

DECEMBER 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/>



December's ZOOM Meetings

Thursday meetings at 3:00 pm:

Dec. 2nd

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

Register in advance for this meeting:

<https://us06web.zoom.us/j/84461212693>

Dec. 9th

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

Register in advance for this meeting:

<https://us06web.zoom.us/j/84461212693>

Dec. 16th

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

Register in advance for this meeting:

<https://us06web.zoom.us/j/84461212693>

NOTE: No meetings on December 23rd or 30th
First meeting in 2022 will be January 6th 2022



No matter how or what you celebrate, we wish you a wonderful Holiday Season and the Happiest of New Years!



Volume 9 Issue 11

Ask the MG Expert

Q. I have problems with Mestinon. Is there something else that would work or something to counteract the side effects?

Huperzine A—Is a natural product made from a fern. Available online and in drug stores, it is used in alternative medicine. Huperzine A has been found to act as a cholinesterase inhibitor, used to prevent the breakdown of acetylcholine and is effective in myasthenia gravis.

What are the Side Effects? —While Huperzine A is a more natural alternative to Mestinon, it can still have many of the same side effects if taking too much, including nausea, diarrhea, vomiting, dry mouth, constipation, sweating, blurred vision, slurred speech, fainting, restlessness, loss of appetite, contraction and twitching of muscle fibers, cramping, increased saliva and urine, inability to control urination, high blood pressure, swelling, dizziness, inability to sleep, and slowed heart rate.

Drug Interactions — Huperzine A may interact with certain medications including cholinesterase inhibitors (Mestinon), beta-blockers, and anti-convulsive agents. Do not take it with Mestinon and always let your doctor and or pharmacist know if you are taking it.

Bentyl—If you are having problems with gastrointestinal problems related to Mestinon, Bentyl acts as an anticholinergic and an antispasmodic. Ask your doctor if Bentyl may be beneficial for you.

Benadryl—Benadryl also acts as a mild anticholinergic. If you think you've overdosed on Mestinon, taking Benadryl may help to lessen the effects.

Other Anticholinesterase Agents—Other agents which act more mildly than Mestinon include: caffeine from coffee, tea, or chocolate, and scents such as Rosemary and Eucalyptus oil.

New Meeting Opportunities

For those of you unable to make our Thursday Zoom meetings, here are two other MG Support Groups having special meetings this month:

MEETING DATE: Saturday 4th, December, 2021

MEETING TIME: 11:00 AM Central Time NOTE: this is 12:00 PM Eastern Time (US and Canada)

EXERCISE and MG with Co-facilitator, Dr. Liz Plowman. She has included a link below of FOUR EXERCISE VIDEOS for you to watch.
VIDEO link: <https://tinyurl.com/mytux23s>

Join Zoom Meeting

<https://us02web.zoom.us/j/85702050779?pwd=SDBLM0ZEY213QXB4NnI0SmU1WDRSdz09>

Meeting ID: 857 0205 0779

Passcode: 671063

Dial by your location

+1 253 215 8782 US (Tacoma)

+1 312 626 6799 US (Chicago)

+1 929 205 6099 US (New York)

+1 301 715 8592 US (Washington DC)

(Disclaimer. Please check with your treating physician before you start an exercise program)

If you have any questions or concerns regarding the videos, please contact Dr. Elizabeth Plowman, PT, DPT, OCS, TPS at 713-794-2077 or eplowman@twu.edu



MEETING DATE: Monday 6th, December, 2021

MEETING TIME: 06:30 PM Eastern Time (US and Canada)

Myasthenia Gravis Support Group of Atlanta, GA invites you to our last meeting of the year with guest neurologist, **Dr. Gavin Brown**.

See Dr Brown's Bio

<https://www.laureatedmed.com/Medical-Team/Bios/BioDetails?uid=127>

Register in advance for this meeting:

https://us06web.zoom.us/meeting/register/tZMucuGpqz4uG9CtptLrR_Sv9uoW1WU1FEq3

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 December 23rd or 30th

First meeting in 2022 is January 6th





What is Rare Patient Voice?

Rare Patient Voice is a survey company that pays you to give your opinion. Rare patient Voice (RPV) helps researchers and pharmaceutical companies get customer feedback about new products and services while still in the development stage.

Sometimes, you may be asked to be a part of a panel of other patients and sometimes you may answer questions over a Zoom chat. RPV needs input from patients with several different diseases—not just MG. So family and friends may join too by taking the simple questionnaire to see if their medical condition is being studied.

All input for these research studies is done anonymously and your identity is kept private.

They usually pay about \$100/hour for your opinion. However, sometimes depending on the research study, you may be paid more or less.

Rare Patient Voice will also help our local MG Group by donating \$5 for every referral using the link below:

If interested, sign up at: <https://rarepatientvoice.com/MGFANortheast/>



Safe Swallowing Techniques—Expanded

For some of us swallowing is already a challenge, but during the Holiday Season when we get together with others for meals, it is easier to get tired while eating and talking and visiting—making it easier to choke. 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 hints:

- Pay attention when eating, concentrate on chewing, and try not to talk while eating
- Take small bites
- Eat softer foods when having problems, avoid tough cuts of meat
- Some great holiday foods to enjoy when chewing is hard include mashed potatoes, sweet potatoes, macaroni and cheese, applesauce, stuffing, and pumpkin pie
- 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
- If water makes you choke, thickener may be purchased at the local drug store
- Train yourself and others on the [Heimlich Maneuver](#)

SAVE THE DATE!

Announcement: MGFA National Patient Conference will be virtual in 2022.

The Myasthenia Gravis Foundation of America has announced that its annual National Patient Conference will be hosted virtually in 2022. This decision was made based on guidance from our Medical Advisory Council as well as feedback from members of the MG community. Our National Patient Conference will be held on Thursday, February 10, and Friday, February 11, 2022, so save the date! Registration will be live soon, so stay tuned for event updates.

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>



Wishing you all the BEST this Holiday Season offers!

UPCOMING DECEMBER MEETINGS:

Adult MG Patients, Family, and Friends—Dec. 2nd, 9th and 16th at 3:00 pm via Zoom (see page 1)

Houston, TX & Atlanta GA Zoom Meetings Dec. 4th and 6th at various times (see page 2)

Thank you to our sponsors:

