

WESTERN PENNSYLVANIA'S

KEYSTONE

of

*Hope*M
G
A**Myasthenia Gravis***Association of Western Pennsylvania*

A Support, Education, & Advocacy Center

MESSAGE FROM THE EXECUTIVE DIRECTOR

MGA EDUCATION/ SUPPORT GROUP SERIES



MGA is pleased to continue our virtual education/support group series throughout the remainder of 2024. The education calendar is as follows...

- **October 23, 2024 at 6:00 PM**
"Emotional Wellness and MG"
– Shelley Gerson, argenx
- **December 11, 2024 at 6:00 PM**
"Care for the Caregiver"
– Amy Grover, Catalyst

These programs are free, but registration is required.

To register for any of the programs, please contact the MGA office at 412-566-1545 or mgaooffice@mgawpa.org.

Dear Friend of MGA:

On March 11, 2024, MGA lost a beloved member of the MGA Family. Donna Kalisek passed away after a short ICU stay at Allegheny General Hospital. For many people, Donna was the face of MGA – she was the first person you would speak to when calling into the office and the first person you would see when you visited the MGA clinic.

Donna lived her life in a way that we should all try to emulate – she was tough, but kind; humble, but proud; and strong, but selfless. When I first started at MGA, Donna quickly became a valued co-worker, mentor and friend. She was a person I could always count on to share her opinion on a number of different subjects and always served as the MGA historian – telling stories and sharing memories of past co-workers, patients, and other friends of MGA.

One of the things that Donna was best known for was creating delicious cookies and other desserts for clinic visitors as well as for many MGA fundraisers. One of the cookies that Donna was most proud of was her famous "Cranberry Puff Cookies." In honor of Donna, we are including that recipe of PAGE 5 of this newsletter. I am confident that Donna would be thrilled if many people enjoyed her cookies for years to come, so please feel free to pass the recipe on to others as well!

Donna was one-of-a-kind and she will never be forgotten. Rest in peace Donna – we miss you!

Jim Joyce, Executive Director
MGA of WPA



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MYASTHENIA GRAVIS SUPPORT GROUP MEETING



SEPTEMBER 21 (12:00pm - 2:30pm)

OCTOBER 19 (12:00pm - 2:30pm)

NOVEMBER/DECEMBER - TBD

Panera Bread - Waterworks

942 Freeport Road, Pittsburgh, PA 15238

Discussion Leader: **Cindy Spring, RN, CCM**
Light refreshments will be provided.

These programs are FREE, but registration is requested. Please contact us at:

412-566-1545 or

mgaoffice@mgawpa.org.

MGA Tour & Tasting

Join MGA as we host our **2nd Annual Tour and Tasting** event at McLaughlin Distillery in Sewickley, Pennsylvania. The distillery tour will take place on **Sunday, October 27, 2024**. Tour #1 will be from 1:15 PM to 2:30 PM and Tour #2 will be from 2:30 PM to 3:45 PM. Tickets will be sold for \$40 for 2 people.

Participants will be treated to a tour of the distillery and after the tour, they will participate in a tasting event of some of the 40+ bourbons, whiskeys, vodkas and flavored moonshine products created by McLaughlin Distillery. There will also be a 50/50 drawing, a bottle raffle, and more!

A special thank you to State Representative Anita Astorino Kulik who will be providing refreshments for the event!

*“To be a person
is to have a
story to tell.”*

- Isak Dinesen

MY MG STORY

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.



IRENE'S ★ ★ MG STORY

My name is Irene and my relationship with Myasthenia Gravis started on the Labor Day Weekend in 1979. At that time I was 48 years old, happily married, had three children (two married and one at home), and was secretary for a local company.

It was that weekend we went camping at a campground near Clarion State Park in Northwestern Pennsylvania. The weather was warm and you could feel the change in the air from summer to fall. The campground was packed with lots to do – swimming, a campground wiener roast, square dancing on the pavilion, craft lessons, horseback riding, and many trails to walk. It was a fun weekend!

Packing to go home, I felt so tired. I was glad to get home, take a shower, and go to bed. I felt extremely tired all that week so I made an appointment with our family doctor. I was told that it was nerves and stress. When driving home, I momentarily saw two roads, one on top of the other in front of me. “What the heck is happening?” The same thing happened that night while I was watching TV – two TVs. “What’s going on?”

I made an appointment with my optometrist and was checked for a brain tumor then was referred to an ophthalmologist. Nothing was found but I was told I had diplopia. I already knew that and bought eye patches so I could see without the double vision. I gave up driving.

For the next 8 months, I experienced strange things happening. At times, I could not chew solid foods so I bought baby food to have available when that happened. I would drink water and it would come out my nose. I could not swallow. While typing, my fingers would stiffen and I could not bend them. My voice would slur. I prayed to God every day that a diagnosis would be found for my issues.

During these 8 months, I had many appointments with specialists upon specialists, even a neurosurgeon. Same diagnosis – stress and nerves. How could it be? I lost my faith in doctors. Why wasn’t there an answer? A few months ago, I was a healthy 48 year old woman enjoying life.

In the meantime, while I am having all of my issues, my oldest daughter is a nurse in the ICU at our local hospital and discussing my problem with a doctor of internal medicine. He told her that he would like to see me. It was at his appointment that I first heard the word Myasthenia Gravis. He prescribed Mestinon and I took my first pill on April 20 – our 29th wedding anniversary. It was like heaven. I threw my eye patches away and I could drive. That little white pill did the trick. My prayers were answered.

The next two months kept me busy. My youngest daughter was getting married so I had a ton of things to do but one Sunday morning I woke up with such a slur in my voice, you could hardly understand me. I called my doctor and he told me to meet him at the ER in 20 minutes. I was admitted to the hospital. He then told me he didn’t know how to further treat me and made an appointment for me to see the doctors at the MG Clinic at Mercy Hospital.

My first appointment at Mercy was with Dr. Guy Corsello, a most compassionate doctor. He hugged me and said “Honey, you have it and we’re going to admit you even if you have to go through the ER.” I was admitted. The next morning, a doctor walked into my room and introduced himself as Dr. Blume. He spent so much time with me that morning explaining the MG disease with no medical terminologies but in plain language. He told me I was too old to have a thymectomy but they had a new treatment that consisted of a large dose of prednisone and mestinon. He explained it would make me so weak that I might be put on a ventilator. He was such an informative and caring doctor. My treatment went very well – no ventilator. I was discharged and had appointments four times a year, then three, then two and finally I was in remission. Over the years, I acquired a moon face and a distended stomach

continued on page 4

that made me look five months pregnant. I didn't care how I looked; just glad to know I was back to normal. Eventually, being off prednisone, my face and stomach went back to normal.

In February of 1992, I retired, still in remission, to take care of my then ill husband. He passed away in November of that year. I had a lot of time on my hands so I did volunteer work at my church, joined a class of water aerobics at our "Y" and could even swim a couple of laps without tiring. Life has been good to me.

I am now 93 years old. Having MG has brought my family much closer. I enjoy our family vacations and had the pleasure of seeing my grandsons grow up and now they have given me eight beautiful great grandchildren. Makes me happy. My prayers have been answered.

A couple of years ago, my youngest daughter had a coworker who had a 90 year old mother having trouble swallowing. My daughter suggested she tell her to be tested for MG. Sure enough it was MG. Everyone in my family is aware of MG's symptoms.

My thoughts go back to my many appointments with doctors and their diagnosis as nerves and stress. They were right about nerves. Back in 1979, MG was very rare and it still is. At the present time, they say there are 83,000 plus cases in the USA which has a population of over 300 million. Needless to say, it's a rarity.

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



MGA BOARD MEMBER

Highlight

MGA is pleased to be able to highlight the members of our Board of Directors. MGA's Board of Directors play a critical role in how MGA operates and provides services to the community. In this issue of the *Keystone of Hope* newsletter, we would like to recognize **Bob Cribbs** who currently serves as the MGA Board President.

Bob was diagnosed with MG in 2003, and he has been a valuable member of MGA since then. Bob retired from Washington Penn Plastics in 2022 where he worked as a Lab Testing Technician since 1998. Prior to working at Washington Penn Plastics, Bob worked as a mechanic and owned his own stone masonry business.

Bob supports MGA in many ways including serving on the MGA Advocacy Committee, participating in national research studies/focus groups, and enthusiastically raising awareness about MG through his family, friends and social media accounts!

