



# MG OHIO NEWSLETTER

July 2023

Volume 11 Issue 7

Supporting the Myasthenia  
Community in Ohio & Beyond

## MG Ohio

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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 (leave a message)

You will find a wealth of information at the website:

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

Want to donate to MG Ohio?

[Contact us](#) to find out how.

Help out MG Ohio:

Use the link below 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.



We are taking a hiatus from the weekly Zoom meetings until August 10th in order to prepare for the MG Ohio Regional Conference (see article page 3)

**Congratulations to Jack Paas winner of a free night's stay at Holiday Inn Express-S Independence the night before the Regional Conference.**

### DO YOU READ THE NEWSLETTER? IT PAID OFF !

Congratulations to Jeanine Haney and John Gerald for being the first two to find the correct amount of teal awareness ribbons.

The answer was 35. They both won a \$10 gift card to Panera.



### UCB Announces FDA Approval of RYSTIGGO®

RYSTIGGO® (rozanolixumab-noli) is a new subcutaneous treatment for gMG patients with AChR or MuSK antibodies. This is the first of its kind with a less invasive sub-cue (under the skin) infusion treatment plan. FDA approval was given after a large Phase 3 trial known as the MycarinG Study showed significant improvement in Activities of Daily Living (ADL) scores for those patients receiving the treatment .

### Ask the MG Expert

**Q. When is a thymectomy appropriate for treating myasthenia gravis?**

A. Myasthenia gravis (MG) is a neuromuscular disease in which the immune system produces abnormal antibodies that destroy muscle receptors for acetylcholine, a neurochemical that activates the muscles and causes a contraction. Antibodies can also target molecules that enable acetylcholine receptors to work properly. Damage to the part of the muscle that reacts to chemical signals from nerve impairs muscle's ability to contract each time signaled to do so by nerve, causing muscle weakness that affects the ability to swallow and move limbs and eyes. Common symptoms include double or blurred vision, drooping eyelids, and difficulty speaking.

The thymus gland—located in the upper chest beneath the breastbone—is thought to be associated with MG as it may trigger and control the production of immune cells that regulate production of the antibodies that damage acetylcholine receptors or that injure molecules that enable the receptors to work properly. About 10 to 15 percent of people with MG also have tumors on their thymus glands, called thymomas, which are usually benign. A CT scan to detect thymomas is part of the medical evaluation for people with MG. Almost 100 years ago surgeons discovered that removing thymomas in people with the disease improved their symptoms. Researchers subsequently discovered that removing the gland itself improved symptoms in people with MG who didn't have thymomas.

(cont. page 3)



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

MG Ohio

July 22—1:00-3:00 pm

Northeast Ohio In-Person Support Group Meetings:

East—Mayfield Library (medium meeting room)

500 SOM Center Road, Mayfield Village, Ohio 44143

MG Ohio

Central Ohio In-Person & Zoom Support Group Meetings:

Join us at the Regional Conference, August 26, 2023

MG Ohio

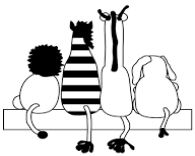
Cincinnati Area In-Person Support Group Meetings:

July 8 —1:00-3:00 pm

Mayerson JCC 8485 Ridge Road, Cincinnati, Ohio 45236.

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

RSVP to [Sharon Meyer](#)



**Announcing New MG Friends Program**

We are pleased to announce a new program for the MG community: the MG Ohio Friends Program.

This is a peer-to-peer phone support program connecting experienced patients and caregivers to other patients and caregivers. In many cases, the first connection will take place after a new diagnosis of MG is made.

MG Friends are trained volunteers who have had MG or have cared for someone with MG for at least a year, many times much longer. Friends offer caring support, answer questions and guide participants towards trusted information and resources. Connections can continue as long as is helpful.

With any major life change, questions are many and pressing. An MG Friend is – first and foremost – a listener. They are there to help on your journey from a being a new patient with MG to – eventually – your old self again, but with MG. As some put it: “I may have MG, but MG does not have me.”

MG Friends do not offer medical advice, or judgments about treatment plans and/or therapies, or any type of products or services. They are not mental health practitioners and do not offer emotional or psychological therapy. However, Friends can guide participants to medical information that has been vetted by board certified neurologists who are knowledgeable in MG. This information includes links to online information, webinars, printed materials and other forms of education.

MG Friends can also help with practical day to day tips on living with MG. At times, an MG diagnosis calls for changes in the manner in which one goes about their daily lives. An MG Friend has “been there and done that” and can provide much needed information on a variety of ways to returning to a more usual pattern of living. Energy conservation, better sleeping habits, exercise, talking to others about MG (when indicated), and many other topics can be covered.

If you are interested in being paired with an MG Friend, please ask your local support group leader and they will connect you with someone. Connections are one of the most important parts of our journeys in MG. We hope you are as excited about this program as we are!

### Ask the MG Expert (continued from page 1)

Today, the procedure, called a thymectomy is one of the ways to treat MG. Other therapies include drugs such as the steroid prednisone that suppress antibody production; plasmapheresis, which removes antibodies from the blood; and high-dose intravenous immunoglobulin, which delivers healthy antibodies from donated blood to temporarily fortify the immune system. Neurologists typically start patients on drugs even if a thymectomy is being considered since it can take a year or more for a thymectomy to be fully effective and not everyone achieves remission after the surgery.

A study in the *New England Journal of Medicine* in 2016 compared the results of a thymectomy plus prednisone versus prednisone alone in 126 people ages 18 to 65 who had generalized MG without thymomas and found that the thymectomy-prednisone combination resulted in improved symptoms, fewer hospitalizations, and a reduced dose of steroids for many participants. A follow-up [study](#) published in 2019 in *The Lancet Neurology* found that five years later thymectomy plus prednisone continued to benefit patients compared with prednisone alone.

The effectiveness of a thymectomy in reducing or eliminating symptoms depends on age, duration and severity of the disease. Remission can be as high as 70 percent a year after surgery. The operation is not usually recommended for people older than 60, who have types other than generalized antibody-associated MG, or whose weakness is limited to the eye muscles.

A thymectomy can be performed via open-chest surgery—which involves cutting the breastbone down the middle and opening the entire chest cavity to remove the gland—and robotic surgery, in which surgeons make small incisions and insert tiny robotic tools that they manipulate by looking at a video monitor. A 2019 study in the *Annals of Cardiothoracic Surgery* found that robotic thymectomy resulted in less blood loss, fewer post-surgery complications, a shorter hospital stay, and more thymus tissue removed than open-chest surgery. During the procedure the entire gland is removed as well as surrounding fat which may contain small amounts of thymus.

Patients usually spend a few days to a week in the hospital while they recover. Returning to pre-surgery activities such as driving and lifting heavy objects will depend on the type of surgery, overall health, and rate of recovery. Patients usually continue any medications they had before surgery. During follow-up appointments, doctors can determine if and how to taper dosages.

For many patients, symptoms begin to improve within a year of the surgery, and some go into remission permanently and no longer experience weakness or take medication.

Thymectomies are generally covered by insurance, but patients may need to document the type of surgery and reason for it. In addition, some insurers only cover the procedure if the surgeon is in their network.

*Dr. Ruff is professor emeritus of neurology and neuroscience at Case Western Reserve University School of Medicine in Cleveland.*

**EDITOR'S NOTE:** This article by Dr. Ruff first appeared in the July 2023 edition of *Brain and Life* magazine.

## Don't Delay! Register Today! MG Ohio Regional Conference—Gathering Together Growing Stronger

### Here's the Conference Agenda

#### Check-in and Continental Breakfast 9:30—10:00 am Main Hall & Vendor Room

##### Main Auditorium—first floor

**Session 1**-10:00-10:45 —Exercise, PT, & MG

**Session 2**-11:00-11:45 —Safe Chewing, & Swallowing & MG

**Lunch 12:00-12:45 and chance to visit vendor space**

**Session 4**-1:00-1:45—MG & Aging

**Session 6**-2:00-3:45—Latest MG Treatments

**Session 9**-4:00-4:45—Ask the MG Expert Panel of Speakers

##### ADMIN Auditorium— second floor (elevator available)

**Session 3**-11:00-11:45 —Insurance Q & A

**Lunch 12:00-12:45 for MG Ohio Board Members**

**Session 5**-1:00-1:45—MG 101

**Session 7**-2:00-2:45—Staying Positive with MG

**Session 8**-3:00-3:45—Preparing for Emergencies

To register click or go to :<https://mgohio.org/regional-conference-1>

**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://rarediseases.org/patient-assistance-programs/financial-assistance/?search=myasthenia%20gravis>—accepting new applications

<https://www.needymeds.org/>

[Good Rx.com](http://www.themedicineprogram.com/)

[http://www.themedicineprogram.com/](http://www.togetherrxaces.com/p/prescription-savings)

<http://www.togetherrxaces.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/> - for patients living in Indiana, Illinois, and Wisconsin

More info at: <https://myasthenia.org/Community-Resources/Resources-External-Assistance-Programs>

Don't forget to register for the Regional conference!  
<https://mgohio.org/regional-conference-1>  
Or call 216-218-0477 and leave a message!



**Need a Ride? Provide a Ride?**  
If you're in need of a ride to doctor's appointment, we have people who have volunteered to drive.  
If you are able to drive someone to an appointment contact me.  
For more info—[mgohio@mgohio.org](mailto:mgohio@mgohio.org)

**UPCOMING JULY 2023 MEETINGS:**

**In Person—**

**July 8 —1:00-3:00 pm**

**July 22—1:00-3:00 pm**

**Save the Date—**

**August 25, 2023 5-7 pm**

**Cincinnati—Mayerson JCC 8485 Ridge Road, Cincinnati, Ohio 45236.**  
**Cleveland East—Mayfield Library (medium meeting room)**  
**500 SOM Center Road, Mayfield Village, Ohio 44143**  
**Pre-Conference Meet & Greet Impulse Lounge Holiday Inn-S**  
**6001 Rockside Rd., Independence 44131**