



# MG OHIO SOUTHWEST Snowflake Newsletter

Spring 2025

Dear Readers,

**This is our first MG Ohio Southwest Snowflake Newsletter. The purpose of this newsletter is to provide clinical information provided by professionals and experts about Myasthenia Gravis that includes different health issues, news, personal stories, and/or updates, etc. We hope these articles will guide you through various methods of supporting yourself**

**or a loved one with MG, from practical help to emotional help. If you have any requests or suggestions of topics that you would like to see in our next newsletter that will come out in Fall 2025, please email [mgohiosouthwest@gmail.com](mailto:mgohiosouthwest@gmail.com). We will be sending out this special "Snowflake Newsletter" twice a year! Spring and Fall!**

**Thank You!**



## **Title: The Crucial Role of Clinical Trials in Advancing Myasthenia Gravis Research**

**Hani Kushlaf, MD, Department of Neurology & Rehabilitation Medicine, University of Cincinnati, Cincinnati, Ohio.**

Myasthenia gravis (MG), a chronic autoimmune neuromuscular disorder, presents unique challenges to both patients and healthcare providers. Despite advances in treatment, there remains a significant need for continued research to better understand and manage this complex condition. Clinical trials play a pivotal role in this endeavor, yet patient participation remains disappointingly low. It is imperative that we address this gap to foster advancements in MG research.

Clinical trials are the cornerstone of medical progress. They provide the structured environment necessary to evaluate the safety and efficacy of new treatments, offering hope for more effective therapies and improved quality of life for patients. In the context of MG, clinical trials have been instrumental in introducing innovative therapies, such as monoclonal antibodies and complement inhibitors, which have transformed the treatment landscape. These trials not only test new drugs but also explore novel approaches to disease management, including lifestyle interventions and diagnostic tools.

However, the success of clinical trials hinges on patient participation. Without sufficient enrollment, trials cannot yield statistically significant results, delaying the introduction of potentially life-changing treatments. For patients with MG, participating in clinical trials is not just a personal decision—it is a contribution to the collective effort to advance scientific knowledge and improve care for all individuals affected by the disease.

Despite the clear benefits, there is a noticeable lack of enthusiasm among patients regarding participation in MG clinical trials. This reluctance can be attributed to several factors, including fear of the unknown, concerns about side effects, and the perceived inconvenience of trial protocols. Additionally, there may be a lack of awareness about available trials or misunderstandings about the potential benefits of participation.

To overcome these barriers, it is essential to foster a more supportive and informative environment for patients. Healthcare providers play a crucial role in this process by actively discussing clinical trial opportunities with their patients and addressing any concerns they may have. Moreover, patient advocacy groups and research institutions should collaborate to increase awareness and accessibility of trials, highlighting the critical role participants play in advancing MG research.

Ultimately, the journey to better treatments and, hopefully, a cure for myasthenia gravis depends on the willingness of patients to engage in clinical research. By participating in trials, patients contribute to a legacy of scientific discovery that extends beyond their own care, paving the way for future generations to benefit from improved therapies.

In conclusion, while the current lack of enthusiasm for MG clinical trials is a challenge, it is one that can be addressed through education, advocacy, and support. By encouraging patient participation, we can accelerate the pace of discovery and bring new hope to those living with myasthenia gravis. Let us work together to ensure that clinical trials are not just an opportunity, but a priority for advancing the field of MG research. ■



## "TOTAL EXHAUSTION"

Jane Marla Robbins

excerpt from

*Myasthenia Gravis: The Musical!*

(p.81)

MG Fatigue, like a lazy wolf,  
suddenly sleeps on top of me  
Its fur coat stultifying, suffocating.

Have to learn to sleep with it,  
nap with it, surrender.

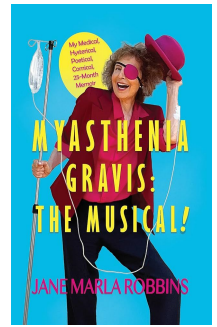
This wolf, not in sheep's clothing,  
Has brutally pulled me to the ground.

But I must fight

I am Little Red Riding Hood  
And my grandmother is dead

He doesn't even pretend to be her,  
drapes over me as if he would melt,  
like a hot blanket, like a Dali clock.

And I haven't the slightest clue,  
at all, about what time it is.



## Title: Five Reasons to Refer Your MG Patient to PT—And Why It Matters

Liz Plowman, PT, DPT, M.Ed, MG Physio

**MG-specialized PT, patient and disability advocate, and the author of *Some Spoons Are Worth Spending: Practical Energy Conservation Strategies to Live Your Best Life With Myasthenia Gravis*.**

Physical therapy (PT) is often overlooked in Myasthenia Gravis (MG) management, yet it plays a critical role in maintaining mobility, preventing falls, and preserving independence. Many MG patients reduce activity due to fatigue or fear of exacerbation, leading to deconditioning, increased fall risk, and unnecessary reliance on caregivers. A well-timed PT referral can help patients maintain function and improve quality of life.

### 1. Struggles with Daily Movement

Proximal muscle weakness, fluctuating endurance, and fatigue make walking, stair navigation, and rising from a chair increasingly difficult. Many patients compensate with poor movement patterns, leading to joint pain and excessive energy expenditure.

A PT can assess gait, posture, and movement efficiency to reduce fatigue and improve mobility. Transfer training, stair navigation techniques, and postural adjustments help patients remain independent at home and in the community.

*When to refer: Your patient reports difficulty walking, increased fatigue with movement, or avoiding daily tasks.*

### 2. Falls, Near-Falls, and General Unsteadiness

Falls in MG are often underreported but can have serious consequences. Fatigue-related instability, core weakness, and postural control deficits increase the risk. Many patients limit movement out of fear, leading to further deconditioning and dependence.

PTs conduct fall risk assessments and develop balance and gait training programs tailored to MG's fatigue patterns. Proprioceptive exercises and safety strategies improve stability and confidence.

*When to refer: Your patient has experienced a recent fall, frequent near-falls, or appears hesitant while walking ("furniture surfing").*

### 3. Post-Exacerbation Recovery

After an MG exacerbation or hospitalization, many patients struggle to regain strength and endurance. Some push too

hard and worsen fatigue, while others avoid activity altogether, leading to further decline.

PT provides structured reconditioning to rebuild mobility and endurance without over-fatigue. Postural training and breathing mechanics can improve function after exacerbations affecting respiratory muscles.

*When to refer: Your patient recently increased medication dosages, was hospitalized for MG-related weakness, or reports ongoing functional decline.*

### 4. Assistive Devices—The Right Tool, the Right Time

Many MG patients resist using mobility aids, believing it signals loss of function. In reality, the right device helps conserve energy and maintain independence.

PTs determine whether a cane, rollator, wheelchair, or other mobility device is appropriate, ensure a proper fit, and train patients in safe use. PT guidance also helps overcome psychological barriers to using devices effectively.

*When to refer: Your patient struggles with fatigue while walking, avoids outings due to mobility concerns, or resists using an assistive device despite instability.*

### 5. Losing Independence

Many MG patients slowly withdraw from hobbies, social events, and travel—not because they want to, but because movement feels exhausting or unsafe. Avoiding activity accelerates decline, making it harder to regain lost function.

PT helps patients stay active without overexertion by teaching pacing strategies, modifying functional movements, and integrating safe exercise into daily life. By tailoring interventions to each patient's goals—walking on vacation, gardening, or returning to work—PT empowers them to stay engaged in what matters most.

*When to refer: Your patient has stopped meaningful activities or expresses frustration that they "can't do what they used to."*

### Final Thoughts: PT Helps MG Patients Maintain Their Independence

PT is an essential but underutilized part of MG care.

Whether addressing mobility, fall prevention, post-exacerbation recovery, or functional independence, PT provides the tools patients need to stay active, safe, and self-sufficient. ■



ARE YOU AFFECTED BY MYASTHENIA GRAVIS, LEMS, OR CMS?



[www.mgohio.org](http://www.mgohio.org)

### Our Mission:

MG Ohio is committed to supporting those living with myasthenia gravis (MG) and MG related disorders as well as their caregivers, friends, family, and the greater MG community by providing information and support through education, community programs, and advocacy; and to raise awareness about MG and MG related disease.



# SOUTHWEST MG OHIO SUPPORT GROUP



WE MEET MONTHLY ON  
THE 2<sup>ND</sup> SATURDAY FROM  
1 PM - 3 PM

AT THE

MAYERSON JCC

8485 RIDGE AVE., CINCINNATI, OH 45236

FOR MORE INFORMATION ABOUT JOINING  
PLEASE CONTACT THE SUPPORT GROUP LEADER, ERICA AMANN  
AT [MGOHIOSOUTHWEST@GMAIL.COM](mailto:MGOHIOSOUTHWEST@GMAIL.COM)

We would love to have you join our support group!

THESE MEETINGS ARE OPEN TO ANYONE AFFECTED BY MYASTHENIA GRAVIS  
INCLUDING AND NOT LIMITED TO PATIENTS, SPOUSES, CAREGIVERS, PARENTS, ETC.

## Order MG OHIO T-SHIRTS!

Option to Purchase T-shirt to wear to represent our group. This t-shirt would be purchased at the cost of the shirt, with no one making any extra money from it.

### Why SHOULD you purchase a MG Ohio T-shirt?

1. It helps spread awareness about our support group when you wear it.
2. We can wear them as a group when we have a group outing and we look more unified.
3. They would be great to wear on the 2nd day of the conference this summer.
4. It gets people to ask questions about MG that may not be aware, so again bringing more awareness.

Click on the link to order:

<https://forms.gle/fATumB8eSSnxW96e8>

**YOU MUST ORDER BY APRIL 11TH**

T-Shirts cost \$15 each + \$1 to ship for Central or Northeast  
Available sizes: S, M, L, XL, 2XL, 3XL, 4XL





**MG's primary symptoms fluctuate, vary in severity and occur in many combinations. Because it is unique from person to person, It is often referred to as The Snowflake Disease.**

## **Healing Starts Here: The Power to Make Small Changes and Move Forward**

**Vickie Petz Kasper, M.D.**

<https://healthylooksgreatonyou.com>

**Host of Healthy Looks Great on You – a lifestyle medicine podcast**

**Author of “Dressing the Wound: Give Yourself the Gift of Forgiveness.”**

**Diplomate of the American Board of Lifestyle Medicine and the American Board of Obstetrics and Gynecology**

How many times have you been asked, “Do you think stress caused you to develop myasthenia gravis?” or how about this one, “Does it run in your family?”

People are genuinely curious, but they're often worried about their own risks too. Because if you did something to cause your MG, then maybe they're safe. But it can feel like blame; as if it's your fault you have this disease. We do it to ourselves too, asking ourselves what we did or didn't do to cause life to be interrupted by weakness. Should we blame 5G cell phone towers, microplastics from cooking utensils, or too many diet soft drinks? Could it be aluminum in deodorant, breast implants or tattoos? Or maybe you stepped on a crack it totally freaked out your immune system and turned it against you.

I don't know, but for me, I blame butter. For many years before I developed MG, I was a self-described health nut. I didn't eat processed food and cooked healthy food for my family... unless you count all that butter. I mean what proper southern woman cooks without pounds of butter?

Well, me. Because now, I understand butter is terrible for my health and cholesterol. But I'm kidding about it causing MG. It didn't, and neither did any of those other things I mentioned.

It used to make me mad that I lived an intentionally healthy lifestyle and still ended up in a recliner barely able to walk, use my arms or chew my food. My pre- MG self had a rewarding career, was plugged into community, exercised every day, ate a balanced diet, managed stress and enjoyed positive relationships with family and friends. Even though I did all the things to optimize my health, I developed this frustrating disease.

Though it's not butter, there is no doubt that lifestyle affects health. Like many, I was prescribed high dose prednisone, which caused steroid-induced diabetes. While MG is frustrating, diabetes is miserable. Fortunately, it went away after I stopped the prednisone, but unfortunately, it started creeping back.

My doctor asked if I was willing to make radical changes in my lifestyle. I looked at him and said, "I'll do anything to not be diabetic." He recommended lifestyle medicine and it changed my

life, and health. I made the changes in my lifestyle and completely reversed the diabetes and as a bonus, lowered my cholesterol.

MG turned my life upside down and ended my 20-year career as an obstetrician/gynecologist. A couple of years later, after a thymectomy, handfuls of pills and countless infusions of IVIG, I returned to work in hospital administration. Then, fueled by success with lifestyle medicine, I obtained board-certification. This sub-specialty of conventional medicine focuses on 6 pillars of lifestyle for optimum health. The 6 pillars of lifestyle medicine are: nutrition, physical fitness, positive social connections, avoiding risky substances, stress management and restorative sleep.

Eighty percent of all diseases treated by primary care physicians can be treated, prevented and sometimes even reversed by lifestyle modifications. In fact, it's often the first line recommendation. Remember, that leaves 20% of diseases that cannot be altered by lifestyle. So, there's not always blame to assign. But regardless, lifestyle can optimize your health.

Of all 6 pillars in my previously healthy lifestyle, I neglected one – restorative sleep. It's not like I had much choice. I was an Ob doctor and babies come at all hours of the day and night. But I never valued sleep or rest. I'm not saying poor sleep caused my MG, but we know that there is a connection between the immune system and sleep.

In our culture, we underestimate the importance of rest and sleep. Now the medical field is recognizing the work that goes on in our bodies and our brains while we are getting our zzz's. Sleep is hard work and it is important work.

Poor sleep contributes to adverse health outcomes: physical, mental, and emotional. It's associated with an increased risk of cardiovascular disease, which is the number 1 killer of Americans. This includes high blood pressure, heart attack and stroke. Sleep is necessary for hormonal balance and lack of adequate sleep is associated with obesity and type 2 diabetes. Without good sleep, especially in mid-life, there is an increased risk of developing dementia. And the risk of depression goes up by 10-fold. Even some types of cancer have been linked to insufficient sleep. So it shouldn't be surprising that chronic sleep loss affects the immune system.

Sleep deprivation also affects the emotional center of your brain - the amygdala. Without enough sleep, this emotional control center becomes hyperactive. It's like having your emotional volume turned up to maximum. Things that normally wouldn't bother you suddenly become overwhelming.

Even if you have a debilitating chronic illness, you can make changes that make a difference. My passion is to share the benefits of lifestyle medicine, especially good sleep and the risky business of poor sleep, helping others get the rest they need without learning the hard way. Prioritizing sleep, and the other aspects of lifestyle can help restore emotional balance. Getting consistent, quality sleep, equips you to better handle life's challenges - including the ups and downs of living with MG.

Tune in to "Healthy Looks Great on You podcast," where I'll take you to mini medical school so you can learn to leverage the power of lifestyle medicine to optimize your health. Though it won't cure MG, it empowers you to make small changes that move you forward to better health. Don't let others, or yourself put the blame on your shoulders. You can take the first steps in your healing journey to better health. Because, healthy looks great on you. ■





# MG OHIO SOUTHWEST SUPPORT GROUP

## UPCOMING MEETINGS & EVENTS 2025 TENTATIVE CALENDAR



## MG OHIO SOUTHWEST TAX DAY...TAKE AWAY YOUR STRESS JOIN US FOR Coffee & Donuts



10:00 am

Hurts Donut, 12110 Mason Rd., Cincinnati, Ohio 45249

**All Meetings are at Mayerson JCC from 1 pm - 3 pm  
Located at 8485 Ridge Rd, Cincinnati Ohio 45236**

### April -

April 12th Meeting: Paul, Madison, Erica Leading  
with MGFA Conference Information  
Extra: April 15th Social - Coffee & Donuts, Hunts  
Donut, 12110 Mason Road, Cincinnati, Ohio 45249

### May -

May 10th Meeting: Lisa Cruz - Argenx  
Extra: May 21st Social Event Cincinnati Scavenger  
Hunt: Cincy's Grand City Sights starting @ 11 am

### June -

June 14th Meeting:  
Extra: June 21st - 22nd MG Walk and Patient  
Education Conference, Eastgate Mall & Holiday  
Inn, Eastgate, 4501 & 4601 Eastgate Blvd.,  
Cincinnati, Ohio 45245

### July -

July 12th Meeting:  
Extra: July 21st Social - Lunch Outing @ 12:30,  
Location TBD

### August -

Aug. 9th Meeting:  
Extra: Aug. 23rd Social Event - Ice Cream Social  
@ 2 pm, The Peach Cobbler Factory, 7736 Dudley  
Dr., West Chester, Ohio 45069

### September -

Sept. 13th Meeting:  
Extra: Reds Game, Sept. 25th @ 12:40 pm

### October -

Oct. 11th Meeting: LeeJean Beringer - Alexion  
Extra: TBD Social - Cincinnati Museum Center  
for their "Off the Rails: Halloween Edition at the  
Hall of Justice" event.

### November -

Nov. 8th Meeting: Argenx  
Extra:

### December -

Meeting: NONE  
Extra: Dec. 6th Christmas Party in Restaurant TBD

### DO YOU WANT TO BE IN THE KNOW?

IF YOU WOULD LIKE TO BE ADDED TO THE  
MG OHIO SOUTHWEST MAILING LIST TO  
STAY UP TO DATE MONTHLY, PLEASE SEND  
[MGOHIOSOUTHWEST@GMAIL.COM](mailto:MGOHIOSOUTHWEST@GMAIL.COM) AN  
EMAIL TO BE ADDED!



**When you have a rare disease, you face two battles. One being the illness itself, and the other living in a world so few people understand what you're up against.**

## Subgroups of Myasthenia Gravis

Often when meeting other MG friends they will often ask you what "type" of MG you have or if you are positive or negative. Some people are often confused by the language used, especially those first diagnosed. Sometimes, people never know what subgroup they belong to. This is a great thing you can ask your neurologist, as some treatments are directed to treat certain subgroups better than others. Other similar diseases to MG are Lambert-Eaton myasthenic syndrome (LEMS), Guillain-Barré syndrome, and congenital myasthenic syndromes, all of which involve muscle weakness and share some similarities in symptoms and mechanisms, though they differ in underlying causes and treatment approaches.

### AChR MG Subtypes

Antibodies against the AChR are found in approximately 80% of MG patients. At least half of the AChR autoantibodies are directed at the AChR  $\alpha$ -subunits. They are believed to be more pathogenic than those directed against the beta subunit. This is likely due to the location of the alpha subunit within the receptor, which leaves it more exposed to antibodies, as well as its role in modulating the receptor sensitivity to ACh binding. In addition, there are two alpha subunits per receptor. AChR antibodies are predominantly of the IgG1 and IgG3 subclasses. IgG2 and IgG4 subclasses are also identified, but in fewer cases. The pathogenic mechanisms and functional spectrum of AChR antibodies are varied, but overall, they impair receptor function by either binding, blocking, or modulating its activity.

### Ocular MG

Most MG patients with ocular symptoms at onset will progress to generalized forms of the disease, usually within two years of onset. Of the remaining, 90% will continue to have ocular manifestations only. Ocular MG is defined by isolated extra-ocular involvement for a period of greater than 2 years. Over half of the patients in this group have antibodies against AChRs.

### Generalized AChR Ab Positive MG (AChR-MG)

#### Early Onset vs Late Onset

Early-onset MG (EOMG) corresponds to patients presenting before age 50. There is a female predominance, with a female to male ratio of 3:1. Patients in this category have a higher incidence of thymic hyperplasia, and a thymectomy has been proven effective in improving clinical outcomes and minimizing the need for immunotherapy. Late-onset MG (LOMG) is defined by onset after the age of 50. There is no female predominance in this group; on the contrary, there can be a slightly higher prevalence among men, especially after age 60. Thymic hyperplasia is rare and response to thymectomy is poorer.

### Thymoma-Associated MG

MG is the most common paraneoplastic disorder associated with thymoma. About 50% of patients with a thymoma develop positive

AChR antibodies without clinical manifestations, and approximately 30% will develop MG. Conversely, 10–20% of patients with MG have thymomas. Though, response to a thymectomy is variable, and usually not effective in patients with LOMG.

### MuSK Antibody-Associated MG (MuSK-MG)

MuSK is a membrane protein that is critical to the clustering of AChRs in the neuromuscular junction. Agrin, which is secreted from the presynaptic terminal, interacts with Lrp4, resulting in the reorientation of the Lrp4/MuSK complex, which in turn leads to the activation of MuSK through its phosphorylation. Phosphorylated MuSK activates a downstream signaling pathway that leads to the clustering of AChRs. Antibodies against MuSK are found in approximately 7–10% of all MG patients and up to 40% of patients with generalized MG who are seronegative for AChR Abs. MuSK has a female predominance, with up to 85% positive patients being female. MuSK-MG predominantly affects young adults, and is more prevalent among patients of African descent and those living close to the equator in European and Asian nations. This is likely due to a genetic predisposition and not to environmental factors. Muscle weakness preferentially affects cranial and bulbar muscles. Over 40% of patients present with bulbar weakness, usually associated with neck and respiratory involvement. Some patients have tongue atrophy. About 30% of patients present with diplopia and/or ptosis. Limb weakness can be uncommon, but when present it tends to be severe and associated with muscle atrophy. Diurnal variations in strength are less common. Patients who are seropositive for both AChR and MuSK are rare, and it is not certain if they should be categorized as an MG subtype.

### Double-Seronegative Generalized MG

This is a heterogenous group of patients who share negative results for AChR and MuSK antibody testing. Cell-based assays can detect lower titers of these antibodies in patients previously reported as double-negative by more common serologic assays. It is likely that this subgroup of patients has antibodies against antigens not yet identified. In general, these patients present similar to those positive for AChR antibodies in regard to the distribution of muscle weakness, severity, and response to treatment. China, Zhang et al. demonstrated that the phenotype of double-seropositive patients is more severe than AChR-MG and more similar to the MuSK-associated MG.<sup>2</sup>

### Lrp4 Antibody-Associated MG (Lrp4-MG)

Lrp4 is the postsynaptic receptor of nerve-derived agrin. The binding of agrin to Lrp4 activates MuSK and initiates a cascade of events leading to the aggregation of AChRs in the neuromuscular junction. Lrp4 antibodies are present in 2–50% of double seronegative MG cases. Many Lrp4-MG patients also have antibodies against agrin. Lrp4 antibodies are mostly of the IgG1/IgG2 subclass and are believed to be directly pathogenic by disrupting the activation of MuSK. In patients with congenital myasthenic syndromes due to gene mutations in agrin, neuromuscular junctions are less stable and AChRs are more dispersed and un-clustered. Given these findings, the most likely pathologic mechanism of anti-Lrp4 antibodies is a reduction in AChR clustering. Other mechanisms are possible as well, as IgG1 can activate complement. There is a female predominance, and age of onset is variable, but most ...**Continued on page 7**





**"Believe in yourself  
our strength grows  
out of our weakness."  
– Ralph Waldo Emerson**

**Continued from page 6...**patients tend to present before age 50. Patients can present with ocular or generalized MG, but it is believed that symptom severity is overall milder in this subgroup. About 20% have only ocular symptoms after 2 years of disease. However, patients with a combination of anti-Lrp4 and anti-agrin antibodies may have more severe symptoms.

## **Pediatric MG**

Juvenile MG (JMG) is defined as MG in patients younger than 18 years of age. A meta-analysis of epidemiological studies estimated the incidence of JMG between 1 and 5 cases per million person-years]. JMG is, however, more prevalent in the Asian than the European populations. In other studies on the Asian population, JMG constituted up to 50% of total MG cases, mostly of ocular type. There is also a higher prevalence in patients of African descent compared to Caucasians. Pediatric cases constituted 10–15% of total MG cases in a US study. Similar to the young adults, JMG has a female preponderance. A total of 16–38% of JMG cases are ocular. Ocular JMG is more common in pre-pubertal children, and post-pubertal children tend to have a greater proportion of generalized MG. As ocular symptoms often occur during critical times during a child's development, there is a risk for long-term sequelae such as strabismus and amblyopia if this condition is not treated aggressively. The generalization of symptoms occurs in 20–25% of JMG patients, much lower than the rate of generalization in adults, which can be up to 80%.

1. Dresser L., Wlodarski, R., Rezaian, K., & Soliven, B. (2021). Myasthenia Gravis: Epidemiology, Pathophysiology and Clinical Manifestations. *J Clin Med*, 10(11):2235.
2. Zhang J., Chen Y., Chen J., Huang X., Wang H., Li Y., Liu W., Feng H. AChRab and MuSKAb Double-Seropositive Myasthenia Gravis: A Distinct Subtype? *Neurol. Sci.* 2021;42:863–869. doi: 10.1007/s10072-021-05042-3. ■

## **Pelvic Floor Dysfunctions in Myasthenia Gravis and the Role of Pelvic Floor Therapy**

### **Chandler Murray, OTD, OTR/L**

While, Myasthenia Gravis (MG) primarily causes weakness in muscles involved in movement and respiration, it can also have an impact on other systems, including the pelvic floor. Pelvic floor dysfunctions in individuals with MG can arise due to muscle weakness, fatigue, and impaired coordination, which can lead to bowel, bladder, and sexual symptoms.

## **Common Pelvic Floor Dysfunctions in Myasthenia Gravis:**

1. **Urinary Incontinence:** A significant percentage of individuals with MG experience urinary incontinence, often due to weakened pelvic floor muscles. The pelvic floor muscles are critical for bladder control, and when these muscles are weakened or fatigued by the autoimmune attack, it can lead to difficulties in maintaining control.
2. **Constipation and Bowel Incontinence:** MG can also affect the muscles involved in bowel movements, leading to constipation or even bowel incontinence. Individuals with MG may experience reduced muscle strength in the anal sphincter, which can impair the ability to control bowel movements. Medications used to manage MG symptoms, such as anticholinergic drugs, can also contribute to constipation.
3. **Pelvic Organ Prolapse:** Due to the weakening of the pelvic floor muscles, women with MG may be at risk for pelvic organ prolapse (POP), where the bladder, uterus, or rectum descends into or outside of the vaginal canal. This condition can result in discomfort, urinary and bowel issues, and sexual dysfunction.
4. **Sexual Dysfunction:** MG-related fatigue, muscle weakness, and impaired coordination may lead to reduced sexual sensation, discomfort during intercourse, and difficulties with arousal or orgasm.

## **How Pelvic Floor Therapy Can Help:**

Although the nature of MG leads to muscle weakness, pelvic floor physical therapy can help by strengthening the remaining muscle function and improving coordination.

1. **Pelvic Floor Muscle Exercises:** Tailored exercises can help strengthen the pelvic floor muscles, improving bladder and bowel control. These exercises may include gentle pelvic floor, glute, core, and hip exercises (bridges, modified plank, Kegels, clamshell, TA bracing), which can help improve muscle tone and reduce incontinence.
  2. **Education and Lifestyle Modifications:** Pelvic floor therapists can provide education on posture, body mechanics, toilet posture (Squatty Potty posture), toileting aids (toilet tongs, peri-bottle), energy conservation strategies, and strategies to reduce strain during daily activities (abdominal massage, double voiding). They can also teach bladder and bowel training techniques (urge suppression, timed voiding, etc.), which can help individuals manage symptoms like constipation and incontinence.
  3. **Relaxation Techniques:** Some individuals with MG may have a hyperactive pelvic floor due to compensatory muscle tension. Relaxation techniques such as diaphragmatic breathing and progressive muscle relaxation can reduce muscle tightness and improve overall pelvic floor function.
- MG presents unique challenges, but pelvic floor therapy can help by addressing muscle weakness, improving coordination, and offering personalized exercises. Thus, pelvic floor therapy provides essential support in managing incontinence, constipation, prolapse, and sexual dysfunction for individuals with MG. ■



# Join Us For Our 2nd Annual MG OHIO Southwest Awareness Walk!

## June 21, 2025

### 'Walk A Mile In Our Shoes'

This MG Ohio Southwest Walk is to raise critical funds for MG Ohio Southwest, to provide MG education, support, advocacy, and awareness for those affected by Myasthenia Gravis (MG). MG is an incurable, autoimmune neuromuscular disease. It causes extreme fatigue and profound muscle weakness. It can impact a person's ability to see, swallow, smile, walk, breathe, or engage in normal, everyday activities.

When you join our walk, you'll experience a profound sense of community, standing shoulder to shoulder with other MG Warriors and their supporters. No matter your mobility or ability, there's a way to participate and raise awareness of this devastating rare disease. They are only rare until they happen to you or a loved one!

There are **4 SIMPLE WAYS** you can support the awareness walk this year!

1. You can join as an individual to walk
2. You can start a team to walk together
3. You can donate to support a friend
4. You can purchase a 2025 Walk T-Shirt \$25 (Adult) or \$15 (Youth)

Once registered, all that's left is to fundraise for the walk, share your connection to MG, and tell your story of why you're walking for Myasthenia Gravis. Then invite your network to support you! Whether you choose to walk with us, join a team, purchase a t-shirt, or make a gift, your contribution brings us one step closer to making a difference.



**'WALK A MILE'  
IN OUR SHOES**

## Eastgate Mall

4601 Eastgate Blvd., Cincinnati, OH 45245

### JUNE 21, 2025

Check in starts at 9:30 AM

Walk is from 10:00 AM - 12:00 PM

**Registration Opens April 15th**

Register for the MG OHIO SW WALK at: <https://mgohio.org/southwest-events>





# MG OHIO Southwest Patient Education Conference

June 21 - 22, 2025

Holiday Inn, Eastgate

**REGISTER APRIL 15TH TO RESERVE YOUR SEAT!**

MG Ohio Southwest will be holding their first Patient Education Conference. The purpose of this conference offers attendees a chance to connect with the organization's mission, leadership, and initiatives. Our conference will be an exciting opportunity to engage, learn, and connect. Join us for an inspiring lineup of interactive sessions designed to empower patients, caregivers, and healthcare professionals alike. Dive into the latest breakthroughs in treatment and management of MG, gain valuable insights from experts, and share experiences with others who understand your journey. For more information, the event schedule, or to register for the conference please visit:

[www.mgohio.org/southwest-events](http://www.mgohio.org/southwest-events)

**REGISTRATION OPENS ON APRIL 15TH AND IS FREE  
FOR PATIENTS AND CAREGIVERS!**

**THANKS TO OUR SPONSORS OF THE CONFERENCE!**



**WOOD-BYER FOUNDATION**

**IF YOU WOULD ALSO LIKE TO BE A SPONSOR PLEASE CONTACT  
ERICA AMANN AT [MGOHIOSOUTHWEST@GMAIL.COM](mailto:MGOHIOSOUTHWEST@GMAIL.COM)  
FOR MORE INFORMATION**



# MG OHIO Southwest would like to thank all of their generous donors!

The following donations were received between 4/1/24 - 3/31/25

Alexion Pharmaceuticals  
Amann, David & Erica  
Amann, Olivia  
argenx  
Baird, Dennis & Linda  
Bolender, Jean  
Borchers, Stephen  
Burbage, Christa  
Burbage, Tabor  
Byer, Pat  
Cincinnati FCC  
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Fender, Jason  
Graeter's Ice Cream  
Grazilla, Ashley  
Holiday Inn, Eastgate Ohio  
Kidwell, Tina  
Kings Island  
Kroger

Lloyd, Ethan  
Mayerson JCC  
Meyer, Jim & Sharon  
McHugh, Molly  
Molloy, Tom & Maggie  
Neal, Phyllis  
Paas, Jack & Sue  
Queale, Andrea  
Roberts, Darlene  
Roehm, Mike & Holli  
Roehm, Seth  
Sepsi, Hallie  
Sharp, Alex  
Sharp, Ellie  
Sharp, Kaitlyn  
Werner, Gloria  
Werner, Jean  
Werner, Mitch  
West, Mary Jane  
West-Kahl, Kristine  
Whittington, Connor & Michelle  
Wiener, Saul

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