

Meeting Updates →

- Meeting information/notes pg. 2
- Virtual Closet pg. 2
- MG WALK 2021 pg. 3
- Regional Conference pg. 3
- Webinar Series—Sleep pg. 3
- Assistance Programs pg. 4

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

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.



March's ZOOM Meetings

**Thursday meetings
at the following times:**

When: **March 4, 2021 11:00 AM** Eastern Time (US and Canada)
Register in advance for this meeting:
<https://zoom.us/meeting/register/tJ0qc-6prTwpEta6koEGsSsTAMa7xKtYRpm6>

When: **March 11, 2021 01:00 PM** Eastern Time (US and Canada)
Register in advance for this meeting:
<https://zoom.us/meeting/register/tJMldeyrpzkrEtY01D7cdf60bIRFvAx6lhum>

When: **March 18, 2021 03:00 PM** Eastern Time (US and Canada)
Register in advance for this meeting:
<https://zoom.us/meeting/register/tJAucOuhrT8tHdBI9InOaVbBW1XD8P4jiRos>

When: **March 25, 2021 07:00 PM** Eastern Time (US and Canada)
Register in advance for this meeting:
<https://zoom.us/meeting/register/tJ0tdu6oqz4pG9TiZ6AyhcjPhBu7hBvdFp2j>

Ask the MG Expert

Q. I'm newly diagnosed. It is overwhelming. What do I need to know about my MG?

A. HERE IS DR. YUEBING LI'S LIST OF THINGS YOU SHOULD KNOW:

- The basis that led to your MG diagnosis (symptoms, test results, response to treatment)
- How old were you when the symptoms started and how long have you had symptoms?
- What are the specific symptoms of your MG?
- Is your MG ocular or generalized? What classification is your MG?
- Which antibody is involved in your MG? (AChR, MuSK, LPR4 or other? Or are you seronegative?)
- What is your thymus gland status? (hyperplasia, tumor, normal)
- What has been your treatment response? (non-refractory versus refractory)
- Which medications have you tried for MG and what was the outcome?
- Which medications have you felt that have worsened your MG?
- What other factors make your MG worse?
- Do you have any other major coexisting health condition?

Download Dr. Li's full presentation at: www.clevelandmggroup.org/presentations



2021 MG Meetings and Events

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.

MEETING NOTES:

The February 18, 2021 Zoom Meeting with Dr. Yuebing Li as guest speaker was well attended. Dr. Li gave an informative talk about MG and Covid-19. In general, Dr. Li recommends getting the vaccine for most MG patients. If you have special circumstances, ask your physician. Getting the Covid-19 virus has more likelihood to cause ill effects for MG patients than does the vaccine which has been proven to be safe and effective. Dr. Li also highlighted the latest treatments currently under study for MG. He ended his talk with a question and answer period. You can find his talk on our website at: www.clevelandmggroup.org/covid-19



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!

**MGFA Southwest Virtual Regional Conference –
Register to Attend**

We are proud and excited to kick off the 2021 VIRTUAL Southwest Regional Conference! This is a one-day series of informative online sessions featuring a host of MG experts, medical professionals and volunteers who will help you learn new ways to manage your myasthenia. Hear from several medical professionals who have not spoken to the MG Community in the past.

Date: Saturday, March 6, 2021

Time: 10:00 AM to 2:00 PM Pacific Time (1:00 PM to 5:00 PM Eastern

[REGISTER FOR THE SOUTHWEST CONFERENCE](#)

Here are two educational opportunities for you this month.

A Regional Conference

A Wellness Series on Sleep

MGFA Wellness Series Webinar – Sleep and MG

Learn helpful tips and methods of improving your sleep patterns with myasthenia. This webinar is part of the MGFA Wellness Series.

Date: Thursday, March 4, 2021

Time: 3:00 p.m. Eastern

Presenter: Dr. Urvi Desai

[REGISTER FOR THE WEBINAR](#)



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 March 8th at 4:30–5:30 pm 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 clevelandmggroup@gmail.com

Feeling a little weaker and looking for ways to conserve your energy in the kitchen? Try these helpful hints:

- Instead of standing to prepare vegetables, sit at the table or use a stool.
- Try using an electric can opener, crock pot, or insta-pot. Double the recipe and freeze left-overs for use on bad days.
- If your microwave is above your counter, use light-weight dishes that won't tire your muscles.
- Try pre-chopping for your favorite dishes when you feel your best, then place the chopped food into baggies in the freezer so they are ready when you are to add to a casserole, soup, or stir-fry.
- Chop herbs ahead of time too and place in olive oil in ice cube trays and freeze.
- Try rearranging your cupboards so that everyday items like dishes and glasses are easy to reach.



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 COVID19assis-

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>



shutterstock.com · 1890817092

Be good to yourself—

You're the only self you have



May you always have—

Walls for the winds, A roof for the rain, Tea beside the fire

Laughter to cheer you, Those you love near you, And all your heart's desire

An Olde Irish Blessing

UPCOMING 2021 ZOOM MEETINGS:

4 Local ZOOM meetings in March! (see inside for details)

Hope to see *you* soon on Zoom !

Thank you to our sponsors:

