



MG OHIO NEWS

June 2024

Volume 12 Issue 6

Supporting the Myasthenia Community in Ohio & Beyond

Are you planning on attending one of the upcoming walks but haven't signed up yet? Do you need some help signing up? Please contact us at 216-218-0477 (text or call) and let us know that yes, you will be attending. We need to know how many people to expect to have enough food and water on hand. OR you can email us at mgochio@mgochio.org and please specify which walk you will be attending – June 22nd in the area Cincinnati or June 30th in the Cleveland area. Thank you!

MG Ohio

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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:

MGOOhio.org

Scan here to donate to MG Ohio



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

When: June 13, 2024 03:00 PM Eastern Time (US and Canada)

<https://zoom.us/join/joinMeeting?j=JllcO6hrDwvHtd61R9VqPmOcl2wqkgs1P1h>

When: June 27, 2024 07:00 PM Eastern Time (US and Canada)

<https://zoom.us/join/joinMeeting?j=Jwpcu6prT4uEtapOZcjHU8ZtWrkYCAyT3Fs>

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

<https://zoom.us/join/joinMeeting?j=JYvcuytqjgHdSBm1nwDkGRL5Mi5jXJWKtd>



Ask the MG Expert

Q. I see you are having an MG Awareness walk; I have trouble walking why should I attend?

A. Our Awareness Walks taking place this month in Northeast and Southwest Ohio are a great opportunity for you to introduce your family and friends to learn about MG. These events are so much more than just a walk. Here is what you will find there:

Community – Meet with others who have myasthenia. This disease can be isolating but when you get to see so many others who have the same illness, you don't feel so alone in this journey. If you've been to one before, it is a time to connect with old friends and make some new ones.

Sponsors – Several sponsors will come with lots of good information and give-a-ways. Come and hear about the latest treatments and ask your questions.

Photo Opportunities – There will be some opportunities to get great photographs as a selfie or with your team.

MG Ohio Swag Basket – If you raise \$200 or more for MG Ohio, you will be entered into a drawing for the MG Ohio basket give-a-way (see page 3 for details).

KONA ICE – A Kona Ice vendor will be selling at both walks. Come and have a special treat and help contribute to MG Ohio.

MG Experience – The MG Experience, an interactive display, will again make an appearance. Here your family members and friends can walk through the activities and experience what it *feels* like to have MG. There is no better way to teach someone what it feels like to have this disease than to experience it themselves.

Silent Auction – There will be a silent auction at the Southwest Walk on June 22nd with lots of special offerings!

Free Lunch – They say there's no such thing as a free lunch, but we are providing a light lunch at the Northeast Walk on June 30th after the walk in the pavilion behind the chalet. Vegetarian and gluten-free options available.

No Walking Necessary – You can choose to stay at the guilt-free zone area of picnic tables instead of walking.

2024 MG Ohio Meetings:

MG Ohio

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

June 3 – 11:00 am

East—Marie Scramblers

NEW!

1394 SOM Ctr Rd, Mayfield Heights, 44124

Please RSVP at 216-218-0477 and leave a message (text or voice)

June 30 – 9:00 am–3:00 pm

MG Awareness Walk Event

Mill Stream Run Reservation - Cleveland Metroparks
16200 Valley Parkway, Strongsville 44136

July 13 – 1:00-3:00 pm

Metro Health November Campus

7800 Pearl Rd. Middleburg Hts. 44130

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

Metro Health November Campus

7800 Pearl Rd. Middleburg Hts. 44130

October 12 – 1:00-3:00 pm

Metro Health November Campus

7800 Pearl Rd. Middleburg Hts. 44130

November 9 – 1:00-3:00 pm

Metro Health November Campus

7800 Pearl Rd. Middleburg Hts. 44130

December 7 – 1:00-4:00 pm

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

MG Ohio

Central Ohio In-Person & Zoom Support Group Meetings:

We will not be meeting in June. Check back next month in this space for more details.

Please contact Sharon or Cathy at centralohiomg@gmail.com or
by phone at 614-334-1140 for information about the next scheduled meeting.

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.

June 22 – 9:30 am

June Awareness Walk Event

Otto Armleder Memorial Park

5057 Wooster Pike, Cincinnati 45227

Check-in and visit with sponsors 9:30 am Walk begins at 11:00 am

WALK T-Shirts
Register by June 2nd
to order yours!

Adults \$30
Youth \$15

Time is running out to get your t-shirt before the walk. Please register by June 2nd to secure your 2024 T-shirt designed by Erica Amann. Erica is an MG patient from Cincinnati who also created the goodies for the MG Basket give-a-way (see below). Just raise \$200 or more for MG Ohio to be entered into the MG Ohio Awareness basket drawing. Here are just some of the goodies in the basket:

Register for one or both of our walks today! Go to www.mgohio.org to register OR you may register by phone call or text 216-218-0477 and please leave a message!

A Phase 3 Study to Evaluate the Efficacy and Safety of Efgartigimod IV in Patients With Acetylcholine Receptor Binding Antibody Seronegative Generalized Myasthenia Gravis (ADAPT SERON)

ClinicalTrials.gov ID NCT06298552

Sponsor argenx

[Brief Summary](#)

The primary purpose of this study is to measure the efficacy and safety of efgartigimod intravenously (IV) compared to placebo in participants with Acetylcholine Receptor Binding Antibody (AChR-Ab) seronegative Generalized Myasthenia Gravis (gMG). Other objectives are to assess long-term efficacy, safety, and tolerability of efgartigimod.

Study will consist of:

Screening

Part A: participants will be randomized to receive either efgartigimod IV or placebo

Part B: participants completing part A will receive open-label efgartigimod IV

Cleveland, Ohio, United States, 44195-0001
Not yet recruiting
 Cleveland Clinic
 Contact: Sabine Coppieters, MD
 857-350-4834
clinicaltrials@argenx.com

For more locations go to www.clinicaltrials.gov/NCT06298552

What's in our virtual closet to borrow?

- Walkers
- Canes
- Potty chair
- Portable 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 www.mgohio.org
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 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>



When bees move into a new hive do they have a house swarming party?

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

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