

Northeast Ohio Area Support Groups

## **JANUARY 2021**

Meeting Updates -----

Meeting information/notes pg. 2 Virtual Closet pg. 2 MG WALK 2021 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: <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.



January's ZOOM Meetings Thursday meetings at the following times:

When: Jan 7, 2021 11:00 AM Eastern Time (US and Canada)

Register in advance for this meeting:

https://zoom.us/meeting/register/ tJAqduqhqzksGdX3CgQ8KBGTeGCDsdk2jROF

When: Jan 14, 2021 01:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

https://zoom.us/meeting/register/ tJ0pfuqorTwqHdW2m8J6r6WpImFGLwAqYTLZ

When: Jan 21, 2021 03:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

https://zoom.us/meeting/register/tJYrd-2urz4uG9U-0ITKK2ISA j8nhyWdVZT

When: Jan 28, 2021 07:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

https://zoom.us/meeting/register/ tJEvdu2hqz4qG9FtVcC\_Y40KFi0xoK2uuUxo

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





## Volume 9 Issue 01

#### Ask the MG Expert

Q. How will I know if I'm going into an MG crisis?

A. MOST MG crises do not happen without advance warning. An MG crisis (one in which you experience trouble breathing) may take days or weeks to develop. But, if you know the signs to watch for, you may avoid a serious crisis or lessen its effect :

**BE AWARE** of your body. Are you experiencing unusual weakness? Weakness that lingers even when you rest? Weakness that doesn't respond to Mestinon or Prednisone?

HAVE YOU SUFFERED an emotional upset strong enough to cause weakness?

HAVE YOU EXPERIENCED a recent viral or bacterial infection?

**ARE YOU HAVING** increased problems with chewing or choking?

**ARE YOU EXPERIENCING** burning in your lungs as if you had just run a mile but haven't moved?

**Do you HAVE** trouble getting enough air in? (to determine this, take a deep breath and while expelling it, try and count to 20) If you can't get beyond 10 or 12, call your doctor.

IF YOU ARE EXPERIENCING any of the above, rest more and do less. If you still feel bad or weakness is increasing, call your doctor. If having trouble breathing call 911 or go to ER.

# 2021 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 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.

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

Need a mask? Email 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

Family and friends welcome!



**Exciting News!** We will be having our Annual MGFA Fund-raising walk at the Metroparks Chalet area in Strongsville on September 18, 2021

This may be the first time we all get together, so please plan on attending! We will have a large outdoor picnic

area where we can enjoy lunch afterward. We will also have a raffle with prize baskets and several door prizes. Come for the walk and stay for the FUN!

Stay tuned for more information as the day gets closer!

It's a New Year and maybe time for a new attitude? I thought I'd share with you some wise words from R.C. Boynton, Ph.D., author of *Living Positively with Myasthenia Gravis* ©2003 that have helped me in my MG journey: "Today I will pray and believe for a brighter tomorrow because of the successes I have had today." "I will take every opportunity life affords me to be courteous and kind to those nearest to me, and to others I meet along the way. It will be this attitude which will lift my own spirit and set me free from depressing moods."

"No one has ever gone blind by looking at the bright side of his circumstances."

January has some unique celebrations and special days. Here's a few things to celebrate this month:

National Bath Safety Month S National Blood Donor Month S National Braille Literacy Month

National Hobby Month 🛞 Hot Tea Month 🛞 National Oatmeal Month 🛞 National Soup Month

There are also some special days to celebrate such as: National Cream Puff Day, Cuddle-up Day, National Hangover Day, Bubble Bath Day, Houseplant Appreciation Day, Backwards Day, Learn your name in Morse Code Day, National Rubber Duckie Day, National Nothing Day, National Butterscotch Day, National Handwriting Day, National Hugging Day, National Puzzle Day, and Compliment Day

For more information about how these days got started and to find many more celebration days, go to:

http://www.holidayinsights.com/moreholidays/january.htm



## 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

#### 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:

http://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

You are Braver than you believe

# Stronger than you seem

and

Smarter than you think

--Winnie the Pooh A.A. Milne

UPCOMING 2021 ZOOM MEETINGS: 4 Local ZOOM meetings in January! (see inside for details)

Hope to see you soon on Zoom !



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