MARCH 2025 VOLUME 48 ISSUE 1

MYASTHENIA GRAVIS
mgmi
FOUNDATION OF MICHIGAN

MG RESEARCH
What's the Future?

COMMUNICATOR

MG RESEARCH: Resiliency in the Face of Uncertainty

Everyone with myasthenia gravis has faced uncertainty. When doctors announce, "You have myasthenia gravis," the journey down a road paved with unknown has only begun. People with MG develop resiliency as they face the daily reminders of their disease.

They often find strength from inside and seek assistance from others. It requires a conscious decision to seek fresh perspectives and sources of hope. The challenges that MG clinicians are experiencing with research cancellations and funding uncertainty at universities, the National Institutes of Health (NIH), and reduction in staffing at the Federal Drug Administration (FDA) are changes to an ecosystem that is not used to uncertainty. To understand this environment, keep the following in mind:

We've been here before... Investment that fueled current FDA-approved medicines for the treatment of MG in the U.S. began more than 10 years ago and included the designation of these therapies as part of the orphan drug designation (ODD) program. Several recently approved medications for treating MG have been awarded ODD status.

Companies that invest in rare diseases through the ODD program receive market-based incentives to assist them in offsetting development costs. Approval of these drugs continues to change the landscape of an MG diagnosis. However, further research is necessary to develop therapies that transform the experience of living with MG. What remains the same, at least for now, is that the ODD program will continue and is a key part of U.S. drug innovation.

The research and pharma landscape is global... While academic research in the United States has produced incredible advances in the causes and therapies for MG, development work on MG and other neuromuscular autoimmune diseases continues in the U.S. and around the world. Investment in research worldwide involves global corporations that have designed their drug pipelines based on solid foundation for addressing clinical needs, regulatory issues, and treatment availability decisions. Innovation and breakthroughs will be available worldwide. *Continued on Page 5*

Registration is Now Open! *See Page 6*

In-Person & Virtual

MG-MI Regional Health Summit & Resource Fair

May 3, 2025 • 10 a.m. to 3 p.m. • Memorial Healthcare Institute for Neuroscience, Owosso, MI

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RESEARCH UPDATES

SOLIRIS®

The FDA has approved expanded use of Soliris for children with generalized myasthenia gravis. Click here for details

Johnson&Johnson

Nipocalimab TRIAL granted U.S. FDA Priority Review to treat gMG
Click here for details

AMGEN

gMG Patients Report Improvement in Ability to Conduct Daily Activities with Twice-Yearly Dosing of Uplizna IN THE Phase Three MINT Trial Click here for details

Clinical Trial Resources

MGNet Myasthenia Gravis Rare Disease Network
mgnet.rarediseasesnetwork.org/

NIH National Institute of Health Clinical Trials
clinicaltrials.gov

Rare Disease Day

MG-MI's Executive Director Rhonda Wentworth connected with those attending the February 2025 Rare Disease Day Gathering at Calvin University, including the Immune Deficiency Foundation volunteer shown behind her. The conference featured speakers who discussed the ever-evolving state of rare disease research and treatment.

Medical/Research

MG-MI Offers Two Grants for MG Education and Research

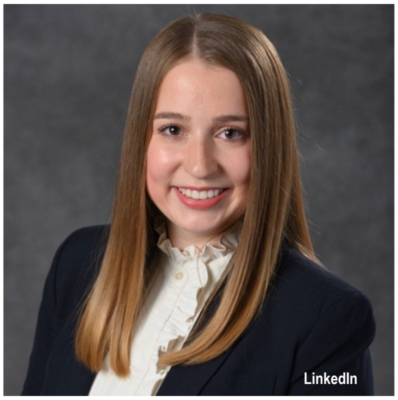
As part of our mission to improve health, well-being, and access to care for individuals living with myasthenia gravis (MG), we are committed to supporting the next generation of neurologists and fostering their interest in neuromuscular medicine.

Our board recognizes the importance of cultivating neuromuscular medicine as a preferred sub-specialty among resident physicians in neurology programs. To that end, MG-MI is focused on ensuring that these residents are exposed to the latest advancements in the care of MG. We aim to encourage Michigan-based resident physicians to establish their practices in the state after completing their training and to consider our organization a reliable partner in patient care.

