

WESTERN PENNSYLVANIA'S

**KEYSTONE**

of

*Hope*M  
G  
A**Myasthenia Gravis**  
Association of Western Pennsylvania  
at Allegheny General Hospital  
A Treatment & Advocacy Center**MG Awareness Dinner @ LeMont**  
**a Special Night**

MGA extends our deepest appreciation to the Edward B. Dunlap Foundation and all of the following donors who helped make this special evening possible:

Bath & Body Works, Ross Park Mall  
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 Sandeep Rana, MD  
 George Small, MD  
 Clarissa Smith  
 Maurice Weinchenker

Board members, staff and long-time supporters of MGA gathered at beautiful LeMont on June 26th for fine food and fellowship celebrating the important work of the Myasthenia Gravis Association of Western PA. The event capped off MGA's National MG Awareness month activities during June. Executive Director Maree Gallagher spoke about the many changes that the organization has experienced since its founding in 1955, and the expectation of more changes in the future. She congratulated those present for their role in helping MGA to be able to continue its services to people with Myasthenia Gravis and their families. Special guest, radio and television personality Ellis Cannon, spoke about the value of volunteering one's time for a cause, and how it has affected his own life, helping him to know what is really important. All in attendance enjoyed the evening, and many expressed hope that it will become an annual event.

**Pooch Parade****Join the 5<sup>th</sup> Annual Pooch Parade  
October 27<sup>th</sup> at South Park**

*Help support MGA and form a team to walk in memory or in honor of a loved one with MG!  
 Details on page 2*





# Your Support Makes Our Support Possible

*If you've ever called our office, or consulted our website, you know the resources that MGA offers are vital to MG patients. We are not just a doctor's office. We are so much more!*

MGA provides patient-centered, coordinated care for MG patients and their families, including expert diagnosis and medical care in our treatment center's weekly clinic; a wealth of up-to-date information and educational resources; emotional support and advocacy; a monthly support group; and a virtual support group on Facebook. The MGA website is one of the most comprehensive and informative sites available on MG, and receives more than 3,000 hits per month, attracting phone and email inquiries from all over the United States.

We are pleased to report that we served a record number of patients this past year. A total of 475 patients received treatment through MGA, a 37% increase over the previous year! In addition, MGA provided 13,066 units of service in advocacy,

outreach and other supportive services, a 23% increase. We are justifiably proud of the amazing level of care coordination that MGA's small team of four people is able to provide, and we look forward to future growth as we continue our affiliation with AGH and the Allegheny Health Network in the ensuing fiscal year.

Despite this growth, this year MGA experienced a significant cut in our budget. We are currently in the process of trying to find other sources of support to sustain present levels of services. Never has YOUR support been more crucial! If you or a loved one has ever been helped by MGA, we hope that you will show your appreciation by giving generously to our annual appeal. MGA is successful because of you. Please help us continue this legacy of service begun 58 years ago.

## Coordination of Your Medical Care is

by Alan E. Weidman L.P.N.,  
Patient Care Coordinator

As we begin the last quarter of the year, it's a good time to reflect on how important a primary care physician is to your overall health.

First off, do you have a primary care physician or PCP? Do you see him/her on a regular or semi-regular basis? Are all medical test results forwarded to his/her attention? Your other medical specialists should be faxing or communicating any and all results with your primary care physician. Informing your primary care doctor of any tests and lab work ordered insures you will not have to repeat that which has already been done.

Secondly, if you use more than one pharmacy it is very important that your primary care physician is aware of all your medications, including any over-the-counter ones such as vitamins or supplements. This will help insure that your medications are compatible and you will not incur any adverse reactions from the medications you are presently

## PRIMARY

taking. This literally could save your life.

Thirdly, any treatments, such as physical therapy, chiropractic, or other outside treatments that another doctor ordered, should always be shared with your primary care physician for his/her approval and guidance.

You should never assume that your primary doctor knows everything that is going on with you. Many times things are forgotten or miscommunicated. You are your own best advocate. No medical professional will ever be upset that you updated them about your healthcare. When you are diagnosed with a chronic illness, communication between doctor and patient is crucial. Your family will appreciate that you are taking charge of your health in this way, and your doctor will too.

All of us at MGA want to keep you as healthy as possible. If we can ever be of assistance to you, please call us at 412-566-1545.

