

Northeast Ohio Area Support Groups

JULY 2020

Meeting Updates -----

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We are here for you and your family to provide help and hope for those living with Myasthenia Gravis

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: Myasthenia.org

Easy way to contribute to MGFA:

If you shop at Amazon.com, go to smile.amazon.com next time you shop. Choose MGFA as your charity. It is that simple. Then every time you shop, do it through smile.amazon.com and a portion of your sales will be contributed to the National MGFA.



July's ZOOM Meetings

Thursdays at the following times:

1st Thursday July 2—11:00 am

https://zoom.us/j/93402215944? pwd=U01ySGF6UkxpSURyTE4xUEhKbnFKUT09 Meeting ID: 934 0221 5944 Password: 762282

Dial in: +1 929 205 6099 US (New York)

2nd Thursday July 9-7:00 pm

https://zoom.us/j/96856863349? pwd=WFNCWDI0VkhRRHBGUIA3UIVuUXZmdz09

Meeting ID: 968 5686 3349 Password: 020835

Dial in: +1 929 205 6099 US (New York)

3rd Thursday July 16-3:00 pm

https://zoom.us/j/93366754897? pwd=WHU4cDdDYjZKVDhVZGZFVIIWcG04UT09 Meeting ID: 933 6675 4897 Password: 034507

Dial in: +1 929 205 6099 US (New York)

4th Thursday July 23—1:00 pm

https://zoom.us/j/99767936916? pwd=VmJacHdxM0hUMmYyblEzekNQa0tvUT09 Meeting ID: 997 6793 6916 Password: 184246

Dial in: +1 929 205 6099 US (New York)

5th Thursday July 30—No meeting

NOTE: Passwords are now required and included in the links above, but if you are joining by phone, you'll need to enter the password. Each meeting has an exclusive ID and password. Also, note change in times. Thank you





Volume 8 Issue 7

Keeping it cool

Many people with MG get weaker in the heat of summer. We are expecting temperatures in the 90's over the next few weeks. Here are some ways to keep cool :

- Apply ice at pressure points (back of neck, wrists, behind knee, at temple)
- Use cooling towels. You • can buy some that are specially made to retain coolness or you can make one yourself with a strip of cloth dipped in refrigerated water.
- Stay hydrated. Drink lots of water and use ice.
- Stay indoors during the middle of the day when it is the hottest—in the airconditioning, if you have it. If not, use fans, shade, and ice.
- If you must be outdoors, consider buying a cooling vest to help keep you cool.**
- If there is no shade outdoors, consider bringing your own by using an umbrella to block the sun.
- Try to plan strenuous activities during the early morning or evening hours when it isn't as hot.

** Greater Atlanta, Georgia MG Group is hosting a speaker from Polar Vests, Monday July 6, 2020 06:30 PM Register in advance for this meeting:

https://zoom.us/meeting/register/ tJEpfuGsqz0tGtKRN4WE8txb6ELbOnFGI3RX

<u>Westside Meetings</u>

Meets every 2nd Saturday except September, November, and December at various places (see below)

No ice cream social this year—I can't justify the risk that we would encounter by meeting in person.

September—MGFA Virtual Walk

October 10-TBD

December 12—Annual Christmas Party TBD

Lorain County Meetings: TBD

NOTE: Everyone is welcome to attend any meeting regardless of where you reside. Family and friends are welcome too! Hope to see you soon at one of our meetings or events.

MEETING NOTES: Due to the coronavirus pandemic, we will not be meeting in person at *least* through September maybe longer depending on circumstances. Therefore we will be having a Zoom online meeting every Thursday at various times (see page 1)



The average attendance at June's Zoom meetings was about 8-12 people per meeting.

We have gone to a "share and care" format. We take turns giving updates, asking questions of our MG expert, Dr. Robert Ruff, and in general just connecting with others like us experiencing the same problems and sharing tips and solutions. I would highly recommend that if you have the time, give Zoom a try. It is a great way to connect and learn more about MG and each other.

Starting in July, Zoom is requiring that all meetings be password protected. Links provided should include the password but if you are phoning in, be sure and enter the password when you join a meeting.

Eastside Meetings

Beginning in January meets every 3rd Saturday of the month *except September*, November, and December, at **various places (see below)**

No ice cream social this year—I can't justify the risk that we would encounter by meeting in person.

September-MGFA Virtual Walk

October 17-TBD

December 12—Annual Christmas Party TBD

What to expect at in-person meetings:

Regular meetings are open to all

Attendance usually ranges from 8 to 30 or more.

All information shared is confidential.

*Speakers will present information at meetings marked with *

Speakers *usually* present during the second half of the meetings allowing the group to introduce themselves to new patients or catch up with old friends.

Introducing the MG Virtual Closet!

Do you need any durable medical equipment?

Do you have some to share?

Email me at <u>clevelandmggroup@gmail.com</u> and I will add it to the closet inventory.

Likewise, if you need some equipment, please state what the item is and your anticipated term of need for the item.

Don't forget to include your name and contact info. Thanks! We can all use a little help now and then.



JUNE MG AWARENESS MONTH EVENT

The June MG Awareness event at Farm House Yoga, LLC in North Ridgeville raised over \$1050.00 for MGFA. Thanks to Katie and the Oradini Family for making this great event so successful! Here are a few pictures from her event. See more info at:

https://www.facebook.com/farmhouseyogallc/



Need help paying for your meds? Check out the following sites:

https://www.needymeds.org/ http://www.themedicineprogram.com/ http://www.togetherrxacces.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

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

LOCAL MGFA GROUP WEBSITE

Visit us at <u>www.clevelandmggroup.org</u>

For all the latest local MG news, upcoming events, and newsletters

Be sure and send in your MG related questions for our Ask the MG Expert column Email at clevelandmggroup@gmail.com

Or snail mail it to: Rebecca Molitoris, 9356 Asbury Lane, North Ridgeville, OH 44039

