SOUTHWEST
MG

WELCOME!

to our
MG Ohio Southwest
Support Group Meeting!

August 9, 2025

Please make sure you **sign in**,
pick up a **name tag**,
choose a seat next to someone you do not typically sit next to,
and
help yourself to 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

Leadership Contact Information

Contact Information:

- **Southwest Support Group Leaders:**
  - Leader - Erica Amann: (513) 767-6750 or mgohiosouthwest@gmail.com
  - Assistant Leader - Kacy Self: kacy_read@me.com
  - Secretary - Sharon Meyer: slmeyer1954@gmail.com
- **MG Ohio President:** Suzanne Ruff: (216-218-0477) or suzanneruff@hotmail.com

Emails:

- **Southwest Support Group** : You should be receiving monthly emails or reminder emails about meetings from MG Ohio Southwest Support Group - Erica Amann or amannerica@gmail.com
  - These emails are to mainly keep you up to date with our local group, to inform you of upcoming meetings, get a head count of attendees, to pass on important information, etc. (Also the email to use to respond to or email questions, comments or concerns to.
- **MG OHIO**: You should be receiving monthly emails from mgohionews@gmail.com
  Sends out mainly monthly emails with a newsletter full of great information about things going on with MG Ohio, monthly advice from an expert, updates on research and/or clinical trials, new information about MG, Meeting Dates for in Person and virtual, Ways to Participate, how to help get Drug Coverage Support

Websites:

- www.mgohio.org
- Facebook Page - MG Ohio
  - https://www.facebook.com/profile.php?id=100091976665013&mibextid=LQQJ4d - Like us and Follow us to keep up with new information!

Today's Agenda

- ☐ **Old Business:**
  - ☐ MG Ohio Southwest Directory
  - ☐ Hospital Health Fair in September
  - ☐ July Lunch Outing - Viva Cincy
- ☐ **New Business:**
  - ☐ **Southwest Leadership Team**
  - ☐ **ICE CREAM SOCIAL - Saturday, August 23, 2025**
    - ☐ 2 pm, The Peach Cobbler Factory, 7736 Dudley Dr., West Chester
  - ☐ **Share Your MG Story!**
  - ☐ **NEXT MEETING - SEPTEMBER 13, 2025 with Alexion**
  - ☐ **Supporting MG Ohio NE Awareness** Walk, 16200 Valley Pkwy, Strongsvill
    - ☐ Registration is now open
- ☐ **Today's Topic:**
  - ☐ **Driving, Traveling, and Going out with MG**
    - ☐ with Erica Amann
- ☐ **Share and Care Time:**
  - ☐ New member introductions
  - ☐ New concerns, symptoms, new medications, doctors
  - ☐ Positives you want to share

MG Ohio Southwest Directory

Information:

We have **52 people** in our group, I would love to be able to include **EVERYONE** in our directory get these made before the end of the year and give them out at the Holiday Party.
So far, we only have **14 people** that have given consent to add their photos and information in the book. If you do not want to add your home address you can leave that out and I am still missing photos of those who have signed the consent form. The idea of this is to be able to put the name to a face and we can put this together easier with a group directory.
Unfortunately, if you do not consent to be apart of the Directory, then you will also not receive a directory for yourself.

Consent Form
&
Send Your Picture to:

Consent form link:
https://forms.gle/jGni66wner7gym5VA

Send your photo to:
amannerica@gmail.com
Or text to
Erica @ 513-767-6750
By September 30th

Email Reminder:

I will go through our list of members and only send reminders to members who those have not signed the consent form or those who have not yet submitted a photo. I will send these emails by **Wednesday, August 13th**, so if you do not get one you did turn yours in.

Some people have signed the consent form, but did not send me a photo to go in the book which is a big part of the directory!

Thanks!

MG Ohio Southwest July Lunch Outing!

Viva Cincy
Restaurant & Bar

FOOD BRINGS US TO THE TABLE—FRIENDSHIP KEEPS US THERE.

11 people in attendance - We started at 12 pm and the last of us stumbled out around 3 pm…It was a nice time! Hopefully more people can join us next month for ice cream!

Introducing You To Our Latest MG Ohio Southwest Leadership Team Serving our MG Patients and Caregivers in Ohio and beyond...

Erica Amann
SW Support Group Leader

Kacy Self
SW Ast. Support Group Leader

Sharon Meyer
SW Group Secretary

Save the Date:
MG Ohio Southwest Ice Cream Social!

August 23rd @ 2 pm

THE
PEACH COBBLER
FACTORY

7736 Dudley Dr.,
West Chester, Ohio 45069

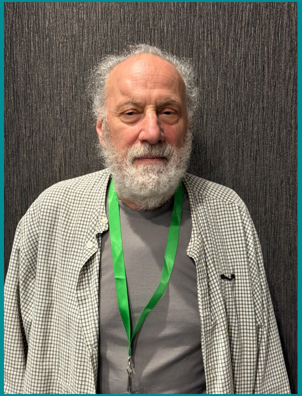
It's a Southern THANG.

SHARE YOUR STORY

August spotlight patient:

Saul Wiener

Cincinnati, Ohio



Saul Wiener

I founded and ran an urban farming non-profit in West Philadelphia (Urban Tree Connection), working with kids from the projects, squatting on vacant land, growing vegetables and starting farmers markets. I started the Urban Tree Connection in my early forties and made it thrive for 30 year. My own Board asked me to retire because they felt I was too old to continue, so not having a pension with limited funds we decided to retire to Mexico.

We had a lovely old Hacienda in San Juan Tlayacapan, Lake Chapala south of Guadalajara. I started to settle in, jogging, gardening, helping the local soup kitchen write grants and secure funding to feed the poorer villagers. One day I noticed that I had slight double vision which a visiting physician said was the stress I felt in managing my husband, an amputee who was living on morphine to manage his pain. I dismissed this and carried on. One day while I was jogging I felt my legs get heavy and before I knew it I was collapsed, lying on the ground immobile in the middle of a busy intersection with cars swishing by.

Dr. Sam, the local doctor, who was managing Robert gave me one of those shots that if your symptoms disappear immediately indicates you have Myasthenia Gravis. My symptoms did disappear and I started to look for a neurologist. It was a dizzying several months, but I finally ended up in the neuro-opthamologist office. She said, after a chest scan, a brain MRI to eliminate a brain tumor and thymus stuff that MG was probable and send me to a neurologist who put me on Mestinon and 5mg prednisone after a blood test in Mexico City diagnosed generalized MG. The clinic in the village did not have specialists, so I had to rely on bimonthly visits and my MG deteriorated with thimble swallowing, eating, breathing and total fatigue.

After several years of trying to regulate my MG, we decided to look for state-side doctors in Texas and scale down our living situation, but with one thing and another our Hacienda sold in 14 days and without a place to live, we decided to return to Philadelphia. We were priced out of the housing market. What used to be hundreds of thousands was now millions. So Robert researched affordable cities with excellent neurology access and Cincinnati emerged with a condo priced at the selling price of our Hacienda. In a month, we were here. I am not sure how we managed it, but we did.

Finding physicians initially was very difficult, but I did find Rebecca Molitoris, who was running her zoom calls from Cleveland and for two years she kept me sane and focused along with many others who were experiencing the challenge of stabilizing their MG. I was lucky, after being told it would take 8 months to see a UC neurologist that through a cancellation I got an appointment with Dr Kushlaf, with whom I have been working for close to 4 years. We went from low dose Mestinon to higher doses with prednisone. But my double vision was staggering and my leg fatigue required a two hour naps in the middle of every day. Some of this, of course is the aging body of an 83 year old man. Dr. Kushlaf said that I did not qualify for any infusion drug based on my ADL score, but that we could move to cellcept. It took a year to activate, which means my MG was not regulated for an entire year. During that year, I contracted a bad flu and Covid and was hospitalized a couple of times. It took six months before I returned to the living, and now I am more stable than I have ever been.

So, my journey of about 10 years has been at times exhausting, debilitating and exhilarating. This year Robert and I will celebrate a marriage of 40 years and our blended family of 5 children and 17 grandchildren is a legacy that we can look to and enjoy, hoping the world around us behaves.

DRIVING, TRAVELING, AND GOING OUT WITH MG

Your Guide to a Safe and Enjoyable Journey or Outing!

DRIVING, TRAVELING, AND GOING OUT WITH MG

Living with MG can often feel limiting, but choosing to engage in the world—through driving, traveling, or simply going out—can deeply enrich your life in powerful ways, but it's important to stay prepared for any situation.

> *These tips will help you enjoy a stress-free and more memorable time or trip any time you go out!*

TIP 1:

PLAN EARLY

The Journey Begins Before You Depart

- ✓ Research your destination.
- ✓ Book flights, accommodations, and activities in advance.
- ✓ Create a flexible itinerary.

TIP 2:
PACK SMART

✅ 1. Medication First, Always

- Bring extra meds—at least a few days' worth beyond your planned trip.
- Keep meds in your carry-on (never checked luggage).
- Health Insurance Card (Physical copy or Digital copy)
- Bring a list of all medications, dosages, and doctor contacts.
- Include medical alert ID or card noting your MG diagnosis. Check out **Lauren's Hope Medical ID**

👕 2. Prioritize Comfort Over Style

- Pack lightweight, breathable clothing (easy to put on/take off).
- Choose supportive shoes, and a pair that has a slip-on option.
- Include layering options in case of temperature changes (MG can be heat/cold-sensitive).

🔋 3. Conserve Energy with Smart Gear

- Use a rolling suitcase or backpack with wheels to avoid muscle strain.
- Consider a portable seat cane or small folding stool for breaks.
- If needed, bring mobility aids—walker, cane, scooter—whatever helps you stay safe and comfortable.

🧼 4. Keep Your Essentials Accessible

- Pack a "daily use" bag with:
  - Meds
  - Water bottle
  - Sunglasses (for ptosis or light sensitivity) [4]
  - Neck pillow (for fatigue support)
  - Snacks (protein-rich and easy to eat)
  - Medical accommodations or disability information (ex. handicap placard) If you do not have one, Myasthenia Gravis does qualify as stated on the **Ohio.gov** website. Speak to your doctor about filling the paperwork for you. **https://ohio.gov/residents/resources/disability-license-plates-and-placards**[2]

Less is More, is this always true?

Pack light, but plan heavy.

A little preparation goes a long way in helping you enjoy the world–on your terms.

TIP 3:

HEALTH IS THE BEST SOUVENIR

Stay energized and healthy on your journey. A well-rested and hydrated traveler enjoys every moment.

1. **If you have noticed that excessive heat triggers your MG symptoms, there are steps you can take to reduce your exposure:** [3, 5]
   - Opt for short showers with warm water instead of hot baths
   - Wait for meals to cool down before eating and avoid spicy foods
   - Try iced coffee and tea instead of hot versions of your favorite drinks
   - When it is hot outside, stay in air-conditioned spaces. If you do not have air conditioning at home, keep **floor fans** or ceiling fans in every room.
   - When you feel warm, place a damp towel around your neck
   - Wear loose, moisture-wicking clothing. **You can also try wearing a cooling vest.**
   - Spend time outdoors during the early morning hours or late evening, when the temperatures are the coolest.

❖ Keep in mind that what works one day may not work the next. You may need to try several things to reduce your exposure to heat and hot temperatures.

2. **Being well-rest is essential - Do not over do it! Many factors often result in fatigue and usually there isn't just one problem that is causing fatigue.** [6]
   - If you are not getting enough rest. Rest periods are important especially when the MG is active and you are still experiencing fluctuating and variable muscle weakness.
   - Muscle weakness, due to MG, results in physical activities becoming harder to do. You have to work harder to achieve what you previously considered a simple task.
   - If the muscles are weak, the brain will send signals back to the muscles instructing the body to do less. This results in an endless cycle of mis-signaling which will result in you feeling sluggish and fatigued.
   - Having poor sleep patterns or taking certain medications such as steroids that can cause insomnia, or if you have a difficult time breathing may become a pattern, which accumulates and results in further feelings of fatigue.

TIP 4:
TAKE PRECAUTIONS

- ✓ Use tools such as timers, alarms, or apps to remind you to take your medicine, rest, and hydrate.
- ✓ Make sure you wear sunblock every time you go outside.
- ✓ Know your limits - plan short outings when possible, rest before and after trips.
- ✓ Don't hesitate to ask for help - let friends and family members help carry items for you, use handicap parking or accommodations such as wheelchairs or walkers.

TIP 5:
BETTER SAFE THAN SORRY

Don't let unexpected events spoil your trip. Insurance is your safety net for a carefree adventure.

🛡 Why Travel or Ticket Insurance Matters When You Have MG

1. **Unpredictable Flare-Ups**
   MG symptoms can worsen suddenly — fatigue, muscle weakness, or breathing issues may force you to cancel or postpone plans last-minute.
2. **Treatment Changes or Medical Appointments**
   New medications, infusions, or emergency appointments can come up and interfere with travel or events you had planned.
3. **Hospitalizations or Medical Setbacks**
   MG can sometimes lead to complications that require hospitalization — even short stays can disrupt plans. Make sure to carry your medical information. **Get your FREE HEAT KIT**
4. **Energy Conservation**
   Even if you're not in crisis, your energy levels may not cooperate. Insurance gives you flexibility to reschedule without financial stress.
5. **Peace of Mind**
   Knowing you can cancel or modify your plans without losing money lets you enjoy events or trips without extra anxiety.
6. **Supportive for Caregivers Too**
   If a caregiver or family member has to cancel due to your health needs, their costs may also be covered under certain policies.
7. **Rare Disease = Extra Risk**
   Because MG is rare and not well understood by all travel or event organizers, insurance gives you a backup plan in case accommodations fall short.

TIP 6: Exploration should always be fun but never reckless.

HAVE FUN, BUT REMEMBER YOU'RE RARE!

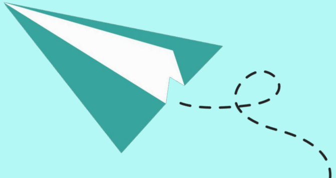
1. **Plan Playfully, Pace Wisely**
   Do what you love, but on your terms. Go out, but make peace with shorter outings or quieter hangouts. You're not missing out–you're customizing joy.
2. **Choose "Yes" Moments That Fit**
   Say yes to things that energize you, not drain you. A game night, movie marathon, or brunch with close friends can be just as joyful as a big event.
3. **Be Proud of Your Rare Status**
   Rock a T-shirt, bracelet, or even a subtle inside joke that reminds you (and others) that you're managing something unique. It's your superhero cape.
4. **Make Fun MG-Friendly**
   Modify activities to work *with* your energy levels. Seated concerts, accessible nature trails, relaxing creative hobbies – it's still fun, just MG-smart.
5. **Use Humor as Armor**
   Keep the mood light when needed. "I'm rare, not fragile," or "I brought my meds and my sass" can turn awkward moments into empowering ones.
6. **Surround Yourself With People Who Get It**
   The best kind of fun is with people who don't question your boundaries–and even better, cheer them on.
7. **Document Your Joy**
   Keep a "Rare Joy" photo album or journal. It's a reminder that even with MG, there are still so many beautiful, hilarious, and powerful moments to be had.

TIP 7:

CONNECTIVITY ON THE GO

- ✓ Get a local SIM card or portable Wi-Fi.
- ✓ Download offline maps and translation apps.
- ✓ Stay in touch with family and friends.

What other reasons would connectivity on the go matter?



TIP 8:
SUSTAINABLE TRAVEL

Be a responsible traveler. Choose eco-friendly options and make sure your journey positively impacts the environment and the community.

💤 1. Stay in Eco-Friendly, MG-Friendly Places

- Look for **green-certified lodging** that also offers **accessibility features** like elevators, grab bars, or ground-floor rooms.
- Book accommodations near rest stops or quiet spaces.

🌱 2. Plan Activities with Both Energy and Environment in Mind

- Choose **nature-based or low-energy** experiences like scenic drives, accessible trails, or slow city tours.
- **Avoid overbooking** — sustainable travel is also about **traveling gently** on yourself.

📅 3. Flexible Planning = Sustainability & Self-Care

- MG requires flexibility. Choosing **refundable bookings** and **insurance** reduces stress and waste from canceled plans.
- Flexibility also prevents burnout — which is its own form of sustainability.

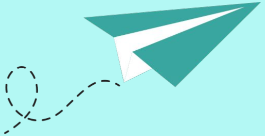
🧳 4. Sustainable Packing Essentials

- **Reusable water bottle, utensils, and snacks** — reduce waste and ensure you always have MG-safe foods and hydration.
- Bring your own **pill organizer** and **cool packs** for temperature-sensitive meds.