### 5<sup>th</sup> Annual Pooch Parade

MGA invites all dog lovers to enjoy a fun day together at South Park on Sunday, October 27th, 2013 for the 5th Annual Pooch Parade. Form a team to raise money for MGA while you walk in honor of a loved one with MG! This family-friendly event features a one-mile fun walk on a paved trail beginning at the Dog Park at South Park. All registered participants will receive morning refreshments, a goody bag, a long-sleeve t-shirt, and a bandana for their dog. Walkers without dogs are welcome too! The event features a costume contest with prizes for best dog and best dog/owner combo costumes. There will be music, fabulous raffles of gift baskets and silent auctions, including a Myrtle Beach vacation. A variety of vendors will be on hand to provide information and products of interest to dog lovers. Registration begins at 9:00 am and the "Pooch Parade" begins at 10:00 am.



So bring your "best friend," canine or human, and enjoy a day of fun while supporting people with myasthenia gravis. For more information about the event, please call (412) 566-1545 or visit [mgawpa.org](http://mgawpa.org) to download a registration form.



# PREVENTING ACCIDENTS IN THE HOME

## for People with MG

by Michelle Dulashaw, Medical & Social Support Specialist

Most accidents happen in the home, even for people that do not have Myasthenia Gravis. The various symptoms that affect someone with MG including, vision problems, difficulty walking, fatigue or overall weakness associated with MG, can increase the risk of injury and have bearing on the overall safety of your home. There are steps you can take to help keep home safe, especially if you live on your own.



### BEHAVIORAL STEPS:

1. Take your time and get your balance!! When you are getting out of bed or a chair, you can be a little off balance. It is important to make sure you maintain sufficient support, especially if you are moving around at a time when you are not at optimum strength.
2. Never rush to the phone or door. If you're expecting a call, keep the phone nearby. Consider leaving a note on the door asking visitors to give you time to answer your door.
3. When picking something up off the floor/ground, try to bend with your knees rather than leaning. If you have an unsteady gait, it is best if you consult your physician about using a walker or cane. Another option is a "reacher" device that can help you pick things up or get something from a high place.
4. Compile a list of emergency phone numbers. Keep them near your telephone, attached to the refrigerator, or any other place that is noticeable and easily accessible.



5. Have an emergency exit plan and always keep your fire extinguisher in working order. Learn how to use it in an emergency.



6. Keep a flashlight and fresh batteries in an easily accessible place.



7. Wear a medical alert bracelet or necklace stating you have MG and any other health conditions.

8. Use caution while in the bathroom. Extremely hot water during a shower or bath may cause weakness. If you feel weak and you need to bathe, have someone assist you if you need assistance getting out of the tub. It may also help to have a hand held shower head and set your water heater to 120 degrees Fahrenheit to help avoid burns.

9. If you live alone, it is important to have someone check-in on you daily either by a short visit or by phone.



10. When cooking, avoid wearing loose clothing and keep all towels and other flammable items away from burners.

### HOUSEKEEPING:

1. Keep walkways and stairs clear. Clean up spills as soon as possible.
2. Do your home cleaning and chores when you are at your strongest. If your home tends to be on the warmer side and you don't have an air-conditioning unit, make sure you do any needed chores early in the morning when your home is still cool. Take frequent breaks and drink plenty of fluids.



### ELIMINATING POTENTIAL HAZARDS:

1. When using area rugs, make sure they are secured in place with tape or have a non-slip backing.
2. Make sure your furniture is sturdy enough to help support you while trying to sit down or stand up. Avoid furniture with wheels that can move out from under you easily.
3. Repair holes on surfaces you walk on as well as making sure they are even, including steps, floors, and sidewalks.
4. Make bathing safer by using slip-resistant bath mats or strips. Also, install grab bars in your bath or shower. A hand held shower head or a shower chair can also make bathing less of a chore.
5. Have proper lighting in every room and entrance. Make sure there is access to light switches near entryways to avoid walking through dark areas. Nightlights are also a great addition to have if you need to get up during the night to use the restroom or get a snack.
6. Keep a lamp and phone near your bedside.
7. Keep smoke alarms and carbon-dioxide alarms in working order. Test them at least once a month, and replace batteries when the clock changes in the spring and fall.





# WHAT DO I DO AT MGA... THE SHORT ANSWER IS:

# I don't do windows!



My name is Donna Kalisek and I am the Administrative Coordinator at MGA in Western PA, but many of you may know me better as the receptionist during MGA's Tuesday morning treatment center here in Pittsburgh. The coffee and homemade cookies available at treatment center are also something I do to bring a smile to those who visit for their appointments.

Recently several clients have asked me *"What do you do in the office when treatment center is over?"*

It's important to realize that the Myasthenia Gravis Association is NOT JUST the treatment center on Tuesday mornings. Our weekly treatment center is an extension of the neurologists' office, staffed with knowledgeable personnel that deal specifically with the treatment of myasthenia gravis and we serve nearly 500 patients annually.

MGA is a non-profit charitable organization staffed Monday through Friday from 8:00 am to 4:00 pm that serves people with MG from 26 counties in Pennsylvania. We also handle calls and emails from people from all over the country. MGA has a Board of Directors that oversees everything that we do. We are a patient-centered organization that provides expert and unmatched treatment and support to anyone with a diagnosis of myasthenia gravis, including family members, friends, & coworkers. And that service and support doesn't end when treatment center is over. We also:

- *authorize and order prescription refills*
- *schedule and analyze needed testing, including authorizations*
- *supply information and referrals to other physicians as necessary*
- *visit MG patients who are in the hospital*
- *advocate with insurance companies*
- *handle referrals and inquiries from other doctors*
- *plan support groups, and other patient outings*
- *provide training opportunities for residents*
- *keep our patient information packets updated*
- *manage our website ([www.mgawpa.org](http://www.mgawpa.org)) and facebook*
- *conduct public awareness campaigns*
- *hold fundraisers and educational seminars*
- *write and mail out newsletters*

As Administrative Coordinator (beyond receptionist and cookie baker) I also:

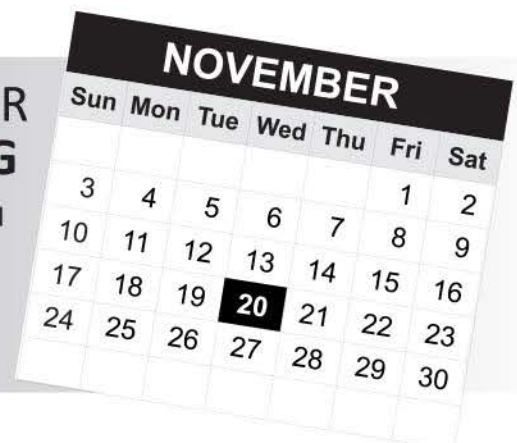
- *assist with bookkeeping*
- *prepare correspondence*
- *generate mailings*
- *update our mailing list*
- *order office supplies*
- *work on fundraisers*
- *answer phones*

I have been a part of MGA for over 45 years, first as a patient myself, then getting involved with fundraisers, doing minor clerical duties, and talking to other people about my experiences. For 20 of those years I've been a member of the staff. Because of my history with myasthenia gravis, I can talk to patients and help them understand and cope with this illness. I've dedicated my life to MGA because of the commitment I feel EVERY DAY that I'm in the office, not just on treatment center day. There is a necessity for this organization because myasthenia gravis is such an unknown and unpredictable disease. I'm here to help others as I was helped so many years ago through this organization and the people that are committed to its mission.

So when you come in for your appointment, remember that there's a lot more to MGA than just the Treatment Center. You can call me any Tuesday, Thursday or Friday between 8:00 am and 2:30 pm (412-566-1545). But remember, I don't do windows!

## MARK YOUR CALENDAR MGA 58<sup>th</sup> ANNUAL MEETING

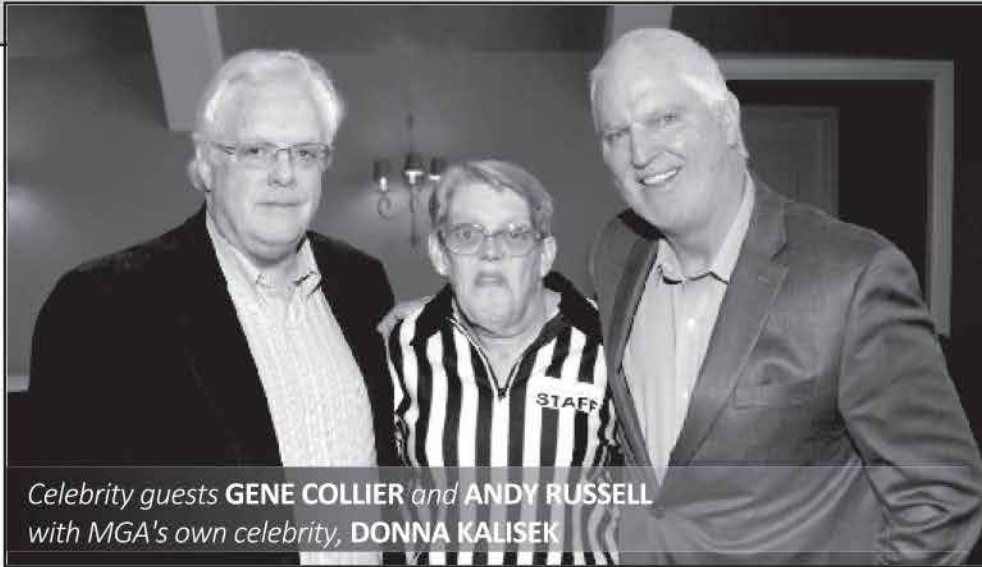
We hope you'll join us for our first-ever weekday afternoon Annual Meeting, Wednesday, Nov. 20, 2013, from 2pm to 4pm at the AGH Magovern Conference Center. Free refreshments, free parking, helpful information about MG, and good company! Watch for your invitation in the mail! This is your organization – and your involvement is vital!





19 YEARS & COUNTING!

# The Annual MGA Sports Memorabilia Auction



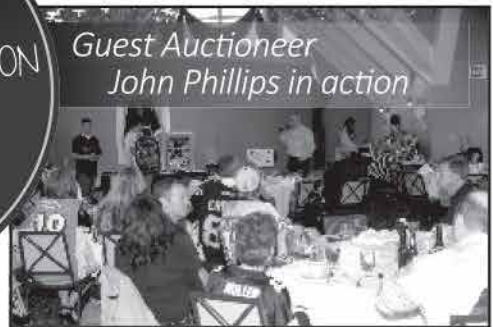
Celebrity guests **GENE COLLIER** and **ANDY RUSSELL** with MGA's own celebrity, **DONNA KALISEK**



A wall of beautiful baskets!



Live Auction Table



Guest Auctioneer John Phillips in action

Thanks to everyone who supported our 19th Annual Sports Memorabilia Auction, held at The Club at Nevillewood on April 7, 2013. We are so grateful to our Co-Chairs, board members Bill Murtha and Ron Balog, our event volunteers: Jim Riley, photographer Brian Ator and his son Uly, Dan Gallagher, Kathryn and Fred Guenther, videographer Tim Ranier, board members Sylvia Danehy (and her husband Bob), Kristen Geary, Denise Beverina Moore, and our celebrity guests: Auctioneer John Phillips, Gene Collier, Marv Kellum, Andy Russell, Rod Salka, Frank Thomas, and singer-songwriter Mike Gallagher.

MARK YOUR CALENDAR FOR NEXT YEAR'S AUCTION SUNDAY April 6, 2014

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The Capital Grille  
The Tin Angel  
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Every effort has been made to insure the accuracy of the listed information. If you see an error or omission, please let us know.

# Thank you to all of our generous donors!

The following donations were received between January 1 and June 30, 2013.

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In Memory of Ronald Claire Grafton  
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Carol Cordner  
By: Daisy Case

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



Your contributions help myasthenia gravis patients continue to receive the outstanding care they need.

**THANK YOU FOR YOUR GENEROSITY.**

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**KEYSTONE** of Hope

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To subscribe by email, please call MGA (412-566-1545) and make sure we have your current email address on file.

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 <p><b>SEPTEMBER</b></p>	 <p><b>OCTOBER</b></p>	 <p><b>NOVEMBER</b></p>
<p><b>MGA SUPPORT GROUP MEETINGS</b> September 21, 2013 1 pm to 2:30 pm Allegheny General Hospital Singer Library</p> <p>LOOK for more meeting dates: Oct. 19, 2013    Jan. 18, 2014 Nov. 16, 2013    Feb. 15, 2014 Dec. 21, 2013    Mar. 22, 2014</p>	<p><b>DAY OF GIVING</b> October 3, 2013 24-hour online giving event at <a href="http://www.pittsburghgives.org">www.pittsburghgives.org</a></p> <p><b>5<sup>th</sup> ANNUAL POOCH PARADE</b> October 27, 2013 (See page 2 for details)</p>	<p><b>MGA 58<sup>th</sup> ANNUAL MEETING</b> November 20, 2013 2 pm to 4 pm Allegheny General Hospital Magovern Conference Center</p> <p> Find us on: <b>facebook®</b></p>