# 18 fundraising news

## The Annual Fund:

- was launched in 2002
- is in its 13th year
- has raised more than \$859,000
- supports operations and 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

# **National MPS Society 13th Annual Fund** Campaign-Inspire to Give

The Annual Fund has become a critical funding source for the National MPS Society. This campaign funds our family support programs, legislative advocacy work and operations of the Society. Giving to the National MPS Society's 2014 Annual Fund Campaign is a partnership opportunity. Your family is making a decision that the National MPS Society is working hard each day to provide support for families.

It is easy to make a donation—send a check or go online to www.mpssociety.org, click "Donate Now" and select Annual Fund. Help us to help our programs grow and make a difference in the lives of children suffering from MPS and related diseases.

This year's Annual Fund chair is Lynn Hopkins. She shares her daughter Michelle's journey through a heroic bone marrow transplant and her life challenges with MPS I. Lynn and her family speak passionately about supporting the Society's Annual Fund. You can view their story at www.mpssociety.org.







Michelle Hopkins (MPS I)



Dawn Checrallah, Nick Boyce (MPS I) with Aidan Carter (MPS II) and the Carter family

# Action for Aidan

The Action for Aidan 5K Run/Walk took place on Sunday, June 29, 2014, in Exeter, NH, in honor of Aidan Carter (MPS II). The event featured local musician Wayne from Maine, a bounce house, skateboard lessons, Home Depot building station and delicious food. More than \$96,000 was raised through corporate sponsors and individuals donors. The support and love of the community was overwhelming, with more than 300 participants.

The Carter family has altogether raised more than \$200,000 for the National MPS Society to fund MPS II research. For more information visit www.actionforaidan.org.

# **Planned Giving or Gift Planning**

Planned giving or gift planning can be both an outlay of cash today to the National MPS Society or a deferred gift that a person decides to give at some future date, either a number of years from now or at death. A deferred gift is a present decision to make a future gift, evidenced by a legal contract.

In a recent publication, *Planned Giving Today* (Vol 25; No 6), the top 10 factors for adding charitable plans include:

- 1. approaching death
- 2. becoming a widow/widower
- 3. diagnosed with cancer
- 4. decline in self-reported health
- 5. divorce
- 6. diagnosed with heart problems
- 7. diagnosed with a stroke
- 8. first grandchild
- 9. increasing assets
- 10. increasing charitable giving

Perhaps considering gift planning doesn't have to be proceeded by one of the above circumstances and instead you can simply plan for your family over time.

## Gift Planning Is Similar to Planting a Garden

Gift planning can be similar to planting a garden. Many of us start our first garden on a bare piece of land. Through the days and years that ensue, it takes on an identity from the various plants we place there, how it is designed and then cultivated to maturity. Some of us live long enough to have a glorious garden stretching to a far horizon, some live only to plant a few rows of flowers or cultivate a couple of trees.

As you plant your life's garden through your deliberation and deeds, will there be a section devoted to charity or philanthropy? Will it include gifts to the National MPS Society?

Our hope is that your garden of life will include many wonderful thoughts and experiences regarding your association with the National MPS Society.

You philanthropic garden might include a gift in trust, like a stand of fruit trees that can yield a harvest every year. Or perhaps an area of rare varieties that, once you have passed, can be transplanted to bring beauty and serenity to all who will visit. Perhaps you'll have an endowment section, where the berries produced each year can feed the program of your choice.

There are many possibilities for filling your garden of philanthropy. We hope that you will consider the Society in your landscape.

A planned gift ensures membership to the Rising Sun Legacy Circle. See page 20 for more information.

## **Fundraising Committee:**

Jeff Bardslev

Erica Blight

Stephanie Bozarth

**Brooke Carter** 

Anne Gniazdowski

Tom Gniazdowski

Steve Holland

Larry Kirch

Terri Klein

Amv Miller

Amber Mongan

Lisa Muller

MaryEllen Pendleton, chair

Lisa Todd

Laurie Turner

Barbara Wedehase

# WAYS TO GIVE AND INSPIRE HOPE IN 2014

- 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—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 2014 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.

**CONTACT:** terri@mpssociety.org or 919.806.0101

# **Rising Sun Legacy Circle Members**

The Rising Sun Legacy Circle, formed in 2011, is a distinguished group of donors who support the National MPS Society with an estate planned gift designated to build a foundation for future research, family support and educational programs. This is a group of forward-thinking individuals whose generosity demonstrates concern for our future.

#### 2011

Christa Armstrong, stocks and will

Becky Clarke, will

Emil Kakkis and Jenny Soriano, endowment gift

#### 2012

Mary Starr Adams, will

Terri Klein and Mike Schleter, life insurance beneficiary

Tracy Szymanski, will

#### 2013

Steve and Amy Holland, retirement plan Brian and Kris Klenke, will

Barbara Wedehase, will

Anonymous, estate

Anonymous\*, remainder trust received

#### 2014

Carol Elwell\*, remainder trust received
Steve and Randy McDonnell\*, remainder trust pending
Austin and Stephanie Bozarth, in planning
Anonymous\*, remainder trust received

\* denotes deceased

# 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.

# New Sub-Committees Have Large Impact on Society's Efforts

by Amber Mongan

In April of this year, the National MPS Society's Fundraising Committee decided it would be more effective by splitting into three sub-committees. This new committee structure helps allocate the "to do" list, keeps us current and up-to-date with today's rapidly changing social streams for fund development, and allows for focused brainstorming, creativity and the opportunity for additional members to join. We are excited about this strategic move. The new sub-committees include:

- Marketing Strategies & Technology sub-committee—focuses on newly developed and current campaigns that exist to raise funds for the Society, to understand their current use and implement new strategies to create record-breaking donations (Ex. rally.org and Courage Pages).
- Gift Planning (Planned Giving) sub-committee—focuses on bequests
  (wills), living trusts and endowment strategies by implementing a monthto-month marketing plan, reviewing and identifying potential prospects
  from our current database, and seeking new prospects from outside of the
  Society.
- Walk/Run Program & National Sponsors sub-committee—focuses on all aspects of the walk/run program, including raising awareness, increasing national corporate sponsorship, gaining traction through social media and creating efforts to increase the amount of walk/run events this year. Money raised through the walk/run program is the backbone of our research initiative.

**ALL** fundraising efforts help fulfill the National MPS Society's mission: Support for Families. Research for a Cure.

Sub-committees meet monthly and report to MaryEllen Pendleton, fundraising chair. Each month the Fundraising Committee as a whole reviews critical paths. Contact Terri Klein at 919.806.0101 or terri@mpssociety.org if you are interested in being part of the newly restructured Fundraising Committee.

Did You Know?

When you shop at smile.amazon.com, Amazon donates to your favorite charitable organization. Designate the National MPS Society, and .5% of your eligible purchases will automatically be donated to the Society. Visit smile.amazon.com for more information.