

Meeting Updates →

- Meeting information/notes pg. 2
- Virtual Closet pg. 2
- MG WALK 2021 pg. 3
- Emergencies-Are you prepared? pg. 3
- Assistance Programs pg. 4

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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.



February's ZOOM Meetings

**Thursday meetings
at the following times:**

When: **Feb 4, 2021 11:00 AM** Eastern Time (US and Canada)
Register in advance for this meeting:
https://zoom.us/meeting/register/tJModO-trjorHt0P_m51y-iNZkaNam_eob5y

When: **Feb 11, 2021 01:00 PM** Eastern Time (US and Canada)
Register in advance for this meeting:
https://zoom.us/meeting/register/tJwscOuprzqkqHtWt51x13p_spc_cvh30QAZo

When: **Feb 18, 2021 03:00 PM** Eastern Time (US and Canada)
Register in advance for this meeting:
<https://zoom.us/meeting/register/tJrde2hrz4rGdZ-YdLxFvDYCYfy4V1Ha5uz>

When: **Feb 25, 2021 07:00 PM** Eastern Time (US and Canada)
Register in advance for this meeting:
<https://zoom.us/meeting/register/tJMqduuopjkgG9wrF653Q6GhRDuZXS6iwrn>

After registering for any meeting, you will receive a confirmation email containing information about joining the meeting.

Ask the MG Expert

Q. My doctor has recommended Prednisone. What can I expect?

A. PREDNISONE—The drug we love and love to hate. Prednisone can be a real life-saver for those with MG. It works relatively quickly and is inexpensive compared to other drugs.

WHAT IS IT? Prednisone is a synthetic version of the hormone cortisone which your body naturally produces.

HOW DOES IT WORK? Prednisone suppresses or “calms” the immune system when it becomes overactive. An overreactive immune system is what causes most forms of MG.

HOW DO I TAKE IT? Most protocols for treating MG start with a dose of 10-20 mg and ramp up to the dose needed to control your MG symptoms. Some doctors may choose to start at a higher dose right away to relieve severe MG symptoms.

WHAT ARE THE SIDE EFFECTS? Prednisone can cause sleep disruptions, mood swings, spikes in blood sugar, fluid retention, and high blood pressure. Long-term it can contribute to cataracts and osteoporosis. Your doctor will monitor you closely for troublesome side-effects

CAN I JUST QUIT TAKING IT? No. You will most likely need to be weaned slowly off of the prednisone and tested to be sure that your body is producing its own cortisone. (cont. pg.3)



February is Rare Disease Month and the 28th is Rare Disease Day! Go to <https://rarediseases.org/> for more information.



2021 MG Meetings and Events

Westside Meetings: TBD

Lorain County Meetings: TBD



LOOKING FORWARD

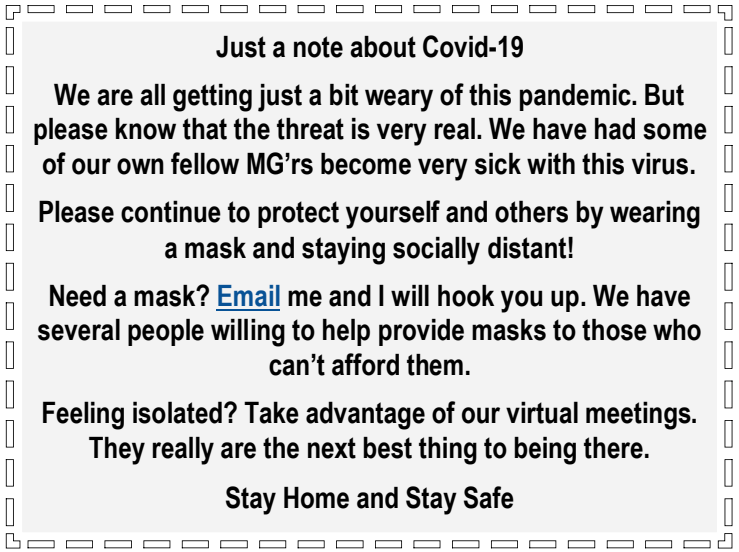
Two big events *will* happen this year and allow a chance to get together in person:

1. Fundraising Yoga event sometime in June.
2. Annual MGFA Walk September 18th

Both will be outside events and masks will be required.

Stay tuned for more information later this spring

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



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.

We are requiring pre-registration this month. 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.

Introducing the 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 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.



MEETING NOTES:

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!

In Memorial

Bill was part of our MG group. We extend our deepest sympathies to Ellen and family.

William Egan



age 73, passed away 12-24-2020. Cherished husband of Ellen Egan for 47 years. Loving father of William A. and Sarah Egan-Reeves (Thomas). Pop Pop to Evelyn, Martin and Lily. Brother of Catherine Rogers (dec), Rosemary Costanzo (Dec), David Egan (Sheila) and Mary Sedlak (Donald). Special uncle and Santa to many nieces and nephews. December 24, 2020. Celebration of Life Party will be held later. Always in our hearts.

(Ask the MG Expert continued)

WHAT'S IT CALLED? - Prednisone goes by many other names including Prednisolone, Dexamethasone, Hydrocortisone, and Triamcinolone. This class of drugs are known as glucocorticoid steroids. They are NOT performance enhancing drugs.

WHAT'S ELSE DO I NEED TO KNOW? - It is very important that you inform all of your doctors and dentists that you are taking prednisone. Besides the other listed side effects, prednisone may lower your ability to fight infections.

If prescribed prednisone, it is best to take it in the morning with some food to avoid an upset stomach.

Tell your prescribing doctor about any side-effects that you notice.

To download a pamphlet about Prednisone, [click here](#)

More information may be found at www.myasthenia.org



Calling all Volunteers! We will be having 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.

An initial National planning meeting is happening in March. We need some people for our local planning committee. Can you help? Your commitment would be a monthly phone planning session, help in one of the categories below, and help on the day of the walk. Please consider utilizing your special talents to help promote MG awareness and help to raise funds to 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

Want to help? Contact Rebecca at 216-218-0477 and leave a message

or email clevelandmggroup@gmail.com

How to Prepare for an Emergency—

Emergencies happen when you least expect it. That's why it's better to prepare in advance. If you have a medical emergency and are unable to talk for yourself, how will you let the ER personnel know that you have MG? Here are a few ways in which you can prepare:

- Get a lock box to hold your door keys. These are placed by your local fire department—call their non-emergency number to find out how you can get one
- Place your pertinent medical info in a plastic bag and hang on the inside of your front door or your refrigerator ([Vial of Life](#))
- Place ICE (in case of an emergency) contacts in your phone and make sure they have your medical info
- Get a medical alert bracelet or necklace ([Medical Alert Jewelry](#))
- Get an ER notification one-button alert system that will call 911 for you ([Great Call](#))



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/>

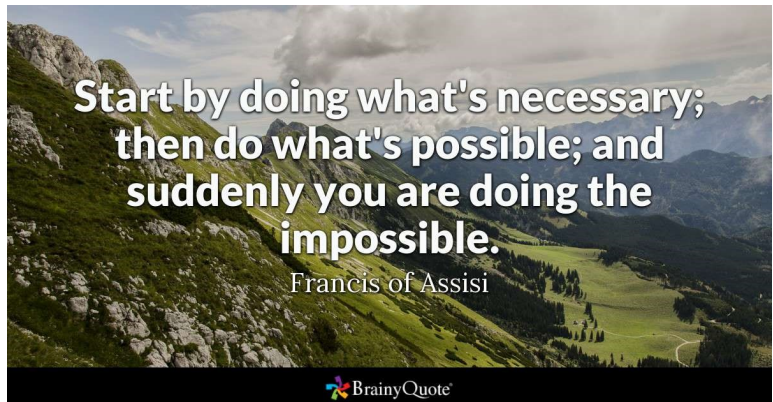
<http://www.togetherrxaccess.com/p/prescription-savings>

<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 2021 ZOOM MEETINGS:

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

Hope to see you soon on Zoom !

Thank you to our sponsors:

