

MG OHIO NEWS

FEBRUARY 2025

Volume 13 Issue 2

Breaking News—Johnson & Johnson's Nipocalimab was granted U.S. FDA Priority Review for the treatment of generalized myasthenia gravis

Biologics License Application acceptance supported by results from the Phase 3
Vivacity-MG3 study

Results demonstrate sustained disease control over 24 weeks in a broad population of antibody positive adult patients: anti-AChR, anti-MuSK, anti-LRP4

MG Ohio

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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: Feb. 6, 2025 03:00 PM ET

https://zoom.us/meeting/register/ tJcrcO6urTgiGtK3l9l RXk1QDozODwbXpFs

When: Feb. 27, 2025 07:00 PM ET

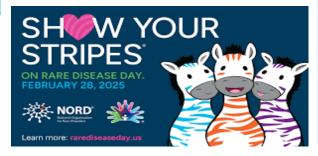
https://zoom.us/meeting/register/ tJUkceCtqj0jHNaMrXHj4XLLH1K4BzKYld_U

Saturday night chats weekly at 6:30 pm (ET)

https://zoom.us/meeting/register/ tJ0ufu6grDsjG9PS1AQG9vWTYeTnNJAZtumm

After registering, you will receive a confirmation email containing information about joining the meeting.





MG Ohio Educates

Ask the MG Expert

Please send your questions to: news@mgohio.org or call 216-218-0477 and leave a detailed message.

This month's expert answer is by Rebecca Molitoris

Q. Do I need to take any special precautions during the cold winter months?

A. We all know that excessive heat can make us weaker, but did you know that extreme cold can also put a strain on our bodies and cause us to feel weaker with MG? Here are a few tips that may help:

Protect Your Hands— When going out in the bitter cold, be sure and protect any exposed skin. A pair of nitrile medical gloves worn under your regular gloves or mittens can help to hold your body heat in.

Warming Devices— An inexpensive rechargeable warming device can help ward off frostbite.

Raynaud's Syndrome— Those of us with autoimmune MG are more susceptible to other autoimmune diseases such as Raynaud's. If you have Raynaud's, you may need to wear gloves even when getting food out of the freezer or at the grocery store when shopping in the frozen food section. Limiting your time in the cold is especially important.

Layering—Dressing in layers can help you keep warmer. Wearing wool or polyester layers is better than cotton in the cold and snow as cotton tends to hold in moisture.

Driving in the Winter— Prepare for emergencies or delays in travel by keeping some basic items in your car such as:

Continued on page 3

MG Ohio Supports

2025 MG Ohio Meetings:

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

February 8, 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 or call to join:

https://zoom.us/j/95377894109?pwd=NoN8jb0pTRZkrtXEdZkuxfmaja2vdd.1

Meeting ID: 953 7789 4109 Passcode: 980913

Dial in: +1 305 224 1968 US +1 309 205 3325 US +1 312 626 6799 US (Chicago)

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:

<u>February 17, 2025—4:30 pm</u>

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:

February 8, 2025 —1:00-3:00 pm Mayerson JCC * Speaker

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 or call to join:

https://zoom.us/j/97131113585?pwd=r52SrnweJG59pfVbfKqyNCrwelzqZh.1

Meeting ID: 971 3111 3585 Passcode: 974695

Dial in: +1 312 626 6799 US +1 646 931 3860 US +1 929 205 6099 US

* Meeting will be presented by LeeJean Beringer our local Patient Education Manager for Alexion.

To celebrate National Rare Disease Day this year, the Southwest Group will be working on building community by completing an Escape Room together on 2/28. If you would like more details or would also like to attend please contact Erica, the SW Support Group

Leader at amannerica@gmail.com

Ask the MG Expert (continue from pg. 1)

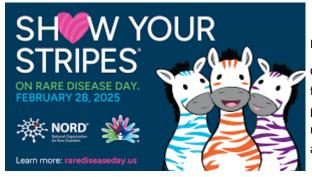
- Blanket
- Water
- Candles
- Fully charged phone
- Snack items or quick meals
- Matches
- Canned Heat

Keeping The House Warm— Our modern homes have more glass which lets in more cold. Keeping blinds or curtains closed on a cold day can help minimize the heat loss.

Avoid Alcohol—While an alcoholic beverage can temporarily provide a feeling of warmth, it may give you a false sense of warmness leading to lingering in the cold longer than is beneficial.

Your Opinion Matters!

The newly formed Education Committee of MG Ohio wants to hear from you. The committee will be gearing future educational programming to topics and concerns important to those of us with MG, our families, and caregivers. Send your suggestions to mgohio@mgohio.org or call 216-218-0477 and leave a message with your suggestion.



February 28th is rare disease day.

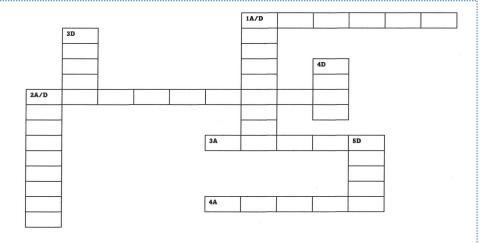
Go to www.rarediseaseday.org to find our more about how you can participate and here to download materials to help you spread awareness.



Did You Know??

Dr. Audrey Shields Penn is a famous Black American neurologist who researched myasthenia gravis. She is:

- A neurologist and emeritus professor
- The first Black woman to act as the director of a National Institutes of Health institute
- The first woman to serve as president of the American Neurological Association (ANA)
- A role model for many women physician-scientists
- Learn more—https://myana.org/audrey-s-penn-biography/



ACROSS

- 1. What Disney character is named after a friend of Walt's with MG?
- 2. What Indian Princess who is now a Mattel doll had MG Wilma____
- 4. What A.A. Milne character is based off of the author's son who had MG? Christopher _

DOWN:

- 1. Myasthenia Gravis is also known as the _____disease
- 2. 2024 Movie about a character with MG?
- 3. Horse-like Zoo animal that represents rare disease?
- What organization advocates for rare disease? Hint acronym
- 5. Actor who had MG David_____

Test your MG rare disease knowledge with this crossword puzzle. Answers next month.

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!

Did you know that at www.mgohio.org you can view educational videos, download newsletters and brochures, and get all the latest information about our in-person and online meetings?

Check out our Resource Partners Page https://mgohio.org/more-resources for information about other MG groups in different parts of the country that hold online meetings.

Just click on their logo and you will be taken to their site. You are always welcome to attend any online meeting wherever you may live.

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

https://www.needymeds.org/

Good Rx.com

http://www.themedicineprogram.com/

http://www.togetherrxacces.com/p/prescriptionsavings

https://mat.org/ (Medication Assistance Tool)

http://www.rxhope.com/Patient/ AssistanceRequest.aspx



"It's the friends you meet along the path that make your journey worthwhile."

In Person— JANUARY 2025 MEETINGS:

February 8—1:00—3:00 pm Metro Health November Campus

7800 Pearl Rd. Middleburg Hts. OH 44130

February 8—1:00—3:00 pm Southwest Ohio - Speaker

Mayerson JCC

8485 Ridge Road, Cincinnati, Ohio 45236

February 14—4:30 pm Central Ohio

The Dempsey Family Education and Resource Center 3535 Olentangy River Road, Columbus, Ohio 43214