

Northeast Ohio Area Support Groups

For Strength, Independence & Life

Volume 8 Issue 10

OCTOBER 2020

Meeting Updates →

Meeting information/notes pg. 2

Virtual Closet pg. 2

Memorial pg. 3

Wellness Series access pg. 3

MGFA Virtual Walk pg. 3

Assistance Programs pg. 4

MDA ADDRESS:

Valerie Galbicsek

Care & Clinical Services Specialist, Muscular Dystrophy Association

Gemini Towers 1, 1991 Crocker Road, Suite 600, Westlake, Ohio 44145

Tel 440.892.3367 ext.1643

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.



October's ZOOM Meetings

Four Thursday meetings at the following times:

Time: Oct 1, 2020 11:00 AM Eastern Time (US and Canada)

Join Zoom Meeting

https://zoom.us/j/95975142168? pwd=VmMvQ09YbVhZSjVYSFNBY1EwWjFaZz09

Meeting ID: 959 7514 2168 Passcode: 215396 Dial by your location: +1 312 626 6799 US (Chicago)

Time: Oct 8, 2020 01:00 PM Eastern Time (US and Canada)

Join Zoom Meeting

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

Meeting ID: 930 5478 0574 Passcode: 734497 Dial by your location: +1 312 626 6799 US (Chicago)

Time: Oct 15, 2020 03:00 PM Eastern Time (US and Canada)

Join Zoom Meeting

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

Meeting ID: 955 0899 2894 Passcode: 064909 Dial by your location: +1 312 626 6799 US (Chicago)

Time: Oct 22, 2020 07:00 PM Eastern Time (US and Canada)

Join Zoom Meeting

https://zoom.us/j/94845871382? pwd=d0RLNWxKYWU2KzVNQjd0U2QybE93QT09

Meeting ID: 948 4587 1382 Passcode: 904435 Dial by your location: +1 312 626 6799 US (Chicago)





Ask the MG Expert

Here are some questions and answers that have come up recently at our Zoom meetings:

- Q: Why does a spoonful of mustard taken under the tongue seem to help muscle cramps?
- A: Cramping muscles not caused by a mineral deficiency, may have something to do with your body's Ph level, The vinegar content in mustard may help lower that Ph level. Taking a teaspoon of vinegar in water may accomplish the same effect. When you place something acidic, such as vinegar, under your tongue which is rich with blood vessels, the effect is almost immediate since it is taken up quickly by the bloodstream.
- Q: Is there anything that can help the GI effects of Mestinon (Pyridostigmine Bromide)?
- A: There are a few things that may help the effects of Mestinon on the stomach and intestines. Try and take Mestinon with a small snack like cheese and crackers. Eating more cheese will also help slow down the intestinal reaction (unless you are dairy sensitive). If you continue to have troublesome Gl symptoms, there is a medication Bentyl that may help.

Thank you, Dr. Bob Ruff, for help with our MG questions!

2020 MG Meetings and Events

Westside Meetings: TBD

October 10-MGFA Virtual Walk

Eastside 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.



Ħ

Y

H A L L O W E E

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.

MEETING NOTES:

We've been averaging 6-9 people per Zoom meeting
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 MGFA VIRTUAL WALK—

Together We Stand!

Meeting this month (see pg. 3)



Our dear friend and fellow MG'r, Tom Roberts passed over to the next dimension on Tuesday, September 22, 2020 after a long and hard-fought battle with pancreatic cancer. Tom's reflective thinking and philosophical musings brought many thoughtful and interesting conversations to our MG meetings. Some of you may

remember him from last year's MGFA Walk where he was one of the Ohio Walk Heroes. His absence leaves behind a big hole in our midst. He will be greatly missed. Our deepest sympathies go out to

Tom's wife, Cheryl and daughter, Erin. As of this date, services have not yet been scheduled. I will send out an email blast when they are set.

If you feel led, please send a condolence card to his wife and daughter at: Cheryl Roberts, 2804 Village Court Vermillion, OH 44089







MGFA Wellness Series

Every Friday throughout the summer, MGFA has offered a Wellness Series on Zoom.

Past MGFA Wellness sessions may be found by clicking the following links: www.myasthenia.org, www.clevelandmggroup.org/upcoming-events, or Jack Peterson's Google Drive

Thanks, Jack for making this possible!!



MGFA Virtual Walk LIVE EVENT 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 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 <u>art contest</u> and on-line <u>scavenger hunt</u>. Although we cannot be together in-person, it does not mean our mission has changed and
 we need your help more than ever!
- 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!

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.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 <a href="mailto:emailto

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 ZOOM MEETINGS:

4 Local ZOOM meetings and 1 National MGFA WALK Meeting in October! (see inside for details)

Hope to see you soon on Zoom!

Thank you to our sponsors:



