



Supporting the Myasthenia
Community in Ohio & Beyond

MG OHIO NEWS

DECEMBER 2024

Volume 12 Issue 12

- Last chance to R.S.V.P. for NEO Annual Christmas Party - December 7th (see pg. 2)
- No *regular* support groups will be held in December. All groups will reconvene in January (see pg. 2)
- Only 1 regular Zoom support group meeting in December (see below)
- Vital Care invites you to their open house December 4th, 2024 (see pg. 4)
- Ongoing MG Clinical Trials thanks to IQVIA (see pg. 5)

MG Ohio

Executive Board

Dr. Suzanne Ruff	President
Dr. Robert Ruff	Vice-President
Rebecca Molitoris	Treasurer
Laura Lodge	Secretary

Board of Directors

Dr. Elsheikh Bakri	Dr. Daniel Benson
Dr. Ben Claytor	Amanda Cordrick
Larry Dix	Dr. Miriam Freimer
Dr. Bashar Katirji	Dr. Hani Kushlaf
Dr. Yuebing Li	Gina Oradini
Sharon Rastatter	Amy Shaper
Dr. Kylie Sramek	Saul Wiener

If we can assist you with medical care referrals, resources, durable medical equipment, or information about MG, **contact us at 216-218-0477** (leave a message)

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

To Donate to
MG Ohio, scan
here



MG Ohio Zoom Support Group Meetings 1st and 4th Thursdays

When: December 5, 2024 03:00 PM ET

<https://zoom.us/meeting/register/tJcrcO6urTgiGtK3l9lRXk1QDozODwbXpFs>

NOTE: No Thursday evening Zoom meeting in December—Happy Holidays!

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

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



MG Ohio Educates

Ask the MG Expert

This month's expert answer is
by Suzanne Ruff, PhD

Q. Why does stress flare MG symptoms?

A. As we all know, stress can lead to an increase in MG symptoms. Why? The short answer is that stress is a physical reaction to a challenge. One of the many physiological changes that occur with stress is that it activates the immune system. And, in MG the immune system does not always act "normally" symptoms can flare.

Ask yourself— Are you worried or stressed or distressed? There is a difference. Worry is common and can lead to thinking and problem solving about the things that concern us. Stress and distress both involve a physical reaction. Some people feel their heart racing, get a queasy stomach, headaches and so forth.

It's helpful— to think of stress as an alarm there is a challenge and you don't have an immediate way to handle it. If you think of stress as an alert, you can get ready to gather your resources: mental, emotional, and social connections; and problem solve. This can be, of course, easier said than done!

Distress is what most people think of when they say "stress"— Distress also includes negative emotions and a decreased ability to problem solve. Your body goes into "fight or flight" mode. This calls for the use of some type of relaxation technique that "resets" the sympathetic nervous system that is causing these physical symptoms.

Continued on page 3 are some guidelines on managing worry, stress and distress.

MG Ohio Supports

2024— 2025 MG Ohio Meetings:

MG Ohio

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

December 7, 2024 —1:00-4:00 pm

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

\$10 / person (children under 10 y.o. free) RSVP 216-218-0477

January 11, 2025 —1:00-3:00 pm

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

This will be a hybrid meeting broadcast over Zoom. Please use the link to join:

Time: Jan 11, 2025 01:00 PM Eastern Time (US and Canada)

<https://zoom.us/j/93436800361?pwd=mhsXgRqysqn9qpDIEzdE82h1rQBSsL.1>

Meeting ID: 934 3680 0361 Passcode: 337957

NOTE: This year regular NEO meetings will be BYOW (bring your own water) Coffee will be available. Donations of baked goods always welcome.

MG Ohio

Central Ohio In-Person & Zoom Support Group Meetings:

January Meeting TBD

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) www.ohiohealth.webex.com 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:

January 11, 2025 —1:00-3:00 pm

Mayerson JCC *Speaker (see pg.3)
8485 Ridge Road, Cincinnati, Ohio 45236.

(Take the Ridge Road Exit from the Ronald Regan Highway)
RSVP to Erica at amannerica@gmail.com.

This will be a hybrid meeting broadcast over Zoom. Please use the link to register: <https://zoom.us/j/92050781296?pwd=636s28r9dgWZH4VgBf0pHH1FH03NSY.1> **NOTE:** If you need to sign on using Meeting ID and Passcode, contact MG Ohio at mgohio@mgohio.org or 216-218-0477.



Ask the MG Expert (Continued from page 1)

Here are some guidelines on managing worry, stress and distress: (There are others; this is a good starting point though.)

- Learn relaxation techniques
 - When we're stressed, our body reacts as though we are facing a physical danger
 - Of all the systems involved in preparing for "fight or flight" we can control our breathing with relative ease - and if we do, all the other systems (heart racing, stomach) calm as well
 - Breathe2Relax is a great app to learn how to use deep breathing to decrease stress
 - For a fast way to calm yourself, learn to ground yourself in the present. Use all your senses - exactly what are you seeing, what are you hearing, what are you touching? Name at least 3 things for as many senses as you can
- Identify the source - naming the actual concern or challenge can lead to problem solving:
 - Can you avoid the stressor? For instance, not going to a tiring event
 - Can you change your behavior? For instance, learning how to balance rest and activity
 - Can you change your thinking? Fact check your thoughts - by yourself or with another person you trust - how likely is this to happen?
 - Can you adapt? For instance, can you "attend" a virtual meeting instead of in person?
 - Accept what cannot be changed. This can be difficult at times but can be very helpful.
- Social contact is one of the most helpful buffers for stress
 - It is important to maintain support - for comfort, for fun, as a sounding board for challenges
 - Maintain social contact through outings, telephone, texts, in-person or virtual Support Groups
- Maintain a healthy life style
 - Continue to care for yourself and your loved ones as best you can
 - Healthy eating, exercising as tolerated and sleeping well go a LONG way in reducing stress
- Prioritize, organize, manage your time
 - What truly needs to be done? Prioritize what is important
 - Ask for help, delegate what you can, learn to say "no" and learn to let go
- Distract yourself
- Listen to music, watch a funny video, take a walk.

As is always the case, it is best if you individualize a plan that works for you. Look over the tips above and choose the ones that suit you and your needs.

Northeast MG Ohio Support Group News—

We had a good turnout for our Special Guest speaker, Amy Shaper, MSW, LSW, from MetroHealth. She talked about **"Shared Decision Making"** Thank you, Amy for a great presentation.

Southwest MG Ohio Support Group News—

The Southwest MG Support Group had a great turn out for our November meeting. We want to thank Shelley Gerson from argenx for her excellent talk on MG & Emotional Support. Her talk brought up exceptional questions that led into curious thought and noteworthy discussions. Our support group really enjoyed her visit and look forward to using the technique skills we learned in our everyday lives.



On January 11th, our guest speaker will be **Dr. Junaid Malik**. He will discuss how MG affects your diaphragm and best breathing machines available to give you support. Dr. Junaid Malik has been practicing medicine for 17 years. He is currently a critical care medicine specialist in Middletown, OH. Dr. Malik has extensive experience in Sleep Apnea and Obstructive Lung Disease. This will be a hybrid meeting.

MG Ohio Website: Visit us at www.mgohio.org

For all the latest local MG news, upcoming events, and newsletters

Is there a topic or subject that you would like to see covered in the monthly *MG News*?

Email us at news@mgohio.org and let us know!

Need help paying for your meds? Check out the following sites:

<https://www.needymeds.org/>

Top 10 Christmas Gifts For MG Patients

- | | |
|------------------------|-------------------------------|
| 1. Alexa device | 6. Self closing blinds |
| 2. Smart plugs | 7. Light weight dishes |
| 3. Electric toothbrush | 8. Step-in shoes |
| 4. Electric can opener | 9. Elastic no-tie laces |
| 5. Medicine timer | 10. Under-cupboard jar opener |

FOOD, WINE TASTINGS & PRIZES!

