

MG KIDS

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/>



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/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/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!

Volume 1 Issue 4

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.





MGFA Virtual Walk November 13, 2021

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

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.



Parents of MG KIDS Zoom Meetings:

We have been averaging about 3-5 people per meeting. It is a great time to connect with each other and share tips and hints for parenting a child with MG

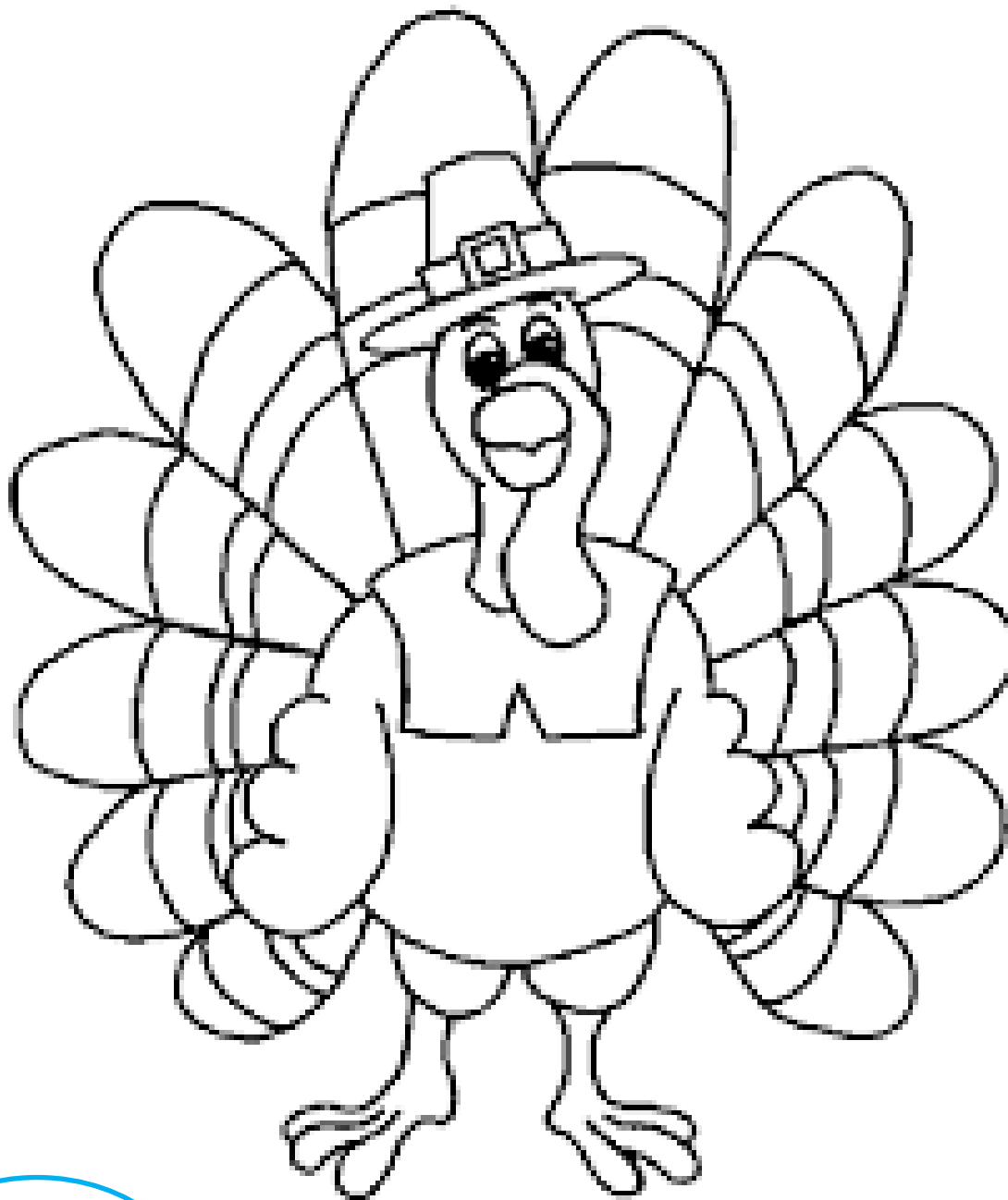
Times listed are in the eastern time zone (U.S.)

Please adjust the time for your time zone

Family and friends welcome!

Come and get your questions answered or share what works for you!





**FUN
FACT!**

Did You Know? Chocolate has a mild muscle stimulant effect much like the Mestinon we take so if you need a pick-me-up in between Mestinon doses try a piece of dark chocolate. Yum!



thanksgiving
gather family
thankful
blessed grateful
together blessings
november

November gives us all a time to reflect on what in our life is good and what we are grateful for. What are you thankful for?

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

RECIPE CORNER—

No-Bake Chocolate Oatmeal Cookies:

Ingredients:

1 cup sugar 1/2 cup milk or almond milk (Note: if allergic to nuts, use other milk)
1 stick (1/2 cup) butter 1/4 cup cocoa powder
3 cups old fashioned rolled oats
1 cup smooth peanut butter (Note: if allergic to peanuts, can use other nut butters or just eliminate)
1 TBS vanilla pinch of salt

Directions:

Line a baking sheet with parchment or waxed paper

Bring sugar, milk, butter, and cocoa to boil in a saucepan and boil for 1 minute. Then add oats, peanut butter, vanilla and salt

Drop by teaspoonfuls onto baking sheets and let cool. Keep in air tight container in fridge for up to 3 days.



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->

UPCOMING NOVEMBER MEETINGS:

International Parents of MG Kids November 4th and 14th at 9:30 pm ET (see page 1)

Thank you to our sponsors:

