



Supporting the Myasthenia Community  
in Ohio & Beyond



# MG OHIO NEWSLETTER

June 2023

Volume 11 Issue 6



June's Thursday 3:00 pm

## ZOOM Meetings

Due to some confusion about which link to use in any given month, we are now using one link per month. Register once and you are good for the entire month!

When: Jun 1, 8, 15, 22 2023 03:00 PM ET

[https://zoom.us/meeting/register/tJcrdOCurz8pGdOZo055vaLzLC7fB\\_5AMmgj](https://zoom.us/meeting/register/tJcrdOCurz8pGdOZo055vaLzLC7fB_5AMmgj)

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

No Zoom meeting on June 29th (5th Thursday)

## MG Ohio

### Executive Board

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

### Board of Directors

Dr. Elsheikh Bakri	Dr. Ben Claytor
Larry Dix	Dr. Miriam Freimer
Dr. Bashar Katirji	Dr. Hani Kushlaf
Dr. Yuebing Li	Jerry Molitoris
Sharon Rastatter	Saul Wiener
Dr. Kylie Sramek	

## Ask the MG Expert

**Q. How does Mestinon (pyridostigmine bromide work)?**

**A. Mestinon is one of a class of drugs that acts as an anti-acetylcholinesterase:**

- When your brain sends a signal for your muscle to move, acetylcholine is released from the nerve side of the neuromuscular junction (NMJ).
- The acetylcholine binds with the acetylcholine receptor on the muscle side of the NMJ to trigger your muscle to move.
- Acetylcholinesterase is then released which breaks down the acetylcholine (ACH) so that frees up the receptors to receive another message.
- Mestinon prevents the rapid breakdown of ACH by acetylcholinesterase which usually results in muscle strengthening.
- Mestinon usually takes 20–30 minutes to act. If you need it more rapidly, you can place the Mestinon under your tongue where it will dissolve and get into your bloodstream faster.
- Mestinon is short lived. It has a half-life of approximately 4 hours. That is why it is helpful to take Mestinon throughout the day.
- Mestinon is hygroscopic. A fancy way of saying that it absorbs water from the atmosphere readily.
- Store Mestinon in a watertight container.

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.

## LAST CHANCE TO WIN A FREE NIGHT'S STAY !!

Register by or on June 1<sup>st</sup> for the upcoming Regional Conference and you will be entered into a drawing for a chance to win a free hotel room the night before the conference for more information see pg. 3

## MG Ohio Regional Conference

August 26, 2023

## DO YOU READ THE NEWSLETTER? IT MAY PAY OFF !

June is MG Awareness Month! Can you find all the MG Ribbons hidden in this newsletter? The first person to contact me with the correct



number of ribbons will win a \$10 gift card to Panera. (You can still get a whole Danish ring at Panera for under \$10 or at least a few cups of coffee)

We are giving away 2 gift cards 1 for those who receive the newsletter by email and 1 for those who receive it by mail. If you have won in the past year, please let someone else try. Email [mgohio@mgohio.org](mailto:mgohio@mgohio.org) or call 216-218-0477 and leave a message

MG Ohio

Northeast Ohio In-Person Support Group Meetings:

June 10—1:00-3:00 pm

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.

June 20—1:00-3:00 pm

**NEW!**

Akron-Canton Area Hartville Kitchen & Bakery

1015 Edison St NW, Hartville, OH 44632

This is a meet and greet lunch meeting. Everyone is welcome especially our MG friends in Summit and Stark counties. Separate checks. Come make a day of it. Lots to see and do in Hartville!

July 22—1:00-3:00 pm

East—Mayfield Library (medium meeting room)

500 SOM Center Road, Mayfield Village, Ohio 44143

MG Ohio

Central Ohio In-Person & Zoom Support Group Meetings:

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

Cincinnati Area In-Person Support Group Meetings:

July 8 —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](#)



**An Invitation From Alexis Rodriguez in Georgia—**

**Monday, June 5th Georgia Support Group Meeting.** You do not want to miss this meeting. **6:30 PM - 8:00 PM** via Zoom Our in person **guest speaker will be Allison Foss, Executive Director for Myasthenia Gravis Association. MGA** Allison is no stranger to Myasthenia gravis (MG). Diagnosed at age 5, Allison was later identified as an MG patient with the MuSK antibody. Raised in southeastern Iowa, Allison graduated from Iowa State University with a Bachelor of Child & Family Services. She spent 18 years working with and advocating for individuals with developmental disabilities and special needs prior to joining the Myasthenia Gravis Association (MGA) in December 2017 as the Executive Director.

.Zoom meeting details.

Register in advance for this meeting:

<https://us06web.zoom.us/meeting/register/tZMtc-ChrzwpG9HQvJ5bWQuUgPOJ8LA6skQF>

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



### ANNUAL ICE CREAM SOCIAL - CELEBRATE JUNE MG AWARENESS MONTH



Due to our upcoming conference, we're having our annual ice cream social a little early this year. AND we get to celebrate MG Awareness month at the same time WIN WIN!

This year we will be having food and FUN for everyone. FUN games and Give-aways!

We will be serving regular vanilla (Breyers) and have a dairy-free vegan option made from coconut milk as well as sugar-free ice cream for those that require it. Bring your favorite topping to share. Bring your family and friends too! Everyone is welcome!

**June 10th 1:00—3:00 pm Parma— Snow Library Meeting Room A/B 2121 Snow Rd., Parma, OH 44134**



## **MG Ohio Regional Conference August 26, 2023**

Sari-Feldman Auditorium  
Cuyahoga County Public Library  
Parma-Snow Branch  
2121 Snow Rd., Parma OH 44134



**Conference 10:00 am – 4:45 pm**

**Doors open at 9:30 am**

**Pre-registration is a must!**

To register, go to <https://mgohio.org/regional-conference-1>

Conference is open to all patients, caregivers, researchers, family, and friends of those affected by myasthenia gravis or other myasthenic syndromes.

**FREE FREE FREE FREE FREE FREE FREE FREE FREE FREE FREE FREE**

Conference, all materials, breakfast and lunch are offered for free thanks to our generous vendors and volunteers.

**Meet & Greet evening of August 25th at the Impulse Lounge**

Holiday Inn Cleveland-S, 6001 Rockside Rd, Independence, OH 44131

**3:00 pm – 7:00 pm**

Special Rates at the Holiday Inn Cleveland-S Independence (located within a few miles down the street from the conference) for the night before and night of the conference. Just mention that you are with the Ohio Myasthenia Gravis Group to receive the special rate.

### **Gathering Together & Growing Stronger**

**Save your spot,  
register today!**

Go to: <http://www.mgohio.org/regional-conference-1>





**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.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>

Don't forget to register for the Regional conference!  
<https://mgohio.org/regional-conference-1>  
Or call 216-218-0477 and leave a message!



**June is Myasthenia Gravis Awareness Month!**

Celebrate by wearing your teal!

Join us for an ice cream social in Parma or at Hartville Kitchen in Hartville to celebrate our month together. See all in-person meeting opportunities on page 2

**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)

**UPCOMING JUNE 2023 MEETINGS:**

**In Person—**

**June 3—11:30 am-1:30 pm** North Columbus [centralohiomg@gmail.com](mailto:centralohiomg@gmail.com)

**June 10—1:00-3:00 pm** Parma-Snow Library, 2121 Snow Rd. Parma, OH 44134

**June 20—1:00-3:00** **NEW** Akron-Canton Hartville Kitchen & Bakery 1015 Edison St NW, Hartville 44632

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

**Weekly Saturday night chats starting at 6:30 pm ET** [https://zoom.us/j/96504171582?](https://zoom.us/j/96504171582?pwd=ODFjbXZGZ1I2V2tjRTNHafVlcGFRdz09)  
[pwd=ODFjbXZGZ1I2V2tjRTNHafVlcGFRdz09](https://zoom.us/j/96504171582?pwd=ODFjbXZGZ1I2V2tjRTNHafVlcGFRdz09)

