



WELCOME!
to our
Southwest Support
Group Meeting!

September 14, 2024

**Please make sure you sign in
and
help yourself to some refreshments!**



MG Ohio Mission Statement

MG Ohio is committed to supporting those living with myasthenia gravis (MG) and MG related disorders as well as their caregivers, friends, family, and the greater MG community by providing information and support through education, community programs, and advocacy; and to raise awareness about MG and MG related diseases in the greater community. MG Ohio provides such support through:

- Regular online and in-person meetings**
- Educational materials**
- Speakers and Seminars**
- Physician referrals**

BESIDES, our in-person meetings - MG Ohio has Zoom Meetings - Every other Thursday (twice a month) that you are welcome to attend! The next one is **Sept. 26th at 7:00 pm**. The link is available in the September newsletter on the first page, that was sent out from MG Ohio.



Today's Agenda

- ❑ **Old Business -**
 - ❑ Last Month's Ice Cream Social
 - ❑ New Members last month
- ❑ **New Business -**
 - ❑ Next month - no planned in person meeting in Cincinnati
 - ❑ Oct. 12th hybrid meeting with NE Support Group will feature speaker, Charles Boone who will speak about the upcoming changes to Medicare in 2025. Just information, no sales pitch! Send me an email, if you would like to join their meeting that day.
- ❑ **How To Prepare For Emergency Situations**
 - ❑ What do you need to have ready and on hand in case of an emergency?
 - ❑ Why it is important to be prepared for emergency situations
 - ❑ How your preparation helps family members, first responders, doctors, and even insurance companies.
- ❑ **Share and Care Time**
 - ❑ New member introductions
 - ❑ New concerns, symptoms, new medications, doctors
 - ❑ Positives you want to share

SouthWest MG Ohio Social Event!



AUGUST 10th @ 1 PM
110 S. 2nd Street,
Loveland, Ohio 45140

ice cream, ice cream
We all scream for
ice cream!

We also had two new people come to our meeting, Madison Cox and Paul Hubler.

We enjoyed visiting, ice cream, socializing and we played a fun get to know you game, "Two Truths and a Fib!"





OHIO
HEALTH
INSURANCE
CONSULTANTS

OCTOBER

- ❑ We DO NOT CURRENTLY HAVE an in person meeting in Cincinnati in October.
- ❑ Opportunity for You:
 - ❑ On Oct. 12th from 1 pm - 3 pm, the NE Support Group will have a feature speaker, Charles Boone who will speak about the upcoming changes to Medicare in 2025. He will be just providing information, and this is not a sales pitch!
 - ❑ If you would like to attend through zoom or in person, please send me an email so I can get you the information you need for the day and also let them know you are planning to attend.

Would you like to add a SW Social Event in the month of October, since we do not have a regular meeting? Some Ideas: see a movie, dinner, lunch, pumpkin farm, fall activity, etc.

The Importance of Preparing for Emergency Situations

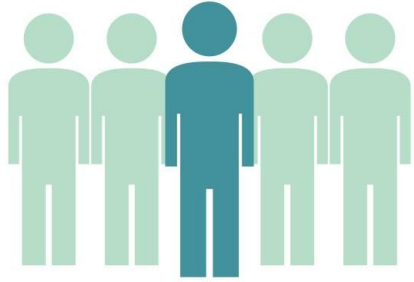
As people who live with rare disease every day - we know there is very little we have control over.

One thing we do have control over is learning information.
Information is POWER!

When Having MG...

Knowing what to expect and being prepared in case of a crisis is crucial to a good outcome.

Myasthenic Crisis and/or Exacerbation



A Myasthenic Crisis happens in about 1 in 5 people with MG or 15% to 20% of patients with MG experience at least one crisis in their lives.

- A Myasthenic Crisis is a serious complication of MG that develops when the breathing muscles become weak.
- **Myasthenic crisis** is a life-threatening exacerbation of myasthenia gravis that is defined as worsening of myasthenic weakness requiring intubation or noninvasive ventilation
- **Myasthenic Exacerbation** is defined as worsening of myasthenic weakness, but does not require intubation or a ventilator to recover.
- These may develop as a reaction to infection, stress, surgery, or after taking certain drugs.
- Half the time there is no known trigger for a myasthenic crisis or exacerbations.

**How can you prepare for these situations,
if there is not often a trigger?**

WHAT'S THE ANSWER?



KNOWLEDGE IS POWER!

Despite the word “crisis” being in the name, a myasthenic crisis does not always come on quickly. The shortness of breath or trouble breathing *usually* builds up over days. That is why it is **important to recognize the early signs of a flare**. If you get help quickly you may be able to **avoid a full-blown crisis** .

Know YOUR Warning Signs

A Myasthenic Crisis may be developing if you feel short of breath and you:

- Have a hard time lying flat in bed without feeling short of breath
- Are breathing very quickly (more than 20 breaths per minute)
- Pause in the middle of what you are saying to take a breath
- Have more slurred speech
- Have a weak cough or have trouble clearing mucus or saliva from your throat
- Have a harder than normal time chewing and swallowing
- Have trouble holding your neck up
- Feel much more weakness than normal in your arms or legs, plus are short of breath
- See the muscles between your ribs, neck, and stomach pull in during a breath
- Cannot count out loud past 20 in one breath

Preparing Ahead of Time

Keep an updated packet of information with your important health details that includes:

- Contact information for your neurologist and other doctors
- List of all your current drugs and supplements and the doses for each
- Health insurance information
- Information about any IV ports, pacemakers, and other implanted devices
- Your emergency contacts (friends or family)
- A list of drugs that can be dangerous to people with MG
- Your medical history and hospital records

Yes! This is a lot of work...

So as we say in teaching, don't recreate the wheel, if there is something already out there created for you! Think smarter, not harder!

IT IS FREE!

It's call the Hospital Emergency Advocacy & Treatment Kit (HEAT Kit)
and is provided by Eosinophilic & Rare Disease Cooperative.

HEAT Kit Components:

- Summary page of each disease for health care providers (source: NIH Rare Disease Center)
- Medical alert, and emergency summary page
- Medication & allergy lists to be kept current
- List of providers to be kept current by patient, including contact information
- Notification of immunocompromised status
- Checklist for to ensure you receive the attention you need if you are admitted to the hospital
- Temporary Power of Attorney
- One page template of the patient's hospital, emergency and surgical medical history for the patient to complete and keep in the HEAT Kit™
- Authorization to release information to identified loved ones and primary provider (not to replace formal release of information, this is to utilize until formal release is completed)
- Hospitalization packing list
- Recommendations to improve your communication with your health care providers
- Two lined pages for you to add notes specific to your care and treatment needs

HOW DO I GET MINE?

1. Go to www.eosinophilraredisease.org
2. Scroll down on the homepage where you see the different diseases listed.
3. Click on your disease, Myasthenia Gravis. (the doctor bag)
4. Fill out your information.
5. Your HEAT Kit will be shipped to you!

Note: Mine did take more time than expected from the website, but they sent emails keeping me updated on the delay. They also informed me of my new expected day and when mine was shipped to me in the mail. They have great communication, especially for something that is FREE!

Creating The Perfect Hospital Bag

Comfort is the **KEY** when you're in the hospital! And making things more **bearable** !

Clothing

- Clothing without metal parts (essential to wear for scans)
- Clothing that is adaptable and allows easy access to your chest for cardiac monitoring and your ports for treatment.
- Slippers or easy slip-on shoes are a **MUST**

Hygiene

- Toothbrush
- Toothpaste
- Body wipes
- Deodorant
- Hairbrush
- Dry Shampoo or No-rinse hair caps

YOUR HEAT KIT

Self-Care Products

- Electronics
- Headphones
- Puzzles
- Books
- Extension cords
- Chargers
- Comfort Items: Small Pillow or Blanket
- Financial means: some cash or a credit card

Speciality medications

It is wise to take some of these with you because they are not always quickly attainable by hospital pharmacies and they can and will use yours IF YOURS IS IN THE ORIGINAL PRESCRIPTION BOTTLE.

Other Emergency Identifiers Available

- Medical Bracelets or Medical Necklaces

<https://www.laurenshope.com>



- Apps for your phone - Phone App Store (iPhone Users it is the Health App that comes on your Phone) - it can mark a person in your phone as ICE for you.
- Add to your Phone Contacts - LIST SOMEONE AS ICE (in case of emergency)
- Medical Keychain
 - Can be purchased on Amazon
- Medical Emergency ID Card
- Medical Strap for Seat Belt
 - Can be purchased on Amazon



Should You Only Be Prepared For Crisis Type Emergencies?



According to recent studies, 65%-88% of people living with Myasthenia Gravis may also deal with one or more additional chronic diseases or conditions. This is what doctors refer to as “comorbidities” (related conditions).

- Most common related conditions are metabolic syndrome, heart disease, high blood pressure, and diabetes.
- People with MG are at higher risks for other autoimmune diseases such as rheumatoid arthritis, lupus, and thyroid disease.

This is why sharing all your medications and conditions with all your doctors is important. The more they know about you the better they can serve you and there are less chances for mistakes to occur.

Remember, it's your life you're gambling. Do you want to win or lose?



**Welcome
and
Introduce
NEW
Group Members!**

Share and Care Time

**Please feel free to update us or share
what is going on in your life.**

- **New symptoms? Less symptoms?**
- **Treatments? Working not working?**
- **Stresses? Less or more?**
- **Questions you may have that you want or need help bringing up to your Healthcare Provider?**
- **Are you currently satisfied with your Healthcare Provider or are you looking?**
- **Would you like to be contacted by someone from MG Ohio to check in with you or become an one on one MG Friend with you?**

SUPPORT GROUP DISCLAIMER –

Anything said here in confidence should remain in confidence. The information presented at this meeting does not necessarily reflect the views or official position of MG Ohio nor carry the endorsement of MG Ohio. For specific medical advice, please contact your treating physician. For more information, visit www.mgohio.org

PRIVACY NOTICE –

Your personal information including name, address, phone, email, and diagnosis will NEVER be shared outside of what you choose to share with this group. You should never be contacted by any third party for any reason. If you think your personal information has been compromised, notify us immediately at mgohio@mgohio.org



Meetings Coming UP...

- Zoom Meeting - September 26th at 7 pm
- **SW MG Ohio Social Event - October ?**
 - **Lunch Date TBA - will send out dates to choose from for options (will be during the week)**
- Zoom Meeting - October 10th at 3 pm
- Zoom Meeting - October 12th at 1 pm with Special Speaker on Insurance Changes at NE MG OHIO Support Group Meeting.
- Zoom Meeting - October 24th at 7 pm
- Zoom Meeting - November 7th at 3 pm
- **In Person - November 9th, 1 pm - 3 pm, Mayerson JCC with catered Lunch from City BBQ!**

Thanks for attending today and feel free to reach out to us before our next meeting if you need anything!

- Your Southwest Support Group Leadership Team