



WELCOME!

to our

Southwest Support Group Meeting!

November 9, 2024

Please make sure you sign in,
pick up a name tag

*Help
Yourself
To
LUNCH!*

LUNCH MENU

- Pulled Chicken or Beef Brisket
- Buns
- Sweet City Sauce BBQ or Brush Fire Sauce BBQ
- Mac & Cheese
- Green Beans with Bacon
- Cole Slaw
- Cookie Brownies from Domino's Pizza

**City
BARBECUE**
&





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 1st and 4th Thursday BUT This month due to Thanksgiving the 4th Thursday meeting will be held on **Wednesday, Nov. 21st at 7:00 pm**. Also Saturday night chats at 6:30 pm weekly! The link is available in the November newsletter on the first page, that was sent out from MG Ohio.



Today's Agenda

- ❑ **Old Business -**
 - ❑ Last Month's Lunch Social at Ford's Garage (8 in attendance)
 - ❑ New Board Members were highlighted in the last newsletter from MG OHIO - NEW PRESIDENT OF MG OHIO - SUZANNE RUFF
- ❑ **New Business -**
 - ❑ Sharon Speaking about Leadership Role Changes
 - ❑ Erica Speaking about Stepping up into Leadership Role
 - ❑ MGFA National Patient Conference - Phoenix, Arizona March 23-25, Patients and Caregivers are FREE to attend - Discussion after the meeting if interested in going
 - ❑ **NEXT MEETING - JANUARY 11, 2025**
 - ❑ **Guest Speaker - Dr. Junaid Malik, who is board certified in Critical Care Medicine, Pulmonary Disease, and Sleep Medicine**
- ❑ **MG and Emotional Well-Being**
 - ❑ Presented by Shelley Gerson from argenx
- ❑ **Share and Care Time**
 - ❑ New member introductions
 - ❑ New concerns, symptoms, new medications, doctors
 - ❑ Positives you want to share

Leadership Changes

When Sharon began as the District Rep in October of 1985, the group was connected with both the Ohio Chapter of the MG Foundation and Cincinnati MDA. When both of these groups left Ohio, the group continued to identify as MG Cincinnati. Jack and Sue Paas joined Sharon as leaders in May of 1993. Then about three years ago they joined MG Ohio, and became the Southwest Group. Sharon continued calling us the "Cincinnati" Group, but we are technically the Southwest Group to cover the smaller cities around the Cincinnati area and we include Dayton. Therefore "Cincinnati" is not as accurate. Sharon has been a leader for 39 years and in remission for over 30 years now! Which is wonderful, but with drug discovery and development over the past 5 years and Sharon not as in touch with the newest information of MG or seeing a neurologist anymore, she felt it was best for the group to take a step back.

SHARON, JACK, NOR SUE ARE LEAVING THE GROUP!

New Support Group Leaders

Erica Amann

Saul Wiener

Leadership Contact Information

Phone Numbers:

- ❖ **Southwest Support Group Leader:**
 - Erica Amann: (513) 767-6750
- ❖ **MG OHIO President:**
 - Suzanne Ruff: (216-218-0477)

Emails:

- ❖ **Southwest Support Group** : You should be receiving monthly emails or reminder emails about meetings from amannerica@gmail.com or SW MG OH Support Group - Erica Amann
 - 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 mgohio@mgohio.org
 - 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>

SW MG OH 2025 Meeting Schedule

**Meetings will be held at the Mayerson JCC
from 1 - 3 pm on the 2nd Saturday of the**

- **January 4, 2025**
- **February 8, 2025**
- **March 8, 2025**
- **April 12, 2025**
- **May 10, 2025**
- **June TBD (Based on MG Walk)**
- **July 12, 2025**
- **August 9, 2025**
- **September 13, 2025**
- **October 11, 2025**
- **November 8, 2025**

Meet Our Guest Speaker, Shelley Gerson

MG & Emotional Well-Being



Shelley Gerson is an Associate Director Global Patient Advocacy at argenx, leading advocacy efforts associated with argenx research for alternative treatments for people living with autoimmune and genetic diseases including Generalized Myasthenia Gravis (gMG), Congenital Myasthenic Syndrome (CMS), Thyroid Eye Disease (TED), Spinal Muscular Atrophy (SMA), Amyotrophic Lateral Sclerosis (ALS) and Immune Thrombocytopenia Purpura (ITP).

Shelley joined argenx in 2021 after working in patient advocacy in rare bleeding disorders at Sanofi, Bioverativ and Biogen. In fact, she was invited to join the rare blood disorders patient advocacy team at Biogen in 2012 because of her extensive work with patient advocacy organizations supporting people living with Hemophilia which Shelley was born and lives with every day.

Shelley's work prior to working in biotech prepared her well for what she does now in patient advocacy at argenx. She began her working life as a biology teacher and still nerds out over learning about and explaining how treatments work to reduce symptoms of rare medical conditions. While teaching science and volunteering with her regional and national patient advocacy organizations, she realized how overwhelming the daily impact of living with chronic illness is for many people.

Shelley decided she wanted to be able to do more to help others like herself, living with chronic illness and enrolled in graduate school to earn her master's degree. She opened a small, private psychotherapy practice and learned so much from her clients and hopes she was able to support them in some small way.

Shelley lives in Michigan with her three children ages 22, 21 and 17 and her "fur" children, who are equally important, Sugar a 5-year-old goldendoodle; Yoshi a 14-year-old mutt; and three cats Jackie, Rosie and a glorious Maine Coon named Kissy. When she is not working, you can find Shelley reading, enjoying the beaches around her home state of Michigan (when weather will allow), crocheting and hanging out with her kids!



MG & EMOTIONAL BEING PARTICIPANT GUIDE

SEE PDF THAT IS ATTACHED IN EMAIL

ALSO WORKING ON GETTING ACTUAL PRINTED GUIDES
MAILED TO US FROM SHELLEY. I WILL HOPEFULLY BRING
THESE TO OUR JANUARY MEETING.



**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 - Wednesday, November 21st at 7 pm
- Zoom Meeting - December 5th at 3 pm
- Zoom Meeting - December 26th at 7 pm
- Zoom Chats weekly every Saturday night at 6:30 pm
- **SW Support Group Meeting - January 11, 2025 at 1 pm**

Have a safe, memorable, relaxing holiday season!

See everyone in person next year!

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