



Supporting the Myasthenia Community  
in Ohio & Beyond

# MG OHIO NEWSLETTER

MAY 2023

Volume 11 Issue 5

## MG Ohio

### Executive Board

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

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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 (leave a message)

You will find a wealth of information at the website:  
[MGOhio.org](http://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.



## May's Thursday 3:00 pm

### ZOOM Meetings

When: May 4, 2023 03:00 PM ET

[https://zoom.us/meeting/register/tJUrceihrj0sG9QTS0T-UPBagH5spYpc\\_5hL](https://zoom.us/meeting/register/tJUrceihrj0sG9QTS0T-UPBagH5spYpc_5hL)

When: May 11, 2023 03:00 PM ET

<https://zoom.us/meeting/register/tJcuf-ysqDkoHNzYzKVKdEIAHzAqYC05-eg7>

When: May 18, 2023 03:00 PM ET

<https://zoom.us/meeting/register/tJUudOuuqzIsHtXk6vJLyZBrRTiFVqf2OMRn>

When: May 25, 2023 03:00 PM ET

<https://zoom.us/meeting/register/tJAKce-grDssHdcLyYJuerEFjnSMlAxt6CvU>

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

## MG Ohio Regional Conference

August 26, 2023

Register early between April 1 and June 1 for a chance to win a free hotel room the night before the conference see special insert for more information



Happy Mother's Day to all our mothers.

## Ask the MG Expert

Q. With summer heat coming up, what can I do to stay strong?

A. Most people with MG experience some weakness when exposed to heat and sun. Here are a few tips to help keep you strong throughout the summer:

- Plan ahead. If you know you will be out in the sun be prepared, invest in a good wide brimmed hat, and some UV protective clothing.
- Stay hydrated. Drink plenty of water. Caffeinated and alcoholic beverages may actually contribute to dehydration.
- Use ice. Ice is a great tool for cooling off quickly. Wrap an ice pack around your wrists, behind your knees, and behind your neck for a quick cool down.
- Limit your time outdoors to early morning or in the evening to avoid the main heat of the day which generally occurs between 10 am—2pm.
- Find the shade. If you can't avoid being outside try to stick to shady areas.
- Use a fan or air conditioner. If you don't have air conditioning at home, go to the library, mall, or movie theatre during the heat of the day.
- Try keeping your make-up or shaving lotion in the refrigerator for a refreshing start to the day.
- Use wet towels that you keep in the fridge to cool down.

MG Ohio

May 13—1:00-3:00 pm

May 24—10:30 am

**NEW**

June 10—1:00-3:00 pm

Northeast Ohio In-Person Support Group Meetings:

West—Parma-Powers Library

6996 Powers Boulevard, Parma, Ohio 44129

East—Brunch Bunch – Cracker Barrel

(Informal meet up everyone responsible for their own check)

6055 Som Center Rd, Willoughby, OH 44094 [This is right off of I90](#)

Central—Parma Snow Library Ice Cream Social!

2121 Snow Road, Parma, Ohio 44134

This is our annual ice cream social and June Awareness Event—Food and Fun for the whole family! Ice cream provided (dairy-free and sugar-free options too) please bring a topping to share.

**NEW**

Do you live in the Akron/Canton area? Would you travel to Hartville for a meeting? Hartville is located 26 minutes from both Akron or Canton and could even be a destination place for anyone in Ohio. I would be willing to schedule a meeting in June to celebrate MG June awareness month in Hartville at the Hartville Kitchen & Bakery /FI had enough others to join us. Please send an email to [mgohio@mgohio.org](mailto:mgohio@mgohio.org) and let me know if Hartville is a viable option. Thanks! - Rebecca

MG Ohio

May 9—7pm

Via Zoom Please email [centralohiomg@gmail.com](mailto:centralohiomg@gmail.com) to register for the meeting link.

June 3—11:30 am-1:30 pm

North Columbus

In-person in north Columbus. We are planning for this to be another potluck (with Sharon and Cathy providing the main dishes and attendees provide side dishes, desserts, etc.) We'll send a Survey Monkey out closer to the date for attendees to note what they'll bring to share with the group. Please email [centralohiomg@gmail.com](mailto:centralohiomg@gmail.com) for details and the location

MG Ohio

June 10 —1:00-3:00 pm

Cincinnati Area In-Person Support Group Meetings:

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

Exciting news from the **American Academy of Neurology's (AANA) Annual Meeting** which ran from April 22-27, 2023 in Boston, MA—

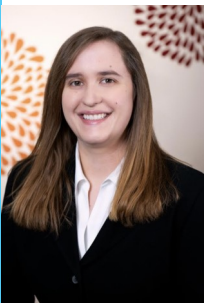
Results from the RAISE study—A randomized Phase 3 trial (NCT04115293) of Zilucoplan in generalized myasthenia gravis (gMG); showed consistent improvement in MG Activities of Daily Living (MG-ADL) scores regardless of sex, age, disease duration, thymoma status, or prior use of other treatments. By week twelve the ADL scores of the Zilucoplan group generally had dropped by 4-5 points from the baseline reading taken at the beginning of the study compared to the placebo group which only dropped 3 points or less. The study consisted of 174 patients all whom were AChR positive.

This study, sponsored by UCB, uses the same type of protein binding activation similar to Soliris and Ultomiris where the active agent, in this case Zilucoplan, binds to the C5 immune protein preventing activation of the complement system—a part of the immune system that is involved in the autoimmune attack that causes disruption at the neuro-muscular junction.

The difference between the already FDA approved Soliris and Ultomiris is that Zilucoplan is administered sub-cutaneously (under the skin) and thus can be done at home by the patient which is a much less expensive and less invasive procedure.

## MEET YOUR MG OHIO BOARD

NOTE: Here are the last three Board Members in our *Meet Your MG Ohio Board* series for 2022-2023



**Dr. Kylie Sramek, DPT, Director**

I work at Synergy Physical Therapy and Wellness. We specialize in orthopedic outpatient and women's health programs and work with a variety of different health specialties including: athletic trainers, personal trainers, and health coaches. I work PRN at Cleveland Clinic Inpatient Rehabilitation Hospital in the stroke, spinal cord injury, and traumatic brain injury unit. I double majored in Pre-Physical Therapy and Exercise Science from BW and received my doctorate from Chatham University. I am certified in Dry Needling.



**Jerry Molitoris, Director**

Jerry is a retired IT Professional. He spent over 42 years working as a Developer, Software Engineer, Programmer, and Project Manager mainly in the financial industry. Currently, Jerry is our go-to guy for anything technology related. He maintains our MG Ohio Database and for the last 10 years has been known affectionately as the “coffee guy” as he makes the coffee for all of our in-person meetings. He also does all of the “heavy lifting” including set-up and take down of everything needed for our meetings.



**Rebecca Molitoris, President**

Rebecca has served as Support Group Leader of the Northeast Ohio MG Support Group for 10 years and as Founder and President of MG Ohio since August of 2022. She is an MG patient having had MG for over 60 years. Rebecca's background is in chemical engineering where she worked in research and development creating methods for testing various products for FDA and EPA protocols. Rebecca's career also included over 30 years of technical writing experience authoring training manuals, Material Safety Data Sheets (MSDS), countless standard operating procedures (SOPs), and web content.

**MG Ohio Website:**

Visit us at [www.mgohio.org](http://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](mailto: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](mailto: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.themedicineprogram.com/)

[http://www.themedicineprogram.com/](http://www.togetherrxaccess.com/p/prescription-savings)

<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>

Don't forget to register for the Regional conference!

<https://mgohio.org/regional-conference-1>

Or call 216-218-0477 and leave a message!

**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](mailto:mgohio@mgohio.org)

HAPPY  
MEMORIAL  
Day



**UPCOMING MAY 2023 MEETINGS:**

**In Person—**

May 13—1:00-3:00 pm Parma-Powers Library, 6996 Powers Boulevard, Parma, Ohio 44129

May 24—10:30 am **NEW** Brunch Bunch—Cracker Barrel, 6055 Som Center Rd, Willoughby, OH 44094

**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)**