

## OCTOBER 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](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/meeting/register/tZEscu6upj0jEtM2-2ufaXHfQh2bJ9k44v5A>

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

Register in advance for this meeting:

<https://us06web.zoom.us/meeting/register/tZMvf-CgrTksHtTqPweK1aFU1zNdr4nmDyz5>

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

<https://us06web.zoom.us/meeting/register/tZlkdOuurjwvH9eCkX2bs2VietaEmGmjNkeW>

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

Register in advance for this meeting:

<https://us06web.zoom.us/meeting/register/tZ0ucOGvqD0oEtXwCbzPurKxj8mb2P4SrrNH>

## 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/home-epley-maneuver), 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 this year. Stay tuned for more information

### 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/84451220663>

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

**Register in advance for this meeting:**

<https://us06web.zoom.us/j/84451220663>

**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](mailto: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.

### 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!**



## In Memorial

We recently lost some special people who had a meaningful connection to our support group:



Nancy Law was the tireless leader of the MGFA and was our greatest advocate/supporter/ and friend. Most recently she was Chairman of the Board for the last two years. Here's what the MGFA posted about her: Our dear Nancy Law passed away on September 23rd and she touched us all in so many meaningful ways. We invite you to post a short tribute to our Tribute Wall in honor of Nancy. Use the form to add your name, email address, and your message, and we will post on the tribute wall.

<https://myasthenia.org/MG-Community/In-Loving-memory-of-Nancy-Law>



Betty Ball was an MG patient attending our Westside group. Betty J. Ball, age 84, passed away on September 14, 2021 in Medina, Ohio. She was born on January 23, 1937 in Cleveland, Ohio and is survived by her husband of 36 years, Daniel D. Ball; children, Rick (Anne-Marie) Springer and Deanna (Larry) Smith; 5 grandchildren, Sarah (Anthony) Galletta, Joan Graziano, Andrew Springer, Aerielle Springer, and Athena Springer; as well as a lifetime of collected friends. She is preceded in death by her daughter, Pam Springer; Grandson, Benjamin Springer; parents; siblings, George, John, Mike and Mary Ann.



STOW -- Roy Allen, age 80, passed away at home July 17, 2021, after a lengthy battle with myasthenia gravis. He was born in Cincinnati to Joseph and Waneta Allen of Norwood, and was a graduate of Columbian High School and a 1978 Kent State graduate. He leaves behind his homecoming queen wife, Joyce (nee Blosser), of 57 years; two sons, Joshua (Becky) of Lebanon, NH and Judson (Mollie) of Doylestown; six grandchildren, Connor and Emma of New Hampshire, Ellie, Sebastian, and Ainsley of Doylestown, and Michael, U.S. Navy; sister, Darlene Ervin of Gerrardstown, WV and niece, Deirdra of Bruceton Mills, WV.



Husband of Drema, an MG westside attendee, Larry K. Swimm "Keith", 76 of Richfield passed away Saturday, July 24, 2021 surrounded by his loving family. Larry was born March 27, 1945 in Logan, West Virginia to William Earl and Mary Princess Swimm. He was a longtime resident of Richfield, Ohio after serving in the Army during the Vietnam War. He is survived by his loving wife of 52 years, Drema Swimm (Pauley) of Richfield; his daughters, Angela Peyton (Joey) of Richfield and Crystal Swimm of Brooklyn Heights; grandchildren, Colton "Nimrod" and Rachael Peyton of Richfield, Brittany Blasinsky (Joe) of Parma and Brent and Brandon Blasinsky both of Brooklyn Heights; brothers, Terry (Noretta) Swimm of Tennessee, Jerry Swimm of Ohio and Freddie (Marcella) Swimm of Indiana; and many nieces and nephews.



**Participants Needed—Calling AChR positive generalized MG patients age between 18-75**

For Phase III Trial of Zilucoplan.

For more information about enrolling in this study, visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and enter study # NCT04115293 in the "other terms" search box. You could also email [UCBCares@ucb.com](mailto:UCBCares@ucb.com) or call 844-599-2273 to learn more

## 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.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>



**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:

