



Supporting the Myasthenia
Community in Ohio & Beyond

MG OHIO NEWSLETTER

March 2024

Volume 12 Issue 3

MG Ohio

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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 Rebecca at 216-218-0477 (leave a message)

You will find a wealth of information at the website:
MGOhio.org

Want to donate to MG Ohio?

[Contact us](#) to find out how.

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 helping to fund this newsletter and run our support groups.

[Click here](#) to sign up.



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

When: Mar 14, 2024 03:00 PM Eastern Time (US and Canada)

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

When: Mar 28, 2024 07:00 PM Eastern Time (US and Canada) **NEW!**

<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>



Central Ohio Hybrid Meeting—
Monday, March 18th 4:30 pm

ohiohealth.webex.com See page 2 for more information



Ask the MG Expert

Q. Is exercising possible with MG?

A. Some form of exercise is very important in maintaining your muscle mass, maintaining weight, and improving your circulation. While the weakness caused by MG make exercise difficult, here are some tips that can help you get that important movement in:

Ask your doctor—Consult your physician before starting any new exercise routine.

Plan it—Plan on exercising when your Mestinon dose is at its peak and you are feeling your strongest.

Limit time—Don't try and do it all at once. Short periods of exercise can be just as useful. Set aside 10 minutes every day. Do some light repetitions for 30 seconds, then rest for 30 seconds. Repeat this until 10 minutes has elapsed.

No Pain is good—You've heard of "no pain no gain"? You want to be sure and *stop* before you cause yourself any pain.

Alternate—Work on your legs one day and arms the next. That way it gives your muscles time to recover.

Build up gradually—You may feel like you can do more and try and push yourself, but by building your exercise routine gradually, you will achieve more and stick with it longer. Try adding 1 minute more every day.

Remember to breathe—You should not hold your breath while exercising and you should be able to breathe normally. If you find yourself getting out of breath, build in more rest periods.

Stay hydrated—make sure to drink plenty of water before and after your workout.

2024 MG Ohio Meetings:

MG Ohio

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

March 12—11:00 am

East—Brunch Bunch at Marie Scramblers

1394 SOM Center Rd. , Mayfield Heights OH 44124

Note: Each person is responsible for their own check.

April 13—1:00-3:00 pm

West—Fairview Park Library

21255 Lorain Rd., Fairview Park, OH 44126

June 30—9:30 am - ?

MG Awareness Walk Event

Mill Stream Run Reservation - Cleveland Metroparks

16200 Valley Parkway, Strongsville, OH 44136

August 10—1:00-3:00 pm

Central—Annual Ice Cream Social

6305 Halle Dr., Valley View OH 44125

October 12—1:00-3:00 pm

East—Location TBD

December 7—1:00-4:00 pm

Annual Christmas/Holiday Party—Pioneer Ridge Lodge
9479 Saw Mill Trace, North Ridgeville, OH 44039

NOTE: This year regular NEO meetings will be BYOB (bring your own beverage) Coffee & water will no longer be available so please bring your own. Donations of baked goods always welcome.

MG Ohio

Central Ohio In-Person & Zoom Support Group Meetings:

March 18, 2024—4:30 pm

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

April 15, 2024—4:30 pm

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

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

These will be **hybrid meetings** 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.)

ohiohealth.webex.com Webex Call-In Phone Number -650.479.3208 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.

March 9 —1:00-3:00 pm

Mayerson JCC

8485 Ridge Road, Cincinnati, Ohio 45236.

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

RSVP to Sharon Meyer slmeyer1954@gmail.com



June 30, 2024 MG Ohio Walk

Mill Stream Run Reservation

16200 Valley Parkway, Strongsville 44136

June is Myasthenia Gravis Awareness Month and we plan to celebrate it with a family friendly walk (pets on leashes welcome too).

Gather your team and get ready to participate in our annual walk / health fair/awareness event.

We will be gathering at the Chalet area at Mill Stream Run—part of the greater Cleveland area MetroParks system. We will have plenty of vendors, fun give-aways, fellowship, food, and fun!

This is also our biggest fund-raising event for MG Ohio. The funds we raise help to support the monthly newsletters, support group meetings, educational materials, and awareness events.

So mark your calendars, invite your teammates, and plan to join us in Strongsville.



MEET THE BOARD 2024 This year we welcome 3 new Board Members. Each month will feature a new member. This month meet: **Daniel Benson, MD**

Daniel Benson, MD, is currently a staff neurologist specializing in neuromuscular medicine at MetroHealth Systems in Cleveland, OH, and an assistant professor of neurology at the Case Western Reserve University School of Medicine.

Dr. Benson completed his medical school training at the University of Tennessee Health Science Center in Memphis, TN, before moving to Ohio in 2016. He completed both his neurology residency and his neuromuscular medicine fellowship at the University Hospitals Cleveland Medical Center. After deciding to remain in Cleveland, he began his practice at MetroHealth, where he serves as a medical co-director of the EMG laboratory and participates in the MetroHealth adult Muscular Dystrophy Association (MDA) clinic and the multidisciplinary Amyotrophic Lateral Sclerosis (ALS) clinic. He is currently board certified in Neurology, Neuromuscular Medicine, Electrodiagnostic Medicine, and Neuromuscular Ultrasound.

When he is not working with patients with neuromuscular conditions, Dr. Benson enjoys spending his time with his wife and their senior cat."

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

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>

[https://rarediseases.org/?](https://rarediseases.org/?gad_source=1&gclid=CjwKCAiA_OetBhAtEiwAPTeQZzEibDNFg0zuHwg9exSkzaYZbYecFcpAf9k1Flp10UVspEvzFCmDe)

[gad_source=1&gclid=CjwKCAiA_OetBhAtEiwAPTeQZzEibDNFg0zuHwg9exSkzaYZbYecFcpAf9k1Flp10UVspEvzFCmDe](https://rarediseases.org/?gad_source=1&gclid=CjwKCAiA_OetBhAtEiwAPTeQZzEibDNFg0zuHwg9exSkzaYZbYecFcpAf9k1Flp10UVspEvzFCmDe)

HELP WANTED!!

May 1, 2024—Rebecca Molitoris is Retiring in 61 Days!

Here are her current responsibilities:

President of the MG Ohio Board

Communication with Board Members & Vendors

Sets Meetings & Agendas

Coordinates with other members of the MG Ohio Board to provide support & education

Co-Leader of Northeast Ohio Support Group

Sets Meetings & Agendas

Directs Meetings & Helps plan Events

Publishes Newsletter and Website

These responsibilities can be divided among more than 1 person.

If you or someone you know is interested in a bigger role supporting the MG Community, please contact Rebecca at 216-218-0477. Training provided. Act Now! Transition time needed.

MARCH 2024 MEETINGS:

In Person—

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