

Northeast Ohio Area Support Groups

APRIL 2021

Meeting Updates

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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: <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.



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

When: Apr 1, 2021 11:00 AM Eastern Time (US and Canada) https://zoom.us/meeting/register/tJYkc-Chrj0jEtAO1h5YOdtRpbf9270YhZaM

When: Apr 8, 2021 01:00 PM Eastern Time (US and Canada)

https://zoom.us/meeting/register/tJMrdOyrrTkvHdUIN389nG0lgSYIXgMu7oL

When: Apr 15, 2021 03:00 PM Eastern Time (US and Canada)

https://zoom.us/meeting/register/tJwtd-2pqTsuGNYtVCYUJptYiA7NID3NNyfH

When: Apr 22, 2021 07:00 PM Eastern Time (US and Canada)

https://zoom.us/meeting/register/ tJwodemgqzsiHdNE369WSTrWBtluyfMkXDMJ

NOTE: THERE WILL NOT BE A MEETING ON APRIL 29TH (5TH THURS.)









Volume 9 Issue 04

Ask the MG Expert

Q. My insurance has changed and now my Mestinon is very pricey. Have any suggestions?

A. While prescription prices

vary greatly depending on your pharmacy and Insurance plan, here is what we found for generic Mestinon (pyridostigmine bromide) for 120 pills using GoodRX:

- Giant Eagle Pharmacy \$21.95
- CVS \$41.37
- Costco \$20.95
- Target Pharmacy \$41.37
- Discount Drug Mart \$20.95
- Kroger Pharmacy \$22.02
- Meijer Pharmacy \$20.95
- Walmart Pharmacy \$35.23
- Walgreens \$38.73
- Rite Aid \$43.67

As you can see by driving perhaps a few extra miles, you can save more than \$20 each month.

The Good RX coupon price saved me \$27 off of what using my insurance would have charged me. It is well worth doing some investigating at <u>goodrx.com</u> before you pick up your monthly prescriptions.

For more help with prescription costs, see the list of organizations and non-profit companies willing to help on page 4.

2021 MG Meetings and Events

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Westside Meetings: TBD

Lorain County Meetings: TBD



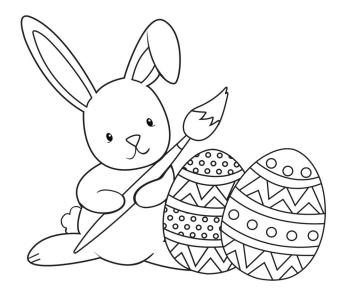
We have gone to a "share and care" format. We take turns giving updates, asking questions of our MG expert, Dr. Robert Ruff, and in general just connecting with others like us experiencing the same problems and sharing tips and solutions. I would highly recommend that if you have the time, give Zoom a try. It is a great way to connect and learn more about MG and each other.

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.

We are hoping to be able to meet someday soon again in person. We are currently looking into outdoor options for meetings. As more and more of us get vaccinated, it will become easier to get together. My questions to you are:

- Would you be comfortable meeting in an outdoor setting? 1.
- 2. Would you be comfortable meeting in a restaurant?
- Do you have any venue suggestions? 3.

Please email me with your answers at: clevelandmggroup@gmail.com



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

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.

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 the following times:

1st—11:00 am	
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3rd - 3:00 pm

2nd-1:00 pm

4th - 7:00 pm

Family and friends welcome!

NOTE: NO MEETING APRIL 28th (5th Thursday)

MGFA National Conference Agenda Features Leading MG Experts

We invite you to join the annual MGFA National Conference online this year, Sunday, April 11 through Tuesday, April 13, as we spotlight amazing examples of Momentum Against MG. <u>You can REGISTER for our conference HERE</u>.

Dates: Sunday, April 11 through Tuesday, April 13, 2021

Time: Exhibits open at 11:00 a.m. Eastern – Sessions begin at 12:00 p.m. Eastern

Review our packed Agenda of Prestigious Speakers HERE:

Dr. James "Chip" Howard to present information about COVID-19's impact on MG patients,

Dr. Charlene Hafer Macko, Michelle Vogel and Anna Reid will speak about navigating insurance and disability coverage,

Dr. Jeff Guptill highlights the challenges of Seronegative MG,

Dr. Amanda Guidon and Dr. Mike Hehir will highlight how to navigate the ER.

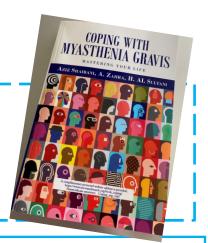
We'll have so many more volunteer and medical professional presentations throughout the online conference. This 3-day, online event is open to anyone worldwide and is the largest and most complete online gathering of the MG Community anywhere. Let's come together and showcase progress and momentum in our fight against myasthenia.

REGISTER FOR NATIONAL CONFERENCE

Share our 2021 Hashtags #MGFANationalConference 2021 and #MomentumAgainstMG with your social friends and fans, and ask them to share this invite with their friends too.

We hope to see you at our annual National Conference. Please register soon.

Recommended reading for people with MG and caregivers alike. This new book contains a brief explanation of MG as well as 50 different patient stories. Each story is accompanied by an MG Expert's opinion about that story. Very informative reading. Showcases just how different AND how alike all of us with MG are.



Available now on Amazon.com



Calling all Volunteers! We need you for our Annual MGFA Fund-raising Awareness-raising walk at the Metroparks Chalet area in Strongsville on September 18, 2021

All National MGFA walks will take place this year between September and December. Ours is one of the first scheduled walks.

ALL INTERESTED IN HELPING—join us on April 19th on Zoom to help plan this great fundraiser [text or email me for the zoom details.]

Please consider utilizing your special talents to promote MG awareness and support the MGFA.

Here is where we need help:

 Inspiring and recruiting walkers 'Planning food 'Contacting Media 'Setting up 'Contacting local businesses for donations 'Donation basket Assembly 'Registration table

Contact Rebecca at 216-218-0477 and leave a message

or email <u>clevelandmggroup@gmail.com</u>



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 COVID19assis-**

Your mind is a garden. Your thoughts are the seeds. You can grow flowers or you can grow weeds.

www.mycupofcocoa.com



Need help paying for your meds? Check out the following sites:

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



UPCOMING 2021 ZOOM MEETINGS: 4 Local ZOOM meetings in April & MGFA National Conference (see inside for details)

Hope to see *you* soon on Zoom !



Thank you to our sponsors:

