



Supporting the Myasthenia Community
in Ohio & Beyond

MG OHIO NEWSLETTER

JANUARY 2023

Volume 11 Issue 1



January's Thursday 3:00 pm ZOOM Meetings

When: Jan 5, 2023 03:00 PM Eastern Time

[https://zoom.us/j/98695206435?
pwd=N1R4dXdENIZsb3diYnlHM292REROUT09](https://zoom.us/j/98695206435?pwd=N1R4dXdENIZsb3diYnlHM292REROUT09)

When: Jan 12, 2023 03:00 PM Eastern Time

[https://zoom.us/j/93107964448?
pwd=K2ZETkdTRXIOSDVKK0VXOVc3cE5NzZ09](https://zoom.us/j/93107964448?pwd=K2ZETkdTRXIOSDVKK0VXOVc3cE5NzZ09)

When: Jan 19, 2023 03:00 PM Eastern Time

[https://zoom.us/j/97837070924?
pwd=U1ZTQkpwenFjCtVzc080Y2RvMTRRZz09](https://zoom.us/j/97837070924?pwd=U1ZTQkpwenFjCtVzc080Y2RvMTRRZz09)

When: Jan 26, 2023 03:00 PM Eastern Time

[https://zoom.us/j/91295232279?
pwd=UG41aWZtUTJkaG5vZklTaEx0SkNyZz09](https://zoom.us/j/91295232279?pwd=UG41aWZtUTJkaG5vZklTaEx0SkNyZz09)

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



Next In-Person Meeting Westside—

January 14, 2023 1-3 pm

Middleburg Hts. Library 15700 E. Bagley Rd.

Middleburg Hts., OH 44130

1:00—3:00 pm



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

MG Ohio

Executive Board

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Bobbi Navarra	Vice-President
Dr. Robert Ruff	Treasurer
Dr. Suzanne Ruff	Secretary
Laura Lodge	Asst. Secretary

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Dr. Yuebing Li	Jerry Molitoris
Sharon Rastatter	Saul Wiener
Dr. Kylie Sramek	

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**

You will find a wealth of information at the website:

MGOhio.org

Help out MG Ohio:

If you use the following link 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.

Ask the MG Expert

Q. How can I safely exercise? My muscles seem to stop after too many reps.

A. While exercise is important to maintain your muscle tone and overall health, people with myasthenia may need to approach exercise differently. Here are some suggestions for exercising safely:

- Check with your doctor first to see if there are any exercises you should avoid.
- Plan your workout for when you feel the strongest. If you take Mestinon, take it 20-30 minutes before your workout.
- Start out slowly. Don't push yourself to exhaustion. If you are sore for the next 3 days, you are less likely to continue with a workout program.
- If your exercise program calls for 10 repetitions, start out with 3-5 and gradually build up to 10 over several weeks if you are able.
- Break up your routine—can't exercise for 20 minutes at a time? Try 3 minutes or 5 minutes every other hour while you are awake.
- Even 1 minute of movement every hour will help those who are bedridden maintain some strength.
- If you start to feel fatigued, **stop**. Resting for 30-60 seconds in between repetitions can help.
- Change it up. Alternate your routine, try exercising your upper body one day and your legs the next.

MG Ohio

Northeast Ohio In Person Support Group Meetings:

January 14—1:00-3:00 pm

New Middleburg Hts. Library

15700 E. Bagley Rd

Middleburg Hts., OH 44130

February 11—1:00-3:00 pm

Olmsted Falls Library

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

Cincinnati Area Support Group Meetings:

January 14 —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](#)

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](#)



MG Ohio—National Informal Zoom

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=ODFjbXZGZ1I2V2tJRTNHhFVlcGFrdz09>

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



2022 Annual Christmas Party at Macaroni Grill
Thanks to Ty Bryant for the pictures!



MEET YOUR MG OHIO BOARD

Yuebing Li, MD, PhD, Director

Dr. Yuebing Li is currently a staff neurologist in the Neuromuscular Center at the Cleveland Clinic Foundation, and professor of neurology at Cleveland Clinic Lerner College of Medicine of Case Western Reserve University

Dr. Li completed his neurology residency at University of Cincinnati in 2002 where he was elected chief resident. This was followed by a one-year fellowship in clinical neurophysiology that was also at the University of Cincinnati. He is board certified in Neurology and Electrodiagnostic Medicine. Dr. Li practiced at Lehigh Valley Physician Group-Lehigh Neurology as a neuromuscular specialist for nine years before joining Cleveland Clinic in 2012.

Dr. Li has published more than 100 articles on neuromuscular medicine and neurology, and received many teaching awards including the award for Neurology Teacher of the Year at Cleveland Clinic in 2014, 2019 and 2020. He has also been voted as best doctors by Best Doctors of America from 2007 to 2022. He was a recipient of the Scientific Impact Award from American Association of Neuromuscular and Electrodiagnostic Medicine in 2020.

Although he has a large practice that includes patients with various neuromuscular disorders, Dr. Li has a special interest in the diagnosis and treatment of myasthenia gravis. He serves as the principal investigator for many investigational myasthenia gravis trials at Cleveland Clinic. He served as a member of the Medical and Scientific Advisory Board for the Myasthenia Gravis Foundation of America up to 2022. He was a recipient of the Doctor of the Year Award from Myasthenia Gravis Foundation of America and he served as the National Myasthenia Gravis Walk Medical Chair in 2017. In 2018, he was also elected as the National Medical Ambassador of the year by the Myasthenia Gravis Foundation of America organization.

Clinical Trials now Recruiting—Click on links below for more information:

A Study to Examine the Efficacy and Safety of Pozelimab (also known as Regeneron) and Cemdisiran Combination Therapy in Adult Patients With Symptomatic Generalized Myasthenia Gravis (NIMBLE) now recruiting at University of Cincinnati Hospital, Cincinnati, Ohio, 45267 For more info: <https://clinicaltrials.gov/ct2/show/NCT05070858>

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://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/>

More info at: <https://myasthenia.org/Community-Resources/Resources-External-Assistance-Programs>



UPCOMING 2023 MEETINGS:

In Person—January 14 Mayerson JCC 1:00-3:00

8485 Ridge Road, Cincinnati, OH 45236

In Person—January 14 Middleburg Hts. Library 1:00-3:00

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

Zoom Meetings—Thursdays 3:00 pm ET via Zoom (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=ODFjbXZGZ1I2V2tJRTNHAFVlcGFRRdz09>