



NEWSLETTER

AUGUST 2022

Volume 10 Issue 8

MG Ohio

Board of Directors

And

Medical Advisory Board

Watch this space next month for a listing of our Board of Directors and a listing of the MG specialists who have agreed to be a part of our Medical Advisory Board. We are in the process of finalizing our governing structure and members.

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 our Local Group:

If you use the following link to sign up for Rare Patient Voice, our local group will receive \$5 for every person chosen to participate. That money goes towards helping to fund this newsletter. Sign up at: <https://rarepatientvoice.com/MGFANortheast/>



August's ZOOM Meetings

When: Aug 4, 2022 03:00 PM Eastern Time (US and Canada)

https://zoom.us/meeting/register/tJUodOGgrzouGtSvQ4P-oVhzorwxB_IX1IV

When: Aug 11, 2022 03:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJcod-2rqzMoG9SRxUuaEu-DZ5feqNZJmOQm>

When: Aug 18, 2022 03:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJwceigrDwjH9GNaT0Uk2dtS0CwSDUoqE4>

When: Aug 25, 2022 03:00 PM Eastern Time (US and Canada)

https://zoom.us/meeting/register/tJUod-GhpzpjGNAWOhc7t_tBdvGO7B7ssA5

Next In-Person Meeting—

**August 13th at the Parma-Snow Branch
of the Cuyahoga County Public Library located at**

2121 Rockside Rd., Parma 44134

We will be meeting in the A/B Meeting Room

1:00—3:00 PM



LOGO CONTEST

Calling all artists! MG Ohio needs a new logo to go with our new name. Mara Somerville designed the temporary LOGO seen here. Thanks, Mara!

But, we'd like to see YOUR ideas. Draw an original LOGO representing MG Ohio. Scan or take a picture and send it to mgohio@mgohio.org.

Deadline to enter is September 1, 2022

Ask the MG Expert

Q. Are any vitamins or supplements harmful to take with MG?

A. As a rule over the counter vitamins are usually safe for someone living with MG. However there are some exceptions:

- Taking excessive amounts of vitamins A, D, E, and K can be harmful to anyone regardless of whether they have MG or not. These vitamins are stored in fat deposits in the body and are not as easily metabolized as more water soluble vitamins such as vitamin C. Always consult your physician before taking more than the recommended daily doses of these vitamins.
- While Magnesium is on the list of drugs contraindicated in MG, the amount you get in a daily vitamin is usually safe to take. Magnesium given by intravenous injection (IV) should be given with caution to someone with MG. Always remind any new doctor you see of your MG diagnosis.

Q. Is the supplement L-carnitine safe to take with MG?

A. In an article of the Kawasaki Medical Journal* a case study was reported where a patient with MG had fewer exacerbations after taking the supplement L-carnitine. *43(1): 1-4, 2017 doi: 10.11482/KMJ-E43(1)1,

- However, please note that this was an individual case study not a scientific trial of L-carnitine.

Next Parents of MG KIDS Meeting—August 14, 2022



When: Aug 14, 2022 02:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJEtc-6orTouH9DN5TyVBR1JhpMXwSK15Bvi>

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

UPCOMING EVENTS—Here are a few of the events we are planning for the rest of 2022

Continued in-person Monthly Meetings 2nd Saturday of the Month with OSHIIP speaker in October

Special Dinner Meeting with the Patient Education Manager from Alexion—November TBD

Annual Christmas Party—December 2022 Exact date TBD

Regional MG Educational Conference—early 2023

Important Things to know about our Support Group Meetings

Our groups are very welcoming and allow for the sharing of helpful hints and tricks for living with MG. However, it should be said that your own doctor is the one who can best manage your care and treatment. Please check any changes in treatments or medications with your physician first.

SATURDAY ZOOM CHATS—Informal Zoom get together—no agenda— just a time to visit. Register once for a Saturday Chat and use the same link to sign in through December 31, 2022.

When: Saturdays Aug 6 - December 31, 2022 07:30 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJ0qduytrT4jH9KSiOgggP8G0xHTCjcYC6b1>



Adult Patient Zoom Meetings:

Our regular Thursday 3:00 pm meetings

continue in August See pg. 1

Even though our name has changed, our services haven't. We will continue to offer a weekly Zoom meeting open to *anyone* interested in MG and MG related diseases no matter where they live. We cover various topics related to myasthenia gravis and usually have Dr. Robert Ruff on the call to answer questions.

Family, friends, and caregivers welcome!

In-Person Meeting Notes:

Nine people attended July's meeting held at the Parma-Snow Library. It was a beautiful day outside which might have kept some people away. We had a share and care session as well as a discussion about the new direction our group was headed. Hopefully more people can join us in August. The room is big and we can be well spaced. Please wear a mask as Cuyahoga County is now considered at a high level for Covid. If you don't have a mask, one will be supplied.

Our next regular meeting will be August 13th in Parma (see pg.1 for details)

Want us to meet in your area? [Let me know](#) and I'll work to make that happen.

Why the Name Change? and What it Means for the Northeast Ohio Support Groups—

Our Cleveland Area MG group has been in existence since the 1960's. The current group was organized under the leadership of Sandy and Maryann in 1982. Back then we started meeting just by phone, then at the Brookpark Library. Through our 40 plus years, we have been affiliated at various times with national MG organizations such as the MGFA and MDA, but we have always stayed true to our calling of supporting MG patients and their family and friends.

We are excited to announce the next step in fulfilling our mission is the creation of MG Ohio. This new structure will allow us to better fulfill the needs of the MG and MG related diseases community in the state of Ohio and surrounding areas. We will remain patient centric, that is, to concentrate on patient programming and education in a way that best suits the population we serve as well as education and awareness for all members of the community touched by MG and MG related diseases. To that end we will continue to hold weekly Zoom meetings for those patients that are unable to get to an in-person meeting. We will also continue to meet regularly in person and to provide special speakers on topics of interest to our fellow patients.

So, what's changed? We are now incorporated as MG Ohio. Our website has changed from clevelandmg-group.org to mgohio.org. We are currently in the process of applying for 501 (c) IRS status for non-profits which will grant us a tax-exempt status. This allows us to do our own fundraising and accept donations to help offset the costs of educational materials, mailings, and the cost of hosting in-person meetings, conferences, and other special gatherings. No salaries will be paid. This is a volunteer organization.

We are partnering with other Ohio Support Groups in the Columbus area and expanding the number of MG Ohio Support Groups throughout the state of Ohio. We are currently working on expansion in the Cincinnati-Dayton area as well as Youngstown, Canton, and Toledo.

We will be governed by a Board of Directors who serve at will in the best interest of MG patients. All members of the MG Ohio governing board and Medical Advisory Board serve on a volunteer basis. The governing board will meet quarterly to ensure that the direction of MG Ohio is consistent with our mission and values. Members of the governing board include patients, caregivers, and MG physicians as well as other MG and MG related diseases experts all dedicated to ensuring the success of MG Ohio.

We will strive to meet your needs and live up to the continued faith you have placed in us over the years to bring you the most up-to-date information about MG and MG related diseases treatments. We will continue to act as a resource for MG patients, families, friends, and caregivers by providing peer to peer support and valuable resources and education for living well with MG. We hope you will continue to partner with us through this exciting new chapter in Ohio's MG history.

MG Virtual Closet is now online. Check it out at mgohio.org

Do you need any durable medical equipment? Do you have some to share?

Email me at mgohio@mgohio.org and I will add it to the closet inventory. Some of the items available for short term use include walkers, wheelchair ramps, and toilet seat raiser. Thanks! We can all use a little help now and then.

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>

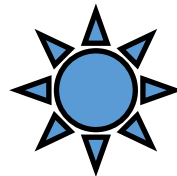
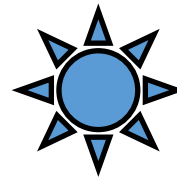
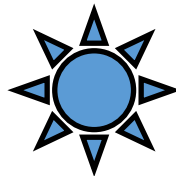
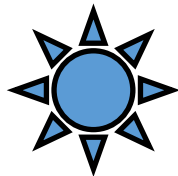
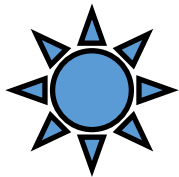
<http://www.myastheniagravis.org/we-can-help/what-we-do/>

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



And suddenly you just know it's time to start something new and trust the magic of beginnings.

Meister Eckhart



UPCOMING August 2022 MEETINGS:

Parents of MGKIDS August 14th 2:00 pm via Zoom (see page 2)

Adult MG Patients & Friends—Saturday, August 13th 1-3 pm (see page 1)

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

OPEN CHAT every Saturday night at 7:30 pm via Zoom (see page 2) *new link!