:** Mackenzie's 5K Run/Walk for MPS
- **Dorothy Mask:** Ryan's Run
- **Scott Hardin and Steve Holland:** MPS Run for Their Lives
- **Stacy Peters:** 9th Annual Run for Erin
- **Alyssa Hajek-Jones/Emmy Houge (Iowa State):** The Heartland Run for MPS
- **Stacey Pevler:** Teagan's Run for MPS
- **Laurel Radius:** Miles for MPS
- **Kristen Myking:** MPS and Mito Walk/Run 2008
- **Dara Persson:** Jack's Run for MPS
- **Stacey and Lew Montgomery:** Laps for Lucas
- **Josh and Sheri Sowden:** Sowden Family & Friends Walk for a Cure
- **Marie and Jonathan Hunt:** River Run for Ryan

continued

Fundraising Committee:

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

Annual Fund

The Society's Annual Fund is in its seventh year. Thanks to your efforts, \$69,000 was raised for the Society. Though we did not do as well as in previous years, we have high hopes for 2009. The Annual Fund is a significant source of funds for our general operating expenses, Family Assistance Program and Legislative efforts. While we know that everyone can't do a walk/run or family fundraiser, we know that everyone can contribute what they can afford to the Annual Fund.

If we all help a little, it will help a lot! Please do your part as members to help the mission of finding cures and treatments for MPS and related diseases, and in supporting families dealing with an MPS or related disease.

Thank you to all who contribute to the work of the National MPS Society!

As part of the Fundamentals of Speech class requirements at the University of Wisconsin-Oshkosh, students must give a persuasive speech. This semester, students did a group speech where they had to persuade their classmates to give a class donation to their selected charity. Students were required to research their charity and analyze their audience (classmates). Their speech had to explain what the problem is that the charity is trying to solve, present the ways the charity is trying to resolve the problem, help the audience understand how they will benefit from donating to that charity, and appeal to donate money. After a final vote, the National MPS Society was selected in honor of Luke Valdez (MPS III).

Each student donated \$3 to \$5; a total of \$81 was raised for the National MPS Society.

"Although our donation may be small, we know that every little bit helps. We all wish you continued success with your efforts to realize your mission and goals," said Susan Kirkham, Department of Communication, University of Wisconsin-Oshkosh.

Inspired by his middle school teacher, Sharon Browne, whose two children have MPS III, Jonathan Formica developed a film about the teacher while in high school.

Jonathan recently showed the film at a fundraising event, to a sold-out crowd at Chapman University's 480-seat Folino Theatre in Orange, CA. The event raised more than \$9,000, 100 percent of which will go directly to the National MPS Society to support research for a cure and support for MPS families.

"I hope this is just the beginning," said Jonathan. "I want to thank everyone for their continued support and guidance. Thanks to Sharon Browne for her strength and 'rocker' personality. She is the true reason behind this event. May the courage continue!"

The Orange County Register ran a story about Sharon and Jonathan, which can be found at www.ocregister.com/articles/sharon-jonathan-says-2275648-know-one.

Jonathan is exploring the possibility of making his film available on DVD.

Ways to GIVE

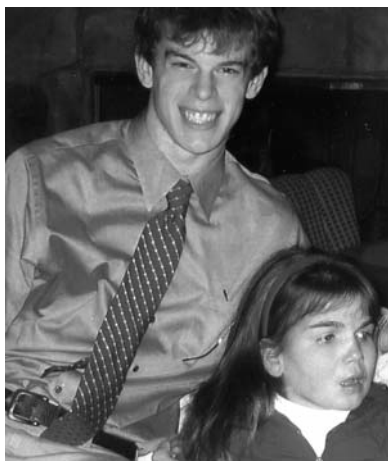
- Renew your membership or sponsor another family
- Gifts in honor of a special person
- Gifts in memory of a special person
- Gifts of cash or marketable securities
- Matching gifts through your employer (check with your human resource office)
 - Request a matching gift form from your employer
 - Complete the employee section of the form
 - Mail to the Society and we'll do the rest
- Contribute through the Combined Federal Campaign if you are employed by the federal government
- 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.
- Annual Fund donation
- Major gift (usually 10 times that of your Annual Fund gift)
- Planned gift
 - Bequest in your will
 - Charitable remainder trust or charitable gift annuity
 - Charitable lead trust
 - Life insurance policy
 - 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: info@mpssociety.org or 877.MPS.1001

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.



Brian Harrell and Kimberly Fowler (MPS III)

Ohio's Bay High School Youth Philanthropy Fellowship (YPF) raised \$1,500 for the National MPS Society during its Halloween dance. The donation is in honor YPF member Brian Harrell's cousin, Kimberly Fowler, who has MPS III. YPF is a group of enthusiastic, energetic students at Bay High School, who symbolize selflessness, altruism and a sincere caring for the human condition.

Include the National MPS Society in Your Estate Planning or Will

It doesn't take much to leave a legacy for future generations. Just ask your financial or legal advisor to help you plan a gift for the National MPS Society.

Whether it's \$50 or \$50,000,000, no planned gift is too small (or too big!) to make a difference.

For more information, contact the Society office at 877.MPS.1001 or info@mpssociety.org.

After reading about all of the great events other MPS families have done, the Weisenbach family (Tom, Theresa, Kayla, Abbey and Megan) decided to create an event and promote awareness of MPS.

Their first effort was tied to International MPS Awareness Day in May. A family friend, Greg Beck, owns an Indy car team and was attempting to qualify for the Indianapolis 500. Greg offered to put MPS Society decals on his car to help promote International MPS Awareness Day. The staff of the Indianapolis Motor Speedway distributed a press release to more than 200 national and local media. The Weisenbach's were interviewed on the public address system that was shown on 13 jumbo video screens and on the televisions of 126 corporate suites at the racetrack.

The Weisenbach's second event, Megan's Mulligans, was held on July 19 at the Links Golf Course in New Palestine, IN. With 100 golfers, 36 hole sponsors and great auction items, the family was able to raise more than \$15,000 for the National MPS Society and Megan's special medical account, which friends set up with Helping Hands Ministries, Inc. The Weisenbachs thank Bernie Vogler, an MPS Society member from Jasper, IN, for his help in making the outing a huge success, Ernie Dummann for his support, and Larry Kirch for great guidance.

The Weisenbachs have big plans for 2009: Beck Motorsports and Team 3G will once again run the MPS Society decals during May as they prepare for the Indy 500 at the speedway, and their golf outing is growing to a two-day event. In addition, the Weisenbachs will host a "family" reunion on July 17 that will include immediate family, their MPS family and all of their friends who have been so supportive of Megan and their battle against MPS. The event will include a professional comedian and a local band. The golf outing will follow on July 18 at the Links again. Their goal is to raise more than \$25,000 for the National MPS Society in 2009.



Weisenbach family
Photo courtesy of the Indianapolis Motor Speedway

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 Laurie Turner at laurie@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.