



Supporting the Myasthenia Community
in Ohio & Beyond

MG OHIO NEWSLETTER

MARCH 2023

Volume 11 Issue

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.



March's Thursday 3:00 pm

ZOOM Meetings

Mar 2, 2023 03:00 PM ET

<https://zoom.us/meeting/register/tJYtde2urzsiHNKMvhDI3RNkGqeAa4cqVfRe>

Mar 9, 2023 03:00 PM ET

https://zoom.us/meeting/register/tJUkf-gsqjvEtV3mL_xtlurb6M92bSNm6BT

Mar 16, 2023 03:00 PM ET

<https://zoom.us/meeting/register/tJcsdO6grjsqG9EuM4rPJ9HskQRRrkYc0Th->

Mar 23, 2023 03:00 PM ET

https://zoom.us/meeting/register/tJEkdumtqj8pGtFQrlve9XHcWjtQGaKI-o_U

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



Northeast Ohio Westside—

Next In-Person Meeting

March 11—1:00-3:00 pm

Middleburg Hts. Library

16699 Bagley Road, Middleburg Hts., OH 44130

(Located just west of Craigmere Dr.)

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. If I'm in an accident or unable to communicate, how can I tell emergency personnel about my MG?

A. There are several ways in which you can communicate your MG diagnosis even if you are unable to talk in an emergency:

- **N.O.K.** Next of Kin This is a new and free Emergency Contact Information Program in Ohio to identify the next of kin you would want notified in the case of an accident or sudden illness. This person can communicate with the ER personnel your medical history. For individuals under 18 with a driver's license or state ID, the NOK must be their parent or legal guardian. For those over 18, choose the person who knows you best and can give information about your MG diagnosis including medications and doctors. You can submit your N.O.K. information at www.bmv.ohio.gov or in person at any BMV office.
- You may also choose to use the following to communicate your medical information:
- 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.medicalert.org/medical-id/>
- MG Alert Car Decal <https://mghope.org/shop/ols/products/myasthenia-gravis-emergency-alert-decal>

MG Ohio

Northeast Ohio In Person Support Group Meetings:

March 11—1:00-3:00 pm

West—Middleburg Hts. Library

16699 Bagley Road, Middleburg Hts., OH 44130

April 22—1:00-3:00 pm

East—Beachwood Library

25501 Shaker Boulevard, Beachwood, Ohio 44122

May 13—1:00-3:00 pm

West—Parma-Powers Library

6996 Powers Boulevard, Parma, Ohio 44129

June 10—1:00-3:00 pm

Central—Parma Snow Library Ice Cream Social!

2121 Snow Road, Parma, Ohio 44134

MG Ohio

Central Ohio In Person/Online Support Group Meetings:

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=ODFjbXZGZ1l2V2tJRTNHaFVlcGFrdz09>

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

Special Evening Zoom March 30th— 6:30 PM eastern time

Since March 30th is the 5th Thursday of the month, we won't be having our normal afternoon Zoom that day. Instead, we will be having a special evening Zoom. **Topic of this Zoom presentation will be MG Trials.**

Come join us and find out first-hand what it is like participating in a trial from a patient's perspective as well as what's involved from a medical professional perspective.

Some things we will be discussing—What does a double-blind study mean? How long do trials typically last? How are patients chosen for trial participation? Bring your own questions and tune into our Zoom for this very special night.

Click the link below to register:

Mar 30, 2023 06:30 PM ET <https://zoom.us/meeting/register/tJ0sf-2prD8pHdWs0xmDKMetd80W4Zhc0EJy>

If you need to join by phone call or text Rebecca at 216-218-0477 and leave a message and she will get back to you with the Meeting ID and Passcode.



MEET YOUR MG OHIO BOARD

Bakri Elsheikh, MBBS, FRCP, FAAN

Bakri Elsheikh is a professor of neurology at the Ohio State University who specializes in neuromuscular medicine and clinical neurophysiology. He serves as the director of the OSU EMG laboratory, the director of the clinical neurophysiology and neuromuscular medicine fellowships, and the director of the OSU Muscular Dystrophy Association Care Center. His clinical practice focuses on individuals with neuromuscular disorders, particularly muscular dystrophy, Spinal Muscular Atrophy (SMA), and myasthenia gravis. His current research focuses on optimizing care models, outcome measures, and therapeutics for adults with neuromuscular diseases. He serves as the principal investigator on several projects on various neuromuscular diseases.



Robert. Louis Ruff, M.D., Ph.D.

Robert Ruff was a member of the MGFA Board of Directors and past Chairman of the Medical Scientific Advisory Board of the MGFA. He previously served several times as a member of the Board of Directors of the National Director of the MGFA and was a Doctor of the Year for the MGFA. He was involved with diagnosis and treatment of myasthenia gravis and neuro-rehabilitation for over 35 years. His research interests include understanding how myasthenia gravis impairs neuromuscular transmission, recovery of motor function after stroke, recovery following traumatic brain injury (TBI) and the use of brain computer interface technology to improve communication ability for individuals with impaired motor skills. Before retiring at the end of July, 2014, he served as the Director of National Neurology Service and acting Director for the Rehabilitation Research and Development Service of the Office of Research and Development within the Department of Veterans Affairs. He was a member of the NICHD advisory council, which oversees the NIH medical rehabilitation research program and a member of the NINDS advisory council, which oversees medical and basic research for diseases including MG. He is Professor Emeritus of Neurology and Neurosciences at Case Western Reserve University. He received his M.D. and Ph.D. degrees from the University of Washington and did his Neurology residency and a postdoctoral fellowship in neurophysiology at Cornell Medical Center in NYC.

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>

Spring: a lovely
reminder of how
beautiful
change can truly be.

✧



Need a Ride? Provide a Ride?

If you're in need of a ride to doctor's appointment, we have people who have volunteered to drive.

If you are able to drive someone to an appointment contact me.

For more info—mgohio@mgohio.org



UPCOMING MARCH 2023 MEETINGS:

In Person—March 11th Middleburg Hts. Library 1:00-3:00 pm

16699 Bagley Road, Middleburg Hts., OH 44130

In Person—March 11th Mayerson JCC 1:00-3:00 pm (see page 2)

8485 Ridge Road, Cincinnati, Ohio 45236

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

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

Weekly Saturday night chats starting at 6:30 pm ET via Zoom (see page 2)