



Supporting the MG Community  
in Ohio & Beyond

# MG OHIO NEWSLETTER

OCTOBER 2022

Volume 10 Issue 10

## MG Ohio

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Dr. Yuebing Li	Jerry Molitoris
Sharon Rastatter	Saul Wiener

We are here for you and your family to provide help and hope for those living with Myasthenia Gravis in Ohio and beyond.

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:  
[MGOhio.org](http://MGOhio.org)

### Help out MG Ohio:

If you use the following link to sign up for Rare Patient Voice, MG Ohio will receive \$5 for every person chosen to participate. That money goes towards helping to fund this newsletter and run our support groups. [Click here](#) to sign up.



## September's Thursday Afternoon ZOOM Meetings

Oct 6, 2022 03:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJ0tdOqprD4rGN8jdHEK94ss718J4uMzQpP>

Oct 13, 2022 03:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJApcO6sqDloHdAvD9m9yTTI0s79grbjY9tg>

Oct 20, 2022 03:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJErdGvpzwoGdbnk2j41135cKNNCUx2rNqp>

Oct 27, 2022 03:00 PM Eastern Time (US and Canada)

[https://zoom.us/meeting/register/tJEkcCsrDkqGtH\\_QV4X5qgEZLowsToi272V](https://zoom.us/meeting/register/tJEkcCsrDkqGtH_QV4X5qgEZLowsToi272V)

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



## Next In-Person Meeting—

October 8, 2022 1:30 – 3:30 pm  
Parma-Snow Branch Room A/B  
Cuyahoga County Public Library  
2121 Snow Rd. Parma, OH 44134

New Time!

Speaker—Donna D'Amico, KAZ Company  
Come learn about the changes in Medicare and Insurance plans for 2023

Light refreshments will be provided.



MG Ohio is a 501(c)(3) designated non-profit

## Ask the MG Expert

Q. Is there a special diet recommended for MG?

A. While eating a balanced diet is recommended by most physicians, some patients have found that eating an anti-inflammatory diet has helped with lowering adverse immune response.

For patients taking immune-suppressants, there are certain recommendations for your diet:

- Avoid raw or rare meat and fish and uncooked or undercooked eggs. Cook meat until it's well-done.
- Thoroughly cook eggs (no runny yolks) and avoid foods containing raw eggs such as raw cookie dough or homemade mayonnaise.
- Avoid unpasteurized beverages, such as fruit juice, milk and raw milk yogurt.
- Avoid salad bars and buffets.
- Consume only pasteurized milk, yogurt, cheese and other dairy products.
- Avoid soft mold-ripened and blue-veined cheeses such as Brie, Camembert, Roquefort, Stilton, Gorgonzola and Bleu or other soft, unpasteurized cheeses.
- Avoid raw sprouts, such as alfalfa sprouts.
- Wash fresh fruits and vegetables before peeling.
- Avoid well water unless it has been tested, filtered, or boiled for one minute before drinking. At home, it's okay to drink tap or bottled water.

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Northeast Ohio In Person Events and Support Group Meetings:

October 8—1:30—3:30 pm

Meeting @ Parma-Snow Library Donna D'Amico, KAZ  
2121 Snow Rd How to choose the best insurance plan for you

October 29—10 am -2 pm

Come Celebrate the Cleveland to Cincinnati Walk-a-thon  
7565 Avon-Belden Rd., North Ridgeville 44039

November 2 or 3, 2022 TBD

Dinner with Crystal Brown, Alexion PEM

NOTE: This is not sponsored by MG Ohio. Here is what Crystal says: I will be hosting a dinner program on November 3rd at 6:30pm. I'm awaiting confirmation on the venue location, but it will be in Independence, OH. The presentation will be focused on Ultomiris.

December 3 or 10, 2022 TBD

Annual Christmas Party Macaroni Grill

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Cincinnati Area Support Group Meetings:

November 12, 2022 1-3 pm

Mayerson JCC 8485 Ridge Road, Cincinnati, Ohio 45236.

(Take the Ridge Road Exit from the Ronald Regan Highway)



**Introducing the Cincinnati Area Support Group Leaders:**

**Sharon Meyer**—Sharon became involved in facilitating a Cincinnati based MG Support Group in 1986, after her diagnosis in November of 1984. With the help of a core group, the group has grown over the years and she now works with co-facilitators Jack and Sue Paas. They look forward to making their SW Ohio Group known to more people looking for help in their area of Ohio and continuing to grow their friendship and bonds with current members.

Sharon is a wife of Jim (48 yrs), mother of 4 adult sons and grandmother of 7(almost 8!) She has a degree in Music Performance and taught private piano in addition to spending 40 years in music ministry.

**Jack & Sue Paas**—Jack and Sue gradually became involved in helping facilitate the Cincinnati-based MG Support Group. They assist with the bi-monthly meetings, facilitate the meetings when Sharon is not available, and participate in Support-Group planning. Their 43-year old son has congenital-MG. Showing no improvement after his thymectomy-surgery at age 13, they were referred to the Mayo Clinic in Minnesota (where it was determined that their son has congenital-MG).

Jack and Sue joined the Cincinnati-based MG Support Group (led then by Sharon Meyer, and supported by Herb Byer) upon receiving their son's original diagnosis (30-years ago). They also joined MGFA, and have participated in six annual MGFA National Meetings (held during the 1990's and 2000's).

Jack and Sue have been married 53-years, have three children, and one grandson. Both Jack and Sue are retired after long work-careers. Sue is a RN, who worked in local hospitals, and then for 30-years in a family-practice. Jack is an engineer, who worked in the aviation-business for 47-years.

## Clinical Trial Now Recruiting (including sero-negative myasthenia gravis)

### Study of Nipocalimab Administered to Adults With Generalized Myasthenia Gravis

Nipocalimab (also referred to as JNJ-80202135 or M281) is a fully human, aglycosylated immunoglobulin (Ig)G1 monoclonal antibody (mAb) designed to selectively bind, saturate, and block the IgG binding site on the endogenous neonatal Fc receptor (FcRn). This study will consist of a screening phase (up to 4 weeks), treatment phase (a 24-week double-blind placebo-controlled phase, and an open-label extension [OLE] phase [up to 2 years]) and a follow-up safety visit (up to 8 weeks after last infusion of study intervention). Efficacy evaluations will include assessments such as Myasthenia Gravis - Activities of Daily Living (MG-ADL) score. Safety evaluations (such as adverse events, physical examination, vital signs, electrocardiogram [ECG], and clinical laboratory tests) will be performed. The overall duration of study will be up to 4 years and 8 months.

This study is actively recruiting in Ohio at

University of Cincinnati Cincinnati, Ohio, United States, 45219

Cleveland Clinic Cleveland, Ohio, United States, 44145

The Ohio State University Columbus, Ohio, United States, 43210

For more information see <https://clinicaltrials.gov/ct2/show/NCT04951622?term=Nipocalimab+Infusion&draw=2&rank=2>

### Speaker's Bureau—Special Monthly Talks by our Dedicated Physicians

What would YOU like to know? Each month one of the physicians serving on the MG Ohio Board of Directors will speak on a subject YOU suggest. Dr. Yuebing Li started us off with MG 101 in September via Zoom. In November, Dr. Ben Clayton will be speaking on an MG topic you wish to learn about. So let us hear from you!

Send your questions to [mgohio@mgohio.org](mailto:mgohio@mgohio.org)

### Meet Your Mg Ohio Board—



Hani Kushlaf, MD, FAAN, FANA, FAANEM

Hani Kushlaf, MD, is Associate Professor of Neurology and Pathology at the University of Cincinnati. He is the Director of Research in the neuromuscular division, the Director of the MDA Care Center, and the Director of the Neuromuscular Medicine Fellowship Program in the Department of Neurology & Rehabilitation Medicine at the University of Cincinnati in Cincinnati, Ohio. He is also a neuromuscular physician at the Comprehensive Neuromuscular Center at Cincinnati Children's Hospital and Medical Center. Dr. Kushlaf received his MD from Tripoli Medical University in Tripoli, Libya. He completed neurology residency training at the University of Kentucky, where he was chief resident, and then continued to subspecialize in neuromuscular medicine, completing three fellowships in muscle disease and peripheral nerve disorders at the Mayo Clinic in Rochester, Minnesota, and advanced neuromuscular medicine fellowship at Duke University. Dr. Kushlaf is board certified in neuromuscular medicine, electrodiagnostic medicine, neuromuscular ultrasound, and clinical neuromuscular pathology.

Dr. Kushlaf practices at the University of Cincinnati Gardner Neuroscience Institute (UCGNI) in Cincinnati, OH.

Dr. Kushlaf won several awards from national associations including Top Doctor awards. Dr. Kushlaf is a fellow of the American Academy of Neurology (AAN), the American Neurological Association (ANA), and the American Association of Neuromuscular and Electrodiagnostic Medicine (AANEM).

Dr. Kushlaf's principal clinical interests include autoimmune and hereditary neuromuscular disorders. Of these, myasthenia gravis is on top of the list. Dr. Kushlaf serves as a principal investigator on several clinical trials, as an Ad Hoc reviewer for several neurology journals, and is on the Editorial Board of Muscle & Nerve.

## MG Ohio Website:

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

Have questions or comments? Send in your MG related questions to our **Ask the MG Expert** column

Email at [mgohio@mgohio.org](mailto:mgohio@mgohio.org)

### 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://GoodRx.com)

<http://www.themedicineprogram.com/>

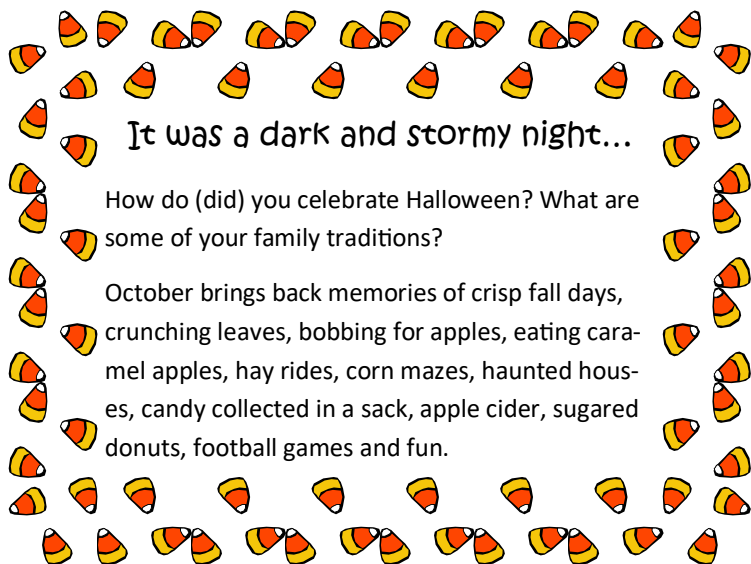
<http://www.togetherrxaccess.com/p/prescription-savings>

<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>



### UPCOMING OCTOBER 2022 MEETINGS:

**In Person—October 8th Parma Snow Library 1:30 –3:30 NOTE: New Time!**

**2121 Snow Rd. Room A/B**

**Zoom Meetings—Thursdays 3:00 pm ET via Zoom (see page 1)**

**OPEN CHAT now every Saturday night at 7:00 pm ET via Zoom (click bellow to register)**

<https://zoom.us/meeting/register/tJ0qduytrT4jH9KSiOgggP8G0xHTCjcYC6b1>