



MG OHIO NEWSLETTER

November 2023

Volume 11 Issue 11

Supporting the Myasthenia
Community in Ohio & Beyond

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.



2nd and 4th Thursdays 3:00 pm
until December 28, 2023

Register once below and get approved for all meetings.

<https://zoom.us/meeting/register/tJlpc-iqqjloHNCPaKAHyOFjGu5rbVORJdlf>

The above link is good for the following dates:

Nov 9 Dec 14 & 28
(No meeting on Thanksgiving)

Weekly Saturday night chats starting at 6:30

pm ET <https://zoom.us/j/96504171582?pwd=ODFjbXZGZ1I2V2tJRTNHafVlcGFRdz09>



Daylight savings ends on Sunday, November 5, 2023.

Don't forget to set your clocks back one hour!

Next in-person meeting in NEO Saturday, November 11, 2023 at the North Olmsted library 1:00—3:00 pm



Ask the MG Expert

by Suzanne Ruff, PhD

Q. How can I get more sleep?

A. Sleep is one of the most important aspects of self-care. Adults need between 7-9 hours of sleep each night. Not many of us get that, but, there are ways to improve sleep. Please remember that everyone is unique and some tips work for some, but not for others. Just try some of the guidelines below – and judge for yourself what works for you:

Environmental conditions—are the easiest to change. These have been shown to improve sleep:

- Darkened room, with natural light if possible upon awakening – i.e., crack a window shade
- Temperature – slightly cooler than daytime comfort – find your most comfortable temperature
- Sound level – low level noise can be helpful in some phases of sleep – white noise or calming music or a familiar audio-book

Behavioral factors—are more important factor in improving sleep. Again, they are under your direct control – a huge plus. And, they have been shown to have a huge effect on improving sleep when applied consistently.

- 2-4-6 rule - Avoid caffeinated beverages 6 hours before bed, avoid exercising and eating 4 hours before bed and begin to get ready for the next day 2 hours before bed
- Establish a bedtime routine that begins about an hour, but at least 30 minutes before bed.

(continued on pg.3)



Upcoming MG Ohio In-Person & Zoom Support Group Meetings:

MG Ohio

Northeast Ohio In-Person Support Group Meetings:

November 11—1:00-3:00 pm

North Olmsted Library (Large Meeting Room)
27403 Lorain Road, North Olmsted, Ohio 44070

For more info, please contact Bobbi at 216-407-4975
or mgohio@mgohio.org

NOTE: No Support Group Meeting in December. We will be having a Holiday Party on December 9th (see page 3)

Meeting Notes—At our October meeting, we discussed the Regional Conference, our Annual Holiday Christmas Party, and the possibility of having a walk at the Zoo in June.

MG Ohio

Central Ohio In-Person & Zoom Support Group Meetings:

November Zoom Meeting—TBD For more information:

Please contact Sharon or Cathy at centralohiomg@gmail.com or by phone at 614-334-1140

December 9—11:30 am-1:30 pm North Columbus

The Dempsey Family Education and Resource Center at the Ohio Health Neuroscience Center at Riverside Methodist Hospital
3535 Olentangy River Road, Columbus, Ohio 43214

NOTE: We are having a potluck in-person on Saturday, Dec. 9 from 11:30-1:30pm. Sharon and Cathy will provide the main dishes while attendees provide side dishes, dessert, etc. We will send a Survey Monkey out closer to the date for attendees to note what they are bringing to share. Please email centralohiomg@gmail.com for details and location.

MG Ohio

Southwest Ohio In-Person Support Group Meetings:

November 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 slmeyer1954@gmail.com

NOTE: No meeting in December.

Meeting Notes—At the October Meeting, we talked about the MG Ohio Conference and discussed continuing to place posters in public places and producing a list of area neurologists/addresses/ phone numbers.



Ask the MG Expert (Continued)

- It is best to think of going to sleep as “dialing down” the day’s activities rather than flipping an “on/off” switch.
- Develop a calming routine of self-care away from the day’s worries or challenges

Mobile phones are the biggest sleep robbers we have today—

- Leave mobile phones outside the bedroom it at all possible
- Silence the ringer for all but crucial contacts
- Set “do not disturb” for an hour before you intend to go to sleep

Avoid naps during the day—

- Taking naps during the day decreases the chance you’ll sleep well at night
- If you need to nap, take short naps, setting an alarm for 30 minutes
- Try to be a little active, outside if possible, if you’re feeling sleepy

Benefits of good sleep—

- Better immune system functioning
- Better mood, especially less anxiety and less anger
- Better memory and clearer thinking during the day
- Reduced risk of chronic illnesses such as heart disease and diabetes, among others
- Reduced physical pain
- Reduced risk of accidents, including driving

Reasons that people have difficulties in falling and staying asleep—

- Physical – some chronic health conditions, the most concerning is **Sleep Apnea**
- Emotional/psychological – stress, anxiety, depressed mood
- Environmental – lighting, sound levels, temperature
- Behavioral – habits can have a positive or negative effect on sleep

NOTE: Excessive daytime sleepiness, including falling asleep during activities and loud snoring at night, are signs of **sleep apnea**. If you have these symptoms, please talk to your primary care medical provider or neurologist about being assessed for Sleep Apnea.

Interested in serving on the MG Ohio Board of Directors? We will be electing Board Members and Officers On November 16th. For an application, email Rebecca at mgohio@mgohio.org by November 12th

Annual Holiday / Christmas Party

Saturday, December 9, 2023 2:00 pm



Romanos Macaroni Grill
25001 Country Club Blvd.
North Olmsted, OH

Approximately \$15/person

Bring a white elephant or other gift (\$5 or under) for gift exchange. 

Please R.S.V. P. by November 18th
(we need to provide an accurate head count)

Email: mgohio@mgohio.org or call Bobbi at (216) 407-4975

From Alexis Rodriguez—Atlanta Georgia MG Support Group

STUDY ALERT—

Are you interested in contributing to Myasthenia Gravis research but unsure how to get involved? Are you looking for a quick side hustle or gig? If you love sharing your input and want to earn some extra money, we have an exciting opportunity for you!

IAA is currently seeking individuals diagnosed with Myasthenia Gravis, as well as caregivers of people with Myasthenia Gravis, to participate in a research study. Your valuable insights and opinions are needed, and in return for just 60 minutes of your time, you will receive a payment of \$250! The best part is, you do not have to take any medication to participate.

This is a great way to make the most of your time while contributing to the advancement of Myasthenia Gravis research. **To participate, simply send an email to iaaresearch@gmail.com.** Feel free to share with your MG friends who might be interested in participating as well. Spread the love and opportunity.

Thank you for considering this opportunity, as your participation will have a meaningful impact on the lives of others with MG.

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

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)



“Gratitude can turn a meal into a feast.” -

- Melody Beattie

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.themedicineprogram.com/)

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

<http://www.togetherrxaces.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>



UPCOMING NOVEMBER 2023 MEETINGS:

In Person—

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