



## Dear Friend of MGA:

If the last two years have taught us anything, it is that change is inevitable and how you deal with change will shape how successful you are in life. In 2022, MGA will be experiencing a lot of changes.

As some of you may have heard, at the end of 2021, Allegheny Health Network (AHN) made the decision to end its relationship with MGA - deciding instead to move all clinical services that MGA was providing to their MG patient population in-house. This was obviously a major concern for MGA as a large portion of our annual funding came from AHN.

After multiple meetings and phone calls with members of the MGA Board of Directors and Executive Committee, a determination was made that MGA would be able to continue operations even without the funding from AHN, although how MGA operates would need to change.

With AHN moving their MG clinical support services in house, MG patients will still have access to their clinical care teams led by Dr. Small and Dr. Rana. MGA is pleased to know that there will be no interruption in the clinical care being provided to our MG patient population.

Moving forward, MGA will continue to focus on the core values that have been in place for the organization since we were founded in 1955 – providing the highest quality patient support, education, and advocacy to all of the patients and families we serve. We are confident that MGA will emerge from these changes stronger than ever and we ask for your continued support during this time.

Thank you for your continued partnership! I hope you enjoy this issue of the Keystone of Hope newsletter – please take a look at all the different ways you can get involved with MGA through new education programs, fundraising events and advocacy initiatives. I look forward to the opportunities that the coming months will bring for us to connect and collaborate.

Jim Joyce, Executive Director  
MGA of WPA

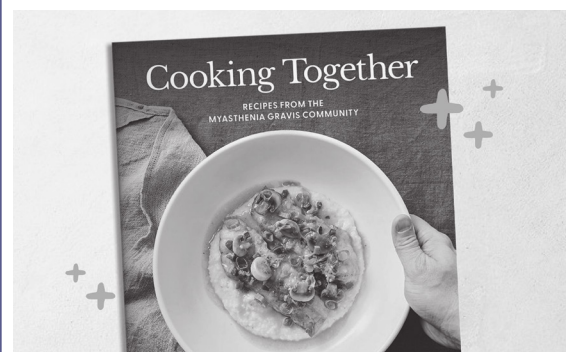
## MESSAGE FROM THE EXECUTIVE DIRECTOR



### THE MG UNITED COOKBOOK IS HERE!

Created by people living with MG,  
for people living with MG.

This limited-edition cookbook features three  
MG-friendly recipes created by **celebrity chef**  
**Sean Brock**, who lives with MG.



Download the cookbook  
at [MG-United.com](https://MG-United.com) today!

MGA United

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# HAPPY Retirement



**DONNA KALISEK**

*"It is with a heavy heart that I leave MGA, I had hoped to see a cure during my time here... May MGA continue to help and support those in need."*

The MGA Board of Directors and Staff would like to congratulate **Donna Kalisek** on her retirement from MGA as of December 31, 2021.

Donna was a critical member of our healthcare team, serving in various roles, including Administrative Coordinator, for the last 30 years. Her personal experiences and challenges with myasthenia gravis gave her a special ability to support many patients and family members because she understood what they were going through with this disease.

Diagnosed with MG in 1968, Donna never let the disease stop her from moving forward. She worked hard over the years to gain more and more independence and self-confidence. With a survival spirit, a quick wit and a kind heart, Donna was always willing to lend a helping hand whenever she could.

In Donna's retirement announcement to the MGA Board of Directors she wrote, *"It is with a heavy heart that I leave MGA, I had hoped to see a cure during my time here. But all things must end sometime. Until a cure is found, there will always be patients and family members that need assistance with the life-challenges of this little-known incurable disease. May MGA continue to help and support those in need."*

Donna also stated her willingness to continue her support of this organization with occasional volunteer projects, so you may still see Donna at different events and programs offered by MGA in the future! Donna has requested that anyone wishing to celebrate her retirement kindly do so by making a donation in her honor to MGA to help continue the needed services provided by MGA of WPA.

Best of luck Donna! We wish you good health and happiness as you begin your new adventures in life!

*"We don't laugh because we're happy, we are happy because we laugh."*

- William James

**SAVE THE DATE:** Don't miss this fun evening with great food and great entertainment! The talent line up at this year's show is sure to tickle your funny bone. This year's event will take place at **Elements in North Huntingdon, PA on Saturday, July 16, 2022.**

We've got a delicious dinner buffet, a wonderful dessert table, a cash bar, and of course our fabulous basket raffle, silent auction and more. Plus Elements features plenty of free parking in their huge lot!

Reserved seat tickets for dinner and show are \$50. Buy tickets on-line at [www.slapsticksproductions.com](http://www.slapsticksproductions.com) or call the MGA Office at **412-566-1545.**

**7<sup>TH</sup> ANNUAL MGA  
COMEDY  
for a  
CAUSE**

# MY MG Story

*"To be a person is to have a story to tell."*

- Isak Dinesen

**Myasthenia Gravis** is often called the **Snowflake Disease** because it impacts each person so differently. Because each MG patient has a unique story to tell, MGA created the [My MG Story Initiative](#).

My MG Story is a new program being offered by MGA to allow patients as well as their families and friends the opportunity to share their stories, shine a light on our patients' lives, and better explain how MG has impacted them.

We hope you enjoy these stories and find strength and inspiration from them.

## Would you like to participate in the My MG Story Initiative?

Contact the MGA Office at  
**412-566-1545** for more information!



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

UW of Allegheny County **#82**  
UW of Erie County **#45146**  
UW of Westmoreland County **#1178**  
UW of Mon Valley **#1178**  
UW of Beaver County **#4861**  
UW of Washington County **#0082**  
UW of Butler County **#5981**

**THANK YOU** for your generous support.



## FLO BURKA'S MG STORY

Hi my name is Jackie Kaye, This is a story of Flo Burka, my Godmother and cousin and how her Myasthenia Gravis story started out of the blue. My relationship with Myasthenia Gravis started in 1972 when I came across a kit sent to our family to collect money for the charity. I was ten years old and I went from house to house in my neighborhood to collect for a disease that I knew nothing about, but would have a connection to later in life.

In September 2014 I was living at my eighty-four year old cousin's house because of my own life happenings. I was working part-time and helping her with daily activities around the house. One day she began slurring her words. It's not funny now, but we were both laughing. About a day later we realized she couldn't swallow her own saliva. Then a day later, on top of that, she started bending at the waist as she was trying to walk. You have to understand, Flo only had a bit of high blood pressure then. All this in less than a week's time. Wow - I thought I better take her to see her PCP.

It was Friday September 18, 2014 and she needed blood work, so I thought we could go to Ohio Valley General Hospital to do that and stop in to see her PCP since his office was just down the hall from the lab. Because Flo didn't have an appointment, he agreed to see her in the waiting room. I explained what was happening and he said he would see her next Tuesday and check her out then. (??? What???) So, we went home. I kept thinking something serious is happening. The next day I called an ambulance to take her to the ER at Allegheny General Hospital. No one in the ER could figure out what was going on with Flo, so they decided to keep her there.

After being admitted and after answering all the questions from an onslaught of doctors, she was moved to the ICU where a pulmonologist

*continued on page 4*



prescribed Mestinon. My sister was there and said Flo's symptoms seemed to magically disappear, except for the pesky Drop Foot. It was then that she was diagnosed with Myasthenia Gravis. How ironic, this was my connection to Myasthenia Gravis that I learned so many years ago when I was a kid. Flo also had three Plasmapheresis treatments which helped her considerably.



It was a long road through physical therapy for her Drop Foot. While at OVGH Acute Rehab, another Allegheny Health Network neurologist saw Flo and just by looking at her diagnosed her with Parkinson's Disease. Wow, that was something, along with Drop Foot and MG; she now has Parkinson's Disease.

Boy, did I learn a lot as her caregiver.

