

MG OHIO NEWS

OCTOBER 2024

Volume 12 Issue 10

Check our the new and improved MG Ohio website! go to www.mgohio.org to see all of the latest treatment options, webinars, meeting updates, and Zoom links!

MG Ohio

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Dr. Yuebing Li Gina Oradini
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Dr. Kylie Sramek Saul Wiener

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 and 4th Thursdays



When: Oct 3, 2024 03:00 PM ET

https://zoom.us/meeting/register/ tJcrcO6urTgiGtK3l9l_RXk1QDozODwbXpFs

When: Oct. 24, 2024 07:00 PM ET

https://zoom.us/meeting/register/ tJwpcu6prT4uEtapOZcjHU8ZtWrkYCAyT3Fs

Saturday night chats weekly at 6:30 pm (ET) Register in advance for this meeting:

https://zoom.us/meeting/register/ tJYvcuytqjgqHdSBm1nwDkGRL5Mi5jXJWKtd

NOTE: Monthly 2nd Thursday meetings will now be on the 1st Thursday. You MUST re-register in order to join on the new meeting dates.



MG Ohio Educates

Ask the MG Expert

This month's expert answer is by Dr. Hani Kushlaf

Q. Is Mestinon (pyridostigmine bromide) an effective treatment alone for MG? Does it cure MG? –

A. Pyridostigmine bromide (generic name), also known as Mestinon (brand name), is an acetylcholinesterase inhibitor.

Acetylcholinesterase is the enzyme responsible for the breakdown of acetylcholine at the neuromuscular junction.

Acetylcholine (ACh) is a chemical substance, also known as a neuro-transmitter, released by the motor axon that binds to the acetylcholine receptor (AChR) on the muscle fiber membrane, which leads to action potential generation and muscle contraction.

Pyridostigmine does not have any effect on the immune system dysfunction and the production of acetylcholine receptor antibodies in myasthenia gravis. Therefore, it does not cure myasthenia gravis and is only used to treat the symptoms of myasthenia gravis.

By inhibiting acetylcholinesterase, pyridostigmine lengthens the time available for the released acetylcholine to produce muscle contraction.

Pyridostigmine alone is rarely sufficient to control the symptoms of myasthenia gravis.

Pyridostigmine can be used alone for patients with ocular myasthenia gravis and droopy eyelids as the only manifestation.

MG Ohio Supports

2024 MG Ohio Meetings:

MG Ohio Northeast Ohio (NEO) In-Person Support Group Meetings:

October 12 – 1:00-3:00 pm Metro Health November Campus

7800 Pearl Rd. Middleburg Hts. OH 44130 *Speaker (pg.3)

This will be a hybrid meeting broadcast over Zoom. Please use the link to register: https://zoom.us/meeting/register/tJ0uf--gpjwvGNfzDxemGwXKgQCGU1OC6-0- NOTE: If you need to sign on using Meeting ID and Passcode, contact MG Ohio at mgohio@mgohio.org or 216-218-0477

November 9 – 1:00-3:00 pm Metro Health November Campus

7800 Pearl Rd. Middleburg Hts.OH 44130

<u>December 7 – 1:00-4:00 pm</u> Annual Christmas/Holiday Party—Pioneer Ridge Lodge (pg.3)

9479 Saw Mill Trace, North Ridgeville, OH 44039

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

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

October 21, 2024—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 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 MG Support Group will be having a **Social Lunch Event in October**. This will not be MG focused! It is just a time to get to know one another! If you are in the Southwest Support Group mailing list then you will receive an email soon to choose amongst the following dates for lunch: **October 21st, 22nd, or 23rd** at 12:30 p.m. along with a few lunch venues. **If you are interested in attending and not on our mailing list please contact Erica at amannerica@gmail.com**.

November 9, 2024 —1:00-3:00 pm Mayerson JCC *Speaker (pg.3)

8485 Ridge Road, Cincinnati, Ohio 45236.

(Take the Ridge Road Exit from the Ronald Regan Highway)

RSVP to Erica at amannerica@gmail.com.

This will be a hybrid meeting broadcast over Zoom. Please use the link to register: https://zoom.us/meeting/register/tuclf-yrqTwpGtLRmnyVhHRsabxfLrz1szh NOTE: If you need to sign on using Meeting ID and Passcode, contact MG Ohio at mgohio@mgohio.org or 216-218-0477

MG Ohio Board of Directors met on September 15, 2024 for their annual in-person meeting. The year was reviewed and the NE and SW walks were discussed. It was decided that these walks are worthwhile for both bringing awareness and raising donations and will be continued. Total net donations from the combined walks was \$5808. A new board member was welcomed see information about Gina Oradini below. A new Executive Board was voted in.

Here is the Executive Board for 2024-2025:

President: Suzanne Ruff; Vice-President: Robert Ruff; Treasurer: Rebecca Molitoris; Secretary: Laura Lodge



RSVP NOW

Reservations are currently being taken for our annual Christmas/Holiday Party to be held on:
Saturday, December 7, 2024 1:00 pm



This year we will have a buffet at the Pioneer Ridge Lodge 9479 Saw Mill Drive, North Ridgeville 44039.

Food will be catered by Stancato's.

We will have fun door prizes, games, and a gift exchange.

The Lodge is decorated for Christmas allowing for photos with your loved ones

As always, family and friends are invited too!

Cost is just \$10/ person

Email mgohio@mgohio.org or Call or text 216-218-0477 (leave a message) to reserve a spot.

Northeast Ohio Support Group October Meeting will feature speaker Charles Boone who will speak about the upcoming changes to Medicare in 2025. Don't miss this exciting presentation by a dynamic gentleman. NOTE: This is NOT a sales pitch – information only.

Bring a friend!



Southwest MG Ohio Support Group News—

In November, we will be having a Special Guest speaker from Argenx to speak about MG and Emotional Support. This will be at such an important time of the year with the holidays right around the corner. We will also be having a catered lunch from City BBQ this day. Please look for more information to come!

MEET THE BOARD 2024 At our annual in-person Board Meeting held on September 15, 2024, we welcomed Gina Dettore-Oradini as our newest board member. Gina will serve on the events planning committee this year. For those of you who attended the walk in NEO, you may recall that Gina and her husband, Mike manned the registration table.

Here's what Gina had to say to introduce herself: "I am an MG patient, diagnosed in 2019, I live in North Ridgeville Ohio on a horse farm. My background is in selling real estate, managing rental offices, racehorse breeding, and as an owner of small businesses. I look forward to retiring and spending more time with my family on the farm."

We are very happy to have Gina join our Board of Directors. Please congratulate her when you see her.

MG Ohio Website: Visit us at www.mgohio.org

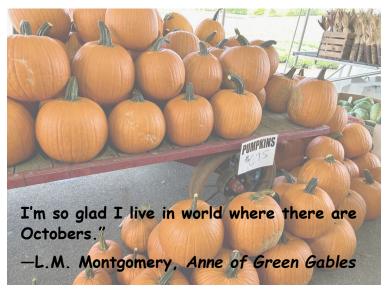
For all the latest local MG news, upcoming events, and newsletters

NOTE: The assistance fund is accepting applications from patients with myasthenia gravis to help with the following out-of-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



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

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/what-we-do/ -for patients living in Indiana, Illinois, and Wisconsin

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

Have a question, comment, or news story you'd like to see in MG OHIO NEWS? Contact us at news@mgohio.org

OCTOBER 2024 MEETINGS:

In Person—

October 12— 1:00—3:00 pm Northeast Ohio

Metro Health November Campus

7800 Pearl Rd. Middleburg Hts. OH 44130 *Speaker

October 21—4:30 pm Central Ohio

The Dempsey Family Education and Resource Center at OhioHealth Neuroscience Center Riverside Methodist Hospital 3535 Olentangy River Road, Columbus, Ohio 43214

October TBD 12:30 pm Southwest Ohio

Lunch Social—watch your email for further updates