



MG OHIO NEWS

May 2024

Volume 12 Issue 5

Supporting the Myasthenia
Community in Ohio & Beyond



Please note that the phone line for MG Ohio is NOT manned 24/7. If you are calling about an emergency, please call 911.

If you are calling for more information about myasthenia or MG Ohio, please leave a detailed message. Someone will get back to you usually within 48-72 hours.

216-218-0477



**MG Ohio Zoom Support
Group Meetings
2nd and 4th Thursdays**

When: May 9, 2024 3:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJllcO6hrDwwHtd61R9VqPmOcl2wqkgs1P1h>

Meeting ID 968 7792 7543 Passcode 786249

When: May 23, 2024 7:00 PM Eastern Time (US and Canada)

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

Meeting ID 984 5713 5482 Passcode 896418

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

Register in advance for this meeting:

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

Meeting ID 922 5554 3070 Passcode 842519

MG Ohio

Executive Board

Rebecca Molitoris	President
TBA	Vice-President
Dr. Robert Ruff	Treasurer
Dr. Suzanne Ruff	Secretary
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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:

www.MGOhio.org

Help out MG Ohio:

Use the link below to sign up for Rare Patient Voice, MG Ohio will receive \$5 for every person chosen to participate. That money goes towards funding our newsletter and our support groups. [Click here](#) to sign up.

Ask the MG Expert

Q. I feel weaker and drained in the summer heat. Any suggestions?

A. Glad you asked! Here's my annual "How to retain strength during the hot summer days" suggestions:

Keep it Cool—If you work out-doors or must be outdoors for a prolonged period, you might want to invest in a good cooling vest. There are two kinds available, vests that cool by evaporation (these must be wet first) and those that contain pockets for ice gel packs that keep you cool for longer. Find them both by Googling "cooling vests"

Hydrate—Drinking enough water in the hot days of summer is critical to maintaining your strength. Keep a bottle of water handy with you whenever you leave the house.

Stay indoors—On days when it is both hot and humid or when the weatherman warns you to stay inside, do so. If you don't have air conditioning and are able, open your windows over-night to let in the cooler breeze, then close the windows in the morning to keep the cool air in. Using a fan to circulate the air helps too.

Cooling towels—Another way to keep cool is to use a cooling towel. You can buy the special cooling towels or make your own using a hand towel. Place it in the fridge overnight in cold water. When needed, apply to pulse points (back of neck, wrists, temples, or back of knees) to stay cool.

Sunscreen — If you are on CellCept as part of your treatment plan, be sure and wear a good high SPF rated sunscreen.

NOTE: If you stop perspiring, become disoriented, or feel faint, ill, or dizzy after exposure to high heat, call 911.



2024 MG Ohio Meetings:

MG Ohio

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

<u>May 22—10:30 am</u>	Brunch Bunch Meet Up Perk-Cup Café & Grille 561 W. Bagley Rd. Berea 44017
<u>June 30—9:00 am - 3:00 pm</u>	MG Awareness Walk Event Mill Stream Run Reservation - Cleveland Metroparks 16200 Valley Parkway, Strongsville, OH 44136
<u>July 13 – 1:00 – 3:00 pm</u>	Metro Health November Meeting Room 7800 Pearl Rd. Middleburg Hts., 44130
<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 Meeting Room 7800 Pearl Rd. Middleburg Hts., 44130
<u>October 12—1:00-3:00 pm</u>	Metro Health November Meeting Room 7800 Pearl Rd. Middleburg Hts., 44130
<u>November 9 – 1:00 – 3:00 pm</u>	Metro Health November Meeting Room 7800 Pearl Rd. Middleburg Hts., 44130
<u>December 7—1:00-4:00 pm</u>	Annual Christmas/Holiday Party—Pioneer Ridge Lodge 9479 Saw Mill Trace, North Ridgeville, OH 44039

NEW!

NOTE: We now have permission to meet back at the Metro Health November Campus on Pearl Road.

Coffee will again be available at this facility! Hope to see you soon!

MG Ohio

Central Ohio In-Person & Zoom Support Group Meetings:

Central Ohio Support Group will be back to in-person meetings in June. Watch this space next month. Please contact Sharon or Cathy at centralohiomg@gmail.com or by phone at 614-334-1140.

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>May 11 —12:00 pm</u>	Bravo! Italian Kitchen	NEW!
	9436 Waterfront Drive, West Chester, Ohio 45069	
	Special Speakers LeeJean Beringer, Patient Education Manager, Alexion Jon Durrani, MD	
	See Special Flyer Insert for registration information.	

June is Myasthenia Gravis Awareness Month

We plan to celebrate it with two family friendly walks, June 22nd in Southwest Ohio, and June 30th in Northeast Ohio.

The walk paths are both fully accessible. Walk as much or as little as you want, or cheer on other participants and teams. There will be sponsors to visit, food, drinks, and more. The MG Walk is an amazing day of friends, togetherness, and fundraising.

When we come together; we create a powerful force for good.

Gather your team and get ready to participate in one or both of our annual walk events.

REGISTRATION OPEN NOW!

MAKE A DIFFERENCE
REGISTER AT WWW.MGOHIO.ORG

SOUTHWEST MG 2024 WALK

OTTO ARMLEDER MEMORIAL PARK
JUNE 22, 2024
REGISTRATION STARTS AT 9:30 AM
WALK STARTS AT 11:00 AM



NOTE: Our Northeast MG Ohio Walk will include a 5 k (3.1 mi) hike, a 1-mile walk, and an opportunity to just hang by the Chalet, cheer on the walkers, and visit with our sponsors. We will be serving a light lunch in the pavilion behind the Chalet after the walk.

MG OHIO WALK
JUNE 30, 2024

Mill Stream Run Reservation
16200 Valley Parkway, Strongsville 44136



Register at MGOHIO.org or call 216-218-0477

For individuals with generalized myasthenia gravis (gMG) finding the strength to complete tasks in your daily life can seem impossible at times. The FLEX Study is investigating a new drug treatment called batoclimab for adults living with gMG to manage their symptoms. The second period of this research study may provide the opportunity for participants to self-administer the injectable study drug.

In this clinical research study, doctors want to evaluate the investigational drug to placebo, which looks like the investigational drug, but contains no active medication. The investigational drug has not been approved for the treatment of generalized myasthenia gravis or any other disease. It is considered experimental and can only be given to patients in clinical research studies. The results of this clinical research study will provide more information about batoclimab and its effect on mild to severe generalized myasthenia gravis.

Who is eligible to participate in this clinical research study?

- You may be eligible to participate if you:
- Are 18 years of age or older
 - Have been diagnosed with mild to severe generalized myasthenia gravis (gMG)
 - Have been treated or are currently being treated with medication for gMG
 - Meet additional study criteria.

Study staff will determine eligibility based on additional study criteria.



FLEX

To learn more about the clinical research study and to see if you may qualify, please visit our website at www.flexMGresearch.com



NEW DONATE OPTION

There's a new option to donate to MG Ohio. If you click the QR Code found here or use the link below, you will be taken to a page where you can donate directly, choose where you want your donation to go and donate in honor or memory of someone. Our donation platform, Zeffy, automatically charges a percentage of the amount as a donation to their platform, however, you can use the right arrow beside that percentage and click "other" and type in 0. Your donation goes a long way in helping provide support and education to patients with myasthenia.

<https://www.zeffy.com/en-US/donation-form/ce90795f-ec2c-498f-8f94-a2982ea049d5>

Have an idea for an article you'd like to see in the MG Ohio News? Or maybe you have a question that you'd like answered by one of our MG Experts?

Call and LEAVE A MESSAGE or email us at

news@mgohio.org

All ideas and suggestions for articles must be sent to the above before the 15th of the month before the next publication.

For instance, articles that will appear in June's issue MUST be forwarded to news@mgohio.org by May 15, 2024

REGISTER TODAY MAKE A DIFFERENCE



Registration Information:

All walkers must register to participate. When you register you will have the opportunity to sign up for an MG Walk t-shirt to wear the day of the walk with your registration. You'll also have the opportunity to download the walk flyer with the MG Walk's mission and an example letter asking to sponsor/donate to you in raising money and awareness for MG. **Raise more than \$200 and be entered into a raffle to win a prize basket!**

OTTO ARMLEDER MEMORIAL PARK

5057 Wooster Pike, Cincinnati, OH 45227

JUNE 22, 2024

Check in starts at 9:30 AM

Walk starts at **11:00 AM**

Adult Walker

Registration with a T-shirt (18 and older) by June 2, 2024

FREE

\$30

Youth Walker

Registration for youth walkers (17 years and younger) with an event t-shirt by June 2, 2024

FREE

\$15

ABOUT THE MG WALK

The walk path is fully accessible. Walk as much or as little as you want, or cheer on other participants and teams. No matter your mobility or ability, there's a way to participate and raise awareness of this devastating rare disease. You can join as an individual, start a team, or donate to support a friend. There will be vendors to visit, food, Kona Ice, a silent auction, and more. The MG Walk is an amazing day of friends, togetherness, and fundraising. When we come together, we create a powerful force for good.



Register at <https://mgohio.org/southwest-walk>





2024 WALK

DARE TO CARE

**JUNE
30th**

Everyone
must register

Mill Stream Run Reservation - Cleveland Metroparks
16200 Valley Parkway, Strongsville, OH 44136
Check-in and visit with Sponsors 9:00 AM
Walk Ceremony at 10:00AM

Lunch following walk at Pavilion behind Chalet

The walking path is fully accessible. Walk as much or as little as you want, or cheer on participants and teams. No matter your mobility or ability, there is a way to participate and raise awareness for MG. Visit with our sponsors, walk through the MG Experience with friends & family, enjoy some great food, and more. The MG Walk is an amazing day of friends, togetherness, and fundraising.



Thank you to our sponsors



You may register and walk for free
If you would like a 2024 MG Ohio Walk T-shirt,
the cost is \$30/adult \$15/child
Donations gladly accepted



Register at www.mgohio.org/northeast-ohio-walk

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 co-insurance) on FDA-approved treatment
- Health insurance premiums
- Therapy Administration costs
- Physician co-pays
- Treatment related travel costs

[The Assistance Fund \(tafcares.org\)](http://tafcares.org)

NOTE: Important!! Be sure and sign up NOW for 2024



Calling all volunteers! We need your help to run a successful walk. Please call or text us at 216-218-0477. Volunteers needed for set-up and clean-up on the day. We'd love to see YOU at the walk!

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.goodrx.com)

<http://www.themedicineprogram.com/>

<http://www.togetherrxaccess.com/p/prescription-savings>

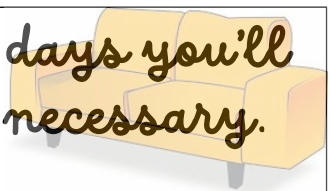
<https://mat.org/> (Medication Assistance Tool)

<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>

Some days you'll move mountains, other days you'll move from the bed to the couch. Both are necessary.



May 2024 IN-PERSON MEETINGS:

May 22— 10:30 am

Northeast Ohio

Brunch Bunch Meet Up

Perk-Cup 561 W. Bagley Rd., Berea 44017

May 11 —12:00 pm

Southwest Ohio

Bravo! Italian Kitchen

9436 Waterfront Drive, West Chester, Ohio 45069