Interested in learning more about being a member of the MGA Board of Directors? Contact Jim Joyce at 412-566-1545 or jjoyce@mgawpa.org to discuss potential opportunities.

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. This year's walk took place at Acrisure Stadium on Saturday, June 22. Although the weather was very hot that day, over 30 walkers came out to support MGA! Based on the generosity of our walkers and other donors, **MGA was able to collect over \$6,000 in donations for the walk!** Many thanks to everyone who supported MGA at the Highmark Walk for a Healthy Community!



DONNA'S CRANBERRY PUFFS



2 cups cranberries
(or raisins)

1 cup water

Boil together in a small saucepan until water is gone.

1 cup veg oil

3 cups flour

1 ½ cups sugar

1 tsp. baking soda

2 eggs, beaten

½ tsp. salt

1 tsp. vanilla

extra granulated sugar

Beat oil and sugar together, add eggs and vanilla. Add flour, baking soda, salt and cranberries (raisins).

Mix by hand, batter will be stiff. Form into 1" balls and roll in extra sugar.

Bake on ungreased cookie sheet at 350 degrees for 15 minutes.

In Memory of Donna M. Kalisek

July 13, 1958 – March 11, 2024

In Memory of DONNA KALISEK



On March 11, 2024 we lost a champion for all Myasthenia Gravis patients. Donna Kalisek, our Administrative Assistant and jack of all things MG, sadly left us after a heroic, life-long battle with MG.

Donna volunteered for the Myasthenia Gravis Clinic for many years in both the Mercy Hospital and AHN locations. She was an advocate and friend, not only for Myasthenia Gravis patients, but for anyone in need who crossed her path. Donna never let her MG slow her down. She would hop on her scooter, plug in her Oxygen and away she went!

Donna was an avid Pirate fan, a patron of the arts, a baker of delicious treats and devoted to her family and friends.

Donna was strongly independent, outspoken, had a brutal sense of humor, was exceedingly compassionate, loyal to a fault and a great, great friend. I know that I am not alone when I say she is sorely missed. There are still many times when I think, "I need to call Donna to discuss this with her!"

Donna, you took a piece of my heart with you when you left us. MGA of WPA will always strive to live up to the high standards that Donna set for herself professionally and generally in life.

Rest well and be at peace, dear friend. You certainly earned it.

— Cindy Spring, RN, CCM



Thank you to all of our generous donors!

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KEYSTONE *of Hope*

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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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Memorials & Honorariums

from January 1, 2024 to June 30, 2024



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.

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MGA is hosting its **5th Annual Virtual Holiday Paint & Sip Celebration** to benefit MGA's FREE patient support services.

This year's event will be held on **Thursday, December 12, 2024 at 7:00PM**. For their \$50 donation to MGA, participants will receive a link to participate in the virtual holiday paint and sip event, the supplies needed to create their own snowflake inspired art, and two bottles of wine from Kavic Winery of Carnegie, Pennsylvania. The creation of the snowflake inspired art will be led by Kristy Walter, Art Therapist and the wine tasting will be led by Michael and Patricia Kavic from Kavic Winery.

Myasthenia Gravis is often called the "*Snowflake Disease*" because it manifests itself differently in every patient. MGA believes that having participants create snowflake inspired art at the event will not only allow them to have a beautiful decoration for their home, but also help raise awareness about Myasthenia Gravis and the work done at MGA.

For more information or to register for this year's celebration, contact the MGA office at 412-566-1545 or mgaoffice@mgawpa.org.

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OCTOBER

**MGA TOUR & TASTING
EVENT**

OCTOBER 27, 2024

McLAUGHLIN DISTILLERY
Sewickley, PA
Details on Page 2



NOVEMBER

**MGA ANNUAL MEETING &
EDUCATION SYMPOSIUM**

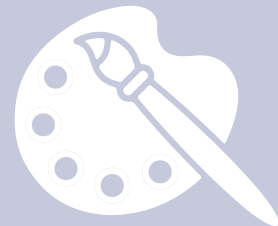
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More details coming soon!

VISIT US AT:

www.mgawpa.org and
on our facebook page:

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DECEMBER

**MGA VIRTUAL HOLIDAY
PAINT & SIP**

DECEMBER 12, 2024

Details on Page 7

**MGA ANNUAL APPEAL
SENT OUT**

DECEMBER 2024

Please give generously!