

## MG OHIO NEWS

**OCTOBER 2025** 

Volume 13 Issue 10

### NEW ZOOM MEETING FOR PARENTS OF MG KIDS

This meeting will be held every month on the 2nd Saturday at 4:30 pm ET

#### MG Ohio

## **Elected Officers**

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Dr. Robert Ruff Vice-President

Laura Lodge Treasurer

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Dr. Hani Kushlaf Dr. Yuebing Li

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If we can assist you with medical care referrals, resources, durable medical equipment, or information about MG, contact us at 216-218-0477 (leave a message)

You will find a wealth of information at the website:

MGOhio.org

To Donate to MG Ohio, scan here





# MG Ohio Zoom Support Group Meetings

#### **1st Thursday**

When: Oct 2, 2025 03:00 PM ET

https://zoom.us/meeting/register/ tJcrcO6urTgiGtK3l9l\_RXk1QDozODwbXpFs

Dial in: 309-205-3325

Meeting ID: 936 7763 3806 Passcode 586068

## 4th Thursday

When: Oct 19, 2025 07:00 PM ET

https://zoom.us/meeting/register/ tJUkceCtqj0jHNaMrXHj4XLLH1K4BzKYld U

Dial in: 301-715-8592

Meeting ID: 919 6954 6962 Passcode 799908

## **Saturday Nights**

Saturday night chats weekly at 6:30 PM ET

https://zoom.us/meeting/register/ tJ0ufu6grDsjG9PS1AQG9vWTYeTnNJAZtumm

Dial in: 646-931-3860

Meeting ID: 993 9782 0917 Passcode 730070

## NEW ZOOM MEETING FOR PARENTS OF MG KIDS

Formed for parents to be able to interact with other parents of MG KIDS.

Lead by Kori Khan, parents will have the opportunity to chat and encourage one another. This meeting will be held every month on the 2nd Saturday at 4:30 pm ET We hope you will join us!

### **2nd Saturday**

**Parents of MG Kids** 

When: Oct 11, 2025 04:30 PM ET https://zoom.us/j/96043460108? pwd=Z3JLrZAFK2EldiN08WHOhSye1dhTGS.1

Dial in: 646-931-3860

Meeting ID: 960 4346 0108 Passcode: 509617

After registering, you will receive a confirmation email containing information about joining the meeting.

#### MG Ohio Educates

## Ask the Expert

## What's the difference in Pharmaceutical presentations?

As most of us know, there has been a huge increase in the number of medications available for those who have Myasthenia Gravis (MG) over the past few years. It is wonderful news to for patients, caregivers, friends and family alike. Pharmaceutical companies – commonly known as Pharma – have become an important part of the MG Community, offering sponsorship for large events such as Walks and conferences, smaller events such as "lunch and learns" and some outings. We are truly grateful for their support.

Pharma has also stepped up with educational offerings. These offerings are developed by professionals with specific expertise. The offerings fall into two distinct categories: 1) purely educational on living with MG and 2) commercial information about medications available through their company. Most of the companies have a strict divide between the sections including different departments and representatives for patient and caregiver information, and for commercial products (medications). In addition, MG Ohio has a set of guidelines to help patients, their caregivers and family understand the different types of presentations. This is done to satisfy our obligations as a non--profit organization with responsibility solely to our members and any state and federal laws that apply.

Both types of presentations are available to Support Groups at the request of the Support Group leader acting on behalf of the group. The educational programs may be presented by a representative from the continued on page 3

## **2025 MG Ohio Meetings:**

MG Ohio Northeast Ohio In-Person Support Group Meetings:

October 11, 2025 - 1:00-3:00 pm Metro Health November Campus

7800 Pearl Rd.

Middleburg Hts., OH 441

We will have a guest speaker. Charles Boone from Ohio Health Care Consultants will talk about insurance, Medicare, and changes that will take place in the coming year. All are welcome - please bring family and friends.

This will be a hybrid meeting broadcast over Zoom. Please use the link or call to join:

https://zoom.us/j/95377894109?pwd=NoN8jb0pTRZkrtXEdZkuxfmaja2vdd.1

Meeting ID: 953 7789 4109 Passcode: 980913

**NOTE:** This year regular NEO meetings will be BYOW (bring your own water) Coffee will be available. Donations of baked goods always welcome.

October 28, 2025 NE Ohio will be coordinating a brunch on Tuesday, October 28 on the

East side of Cleveland for anyone who would like to join us.

## MG Ohio Central Ohio In-Person & Zoom Support Group Meetings:

October 27, 2025 - 4:30 pm

The Dempsey Family Education and Resource Center

at OhioHealth Neuroscience Center Riverside Methodist Hospital

3535 Olentangy River Road, Columbus, Ohio 43214

Parking is free (with vouchers we will provide at the meeting). Park in the

"Red" parking garage.

We plan for this to be a hybrid meeting for in-person support group members and their caregivers/families as well as online via WebEx for those unable to attend in-person. (WebEx is an online meeting platform similar to Zoom) www.ohiohealth.webex.com Please contact Sharon or Cathy at <a href="mailto:centralohiomg@gmail.com">centralohiomg@gmail.com</a> or by phone at 614-334-1140 for the Webex meeting code.

## MG Ohio Southeast Ohio In-Person Support Group Meetings:

To Be Determined Wheeling Park at the White Palace

1801 National Rd, Wheeling, WV 26003

This is a historic building located in beautiful Wheeling Park. The building is handicap accessible and has a Starbucks, important to members as they like coffee to go with the cookies that I provide at each meeting. The building also has ample free parking.

For more details regarding time and location, please contact Jay Adams at 304-780-9274.

## MG Ohio Southwest Ohio In-Person Support Group Meetings:

October 11, 2025 - 1:00-3:00 pm Mayerson JCC

8485 Ridge Road, Cincinnati, Ohio 45236.

(Take the Ridge Road Exit from the Ronald Reagan Highway

RSVP to Erica at <a href="mailto:mgohiosouthwest@gmail.com">mgohiosouthwest@gmail.com</a>

Guest Speaker: Wendy Kobler, Medicare Pro, Medicare Resource Center

Wendy will share insights on Medicare health plans—breaking down the Advantage Plan vs. Medicare A & B, making comparisons, and helping you find the plan that best fits your needs. This meeting is open to patients, caregivers, friends, and family. A must-attend for those nearing retirement age or already on Medicare—with or without MG!!

This will be a hybrid meeting broadcast over Zoom. Please use the link or call to join:

https://zoom.us/j/97131113585?pwd=r52SrnweJG59pfVbfKgyNCrwelzgZh.1

Meeting ID: 971 3111 3585 Passcode: 974695







Thank you so much to everyone who was able to attend our NE Ohio MG Awareness Walk on Sunday, September 7 at The Chalet in the Cleveland MetroParks!



It was a wonderful gathering of 90+ MG patients, caregivers, family, medical professionals, and all kinds of caring, supportive groups within our MG community. We were so lucky to have such a gorgeous Fall day!



Dr. Bob Ruff welcomed everyone & spoke prior to the walk, and Dr. Kylie Sramek guided the group through some warm up exercises before heading out on the path.



Through our silent auction and raffles we were able to raise \$1400 over and above sponsorship donations, which will go straight back into educational support and community building for our membership.



We are grateful for the participation and support of our sponsors for making this event possible: Alexion, Argenx, Johnson and Johnson, UCB, VitalCare Infusion Services, and our SW MG Ohio friends in the greater Cincinnati/ Dayton area.



We also would like to extend thanks to all of the individuals and greater Cleveland area businesses that donated to our silent auction and raffle. Please support them as you can: The Cleveland Museum of Art, The Jack Casino Cleveland, Drs. Bob & Suzanne Ruff, Cleveland Browns Football, Rebecca Molitoris, Sportsville, Main Event, Panera Bread, Cleveland Monsters, Cleveland Botanical Gardens, USS Cod Submarine Memorial, Crushers Baseball, O'Neil Healthcare, Playhouse Square, Western Reserve Historical Society, Maltz Museum, The Ohio State Reformatory, Cleveland Cavaliers, Dave & Buster's, Dr. Liz Plowman, and the Red Wagon Farm.



Many thanks to our NE Ohio Event Team (Laura, Gina & Rebecca) for making it all happen, to Jack Petersen for creating our signage, to Erica Amann for her graphic design work, including the walk logo and t-shirt design, to Jerry Molitoris for his technical support with walk registration, and to Kylie & the Tri-C PT class for setting up the walk course signage/water stations. Huge props to all of our families & volunteers - we simply can't do it without you!



#### Save the Date

## Tuesday, October 28

NE Ohio will be coordinating a brunch on on the East side of Cleveland for anyone who would like to join us.



## **Celebrate! October Events**

• October 6 National Noodle Day

October 11 World Origami Day

October 12 National Fossil Day

October 13 Columbus Day

• October 24 United Nations Day

• October 28 Frankenstein Friday

October 31 Halloween

continued from page 1 company or materials may be sent to the Support Group leader. Topics include the "Activities of Daily Living" scale and its importance, nutrition, communicating effectively in a doctor's visit and others. The commercial product presentations are usually given by a neurologist with expertise in MG.

Whenever you see an MG Ohio Support Group meeting featuring a guest speaker from a major pharmaceutical company, the guest speaker will be giving an educational talk. Speakers cannot legally discuss the merits of their medication products or treatments during these meetings.

Whenever you see a poster advertising a special event, lunch, or dinner given by a pharmaceutical company, that company will bring in a doctor versed on their medication product or treatment and demonstrate how that product works for some patients with MG.

MG Ohio doesn't endorse any one medication product or treatment over another. Not every treatment works for every patient. It is important to discuss any changes to your treatment plan with your own personal neurologist or medical provider and make informed decisions together.

#### DID YOU KNOW?

- You can find the latest clinical trials for myasthenia gravis by going to:
  - www.clinicaltrials.gov
- MG Ohio has formed an alliance with other independent MG Support Organizations across the country. Go to <a href="https://mgohio.org/mg-alliance">https://mgohio.org/mg-alliance</a> to find such virtual groups as Black with MG, Muscle Makers (for crafters), Young Adults, and LGBTQ+
- MG Ohio offers one-on-one mentoring in our MG Friends program. Contact us at mgohio@mgohio.org to participate.

## MG Ohio Website: Visit us at <a href="https://www.mgohio.org">www.mgohio.org</a>

## For all the latest local MG news, upcoming events, and newsletters

Is there a topic or subject that

you would like to see covered

in the monthly MG News? Email us at news@mgohio.org

and let us know!

## Need help paying for your meds? Check out the following sites:

https://www.needymeds.org/

Good Rx.com

http://www.themedicineprogram.com/

http://www.togetherrxacces.com/p/prescription-savings

https://mat.org/ (Medication Assistance Tool)

http://www.rxhope.com/Patient/AssistanceRequest.aspx

https://accessiahealth.org/patient-programs/

## MG OHIO SOUTHWEST SEPTEMBER Recap & OCTOBER Highlights



#### September Recap:

In September, our group gathered for an educational discussion on how to have productive conversations with medical professionals, presented by Nikita Lyons Murry from Alexion. Nikita did a fantastic job leading us through the topic, and our group shared helpful strategies on preparing for appointments, communicating with doctors, and following up afterward. The biggest takeaway? Make sure your questions are answered and that you fully

understand the health plan you and your doctor set together.

## Our MG Ohio Southwest September Patient Spotlight is Kacy Self!

Kacy has been living with MG for 9 years. She was born in Plainview, TX, later moved to Sierra Vista, AZ, then Seattle, WA, and for the past 3 years has called **Cincinnati, Ohio** home. Visit the **MG Ohio website, Southwest Group page** to read Kacy's inspiring MG journey. Thank you, Kacy, for sharing your story with us!

#### **Upcoming Events:**

Thursday, Sept. 25 – Reds Game 12:40 PM

We're heading to the last home game of the season! A few tickets are still available—don't miss out. Please contact Erica @ mgohiosouthwest@gmail.com

Saturday, Oct. 11 – Monthly Meeting 1:00 – 3:00 PM Mayerson JCC – Hybrid Format (join in person or on Zoom) Guest Speaker: Wendy Kobler, Medicare Pro, Medicare Resource Center

Wendy will share insights on Medicare health plans—breaking down the **Advantage Plan vs. Medicare A & B**, making comparisons, and helping you find the plan that best fits your needs. This meeting is open to **patients**, **caregivers**, **friends**, **and family**. A mustattend for those nearing retirement age or already on Medicare—with or without MG!

We hope to see you at an upcoming meeting, event, or social gathering—whether in person or online.

#### **IN PERSON - OCTOBER 2025 MEETINGS:**

Northeast Ohio

October 11 - 1:00-3:00 pm Metro Health November Campus

7800 Pearl Rd. Middleburg Hts. OH 44130

**Central Ohio** 

October 27 - 4:30 pm The Dempsey Family Education and Resource Center

3535 Olentangy River Road, Columbus, Ohio 43214

Southeast Ohio

To Be Determined Wheeling Park at the White Palace

1801 National Rd, Wheeling, WV 26003

**Southwest Ohio** 

<u>October 11 - 1:00-3:00 pm</u> Mayerson JCC

8485 Ridge Road, Cincinnati, Ohio 45236