

## SEPTEMBER 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/>



### September's ZOOM Meetings

#### Thursday meetings at 3:00 pm:

When: Sept. 2, 2021 03:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/j/83551436881?pwd=SjlxNm8vT1p2NmZiYk03NXVlV3ZlUT09>

When: Sept. 9, 2021 03:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/j/87546888259?pwd=UnNhRFgzd2gzMmdxRkwxjdxc2dkdz09>

When: Sept. 16, 2021 03:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/j/82324061008?pwd=ZXhGM2dKSEp1V0dGQTUxRnZlQjFCQT09>

When: Sept. 23, 2021 03:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/j/83475784142?pwd=S2lyUGFKaGFkNjhNTFFKN1NZeHNrdz09>

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

**No Meeting on September 30th—fifth Thursday**

## DID YOU KNOW?

Stress of any kind—good or bad—can aggravate your MG and cause weakness? Try and get extra rest during times of stress.



## Volume 9 Issue 08

### Ask the MG Expert

**Q.** I thought the Covid-19 virus was easing up, how do I protect myself now that cases are increasing again?

**A.** While it is a little disheartening that we are still in the thick of fighting this pandemic virus, there are several things you can do to protect yourself and avoid getting sick.

**Take it Seriously**—This is still a very deadly virus. The best defense you can do is to get vaccinated as soon as possible if you haven't done so. Do not be afraid to get the vaccine. Once you get sick it is too late for the vaccine to save you.

**Use Caution**—If you are currently on immunosuppressants such as Prednisone, Imuran, Cellcept, or one of the monoclonal antibodies like Rituximab or Soliris, you should continue to protect yourself by avoiding crowds, wearing a mask, and practicing social distancing when you go out even if you are vaccinated. Check with your doctor as to when you should get the third shot to boost your immunity.

**Public Transportation**—Avoid public transportation whenever possible but if you must, always wear a mask and distance yourself from others.

**Working**—Check with your employer to see if working from home is possible for you. If not, ask what provisions they have in place to protect you. Wear a mask whenever indoors. Try and seclude yourself from anyone who hasn't been vaccinated.

**Isolate**—Avoid large gatherings and get-togethers. Connect with others by phone or computer instead.



## 2021 MG Meetings and Events

The MGFA Annual Walk will be virtual this year. Stay tuned for more information



### MDA clinical trial opportunity for adults living with generalized myasthenia gravis (gMG).

Researchers at The Neurological Institute, PA, located in Charlotte, North Carolina, are seeking adults living with gMG to participate in a phase 3 clinical trial to evaluate the efficacy and safety of the investigational drug rozanolixizumab. Rozanolixizumab is designed to alter the immune response and reduce antibody production, potentially improving strength, fatigue, swallowing, and some visual disturbances in people living with gMG.

This study is a randomized, double-blind, placebo-controlled study, meaning that study participants will be randomly assigned to either receive rozanolixizumab or an inactive placebo control during the study period. The total trial duration for each patient will be about 18 weeks, consisting of a screening period (between one and four weeks), a treatment period (six weeks), and an observation period (eight weeks). The drug/placebo will be administered in 12 doses through subcutaneous (under-the-skin) injections given at weekly visits over the study period. Participants will be evaluated for various outcome measures, including severity of symptoms, ability to perform activities of daily living, and quality of life. At the end of the study, participants may be given the option of enrolling in a long-term, open-label extension study.

To learn more or enroll in the study, please contact the study coordinator, Katelyn Eudy, BS, CRC, at phone: 704-449-6064 ext. 110 or e-mail: [keudy@neuro-institute.com](mailto:keudy@neuro-institute.com).

### 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.

### No In-Person Meetings planned for Northeast Ohio MG Support Groups

**We will not be meeting in person until given the ok from the National MGFA.**

**We will continue to have our weekly Zoom meetings until it is determined that it is safe to meet in person again. Even after the pandemic has subsided, we will continue Zoom meetings for those who are unable to attend in-person meetings.**

**NOTE: If you can't make our Thursday Zoom meetings, check out the other virtual meetings at [www.myasthenia.org](http://www.myasthenia.org)**



Zoom Meetings:

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 3:00 pm ET (see pg. 1)

Come and see old friends or make new ones.

**Family and friends welcome!**



## TWO NEW PATIENT TRIALS FOR MYASTHENIA GRAVIS:

PLEASE CLICK ON THE LINKS FOR MORE INFORMATION IF YOU ARE INTERESTED IN PARTICIPATING:

### Cartesian Phase 1/2 Car-T Clinical Trial for Generalized Myasthenia Gravis (GMG)

Phase 1/2 clinical trial (NCT04146051) of our lead CAR-T product, Descartes-08, to treat patients with Generalized Myasthenia Gravis (GMG). This program is the first CAR-T product to enter clinical development for autoimmune diseases globally to the company's knowledge.

In contrast to most CAR-T therapies, which are DNA-based, Descartes-08 uses RNA transfer to create a population of CAR-T cells. The use of RNA prevents the uncontrolled proliferation of CAR-T cells in the patient.

Descartes-08 uses a CAR directed against BCMA. BCMA is a highly sensitive and specific marker for plasma and myeloma cells. BCMA has been validated as a target with conventional, DNA-based anti-BCMA CAR-T therapies, which have shown considerable promise in patients with GMG.

[https://www.prnewswire.com/news-releases/cartesian-initiates-car-t-clinical-trial-in-myasthenia-gravis-300951371.html?tc=eml\\_clearime](https://www.prnewswire.com/news-releases/cartesian-initiates-car-t-clinical-trial-in-myasthenia-gravis-300951371.html?tc=eml_clearime)

<https://clinicaltrials.gov/ct2/show/NCT04146051>

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## UPCOMING EVENTS

This is the space where I would normally be promoting our next gathering or fund raising event. Remember the clambakes? Our Goodtime III excursions or the ride on the Cuyahoga Valley Scenic Railway train? Unfortunately, I can't tell you about any of these events due to our ongoing pandemic. Are you as fed up as I am with Covid? If so, let's do something about it! If you haven't been vaccinated yet, please get it to protect yourself and others. If you are fully vaccinated, be sure and get the third booster shot as soon as it is offered to you. Wear your masks in public and stay home if you are feeling sick. Together we can beat this thing!

### Vaccination Card

Worried about Losing your Vaccination Card? One way to keep your important vaccination information is to take a picture of it with your smart phone and store it on your phone. If you have a home printer/scanner, scan it in and put it in a special folder on your computer. Please resist the temptation to post your vaccination card online or in social media. Card scammers are copying innocent people's posted cards and reselling them online. Bring your card with you when getting your booster shot.

### Safe Swallowing Techniques

For some of us swallowing is a challenge. Choking can come on unexpectedly and it may happen even when you are otherwise feeling strong. Practicing safe chewing and swallowing techniques may help you avoid choking. Here are a few techniques:

- Pay attention when eating, concentrate on chewing, and never talk while eating
- Take small bites
- Eat softer foods when having problems, avoid tough cuts of meat
- If starting to choke, tilt your chin to your chest
- If food won't go down, try either sipping warm soda or ice water you will find what works best for you
- Train yourself and others on the [Heimlich Maneuver](#)



LOCAL MGFA GROUP WEBSITE  
Visit us at [www.clevelandmggroup.org](http://www.clevelandmggroup.org)

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)



**New beginnings are often disguised as painful endings.**

—Taken from a sign at Farm House Yoga

**You've only got 3 choices—Give up, Give in, or Give it all you've got! (I hope you choose the latter)**

—Taken from a sign at Farm House Yoga

**UPCOMING SEPTEMBER MEETINGS:**

Every Thursday at 3:00 pm via Zoom (except 5th Thursdays)

Thank you to our sponsors:

