

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****Dear Friend of MGA:**

If you have turned on the television recently, there is a good chance that you have seen some commercials focusing on Myasthenia Gravis. With the FDA approving treatments like Ultomiris and Vyvgart, the number of commercials, social media posts, and podcasts highlighting Myasthenia Gravis have increased greatly.

In turn, MGA has also seen a large increase in the number of people reaching out to our office via the telephone, email and through the MGA website. Many of these people are looking for more information about Myasthenia Gravis either for themselves, a relative or a friend. In the last few months, MGA has supported not only people in our region, but people from across the United States and the world.

This truly is an exciting time in the advancement of treatment and support services for people with Myasthenia Gravis. MGA is proud to play our part in offering continued support, education and advocacy for all the people we serve.

My message to you today is that MGA can't do this alone – we need your support! I welcome you to read this issue of the *Keystone of Hope* newsletter and to think about ways you could be involved – promoting and participating in an education program to raise awareness about Myasthenia Gravis, hosting a fundraising event to benefit MGA, getting involved in a Myasthenia Gravis research study, or joining the MGA Board of Directors. Every action – big or small – will help in supporting MGA and the people we serve!

I hope you enjoy this issue of the *Keystone of Hope* newsletter. 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



As part of the **2023 MGA Annual Appeal**, MGA is thrilled to be able to offer a raffle with a chance to **win a full-size guitar autographed by Taylor Swift** (COA included).

For your \$20 donation to MGA, you will receive a lottery ticket for your chance to win the Taylor Swift guitar. Winning number determined by the first number drawn from the 7:00 p.m. **PA Pick3 Lottery** on **December 13, 2023** (in honor of Taylor's birthday)! Contact the MGA Office at **412-566-1545** or **mgaooffice@mgawpa.org** to purchase your tickets. Act fast as we are sure that these tickets will go fast!



The ME&MGopen study - Understanding Myasthenia Gravis, Together

ME&MGopen is a smartphone application developed by Ad Scientiam. The ME&MGopen application is an investigational software for research purposes only. It features active tests to assess breathing, dysarthria (difficulty speaking), ptosis (eyelid drooping), arm and leg weakness. The mobile app also includes online questionnaires related to activities of daily living, pain, insomnia, quality of life and depression.

The ME&MGopen study is a research study which aims to better understand and manage Myasthenia gravis.

Participants will get free access to the ME&MGopen app, which allows participants to complete digital assessments and answer simple questionnaires; and take part in the study from the comfort of home. The study takes place entirely online, so you don't need to visit a doctor or clinic to take part. The study lasts 12 months, and participants will be compensated up to \$500 USD for taking part!

Join our trial and help us explore innovative approaches for people with Myasthenia Gravis. Your participation can make a difference!

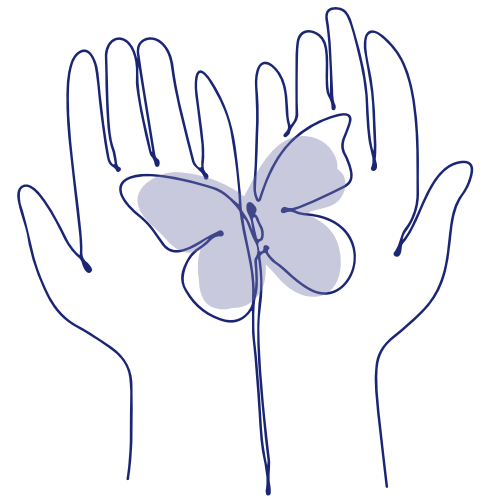
Sign up now directly with QR code or at:
www.meandmgopen.com/mgawpa

SCAN HERE →

Or contact the study team directly at:
meandmgopen@lindushealth.com



A webinar to raise awareness on Myasthenia Gravis and present ME&MGopen study will be hosted in October by Ad Scientiam. Stay tuned for more information.



Myasthenia Gravis SUPPORT GROUP MEETING

**SATURDAY,
SEPTEMBER 30, 2023**

12:00PM TO 2:00PM

**SATURDAY,
OCTOBER 28, 2023**

12:00PM TO 2:00PM

LOCATION:

PANERA BREAD - WATERWORKS
942 FREEPORT ROAD
PITTSBURGH, PA 15238

DISCUSSION LEADER:
CINDY SPRING, RN, CCM

Light refreshments provided.
This program is free,
but registration is requested:

CALL: 412-566-1545
or email:
MGAOFFICE@MGAWPA.ORG

Tour & Tasting Event



Many thanks to **McLaughlin Distillery** for partnering with MGA to host a tour and tasting fundraiser at their distillery in Sewickley, Pennsylvania.

Participants were treated to a tour of the distillery and after the tour, they were able to participate in a tasting event of some of the 40+ bourbons, whiskeys, vodkas and flavored moonshine products created by McLaughlin Distillery.

MGA would also like to send a special thanks to **State Representative Anita Astorino Kulik** who provided appetizers for the event and **Jo Beth Barr** from **Ooh La La Boutique** for providing a wonderful gift basket that was raffled off at the event!



SUPPORT FOR MYASTHENIA GRAVIS (MG)

Find what makes you



MORE THAN MG

Join the community of patients, caregivers, and other advocates

Whether you're looking to hear more about MG, find a friend with the same diagnosis, or receive some motivation, there's a place for you in the More Than MG community.



[MORETHANMG.COM](https://www.morethanmg.com)

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@MoreThanMG



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MGA VIRTUAL HOLIDAY PAINT & SIP FUNDRAISER

MGA is hosting its **4th Annual Virtual Holiday Paint & Sip Celebration** to benefit MGA's FREE patient support services.

This year's event will be held on **Thursday, December 7, 2023 at 7:00 p.m.** 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, PA**. 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.

Contact MGA at mgaoffice@mgawpa.org or **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 **Tom Golden** who has served on the MGA Board of Directors for many years.

Before joining MGA’s Board of Directors, Tom had a long professional relationship with MGA. As the professional relationship was concluded, Tom’s recommendation for board service was a natural fit.

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.

WALKING AN MG JOURNEY:

Raising Awareness and Funds at the Highmark Walk for a Healthy Community

MG and Me by Wendy McIntyre

While taking pictures for our family Christmas card on my birthday in 2017, I noticed a one-sided droopiness in my smile... was I having a stroke? As a nurse, I was aware that a trip to the ER seemed to be looming, but as fast as it appeared, it was gone, and I returned to my normal self.



As the months continued, I developed droopiness (ptosis) in my eyelids, my speech would intermittently become slurry, and swallowing became difficult at times. After the long-awaited neurology appointment, I was diagnosed with Myasthenia Gravis AChR positive in September 2018.

Compared to many stories I’ve heard; this was a quick diagnosis for which I am very grateful. As many can relate, the emotional struggle while waiting for answers was hard. The usual medication course (prednisone, pyridostigmine, and then mycophenolate) and some dosage adjustments along the way were able to control my symptoms. Through the process, I continued my lifelong career as an Operating Room nurse for three more years. Knowing the demands of this role, I transitioned to the less physical position of screening patients for surgery in 2020.

Day to day life continued as “normally” as possible with this “snowflake” disease, until a couple of months after a battle with Covid in July 2022. Suddenly, no medication adjustments were able to manage my breakthrough MG symptoms, so I was hospitalized for IVIG. The months to follow included various treatments with additional medication adjustments, plasmapheresis, speech evaluations, testing, Vyvgart infusions, and now pending plans for Ultomiris.

Along with the daily fatigue, the unpredictable, intermittent symptoms of blurry vision, difficulty swallowing, chewing fatigue, shortness of breath, arm and leg weakness, and—most noticeable to others—slurry speech (dysarthria) is like riding a roller coaster. It is explained that everyone experiences different symptoms, and each day is different. Life has changed from fast-paced multi-tasking to a snail’s paced attempt to accomplish small tasks each day while keeping a positive attitude.

My faith and trust that God is in control and guiding my journey gives me hope each day. I am blessed with an incredibly supportive and loving circle of family and friends who lift me up, a caring medical team, and my amazing husband who walks each step with me (even though my steps are much slower). I am grateful for each one, as well as the dedicated work of Jim Joyce and MGA of WPA.

Although I knew it was unrealistic for me to walk in the Community walk, I wanted to help by creating a team. The love and generosity shared by so many was overwhelming and a great encouragement for increasing awareness of this little-known disease.



A SON'S PERSPECTIVE

by Andy McIntyre

Aside from The Purple Party my mom invited me to a couple years ago, I didn't know much about her battle with MG. I remember the fear during that Christmas card moment when her symptoms first appeared, and her confusion trying to figure out why her body refused to smile. It made me angry—that a woman so in love with taking pictures with her friends and family had something attacking her smile.

She sheltered me and my sister because it seemed to be managed, and because she wanted to protect us. But over the last year or so, her increased flare-ups made it time for all of us to fight together, so to speak.

But how? I tried to understand the situation (challenging in itself), told her I loved her, and made myself available as best as I could, but otherwise, my hands felt tied. Then, five days before the Highmark Walk for a Healthy Community, my mom invited me to join her team.

I thought—dang, a little last-minute. I wished I had more time. But, following my mom's optimistic lead, I figured this was as good a chance as any to support her. I needed to work with what I had.

Four days before the walk, I made a post on Instagram to raise awareness, explain my mom's situation, and announce that we hoped to raise \$500 for MG at the Highmark Walk. I knew it was a longshot, so to encourage donors in this tough economy that a little would go a long way, I started

the hashtag: "#throwten" asking that people donate just \$10 each to the cause—OR— simply, walk with us.

Quickly, people messaged and commented with support. Some even used the space to share their own MG stories. It was a beautiful, invigorating response, and soon, the donations came in.

And then they came in some more. We reached our goal on the first night!

Each day, to thank and encourage donors, I made new posts with updates, responses, and shout-outs. In two days, we raised \$1000. My friends, some who have known my mom almost as long as me, made videos on their own pages. One, who couldn't walk in the event, filmed himself playing a hole of disc golf in his yard. It was creative, hilarious, and he directed folks to my mom's team page, generating more contributions.

Usually on my Instagram, I make goofy, informal coffee reviews. So as a final incentive, I promised to review the free coffee provided at the Highmark Walk for a Healthy Community if we could reach a new goal of \$1500.

But the cause maintained its own momentum. What started as a slap dash campaign snowballed into an energized community of friends and family who felt my mom's care and generosity and decided to return the favor.

On event day, we had a great crew for the rainy walk. We found out together that our team raised the most money for the MG cause, which meant our donation would be matched by a generous donor up to \$2000! I shared the news with our online community, and donations even continued for a few days after the event. By the end, all combined donors raised a total of \$5856.

We were blown away and so thankful. It was a display of love, and not only did it culminate in financial support, but more importantly, it raised awareness and increased support for all MG patients, especially my mom, from the people who love and walk beside her on her MG journey.



Thank you to all of our generous donors!

The following donations were received between January 1, 2023 and June 30, 2023.

Alexion Pharmaceuticals
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KEYSTONE *of Hope*

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If you would prefer receiving this newsletter electronically instead of through the mail, please contact the MGA Office at 412-566-1545.

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

**Alexion Pharmaceuticals, argenx,
and Catalyst Pharmaceuticals**

ALEXION

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Honorariums & Memorials

from January 1, 2023 to June 30, 2023



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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In memory of
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Randall Shellhammer

Suzanne Doppelheuer
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MGA EDUCATION/ SUPPORT GROUP SERIES:



MGA is pleased to continue the MGA Education/Support Group Series in the fall of 2023. The education calendar for the remainder of the year includes...

- **October (10/19/23 at 6:00 pm)**
– “Taking Charge or your Care: Accessing Insurance”
– Shelley Gerson, argenx
- **December (12/13/23 from 6:00 - 7:00 pm)**
– “Traveling with an Invisible Disease”
– Amy Grover, Catalyst

For more information or to reserve a space for these programs, contact the MGA office at **412-566-1545** or mgaoffice@mgawpa.org.

Myasthenia Gravis Association
of Western Pennsylvania
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SEPTEMBER

MGA GOLF OUTING
SEPTEMBER 24, 2023

PHEASANT RIDGE GOLF CLUB
GIBSONIA, PA



NOVEMBER

**MGA ANNUAL MEETING &
EDUCATION SYMPOSIUM**
NOVEMBER 4, 2023

More details coming soon!

VISIT US AT:
www.mgawpa.org and
on our facebook page:
 /mgawpa



DECEMBER

**MGA VIRTUAL HOLIDAY
PAINT & SIP**

DECEMBER 7, 2023

Details on page 3

TAYLOR SWIFT RAFFLE
DECEMBER 13, 2023

Details on page 1

MGA ANNUAL APPEAL

Sent Out

DECEMBER 2023

Please give generously