

Northeast Ohio Area Support Groups

For Strength, Independence & Life

DECEMBER 2020

Meeting Updates →

Meeting information/notes pg. 2

Virtual Closet pg. 2

In Memorial 2020 pg. 3

Assistance Programs pg. 4

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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.



December's ZOOM Meetings

Thursday meetings at the following times:

When: Dec 3, 2020 11:00 AM Eastern Time (US and Canada)

Register in advance for this meeting:

https://zoom.us/meeting/register/tJMrf-CsqzIqG9Bz7FDRoNbuV8xMcmn7zhMM

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

When: Dec 10, 2020 01:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

https://zoom.us/meeting/register/ tJEkcuitqTkrGtSEpfqETq2WILF HZkWqSGE

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

When: Dec 17, 2020 03:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

https://zoom.us/meeting/register/tJEvcyqrzgiHdaLKLDMjYVUjChuUSp0psN4

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

There will be no 4th Thursday Meeting this month Merry Christmas!

NOTEL We have gone to a registration system for meetings. Please register in advance. If joining by phone and unable to register, call or text me for the phone number and passcode to enter the meeting







Volume 8 Issue 12

What are the best Holiday gifts for someone with MG?:

Ask the MG Expert

Some of the best gifts for people with muscle weakness are gifts that help conserve energy and make life easier. Here's some of our top picks:

- Jar opener with large grip handle.
- Smart home device such as Google or Alexa.
- Smart plugs—can be paired with Google or Alexa device to turn on lights, play music, and more.
- Ring Doorbell or other smart doorbell which allows you to answer the door remotely and to keep an eye on your front door.
- Smart thermostat that can be controlled through a smart device like Google or Alexa or with a smart phone.
- Small waterproof portable pill container with twist off lid. Small enough to fit conveniently in your pocket or on your key ring.
- Home pill container that can hold between 1-4 weeks worth of medicine at a time. Allows you to save time sorting your daily pills.
- Fit Bit or other smart watch that can: monitor your heart rate, set a pill timer, and track your steps



2020 MG Meetings and Events

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Westside Meetings: TBD

Lorain County Meetings: TBD

NOTE: Everyone is welcome to attend any meeting including on ZOOM, 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.

We are requiring pre-registration this month. Click on the links provided where you can register. You must register for each meeting separately. You will be sent an email with the link and passcode for each meeting. Zoom has added these extra protections to keep our meetings safe.



Eastside Meetings: TBD

Just a note about Covid-19

We are all getting just a bit weary of this pandemic. But please know that the threat is very real. We have had some of our own fellow MG'rs become very sick with this virus.

Please continue to protect yourself and others by wearing a mask and staying socially distant!

Need a mask? <u>Email</u> me and I will hook you up. We have several people willing to help provide masks to those who can't afford them.

Feeling isolated? Take advantage of our virtual meetings.
They really are the next best thing to being there.

Stay Home and Stay Safe

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 have been averaging about 9-12 people per meeting. It is a great time to connect with each other and share tips and hints for living well with MG

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

NOTE:

There will be no 4th Thursday meeting this month due to the Christmas holiday



In Memorial 2020—

To all those who have gone before us to that great unknown during this past year:

Dave Bryne—husband of Anne

Norman Gera

Beverly Hendricks

Samuel Martin—father of Brenda Hilpert

Thomas Roberts

Judi Schiebli

If I missed your loved one please email me.



For Strength, Independence & Life

Self-care for Caregivers
Join MDA and neuroscience social worker Jennifer Reidell
on Dec. 3 from 4 p.m.-5 p.m. ET for a new webinar all
about caregiving. Learn self-care strategies and how to focus on caregiver mental health.

REGISTER NOW >>

MDA ENGAGE SEMINAR

Join us for this Engage Seminar where we discuss mental health for caregivers.

Caregivers are an important member of the MDA community. Often times caring for themselves is put behind caring for their loved one living with a neuromuscular disease. In this MDA webinar, we will discuss the role of being a caregiver, how to take care of your own needs and prioritize your mental health, as well as share caregiver resources.

This webinar will be live from 4-5pm EST and will include a Q&A.

Want to try out another MG Group's meeting? You're cordially invited to register for the Atlanta, Georgia meeting on December 7, 2020

The Georgia Support Group will have the last meeting of 2020. We will have as our guest **speaker Neurologist Dr. Gavin Brown** (https://www.laureatemed.com/MedicalTeam/Bios/BioDetails.aspx?uid=127)

You are invited to a Zoom meeting.

When: Dec 7, 2020 06:30 PM Eastern Time (US and Canada)

Register in advance for this meeting:

https://zoom.us/meeting/register/tJAode2trTIsEtOO7sraJ2MvCcok3BIo-H15

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





From our house to yours Rebecca and Jerry

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 $\pmb{\mathsf{Ask}}$ the $\pmb{\mathsf{MG}}$ $\pmb{\mathsf{Expert}}$ 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



We are all like

SNOWFLAKES

Each different in our own

beautiful way

—-Unknown

UPCOMING 2020 ZOOM MEETINGS:

3 Local ZOOM meetings in December! (see inside for details)

Hope to see you soon on Zoom!



Thank you to our sponsors:

