

Northeast Ohio Area Support Groups

SEPTEMBER 2020

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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: <u>Myasthenia.org</u>

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.



September's ZOOM Meetings

Four Thursday meetings at the following times:

1st Thursday September 3—11:00 am

https://zoom.us/j/95975142168?

pwd=VmMvQ09YbVhZSjVYSFNBY1EwWjFaZz09

Meeting ID: 959 7514 2168 Passcode: 215396

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

2nd Thursday September 10—1:00 pm

https://zoom.us/j/93054780574? pwd=dm5RWTNWWjFnUmwwTE5vbzBPUDNzUT09

Meeting ID: 930 5478 0574Passcode: 734497

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

3rd Thursday September 17—3:00 pm

https://zoom.us/j/95508992894? pwd=bi80Znh6aFIRM2VHVTRZeVIMNzlyUT09

Meeting ID: 955 0899 2894 Passcode: 064909

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

4th Thursday September 24-7:00 pm

https://zoom.us/j/94845871382? pwd=d0RLNWxKYWU2KzVNQjdOU2QybE93QT09

Meeting ID: 948 4587 1382 Passcode: 904435

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





Volume 8 Issue 9

MGFA Virtual Walk 10/10

It's coming up—Get your teams together:

- In case you haven't heard, we are moving our walk season into a virtual live event called <u>Together We</u> <u>Stand!</u> It will be held on October 10 at noon eastern and you will receive an email and link to the live event as we get closer to the date.
- We are combining our 2020 MG Walks and ALL additional fundraising efforts to highlight and recognize our Walk leaders, volunteers, fundraisers, and participants as part of the Together We Stand virtual event. We also have some fun activities leading up to the event such as our art contest and on-line scavenger hunt. Although we cannot be together in-person, it does not mean our mission has changed and we need your help more than ever!
- Team Captains Please join us for our next <u>ZOOM Team Captain</u> <u>meeting</u>! Tuesday, September 1 at 7 pm EST
- Start a virtual walk team and share fun photos or videos of your friends and family "walking" in their neighborhoods to show their support, while fundraising and earning the fabulous 2020 prizes!

REGISTER NOW!

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.

NOTE: 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).



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.

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 <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.

MEETING NOTES:

We've been averaging 6-9 people per Zoom meeting

The Special Ice Cream Social Meeting only had 3 participants.
Thank you Sandy, Carolyn, and Peg. I hope you enjoy your prizes. We will not be having any more Zoom Saturday meetings,
Instead, we will continue to hold weekly Thursday meetings at the following times:

1st—11:00 am	3rd 3:00 pm
2nd—1:00 pm	4th 7:00 pm

Check out the Special MDA Symposium this month (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 <u>email</u> me and I will forward it to you. —Rebecca

Myasthenia Gravis Symposium Saturday, September 12 11:00 a.m. - 4:00 p.m. ET Please Register by September 10th • MDA Mission Spotlight (11:00am ET) • Keynote Presentation: Pediatric Care in MG (11:15am ET) Dr. Emmanuelle Tiongson, Pediatric Neurologist • Drug Development Roundtable Discussion (12:10pm) • Clinical Trials Update (1:00pm ET) Dr. Amit Sachdev • Research Update (1:50pm ET) Dr. Gil Wolfe • Therapeutic approaches with Subtypes of MG (2:40 pm ET) Dr. Anthony A. Amato • Exercise and MG (3:25pm ET) Dr. Charlene Hafer-Macko

"And autumn is the best time for adventures, because even the world is feeling a little more alive."

Marisa Casciano





Are you a Lucky Duck?

Then adopt a rubber duck for the first annual Lucky Duck Derby. This specDuckular event will be held on **September 26, 2020 at 1:00pm EST on Facebook LIVE**. Join us to experience

thousands of rubber ducks duke it out on the water, and see whose duck crosses the finish line first!

You can paddle with us and help raise vital funds to support tens of thousands of Americans living with MG by adopting a duck or forming a Ducky Derby Pack of your own.

Get more chances to win by purchasing a Quack Pack (5 ducks for \$20), a Quacker's Dozen (13 ducks for \$50), or a Flock of Ducks (30 ducks for \$100)!

Prizes include Amazon gift cards for first, second, and third place.

Team Packs are forming now. Put together a group of friends, colleagues, or family members to join the fun. Teams compete for bragging rights and great prizes.

Register on the link below and share with your friends, family, and networks.



ADOPT A RUBBER DUCK

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 <u>clevelandmggroup@gmail.com</u>

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.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

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 <u>email</u> 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

