

JULY 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/>



July's ZOOM Meetings

Thursday meetings at 3:00 pm:

July 1, 2021 03:00 PM Eastern Time (US and Canada)

<https://zoom.us/join/joinMeeting?zmt=0tE92wB0jHwSERXvgTUI5LgFU>

July 8, 2021 03:00 PM Eastern Time (US and Canada)

<https://zoom.us/join/joinMeeting?zmt=ivrT0iHNMBkmYhCVSszePQPbfnSrLQ>

July 15, 2021 03:00 PM Eastern Time (US and Canada)

<https://zoom.us/join/joinMeeting?zmt=tJMsdqggTluGt3uBnPtMu4p5FEs12v4JPrD>

July 22, 2021 03:00 PM Eastern Time (US and Canada)

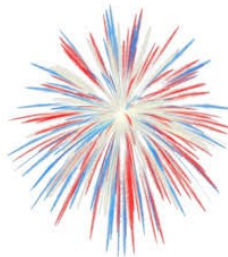
<https://zoom.us/join/joinMeeting?zmt=tJcucuCvqDIsEteY75cJhhEFuzx6aQiadVTm>

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

No Meeting on July 29th—fifth Thursday

June was MG Awareness Month!!

Congratulations to Tammy L. and Peg R. who were the winners of the snowflake contest and both received a copy of the book *Coping with Myasthenia Gravis*.



HAPPY
4th of July

INDEPENDENCE DAY

Remember to stay hydrated during the hot summer days!

Volume 9 Issue 07

Ask the MG Expert

Q. Now that Covid restrictions are easing, is it safe for someone with MG to travel?

A. The answer is a little complicated. With some preplanning, you can still enjoy some summer trips:

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.

Public Transportation—Masks are still required whenever you fly, take a train, or ride on a bus. Try and distance yourself from others while using these forms of transport.

Driving—If you decide to drive yourself, take frequent breaks about every 2-3 hours. These breaks give your eyes a rest and allow you to stretch your legs.

Plan Ahead—Be sure to pack extra medication in case you need it. Other essential items may include hand sanitizer, extra masks, and sanitizing spray.

Research—Know which hospitals are closest to your destination and if they accept your insurance. Consider buying medical travel insurance.

Conserve Energy—Don't be afraid to use the free transport cart at the airport or a scooter at a store. Build in some rest periods in your itinerary. Even doing fun things like sightseeing can be physically taxing. Be sure and plan some down time.

Relax and enjoy your summer.



2021 MG Meetings and Events

IMPORTANT ANNOUNCEMENT: MG Walks will be Virtual in 2021

On behalf of MGFA, and the guidance of our Medical Advisory Council, we are writing to inform you that we have decided to host our fundraising season VIRTUALLY again this year. Although recent developments with vaccines have spurred hope and anticipation for a return to “normal,” we are still very much in a pandemic and the health and safety of our MG Community is paramount.

We cannot host in-person events and be confident that community members would not be at risk. The very nature of walks and fundraising events is to bring large numbers of attendees together and we are still being advised not to do so. Data to date suggests that MG patients appear to have higher risk of severe COVID infections than the general population because treatments can leave them immunocompromised. As an organization, we cannot in good faith put those we serve in any type of harm’s way or risk of their health.

We very much understand that there is a segment of our population and supporters that feel life should get back to pre-pandemic normal, and that we should offer the opportunity to get together in a mass setting if it is for the greater good of raising funds for the organization. Yet, we strongly believe that raising funds can continue but not at the risk of any one person getting sick at an MGFA function. Currently, in the non-profit sector, the vast majority of organizations have pivoted to virtual fundraising seasons for 2021. This very much remains a standard practice.

With this said, we will not be conducting in-person walks for this year but will plan to bring back our mass gatherings in 2022. Let us catch our breath and put health ahead of the desire to get together in person. We will be back in touch with our plans for a Virtual 2021 Coast to Coast MG Walk.

We so very much appreciate your desire, passion, and commitment to support the MGFA. Should you have any questions, please contact Craig Strenger, VP of Development, at Cstrenger@myasthenia.org or call (949) 633-7878.

****Medical Professionals Disclaimer:** We must reinforce that researchers still do not have adequate data on the level of protection that the vaccine provides patients that are on immunosuppressive treatments. Most MG patients are using a form, or multiple forms of immunosuppressants. Therefore, we will continue to recommend that MG patients follow the CDC guidance for unvaccinated people (that is, masking, social distancing, hand washing) – particularly when patients are in close proximity to people with an unknown vaccination status.

Continue consulting with your treating neurologist to discuss your individual situation and risks. And also continue encouraging those with whom you live with, or people you socialize with, to get vaccinated to keep you safe CDC Vaccine statements and updates can be accessed at this [webpage](#).



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

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_cleartime

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

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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.

2nd Annual MGFA Fund Raiser at Farm House Yoga was held on June 13, 2021 by Katie Oradini.

It was a beautiful sunny day and a great MG awareness event. Although turnout was low due to Covid, Katie still managed to raise over \$2,000.00 for MGFA.

Thanks you to all who came out and supported Katie and the MGFA.

Pictures provided by Geno Oradini inbloomprod.com/about



LOCAL MGFA GROUP WEBSITE
Visit us at www.clevelandmggroup.org

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/>

[Good Rx.com](http://www.GoodRx.com)

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

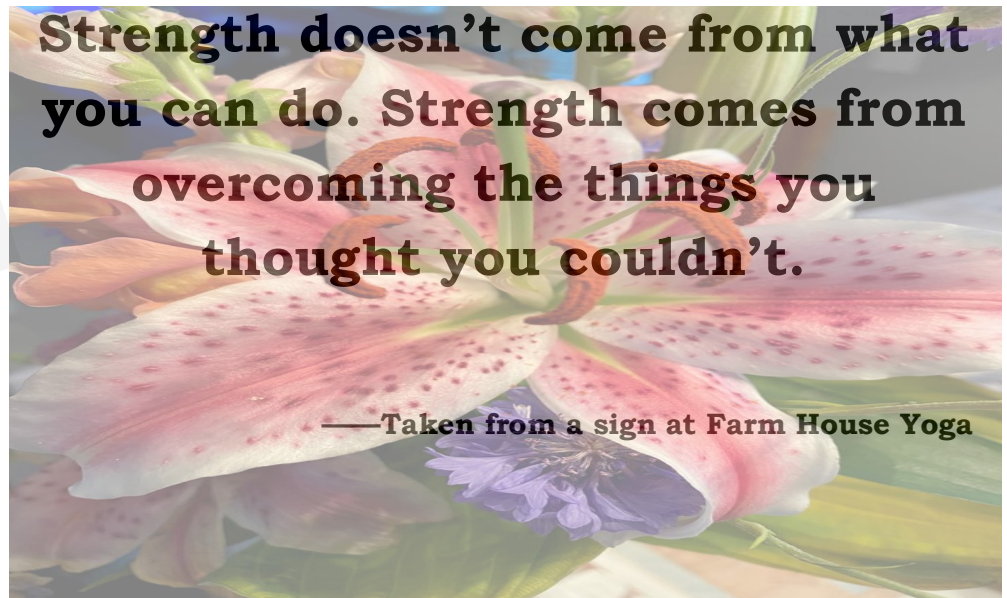
<http://www.togetherrxaccess.com/p/prescription-savings>

<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 JULY MEETINGS:

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

Thank you to our sponsors:

