

## JUNE 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](http://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/>



## Volume 9 Issue 06

### June's ZOOM Meetings Thursday meetings at the following times:

When: Jun 3, 2021 11:00 AM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJlqcOiprj0jEtQaYhW76evBxQQdTBHl4AjG>

When: Jun 10, 2021 01:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJ0sdOyurDktGdcWdTUWjxl1pbf5y3Bhc5Yr>

When: Jun 17, 2021 03:00 PM Eastern Time (US and Canada)

[https://zoom.us/meeting/register/tJwtdOygpjwsHtISSMc0-NqZPTS2HUx\\_9\\_yR](https://zoom.us/meeting/register/tJwtdOygpjwsHtISSMc0-NqZPTS2HUx_9_yR)

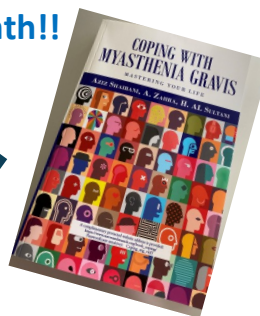
When: Jun 24, 2021 07:00 PM Eastern Time (US and Canada)

[https://zoom.us/meeting/register/tJUtce6vpzspGtxPZNNqCf1G-HZ\\_O2VpgjF](https://zoom.us/meeting/register/tJUtce6vpzspGtxPZNNqCf1G-HZ_O2VpgjF)

## June is MG Awareness Month!!

Do you read the newsletter? Want to win a prize for doing so?

Be the first person to find the two matching snowflakes in this newsletter to win *Coping with Myasthenia Gravis*



There will be two winners—one from our online newsletter readers and one from the printed newsletter readers. If you get the online version, email me with your answer at [clevelandmg-group@gmail.com](mailto:clevelandmg-group@gmail.com) if you receive the printed copy, call me and leave a message. Winners will be contacted by phone and announced in next month's newsletter.



### Ask the MG Expert

**Q.** I feel weaker and drained in the summer heat. Any suggestions?

**A.** Glad you asked! Here's my annual "How to retain strength during the hot summer days" suggestions:

**Keep it Cool**—If you work outdoors or must be outdoors for a prolonged period, you might want to invest in a good cooling vest. There are two kinds available, vests that cool by evaporation (these must be wet first) and those that contain pockets for ice gel packs that keep you cool for longer. Find them both by Googling "cooling vests"

**Hydrate**—Drinking enough water in the hot days of summer is critical to maintaining your strength. Keep a bottle of water handy with you whenever you leave the house.

**Stay indoors**—On days when it is both hot and humid or when the weatherman warns you to stay inside, do so. If you don't have air conditioning and are able, open your windows overnight to let in the cooler breeze, then close the windows in the morning to keep the cool air in. Using a fan to circulate the air helps too.

**Cooling towels**—Another way to keep cool is to use a cooling towel. You can buy the special cooling towels or make your own using a hand towel. Place it in the fridge overnight in cold water. When needed, apply to pulse points (back of neck, wrists, temples, or back of knees) to stay cool.

**NOTE:** If you stop perspiring, become disoriented, or feel faint, ill, or dizzy after exposure to high heat, call 911.

# 2021 MG Meetings and Events



Westside Meetings: See Big News below

Lorain County Meetings: See Big News below



We will continue to have our weekly Zoom meetings even when meeting in person.

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.

Eastside Meetings: See Big News below

## Update about Covid-19

The latest CDC guidelines for people who are immune-suppressed say that even after being fully vaccinated, you should still 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 Careful and Stay Safe

## BIG NEWS!

On June 26<sup>th</sup> we will be meeting in person outdoors at the picnic area behind the Chalet in the Metro-parks located at 16200 Valley Pkwy, Strongsville 44136 from 11:00 am—1:00 pm

Please bring your own food and drink for your lunch.

Family and friends welcome

Cupcakes will be provided to celebrate MG June Awareness Month and 39 years for our group

There is enough space in the outdoor pavilion behind the Chalet to be safely distanced.

Rain or shine—(the pavilion is covered)

Please R.S.V.P. 216-218-0477 and leave a message

## MG Virtual Closet!

Do you need any durable medical equipment?

Do you have some to share?

Email me at [clevelandmgroup@gmail.com](mailto: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.

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

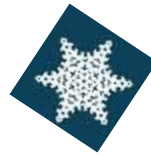
4th —7:00 pm

Family and friends welcome!



June is Myasthenia Gravis Awareness Month





## MG June Awareness Events—Registration Open Now!

**ONLINE YOGA SEMINAR FOR MG:** Join Katie Oradini on **Tuesday, June 8<sup>th</sup> at 6:00 p.m. Eastern** for an online, low-impact Yoga Class that can help all our friends in the MG Community. Katie honors her Mom who has MG, and her class starts with seated yoga and moves to some slightly advanced and relaxing movements. MG patients will learn a lot to help with their physical and mental wellness. [Registration is now open.](#)

**PAINT N' SIP:** Join several artists from the MG Community including Erin Bernau on **Tuesday, June 22 at 7:00 p.m. Eastern** for a fun, online, Paint n' Sip event, so you can learn some best practices and techniques for acrylic and watercolor painting. By the end of the session, you'll have a full acrylic painting that you can frame. [Registration is now open.](#)

**First-ever MGFA Caregiver Support Group:** We are pleased to announce the formation of MGFA's first Caregiver's Support Group. The very first meeting will be **on Saturday, June 12 at 1:00 p.m. Eastern.** MGFA will introduce our new Support Group Leader Toni Gitley who is a caregiver consultant and MG Patient. Join the zoom meeting on the appropriate date and time. <https://zoom.us/join/zoom/register/tJlvde2rqTIsEtYqY8iXRpWPrjfCVBTDhyZo>

**MGFA Wellness Series Webinar about Inspiration:** **Thursday, June 17** – Learn to be positive and hear about inspirational stories of myasthenia community members. [Registration is now open.](#)

**What's New in MG Research: Update on Rozimab:** **Thursday, June 24** – Join us for this UCB clinical trial update on Rozimab presented by Dr. Bril. [Registration is now open.](#)

**MGFA Southeast Regional Online Conference:** **Saturday, June 26** – Join our community friends and medical professionals in the Southeast USA. Open to anyone, anywhere. [Registration is now open.](#)

**For more information:** <https://myasthenia.org/Get-Involved/MG-Awareness-Month-Turning-Awareness-into-Action>

## Ohio Walk Page Now Active!

Go to [http://donate.myasthenia.org/site/TR?fr\\_id=1092&pg=entry](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 18<sup>th</sup> 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 above 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  
or email [clevelandmgroup@gmail.com](mailto:clevelandmgroup@gmail.com)



**JUNE  
13,  
2021**



**Noon to 3:00 pm - 37000  
Center Ridge Rd. North  
Ridgeville 44039 - Register  
Now!**

**2<sup>nd</sup> 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 web-  
site / info:**

<https://farmhouseyogallc.com/mgfa>





## LOCAL MGFA GROUP WEBSITE

Visit us at [www.clevelandmggroup.org](http://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](mailto: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](mailto:COVID19assistance@rarediseases.org)

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

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

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

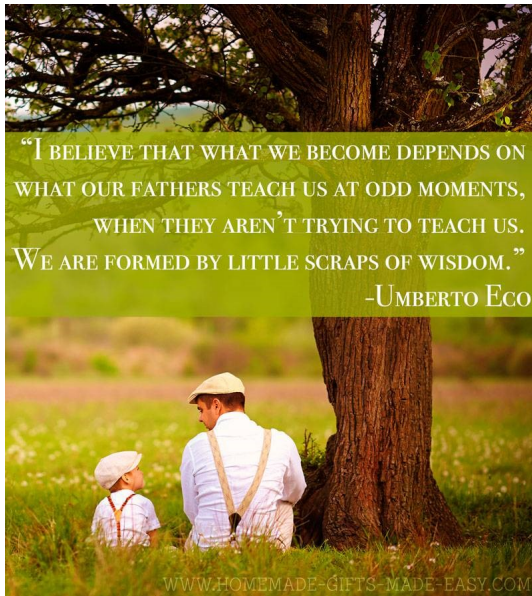
<http://www.togetherrxaces.com/p/prescription-savings>

<https://mat.org/> (Medication Assistance Tool)

<http://www.rxhope.com/Patient/AssistanceRequest.aspx>

<http://www.myastheniagravis.org/we-can-help/what-we-do/>

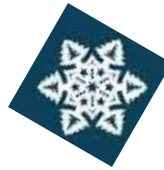
More info at: <https://myasthenia.org/Community-Resources/Resources-External-Assistance-Programs>



"I BELIEVE THAT WHAT WE BECOME DEPENDS ON WHAT OUR FATHERS TEACH US AT ODD MOMENTS, WHEN THEY AREN'T TRYING TO TEACH US. WE ARE FORMED BY LITTLE SCRAPS OF WISDOM."  
-UMBERTO ECO



# HAPPY FATHER'S DAY!



### UPCOMING JUNE MEETINGS:

Sunday June 13<sup>th</sup> Outdoor Fundraising Event—North Ridgeville 12:00—3:00 pm (pg.3)

Saturday June 26<sup>th</sup> (behind) The Chalet 16200 Valley Pkwy Strongsville 11:00 am—1:00 pm

Plus 4 ZOOM meetings in JUNE

Thank you to our sponsors:

