

MAY 2022

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MDA NOTES:

While the MDA Clinic at MetroHealth is still in operation for MG patients, there is no longer a physical MDA liaison present at the Clinic. You can reach MDA at the national level by calling 800-572-1717 or online at MDA.org

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

Help our Local Group: If you use the following link to sign up for Rare Patient Voice, our local group will receive \$5 for every person chosen to participate. That money goes towards helping to fund this newsletter. Sign up at : <https://rarepatientvoice.com/MGFANortheast/>

IN-PERSON MEETING!!

We will be meeting at the Parma-Snow Branch of the [Cuyahoga County Public Library](#) on

Sunday May 15, 2022 from 2-4 pm

2121 Snow Rd. Parma OH 44129

Conference Room A/B

NOTE: New day, place, and time!



May's ZOOM Meetings

NOTE: Our regular Thursday afternoon Zoom Meetings will resume in May at 3:00 pm

When: May 5, 2022 03:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

[https://us06web.zoom.us/join/join?zmt=0300PM%20Eastern%20Time%20\(US%20and%20Canada\)&meetingRef=1](https://us06web.zoom.us/join/join?zmt=0300PM%20Eastern%20Time%20(US%20and%20Canada)&meetingRef=1)

When: May 12, 2022 03:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

[https://us06web.zoom.us/join/join?zmt=0300PM%20Eastern%20Time%20\(US%20and%20Canada\)&meetingRef=2](https://us06web.zoom.us/join/join?zmt=0300PM%20Eastern%20Time%20(US%20and%20Canada)&meetingRef=2)

When: May 19, 2022 03:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

[https://us06web.zoom.us/join/join?zmt=0300PM%20Eastern%20Time%20\(US%20and%20Canada\)&meetingRef=3](https://us06web.zoom.us/join/join?zmt=0300PM%20Eastern%20Time%20(US%20and%20Canada)&meetingRef=3)

When: May 26, 2022 03:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

[https://us06web.zoom.us/join/join?zmt=0300PM%20Eastern%20Time%20\(US%20and%20Canada\)&meetingRef=4](https://us06web.zoom.us/join/join?zmt=0300PM%20Eastern%20Time%20(US%20and%20Canada)&meetingRef=4)



Volume 10 Issue 5

Ask the MG Expert

Q. Is it MG or something else?

A. I'm often asked about a variety of symptoms that go along with having MG. But sometimes, these seemingly MG-like symptoms can come from different causes. Here are some common symptoms that may or may not be from MG and how to tell the difference:

Brain Fog—Not being able to think clearly especially when feeling weak is a common MG symptom. However, if you are finding it harder and harder to process normal thoughts, can't remember where you live or where you are when driving, it is time to consult your physician for the cause. MG related brain fog is intermittent meaning that it doesn't last long and does not keep getting worse.

Excess Mucous/Saliva—MG that includes bulbar symptoms (those that include weakness of the jaw, tongue, difficulty swallowing, and difficulty talking) may create problems with excess saliva. Mestinon (pyridostigmine bromide) can also increase saliva production. However, neither should increase mucous or cause excess congestion in your sinuses or lungs. Excess mucous is usually but not always associated with an infection or allergy.

Feeling Off Balance—Recurring MG can throw off your balance, especially when turning a corner too quickly or trying to walk fast. I personally have bounced off many walls trying to make a corner. But the feeling of the room spinning or excess dizziness while sitting still may be from another reason such as an inner ear infection or disturbance, change in blood pressure or change in blood sugar. If these symptoms persist, call your doctor.

Muscle Cramps—Muscle cramps and MG seem to go hand in hand. Sometimes due to excess use, Mestinon, or electrolyte deficit, muscle cramps can be troubling (cont. pg.3)

Next Parents of MG KIDS Meeting—June 2022



When: Saturday, June 11, 2022 02:00 PM Eastern Time (US and Canada) Register in advance for this meeting:

<https://us06web.zoom.us/meeting/register/tZAtf-ggrzkiG9E3rkvxi7HLQCKgwDVt5S54>

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

Next in-person meeting Sunday, May 15, 2022 from 2-4 pm

We will be meeting at the **Parma-Snow Branch of the Cuyahoga County Library located at 2121 Snow Rd., Parma, OH 44134 Meeting Room A/B**

If you are feeling ill with Covid-like symptoms, please do not attend. We have Zoom meetings every Thursday at 3:00 pm ET (see page 1) and also our informal chat nights every Saturday night at 7:30 pm.

Hope to see you at a meeting soon!

Important Things to know about our Support Group Meetings

Our groups are very welcoming and allow for the sharing of helpful hints and tricks for living with MG. However, it should be said that your own doctor is the one who can best manage your care and treatment. Please check any changes in treatments or medications with your physician first.

FREE CHATS CONTINUE SATURDAY ONLY—Informal Zoom get together—no agenda— just a time to visit. Register once for a Saturday Chat and use the same link to sign in through October.

Saturdays Apr 2, 2022—October 29, 2022 07:30 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/meeting/register/tZEkf-uppzspGN2sscHNI1sjg6lbaqOD5ikU>



Adult Patient Zoom Meetings:

We are back to our regular Thursday 3 pm meetings in May. See pg. 1

Our informal chat nights will continue on Saturdays only at 7:30 pm. This is in addition to our structured Zoom meeting. It's a chance for those of you who are homebound to visit with fellow MG'rs in a friendly chat. Registration is still required but you only need to register once for Saturdays. You will be given a link that will be good until the end of October. See above.

Family, friends, and caregivers welcome!

Meeting Notes:

There were 17 people in attendance for our first regular meeting since 2020. It was great to see everyone, and especially to meet some of you in person for the very first time.

We enjoyed Jerry's great coffee and delicious bakery made by Suzanne. As always, the cheese and crackers made an appearance. But food aside, the best part of the meeting was seeing each other after more than 2 years.

We will continue to meet monthly as long as it is safe to do so. You can help us stay safe. Please don't attend any in-person meetings if you are having any COVID or flu-like symptoms. Masks are encouraged especially for those immune-compromised.

Ask the MG Expert (cont.)

If muscle cramping persists over several hours and is debilitating, consult your physician who may want to order some bloodwork to test your electrolyte levels.

Shortness of Breath—When your weakness is severe, you may experience shortness of breath, but if you have a sudden onset of breathing trouble, without feeling weak, call 911. Feeling short of breath can be caused by other illnesses besides MG including heart related problems, infections, and asthma. If you feel that your shortness of breath is severe or if it is long lasting, call your doctor or 911.

Gastrointestinal Problems—If you take Mestinon (pyridostigmine bromide) or Prednisone, you may experience some gastrointestinal problems such as diarrhea, upset stomach, or bloating. Prednisone may also cause GERD syndrome. However, these symptoms may also be caused by other diseases. Consult your doctor if they are problematic. They may recommend a trial stoppage of your medication to see if that helps.

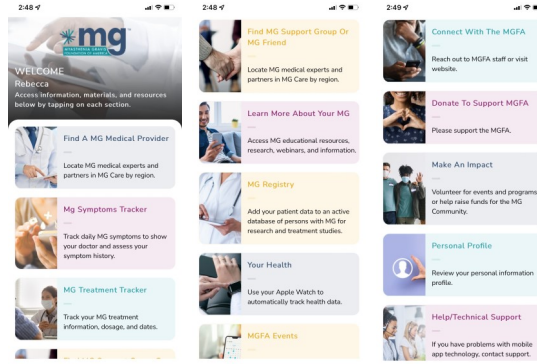
MG Virtual Closet!

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 length of time that you'll need the item. Don't forget to include your name and contact info. Thanks! We can all use a little help now and then.



Brand New MGFA MyApp

The new MGFA MG app for Android and IOS is here. From the app you can find brochures, webinars, and blogs as well as find a neurologist specializing in MG. You can also connect to a support group, donate to the MGFA or contact a staff member.

You can also use it to keep track of your daily symptoms and to inform your physician about them.

Check out the new MGFA app for your smart phone.



Save the Date!

June is Myasthenia Gravis Awareness Month
To help celebrate June MG Awareness Month, we will be having our annual ice cream social a little early.

Saturday June 25, 2022

1– 4 pm

Pipefitters Local 120 Hall

6305 Halle Dr, Cleveland, OH 44125

Watch this space for more information next month.



LOCAL MGFA GROUP WEBSITE

Visit us at www.clevelandmggroup.org

Have questions or comments? Send in your MG related questions to 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:

<https://www.needymeds.org/>

[Good Rx.com](http://www.goodrx.com)

<http://www.themedicineprogram.com/>

<http://www.togetherrxaccess.com/p/prescription-savings>

<https://mat.org/> (Medication Assistance Tool)

<http://www.rxhope.com/Patient/AssistanceRequest.aspx>

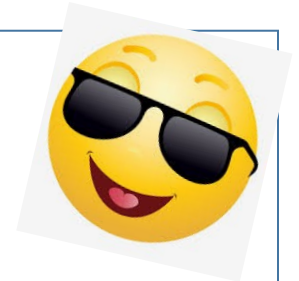
<http://www.myastheniagravis.org/we-can-help/what-we-do/>

More info at: <https://myasthenia.org/Community-Resources/Resources-External-Assistance-Programs>

Funny FaceBook Memo: (could also apply to having MG Brain Fog)

Things I'm Super Good At:

1. Forgetting someone's name 10 seconds after they tell me.
2. Buying Produce then throwing it away 2 weeks later.
3. Digging through the trash for the food box because I already forgot the directions.
4. Making plans and then immediately regretting making plans.
5. Leaving laundry in the dryer until it wrinkles. Then turning the dryer back on to de-wrinkle, then forgetting it again.



UPCOMING May 2022 MEETINGS:

Adult MG Patients, Family, Friends, Caregivers—

In Person—Sunday, May 15th 2-4 pm 2121 Snow Rd., Parma, OH meeting room A/B (see page 1)

Zoom Meetings—Thursdays 3:00 pm via Zoom (see page 1)

OPEN CHAT every Saturday night at 7:30 pm via Zoom (see page 2)

Thank you to our sponsors:

