

NOVEMBER 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/>



November's ZOOM Meetings

Thursday meetings at 3:00 pm:

When: Nov 4, 2021 03:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

[https://us06web.zoom.us/meeting/register/tZUqfumhqTOrHdRbNv0_PykC71Kjt2OR864r](https://us06web.zoom.us/join/https://us06web.zoom.us/meeting/register/tZUqfumhqTOrHdRbNv0_PykC71Kjt2OR864r)

When: Nov 11, 2021 03:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

[https://us06web.zoom.us/meeting/register/tZAlceGgqj0sHdW-p7qu7dgYkINgWEoDQDjI](https://us06web.zoom.us/join/https://us06web.zoom.us/meeting/register/tZAlceGgqj0sHdW-p7qu7dgYkINgWEoDQDjI)

When: Nov 18, 2021 03:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

[https://us06web.zoom.us/meeting/register/tZlpdeqorDwpH9cQOoldrsf_0-Q8JaLJ23kh](https://us06web.zoom.us/join/https://us06web.zoom.us/meeting/register/tZlpdeqorDwpH9cQOoldrsf_0-Q8JaLJ23kh)

No meeting on Thursday 11/25—Happy Thanksgiving!

Volume 9 Issue 10

Ask the MG Expert

Q. How can I tell if my symptoms are bad enough to go to the hospital?

A. None of us like to be in the hospital especially during the holiday season. But sometimes it is necessary to get your MG under control. If you are experiencing any of the problems below, then it is time to get help:

Having trouble catching your breath?—If you are getting out of breath even when just sitting still, call your doctor immediately or call 911. Not sure if you are getting enough air? Take as deep of a breath as you can and slowly blow it out counting as you go. If you are unable to reach 15, call the doctor. You can also try taking a breath and then blowing through a straw into a glass of liquid (this works great with kids) and count how long you are able to blow bubbles. Again, if you can't reach 15, call the doctor.

Burning in your chest?—If your diaphragm muscles feel like they are burning and getting fatigued after slight activity AND resting or Mestinon does not help, call your doctor or 911.

Can't swallow?—If you are having problems with chewing and swallowing that are so severe that you are unable to take your medication, or swallow liquids, call your doctor and go to the ER immediately. Don't wait until you are dehydrated to get to the hospital. NOTE: Mestinon may be placed under your tongue and allowed to dissolve there.

Call First—Unless you are experiencing inability to breath and need to call 911, it is helpful to call your neuro-muscular specialist and let them know what you are experiencing. They may be able to contact the hospital before you get there to direct your care.





November 13, 2021

You can get all the info about the MGFA Virtual Walk by clicking here:

[https://
donate.myasthenia.org/site/
SPageNavigator/mgfa/](https://donate.myasthenia.org/site/SPageNavigator/mgfa/)

[Landing Page MGFA Walk 2021.html](#)

Join a local team or form one of your own by clicking here: [https://
donate.myasthenia.org/site/TR?](https://donate.myasthenia.org/site/TR?)

International Parents of MG KIDS Zoom Meetings—

We will hold two meetings this month for parents of children with MG. Please click on the links below to register for the meetings:

Nov. 4th

When: Nov 4, 2021 09:30 PM Eastern Time (US and Canada)

Register in advance for this meeting:

[https://us06web.zoom.us/meeting/register/
tZYvfuChrDgijGN2Cb3A_fBqE2Dz9EL0POgDI](https://us06web.zoom.us/j/84451200000)

Nov. 14th

When: Nov 14, 2021 09:30 PM Eastern Time (US and Canada)

Register in advance for this meeting:

[https://us06web.zoom.us/meeting/register/
tZUrcuqtqTspEtKjzzSeGMbaK7phl-EKcV3o](https://us06web.zoom.us/j/84451200000)

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

Please adjust for your time zone

Hope to see you soon on Zoom!

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 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.

Adult Patient 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 (pg. 1)

Come and see old friends or make new ones.

Family and friends welcome!

NOTE: No Meeting on November 25th



Two New Research Studies Now Recruiting Patients

Elizabeth Gehlmann a Clinical Research Professional in the Department of Neurology - Neuromuscular Division at University of Cincinnati Hospital spoke to our support group via Zoom. She explained that there are two studies currently enrolling patients for testing of new MG medications. The patients enrolling must be either AChR or MuSK antibody positive to be considered. There are other elimination criteria too.

Both studies are featuring a simple injection method instead of an infusion method for the medication. Both studies are double-blind which means that neither the researcher or the patient know until after the study whether you are receiving the placebo or the medication. However, once the initial study period is over, the medication will be offered to all patients participating. Both studies offer compensation for travel expenses to get to the study location. For more information please click on the links below or you may contact Elizabeth directly at (cell) 216-618-2270 (office): 513-558-4497 gehlmaem@ucmail.uc.edu :

MINT Study—Phase III <https://myastheniagravismintstudy.com/>

Takeda Study—Phase II (closing soon) <https://clinicaltrials.takeda.com/study-detail/5f6b603c4db2bf003ab4a369?location={%22lat%22:64.9648751621697,%22lng%22:17.6754094331351,%22city%22:%22Sweden%22,%22state%22:%22%22}>

NEWLY DIAGNOSED? Check out this MGFA Blog—<https://myasthenia.org/About-Us/Blog/newly-diagnosed-heres-what-you-need-to-know>

New Meeting Opportunity

For those of you unable to make our Thursday Zoom meetings, you are cordially invited to join the Atlanta Georgia MG Group on Monday November 1st. Here's what Alexis Rodriguez says: "We will have as our guest speaker Dr. Gretchen Wilber Clinical Psychologist. I will ask that you take a moment and send me ahead of time any questions you may have or that you would want to ask but stay anonymous."

Dr. Gretchen H. Wilber is a licensed Clinical Psychologist who provides treatment for adolescents, adults and military service members with Post-traumatic Stress Disorder, anxiety, depression, addiction, sexual assault, interpersonal relationship concerns and chronic medical illnesses. Dr. Wilber completed advanced clinical training in empirically supported PTSD and chronic pain treatments. She completed her pre-doctoral training at the APA Accredited, Albany Psychology Internship Consortium and her postdoctoral year at the George Washington University Counseling Center.

For more information on Dr. Wilber <https://www.drgretchenwilber.com/home-about-drwilber>

When: Nov 1, 2021 06:30 PM Eastern Time (US and Canada)

Register in advance for this meeting:

<https://us06web.zoom.us/meeting/register/tZMldu-urD0uHdIhqlf5n1Ytkn3MgITBRify>

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

Alexis Rodríguez

Patient/ Leader/ Volunteer
Georgia MG Support Group
404-313-6958

mगतalk@gmail.com
www.mggeorgia.org/

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.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>



Over The River And Through The Woods - Lyrics

Over the river, and through the wood,
To Grandmother's (Grandfather's) house we go.
The horse knows the way to carry the sleigh,
Through the white and drifted snow.

Over the river, and through the woods,
To Grandmother's (Grandfather's) house away!
We would not stop for doll or top,
For it's Thanksgiving Day!

For the complete lyrics to "The New-England Boy's Song About Thanksgiving Day", go to <https://www.nurseryrhymes.org/over-the-river-and-through-the-woods.html>

UPCOMING NOVEMBER MEETINGS:

Adult MG Patients, Family, and Friends—Nov. 4th, 11th and 18th at 3:00 pm via Zoom (see page 1)

International Parents of MG Kids November 4th and 14th at 9:30 pm (see page 2)

Thank you to our sponsors:

