



Supporting the Myasthenia
Community in Ohio & Beyond

MG OHIO NEWS

September 2024

Volume 12 Issue 9

MG Ohio Educates

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 MG Ohio at 216-218-0477 (leave a message)

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

Scan here to
donate to
MG Ohio



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

September 12, 2024 3:00 PM ET

<https://zoom.us/meeting/register/tJllcO6hrDwvHtd61R9VqPmOcl2wqkgs1P1h>

September 26, 2024 7:00 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>

See page 2 for new hybrid meetings!



MG Ohio is a 501(c)(3) designated non-profit organization.

Ask the MG Expert

Today's column is by Dr. Robert Ruff

Q. Why does heat make me weak?

A. The answer relates to the effect of heat or body temperature on electrical transmission. At the neuromuscular junction (NMJ) the nerve terminal releases a chemical, the neurotransmitter called acetylcholine (ACh). ACh induces a small electrical response in muscle fibers. The small localized electrical response induced by ACh, called the endplate potential (EPP), has to be large enough to trigger a larger electrical response that travels the entire length of the muscle fiber.

The larger electrical response, called an action potential (AP), involves entire muscle fibers. The AP is what triggers muscle fibers to contract. The electrical response at the NMJ and the AP are both chemical electrical phenomena. A simple electrical response such as turning on a room light has little temperature variation. In contrast the electricity associated with a chemical electrical process is sensitive to temperature. Recall that the chemical electric batteries in cars are sensitive to temperature.

The chemical electrical responses of the EPP and muscle AP are more complex than a battery. The EPP and muscle fiber AP have complex sensitivities to temperature. In people with MG, the coupling between the EPP and the AP becomes weaker as body temperature rises.

For people without MG, the EPP remains large enough to trigger an AP as temperature rises due to the safety factor. A characteristic of MG is that the EPP is smaller so people with MG have little or no safety factor.

For a person with MG, due to the small safety factor, even small rises in temperature can lead to weakness. In MG, a snowflake disease, the compromise of neuromuscular transmission varies from muscle to muscle in a person as does the temperature sensitivities of muscles.

There are several strategies to reduce heat-induced weakness:

Avoid high temperatures – or unprotected exposure to heat or sunlight. Seek out cooling shade.

See **Heat** on page 3

2024 MG Ohio Meetings:

MG Ohio

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

September 14 – 1:00-3:00 pm

Metro Health November Campus
7800 Pearl Rd. Middleburg Hts. OH 44130

This will be a hybrid meeting using OWL technology it will also be broadcast over Zoom. Please use the link to register: <https://zoom.us/meeting/register/tJ0pce2qpz4pGNee7IHlc-zqTG7RpZu8J7W> NOTE: If you need to sign on using Meeting ID and Passcode, contact MG Ohio at mgohio@mgohio.org or 216-218-0477

October 12 – 1:00-3:00 pm

Metro Health November Campus
7800 Pearl Rd. Middleburg Hts. OH 44130

November 9 – 1:00-3:00 pm

Metro Health November Campus
7800 Pearl Rd. Middleburg Hts. OH 44130

December 7 – 1:00-4:00 pm

Annual Christmas/Holiday Party—Pioneer Ridge Lodge (see page 3)
9479 Saw Mill Trace, North Ridgeville, OH 44039

MG Ohio

Central Ohio MG In-Person Support Group Meeting:

Monday, September 16 – 4:30 pm

The Dempsey Family Education and Resource Center at the OhioHealth Neuroscience Center at Riverside Methodist Hospital
3535 Olentangy River Road, Columbus, OH 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.)

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.

September 14 – 1:00 – 3:00 pm

Mayerson JCC Community Center
8485 Ridge Avenue, Cincinnati, OH 45246

This will be a hybrid meeting using OWL technology it will also be broadcast over Zoom. Please use the link to register: <https://zoom.us/meeting/register/tJYofu2uqzgjH9XwSc264QwWD3ettU7Yd3S9> NOTE: If you need to sign on using Meeting ID and Passcode, contact MG Ohio at mgohio@mgohio.org or 216-218-0477

Heat continued from page 1—

Stay well hydrated – so that your body can sweat properly to help keep you cool. Cold drinks can help to keep you cool. Alcohol can have complex effects on neuromuscular transmission, so be careful.

Consider using cooling devices – if you are outside, such as personal electrical fans.

Wear a cooling garment – can be purchased or made by you. I suggest getting a fishing vest from a sporting goods store with many external pockets. Pick one that is light and roomy and that you can wear inside out. Place cooling packs in the inside out vest. You will need to experiment to get the distribution of cooling packs that is effective and comfortable for you.

NOTE: Do not use “dry ice” as this is too cold.

MG Ohio Advocates



AUGUST
5-16
2024

Rebecca Molitoris, of MG Ohio, recently participated in Rare Across America Legislative Advocacy Week. Advocates from several different rare diseases met with their local Senator's and Representative's health advisors. Rebecca had a chance to meet with the representatives in J.D. Vance's and Sherrod Brown's offices via Zoom. She also met in person with Representative Bob Latta's health advisor in Lorain County.

The purpose of the Rare Across America Legislative Advocacy Week was to bring awareness to our Congressional leaders about bills currently stalled in Congressional Committees.

Rebecca presented the **Safe Step Act S.652 and H.R. 2630**. This bill when passed, will make it easier for a patient to appeal Insurance rulings concerning medications and treatments ordered by their doctor, and yet denied by their insurance company. Senate bill S.652 is currently stalled in the Health, Education, Labor, & Pensions Committee and House Bill H.R. 2630 is stalled in the Education and Workforce Committee. We urge you to contact your local Congressional Representative and ask that they help sponsor these bills and get them moving to become law. For more information go to www.congress.gov and enter the bill you wish to view.



SAVE THE DATE!!!

NEO Annual Holiday Party -
Saturday, December 7, 2024 1:00 pm
New Venue!

This year we will have a buffet at the Pioneer Ridge Lodge located in North Ridgeville. 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 photo ops.

As always, family and friends are invited too!



HEAT Kit!

Hospital Emergency Advocacy & Treatment (HEAT) Kit

We are a patient and care partner run organization finding pragmatic and effective solutions for our every day quality care and medication access challenges. We know that time and energy is precious so we will be careful and thoughtful with all communication.

We Hear You.
We See You.
Because We ARE You



Order your HEAT KIT at:

<https://www.eosinophilrareidisease.org/heat-kit-2-3/>

NOTE: When you fill out the online form select myasthenia gravis for your HEAT kit. They have one just for MG.

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!



Charles Boone



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INSURANCE
CONSULTANTS

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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://GoodRx.com)

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

<http://www.togetherrxaccs.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>

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



SEPTEMBER 2024 IN-PERSON MEETINGS:

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