

WESTERN PENNSYLVANIA'S

KEYSTONE

of

*Hope*M
G
A**Myasthenia Gravis**
Association of Western Pennsylvania
A Support, Education, & Advocacy Centerthe **Purple**
Party

MGA is pleased to invite you to the **7th Annual Purple Party on Friday, April 17, 2026** 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@mgawpa.org.

**MESSAGE FROM THE EXECUTIVE DIRECTOR***Dear Friend of MGA:*

A few weeks ago, I am sure most of us were disappointed to hear that Punxsutawney Phil saw his shadow indicating we were in for 6 more weeks of winter. Not exactly what we wanted based on how cold and snowy this winter has been. But as we switch the calendar from February to March, the promise of spring is just ahead.

As we transition from winter to spring, many of you may be looking for activities to fill your time. If that is the case, I suggest you consider getting more involved with MGA! There are many things you can do to become more active within the organization...

- 1) Attend one of our monthly in-person or virtual support group meetings** where you will have the chance to interact with others living with Myasthenia Gravis.
- 2) Participate in an MGA fundraiser** – the Purple Party, the Highmark Walk for a Healthy Community, the Fourth of July Lottery Ticket – all are fun and wonderful ways to support MGA.
- 3) Consider becoming a volunteer with MGA** – as a member of the board of directors, getting involved with a specific MGA program, or creating a new program based on a specific skill you may have – we want to hear from you!

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

LEMS *aware*

ARE YOU DIAGNOSED WITH SERONEGATIVE

MG?

MG=myasthenia gravis.

If you tested negative for MG antibodies, you could have another disorder, like LEMS.

LEMS is a rare neuromuscular disorder that often shares similar symptoms to MG. An anti-VGCC antibody test can confirm a LEMS diagnosis. Ask your doctor if a LEMS test is right for you.

LEMS=Lambert-Eaton myasthenic syndrome.
VGCC=voltage-gated calcium channel.

Scan the QR code or visit **LEMSAWARE.com** to learn more about the role of antibodies in diagnosing LEMS.



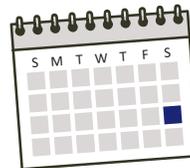
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MGA IN-PERSON & VIRTUAL SUPPORT GROUP MEETINGS



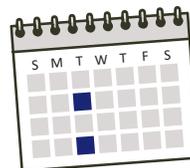
MGA invites you to participate in one of our 2026 in-person and virtual support meetings.

The in-person support group meetings are led by **Cindy Spring, RN, CCM** and are held once a month on the third Saturday of each month at the Panera Bread in the Waterworks Mall. Dates for the remaining 2026 in-person support group meetings are:



**THIRD SATURDAY
OF EACH MONTH
12:00PM – 2:30PM**

**March 21 • April 18 • May 16 • June 20 •
July 18 • August 15 • September 19 •
October 17 • November 21 • December 19**
(All meetings take place from 12:00 PM to 2:30 PM)



**2ND & 4TH TUESDAY
OF EACH MONTH
ONLINE @ 7:00PM**

The virtual support group meetings are led by **Jeff Weinberg, M.ED, M.PH, NHA** and are held via Zoom twice a month at 7:00 PM on the second and fourth Tuesday of each month.

Both the in-person and virtual support group meetings are meant to 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 any of the support group meetings, but we ask that you RSVP by phone at 412-566-1545 or by email at mgaoffice@mgawpa.org.

EVERY STEP makes a DIFFERENCE



Walk For A
Healthy Community

SATURDAY,
MAY 30, 2026

9:00AM | POINT STATE
PARK

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 **Point State Park** on **Saturday, May 30 at 9:00 am**. There are multiple ways to get involved and support MGA!

Go to the Highmark Walk online portal (www.walkforahealthycommunity.org) and select "Pittsburgh" as your walk location/region. On

the Pittsburgh location/region page, you can search for and select "MGA of WPA" 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.

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.

If you have any questions or any trouble accessing the Highmark Walk website, please contact Jim Joyce at **412-566-1545** or jjoyce@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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MGA BOARD MEMBER

Highlight



MGA is proud to spotlight members of our Board of Directors. In this issue of the Keystone of Hope, we recognize **Mitchell Robbins** and his vital role in supporting our mission.

Mitch was diagnosed with MG when he was 17 years old. Although he was diagnosed at a young age, Mitch has never let his Myasthenia Gravis slow him down. Mitch competed in the NYC Marathon on 5 different occasions, carrying oxygen with him during the race. He served as chairperson of the MG Alliance of Greater New York, Inc. for fifteen years and was very involved with the organization for many years before that. Mitch is a strong supporter of people with MG through many research and advocacy efforts. He lives in Rosendale, NY, and participates in MGA board meetings and other MGA activities via conference call and virtual meetings.

Interested in serving on the MGA Board? Contact Jim Joyce at 412-566-1545 or jjoyce@mgawpa.org.

MENTAL HEALTH INITIATIVES:



MGA is excited to partner with **GIVE AN HOUR**, a national mental health organization with a focus on the rare disease community to create a Mental Health Toolkit which will be kept on the MGA website for people to access for mental health support tools.

Julie Wells, Director of Strategic Relationships, at Give an Hour explains “*focusing on mental health is a part of focusing on overall health. We know the rare disease journey has emotional impacts that are felt by both patients and the care partners. We help organizations like MGA develop resources and opportunities to dig deeper into wellness practices.*”

This toolkit will be available to access in the near future, so stay tuned for updates on the toolkit and other mental health initiatives being planned by MGA and Give an Hour.

When considering a treatment, it helps to know what to look for.

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NURSING NOTES

MYASTHENIA GRAVIS: WHAT IT IS AND HOW IT IS DIAGNOSED

By Cindy Spring RN, CCM

The name Myasthenia Gravis (MG) is of Greek and Latin origin meaning Grave Muscle Disease. With today's treatments, most people with MG can live fairly normal lives and expect a normal life expectancy. The cause of MG remains unclear and there is no cure currently. MG is an Autoimmune Disease which means that, rather than attacking foreign invaders such as viruses, bacteria, fungi, your Immune system is producing antibodies which are attacking your healthy tissue. There are many Autoimmune Diseases that do this, such as Rheumatoid Arthritis, Lupus, some forms of Asthma and many more. In the case of Myasthenia Gravis, the antibodies are attacking your Neuromuscular Junction, which is the area where your nerves, bringing impulses from your brain, send the messages to your muscle fiber to contract. The damage that is caused by these antibodies makes your muscles feel weak and unable to function properly, therefore producing symptoms of drooping eyelids, double vision, difficulty swallowing, talking, chewing, breathing, walking,

or using your arms. You will likely have only a few or many of these symptoms. Every patient is different in the number and severity of symptoms, which is why this is often referred to as The Snowflake Disease.



Diagnosis is most often reached through testing for antibodies in your blood. These antibodies all, in some way, interfere with the ability of nerve cells to communicate with muscle cells in your Neuromuscular Junction. The most common test is for AChR antibodies (Acetylcholine Receptor). These antibodies attack the AChR proteins within the receptors on your muscle fibers that receive impulses from nerve cells, thus impeding the ability of your muscle fibers to contract. The second most common antibody test is for MUSK antibodies (Muscle-Specific Kinase). MUSK is vital for clustering of the AChR protein. These antibodies cause a reduction in the number of available receptors in the Neuromuscular Junction.



If the previous two results are negative, you may or may not be tested for LRP4 antibodies (Low-Density Lipoprotein Receptor-Related Protein 4) which is considered a "Sero-Negative" result because of absence of AChR and

MUSK antibodies. When a patient is considered "Sero-Negative" further testing is done with an EMG or Single Fiber EMG to try to determine if the patient does have MG. These tests evaluate the electrical signals produced by sodium and potassium ions moving across muscle cell membranes. By evaluating these signals for pattern, strength and timing your nerve and muscle function can be determined. Most of these tests will be done by a Neurologist, however, at times some of the initial antibody testing is done by a Neuro-Ophthalmologist if you begin with eye symptoms.



Other common testing methods used are a Brain MRI to rule-out Multiple Sclerosis and Stroke and an MRI of the chest to locate a possible Thymoma (either benign or cancerous tumor) within your Thymus Gland. This is most associated with AChR positive patients. The Thymus Gland is part of your Lymphatic System which is also a part of your Immune System. The Thymus Gland lies behind your breastbone and in front of your heart. This gland is functional primarily during infancy and early childhood at which time it produces all of the special white blood cells called "T-cells" which will then be used during the remainder of your life to help fight infection.

If your chest MRI shows a Thymoma this needs to be removed surgically. This can be done through Robotic Surgery by a Cardiothoracic surgeon which is far less invasive.

PICK 3

MGA LOTTERY TICKET:

FOURTH OF JULY SPECIAL

The "MGA Fourth of July Special" Lottery Ticket 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, 2026: \$100 cash

JULY 3, 2026: \$250 cash

JULY 4, 2026: \$500 cash

JULY 5, 2026: \$250 cash

JULY 6, 2026: \$100 cash

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

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

SAVE the DATE

MGA PURPLE PARTY

APRIL 17, 2026

CEFALO'S BANQUET CENTER
Carnegie, PA - details on page 1



Thank you to our generous donors!

The following donations were received between July 1, 2025 and December 31, 2025.

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from July 1, 2025 to December 31, 2025



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KEYSTONE *of Hope*

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HOW TO BE YOUR OWN ADVOCATE

By Jeff Weinberg, M.ED, M.PH, NHA

Some quick tips on being your own best advocate when you are in the hospital or at a doctor's visit...

- **Have someone visit with you regularly** in the hospital. They can help get someone's attention when you have to go to the bathroom or have some other need. They can also write things down when physicians and staff are speaking with you.
- **Write down names of physicians** and staff who are talking with you.
- **Write down your questions** in hospital and in the office.
- **Make sure you get your questions answered.** The average time spent by a physician for an office visit is less than 7 minutes.
- **If you are not satisfied, get a second opinion.**

These small suggestions can go a long way in insuring you receive the best care possible for YOU!

SAVE THE DATE

HIGHMARK WALK
FOR A HEALTHY
COMMUNITY



MAY 30, 2026

POINT STATE PARK
Details on Page 3

FOURTH OF JULY
LOTTERY TICKET



JULY 2026

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Details on Page 6

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