

## OCTOBER 2021

### Meeting Updates →

- Parents of Mg Kids pg. 2
- Puzzle pages pg. 3
- Did You Know? pg. 3
- Assistance Programs pg. 4

#### 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](http://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](http://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/>



### October's ZOOM Meetings

#### Thursday meetings at 3:00 pm:

When: Oct 7, 2021 03:00 PM Eastern Time

Register in advance for this meeting:

<https://us06web.zoom.us/j/8446121212>

When: Oct 14, 2021 03:00 PM Eastern Time

Register in advance for this meeting:

<https://us06web.zoom.us/j/8446121212>

When: Oct 21, 2021 03:00 PM Eastern Time Register in advance for this meeting:

<https://us06web.zoom.us/j/8446121212>

When: Oct 28, 2021 03:00 PM Eastern Time

Register in advance for this meeting:

<https://us06web.zoom.us/j/8446121212>

## Volume 9 Issue 09

### Ask the MG Expert

At a recent Zoom meeting we had a good discussion about balance and MG.

**Q. Does MG cause problems with balance?**

**A.** While weakness can cause balance problems, if you feel a sensation of the room spinning, it may have to do with the crystals in your inner ear.

**What are ear crystals?**—Tiny calcium crystals that sense gravity are found within the chambers of the inner ear. The crystals sit atop of cilia and are attached to nerves in your inner ear. When the crystals move, it stimulates the nerves to fire, which tells the brain your head is moving. This crystal matrix serves as a reliable motion-sensing map—until crystals break free, drifting into one of the ear's three semicircular "balance" canals, and create havoc.

**Why do loose crystals make you dizzy?**—Normally, the fluid in the semicircular canals and the small, direction-sensing cupula in your inner ear move only when your head moves. "When the crystals are all connected, the fluid in the canals settles down as soon as your head stops moving," says Dr. Cherian. "But when the crystals are disconnected, they keep moving in the fluid for up to a few seconds afterward. The condition, called [benign paroxysmal positional vertigo \(BPPV\)](https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/benign-paroxysmal-positional-vertigo), is downright scary because it takes you by surprise.

**Is there a treatment?**—Yes, a special physical therapy technique known as the Epley maneuver can realign the inner ear, go to <https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/home-epley-maneuver> for more info.





## 2021 MG Meetings and Events

The MGFA Annual Walk will be virtual in November. Watch this space next month for more info.

### 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:

**When: Oct 5, 2021 12:30 PM Eastern Time (US and Canada)**

**Register in advance for this meeting:**

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

**When: Oct 16, 2021 01:30 PM Eastern Time (US and Canada)**

**Register in advance for this meeting:**

<https://us06web.zoom.us/j/91989123456>

**Hope to see you soon on Zoom!**

### Answer Code to Halloween Rebus on pg.3.

- 5. TREAT
- 4. TRICK
- 3. MOON
- 2. EYEBALL
- 1. CAPE



### No In-Person Meetings planned for Northeast Ohio MG Support Groups

We will not be meeting in person until given the ok from the National MGFA.

We will continue to have our weekly Zoom meetings until it is determined that it is safe to meet in person again. Even after the pandemic has subsided, we will continue Zoom meetings for those who are unable to attend in-person meetings.

**NOTE:** If you can't make our Thursday Zoom meetings, check out the other virtual meetings at [www.myasthenia.org](http://www.myasthenia.org)



### 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.






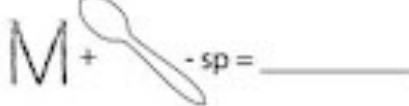







**Family and friends welcome!**



Name \_\_\_\_\_

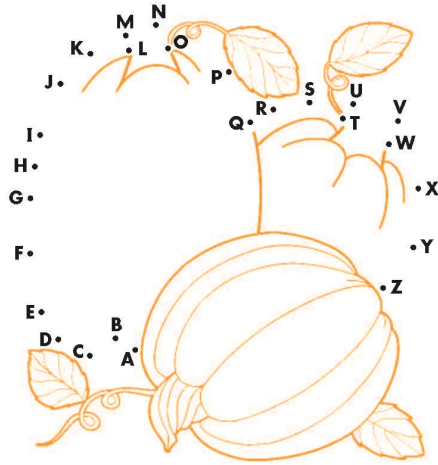
### Halloween Rebus Puzzles - Easier

In this puzzle, you need to break the rebus codes to discover words related to Halloween. To decode the rebuses, first identify the pictures and then add and subtract letters as required. If you figure them out correctly, the remaining letters will spell out a word! Can you decode them all?

-  1.  + E = \_\_\_\_\_
-  2.  +  = \_\_\_\_\_
-  3. M +  - sp = \_\_\_\_\_
-  4.  - sa +  - e + K = \_\_\_\_\_
-  5.  - i +  - b = \_\_\_\_\_

## Big and Orange

Connect the dots from A to Z.



Additional free resources available at [www.carsondellosa.com/freebies](http://www.carsondellosa.com/freebies).  
For more great educational products, visit [carsondellosa.com](http://carsondellosa.com) or your local retailer.

## DID YOU KNOW?

Did you know that frequent rest breaks help you to stay strong? So if you feel your energy fading, chill out with a cool drink of water or juice and take some time to relax. You may only need to pause a few minutes before you feel your energy start to increase.

Have some "down time" activities planned such as listening to music, watching a favorite show, or other things you can do sitting down such as coloring, reading (if you're not having double vision), or jigsaw puzzles.

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

### Safe Swallowing Techniques

For some of us swallowing is a challenge. 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 techniques:

- Pay attention when eating, concentrate on chewing, never talk while eating, and take small bites
- Eat softer foods when having problems, avoid tough cuts of meat
- 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
- Train yourself and others on the [Heimlich Maneuver](#)



## LOCAL MGFA GROUP WEBSITE

Visit us at [www.clevelandmggroup.org](http://www.clevelandmggroup.org)

Be sure and send in your MG related questions for our **Ask the MG Expert** column

Email at [clevelandmggroup@gmail.com](mailto: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](mailto: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.togetherrxaccs.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>



**I've learned there are three things never to discuss with people: religion, politics, and the Great Pumpkin.**

### UPCOMING OCTOBER MEETINGS:

**MG Patients, Family, and Friends—Every Thursday at 3:00 pm via Zoom (see page 1)**

**International Parents of MG Kids October 5th 12:30 pm and October 16th 1:30 pm (see page 2)**

Thank you to our sponsors:

