

# MG OHIO NEWS

**July 2024** 

# Volume 12 Issue 7

Supporting the Myasthenia Community in Ohio & Beyond



# MG Ohio

ive Board
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Dr. Daniel Benson
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Dr. Hani Kushlaf
Sharon Rastatter
Saul Wiener

### We are here for you and your

family to provide help and hope for those living with Myasthenia Gravis in Ohio and beyond.

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

You will find a wealth of information at the website:

MGOhio.org







When: July 11, 2024 03:00 PM Eastern Time (US and Canada)

https://zoom.us/meeting/register/tJllcO6hr DwvHtd61R9VqPmOcl2wqkgs1P1h

When: July 25, 2024 07:00 PM Eastern Time (US and Canada)

https://zoom.us/meeting/register/tJwpcu6p rT4uEtapOZcjHU8ZtWrkYCAyT3Fs

Saturday night chats weekly at 6:30 pm (ET)

Register in advance for this meeting:

https://zoom.us/meeting/register/ tJYvcuytqjgqHdSBm1nwDkGRL5Mi5jXJWKt



## Ask the MG Expert

**Q.** I would like to be able to travel again. Do you have any tips for traveling for someone diagnosed with MG?

**A.** The answer is a little complicated. With some preplanning, you can still enjoy some summer trips:

Use Caution—If you are currently on immunosuppressants such as Prednisone, Imuran, Cellcept, or one of the monoclonal antibodies like Vvgart, Rituximab, or Soliris, you should protect yourself by avoiding crowds, wearing a mask, and practicing social distancing when you go out. Even though the threat of COVID has diminished, there are still plenty of other viral illnesses making the rounds.

**Public Transportation**—Masks are still a good idea whenever you fly, take a train, or ride on a bus. Try and distance yourself from others while using these forms of transport.

**Driving**—If you decide to drive yourself, take frequent breaks about every 2-3 hours. These breaks give your eyes a rest and allow you to stretch your legs.

Plan Ahead—Be sure to pack extra medication in case you need it. Other essential items may include hand sanitizer, extra masks, cooling towels or vest, sanitizing spray, and snack items to eat when taking your mestinon.

**Research**—Know which hospitals are closest to your destination and if they accept your insurance. Consider buying medical travel insurance.

**Conserve Energy**—Don't be afraid to use the free transport cart at the airport or a scooter at a store. Build in some rest periods in your itinerary. Even doing fun things like sightseeing can be physically taxing. Be sure and plan some down time.

Relax and enjoy your summer.

2024 MG Ohio Meetings:		
MG Ohio Northeast O	hio (NEO) In-Person Support Group Meetings:	
<u>July 13 – 1:00-3:00 pm</u>	Metro Health November Campus 7800 Pearl Rd. Middleburg Hts. 44130	NEW!
<u>August 10 – 1:00-3:00 pm</u>	Central—Annual Ice Cream Social 6305 Halle Dr., Valley View OH 44125	
<u>September 14 – 1:00-3:00 pm</u>	Metro Health November Campus	
<u>October 12 – 1:00-3:00 pm</u>	7800 Pearl Rd. Middleburg Hts. 44130 Metro Health November Campus 7800 Pearl Rd. Middleburg Hts. 44130	
<u>November 9 – 1:00-3:00 pm</u>	Metro Health November Campus 7800 Pearl Rd. Middleburg Hts. 44130	
<u>December 7 – 1:00-4:00 pm</u>	Annual Christmas/Holiday Party—Pioneer Ridge L 9479 Saw Mill Trace, North Ridgeville, OH 44039	odge

MG Ohio	Central Ohio MG In-Person Support Group Meeting:
<u>Monday, July 15 – 4:</u>	D pmThe Dempsey Family Education and Resource Center at the OhioHealth Neuroscience Center at 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.)

Please contact Sharon or Cathy at centralohiomg@gmail.com or by phone at 614-334-1140 for the Webex meeting code.

MG Ohio

Southwest Ohio In-Person Support Group Meetings:

The Southwest Ohio MG Support Group will meet the following months in 2024: Jan. ,Mar., May, Jul., Sept., and Nov. The exact Saturday we meet during these months will be added as soon as our meeting place confirms the dates.

<u>July 13 – 1:00 – 3:00 pm</u>

Mayerson JCC Community Center 8485 Ridge Avenue Cincinnati, Oh 45246 The MG Ohio Southwest Walk was a great success even with the last-minute change in venue due to the excessive heat.

Erica Amman, Sharon Meyer, and Jack Paas did a tremendous job. Thanks especially to Erica who designed the T-shirts, arranged all the silent auction gift baskets, found the new venue, and so much more! Looks like everyone had a wonderful time!



# A Few Words from Rebecca – Outgoing President of MG Ohio –

It has been my rare privilege and honor to serve as your Support Group Leader, Founder, and President of MG Ohio for the past decade +. I'm both saddened and excited to be stepping down as President. Saddened because I've really enjoyed getting to know each and every one of you and trying my best to help make a difference and hopefully giving *you* hope in your journey with MG. I will miss seeing you and interacting with you all on a regular basis.

I'm also excited by the new possibilities that have presented themselves to me to continue to make a difference for MG patients and their families in a broader way. You will see less of me, but I will still be around. In January when I planned the events for the year, I scheduled our annual Ice Cream Social in August and annual Christmas/Holiday party in December (see page 2). I will still be present at both those events. I'm taking a step back from all other inperson meetings and Zoom meetings to concentrate on my family, my health, and my advocacy efforts to continue to bring awareness and education about myasthenia gravis to a broader audience.

I am leaving you in the very capable hands of Dr. Robert Ruff and Dr. Suzanne Ruff who will continue to provide the support, education, and information at the support group meetings; and I trust them to guide MG Ohio to fulfill our mission to provide that help and support throughout Ohio and beyond. The Ruffs have spent over 40 years supporting those with MG. We are truly blessed to have them. Lastly, I would like to thank you all. Thanks for showing me grace when I couldn't get back to you right away, for encouraging me to take care of

myself, and for providing helping hands when needed. All the Best, Rebecca

# What's in our virtual closet to borrow?

- Walkers
- Canes
- Potty chairPortable Aluminum Ramps

If you need one of these items, call or text 216-218-0477 and leave a message. If you have something you'd like to donate to our virtual closet, let us know.

Someone is looking for a way to attach a wheelchair to the back of their car. If you know of a device, let us know.

# MG Ohio Website: Visit us at <u>www.mgohio.org</u>

# For all the latest local MG Ohio news and upcoming events.

# NOTE: The assistance fund is accepting applications from patients with myasthenia gravis to help with the following outof-pocket costs:

- Prescription drug assistance (copays, deductibles, and coinsurance) on FDA-approved treatment
- Health insurance premiums
- Therapy Administration costs
- Physician co-pays
- Treatment related travel costs

# The Assistance Fund (tafcares.org)

NOTE: Important!! Be sure and sign up NOW for

2024



<u>Need help paying for your meds? Check out the fol-</u> <u>lowing sites:</u>

https://rarediseases.org/patient-assistance-programs/ financial-assistance/?search=myasthenia%20gravis accepting new applications

https://www.needymeds.org/

Good Rx.com

http://www.themedicineprogram.com/

http://www.togetherrxacces.com/p/prescriptionsavings

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

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

http://www.myastheniagravis.org/we-can-help/whatwe-do/ -for patients living in Indiana, Illinois, and Wisconsin

More info at: <u>https://myasthenia.org/Community-</u> <u>Resources/Resources-External-Assistance-Programs</u>

Want to see an article in the MG Ohio News? Send in your questions or ideas by the 15<sup>th</sup> of the month to <u>news@mgohio.org</u>

# July 2024 IN-PERSON MEETINGS:July 13 - 1:00 - 3:00 pmMetro Health November Campus<br/>7800 Pearl Rd. Middleburg Hts. 44130July 13 - 1:00 - 3:00 pmMayerson JCC Community Center<br/>8485 Ridge Avenue<br/>Cincinnati, Oh 45246July 15 - 4:30 pmThe Dempsey Family Education and Resource Center at the OhioHealth<br/>Neuroscience Center at Riverside Methodist Hospital<br/>3535 Olentangy River Road, Columbus, Ohio 43214