

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:***

The year was 1955. Disneyland opened in California, the \$64,000 Question was the top-rated television show, "Cherry Pink and Apple Blossom White" topped the Billboard Charts, and Lady and the Tramp was the top grossing movie of the year.

It was also the year that a small group of individuals got together in Pittsburgh to discuss and learn more about a mysterious illness called Myasthenia Gravis. It was from these humble beginnings that the Myasthenia Gravis Association of Western Pennsylvania was born.

Seventy years have passed since that first meeting, but I am very proud to say that MGA is still going strong providing education, advocacy and support services to people with Myasthenia Gravis, their family members, the healthcare community and the general public.

MGA has expanded our reach to cover not only Western Pennsylvania, but also across the United States and the world.

As MGA celebrates our 70th anniversary, I would ask that you read the *Keystone of Hope* newsletter and I challenge you to get more involved with the organization – promoting and participating in an education or support group program to raise awareness about Myasthenia Gravis; attending a fundraising event to benefit MGA; getting involved in a Myasthenia Gravis research study; or joining a MGA Committee or the MGA Board of Directors. Every action will help MGA and the people we serve and ensure that MGA can continue our mission for another 70 years!

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

**AT-HOME RESEARCH
OPPORTUNITY**

Sanguine Biosciences is looking for patients with myasthenia gravis to participate in an at-home research study to help advance diagnostic and treatment options.

See page 5 for more information.



the Purple Party



MGA is pleased to invite you to the **6th Annual Purple Party on Saturday, April 5, 2025** at Cefalo's Banquet Center in Carnegie, PA. For your \$80 donation to MGA, you will be treated to live music, dancing, delicious food and desserts. A cash bar will also be available.

There will be multiple raffles and everyone who wears something purple will be entered into a special raffle.

For more information or to purchase tickets to the Purple Party, please contact the MGA Office at 412-566-1545 or mgaoffice@mga-wpa.org.



EXPLORE THE POSSIBILITIES

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Walk For A Healthy Community

HIGHMARK | Bright Blue Futures

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 at Stage AE (beside Acrisure Stadium) on **Saturday, June 14 at 9:00 a.m.** There are multiple ways to get involved and support MGA!

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 by using the Highmark Walk online portal (www.walkforahealthycommunity.org). 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/admin/mgawpa2025> 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.



SATURDAY,
JUNE 14, 2025
9:00AM | STAGE AE



MY MG STORY

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

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

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 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.

"To be a person is to have a story to tell."
- Isak Dinesen

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 Louise Vouno, Esquire.

Louise is the Managing Member at Vuono & Gray, LLC in Pittsburgh, and has been practicing law for 30 years in the areas of corporate law, succession planning, commercial real estate, estate and trust planning, and probate and estate administration. She has three sons, the youngest of whom was diagnosed with MG when he was just three years old. A long-time donor to MGA, Louise joined the Board to become more involved in MGA to help her son and others with MG.

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.



YOU ARE NOT ALONE!

MGA invites you to attend our 2025 in-person support group meetings held at the Panera Bread in the Waterworks Mall. These meetings give patients and their family members a chance to interact with other individuals with Myasthenia Gravis in a safe and relaxed environment.

There is no charge to attend the support group meetings, but we ask that you RSVP by phone at **412-566-1545** or by email mgaoffice@mgawpa.org.

UCB is committed to helping improve the lives of people living with **generalized myasthenia gravis (gMG)**



No two individuals with gMG have the same needs. At UCB, we recognize that every individual has a different journey—that's why we're proud to offer two treatment options for adults living with gMG.

Explore our two targeted treatment options at UCBforGMG.com



Inspired by **patients**.
Driven by **science**.

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2025 MYASTHENIA GRAVIS SUPPORT GROUP MEETINGS

March 15

(12:00pm - 2:30pm)

April 19

(12:00pm - 2:30pm)

May 17

(12:00pm - 2:30pm)

June 21

(12:00pm - 2:30pm)

July 19

(12:00pm - 2:30pm)

August 16

(12:00pm - 2:30pm)

September 20

(12:00pm - 2:30pm)

October 18

(12:00pm - 2:30pm)

November 15

(12:00pm - 2:30pm)

Panera Bread - Waterworks

942 Freeport Road
Pittsburgh, PA 15238

Discussion Leader:

Cindy Spring, RN, CCM

Light refreshments will be provided. The programs are free, but registration is requested: **412-566-1545** or **mgaooffice@mgawpa.org**.

AT-HOME RESEARCH OPPORTUNITY



The Myasthenia Gravis Association of Western Pennsylvania, in partnership with Sanguine Biosciences, is reaching out to raise awareness about an at-home research opportunity for patients diagnosed with myasthenia gravis.

What is the goal of the at-home research?

The goal of this research is to enhance their understanding of myasthenia gravis in support of developing new diagnostic and treatment options for patients living with the condition.

Who can participate?

You may qualify to participate if you:

- Are 18 to 85 years of age
- Are diagnosed with myasthenia gravis (AChR+, MuSK+, Seronegative, or Ocular)
- Are not taking B-cell modifying therapies, such as Rituxan (rituximab), Enspryng (satralizumab), Actemra (tocilizumab), Uplizna (inebilizumab), Ocrevus (ocrelizumab), Kesimpta (ofatumumab), Briumvi (ublituximab), atacicept, telitacicept, belimumab, tolebrutinib, evobrutinib, fenebrutinib, remibrutinib, and CAR-T within the past 12 months
- Live in the United States

What would I have to do to participate?

Patients who qualify can support research by providing a one-time blood donation from the comfort of their own homes. As a thank you for participating, you will receive a \$100 prepaid gift card after the collection is complete.



To learn more or sign up, scan the QR code or call (818)-583-8844 to speak with a research coordinator and see if you qualify.

MYASTHENIA GRAVIS RESEARCH STUDY

Sanguine

**Help Advance Myasthenia Gravis
Research by Donating
White Blood Cells**



MGA LOTTERY TICKET:

FOURTH OF JULY SPECIAL

Based on the popularity of this fundraiser over the last several years, MGA will be offering a lottery ticket again this year.

This year's lottery ticket – "MGA Fourth of July Special" – is now available for purchase. For your \$10 donation to MGA, you will receive a lottery ticket with four numbers on each ticket (only 250 tickets will be sold). Prizes for the lottery include:

JULY 2, 2025: \$100 cash

JULY 3, 2025: \$250 cash

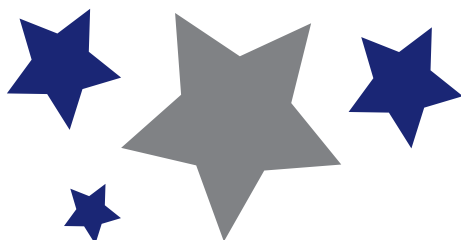
JULY 4, 2025: \$500 cash

JULY 5, 2025: \$250 cash

JULY 6, 2025: \$100 cash

Winning number determined by the first number drawn from the 7:00 p.m. PA Pick3 Lottery.

To purchase your tickets, contact the MGA Office at **412-566-1545** or **mgaooffice@mgawpa.org**. Act fast as we have sold out of these tickets the last three years!



Thank you to our generous donors!

The following donations were received between July 1, 2024 and December 31, 2024.

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KEYSTONE of Hope

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**MGA PURPLE PARTY
APRIL 5, 2025**

CEFALO'S BANQUET CENTER
Carnegie, PA
Details on Page 2



JUNE

**HIGHMARK WALK FOR A
HEALTHY COMMUNITY
JUNE 14, 2025**

STAGE AE
Details on Page 3



JULY

**FOURTH OF JULY
LOTTERY TICKET
JULY 2024**

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Details on Page 6

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