TIP 9:

MANAGE TIME WISELY

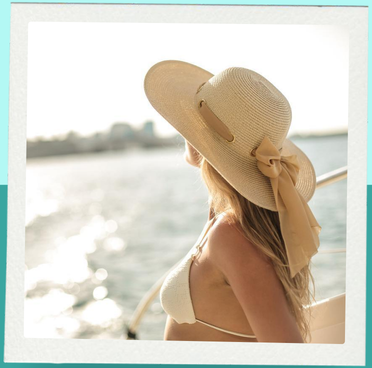
- Arrive early for flights and tours.
- Prioritize must-see attractions.
- Allow time for relaxation and spontaneity.

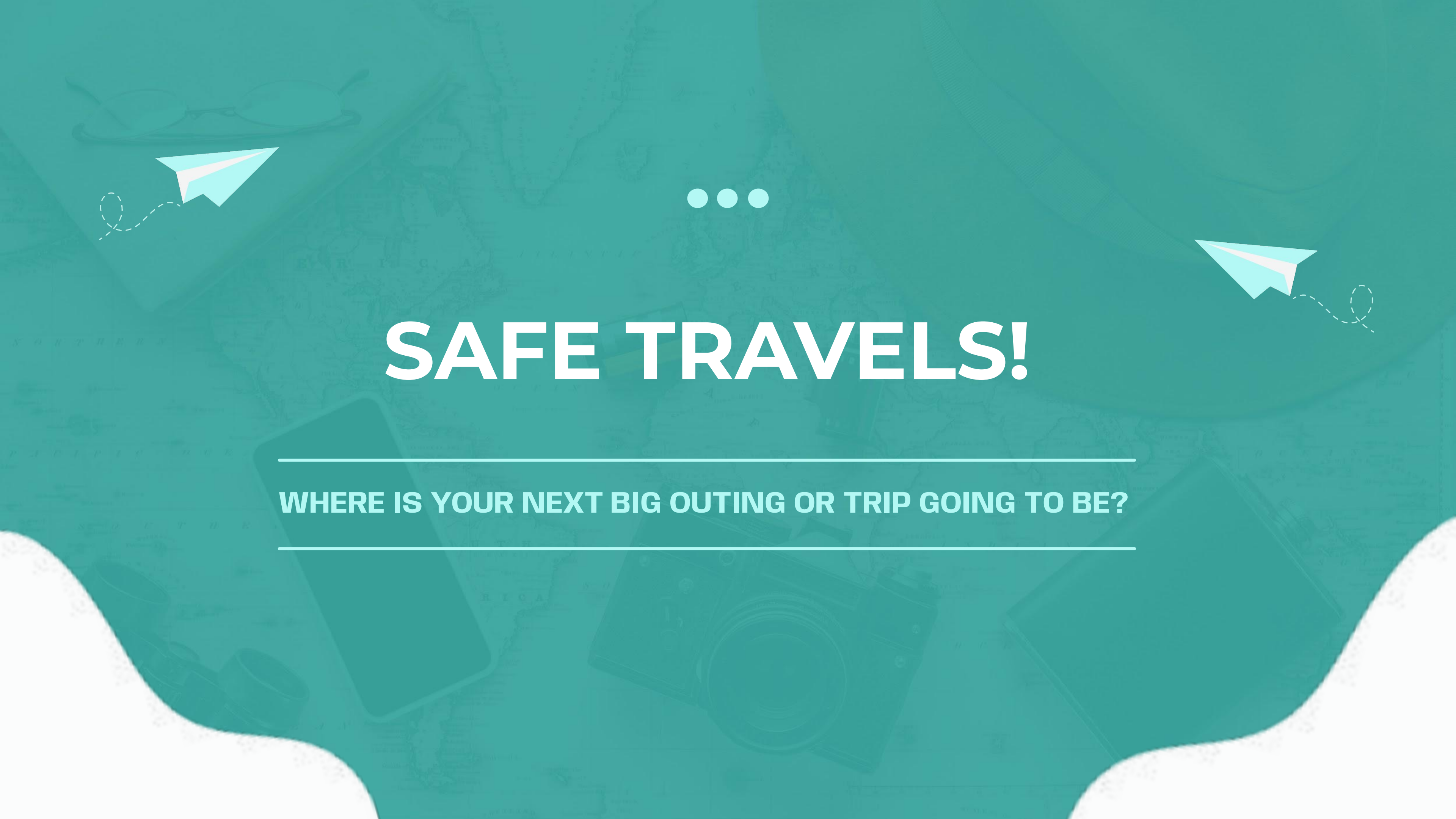


TIP 10:

ENJOY EVERY MOMENT!

Each trip is an opportunity to grow, learn, and experience the world from a new perspective. Soak in every moment!





SAFE TRAVELS!

WHERE IS YOUR NEXT BIG OUTING OR TRIP GOING TO BE?

REFERENCES

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3. Lifestyle tips for myasthenics. The Australian Myasthenic Association in NSW. Available at https://www.myasthenia.org.au/patient-support/lifestyle/. Accessed 3/5/2021.
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SOUTHWEST MG

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?

**Welcome
and
Introduce
NEW
Group Members!**

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. Information that has worked for you is welcomed to be shared with the group as a recommendation, but as a member know that just because it works for one does not mean it works for all. **YOU SHOULD NOT MAKE ANY MEDICAL DECISIONS FOR YOURSELF WITHOUT CONSULTING YOUR OWN PHYSICIAN FIRST**. **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…

- Saturday, August 23rd, 2 pm: Peach Cobbler Factory, West Chester
- Saturday, September 13th, 1 pm - 3 pm: Support Group Meeting, Mayerson JCC
- Next Year's Goals Survey - Earlier than last year, but it is due earlier this year. Please fill this out and return it no later than September 19th.
- Thursday, September 25th, 12:40 pm: Red's Game
  (Handicap accessible seating - under shelter/in the shade)
- Directory Authorization (Permission Form): Return by September 30th with photograph - email to amannerica@gmail.com or text to 513-767-6750
  https://forms.gle/BeYdntbSdiiqFyaG8
- SAVE THE DATE: Sunday December 7th, 1 pm - 4 pm Holiday Party - Maggiano's Little Italy, Kenwood. $10/person & $10 gift from grocery checkout line!

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,
Erica, Kacy & Sharon

MG OH SW Support Group (Tentative) Meetings/Events Calendar 2025

All Meetings are at Mayerson JCC from 1 pm - 3 pm , Located at 8485 Ridge Rd, Cincinnati Ohio 45236

January -

Jan. 11th Meeting: Zoom: Clinic Studies and New Research
Extra: NONE

February -

Feb. **8th** Meeting: LeeJean Beringer - Alexion
Extra: Feb 28th Rare Disease Day - Escape Room @ **2:45 pm**

March -

March 8th Meeting: Dr. Malik - MG and the Diaphragm
Extra: March 29 - April 1 MGFA Conference - 3 attending

April -

April **12th** Meeting:
Extra: April **15th** Social - Coffee & Donuts @ **10 am**, Hunts Donut, 12110 Mason Road, Cincinnati, Ohio 45249

May -

May **10th** Meeting: Lisa Cruz - argenx
Extra: May **21st** Social Event Cincinnati Scavenger Hunt: Cincy's Grand City Sights @ **11 am**

June -

June **14th** Meeting: Preparation for Walk/Conference
Extra: June **21st - 22nd** , MG Walk and Patient Education Conference

July -

July **12th** Meeting:
Extra: July **21st** Social - Lunch Outing @ **12 pm** Location TBD

August -

Aug. **9th** Meeting:
Extra: Aug. **23rd** Social Event - Ice Cream Social @ **2 pm**
Peach Cobbler, 7736 Dudley Dr., West Chester, Ohio 45069

September -

Sept. **13th** Meeting: Alexion
Extra: Social Event: Sept. **25th** @ **12:40 pm Cincinnati Reds Game**

October -

Oct. **11th** Meeting: Wendy Kobler, Medicare Pro, Medicare Resource Center
Extra: TBD Social - Cincinnati Museum Center for their “Off the Rails: Halloween Edition at the Hall of Justice” event.

November -

Nov. **8th** Meeting: argenx
Extra: Social Event: TBD Holiday Movie

December -

Meeting: NONE
Extra: Dec. **7th** Christmas Party @ **1 pm** at Maggiano's