

The Myasthenia Gravis Association of Western PA

1515 Locust Street Suite 709

Pittsburgh, PA 15219

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## **MGA SPORTS MEMORABILIA AUCTION**

**ORDER YOUR TICKETS TODAY ! ! !**

The 14th Annual MGA All-Star Sports Memorabilia Auction will be held on **Saturday, April 19th at the Keystone Corner Room at PNC Park** starting at 6:00 pm, This event will auction over 200 items from both local and national sports teams and athletes while raising funds for MGA. In addition, several local sports personalities will be on hand to sign autographs for guests. A big THANK YOU to the generosity of **The Koter Group at Smith Barney**, the major sponsor for this years event, with additional sponsorship from West Penn Allegheny Health System, Highmark , Matthew James Creative and countless in-kind donations of goods and services.

Tickets are \$20 per person — with only 250 tickets available on a first come first serve basis we are already heading for a fast sell out!. Those attending will be treated to a live and silent auction of extraordinary sports memorabilia, a delicious buffet, a “goodie” bag , a basket raffle, \$20 & \$30 grab bags loaded with sports related items, and much more. **Guaranteed to be a fun event!**

Bill Neofes, whose leadership has guided this fundraiser for MGA said, “Being involved in an event that helps raise awareness for Myasthenia Gravis has been gratifying. That we have been able to help provide for the needs of MG patients and at the same time stage such a fun quality event these past 13 years makes it that much more special.”

For more information or to be added to the invitation list for the 2009 event please contact the MGA office at 412-566-1545.



MYASTHENIA GRAVIS  
TREATMENT & ADVOCACY CENTER

*A program of the Myasthenia Gravis Association  
of Western Pennsylvania*

SPRING 2008

Hope!

## Western Pennsylvania's Keystone of

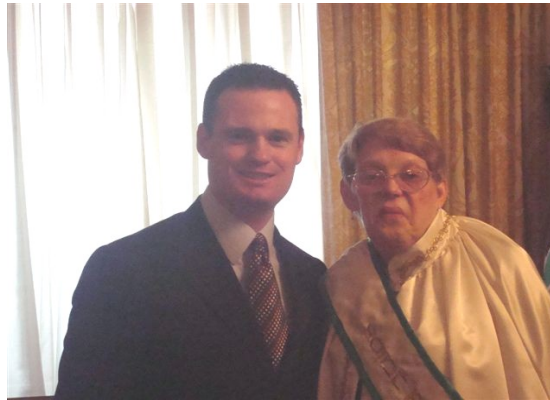
### St. Brigid's Court Selects Donna Kalisek as Representative

Pittsburgh has the oldest and second largest St. Patrick's Day Parade in the country. MGA received an invitation to nominate a candidate to ride in the parade. The St. Brigid's Court Committee was looking for a woman to participate in the St. Patrick's Day festivities who exemplifies the qualities of St. Brigid. They were seeking a woman of courage and grand will in the face of adversity, and someone who demonstrates spiritual strength. MGA staff didn't have to think very hard about who to nominate.

In 1966, Donna Kalisek was afflicted with a neuromuscular disease characterized by muscle and nerve weakness of the voluntary muscles of the body. Donna was eight years old at the time. With no cure for Myasthenia Gravis (MG), Donna realized that she would never ride a bike; she would have difficulty keeping her eyelids open and often be hospitalized with respiratory difficulties. She eventually became a fourth grade 'drop-out' because administrators felt that the school was not equipped to accommodate her needs.

But Donna fought back with hope, faith and humility. She was always among the first to submit herself to experimental treatments to relieve some of the symptoms of MG. Donna's personal sacrifice and a courageous spirit is an inspiration to others who are afflicted with MG. Consequently, Donna's example also touches the families of people with MG and the greater community who provide for needs of

Donna's self-esteem has flourished since the days that passed her by, due to her illness, in her youth. The school began a more inclusive program when Donna was 13. Although her peers often treated her differently, and she continued to miss school days due to the symptoms of MG, Donna now proudly proclaims, "I'm myself. I don't care anymore what other



Donna with Pittsburgh Mayor Luke Ravenstahl

people think. I used to be jealous that they could do more than I. Then I learned I could do things they can't. If other's can't accept me, that is inside of them. That's not me."

Additionally, Donna reinforced her worth as an invaluable asset to the Myasthenia Gravis Association of Western Pennsylvania (MGA of WPA) when she relinquished her volunteer role with the organization in lieu of a paid staff position. Donna is now the Administrative Coordinator for MGA of WPA and her contribution is essential to its day-to-day operations.

Again, with confidence, Donna says, "I now live in my own apartment and enjoy the independence and responsibility that go along with it. And yes, I am still making adjustments in my life. Having a positive attitude, a strong support system, and an active will to live life to the fullest have kept me going." Not unlike the "Spirit of the Fighting Irish", Donna will make Saint Brigid proud!

## A MESSAGE FROM MGA'S BOARD PRESIDENT

Dear Friends of the MG Assoc. of Western PA,

It is with great pleasure that I share my thoughts with you regarding the future of this wonderful Association. I am proud to be the President of the Board of Directors of this 50-year strong contributor to people in Western Pennsylvania and across the country whose lives, like mine, are affected by Myasthenia Gravis.

I cheerfully acknowledge the renewed enthusiasm, contribution and commitment of MGA's faithful Board of Directors. I welcome Ron Balog, of The Koter Group at Smith Barney, to our Board, as well as others who are in the nomination process. Your energy and perspectives will enhance the vision of MGA.

As with every nonprofit organization, the Board of Directors is inherent of change. With gratitude for service well done, I express my sincere thanks to Board Member, Donna Bevan who found it necessary at this time to resign from the Board — Donna Bevan, thank you for sharing your time and talents with MGA.

As you read this issue of MGA's newsletter, I'm sure you will be enlightened by the participation of our amazing community. From individuals and their companies, to schools and their students, many generous contributions insure that MGA continues to leave a path of good works in this beautiful region. Thank you for enhancing MGA's bright future!

Sincerely,

Peggy Gursky, MGA of WPA Board President

### 2007 Annual Appeal Exceeds Expectations

MGA would like to thank everyone who donated to this year's Annual Appeal Campaign. The \$10,000 goal was exceeded by 30% when contributions totaled over \$13,200. Your gift aids to continue the needed services provided to those with myasthenia gravis. People in Western Pennsylvania who access MGA's Treatment Center and other services depend on the generosity of people like YOU.

Contributions made through this donor appeal, memorials for loved ones, honorariums for special occasions, general donations, or remembering MGA in your will, you have helped people find the right medical care, generated public awareness, kept the [www.mgawpa.org](http://www.mgawpa.org) website current, and gave HOPE to someone who needed it.

### MGA of WPA

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### BOARD OF DIRECTORS

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\* *Italicized font* above indicates a new board member for 2007.

*A copy of the registration and financial information of The Myasthenia Gravis Association of Western Pennsylvania may be obtained from the PA Dept. of State by calling toll-free within PA, 1-412-566-1545. Registration does not imply endorsement. MGA of WPA is a United Way Member Agency.*

## MEMORIAL AND HONORARIUM CONTRIBUTIONS (FROM JULY 2007 THRU FEBRUARY 2008)

Memorials & Honorariums are meaningful ways to acknowledge important people in your life. Your donation will help support MGA's services for persons with myasthenia gravis.

If you would like to make an honorarium or memorial gift, please send the name of the person being honored or remembered and an address for the person or their family (a special card will be sent notifying them of your donation) along with your contribution to the MGA office. Please contact the MGA office at (412) 566-1545 for more information. You may also call the office to make a credit card donation or make your payment through our website at [www.mgawpa.org](http://www.mgawpa.org).



### In Memory Of

#### MARY BARR

By Helen Beck

#### FATHER OF ED BOWMAN

By Joseph & Ida Calvarese  
Deborah Mahoney

#### JOHN CALDWELL

By Tom & Denise Blasko

#### RUTH ROSE GORDON

By Milton & Lucille Gordon

#### RONALD C. GRAFTON

By Doris E. Grafton

#### ROSEMARY GREENBERG

By Robert & Nancy MacLachlan

#### ROBERT HUBER

By Thomas & Linda Andrews  
Dana Beck  
Coworkers @BNY Mellon  
Gary & Terri Ellis  
Terri Findle  
Avilla Frankenberg  
John & Sandra Guttman  
Robert & Rita Herd  
Hertz Claim Mgmt-PGH  
William Hughes  
Residents of Redstone—  
North Huntington  
Edmond Rosky  
Melvin Scarpaci Family  
M/M Douglas Sullivan  
Kate Wright

#### EDNA HUDACHEK

By Joan & Mike DiCicco & Dan  
Carol Hudachek

#### MR EDOUARD MRAVYAN

(Dr Z/s father)

By Sylvia Danehy  
Donna Kalisek  
Pearl G McNall MD

#### MR GEORGE MRYAS

By Joseph & Ida Calvarese  
Deborah Mahoney

#### IRMA PHLEGAR

By Kathryn & Fred Guenther

#### KENNETH ROWE

By Richard E. Stees

#### JOHN SAKALA

By Judith Udavcak

#### RUDY SPINCIC

By Sylvia Spincic Danehy

#### HUSBAND & FATHER OF RUTH ANN DUKES FAMILY

By Joseph & Ida Calvarese  
Deborah Mahoney

#### GEORGE SAYENGA

By Scott & Emily Lynn

#### ANTHONY WELESKI

By Mrs. Marcella Dobrzynski  
Arthur & Carole Gildner  
Lois Lettrich  
William A Gray  
Mrs. Marie Jack  
The Lee Family / SoHills Movers  
Robert & Joy Porter  
Gary & Susan Sobkiw  
John A Vuono  
Vuono & Gray LLCI

### In Honor of

#### GINNY EVERARD

By Rosalyn Serrins

#### BARBARA & TRACY GREENHOLT

By Lawrence & Ina Gumberg Fdn.

#### DONNA KALISEK

By Rosalyn Serrins

#### CAROL SAYENGA LYNN

By Ed & Julianne Biehl

#### MGA TREATMENT CENTER - 50TH ANNIVERSARY

By Art Falsetti

#### JACKIE MURTHA

By Pearl G. McNall MD

#### KENT TEKULVE

By Donald Seggerman

#### ED & DEE RILEY and LENORA O'TOOLE

By Donna Kalisek

# MEET MGA'S NEW EXECUTIVE DIRECTOR

## WELCOME, BARB!



MGA of WPA is pleased to welcome BARBARA LEFLER to our organization. Barbara has been serving as the Executive Director since October 2007. She has been married to Doug for 29 years and is the proud mother of one daughter, three sons, a daughter-in-law, and a beautiful new granddaughter. She moved to the Pittsburgh area from Anchorage Alaska 3 1/2 years ago to fulfill her goal to work in upper management within the nonprofit sector.

Barbara comes to us with a respected background in nonprofit management on local, state and national levels. Her Certificate of Nonprofit Management from the University of Chicago, coupled with her experience in legal rights advocacy for people with disabilities makes her well qualified to serve our clients and work with our Board of Directors in the capacity of Executive Director. Barb has also been involved with a nonprofit consulting firm in the Pittsburgh area which allows her to bring a solid background in strategic management to MGA. Barb's compassion, energy, and enthusiasm are an excellent fit for our forward moving nonprofit organization which has been serving those people diagnosed with myasthenia gravis for over fifty years.



## United Way Donor Designation

If you donate to a United Way agency in Western PA, did you know you can designate your donation to go directly to MGA? When making your donation, simply designate your payment to MGA by using the following codes:

**United Way of Allegheny County #82**    **United Way of Beaver County #4861**    **United Way of Butler County #5981**  
**United Way of Erie County #45146**    **United Way of Mon Valley #1178**    **United Way of Wash. County #0082**

If you are a state or federal employee and want to use payroll deduction to make a donation to MGA, please check with your employer to verify codes (due to changes):

**SECA (For State Employees)** - Use **S460124** (please note, the first character is the letter 's')

**CFC (For Federal Employees)**: There were some changes and we have been informed that **# 38076** is our new five digit code. Again, please double check - especially if you live in Allegheny, Armstrong, Clarion, Crawford, Erie, Fayette, Forest, Greene, Lawrence, Mercer, Venango, Washington, or Westmoreland County.

**IF YOU HAVE ANY QUESTIONS REGARDING UNITED WAY DONOR DESIGNATION, SECA, OR CFC, PLEASE FEEL FREE TO CALL THE MGA OFFICE.**

## CMU Student Provides Technology Consultation to MGA

MGA is fortunate to be involved in the Technology Consulting in the Community class in conjunction with Carnegie Mellon University. Under the direction of Professor Scott McElfresh, students enrolled in his class are partnered with interested nonprofit organizations in Pittsburgh. The student's assignment is to provide solutions regarding technology related problems to their partner agency. Ayush Raman has been partnered with MGA. Mr. Joseph F. McLaughlin is a mentor for this project.

Ayush is a Graduate Student in Computational Biology at Carnegie Mellon. He obtained a degree in Engineering in Biotechnology-Bioinformatics from his home country, India. Ayush's interest in Bioinformatics urged him to pursue his Masters Degree in the United States. He will conclude his studies in the US in 2009.

Ayush's father is a Vice President and working with Reliance Energy Ltd., India. Ayush's grandfather is a local doctor in India and diagnosed cases of MG in his community. Partnering with MGA piqued an interest for Ayush since he was familiar with the disease. Additional interests include learning and reading about new technology. Ayush also enjoys playing and watching Soccer and Cricket (kind of Indian Baseball!!)

After returning home to India, Ayush plans on working for a consulting company where he can help his clients with new technology especially related to Health Care. He also has an interest in consulting and establishing new Biotechnology firms. With a love of learning, Ayush plans to continue his education in India and will receive a Masters in Business Administration.



MGA is fortunate to have a talented and diligent student on board for the semester.

## UPMC Mercy—MGA Negotiations Continue

Mercy Hospital of Pittsburgh and MGA of WPA have been partners for more than 50 years. UPMC acquired Mercy Hospital in January, 2008. Since that time, MGA Board and staff have been working with UPMC Mercy representatives to finalize a Shared Services Agreement. UPMC has indicated an interest in maintaining a partnership on behalf of people with Myasthenia Gravis.

Have an Email Address?

Send it to us at [mgaoffice@mgawpa.org](mailto:mgaoffice@mgawpa.org)

We'll add you to our mailing list and you can receive our emailed newsletters full of information about myasthenia gravis and current happenings at MGA!

Join us for the  
14th Annual All-Star Sports Memorabilia Auction  
Sponsored by The Koter Group at Smith Barney



Proceeds benefit the  
Myasthenia Gravis Treatment and Advocacy Center of Western PA

**WHEN:** Saturday, April 19th, 2008 - - Doors open at 6:00 pm

**WHERE:** PNC Park's "Keystone Corner" Room

**COST:** \$20 per person -  
Includes FREE buffet, cash bar, raffles, auctions, grab bags, and more

**ONLY 175 TICKETS LEFT!!**

Approximately 200 autographed sports related items will be available.  
Many items signed by sports heroes including: Pirates **FREDDIE SANCHEZ** and  
**ADAM LAROCHE**, Steelers **HINES WARD** and **WILLIE PARKER**, Penguins **EVGENI**  
**MALKIN**, **RYAN MALONE** and **RON FRANCIS**, quarterback **PEYTON MANNING**, basket-  
ball great **VINCE CARTER**, Philadelphia Eagle **DONOVAN McNABB**, and many more  
local and national athletes.

**FREE AUTOGRAPHS FROM SPECIAL CELEBRITY GUESTS**

To order tickets or for more information, call (412) 566-1545.  
Cash, Check, Visa, MasterCard or Discover accepted as payment to:

MGA of WPA  
1515 Locust Street #709  
Pittsburgh PA 15219

Anyone wearing their favorite team apparel will be eligible for a prize drawing!

**Tickets will be sold on a first come first served basis!!!**

## SPRING & SUMMER TIPS FOR THOSE WITH MYASTHENIA GRAVIS

Are you a patient with myasthenia gravis that becomes weak in the hot summer weather?

Below are some helpful tips to make your spring and summer time activities as pleasant as possible.

<ul style="list-style-type: none"> <li>◆ If it is raining outside, make sure you are wearing shoes with good traction .</li> <li>◆ Perform strenuous activities during peak medication times.</li> <li>◆ Use a cart, wagon, or basket to carry hand tools around the garden so that you do not have to retrace your steps.</li> <li>◆ Try to do your gardening before 10:00 am or after 5:00 pm when it is not as hot.</li> <li>◆ Watch the weather for <b>ALERT</b> days. You should stay in air conditioned rooms during periods of extreme heat. Remember <b>HEAT IS NOT YOUR FRIEND.</b></li> </ul>	<ul style="list-style-type: none"> <li>◆ Build in rest periods during activities you have planned.</li> <li>◆ If it is hot outside try carrying ice water with you. Ice water or ice chips will also help if you are experiencing difficulty chewing or swallowing.</li> <li>◆ If you are having neck weakness, ice can be applied to the back of the neck.</li> <li>◆ If your neck weakness continues to be a problem ask your doctor for a prescription for an ice collar, or ice jacket (although the jacket is somewhat heavy though).</li> <li>◆ If you plan on golfing, make your tee off early. Take a break if you plan on playing 18 holes.</li> </ul>	<ul style="list-style-type: none"> <li>◆ If you are experiencing severe problems with breathing or swallowing <b>GO TO THE EMERGENCY ROOM!!!</b></li> <li>◆ Keeping yourself hydrated can minimize cramping. Drink plenty of fluids, and keep in mind that popsicles and jell-o are considered liquids. If drinking a product containing electrolytes, read the label carefully to avoid consumption of magnesium.</li> <li>◆ If you are planning to go out of the country and need vaccines ... <b>ASK YOUR DOCTOR!!!</b> There are risks!!!</li> </ul>
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Please keep these tips posted somewhere handy. As always, if you are having any problems and need help, feel free to call Ginny at the MGA office at (412) 566-1545

- Every Patient with MG needs:**
- ◆ **Timely diagnosis**
  - ◆ **Care from providers who know them and specialize in MG**
  - ◆ **Up-to-date information**
  - ◆ **Support — especially in the difficult times**
  - ◆ **HOPE**