

WESTERN PENNSYLVANIA'S

**KEYSTONE**

of

*Hope*M  
G  
A**Myasthenia Gravis**  
Association of Western Pennsylvania  
at Allegheny General Hospital  
A Treatment & Advocacy Center

## MGA ANNOUNCES LEADERSHIP CIRCLE

Founded in 1955, MGA is one of the oldest and largest organizations of its kind in the US, and yet it is also one-of-a-kind, thanks to our very unique joint venture with Allegheny Health Network/Allegheny General Hospital. This partnership provides the ultimate in coordinated care and treatment for people with myasthenia gravis. Unfortunately, due to recent cuts in funding, support from this partnership is not sufficient to continue operations at the level of quality care our patients have come to depend upon.

In order to ensure that MGA will have the funds necessary to maintain the highest quality of care and achieve future sustainability, the MGA board has formed a **LEADERSHIP CIRCLE** of supporters. The MGA Board invites supporters of MGA to become LEADERSHIP CIRCLE members and make a special gift of \$1,000 or more to help raise these needed funds. Leadership Circle members will enjoy a variety of rewards in return for their generosity. Several lead gifts to this fund have already been received or pledged, including from MGA volunteers Kathryn & Fred Guenther and MGA board member Mark Daday and his wife Rose Peluso.

The Leadership Circle goal for 2020 is 25 members. Won't you consider becoming part of this very special circle of friends of the organization that is dedicated to you or your loved one's health and well-being? For more information, please call Donna at 412-566-1545.



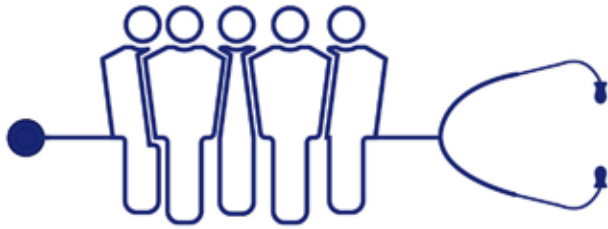
*Please note: Leadership Circle membership is separate from, and in addition to, our Annual Holiday Appeal which so many of our patients and friends contribute to so generously each holiday season. This year's Holiday Appeal will go out in mid-December.*

## MARK YOUR CALENDAR MGA 63<sup>RD</sup> ANNUAL MEETING

Please join us for this year's annual meeting and educational seminar on **Saturday, November 2<sup>nd</sup>**, from **11am to 1:30pm** in the Ambrose/Berg rooms on the 2<sup>nd</sup> floor of the Magovern Conference Center, Allegheny General Hospital. This is a great chance to bring your family and meet other patients, hear guest speakers and ask questions of the MGA medical team. Free admission, lunch and parking, but rsvp is required. Call 412-566-1545 to RSVP.

# reminder:

## TO OUR MG TREATMENT CENTER PATIENTS



MGA has a small (but awesome!) medical team, and a large (and wonderful!) patient roster. Please allow at least 3 days for processing of prescription refill requests. Do not wait until you are out of medication and put your health at risk by unnecessary delays. Also, if you are asked to get blood work before your next appointment, be sure and mark your calendar as a reminder. It's important to get your blood work done well in advance of your next appointment at the MG Treatment Center, so your doctor can view the results and adjust your medication if needed.

# MG SUPPORT GROUP

You are invited to attend a **SUPPORT GROUP** every **third Saturday of the month** from **1:00pm to 2:30pm**. Join us with your questions and concerns, or just to share your experiences to support others. We meet in the **MG Treatment Center location in the Allegheny Professional Building, 490 E North Ave Suite 410, Pittsburgh PA**. Contact MGA at [donnak@mgawpa.org](mailto:donnak@mgawpa.org) to be added to our email list or call **412-566-1545**. RSVP's are requested. We encourage everyone, including newly diagnosed and seasoned patients, their family members and friends to attend.



\*\*\*We regret to inform you that the **Beaver County Support Group** that met at the Heritage Valley Health System has been **DISCONTINUED** due to lack of participation. Please contact MGA if you would like to start a support group in your area.



## HIGHMARK WALK

**Thanks to all who participated** in this year's Highmark Walk for a Healthy Community! MGA raised a total of **\$3,370.00** including sponsorships from AmGen, NuFactor, Seniors Blue Book and Vitas Hospice. We can do even better next year, with your help!



# What YOU SHOULD KNOW about ADVANCE DIRECTIVES



As a person with a chronic illness, you have a say in the health care you receive. When you are ill, your doctor should explain what treatments there are for your illness so that you can decide which one is best for you. But if you were too ill to understand your treatment choices or to tell your doctor what treatment you want:

- Who would you want to make decisions for you?
- What type of health care would you want?
- What health care wouldn't you want?

Questions like these may be hard to think about, but they're important. That's why MGA wants you to know about a legal form you can complete. It's called an **Advance Directive**.

**What is an Advance Directive?** An advance directive is a legal form that helps your doctors and family members understand your wishes about health care. It can help them decide about treatments if you are too ill to decide for yourself. For example, if you are unconscious or too weak to talk. There are two types of advance directives: [durable power of attorney for health care](#) and a [living will](#).

*Your advance directive is used only when you aren't able to make decisions yourself.*

A **durable power of attorney for healthcare** lets you name the person you trust to make health care decisions for you if you can't make them yourself – your "health care agent." He/she will have the legal right to make health care decisions for you. You can choose any adult to be your agent. It's best to choose someone you trust, who knows you well and who knows your values. You should make sure the person is willing to serve as your agent. If you don't choose an agent, your doctor will choose someone to make decisions for you in the following order: legal guardian (if you have one), spouse, adult child, parent, sibling, grandparent, grandchild, or a close friend. Your health care team, or a court, will make decisions for you if none of the above is available.

A **living will** is a legal form that states what kinds of treatments you would or wouldn't want if you become ill and can't decide for yourself. It can help your health care agent and your doctor make decisions the way you want them to. Writing down what kind of treatment you would or wouldn't want can help make it easier for those who are asked to make decisions for you. Talk with your family, your health care agent, and your doctor about your wishes so they won't have to wonder what you want and if they're doing the right thing. If you don't have a living will, decisions will be made for you based on what is known about you in general and about your values. That's why it's important to discuss your wishes with your loved ones, your doctors, and your health care team.

You may change or cancel your **advance directive** at any time. In fact, you should review your advance directive periodically, especially if there is a change in your health, to make sure it's up to date. If you change it, be sure to tell your health care team and have them put it in your health record. Share your new directive with your family members and other loved ones.

For more information – check out [medicare.gov](#) or call the MGA office.

## KEYSTONE <sup>of</sup> Hope

Keystone of Hope is published twice a year by the Myasthenia Gravis Association of Western PA, and direct mailed to patients, donors and friends. It is also available at [www.mgawpa.org](#).

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(412) 566-1545 • [www.mgawpa.org](#)

# Thank you to all of our generous donors

The following donations were received between January 1 through June 30, 2019

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## Memorials & Honorariums

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.

### PERPETUAL DONATION

In Memory of **Ronald Clair Grafton**  
By Doris Grafton & Family

### HONORARIUMS

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By GeorgeAnn Goff-Ridge  
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#### Lena Colasurdo

By Debra Santulli-Barone  
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#### Donna Kalisek

By Debra Ann Davis  
Stan Kaczorski

#### Annamarie Lazzara

Frank Lazzara

#### John McMurray's birthday

By Jill Methven

#### MGA Staff of the 70s, 80s & 90s

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#### Sophie Mileto

By The Loons Group

#### Jane Rohrbaugh

By Bernice Ehrensall

#### George Small, MD

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By Judith & Richard Holman

#### Bill Dinger

By Brian & Elaine Richardson

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By Charles Levison

#### Dennis Felice on our 34<sup>th</sup>

#### wedding anniversary

By Gerri Felice

#### Ralph Getz

By Charlene Getz

#### Mable C. Gifford

By Phyllis Linton

#### Ruth Rose Gordon

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#### David Sousa

By Diana D'Arco

#### Karen E. Swenson

By The Swenson Family

Westview Water Authority

#### Mary L. Verry

By Patrick & Barbara Walters



# fundraising for MGA



Last year at this time, MGA sponsored our 10<sup>th</sup> Annual Pooch Parade at South Park. Despite the rainy, cold day, we still had many of our loyal Pooch Parade participants attend, although considerably fewer than in years past. Faced with declining attendance, we have come to realize how difficult it is to sustain and grow this event with weather challenges and our small staff, so we have decided to discontinue the

Pooch Parade. We want to express our deepest gratitude to former board members **David and Arlene Weintraub**, who created this event, and worked so hard to make it a success, and to all of our generous and loyal participants over the past ten years.

For all of you dog lovers, we encourage you to bring your pooches to the Highmark Walk in May of 2020

(date to be announced). We plan to incorporate some elements from the Pooch Parade into next year's Highmark Walk. It's a great event, and fun for the whole family.

Looking ahead to next year, we will be planning a new Fall Fundraiser, in consultation with our Fund Development committee. If you have suggestions, please email [Donnak@mgawpa.org](mailto:Donnak@mgawpa.org).

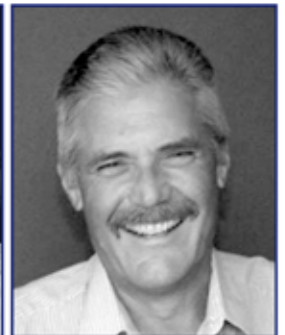
## WELCOME NEW MGA BOARD MEMBERS



Patty Zurawski



Al Parris



Joe Kulik

Former MGA employee **Patty Zurawski** brings experience from her long and varied medical career, including serving as the MGA nurse, along with the personal experience of her aunt and uncle both having been diagnosed with MG.

**Al Parris** currently works in management for Collins Aerospace on Long Island. He is eager to assist the organization that has educated him and so many others about life with MG. Having recently moved from the Pittsburgh area, he currently resides in South Carolina with his wife, and will join most meetings via telephone.

Attorney **Joe Kulik** supports MGA because his father had MG. Joe is the managing partner of Kulik Law Offices and is married to State Representative Anita Astorino Kulik. Joe also serves his community as a volunteer firefighter and through his involvement with various nonprofit organizations.



# 5<sup>TH</sup> ANNUAL MGA COMEDY for a CAUSE

On fire!!!



hahaha!!



LOL

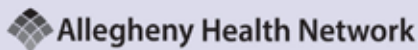


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Wood Street Frames

*Please note: Every effort has been made to ensure the accuracy of this list of donors. We apologize if there are any errors or omissions.*





## A NOTE FROM **DEBRA SANTULLI-BARONE**, *former Director of the MG Alliance in NYC*

### **Dear MG Donors & Friends:**

*It's been four years since I closed the NY MG Alliance office and asked MGA of WPA to take over. They have done a wonderful job through the years. I commend the staff, volunteers and Maree Gallagher, the Executive Director. She made the transition quite easy for me. As I read the MGA Spring newsletter, I was overjoyed to see how committed my former donors are to the cause. You are still donating! Wow!! It touches my heart to see all the familiar names. I thank you all for believing in me, and my decision, and believing in the MG Association of WPA. My decision was based on*

*their integrity, commitment and love for the myasthenic patient.*

*As I have mentioned, I closed the NY office (it was a one person office – me!) when I was diagnosed with breast cancer. Now, four years later, so far, so good. In 2015, I was diagnosed with CML (Chronic Myeloid Leukemia). I'm happy to say it is now in remission, and I'm feeling better.*

*I am co-host of a community television show, Cancer Tamer Talk Show ([www.cancertamer.org](http://www.cancertamer.org)), educating the community and interviewing doctors, lawyers, and fitness profes-*

*sionals, while discussing my diagnosis with the founder of the show, Dr. Charley Ferrer. We also do workshops in the community. In between helping my mom, who is 90, I also run a support group for kids who have been bullied. In my "spare" time, I'm learning to play the ukulele, and enjoying time with my family.*

*Whatever time you have on this earth, I encourage you all to start one new thing that you never did before and enjoy it!*

*With love, and grateful appreciation,  
Debra Santulli-Barone*

## **THANK YOU** for **CHOOSING** **MYASTHENIA GRAVIS ASSOCIATION** OF WPA WHEN SHOPPING ON **AMAZONSMILE.COM**

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It's easy — **and it will help support MGA all year long.** AND remember to invite your family, friends and co-workers to do the same.



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**MG Support Group**  
**OCTOBER 19, 2019**  
1pm to 2:30pm  
MGA Treatment Center  
Call Donna to RSVP: 412-566-1545



NOVEMBER

**63<sup>rd</sup> Annual Meeting  
and Educational Seminar**  
**NOVEMBER 2, 2019**  
11am to 1:30pm  
See info on page 1



DECEMBER

**MGA Holiday Appeal  
Goes out.**  
Please give generously!

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and on our facebook page:  
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