

MG KIDS

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

Parents of MG KIDS

Sunday, Dec 12, 2021 12:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

<https://us06web.zoom.us/j/8442111111>

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

Adult MG Meetings Friends & Families Welcome

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/8442111111>

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/8442111111>

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/8442111111>



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: NOTE: These meetings are open to anyone interested in MG.

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>

(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



Here's a link to a time conversion app that will tell you what time the meetings will happen in your part of the world—

<https://www.timeanddate.com/worldclock/converter.html>



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

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



CHRISTMAS WORD SEARCH



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| CANDLES | SANTA | FROSTY | MERRY |
| CANDY CANE | SEASON | GIFT | MISTLETOE |
| CARDS | SLEIGH | GIVING | NOEL |
| CELEBRATE | STOCKING | GREETINGS | NORTH POLE |
| CHIMNEY | TREE | HOLIDAY | REINDEER |
| CHRISTMAS | WREATH | JOLLY | |



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LOCAL MGFA GROUP WEBSITE

Visit us at www.clevelandmggroup.org

For all the latest local MG news, upcoming events, and newsletters

DID YOU KNOW?

Did you know that even “good stress” like family parties and opening presents can make you feel weaker?

If you find yourself getting a little weaker around the Holidays—don't panic. This is normal. Just allow yourself some down time. Take a nap, chill on the couch or listen to music.

Soon you'll be back up to your normal activity level.

*It's not what's under the
Christmas tree that matters*



it's who's around it...

Wishing you all the BEST this
Holiday Season offers!

RECIPE CORNER—

Easy Peanut Butter Cookies:

Ingredients:

1 cup sugar

1 egg

1 cup smooth peanut butter (Note: if allergic to peanuts, can use almond butters)

Directions:

Line a baking sheet with parchment or waxed paper. Preheat oven to 350° F

Mix all ingredients. Drop by teaspoonfuls onto baking sheets. Sprinkle a little colored sugar on top. With a fork, make a criss-cross to help flatten the cookie

Bake in preheated oven for about 10 minutes

Let rest on cookie sheet for 10 minutes before moving to cooling rack.
Enjoy!

UPCOMING DECEMBER MEETINGS:

Parents of MG KIDS—Dec. 12th 12:00 pm Zoom Meeting (see page 1)

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)



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