



MG OHIO NEWSLETTER

February 2024

Volume 12 Issue 2

Supporting the Myasthenia
Community in Ohio & Beyond

MG Ohio

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Dr. Suzanne Ruff	Secretary
Laura Lodge	Event Coordinator

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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

2nd Thursday (Feb. 8th) at 3:00 pm (ET)
Register in advance for this meeting:

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

4th Thursday (Feb 22) at 7:00 pm (ET) **NEW!**
Register in advance for this meeting:

<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, February 19th 4:30 pm

ohiohealth.webex.com See page 2 for codes



Ask the MG Expert

Q. Is muscle cramping common in myasthenia gravis?

A. Nearly everyone with MG complains about muscle cramping at one time or another. Here are some reasons why it occurs and how to combat muscle cramps.

—Some of the common causes of muscle cramps are dehydration, electrolyte imbalances (sometimes caused by high-dose prednisone), Mestinon™ (pyridostigmine bromide), and overuse.

—To prevent cramps set limits for yourself and your activities so you don't get so weak that your muscles complain. Try and drink enough water to avoid dehydration which can certainly aggravate the cramps.

—To treat cramps once they have started, here are various remedies tried by fellow patients:

- Try and hold an unwrapped bar of unused soap for cramping hands.
- Getting up and walking around sometimes helps with cramps of the legs or feet, but often, the dreaded cramping begins again, so this process needs to be repeated over and over again.
- A spoonful of mustard, or a swig of lemonade, or vinegar some people swear is a cure. It's the acidity level of these products that will help ease the cramps.
- Using a heating pad on the affected muscle or standing in the bathtub and letting the hot water run over your legs and feet or other affected part until the cramping subsides.

Continued on page 3.

2024 MG Ohio Meetings:

MG Ohio

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

February 10—1:00-3:00 pm

West—Parma-Powers Library Celebrating Rare Disease Month

6996 Powers Boulevard, Parma, Ohio 44129

Speaker Suzanne Ruff, PhD—Topic: Dealing with Depression and Anxiety when diagnosed with a life-changing illness

February 17—1:00-3:00 pm

East—Mayfield Library Celebrating Rare Disease Month

500 SOM Center Rd., Mayfield Village, Ohio 44143

March 9—1:00-3:00 pm

West—Parma-Powers Library

6996 Powers Boulevard, Parma, Ohio 44129

April 13—1:00-3:00 pm

East—Location TBD

May 11—1:00-3:00 pm

West—Location TBD

June 30—all day event

Central—MG Awareness Walk Event - TBD

July 13—1:00-3:00 pm

East—Location TBD

August 10—1:00-3:00 pm

Central—Annual Ice Cream Social

6305 Halle Dr., Valley View OH 44125

September 14—1:00-3:00 pm

West—Location TBD

October 12—1:00-3:00 pm

East—Location TBD

November 9—1:00-3:00 pm

West—Location TBD

December 7—1:00-4:00 pm

Annual Christmas/Holiday Party—Pioneer Ridge Lodge

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:

February 19, 2024—4:30pm

**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.) ohiohealth.webex.com Meeting number (access code): 736 294 987 **Webex Call-In Phone Number -650.479.3208** Questions? 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.

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)



June 30, 2024 MG Ohio Walk

Save the Date!

We are still having our MG Ohio Walk/Awareness Event on June 30th—just NOT at the Zoo. When

we received the contract from the Cleveland Metroparks Zoo Office, we discovered that the walk we were planning there needed to be completed by 9:30 am which meant a very early start for all of us. That, and fact that we had to guarantee 300 participants, led us to see that the Zoo isn't the right fit for our group at this time.

Laura Lodge is scouting out new locations for our Walk/Awareness Event and I'm sure it will still be a great venue. Stay tuned for more news to come about the walk in the March Newsletter. — Rebecca



Ask the MG Expert Continued

Muscle Cramping Question Continued from page 1

- Epsom salts in a hot foot bath. Epsom salts is essentially magnesium in salt form. Magnesium is usually a no-no for those of us with MG, however, the amount of it in a foot bath is generally not enough to provoke weakness. But I've found this method to be no more effective than just plain hot water.

NOTE: As with any type of advice given here or at a support group, this is what works for some of us. It may not work for you. Check in with your own doctor before trying anything to cure your cramps. Please consult your treating physician, especially if you are frequently experiencing the contortion type of muscle cramping as your doctor may want to check your electrolyte levels. I hope you can find something that works for you.

Clinical Trials for Generalized MG Now Recruiting—

Phase 3 Study to Assess the Efficacy and Safety of Batoclimab as Induction and Maintenance Therapy in Adult Participants With Generalized Myasthenia Gravis ClinicalTrials.gov ID NCT05403541 Sponsor Immunovant Sciences GmbH

Information provided by Immunovant Sciences GmbH (Responsible Party) Now recruiting at the Cleveland Clinic 44095

A Study to Examine the Efficacy and Safety of Pozelimab and Cemdisiran Combination Therapy in Adult Patients With Symptomatic Generalized Myasthenia Gravis (NIMBLE) ClinicalTrials.gov ID NCT05070858 Sponsor Regeneron Pharmaceuticals

Information provided by Regeneron Pharmaceuticals (Responsible Party) Now recruiting at Centerville, OH 45459 and at Cincinnati OH University of Cincinnati Gardner Neuroscience Institute

A Study To Evaluate Efficacy, Safety, Pharmacokinetics, And Pharmacodynamics Of Satralizumab In Patients With Generalized Myasthenia Gravis ClinicalTrials.gov ID NCT04963270 Sponsor Hoffmann-La Roche

Information provided by Hoffmann-La Roche (Responsible Party)

Now Recruiting at The Ohio State University Wexner Medical Center , Department of Neurology



MEET THE BOARD 2024 This year we welcome 3 new Board Members. Each month will feature a new member. This month meet: **Amy Shaper MSW, LSW**

Amy Shaper MSW, LSW is the pediatric and adult neuromuscular social worker at Metro-Health, which is Northeast Ohio's designated Muscular Dystrophy Association Care Center. Amy also presently serves as the Hospital Based Regional Child Find Specialist for the Help Me Grow program and links children (ages 0-3) with identified developmental delays to Ohio Early Intervention services.

Throughout her career she has over twenty-five years of hospital-based experience, which includes working for three major health care systems across the state of Ohio, spanning all age groups. Amy's current focus remains providing support and promoting quality of life for those with neuromuscular or developmental disorders. She is also a Cuyahoga County Master Gardener, member of the Junior League, and she recently served as the Welcome Circle Leader for the Church of the Resurrection and helped welcome a Ukrainian family to the Solon area in 2023.

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 \(tafcare.org\)](http://tafcare.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 90 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.



FEBRUARY 2024 MEETINGS:

In Person—

February 10— 1:00-3:00 pm

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February 17—1:00—3:00 pm

Northeast Ohio—Mayfield Library

500 SOM Center Road, Mayfield Village, Ohio 44143

February 19—4:30 pm

The Dempsey Family Education and Resource Center at

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