



Supporting the Myasthenia Community
in Ohio & Beyond

MG OHIO NEWSLETTER

APRIL 2023

Volume 11 Issue 4

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.



April's Thursday 3:00 pm

ZOOM Meetings

When: Apr 6, 2023 03:00 PM ET

https://zoom.us/meeting/register/tJlvdOyopj4sGdVjrEnX2OsJ0oIM85DIP4_0

When: Apr 13, 2023 03:00 PM ET

<https://zoom.us/meeting/register/tJcruirzktGdW0EUScNPiu8ROi98SKPa2m>

When: Apr 20, 2023 03:00 PM ET

<https://zoom.us/meeting/register/tJUld-mpqj4oHdBj10POE2IJJNfy2dktL-5Q>

When: Apr 27, 2023 03:00 PM ET

<https://zoom.us/meeting/register/tJYtcuGvrDsoGtFRVEjv5zUu1Ls3mvLCMZKS>

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



**Gathering Together
and
Growing Stronger**

MG Ohio Regional Conference

August 26, 2023

Early Registration Starts April 1st

Register between April 1 and June 1 for a chance to win a free hotel room the night before the conference see page 3 for more information



Ask the MG Expert

Q. What is a Regional Conference and why should I go to one?

A. A Regional Conference is a full day of interactive learning experiences for people dealing with an MG or MG-like diagnosis. Here are 10 reasons why you may want to attend:

1. The MG Ohio Regional Conference is easily accessible from several major highways and close enough to be a day trip for MG patients and family from Ohio, Michigan, Indiana, Kentucky, Pennsylvania, New York, Illinois, Tennessee, and West Virginia.
2. You will be able to learn about a variety of subjects important to MG patients directly from MG Experts.
3. You will meet fellow MG patients from across Ohio and beyond and know that you are not alone.
4. There will be a complimentary continental breakfast.
5. You will get to meet and ask questions of exhibitors and vendors interested in providing various services helpful to those with MG.
6. You can ask questions of a panel of experts about any MG subject.
7. There will be a complimentary boxed lunch.
8. Find out about all the latest MG treatment options.

Continued on pg. 3

MG Ohio

Northeast Ohio In-Person Support Group Meetings:

April 12th 10:30 am

Brunch Bunch – Perk-cUP Café and Grille

(Informal meet up everyone responsible for their own check)

561 W. Bagley Rd., Berea 44017

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 & Zoom Support Group Meetings:

April 15 -- 11:30 am-1:30 pm

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.

May 9 - 7pm

North Columbus

Via Zoom Please email 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 for details and the location

MG Ohio

Cincinnati Area In-Person Support Group Meetings:

May 13 —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=ODFjbXZGZ1I2V2tJRTNHaFVlcGFrdz09>

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

Ask the MG Expert continued from pg.1

- 9. An informal meet and greet gathering will be held the night before at the Holiday Inn Independence, giving you a chance to catch up with old friends and meet new ones.
- 10. Most of all—the entire conference is FREE. Your only cost would be if you chose to stay at a nearby hotel for the weekend. We've made special arrangements with the Holiday Inn for discount pricing for our group. If you register early you will be entered in a drawing for a free stay the night before the conference at the Holiday Inn.



Gathering Together and Growing Stronger

MG Ohio Regional Conference Registration

Event: August 26, 2023 10am-5pm Doors open at 9:30am

Cuyahoga County Public Library Parma-Snow Branch 2121 Snow Rd Parma, Oh 44134
Contact us at (216) 218-0477 or mgohio@mgohio.org

Register before June 1st to be entered into the drawing for a one-night hotel stay the evening before the conference on August 25.

This event is a MG OHIO event - MG OHIO is a 501(c)(3) designated non-profit organization
More information about MG OHIO can be found at <https://mgohio.org/regional-conference-1>

Registration starts April 1st
Reserve your spot today!

Click on link to register



If you do not have access to a computer or are unable to register for the conference online, please call Rebecca @ (216) 218-0477 to register.

MEET YOUR MG OHIO BOARD



Suzanne Ruff, Director, Secretary of the Board

I am a clinical psychologist, specializing in health psychology and now retired from active practice. Working at the Cleveland VA Medical Center for twenty years in the department of Neurology, I saw patients with chronic medical conditions, including MG. I served on the MGFA Board of Directors for nine years. In 2017, Nancy Law and I launched the Patient and Community Services Committee, collaborating with patients and caregivers to develop and evaluate national support and educational programming. My husband, Bob and I spend much of our time watching our beautiful grandchildren play sports and just be kids.



Larry Dix, Director

Larry Dix is President of Quality Switch Inc., which manufactures high voltage and high current switches that are used in the electrical industry all over the world. He was first diagnosed with Myasthenia Gravis in 2013 by doctors at the Cleveland Clinic. At that time his primary symptoms were difficulties in speaking, swallowing, chewing, breathing, and overall fatigue. MG was initially brought under control by the use of large doses of steroids and Mestinon. Cellcept was started and eventually the steroids were eliminated with Mestinon as a backup. In 2021 fatigue began again but he thought it was related to age. However, the original symptoms flared in November and it was decided that a Thymectomy might offer some relief. At this time the steroid doses are being reduced and Cellcept is continuing. However, the majority of symptoms have been minimized and life is returning to normal. As his job requires frequent travel in the US and internationally, he is now returning to that along with his exercise program which includes a personal trainer and weekly lessons in Jiu Jitsu. Larry was the face of the 2017 Ohio MG walk and the Cleveland Clinic Team Captain. He participated in several MG conferences and communities. He hopes that by continuing to move forward he can help others struggling with MG.

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 COVID19assis-



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>

SUCCESS IS NOT FINAL

FAILURE IS NOT FATAL

IT IS THE COURAGE TO CONTINUE THAT COUNTS

—WINSTON S. CHURCHILL

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 APRIL 2023 MEETINGS:

In Person—April 12th 10:30 am– Perk-cUP Café and Grill 561 W. Bagley Rd., Berea 44017

April 22—1:00-3:00 pm Beachwood Library 25501 Shaker Boulevard, Beachwood, Ohio 44122

April 15 -- 11:30 am-1:30pm North Columbus contact centralohiomg@gmail.com

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)