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.

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**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

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
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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
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**Leader**

$500–$999
Mary Starr Adams
Frederick and Nancy Andrews
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Cecilton Lions Charities, Inc.
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  in memory of Max Ciacciarelli
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  of Sean and Shaye LaBeth
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Denmar and Ellen Dixon
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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
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Jeff and Mary Von Handorf
Billy and Diane Hardison
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  Mark Bernbaum
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Mike and Amy Legendre, in honor of
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Ron and Monica Leone
Katheryn and Hai Leu
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Gene and Cynthia Logan
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Judith Maas
George and Barbara Malina,
  in memory of Glen Malina
Eileen Marchica
Pamela Eddy and Robert Martinez,
  in memory of Danny Gniazdowski
Robert and Constance Martinez
Joseph and Paige Migliozzi, in memory
  of Christopher Migliozzi
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
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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
  Alyssé Matus
Michael and Veronica Vaccar
Charles Vite
Anna and Steven Webersen,
  in memory of Edie Burke
Tom and Theresa Weisenbach
Lewis Whitaker Jr., in honor of
  Logan Pieler
Lynn Ann Witt
Marybelle Yeazel, in memory of
  Danny Gniazdowski
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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
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Donald and Nina Bergquist
Michael and Grace Bodura
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Tammy Brown
Sharon Browne
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Steve and Karole Chesser
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Esther Conrad
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Jeffrey and Mary Dozbaba
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  in honor of Matthew Wells
Geraldine Faucett, in honor of
  Michelle Hopkins
Neil and Ruthie Forman, in honor of
  Jack Frye
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Lee and Tammy Gottschall
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Donna and Rodney Hardy
Larry and Barbara Hays
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William and Elizabeth Hooper, in memory of Maggie Langford
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Sally Johnson
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Margaret and Sean Offut, in honor of Marcus Garvin
Jeanne Palzer, in honor of Brianna Palzer
Ronda Paullin
Teresa Peecock
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
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Thomas and Carolyn Russo, in memory of Stephanie DeAngelis
Donald and Carol Scott
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$5–$25
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Bernadine Nardine
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Douglas and Lauren Sanford
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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

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

- 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 Checrallah: Pampered Chef fundraiser

- Jill and Christopher Valdez: Lukie’s Legacy—A Walk for A Cure, second year
- Stacey and Lew Montgomery: Links for Lucas golf tournament
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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.

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.

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Contact: info@mpssociety.org or 877.MPS.1001
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.

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.