



Supporting the Myasthenia
Community in Ohio & Beyond

MG OHIO NEWSLETTER

October 2023

Volume 11 Issue 10

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-iqjloHNCPaKAHyOFjGu5rbVORJdlf>

The above link is good for the following dates:

Oct 12 & 26 Nov 9 Dec 14 & 28

(No meeting on Thanksgiving)

Weekly Saturday night chats starting at 6:30

pm ET [https://zoom.us/j/96504171582?](https://zoom.us/j/96504171582?pwd=ODFjbXZGZlI2V2tJRTNHafVlcGFRdz09)

[pwd=ODFjbXZGZlI2V2tJRTNHafVlcGFRdz09](https://zoom.us/j/96504171582?pwd=ODFjbXZGZlI2V2tJRTNHafVlcGFRdz09)

MG Ohio Regional Conference Videos are
now online!

Go to mgohio.org and click "More" then click on the *NEO MG Presentations Tab* or click the link below:

<https://mgohio.org/neo-mg-presentations>

Thank you to Dr Robert Ruff and his grandson Matthew for filming & processing the videos

Ask the MG Expert

This month's column was written by Suzanne Ruff, PhD

Q. How can I be an effective caregiver?

A. Caregiving is an important and complex topic. Caring for a loved one, or friend, with MG can be so very rewarding. It can also pull on all of your resources – physical, emotional, financial and others. There are several approaches that can help you rise to the challenges that caregiving asks of you:

TAKE CARE OF YOURSELF. It is very important to care for yourself as well as your loved one. Sleep is crucial (Next month's column will address improving sleep) Eating well and exercising round out the basics of physical well-being. Reducing stress, carving out some downtime, and having someone to talk to is also very important for your emotional well-being. Another way of caring for yourself is to ask for and accept help. Try to be clear when talking to a friend about whether you just want to "vent" or need suggestions or maybe even just a hug!

STAY ORGANIZED. Schedules are important for everyone. They become more important when someone has a medical condition or is caring for someone with a medical condition. Keeping track of medications, appointments, treatments certainly need to be scheduled.

(continued on pg.3)



MG Ohio In-Person Support Group Meetings:

MG Ohio

Northeast Ohio In-Person Support Group Meetings:

October 14—1:00-3:00 pm

Brook Park Library (Large Meeting Room)
6155 Engle Road, Brook Park, Ohio 44142

For more info, please contact Rebecca at 216-218-0477
or mgohio@mgohio.org

MG Ohio

Central Ohio In-Person & Hybrid WebEx Support Group Meeting:

Monday October 16—4:30 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: Parking is free (with vouchers we will provide at the meeting). Park in the "Red" parking garage.
This will be a hybrid meeting with attendees in-person and online using WebEx (an online meeting platform similar to Zoom. This is what the meeting space uses).

For more information:

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

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



Ask the MG Expert (Continued)

Think about how you spend your time. Planning allows you to spend more time on things that are important but not urgent. That's a stress reducer!

LEARN TO BECOME A GOOD ADVOCATE.

Being a good medical advocate is a role that is thrust upon caregivers. It comes more naturally to some of us but everyone can learn the basic steps. It's important to be prepared for medical appointments, ask questions when things are not clear, and remain respectful of everyone involved – your loved one, the staff, and yourself. Learn as much about MG as you can from *trusted sources* such as the MG Ohio website, recognized organizations such as University Hospitals of Cleveland, Cleveland Clinic, NIH, and Support Groups. Learn from other caregivers how they have traveled this path – some of their suggestions may be just what you need to hear – even if it's "you're doing well. Give yourself credit!"

CONSIDER QUALITY OF LIFE. Are you and your loved one able to do what you want to do – within reason? Think about what it would take to get back to your life as much as possible. Have hope! Know that there are others who are here to help you. Reach out and then, eventually you will be able to give back – and give hope to others

—WANTED—

We are looking for a few new volunteers to serve on the MG Ohio Board of Directors.

The Board meets virtually 3 times a year and in-person annually. Meetings take place once per quarter. Directors are asked to serve for a maximum of 3 years but this is an "at-will" position, meaning you may request to leave the board earlier than the 3 year commitment.

The Board elects the following positions at its first meeting following November elections. Here are the duties of each position:

Chair—

- Presides at all meetings
- Ex-officio voting member of all committees of the Board, except the Nominating Committee and the Audit Committee
- Appoints the chair of each committee,
- Performs such other duties as may be prescribed by law, the certificate of incorporation, or these bylaws, or as may be assigned to him or her from time to time by the Board.

Vice Chair—

- During the absence or inability of or refusal to act by the Chair, shall perform the duties and exercise the powers of the Chair. In addition, the Vice Chair shall perform such other duties as may be assigned from time to time by the Chair or the Board of Directors.

Secretary and Assistant Secretaries—

- Attends all meetings of the Board of Directors
- Records the minutes of the meetings

Treasurer and Assistant Treasurers—

- Keeps electronic documentation of all income and expenses for MG Ohio
- Deposits money
- Works with the tax attorney or accountant to file annual tax returns as required by state and federal law.
- Provides a report for every Support Group and Board meeting on the previous month's banking statement and of the financial condition of MG Ohio.

Interested? We will be electing Board Members and Officers On November 16th. For an application, email Rebecca at mgohio@mgohio.org



SAVE THE DATE!

Annual Christmas Party will be held on December 9, 2023

2:00 pm at the Romanos Macaroni Grill

Located at 25001 Country club Blvd. (cost TBD)

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)

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 OCTOBER 2023 MEETINGS:

In Person—

Saturday October 14, 2023 1-3 pm Northeast Ohio—Brook Park Library (Large Meeting Room)
6155 Engle Road, Brook Park, Ohio 44142

Monday October 16—4:30 pm North Columbus—Riverside Methodist Hospital
Dempsey Family Education and Resource Center
at the OhioHealth Neuroscience Center