

fundraising news

Text to GIVE – CUREMPS

The National MPS Society has launched a new tool for fundraising through Mobile Causes. It is easy and the awareness and funds raised will be tremendous!

Text CUREMPS to 80888 on your mobile phone and you will automatically donate \$10 to the National MPS Society.

Text to Give is our mobile giving tool that will give the Society \$10 for each text. Text to Give donations are billed directly to cell phone bills of each unique donor.



This powerful fundraising tool is designed to help with fundraising campaigns, for individual convenience and for social media outreach. A corresponding iPhone application also is available. Help us spread the word and let us win in the fight against MPS and related diseases.

For more information contact Terri Klein, development director, at 919.806.0101 or terri@mpssociety.org.

4th Annual Sponsor A Child For A Cure 2012 – Don't Get Left Behind!

If your family has wanted to participate in a walk/run event to raise money for research but aren't able to attend an event, we have created that opportunity. Sponsor A Child For A Cure reaches out to families and members of the Society who want to sponsor an affected loved one or an angel and help find cures for MPS and related diseases.

Walk/runs across the country will be participating in this program. Event coordinators are ready for your calls.

WAYS TO GIVE

- Renew your membership or sponsor another family
- Gifts in honor of a special person
- Gifts 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'll do the rest
- 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)
- Annual Fund donation
- Major gift (usually 10 times that of your Annual Fund gift)
- Planned gift
 1. Bequest in your will
 2. Charitable remainder trust or charitable gift annuity
 3. Charitable lead trust
 4. Life insurance policy
 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 designated programs.

CONTACT: terri@mpssociety.org or 877.MPS.1001

continued >>

Fundraising Committee:

Ernie Dummann
 Anne Gniazdowski
 Tom Gniazdowski
 Steve Holland
 Larry Kirch
 Terri Klein
 Austin Noll
 MaryEllen Pendleton, *chair*
 Kelly Rose
 Lisa Todd
 Laurie Turner
 Barbara Wedehase

>> All you need to do is:

- submit a photo of your loved one to the race you wish to participate
- include the name of your child and address
- get sponsorship and send donations to the National MPS Society

In turn, the event will:

- assign a runner to participate on behalf of your loved one
- send you a courage medallion and photo with your assigned participant
- publish your participation and the money raised in an upcoming issue of *Courage*

Sponsor A Child For A Cure has raised more than \$35,000 in the last three years. We are very excited to have your family be part of the team. Contact Angela Guajardo for more information at angela@mpssociety.org or 919.806.0101.

Dancing to Find a Cure



Dominic (MPS II), Freddy, Jeanette and Jasmine Henriquez



Dominic Henriquez (MPS II)

On March 24, 2012, my family and I hosted a family-friendly event, Dancing with Dominic in Fairfax, VA. I was diagnosed with MPS II in October 2011. I love music and dancing so within just days of my diagnosis, my mommy, Jeanette Espinola, thought of the idea of a dinner/dance event to help raise awareness.

Dancing with Dominic started off as a small event. However, the response from the community was amazing and the event size grew. A local musician who plays monthly at my day care donated a kid's concert and the Kenah Shriner's Klown Unit donated the clowns. My sister, Jasmine, is a Girl Scout and several Girl Scout troops in the area volunteered to help with decorations, face painting and arts/crafts. Little by little donations started coming in. Two of my most memorable donations were from a bake sale that my mommy's co-workers held that raised \$270.65, and a lemonade stand operated by a 12-year old boy that raised about \$20.

Thanks to all the community support, Dancing with Dominic was a huge success and included many fun activities such as raffles, clowns, face painting, arts and crafts, a kid's concert, and of course music and dancing. I had lots of fun dancing and also had a chance to show off my DJing skills! For more event pictures and videos of me (aka DJ Monchy), please visit www.dancingwithdominic.webs.com.

About 150 people attended the event, including MPS families from Virginia, Maryland and Pennsylvania. The event raised about \$15,000 for the Society for MPS research, and for family support programs. Stay tuned for information about Dancing with Dominic 2013!

Dominic Henriquez (MPS II, age 2)

Jumping In

Getting involved with the MPS Society's board of directors

When my son Jack was diagnosed in July 2011 with MPS II, I was grateful to have the opportunity to attend the annual conference in St. Louis within a few weeks. Everything was new and overwhelming and the last thing I was thinking about was joining the MPS Society's board of directors. At the conference, I attended the annual meeting and I learned more about the inner workings of the Society. What was clear to me was that being a board member was a priceless opportunity. As a new MPS parent, I was eager to dive right in and help in any way possible. I felt that up to the point of my son's diagnosis, all of my professional and community service experiences was God's way of preparing me for doing something that meant more to me than anything—fighting for my son's life. So, I decided to run for the board.

My board term began in January 2012 and I currently am a member of the Fundraising Committee. The reality of non-profit organizations is that resources must be obtained to achieve the mission of the organization and the Society is no different. Being a part of the Fundraising Committee, which directly facilitates that process, is very exciting and empowering for me. Our board and committee meetings provide firsthand knowledge of the front battle lines and inner workings of the Society to help achieve our mission of supporting families and individuals affected by MPS and related diseases and funding research for treatments and cures. Having this knowledge makes me a better mother and caregiver to my son, and also allows me to share that knowledge and insight with other families in the MPS community. The board also provides a special comradery amongst a group of people who really understand the day-to-day struggles we all face with MPS in our lives.

One of the things we all know about MPS and related diseases is that there are a lot of things out of our control. For me, being a part of the board allows me to give back in a way that I can control and to assist in continuing our march forward and fight for a cure.

Lisa Todd (parent of Jack Todd, MPS II, age 9)

National MPS Society Earns 4-Star Rating

The National MPS Society has received four out of a possible four stars from Charity Navigator, America's premier charity evaluator. The four-star rating indicates that the Society adheres to good governance and other best practices that minimize the chance of unethical activities and consistently executes its mission in a fiscally responsible way. Approximately one quarter of the charities evaluated by Charity Navigator have received the four-star, or highest rating, indicating that the National MPS Society outperforms most other charities in America. This exceptional designation differentiates the Society from its peers and demonstrates to the public it is worthy of their trust.



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 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.

CORRECTIONS

The following generous donors were missed in our 2011 Annual Fund publication list in the spring issue of *Courage*.

Thank you to the following donors:

Stephanie and Austin Bozarth,

Philanthropist

Elizabeth Karas, *Leader*

Gary and Carol Moss, *Donor*

Austin and Cheryl Noll, *Philanthropist*

Joel Bloom and Jody Shapiro,

Patron

Kim and Tom Whitecotton,

Philanthropist

Corrected Giving Category:

Mike, Lisa, Maria, Molly, Sarah,

Johnny and Gracie Day, *Friend*

Tara and Jack Elston, *Volunteer*

Janet Forde, *Volunteer*

Jack and Lynn Griffin, *Friend*

Brian and Kristine Klenke, *Friend*

Ralph and Bonnie Rennaker, *Friend*

Ellis and Jeanette Taylor, *Friend*

donations

in memory of...

Earl Adams Jr. in memory of his grandson Mitchell Stump

Frank and Mathilde Bachman
Kathleen Brandt
Norma Lewis
James and Hildegard McGeehan
Joseph and Patricia McGuriman
Jim and Lynn Shebesta
Betty Skipper
Thomas and Barbara Symons
Dirk Vandersteen
Vera Veil
Delores Volz
John and Margaret Volz
William Volz

Kristofer Arnold's 30th birthday

Bill and Marge Hughes*
Tony and Sherrie Roman

Carter Brotherton

Jeffrey Hunter

Eddie Burke

Doug and Kirsten Laraby*

Owen Caldwell in memory of his grandson Drew Wanstall

Marguerite Caldwell
Barbara Jacoby

Matthew Caldwell on his 18th birthday

Marjorie Austin

Brendan Carter

Pat and Laura Jackson

John McGhee Cowin

Ron and Beckie Adams*
Mr. and Mrs. Thomas Adams Jr.
Ashley Banks
Thomas and Mary Elizabeth Hoyt
Stephanie Landau
Deborah Luthy
Michael and Jo Alice Mospan
Ryan Ortiz and Capital One's
Southeast Commercial Banking
Rainbow Committee of Milton United
Methodist Church
Mary Bess Simmons
Charlie and Rosie Waters
Dr. Keith and Debby Waters
Dr. Marshall and Emilie Waters, III
Durand Wayland
Rev. George and Joyce Wheatley Jr.

Norman Dorsey

Foster and Mary Ann Wick

Petey Feibelman on his birthday

Phyllis Feibelman

Gabriella Giannone

Christy Little

James Healy in memory of his son Scott Healy

Catherine Bromberek
Irene Clark
Mike, Annette and Rick DuPlanty
James and Jackie Gloyd
Tommy and Marianne Healy
Nanny and G. Tom Maher
Thomas C. and Nancy Maher
Robert McCormick Foundation
Jeffrey and Katrina Shebesta
Jean Willard

Andrea Johnson in honor of her nephews Wynn and Dorian Johnson

Shedera Bausch
Sylvia Bevilacqua
Big Red Basketball
Elsie Connelly
Goodwill Industries of SE Nebraska
Steve and Mary Jo Graphenteen
Stephanie Kinser
Vicki Marker
Afiya McLaughlin-Johnson
Ken and Linda Nicholson
Kiley Roelfs
Chris and Jason Sand
Caitie Schrotberger
Charles and Connie Stevens

Loyde Kiker in honor of his granddaughter Lindsey Efird

Kate O'Loughlin
Stephen and Patricia Sasser
Storm Technologies

Mary Kirch in honor of her granddaughter Allison Kirch

Lorraine Baron
Rick Baron
Karen Beckley
John and Jane Benedict
Robert and Susan Byers
Marjorie Carpenter
Robert and Elizabeth Clarke
Ruth Clarke
Harold and Joyce Cohen
James Doyle and Mary Coldsmith
Randal and Mary Coldsmith

Jean Delmonico
Rose Delmonico
Liana Escott
Johnnie and Katherine Hartgraves
Noreen Howlett
Pamela Jackson
Susan Kaufman
Catherine Kelleher
Brian, Kris and Chelsey Klenke
Theresa Kronebusch
Charolotte Kurland
Eugene and Bette Laatsch
Annette Larson
Ron and Kathleen Leishman
Eduardo and Anita Luera
Kristin Mateja
Carri Mitrick
Carolyn O'Malley
Jean O'Malley
Tim and Nancy O'Malley
Jeffrey and Mary Orlando
Chris and Beth Pattock
Robert and Josephine Pauli
Donald and Marie Reising
Richard Robbins
The Sarra family
Mike Schleter, Terri and Jennifer Klein
Baker Shelton
Mary Stevens
Joseph and Judy Vietri
Brian and Julie Vietri

Thomas Koss

Anne Marie and Bob Siudzinski

Mark Lessing Jr.

Katie Herbst

Lee Matthews

Lori Spinney-Flagg and John Flagg
David Hooper
Melissa King
Maria Leone
Milne and Janice Matthews
Lisa McCarthy
Brian Nowicki
Michael and Cheryl Sciaraffa
Elinor Twomey

Judge Howard Mays Jr. in honor of his great-granddaughter Annabelle Bozarth

Robert and Marsha Bozarth

Cade Morrissey

Nicole Morrissey

Andrea Priest

Cynthia Anhalt

Irving Schatzberg

John and Bonnie Hoegl

John Schmake's father

Cynthia Anhalt

Katie Shine

Frank and Nancy Aiello*

Clint and Zach Szemanski in honor of all those working toward a treatment

Tracy Szemanski

Hannah Taulton

Michael and Laurie Dorsey
Susan Flaherty
Jerry and Sheryl Hall
Dennis and Teresa Shafer
Scott and Suzanne Stauffer*
Robby, Anita and Sam Taulton

Hobby Vanzandt

Mr. and Mrs. Jerry Deutser

Eleanor Walker in memory of Steve Walker, and Nicholas and Matthew McNally

Phil Brown family

in honor of...

Conner Anhalt

Mr. and Mrs. Jerry Deutser

Millie Anhalt

Joe and Nina Brown
Barry and Barbara Lewis*
Sally Roberts

Millie Anhalt's birthday

Barbara Eaker
Gerry and Jay Karkowsky*
Saranne Kosberg

Mel and Millie Anhalt

Schlesinger Family Philanthropic Fund
of the Jewish Communal Fund

Aidan Carter

Julie Held

Sam Caswell

Keith and Heidi Caswell*

Alexandra Collins

Rachel Braukman

Jerry Deutser's birthday

Marvin and Joan Kaplan
Susie Miller
Dede and Connie Weil
Melvyn and Cyvia Wolff

Sue Deutser

Mr. and Mrs. Richard Pulaski

Jill Ditto

Cynthia Anhalt

Allie Ehlinger's birthday in honor of Jack Frye

Rachel Lowe

Braden Farrell

Beryle Ramsey

continued >>

- >> **Jack Fowler**
Janice Peterson
- Kimberly Fowler**
Steve and Cynthia Hamblen
- Kimberly Glover**
Cynthia Anhalt
- Karina Guajardo's 20th birthday**
Veronica Cortez
Antonietta Ellard
Carla Ellard
Lucille and Kathie Fernandez
Luis and Angela Guajardo
- Olivia Guidry**
Amy Richardson
- Lucas Hembree**
Joe and Nina Curcio
- Ford Inglis**
Darla Elswick*
- Sydnee Jensen**
Linda Cohen
- Jennifer Klein**
Mike Schleiter and Terri Klein
- Michael Lewandowski**
Sarah Varro
- Olivia Lovell**
Marjorie Lovell*
- Mr. and Mrs. James Maffitt**
Amy Barkley
- Clayton Martin**
Hershel and Judy, Kaye, Josh
and Joy Gilliland
- Dustin Matz**
LeeAnn Adams
- Danny Miller**
Dawn Morrison
Douglas and Anita Richmond
- Matthew Montano**
Amber Snow
- Austin Nace**
Mr. and Mrs. E. Paul Kurst
- Andre Neveu**
Faculty Senate of James Madison
University
- Reese O'Connell's birthday
in honor of Jack Frye**
Rachel Lowe
- Grady Savage's birthday
in honor of Jack Frye**
Rachel Lowe

- Brittany Sheaffer**
Jeff and Libby Aiken
- Brynlee Thompson**
Donald and Julie Ames
Michael Ames
Robert and Joanne Ames
Ronald and Nancy Rossi
- John T. Thornton**
Mark and Cindy Prosciak
- Carley Trocheck**
Vickie McFarlan
- Megan Weisenbach**
Mr. and Mrs. Richard Madden
- Scotty Whitecotton**
Lennie Forkas*
Frank and Jane Middleton
- Christian Yard**
Employees of Schneider Downs
Pittsburgh Internal Audit Team

fundraisers

- Dancing with Dominic**
hosted by Jeanette Espinola in
honor of Dominic Henriquez
- Ernst and Young Jeans Day**
in honor of Alexandra Collins
- Post Office Café Case Race**
in honor of the Lessing family
- Trivia Night for Noah Mehling**
held by Hamilton County
Firefighters Local 4416

matching gifts

- Alliant Energy Foundation, Inc.
Allstate Giving Campaign
Arch Capital Services
Hewlett-Packard
IBM Employee Charitable
Contribution Campaign
McGraw-Hill Companies
Progress Energy Foundation

donations

- Sarah Aaserude and Todd Waddell
Bill and Cathy Abernathy
Stuart and Karin Adams
Mary Starr Adams
Dr. Mel and Millie Anhalt
Randy and Cynthia Anhalt*
Tim and Mikki Annis
Anonymous
Robert and Marjorie Austin
Paula Baker Bryan

NEW MEMBERS

- Brook Benefield**
Moss Point, MS, adult with MPS IV
- Ronald Brown**
Kearney, MO, father of Isaiah and
Christian Brown, MPS III A
- Brittany Clubbs**
Harpersville, NY, mother of
Hunter and Kingston Clubbs, MPS II
- Mary and Jimmy Dushane**
Fairland, OK, parents of
Peyton Dushane, MPS I
- Lori Fresina**
Wilmington, MA, friend
- Andrew and Stephanie Glock**
Williston, VT, parents of
Travis Glock, MPS I
- Pam Gross**
Sammamish, WA, mother of
Courtney Gross, MPS IV
- Colleen and Shane Hood**
Caro, MI, parents of Lauren Hood,
MPS I
- Sachin Kamble**
Irving, TX, parent of Sarvjeet Sachin
Kamble, MPS III A
- Attila Lajko**
Washington, DC, aunt of
Peter Lajko, MPS IV
- Charles Litchfield**
Bonneau, SC, father of
Madison Litchfield, MPS IV B
- Ruth Major**
Maumee, OH, mother of
Aric Daniel Major, MPS II
- Jamie McGuinniss**
Bronx, NY, parent of
Michael McGuinniss, MPS I
- Sucely Miranda**
Brooklyn, NY, parent of
Wiliam Zaldana Miranda, MPS I
- Nicolette Moinet**
Raleigh, NC, friend of Megan Dean,
MPS I
- Jim Monaco**
Elmwood Park, NJ, cousin of
Jason and Justin Leider, MPS II
- Isabel Morales**
Bloomington, CA, mother of
Ileany Ramos, MPS III
- Carmen Mosley**
Monroeville, PA, mother of
Andrue Mosley, MPS I
- Morgan Motsinger**
Tillamook, OR, mother of Annika Rose
Motsinger, MPS III
- Regina Osterhoudt**
Billings, MO, grandmother of
Reiley Osterhoudt, MPS II
- Deb Purcell**
North Vancouver, BC, mother of
Trey Purcell, MPS II
- Mike Schneider**
Halethorpe, MD, adult with MPS II
- Amber Snow**
Salt Lake City, UT, mother of
Matthew Jay Montano, MPS II
- Marcy Squires**
Phoenix, AZ, mother of Jason
Lawrence Byrum, MPS I
- Ken and Courtney Walker**
Woodland, WA, parents of
Trinity Walker, MPS III A
- Trenace Walker**
Pompano Beach, FL, mother of
Tyler Walker, MPS I
- Jodi Westerlund**
Naches, WA, adult with MPS VI
- Cindy Wiley**
Lula, GA, mother of Andrew Wyatt
Oliver, MPS I

continued >>

>> Wayne and Catherine Bardsley
 Dwight and Debbie Barkley
 Cynthia Barry*
 Jason and Amy Blair
 Mike and Grace Bodura
 Joe and Katherine Bonville
 Marie Bonville
 Daniel and Debra Brockman
 Jay and Judie Brooks
 Sharon Browne
 William Brubaker
 Bryson Foundation
 Nancy Bucher
 Mark and Stephanie Caldwell
 Rob and Diane Cassil
 Camille Chaires
 Michael, Margaret and
 Grace Ciacciarelli
 Rebecca Clarke
 Kent and Karlene Classen
 Stephen and Denise Clayton
 Leo and Janet Cook
 Billi and Jeremy Crockett
 Bart Barner and Patricia Cuddihee*
 Dr. Robert Desnick
 William and Bonnie Doster
 Jack and Tara Elston
 Josh Nall and family

Steven and Maria Foshay
 Jason and Jamie Fowler
 Steve and Betsy Fowler
 Atul and Surabhi Garg
 Richard and Ronni Gates
 Dennis and Chris Goggins
 Julia Gossett
 Charles and Shirley Hagermann
 Gerald and Sheryl Hall
 Mark Haskins
 Walt and Judi Hauck
 Mark and Darlene Hesprich
 Jacqueline Holt
 Todd and Jennifer Howard
 W. Andrew and Lauran Jack
 Earl and Doris Klenke
 Fred and Joyce Koehler
 John and Joyce Lane
 Robert and Katie Lawson
 Judith Leger
 Jeff and Deena Leider
 Monica Leone
 Hai and Kathryn Lieu
 Jamie and Jennifer Lipscomb
 Cynthia Logan*
 Barbara Lyons
 Dorothy Mask
 Michael McAtee

Patricia McCann
 Judith McKinstry
 Bill and Karen McNeil
 Monsanto Fund
 Theresa Morris
 Jim and Paula Moskal
 Mark and Tina Mulder
 Michael and Anita Muonio
 Austin and Dorothy Noll
 Bruce and Jeanne Palzer
 Thomas and Vickie Patterson
 Mark and MaryEllen Pendleton
 Beth Pletcher, MD
 RA Bryan Foundation*
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 Katheryn Ruthruff
 Karlen Sanberg
 John and Sue Scott*
 Mike and Barbara Smith
 Joseph Smith
 Mr. & Mrs. William Stark Jr.*
 Tracy Szemanski
 Hal and Laura Thorsrud
 Jon and Ellie Totz

Michael and Veronica Vacca
 Sent and Mary Visser
 Charles Vite*
 Marie Wegener
 Tom and Theresa Weisenbach
 Claude and Roselyn Wells
 Roy and Zezee Zeighami

*Annual Fund donor

NATIONAL MPS SOCIETY MEMBERSHIP FORM

YOUR NAME _____

AFFECTED INDIVIDUAL'S NAME _____

DATE OF BIRTH _____

DIAGNOSIS _____

RELATIONSHIP _____

ADDRESS _____

CITY / STATE / ZIP _____

PHONE _____

E-MAIL _____

\$50 Family

\$80 Foreign

\$75 Professionals

Corporate Memberships Available

Would you like your name to appear in our online directory? Yes No

Would you like to receive *Courage*, the Society's newsletter? Yes No

Would you like our publications in

electronic (e-mailed) format **or**

hardcopy (mailed) format

Please send your membership form and check to:

National MPS Society / PO Box 14686 / Durham, NC 27709-4686

Join or renew your membership online at www.mpsociety.org/become-a-member.

LETTER FROM THE **DEVELOPMENT DIRECTOR**

FUNDRAISING IS IN FULL SWING FOR 2012! We are gearing up for the family conference in Boston, and the Fundraising Committee has been preparing presentations to help fundraising hosts utilize technology to make the most of their events.

The Society has launched the Text to GIVE program, and you can now donate \$10 simply by texting CUREMPS to 80888! We also are beginning a pilot program called Donor Pages. This program will allow families to share their individual stories on our Web site, and will provide a link for friends and family, creating a source



of giving to help fund Society programs. Donor Pages will be unveiled at our 2012 conference.

This year marks the fourth year for the Sponsor A Child For A Cure program. Last year 30 children, young adults and families participated, raising more than \$25,000. We hope this year more families will be able to participate

in the joy of raising awareness and money for research. This program is embraced by runners nationwide and we are thrilled that families unable to attend a walk/run in person can still make a difference.

Keep up to date by visiting the National MPS Society's Facebook page or follow us on Twitter! For more information about Planned Giving, Sponsor A Child For A Cure or any other fundraising programs, please contact me at terri@mpssociety.org. Happy summer everyone! ☘

Terri Klein

LETTER FROM THE **PROGRAM DIRECTOR**

THE FAMILY SUPPORT COMMITTEE (FSC) has been very busy. They have awarded 25 Continuing Education Scholarships to individuals with MPS and their siblings. A record number of applications were submitted this year, and there was not enough money available to fund all applicants. However we would like to thank everyone for applying and please remember to apply again next year. The Society is proud to be able to help our membership with these college scholarships.

In addition, the Family Conference Scholarship Program will assist



families in attending what promises to be an amazing, informational and educational conference. We hope to see you and your family in Boston. It is a fantastic time to re-energize and catch up with your extended MPS family.

We have helped five families through our new Emergency Relief

Program, which is designed to help families in a short-term financial crisis with expenses such as car repairs, utility bills, bereavement expenses and rent. Other FSC programs continue to be in demand; please contact me with any questions.

We love to hear and share news and photos with everyone—remember to submit photos of your family for *Courage*. ☘

Laurie Turner