

APRIL 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/>

EXCITING NEWS! IN-PERSON MEETING!!

We will be meeting at the Parma-Powers Branch of the Cuyahoga County Public Library on **Sunday April 10, 2022 from 2-4 pm**
6996 Powers Blvd., Parma OH 44129
Meeting Room C



April's ZOOM Meeting

NOTE: Due to our in-person regular meeting, there will only be one Zoom meeting in April (see below)

When: Wednesday, Apr 6, 2022 07:00 PM Eastern Time (US and Canada) Register in advance for this meeting:

<https://us06web.zoom.us/meeting/register/tZAtc--oqiMvG9wZen6TEAujUGoNzoHvwDUT>

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--uppzspGN2sscHNi1sjg6lbqlOD5ikU>



Volume 10 Issue 4

Ask the MG Expert

Q. How can I avoid feeling down when I have a bad day? I hate having to change plans and interrupt my normal life when my body won't cooperate.

A. I agree it's hard to predict those bad MG days and it's disheartening when we're unable to attend fun functions; but we can minimize those bad effects by some planning ahead.

Let People Know—Don't keep your diagnosis to yourself. Letting those closest to you, your friends, family, and coworkers, know about your illness can help prepare them for your last minute absences. Give them literature to read that explains what MG is and how it affects you.

Divide It Up—Take an hour or so to examine your normal activities. Divide them into things you can do while feeling your best, things you can do on a regular energy day and those things that you can do to occupy yourself on bad days.

Ask For Help—If you have scheduled chores or work activities that can be done by someone else who is willing to help, write those things down along with how you would normally do them. Then when you are feeling too weak to communicate, your helper can know what to do.

Let It Go—Don't have help? Don't stress. The world is not going to end if you don't do the dishes, make the bed, or get out of your pjs. Thanks to Covid, we now have multiple services that can deliver food and other goods so you can save your energy for just getting stronger.

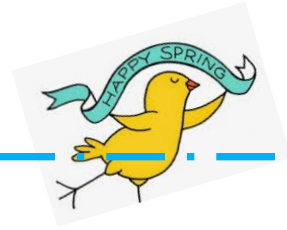
Plan For It—If ordering food is not an option, plan ahead for bad days. Make a little extra and freeze meals for those days when cooking is impossible. You could also prepare easy crock pot ingredients ahead of time and freeze in packets that can just go in the crock pot on bad days.

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Parents of MG KIDS Meetings – April – May 2022

We will be on hiatus until June 2022. Check back in May for more information.

In the meantime, any questions can be asked through clevelandmggroup@gmail.com



We're back!

And excited to meet you all in person on **Sunday April 10, 2022 from 2-4 pm.**

We will be meeting at the **6996 Powers Blvd location of the Cuyahoga County Library in meeting room C.**

If you are feeling ill with Covid-like symptoms, please do not attend. We will still be continuing our Zoom meetings at least one per month for our regular meetings and also continuing our informal chat nights every Saturday night at 7:30 pm.

As time goes on, we will assess future meeting locations and Zoom meeting dates and times that are suitable for most.

We hope to eventually return to our eastside and westside meetings as well as Lorain County on a regular basis.

This month we chose a central location that is easily accessible by most. **Hope to see you there!**

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 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 only have 1 Zoom meeting this month Wednesday, April 6th at 7:00 pm ET

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 pg. 1

Family, friends, and caregivers welcome!



Do you read the newsletter? Sometimes it pays to read it! The winner of the “Count the Shamrocks Contest” from the March newsletter was Chuck Repede. Chuck has won a \$10 gift card for Panera.



Ask the MG Expert (cont.)

Be Good To Yourself—It’s hard to let go of expectations you have for yourself. Please tell yourself that it’s ok. You don’t have to live up to anyone’s expectations including your own. Use your “down days” to catch up on watching funny videos, or listening to your favorite songs.

This Too Will Pass—Know that your bad days won’t last forever. If you find them happening more frequently, have trouble breathing or swallowing, contact your treating physician. It’s normal to have bad MG days. It’s not normal for those days to extend into weeks or months without contacting your doctor.

Call 911—If you are having sudden and severe shortness of breath or can’t swallow water.

Education—Here is a link for brochures about several MG topics and treatments. Download and share with your family and peer group:

<https://myasthenia.org/MG-Education/Learn-More-About-MG-Treatments/MG-Brochures>

MG CLINICAL TRIALS

There are currently 158 myasthenia gravis trials ongoing around the world and listed at www.clinicaltrials.gov. This is an astounding amount of studies in various stages of completion for our rare disease. I’ve listed some of the actively recruiting trials below:

Active MG Study Trials Recruiting—

Myasthenia Gravis Inebilizumab Trial (MINT) Phase 3 Trial

<https://www.clinicaltrials.gov/ct2/show/NCT04524273?cond=myasthenia+gravis&draw=2&rank=1>

Efficacy and Safety of Tolebrutinib (SAR442168) Tablets in Adult Participants With Generalized Myasthenia Gravis (URSA)

<https://www.clinicaltrials.gov/ct2/show/NCT05132569?cond=myasthenia+gravis&draw=4&rank=29>

A Study of Nipocalimab Administered to Adults With Generalized Myasthenia Gravis

<https://www.clinicaltrials.gov/ct2/show/NCT04951622?cond=myasthenia+gravis&draw=3&rank=30>

The EXPLORE MG Registry for Myasthenia Gravis

<https://www.clinicaltrials.gov/ct2/show/NCT03792659?cond=myasthenia+gravis&draw=3&rank=31>

A Study of TAK-079 in People With Generalized Myasthenia Gravis

<https://www.clinicaltrials.gov/ct2/show/NCT04159805?cond=myasthenia+gravis&draw=3&rank=35>



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.

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

You don't have to be tidier, thinner, funnier, or smarter. You don't have to be more assertive, more ambitious, more social, or more productive. You can keep growing, but you don't have to be more of anything in order to be enough. You already are.

____ Erica Layne

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>



UPCOMING April 2022 MEETINGS:

Adult MG Patients, Family, Friends, Caregivers—

In Person Sunday, April 10th 2-4 pm 6996 Powers Blvd, Parma, OH meeting room C (see page 1)

Zoom Meeting—Wednesday, April 6th at 7:00 pm via Zoom (see page 1)

OPEN CHAT every Saturday night at 7:30 pm via Zoom (see page 1)

Thank you to our sponsors:

