



## Welcome MGA Alliance Members from New York City

The Myasthenia Gravis Alliance (also known as Myasthenia Gravis Foundation of Greater New York, Inc.) notified us that they are closing their doors, after more than forty years of advocacy and service to people living with MG. Their Executive Director, **Debra Santulli-Barone**, contacted us to ask that we take over serving their remaining members, since we already serve people from all over the United States, and she was familiar with our organization. The MGA of WPA Board of Directors expressed regret to learn of the MG

Alliance's impending closure due to lack of funding, and voted unanimously to add their members to our MG family. We are humbled by this request, and will do all that we can to support and serve all of you as our newest members. Please call our office to talk with our experienced medical staff about any of your concerns (412-566-1545) or email us at [mgaoffice@mgawpa.org](mailto:mgaoffice@mgawpa.org).

Our website [www.mgawpa.org](http://www.mgawpa.org) offers a wide range of information about MG, along with links to our archived newsletters, event photos, board and staff list and much more.

We look forward to getting to know our NYC members. We offer a monthly support group at Allegheny General Hospital in Pittsburgh if you are ever in the area, and a virtual support group on facebook. You can expect to receive this newsletter twice per year, and other occasional mailings. Please notify us if you wish to be removed from our mailing list.



# Happy Hour at

## Caliente

Pizza & Draft House

Hottest Draft Selection & Gourmet Pizza in the Burgh

## DELICIOUS FUN

MGA held a fundraiser at Caliente Pizza and Draft House on Liberty Avenue in Bloomfield on June 25th, as part of our MG awareness month activities. The owners, **Angie and Nick Bogacz**, generously donated 20% of food and beverage purchases to MGA. Thanks to board members **Bill Gandjos**, **Bob Cribbs**, **Louise Vuono**, **Kathy Clouse** and former board member **Bill Murtha** for attending and bringing friends and family. Several of our patients also attended. Thanks also to **Larry Kirchner** for framing the Lemieux lithograph and **Clarissa Smith** for making the gorgeous quilt that were raffled off, along with a fabulous Sports Fan basket. The restaurant was packed and guests learned about MG and the supportive services MGA provides.



6<sup>th</sup> ANNUAL **Pooch Parade**  
October 26<sup>th</sup> at South Park

See Page 2 for details and registration information.

# DON'T miss the 6<sup>th</sup> Annual Pooch Parade

Make your *Holidays* **EVEN HAPPIER** with AmazonSmile

Shop at AmazonSmile and Amazon will make a donation to:

*Myasthenia Gravis*  
Association of Western Pennsylvania

Get started

amazonsmile

When you are making your list and checking it twice this holiday shopping season, you can support MGA at the same time and it won't cost a penny extra. Simply start your online shopping at [smile.amazon.com](http://smile.amazon.com), and Amazon will donate a portion of the price of all eligible purchases to MGA. On your first visit to AmazonSmile, you'll need to select Myasthenia Gravis Association of Western PA as your designated nonprofit. AmazonSmile will remember your selection, and a portion of every purchase you make will be donated to MGA.

## OCTOBER 26<sup>TH</sup> AT SOUTH PARK

Join your friends (human and canine) and form a team to walk in memory or in honor of a loved one with MG! It's a fun, affordable way to support the FREE patient support services at MGA. The level, paved one mile trail is perfect for people of all fitness levels. Walkers receive morning refreshments, courtesy of United Dairy and Dunkin Donuts, an MGA canvas tote bag, a commemorative t-shirt, and a bandana for your pooch! Walkers without dogs are welcome too! Prizes will be awarded to the best dog costume and best owner/dog combo costume, along with basket raffles, silent auctions, music, vendors and much more! Registration begins at 9am and the Pooch Parade starts at 10am. Forms and information are available at the MGA website [www.mgawpa.org](http://www.mgawpa.org) or call our office (412-566-1545) and we will mail you one. T-shirt sizes are guaranteed for registrations received by Sept. 30<sup>th</sup> so don't wait!



## MARK YOUR CALENDAR MGA 59<sup>th</sup> ANNUAL MEETING

Please join us on Saturday, November 8th from 10am to 12noon, for this year's annual meeting. It will be held in the Kent-Frazier Rooms of the Magovern Conference Center, second floor of Allegheny General Hospital. Free morning refreshments, free parking, and the latest information on MG research, treatments and more! Watch for your invitation in the mail and call to RSVP. We hope to see you!

NOVEMBER 2014						
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# ADVOCATE for YOURSELF...

*By Donna Kalisek, MGA Administrative Coordinator*



Facing a neuromuscular disease diagnosis can be devastating, overwhelming and confusing, but empowering yourself to take charge of your care or the care of a loved one is more important than ever.

Whether you are newly diagnosed or have been living with a neuromuscular disease for years, there is arguably one guiding principle that is most important when it comes to making decisions about your care and quality of life: You are in charge.

*And with good reason.*

Researchers, physicians, therapists, social workers, community advocates, and more are all indispensable resources for helping you manage your disease. But remember: This is your health, your body, your life. So there is no person better suited than you – with the exception of a parent/guardian of a young child – to coordinate the efforts of health care professionals and directly oversee your care and treatment plans.

Think of yourself as the lead actor/director, the quarterback/coach. You still need a great supporting cast and crew and dedicated teammates in pursuing your care. But as the one person who lives with the medical outcomes, it's only fitting that you also be the one who's calling the shots along the way.

Assuming a central role in your care is more important than ever because with today's improved treatment options, we benefit from longer life expectancies – along with more life choices and opportunities. Choice is usually a good thing, but it can also be overwhelming, especially if you or a loved one has only recently received a neuromuscular disease diagnosis.

Sometimes logic goes out the window when faced with a devastating diagnosis. However, you can gain some control back by creating a support structure. With that goal in mind, it is recommended that you play an active role in assembling your care team and resources. Remember: Being in charge of your care doesn't mean you are alone in the fight – you're not.

Since 1955, the Myasthenia Gravis Association of WPA has been helping individuals and families confront the daily challenges of living with a chronic illness, so consider MGA's website, [www.mgawpa.org](http://www.mgawpa.org), a primary resource for educating yourself and gain knowledge of your illness. Look to MGA's staff for strength, support, information, and HOPE.

Once you've started putting your support team together, your next steps will depend on your diagnosis, age, and available support from friends and family. However, at the heart of every care plan is

self-education and self-empowerment. It's crucial that you educate yourself about your disease and start asking questions.

For adults living with a neuromuscular disease, empowerment comes in the form of education and communication. Adults with a chronic muscle weakness disease can face challenging decisions about family, work and even other health issues, so it's important to have the difficult conversations sooner rather than later.

Proactive management of symptoms can ease the burden, so early diagnosis and regular visits to your neurologist are crucial. Maintaining your medication regimen and consulting your physician of any medication changes is also a must.

Taking charge of your care and related life choices can be daunting at first. But, ultimately, it's the best way to ensure your independence and maximize your quality of life.

MGA holds monthly support groups in Pittsburgh. Call the office for more information. We are also on the following social media sites:

**f:** [www.facebook.com/mgawpa](http://www.facebook.com/mgawpa)  
**@** [@mgawpa](https://twitter.com/mgawpa)  
**tumblr:** [mgawpa.tumblr.com](http://mgawpa.tumblr.com)





## WHY PLAN FOR MGA IN YOUR WILL?

There are almost as many reasons people decide to make a planned charitable gift to MGA as there are dedicated members of the MGA family. A few common reasons are to:

- Leave a legacy: “With a gift to MGA (large or small), you are leaving something behind that speaks to the values that you had in your life.” You’ll be leaving something that will continue into the future and do good for others. If the support and services you received made an impact on your life, a planned gift would keep that going for those in the future.
- Finalize one’s will: If you haven’t made a will, needing to allocate a planned gift would be a good reason to think about it. By not planning, you’re not opting out of anything, and you’re choosing a plan governed by statute rather than your own life wishes.
- Think long term – and short: If you are hesitant to donate during your lifetime, despite a commitment to MGA, because you might need extra money now for personal medical reasons, a planned gift ensures you have the money today while still supporting MGA in the future.
- Benefit one’s estate: Depending on the state you reside in, giving a gift to MGA could reduce the state taxes your estate would pay.

The Myasthenia Gravis Association of Western PA is a 501c3 nonprofit organization helping those diagnosed with this chronic muscle weakness disease. Its symptoms can be life changing and life limiting. Remember MGA in your will today. Call 412-566-1545 for more information. THANK YOU.

## Giving to MGA through Payroll Deductions, United Way Contributor Choice, CFC & SECA

If you donate to a United Way agency in Western Pennsylvania, please consider designating your donation to directly benefit MGA. When making your donation, simply use the following MGA codes:



ALLEGHENY # 82  
BEAVER # 4861  
BUTLER # 5981  
ERIE # 45146  
MON VALLEY # 1178  
WASHINGTON # 0082  
WESTMORELAND # 1178

If you are a state or federal employee, use these codes for your combined appeals:

PA State Employees  
combined Appeal # S460124  
Combined Federal Campaign # 38076

If you have any questions regarding United Way donor designation, SECA or CFC, please feel free to call the MGA office. **THANK YOU** for your continued and generous support of MGA.



## You May Be Able to Lower Your Prescription Co-Pays

*By Michelle Dulashaw,*  
MGA Medical & Social  
Support Specialist

Over the past year or so, you may have noticed an increase in your copays for Mestinon®, Mestinon® Syrup, the generic Pyridostigmine Bromide and even the extended release formulation Mestinon Timespan® (the extended release does not yet have a generic substitution). Some insurance plans have moved all these formulations to a “higher tier” resulting in higher copays for their customers. Since there are no other alternatives for these medicines, your prescribing physician’s office may be able to help lower your cost.

If you are paying more than your Generic preferred or Brand preferred copay, call your insurance company and see if your medication is on a higher “tier” for coverage and if your plans supports your physician’s office processing a Tier exception on your behalf. If so, contact your ordering prescriber’s office and have them work with your insurance to assist in lowering your copay.

If you are unable to resolve the issues directly with the insurance company, you can file a Health Care Complaint Form with the Attorney General’s office at [www.attorneygeneral.gov](http://www.attorneygeneral.gov). It may also be necessary to switch your insurance plan if no resolution can be met.

Feel free to call our office if you have questions or need advice. We will do what we can to make sure you are receiving the best affordable care!

# MGA SPORTS MEMORABILIA AUCTION

## APRIL 6<sup>TH</sup> GRAND FINALE OF TWO DECADES OF FUN

Thanks to all who attended and supported this year's MGA Sports Memorabilia Auction. It was another wonderful success. We were so happy to welcome back our dear friend Ellis Cannon as our host once again. Those who have attended this event for many years have watched Ellis' sons grow up before their very eyes.

Twenty years is a long time (Just ask the Pirates!) and all good things must come to an end. The MGA development committee decided this year would be the final one for our Sports Memorabilia Auction. Plans are underway for a fun, fresh and affordable event to be held in the spring. Watch for details in our next newsletter and thanks for your support of our sports memorabilia auction for all these years, especially to our co-chairs Ron Balog and Bill Murtha.



(L to R) Andy Russell, Steve Blass,  
Bill Murtha, Ellis Cannon and Ron Balog

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Waterworks Cinema



Steve Blass gets the bidding started alongside  
Host Ellis Cannon and his three sons.

### Welcome New Board Members

The MGA Board of Directors welcomed two new board members at its June meeting: Karen Shastri and Louise Vuono Schrage. Both have been long time supporters of MGA. Karen has participated in the MGA pooch Parade for many years and last year served as a volunteer at registration. She is a Professor of Business Administration at the University of Pittsburgh and is active in several financial organizations. She was invited to join the MGA board by her good friend and fellow board member Arlene Weintraub. Louise is an attorney and partner at Vuono & Gray, LLC and has practiced law for 19 years. She has three sons, and her youngest was diagnosed with MD when he was 3 years old. She has been a donor to MGA for many years, and joined the board because she wanted to get more involved in the organization. We are glad to have you both and look forward to working with you!

# Thank you to all of our generous donors

The following donations were received between January 1 and June 30, 2014

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In Memory of Ronald Claire Grafton  
By Doris Grafton & Family

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Donna Kalisek

Jack Seewald  
By David & Arlene Weintraub

Marlene Wagner  
By Mary Wagner

## HONORARIUMS

Gerald & Janet Barnes  
In honor of our 42<sup>nd</sup> Wedding  
Anniversary

Phyllis Linton  
By Nicholas & Linda Matteo

MGA Staff & Physicians  
By Gerald & Janet Barnes

*Please note: Every Effort has been made to ensure the accuracy of this list of donors. If you an error or omission, please let us know.*

# KEYSTONE of Hope

is published twice a year by The Myasthenia Gravis Association of Western Pennsylvania and direct mailed to donors, patients and friends. It is also available by email and at the MGA website [www.mgawpa.org](http://www.mgawpa.org).

**Editor:** Maree Gallagher, MGA Executive Director

**Editorial Assistant:** Donna Kalisek, MGA Administrative Coordinator

**Contributors:**

Donna Kalisek, MGA Administrative Coordinator

Michelle Dulashaw, MGA Medical & Social Support Specialist

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490 East North Avenue, Suite 410, Pittsburgh, PA 15212 • 412-566-1545 • [www.mgawpa.org](http://www.mgawpa.org)

Myasthenia Gravis Association of Western Pennsylvania  
at Allegheny General Hospital  
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SEPTEMBER

### MGA SUPPORT GROUP MEETINGS

October 18, 2014

1 pm to 2:30 pm

Allegheny General Hospital  
Singer Library

More dates in 2014 and 2015:

Nov. 15, 2014

Jan. 17, 2015

Dec. 20, 2014

Feb. 21, 2015

Mar. 21, 2015



OCTOBER

### 6<sup>th</sup> ANNUAL POOCH PARADE

October 26, 2014

(See page 2 for details)



NOVEMBER

### MGA 59<sup>th</sup> ANNUAL MEETING

November 8, 2014

10 am to 12 pm

Allegheny General Hospital  
Magovern Conference Center



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