



Supporting the Myasthenia Community
in Ohio & Beyond

MG OHIO NEWSLETTER

FEBRUARY 2023

Volume 11 Issue 2

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 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.



February's Thursday 3:00 pm ZOOM Meetings

When: Feb 2, 2023 03:00 PM Eastern Time

https://zoom.us/meeting/register/tJYkfuqoqT8uEtTdEzRX1kHeu6j00Q_fNiZ1

When: Feb 9, 2023 03:00 PM Eastern Time

<https://zoom.us/meeting/register/tJlpc-2oqj4vHNZaMwTlrZFvc-uO9knKI5Vw>

When: Feb 16, 2023 03:00 PM Eastern Time

<https://zoom.us/meeting/register/tJMof-6vrjgrEtW2rJqKp4nATbJ5Su3gsKLY>

When: Feb 23, 2023 03:00 PM Eastern Time

<https://zoom.us/meeting/register/tJlvde2opzozG9T-kvTzRqXJwIWG76Xb8P6r>

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



Northeast Ohio Westside— Next In-Person Meeting

February 11—1:00-3:00 pm

Olmsted Falls Library

8100 Mapleway Dr.

Olmsted Falls, OH 44138

NOTE—Information for Columbus and Cincinnati area meetings found on page 2



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

Ask the MG Expert

Q. How can I tell if my symptoms are from MG or something else?

A. With MG, both you and your PCP may tend to blame every symptom you have on your disease. But sometimes, other illnesses or diseases may be present. Here are some common symptoms that may have other causes:

- **Racing pulse or elevated heart rate.** Although extreme weakness like that found with MG can sometimes artificially raise your heart rate because it is more difficult to move, prolonged increased heart rate or elevated heart rate while at rest should be investigated by your PCP or cardiologist. Contact your PCP or cardiologist if your heartbeat is irregular (not beating at a steady rate—speeding up then going slower) or you have beats that are not in time with your baseline heart rhythm.
- **Pain.** Feeling as if you have pulled or strained your muscles is common with MG, prolonged pain in your muscles, nerves, joints, or bones should be investigated for other causes.
- **Brain Fog.** Feeling a little slow in your thinking is a common malady for many with MG. Some think it may be caused by lack of quality sleep also common for those with MG. But if you start to notice that you are unaware of your surroundings and can't remember how to do simple tasks, you should consult your PCP.

Continued on page 3

MG Ohio

Northeast Ohio In Person Support Group Meetings:

February 11—1:00-3:00 pm

Olmsted Falls Library - Speaker Hallie Good from Vivo Infusion
8100 Mapleway Dr.
Olmsted Falls, OH 44138

March 11—1:00-3:00 pm

New Middleburg Hts. Library
15700 E. Bagley Rd
Middleburg Hts., OH 44130

MG Ohio

Central Ohio In Person/Online Support Group Meetings:

February 11—11:30 am -1:30 pm North Columbus

Please feel free to bring your own lunch, snacks and drinks since we'll be meeting during lunchtime. Please RSVP to centralohiomg@gmail.com so we have a general idea of how many folks to expect. (Caregivers are encouraged to attend, even if the person with MG is not attending.) centralohiomg@gmail.com for details and the location.

Tuesday, March 7 -- 7pm via Zoom. Please email centralohiomg@gmail.com to ask to be added to our email distribution list so you can receive this link once it's ready (we'll send the link closer to the date).

April 15 -- 11:30 am-1:30pm North Columbus

We are planning for this to be another potluck (with Sharon and Cathy providing the main dishes and you all provide side dishes, desserts, etc.) We'll send a Survey Monkey out closer to the date for you to let us know what you'll be sharing with the group. centralohiomg@gmail.com for details and the location.

MG Ohio

Cincinnati Area Support Group Meetings:

March 11 —1:00-3:00 pm

Mayerson JCC 8485 Ridge Road, Cincinnati, Ohio 45236.
(Take the Ridge Road Exit from the Ronald Regan Highway)
RSVP to Sharon Meyer

OPEN CHAT continues for 2023. Drop in every Saturday night beginning at 6:30 pm ET via Zoom

(click below to register)

<https://zoom.us/j/96504171582?pwd=ODFjbXZGZ1I2V2tJRTNHAFVlcGFRdz09>

Registration required—register once for a link that is good every Saturday until December 16, 2023



February 28th is Rare disease Day. How will you show your stripes? Use Rare Disease day to tell your story. Share on social media or share your journey with friends and family.

Check out <https://www.rarediseases.org/> for information and tips about living with a rare disorder.

There is also information on this site for help with co-pays and medical expenses.

Ask the MG Expert (continued from page 1)

- **Fatigue.** MG can cause fatigue while experiencing weakness. In fact, you may feel fatigued at various times throughout the day. When caused by MG, fatigue is usually short lived and can be helped by taking a rest. Long lasting fatigue may have another cause.
- **Repeatedly falling asleep** during the day especially when a car passenger or watching TV can be signs of poor sleep at night or medication side effects. Falling asleep while driving is obviously dangerous. Daytime sleepiness can be due to sleep apnea—not breathing correctly during sleep. MG can predispose people to sleep apnea by weakening muscles that keep the airway open when you sleep. In addition, weight gain associated with taking medications such as prednisone increases the likelihood that a person will develop sleep apnea.

Thanks to Dr. Robert Ruff for his contribution to this column

What to Do in Case of an Emergency—

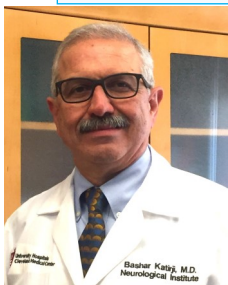
Emergencies, we can't always avoid them but we can plan for them. How would you communicate to EMS in an emergency if you couldn't talk? Does your family or friends know where to find your medical information? Here are some ways to identify that you have MG when you can't talk—

Vial of Life Program—FREE forms can be found at <https://www.vialoflife.com/>

Myasthenia Gravis identity awareness bracelet <https://www.amazon.com/myasthenia-gravis-bracelet/s?k=myasthenia+gravis+bracelet>

Medical Alert Jewelry <https://www.medicalalert.org/medical-id/>

MG Alert Car Decal <https://mghope.org/shop/ols/products/myasthenia-gravis-emergency-alert-decal>



MEET YOUR MG OHIO BOARD

Bashar Katirji, M.D., F.A.C.P., Director

Dr. Katirji currently serves as Professor of Neurology, Case Western Reserve University School of Medicine, and since 1987 he has been Director of the Neuromuscular Center, Neurological Institute at University Hospitals Cleveland Medical Center and Director of the EMG laboratory at University Hospitals Cleveland Medical Center. Dr. Katirji's credentials include the following Academic Appointments and Positions: 1992 - 1997 Associate Professor of Neurology, Case Western Reserve University School of Medicine, and 1987 - 1992, Assistant Professor of Neurology, Case Western Reserve University School of Medicine. His Hospital Appointments also include Director of the Neuromuscular Medicine fellowship, University Hospitals Cleveland Medical Center from 1990-2022.

Dr. Katirji's many awards, honors, and memberships include: 1989 Fellow, American College of Physicians; 1995 Fellow, American Academy of Neurology; 1994 through 2022 The Best Doctors in America; 1996 through 2022 The Best Doctors in Cleveland; 2001 Fellow, American Neurological Association; 2011 The Dennis M. Landis teaching Award, University Hospitals Cleveland Medical Center and Case Western Reserve University; 2017 The Robert B. Daroff teaching Award, University Hospitals Cleveland Medical Center and Case Western Reserve University; 2019 The Distinguished Physicians Award, University Hospitals Cleveland Medical Center and Case Western Reserve University; 2019 The Distinguished Physicians Award, University Hospitals Cleveland Medical Center

In addition, Dr. Katirji has authored many books, periodicals and peer reviewed publications. More information can be found at mgohio.org/mgohioboard.

MG Ohio Website:

Visit us at www.mgohio.org

Have questions or comments? Send in your MG related questions to our **Ask the MG Expert** column
Email at mgohio@mgohio.org

Has COVID-19 Left You Financially Strapped?

The National Organization for Rare Disorders (NORD) has opened a financial assistance program for people in the rare disease community including those with MG, who are affected by the COVID-19 pandemic in the U.S. Called the NORD COVID-19 Critical Relief Program, the effort will provide up to \$1000.00 annually to those eligible to support critical non-medical needs. For further information about eligibility or how to apply, call NORD at 203-242-0497 or send an email to COVID19assistance@rarediseases.org

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>



Always remember you matter, you're important and you are loved, and you bring to this world things no one else can."

—Charles Macksey

"The boy, the mole, the fox, and the horse"

UPCOMING FEBRUARY 2023 MEETINGS:

In Person—February 11th Olmsted Falls Library 1:00-3:00 pm

8100 Mapleway Dr., Olmsted Falls, OH 44138

In Person—February 11th North Columbus 11:30 am—1:30 pm (see page 2)

Columbus Zoom Tuesday February 7th 7:00 pm (see page 2)

Weekly Zoom Meetings—Thursdays 3:00 pm ET (see page 1)

OPEN CHAT now every Saturday night starting at 6:30 pm ET via Zoom (click bellow to register)

<https://zoom.us/j/96504171582?pwd=ODFjbXZGZ1I2V2tJRTNHAFVlcGFRdz09>