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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.



August's ZOOM Meetings

Five meetings at the following days and times:

1st Thursday August 6—11:00 am

<https://zoom.us/j/94397315170?pwd=b1hyOWh1YURsdGdRSXIFyOJSYUhpPz09>

Meeting ID: 943 9731 5170 Passcode: 668827

Dial by your location +1 929 205 6099 US (New York)

2nd Thursday August 13—1:00 pm

<https://zoom.us/j/99685363254?pwd=YnRuNm9BcEdzU05acXVJWHNwZDBXQT09>

Meeting ID: 996 8536 3254 Passcode: 036427

Dial by your location +1 312 626 6799 US (Chicago)

3rd Saturday August 15 —1:00 pm**

<https://zoom.us/j/98052750518?pwd=bjcOV0kzbTIVblhBaFIMU1c3MFJ2dz09>

Meeting ID: 980 5275 0518 Passcode: 710409

Dial by your location +1 312 626 6799 US (Chicago)

3rd Thursday August 20—3:00 pm

<https://zoom.us/j/95968884530?pwd=dFdHMVRCZ2I2MkIQVjZsV2xKNGZIQT09>

Meeting ID: 959 6888 4530 Passcode: 993905

Dial by your location +1 312 626 6799 US (Chicago)

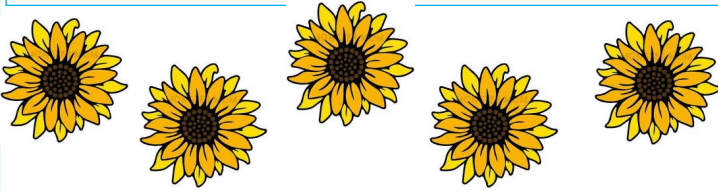
4th Thursday August 27—7:00 pm

<https://zoom.us/j/97793330511?pwd=MVcxWdxVndidUxKbEhaZxNINvZ6QT09>

Meeting ID: 977 9333 0511 Passcode: 658388

Dial by your location +1 312 626 6799 US (Chicago)

****NOTE: Special Meeting this month on the 3rd Saturday**



Clinical Trials

The following Clinical Trials are in progress and accepting new patients:

- Alexion Pharmaceuticals is conducting a phase 3 research study to learn about the safety and effectiveness of a medication called ravulizumab-cwvz for use with those diagnosed with myasthenia gravis. The study will assess how the treatment impacts your daily activities. You must be 18 years old or older to participate. Visit this [Survey to determine](#) if you're eligible. You can contact mgchampion@alexion.com. [Learn More»](#)
- Zilucoplan https://myasthenia.org/Portals/0/MGFA_Research_Announcement%20Form_RaPharma_RAISE.pdf
- Rozanolixizumab https://myasthenia.org/Portals/0/A%20Study%20to%20Test%20Efficacy%20and%20Safety%20of%20Rozanolixizumab%20in%20Adult%20Patients%20With%20gMG_1.pdf
- Descartes-08 <https://myasthenia.org/Portals/0/MGFA%20Research%20Announcement%20Form%20Descartes-08.pdf>
- For more Clinical Trials go to: <https://myasthenia.org/Research/Clinical-Trials>

2020 MG Meetings and Events

Westside Meetings: TBD

October 10—MGFA Virtual Walk

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 until 2021. Therefore we will be having a Zoom online meeting every Thursday at various times (see page 1) This month we will have a special meeting on Saturday, August 15 from 1-3 pm see pg. 3



We continue to have an average attendance of about 8-12 people per Zoom 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.

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

We will have a special extra meeting in August see pg. 3

MGFA Wellness Series

Every Friday at 2 pm ET, the MGFA offers a Wellness Series on Zoom.

Watch your email box for an invite to register for each week's meeting or [email](#) me and I will forward it to you. —Rebecca

Eastside Meetings: TBD

October 10—MGFA Virtual Walk

Hopefully we will resume in-person meetings in 2021

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 clevelandmggroup@gmail.com 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.



ANNOUNCING SPECIAL AUGUST SATURDAY MEETING

Some of you have been asking for a Saturday meeting instead of our regular Thursday Zoom meetings. As many of you know, in August we usually hold our annual ice cream social. It is always a big hit and is one of our best attended meetings of the year. This year due to Covid-19 we will be having a virtual ice cream social on the third Saturday, August 15, 2020 at 1 pm via Zoom.

So grab your favorite flavor ice cream and put it in a cone or sundae, or just have a popsicle and join us live for a different kind of Zoom meeting. There will be drawings with prizes, a Trivia contest, and fun for all!

Hope to see you at our virtual event!



You bring the ice cream
we'll bring the

FUN!

PRIZES!

Did you know?? John Gerald found the following in the Cleveland Press *Showtime* from November 22, 1963: The Northeast Ohio MGFA Chapter holds a card party at Amazon Hall, Lorain Ave., tomorrow 8 p.m. (Amazon Lodge Temple, 2848 Lorain Ave.) *Thanks, John!*

What Are You Doing During The Covid-19 Quarantine?

As you know, those of us with underlying conditions or who are immune-compromised should continue to use precautions during this pandemic including: staying home as much as possible to limit your exposure to others, meeting with only a small group of people (immediate family or close friends) who choose to quarantine together, wearing masks even in multi-generational families, and following safe hand-washing protocols.

But what are you doing for fun?

My family and I have been socially distanced not only by the virus but by actual physical distance as well. However, because of Covid-19, we have started new traditions even though we are scattered across the U.S. We have been playing Trivia games as a team via Zoom and even played an escape room game together virtually. We have also met to celebrate birthdays, graduations, and anniversaries via Zoom meetings. It's not always ideal, but we get to see each other face-to virtual-face at least twice a week. We are visiting much more than we were before this started. Some of my family members have started taking classes, learning new hobbies, finding new ways to exercise, and playing card games together via online offerings.

Here are a few opportunities for you if you would like to start something new:

- www.BrainSportz.com Click the following RECURRING ZOOM LINK prior to or at 7:00pm CST/8:00pm EST/5:00pm PST every Tuesday, Wednesday, Thursday & Friday, and you'll be brought directly to the game: <https://us02web.zoom.us/j/85106699719?pwd=UXJyOW1vU2RLNjhQSGFYd2V4clFhQT09>
- Free Harvard Courses: <https://online-learning.harvard.edu/catalog/free> Scroll down past the web classes and you will find history, art, social studies, etc.
- Free Courses on Coursera: <https://www.coursera.org/courses?query=free>
- Smart Phone apps: Trickster Cards (where you can play card games with family and friends); Explore.org (where you can view virtual cameras across the world)
- Harry Potter virtual escape room game Free! <https://t.co/9LmL3vtiRZ?amp=1>
- Do you have a virtual site to suggest or other way to have fun during Covid-19? [Email](#) me and pass it on!

LOCAL MGFA GROUP WEBSITE

Visit us at www.clevelandmggroup.org

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

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/>

<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>

Need a ride to the doctor?

Can you give a ride to an appointment?

We are setting up a data base to match willing drivers to those needing an extra hand right now.

If you are able to pick up and drive a fellow MG patient near you to an appointment (you will NOT have to go into the building with them), then please [email](mailto:rebecca@mggroup.org) me and let me know. Everyone MUST wear a mask!

You will be matched with those in your area who are in need of a ride.

Thanks in advance for considering this request.

—Rebecca

UPCOMING 2020 MEETINGS:

Five ZOOM meetings in August! (see pg.1 for details)

See you soon !

Thank you to our sponsors:

