

2008 Annual Fund Results

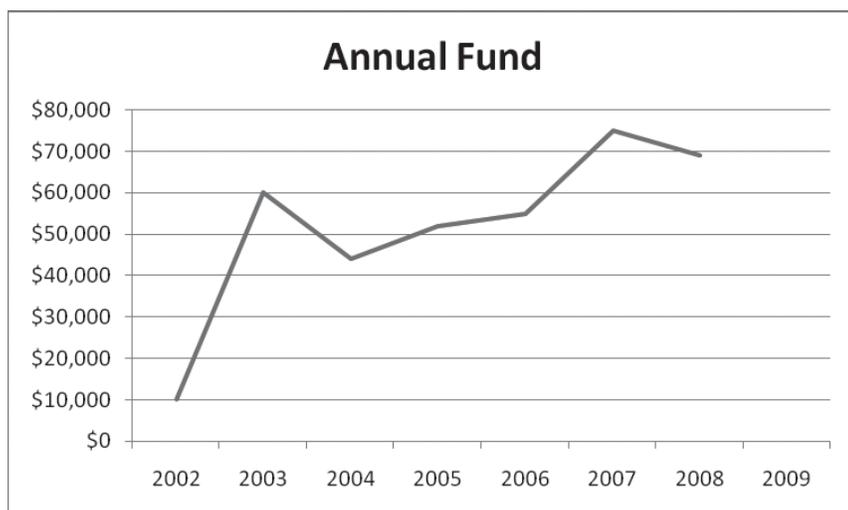
In 2008, the Society completed its seventh Annual Fund campaign raising \$69,000. Over the past seven years you helped raise more than \$365,000 to sustain the mission of the National MPS Society. In 2002, the first year of the Annual Fund, a total of \$10,000 was raised; now the Annual Fund consistently raises more than \$60,000 yearly. With your help and through the leadership of the board of directors and the Fundraising Committee, it is hoped that this amount continues to increase each and every year. The success of the campaign is primarily because of the generosity of members and special donors who best know the wonderful work of the National MPS Society. As we kick off the 2009 Annual Fund later this summer, please consider making a gift to this important campaign.

The Annual Fund is a significant source of funds for our Family Assistance Program, legislative program and our general operating expenses. Much of the fundraising that takes place by members includes family fundraisers and walk/run events. Giving by individuals outside of these events also is important. The original intent of the Annual Fund remains the same, it gives those of us who might not be able to host a fundraiser the opportunity to make a personal gift on an annual basis to these important aspects of the mission of the Society.

A sincere thank you to all who contributed to the 2008 Annual Fund!

Larry Kirch

Chair, 2009 Annual Fund



Fundraising Committee:

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

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—Casual Dress for MPS, the Annual 5K Walk/Run and the Annual Fund are great ways to raise money for the National MPS Society.

Hosting a golf outing as easy as 1-2-3

Hosting a golf outing can be an excellent way to raise funds and awareness of MPS. Family and friends usually rally around this type of event, but some fundraising organizers feel that the event should involve something you have an interest in as well as be compatible with the interests of family and friends.

1. Select the date and location. These are the most important first steps. Be aware of off- and on-seasons for golf in your area. The best deals may be found during off-season but courses are not always in the best shape. However, being a fundraiser, a better price may outweigh this. Look at how often you feel you can tap into your friend support network. You can easily make \$10,000–\$25,000 a tournament, but not if you expect the backing of the same supporters. Events held every 18 months is a good timeframe.

2. Build a committee of organizers. The first year is the most difficult to organize. Breaking down tasks into committees headed by one or two people is most efficient. Suggested committees include:

- **Golf course negotiator/communications with golf course.** The person handling this should try to negotiate for as many extras as possible. This is especially important in today's economy. Golf courses should be willing to supply practice balls, free rounds of golf (for prizes), etc. This also holds true when negotiating with catering staff for a luncheon. Feel free to tell courses that you are negotiating with other courses.
- **Person(s) to set up spread sheets and maintain lists of golfers and donors.** This person should have the best computer skills of the group. Accuracy in maintaining lists of golfers and donors will make sending thank you notes a much easier task.

- **Silent auction/raffle.** Everyone can help with obtaining items for an auction and raffle, but keeping items in a central location allows for better organization. It is important to have items in every price range. It can be a stretch for some friends to pay the greens fees, so keeping some auction items in the \$10–\$50 range allows them to bid comfortably. Grouping like items together can generate more funds.
- **Collecting money and making deposits.** Set up a separate checking account with the name of the tournament; this makes depositing checks very easy. Make photo copies of all checks. Addresses and phone numbers from checks are important for recordkeeping and thank you notes.
- **Hole sponsors/extras.** This is the best money making aspect of a tournament. You can have many levels of sponsors. Each hole can have a separate sign listing the level and names of sponsors. (i.e., gold, silver, etc.) Sponsors should be listed prominently on posters, flyers, etc. Additional extra games are a source of fun and funding. Sell mulligans, and have a closest-to-the-pin and longest drive contest.

It is useful to have monthly meetings for four to six months prior to your event, then switch to bi-weekly, then weekly. Meetings can be done by phone or e-mail; communication is essential so you are not duplicating efforts.

3. Relax and have fun the day of the tournament.

The National MPS Society has more detailed information available about hosting a golf tournament. Contact Terri Klein at terri@mpssociety.org or 909.806.0101.

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.

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)

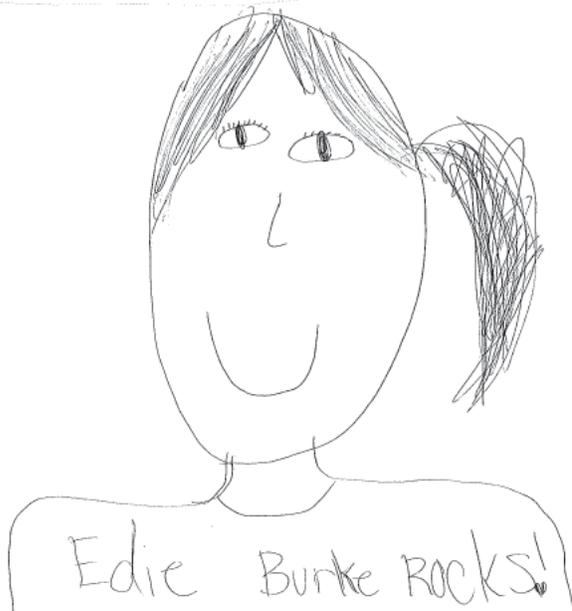
Gifts may be applied to the Society's general operating purposes or restricted to one of our designated programs.

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

Special thanks to Eliza Burke for her fundraising efforts in memory of her sister, Edie (MPS I)

Dear MPS Society,
I raised \$5.31 by selling
cookies, I hope you
can spend it for something
important!

~~Sincerely~~ Eliza Burke



The 5th annual Play for Taylor piano recital was held in honor of Taylor Geary (MPS III) in Hilliard, OH, on March 14, 2009. Taylor's mother, Rachel Wojnarowski, teaches piano and every year her students hold a fundraiser concert in honor of Taylor. This year's event raised nearly \$500.



Taylor Geary (MPS III) and Clara Gibson (MPS III)



It is a privilege to begin a new chapter with the National MPS Society in fund development. I have been a member of the Society since the diagnosis of my daughter with ML III in 1999. In my new role as the Society's development director, I bring compassion, conviction and support for

fundraising events that will benefit our children and adults affected by MPS and related diseases.

"Back to the basics," working harder and stronger to develop funds is a goal for 2009. Our supporters will soon be given the opportunity to contribute to the 8th Annual Fund to support the Society in research, programs and operations. Many of our families and supporters appreciate giving to the National MPS Society through this annual contribution. It also is a wonderful time to share information about our Annual Fund with family, friends and co-workers. If your company participates in a corporate match program, explore raising awareness through the Annual Fund at your workplace.

The walk/run season will soon be here as well. Several new families are excited to host an event this year. I am here for support and to answer questions, and a number of previous event coordinators are available to mentor new

organizers. We also have established online resources and a guide to make the planning of an event easier.

Driving from Michigan to my new home in North Carolina, I reflected on ways the National MPS Society continuously supports our families. The Society is a leading authority on MPS and related diseases and provides support to our families at the time of diagnosis and beyond. We are a working community of families, gathering knowledge and sharing experiences, while providing support with numerous publications and annual conferences. Our family support programs provide essential assistance for scholarships and medical equipment. And lastly, as we strive to attain the goals in our mission to find cures for these diseases, are the advocacy work of the Society's Legislative Committee and the research funding.

It is important to stay encouraged, motivated and compassionate even in the most difficult of times. The Society counts on the continued support of our families and friends. With each fundraising event, increased awareness about MPS and related diseases escalates! Call and let me know how I can help make your event more successful.

A handwritten signature in cursive script, reading "Julie L. Klein". The signature is written in dark ink on a white background.