MG-MI Spark Curiosity Award

We are pleased to offer the *Spark Curiosity Award* to post-graduate year 1–4 resident physicians interested in attending the Myasthenia Gravis Foundation of America (MGFA) Scientific Session at the American Association of Neuromuscular and Electrodiagnostic Medicine (AANEM) Annual Meeting. This grant provides travel support to help offset costs not covered by institutional funding. The award will be granted on a first-come, first-served basis and is open to residents in neurology programs throughout Michigan. Two grants of $500 are available. Applicants are to contact the MG-MI office.

Research Grant Award – Madeline Niblock

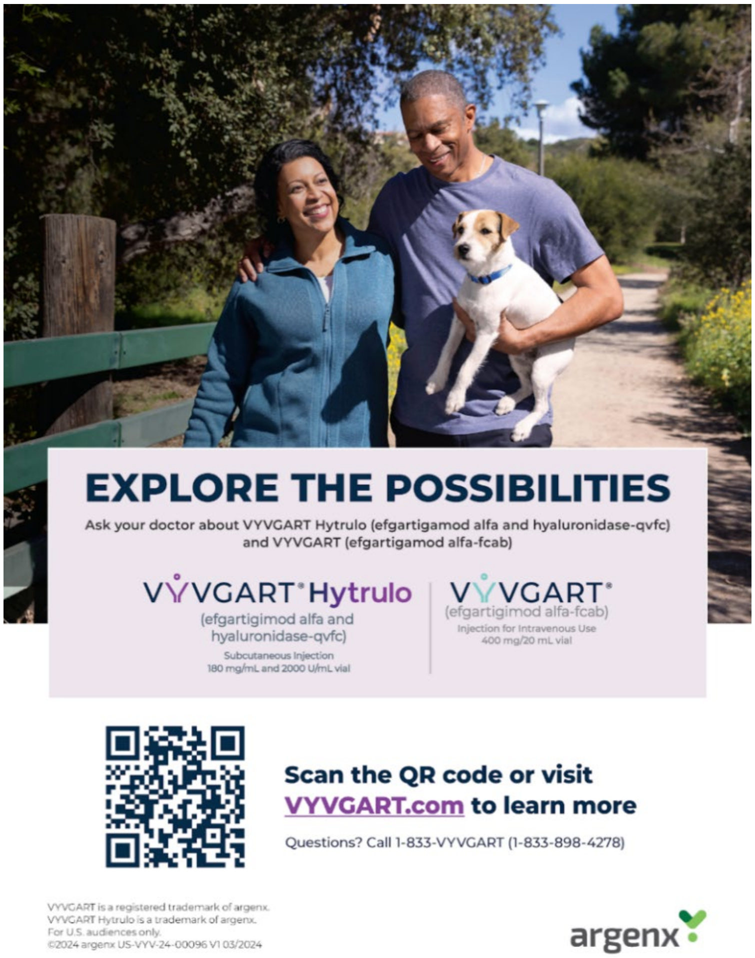

LinkedIn

Madeline Niblock

MG-MI is also pleased to announce the *MG-MI Esther Land 2025 Finding Solutions in Myasthenia Gravis* research project grant has been awarded to Madeline Niblock, a fourth-year Doctor of Osteopathic Medicine MSU student.

The project will focus on finding therapeutic selection for patients with both autoimmune myasthenia gravis and an additional autoimmune condition. It will include a comprehensive literature review and the creation of a scientific poster.

The grant, with a total funding potential of $2,000, will be distributed across several deliverables, each offering $250. The project will culminate in Madeline's travel to the 2025 AANEM or MDA meeting. We look forward to seeing the outcomes of her work and its contribution to the field as she presents at our conference on October 11, 2025.



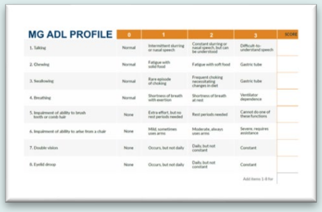
Wellness

How to be Your Own Best Advocate

MG patients at the MG-MI Patient Education Conference last fall were particularly interested in hearing about patient self-advocacy in a presentation by Rosemarie Walch, DO, a neurologist at the Memorial Healthcare Institute for Neuroscience. She gave some valuable tips to patients who often worry about what to talk about during a doctor's appointment, Dr. Walch recommended choosing one or two "domains" to discuss at each appointment. These may include:

- **Physical symptoms and impact**
- **Psychological impact**
- **Social impact of MG on relationships with others**
- **Reproductive and parenting issues**
- **Activities and participation**
- **Flare-ups and myasthenic crises**
- **Treatment burden**
- **Unmet needs**

Download an ADL Form



MG ADL PROFILE

	0	1	2	3	SCORE
1. Talking	Normal	Intermittent slurring or nasal speech	Constant slurring or nasal speech, but can be understood	Difficult-to-understand speech	
2. Chewing	Normal	Fatigue with solid food	Fatigue with soft food	Gastric tube	
3. Swallowing	Normal	Rare episode of choking	Frequent choking necessitating changes in diet	Gastric tube	
4. Breathing	Normal	Shortness of breath with exertion	Shortness of breath at rest	Ventilator dependence	
5. Impairment of ability to brush teeth or comb hair	None	Extra effort, but no rest periods needed	Rest periods needed	Cannot do one of these functions	
6. Impairment of ability to arise from a chair	None	Mild, sometimes uses arms	Moderate, always uses arms	Severe, requires assistance	
7. Double vision	None	Occurs, but not daily	Daily, but not constant	Constant	
8. Eyelid droop	None	Occurs, but not daily	Daily, but not constant	Constant	
				Add items 1-8 for	

https://mg-mi.org/wp-content/uploads/2024/12/ADL-chart-1.pdf

ASK THE SPECIALIST

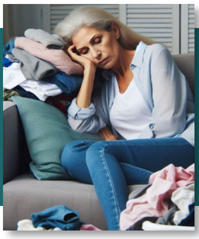
Our popular feature, *Ask the Doctor,* is being renamed to *Ask the Specialist* to accommodate inquiries about drugs and interactions, physical and emotional challenges, and navigating life with MG. Questions that can help the greater community will be directed to a doctor, qualified pharmacist, physical therapist or mental health practitioner who knows about MG and can provide a valuable response. You can find various questions and answers on our website page, *Ask the Specialist.* You may also submit a question using the link on that page, or simply contact us at info@mg-mi.org or call 616-956-0622.

High AST Levels and MG or Prednisone Usage

Question ***Just wondering if there is any correlation between a high AST of the blood and myasthenia gravis or prednisone usage. My neurologist just sent me to a liver doctor as my AST went up to 70 after taking Imuran one month but now it's down to 40 six months later. Liver tests are negative except for moderate fatty liver, no cirrhosis. On just 2.5 prednisone now and Mestinon as needed, usually two or three times a day.***

Paul Twydell, DO
Neurology, Corewell Health

Answer Liver function tests such as AST and ALT can go up in the setting of treatment with Imuran which is why we monitor them on patients taking it. There are other things not related to myasthenia that can obviously affect the liver. Heavy alcohol use can cause the AST to be relatively higher than the ALT in most people. Prednisone can have some effects on the liver such as those that you described but it should not cause the liver enzymes to become elevated. Typically, before starting a patient on Imuran, there is a blood test called TPMT activity. This is a test to make sure that you have the proper enzymes to metabolize the Imuran. If not, you may experience toxic effects of the drug. Mycophenolate is a safe alternative to Imuran if long term immunosuppressive therapy is needed. There is no need for monitoring the liver or kidney function, but we still have to monitor the white blood cell counts. Hope this helps!



WELLNESS

Coping with Fatigue

Aimee Smithem, an MG patient and licensed Michigan Occupational Therapist, presented her story and discussed coping with fatigue at a recent MG-MI virtual support meeting. She, along with other attendees, shared some practical adaptations to help MG patients live a productive and meaningful life.

Aimee Smithem, OTL

- Create a weekly or bi-weekly schedule.
- Establish a routine and adjust your day based on the planned schedule.
- Journal or log your activities and diet.
- Plan your time to minimize stress (e.g., shop during slower times or order online).
- Be aware of your limitations and listen to your body.
- Use systematic pacing.
- Schedule rest and balance it with activity.
- Work smarter, not harder—make small adjustments to conserve energy and stay safe.
  Examples: Use grab bars and assistive devices such as a shower seat or use a long-handled reacher; rest your elbows on a table, reduce unnecessary tasks, maintain good posture (head over shoulders, over hips).
- Limit or monitor heat exposure (e.g., sauna, hot tub, hot showers, summer heat).
- Rest before eating or time your Mestinon to be optimal before eating/chewing.

