

MAY 2021

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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/>

See page 3 for more information



May's ZOOM Meetings

**Thursday meetings
at the following times:**

When: May 6, 2021 11:00 AM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJEkfuCrpj0tHdAnFmuK4rDQ6Y8DKSOUBuLA>

When: May 13, 2021 01:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJUkcuqqqD0sGtJnRRQnUUHwOUQ4bB2P0eJg>

When: May 20, 2021 03:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJwpcuisrDwrHdH8L13VsrZn9Id-3s77RomV>

When: May 27, 2021 07:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJMkdOmvrijpE9VL3fCmuGURUbcS15iJ9KJE>



June Awareness Month Art Auction—

Chuck Repede has created the beautiful quilt on the right to enter into this year's MGFA Art Auction.

Stay tuned next month to find out how this beauty may be yours!!



Volume 9 Issue 05

Ask the MG Expert

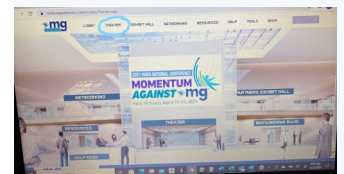
Q. I missed the MGFA National Conference. If there any way to view the presentations?

A. While the presentations are not yet on youtube.com, you can still view them by clicking the this link:

[REGISTER FOR NATIONAL CONFERENCE.](#)

Even though the conference is over, the link is still active. You will be asked for your name, email address, phone, and city and country. Once registered, you will be able to view the conference home page.

Click on the Theater Tab as shown below:



Next, click on any date and you will see a list of available presentations.

Click on any presentation to view it on your computer.

Topics range from Navigating Insurance Denials to Thymectomy to Sero-negative MG and beyond.

If you receive this newsletter in the printed version, the url to register to view the presentations is: <https://onlinexperiences.com/scripts/Server.nxp?LASCmd=AI:4;F:QS!10100&ShowUUID=3DB784CC-A960-45F1-A994-AEDAD-10562A1&Referrer=https%3A%2F%2Fmyasthenia.org%2F>

2021 MG Meetings and Events

Westside Meetings: TBD

Lorain County Meetings: TBD



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.

ARE YOU VACCINATED?

WANT TO START MEETING IN PERSON?

If you are fully vaccinated and would like to start meeting in small groups, please email me at the link below or call me at 216-218-0477 and please leave a message (I don't answer to numbers that I don't know or recognize, but I will call you back if you leave a message)

I have been checking restaurants both east and west that are willing to let us meet in small numbers. Let me know if this is something you would like to do.

Please email me with your answers at: clevelandmg-group@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's become very sick with this virus.

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

3rd —3:00 pm

2nd—1:00 pm

4th —7:00 pm

Family and friends welcome!

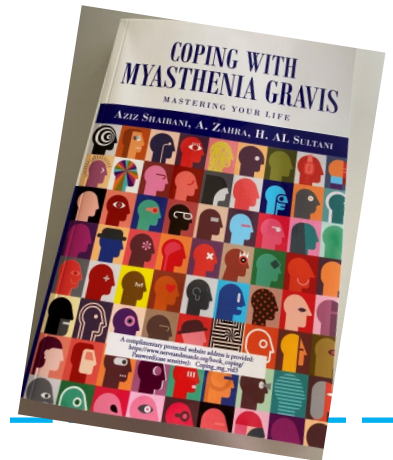
NOTE: NO MEETING APRIL 28th (5th Thursday)

NEED SOME PASSIVE INCOME? WANT TO HELP OUT OUR GROUP?

Now you can do both things at once. Rare Patient Voice connects you with researchers who are developing products and services which can help you and others with your condition. These researchers need patient input so that they develop products and services that have a meaningful impact on patients' lives.

Here is a link to Rare Patient Voice that allows you to register for participation in surveys and focus groups. All focus groups take place via computer or phone. Currently they are paying \$100 per hour. So if you answer a 15 minute survey, you've just made \$25 or if you participate in an hour long group chat, you get \$100. Nice passive income. It is not just for MG. List all of your conditions and you may find you qualify for several studies. Please pass this link on to your friends and family members as well so they can participate. They do not share any identifying or personal information. These focus groups and surveys do not compete with the MGFA Patient Registry. <https://rarepatientvoice.com/MGFANortheast/>

Want to win this book? Find out how next month during June MG Awareness Month. Check back in next month!



COMING JUNE 13, 2021 Noon to 3:00 pm

Second Annual MGFA Fund Raiser at Farm House Yoga:

Facebook Event:

<https://www.facebook.com/events/912426729535389/>

Classy [Virtual] Donation Site:

<https://give.classy.org/FarmhouseYoga-MGFA>

Farmhouse Yoga website / info:

<https://farmhouseyogallc.com/mgfa>

THANKS KATIE!!



Ohio Walk Page Now Active!

Go to http://donate.myasthenia.org/site/TR?fr_id=1092&pg=entry

To sign up as a volunteer, individual walker, or join or start a team.

Every MG patient that signs up will get a free T-shirt!

Yes, FREE really! Only catch is that you need to sign up by AUGUST 18th to qualify to get your shirt.

This year you can earn a whole MG walk outfit by getting donations for your team.

Go to the link for further info.

There will be NO T-shirts handed out on walk day.

All clothing items will be mailed to your home ahead of time.



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

LOCAL MGFA GROUP WEBSITE

Visit us at www.clevelandmggroup.org

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:

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

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

<http://www.togetherrxaces.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>

All that I am or ever hope to be,
I owe to my angel mother.”

— Abraham Lincoln

HAPPY MOTHER'S DAY!

UPCOMING 2021 ZOOM MEETINGS:

4 Local ZOOM meetings in MAY

Hope to see you soon on Zoom !

Thank you to our sponsors:

