



MARCH 2022

Meeting Updates →

Meeting notes pg. 2

Rare Patient Day pg. 2

Beating Seasonal Depression
pg. 3

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/>



March's ZOOM Meetings

Thursday meetings at 3:00 pm:

When: Mar 3, 2022 03:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/j/91234567890>

When: Mar 10, 2022 03:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/j/12345678901>

When: Mar 17, 2022 03:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/j/23456789012>

When: Mar 31, 2022 03:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/j/34567890123>

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

NOTE: No meeting March 24, 2022

FREE CHATS CONTINUE—Informal Zoom get togethers.—no agenda— just a time to visit. Register once for either Tuesday or Saturday and use the same link to sign in through March.

Tuesdays through March 29 2022 07:30 PM ET (US)

<https://us06web.zoom.us/j/45678901234>

Saturdays through March 26 2022 07:30 PM ET (US)

<https://us06web.zoom.us/j/56789012345>

NOTE: New codes will appear next month for April and May



**DAYLIGHT SAVINGS TIME
STARTS MARCH 13TH**

Volume 10 Issue 3

Ask the MG Expert

Q. What kind of devices are available to help those of us with weak hands and arms do our daily tasks?

A. If you are having difficulty performing your regular daily tasks, consider adding some gadgets to your life to make things a little easier saving you some energy:

In the Kitchen—For opening cans, bottles, and jars, try electric can openers or under-the-cupboard mounted jar and bottle openers that come as both manual & electric.

For getting around your kitchen, look for counter height wheeled lab stools that let you sit while preparing food or washing dishes.

For help in reaching items, there are many after-market sliding drawers that you can add to your cupboards to make them more accessible. Also, think about leaving the items you use most within easy reach and use open shelving for everyday dishes and glasses.

Hygiene—There are several brands of electric toothbrushes on the market that can help you save energy while brushing.

Electric razors are also very useful in energy conservation.

A Hand-held shower and having a shower chair in the bath or shower can conserve your energy for more important things during the day.

House Cleaning—Even if you don't need a walker to steady yourself in the house, using a walker with a basket under the seat is very beneficial when picking up. If you don't want to use a walker, a small cart on wheels will also help. Place items to go to different rooms on the cart or in the basket. Then when you are done picking up, simply travel to other rooms to deliver the items. Using this method instead of traveling to other rooms with each item will save you countless energy .

Continued on page 3

Parents of MG KIDS Meetings – March 2022

2nd Sundays of the month –

Parents of MG KIDS

When: Mar 13, 2022 12:00 PM Eastern Daylight Savings Time (US and Canada)

<https://us06web.zoom.us/meeting/register/tZ0vcuqtrjlqGdUHtSfxVxRS7xvBWTv9Y5js>

When: Mar 13, 2022 09:00 PM Eastern Daylight Savings Time (US and Canada)

<https://us06web.zoom.us/meeting/register/tZAqdu2rpi0iH9y2WiR5uuEmVnqFjXuELrbE>

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

NOTE: The Parents of MG KIDS Meetings are open to any family, friends, or caregivers of a pediatric MG patient. However, if you are an adult patient who has had MG since childhood and can provide some helpful insight and encouragement to the



SPRING

NOTE: ET time on March 13th is one hour earlier due to daylight savings time. Please adjust if you don't have daylight savings time in your part of the world.

CAN IT BE TRUE? Could we possibly meet in person again soon? The CDC has relaxed certain restrictions due to the recent drop in COVID-19 Omicron variant positive cases. As of 2/23/2022, in our area:

Cuyahoga County 74.8 cases / 100,000

Lorain County 79.4 cases / 100,000

Lake County 84.3 cases / 100,000

Medina County 104 cases / 100,000

The Cuyahoga County Public Library System is again accepting reservations for their meeting rooms, but no food or drink is allowed to be served. OR we could wait until warmer weather and then book an outdoor pavilion at a local park. Let me hear from you! Would you be willing to attend an in-person meeting? If so, indoors or only outdoors?

Please email me with your answer clevelandmggroup@gmail.com

Important Things to know about our Zoom Support Group

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 medications with your physician first.



Adult Patient Zoom Meetings:

We have been averaging about 9-20 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 3:00 pm ET (pg. 1)

NEW for March—twice weekly open informal chat nights at 7:30 pm. This is in addition to our Thursday structured meetings. 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 Tuesdays and once for Saturdays. You will be given a link that will be good until the end of March. see pg. 1

Family, friends, and caregivers welcome!



<https://www.rare diseaseday.org/>

February 28th is Rare Disease Day. This is a day set aside to bring awareness to more than 300 rare diseases including myasthenia gravis. Find out how you can help bring awareness to your community, school, or business by clicking on the link above. There you will find Rare Disease Day events and downloadable files such as banners to place on your FaceBook page to help you celebrate the day.

Ask the MG Expert continued

Q. How do I get these devices?

A. If you have access to a computer, you can do a search on Google, Bing, Edge, Amazon, or at a retail store's website.

You may be able to get some help paying for some of these items as durable medical equipment through your medical insurance.

Ask your doctor for an occupational therapist referral. Tell the therapist what you are having trouble doing in performing your daily tasks. Occupational therapists have access to medical catalogues containing hundreds of items that will help you conserve energy.



MG Virtual Closet!



Do you need any durable medical equipment?

Do you have some to share?

Email me at clevelandmgroup@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.

Got those winter Blues?

A lack of sun in the wintertime, especially for those of us living in the northern U.S., can lead to low vitamin D and seasonal depression. Complicate that with the isolation caused by Covid, our own MG symptoms, and the current state of the world and it's no wonder we are feeling somewhat blue. While severe clinical depression may need medication and therapy to alleviate its symptoms, there are several things you can do to take hold of your seasonal or situational depression and help yourself feel better:

Get out of your normal pattern. If you eat the same thing every day, drive to work the same way, and do the same things day in and day out, shake it up a little. Take a new path to work or to the store. Try a food you've never tried before. Watch a different show or listen to different music. Learn a new skill or read a new book. Our library system is one of the best in the country. They have plenty of online and in person classes and lectures. They even have maker spaces where you can go and learn a new craft.

Light it up. Purchase a full spectrum light bulb and spend some time under it each day to increase your vitamin D absorption. While you're at it, play some island tunes or other music to feel like you're on a beach somewhere. *Three Little Birds* by Bob Marley is a good choice.

Reach out. Contact an old friend or family member. Ask them how they are doing. Try and make the entire conversation about them. This way it may help to stop dwelling on your problems by concentrating on someone else and giving your brain a break.

Retrain your brain. Be aware of your thoughts. Every time you catch yourself thinking about how bad it is (whatever "it" is for you), tell yourself to STOP. And mindfully think about something or someone else. Look at funny videos, play happy music, do whatever you can to divert your thoughts from your downward spiral. I'm not advocating that you ignore problems that you can solve, but when you find yourself dwelling on things over which you have no control, these methods can help you retrain your brain.

Be kind to yourself. Conquering depression takes time and practice, but by learning some new skills to help you cope, you'll get there.



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>



Do you read the newsletter? Count the shamrocks to win a special prize. One winner from those that get the newsletter electronically and one winner from the mailed newsletter recipients. Email your answer to clevelandmggroup@gmail.com

Happy St. Patrick's Day to all our Irish friends!



UPCOMING March 2022 MEETINGS:

Adult MG Patients, Family, Friends, Caregivers—March 3rd, 10th, 17th, 31st

at 3:00 pm via Zoom (see page 1) NOTE: No meeting March 24th

OPEN CHAT every Tuesday and Saturday nights at 7:30 pm (see page 1)

Parents of MG KIDS Zoom Meetings March 13th at 12:00 pm and 9:00 pm ET (see page 2)

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