Flo did not have any extreme medical issues prior to her MG crisis. We both learned about Pyridostigmine (Mestinon), Prednisone, Plasmapheresis, Dyskinesia, Trazadone, Drop Foot, Cyprofloxacin and C-Diff. We also learned how all the meds work together and sometimes against you. I'm speaking of Cipro, an antibiotic that was given to her for an infection, which totally wiped her out. She had a hard time walking, moving and speaking. She was given another antibiotic and resumed to her prior state. Yikes, anyone with MG, watch those antibiotics.

During the COVID pandemic on July 30, 2020 Flo turned 90 years old. We had a zoom birthday party for her. It kept everyone away (too bad COVID, not on my watch) and at the same time she was able to see her family and enjoy the experience.

I took care of Flo to the best of my ability for six years. She was in remission from Myasthenia Gravis for a few years but still dealing with Parkinson's symptoms. But on January 18, 2021 she developed a Myasthenia Gravis exacerbation which brought her to the AHN ER. Because of the pandemic the hospitals were on lockdown and patients could not have visitors or family members or their spokespersons there to help. I was Flo's spokesperson and advocate and I'm sure that it was scary for her being alone in the ER. But eventually we got through it

with phone communications. After the ER, she was transferred to the ICU for a round of Plasmapheresis, 5 treatments, one every other day. She did well and the Myasthenia Gravis symptoms faded. But as fate should have it, she developed an infection and on February 6, 2021 she passed away.

I must say that I would never have gotten through those six years, the hospital stays and her hospice care before her passing, without the help of the Myasthenia Gravis Treatment Center, Dr. Rana and Cindy Spring, RN. Cindy would answer all my calls and questions and give me the best suggestions to help me manage Flo's care at home. I can't say enough positive things about the clinic.



**Would you like to participate in the My MG Story Initiative? Contact the MGA Office at 412-566-1545 for more information!**



**The Myasthenia Gravis Association of Western PA (MGA) is hosting an on-line auction to benefit MGA's FREE patient support services.**

The on-line auction will be available from **8 a.m. on Thursday, April 21, 2022 to 8 p.m. on Tuesday, April 26, 2022**. The on-line auction will feature 20 items including signed sports memorabilia, gift baskets and many more great items! Go to [www.32auctions.com/mgaspring22](http://www.32auctions.com/mgaspring22) to view the items and place your bids. Contact the MGA Office at **412-566-1545** or email [mgaoffice@mgawpa.org](mailto:mgaoffice@mgawpa.org) for more information.

# 2022

# HIGHMARK®



## WALK FOR A HEALTHY COMMUNITY

The Highmark Walk for a Healthy Community is an annual fundraising event to help participating organizations raise money and public awareness for their missions. The Myasthenia Gravis Association is excited to be participating again this year, and we hope you will join us to make it a success!

This year the walk will take place on **Saturday, May 7 at 9 a.m.** There are multiple ways to get involved and support MGA! Using the Highmark Walk online portal ([www.walkforahealthycommunity.org](http://www.walkforahealthycommunity.org)) you can select Myasthenia Gravis Association of Western Pennsylvania as your nonprofit of choice and then register to walk as an individual or as part of a team. On the same site you can also donate directly to an individual or team to help them meet their fundraising goals.

Registration is now open! Please consider supporting MGA by walking, raising money, and spreading the word! Access the MGA page at <http://hcf.convio.net/mgawalk2022> and then select one of the 4 options listed below:

1. Register as an individual
2. Form a team
3. Join an existing team
4. Donate

You can also send a check to MGA, 505 Jackson Drive, Apollo, PA 15613. Be sure to note that your donation is for the Highmark Walk. Contact Jim Joyce with questions, at **412-566-1545** or [jjoyce@mgawpa.org](mailto:jjoyce@mgawpa.org).



### 50/50 RAFFLE

Proceeds will benefit **MGA** as part of the Highmark Walk for a Healthy Community. Tickets are available until **May 1, 2022**.

**TICKETS:**    **1 ticket @ \$ 1.00**  
                  **6 tickets @ \$ 5.00**  
                  **15 tickets @ \$10.00**

For details or to purchase tickets, call Jim at **412-566-1545**

*"The wings of hope carry us soaring high above the driving winds of life."*

- Ana Jacobs

Starting in 2020, as a part of our Butterflies of Hope program, MGA established the **BUTTERFLY TRIBUTE TREE**. The Butterfly Tribute Tree provided individuals and families with a meaningful way to honor or memorialize a loved one or friend with whom they have shared special memories with over the years. Based on the positive response that we received regarding the Butterfly Tribute Tree over the last 2 years, we decided to make this an annual event that would coincide each year with National Myasthenia Gravis Awareness Month.

In June 2022, a butterfly shaped ornament will be mailed to past donors and supporters of MGA. They will be invited to decorate the ornament as they wish – potentially including their loved one's name, some special words or something meaningful in the decoration and maybe a small photo. All returned ornaments will be displayed from July 2022 – June 2023.

If you are interested in receiving a butterfly ornament to decorate for the Butterfly Tribute Tree, please contact Jim Joyce at **412-566-1545** or [jjoyce@mgawpa.org](mailto:jjoyce@mgawpa.org).

## 2022 BUTTERFLY TRIBUTE TREE



# Thank you to all of our generous donors!

*The following donations were received between July 1, 2021 and December 31, 2021.*

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## KEYSTONE of 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](http://www.mgawpa.org).

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**Editorial Assistant:** Donna Kalisek

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MGA, 505 Jackson Drive, Apollo, PA 15613 | (412) 566-1545

**MGA would like to thank our newsletter sponsors:**

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# Honorariums & Memorials

from July 1, 2021 to December 31, 2021

## PERPETUAL GIFT

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

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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.

# MGA VIRTUAL HOLIDAY PAINT & SIP FUNDRAISER

Many thanks to everyone who supported the MGA Virtual Holiday Paint and Sip Fundraiser on December 9, 2021.

Over 80 people participated in the event and everyone who attended had a wonderful time!

A special thanks to Ms. Kristy Walter who led the creation of the snowflake decoration that evening and to Dr. Michael Kavic and Mrs. Patricia Kavic from **Kavic Winery in Carnegie, PA ([www.kavicwinery.net](http://www.kavicwinery.net))** who provided the wine for the wine tasting portion of the program.

The MGA Board of Directors and Staff would like to thank everyone who supported this event!



## MGA EDUCATION/SUPPORT GROUP SERIES:

As part of the ongoing MGA Education/Support Group Series, MGA is pleased to announce that they will be offering a new virtual education program for our patients and their family members. MGA is partnering with Alexion Pharmaceuticals to offer the program which will take place on **Wednesday, April 27, 2022 at 6 pm.**

Megan Miller, Patient Education Manager with Alexion Pharmaceuticals will be discussing *"Partners in Care – It Gets Emotional."* The program is free, but registration is required. To register, please contact the MGA Office at **412-566-1545** or **[mgaoffice@mgawpa.org](mailto:mgaoffice@mgawpa.org)**.

Myasthenia Gravis Association  
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APRIL/MAY

**MGA ON-LINE AUCTION**  
**APRIL 21-26, 2022**  
(8am Thursday to 8pm Tuesday)  
Details on page 4

**HIGHMARK WALK FOR A  
HEALTHY COMMUNITY**  
**MAY 7, 2022** (at 9am)  
Register online at  
[walkforahealthycommunity.org](http://walkforahealthycommunity.org)  
Details on page 5



JUNE/JULY

**BUTTERFLY TRIBUTE TREE**  
**JUNE 2022**  
Details on page 5

**7<sup>TH</sup> ANNUAL COMEDY FOR  
A CAUSE FUNDRAISER**  
**JULY 16, 2022**  
Details on page 2  
Buy tickets on-line at  
[slapsticksproductions.com](http://slapsticksproductions.com)



AUGUST

**2<sup>ND</sup> ANNUAL MGA GOLF  
OUTING**  
**AUGUST 2022**  
More details to follow!

VISIT US AT:  
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and on our facebook page:  
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