GRAND OPENING!
vitalcare®
of NORTHFIELD

December 4th
4:30 - 8:00 pm

34 East Aurora Rd.
Northfield Township, OH
44067



The best way to spread Christmas cheer is singing loud for all to hear. —Elf



In Person— DECEMBER 2024—JANUARY 2025 MEETINGS:

December 7— 1:00—4:00 pm

Northeast Ohio

Christmas Party

Pioneer Ridge Lodge 9479 Saw Mill Drive, N. Ridgeville 44039 RSVP

January 11—1:00—3:00 pm

Metro Health November Campus

7800 Pearl Rd. Middleburg Hts. OH 44130

January TBD

Central Ohio (see January's MG News for more info)

January 11—1:00—3:00 pm

Southwest Ohio

Mayerson JCC *Speaker (pg. 3)

8485 Ridge Road, Cincinnati, Ohio 45236

Myasthenia Gravis clinical trial landscape

As of June 2024, Trial Link listed 17 ongoing clinical trials, including 11 trials in Phase 2/3 and Phase 3 development, as listed in the table below.

Table 1: Ongoing clinical trials, including 11 trials in Phase 2/3 and Phase 3 development

TRIAL ID	PROGRAM STUDIED	COMPANY	PHASE	STATUS	TARGET	NUMBER OF SITES (COUNTRIES)	PRIMARY OUTCOME MEASURES	START DATE	ESTIMATED PRIMARY COMPLETION DATE
NCT 05332210	BATOCLIMAB (HBM9161)	Harbour Biomed	Phase 3	Recruiting	FCGRT	1 (China)	Adverse events (safety)	Jun-2022	Sep-2023
NCT 04951622 (VIVACITY)	NIPOCALIMAB (JNJ-80202135)	Johnson & Johnson, Momenta	Phase 3	Recruiting	FCGRT	111 (USA+16)	MG-ADL total score (efficacy)	Jul-2021	Nov-2023
NCT 05403541	BATOCLIMAB (HBM9161)	Harbour Biomed, Roivant	Phase 3	Recruiting	FCGRT	78 (USA+11)	MG-ADL total score (efficacy)	Jun-2022	Apr-2024
NCT 04524273 (MINT)	INEBILIZUMAB (UPLIZNA)	Amgen, Mitsubishi Tanabe Pharma	Phase 3	Active, not recruiting	CD19	103 (USA+18)	MG-ADL total score (efficacy)	Aug-2020	May-2024
NCT 04833894	EFGARTIGIMOD ALFA (VYVGART)*	Argenx	Phase 3	Recruiting	FCGRT	24 (USA+11)	Clearance (pharmaco-kinetic), ACHR-AB (efficacy), +2	Oct-2021	Aug-2024
NCT 05265273	NIPOCALIMAB (JNJ-80202135)	Johnson & Johnson	Phase 2/3	Recruiting	FCGRT	18 (USA+3)	Total IGG levels (efficacy), AUCSS (pharmaco-kinetic), +8	Jul-2022	Mar-2025
NCT 05070858 (NIMBLE)	POZELIMAB (in combination with CEMDISIRAN)	Alnylam, Regeneron	Phase 3	Recruiting	C5	116 (USA+19)	MG-ADL total score (efficacy)	Dec-2021	Aug-2025
NCT 05556096	GEFURULIMAB (ALXN1720)	Alexion, AstraZeneca	Phase 3	Recruiting	C5	163 (USA+21)	MG-ADL total score (efficacy)	Nov-2022	Aug-2025
NCT 05644561	RAVULIZUMAB (ULTOMIRIS)*	Alexion	Phase 2/3	Recruiting	C5	18 (USA+8)	Plasma concentration, (pharmaco-kinetic), Serum free C5 concentration (efficacy)	Jun-2023	Jul-2026
NCT 05737160	TELITACICEPT (RC18)	Remegen	Phase 3	Recruiting	TNFS 13B; TNFS 13	51 (China)	MG-ADL total score (efficacy)	Mar-2023	Dec-2026
NCT 05374590 (ADAPT JR +)	EFGARTIGIMOD ALFA (VYVGART)*	Argenx	Phase 2/3	Recruiting	FCGRT	8 (USA+4)	Adverse events (safety), Body weight (efficacy), +3	Aug-2022	Sep-2028

Source: IQVIA Trial Link

* denotes products that are already available in the market for this indication