Aimee shares her expertise in her own practice, *AdaptABLE Therapy Solutions, PLLC*

RESILIENCY: *(from Page 1)*

You are not alone…There are more advocacy groups assisting patients with MG and related diseases than ever before. Just a few weeks ago, approximately 40 advocacy organizations from the Neuromuscular Advocacy Collaborative gathered for a meeting organized by the Muscular Dystrophy Association to unify advocates on legislative goals.

MG-MI is here for you! MG-MI is strengthening capabilities with the Michigan patient database. We are bringing together medical and wellness specialists for free virtual and in-person patient education sessions across Michigan. We are sponsoring senior medical students to encourage them to choose MG research as a career choice. Most importantly, we continue to advocate for patients with MG.

What can you do? Contact your state and national elected officials. Personalize the impact of MG as a medical issue. Show up to town halls. Stay in touch. Above all, remain strong and resilient. **That's your MG superpower!**

MG-MI In Action!

MG-MI Regional Health Summit & Resource Fair

Saturday, May 3, 2025 10 a.m. to 3 p.m.

Registration is Now Open!

Registration is now open for MG-MI's first Regional Health Summit & Resource Fair that will be held Saturday, May 3, from 10 a.m. – 3 p.m. at the Memorial Healthcare Institute for Neuroscience, Owosso, MI. In-person and virtual attendance are both available. While the Patient Education Conference last October centered on medical and research issues, this event will put the spotlight on health and wellness. Memorial Healthcare has a comprehensive neurology department which serves about 200 MG patients from around the state. They also have a wellness center which will be featured in the program. Here's a tentative schedule for the event.

9:00 Sign In & Visit our Partners' Tables
10:00 Welcome
10:15 Margaret Frey, DO: "Living & Thriving with MG"
11:15 Exercise Physiology – Balance
12:00 Lunch – Visit Partners, Get a Shoulder Massage
1:00 Rosemarie Walch, DO: "Help Me Help You – Advocating for Yourself & Your Safety"
2:00 Nutrition Speaker – Sarah Smith, RDN
2:30 Yoga Therapy
3:00 Closing Remarks

Margaret Frey, DO

Rosemarie Walch, DO

Memorial Healthcare | Institute for Neuroscience

How to Register

The cost for in-person attendees is $10 per person and includes a box lunch, snacks and refreshments at the event. There is no charge for attending virtually. You may register for either the virtual or in-person presentation here.

https://secure.qgiv.com/for/MG-MIConferences/event/mg-mihealthsummit/

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MG-MI In Action!

SUPPORT MEETINGS: The Pulse of MG-MI

For a small organization, the Myasthenia Gravis Foundation of Michigan has developed a long list of tasks and goals to serve the MG community throughout the state. Organizing regular support group meetings, either in-person or virtually, is one of the most important things we do. Virtual meetings occur at least once a month.

In-person meetings are held regularly in many areas of the state during spring, summer and fall. You can find out when and where support meetings are held at mg-mi.org/living-with-mg/support-groups/

Why Attend a Support Meeting?

1. **You can connect with others who understand and live with the challenges of MG**
2. **Give and get encouragement through open discussion**
3. **Learn about MG treatment options and how others have benefited from them**
4. **Be educated about resources in your area**
5. **Learn workarounds from others who have lived with MG for years**

While the platform is different, many of these advantages are available on our Zoom sessions also. We hope you consider joining in-person or virtually on the dates indicated on the “2025 Calendar" on page 8.

Find a support group meeting by clicking here

We Need Volunteers!

MG-MI depends on volunteers…*for everything*! If you would like to help, consider hosting a support group or serving on our board of directors. Being an MG patient is not required. Interested? Email us at info@mg-mi.org or call us at 616-956-0622.

A Sad Farewell to Our Friend and Colleague, Janet Gentle

The MG community lost a dear friend and very special advocate, Janet Gentle of Harbor Springs, who died unexpectedly February 13, 2025. Janet's passion to encourage and support MG patients was evident by her involvement in our MG family. Having lived and struggled with life as an MG patient for over 10 years, in 2023 her condition finally stabilized sufficiently to allow her to give back and support others as she voluntarily facilitated over six in-person support meetings in Northern Michigan. At the time of her untimely passing, Janet was working with our office to set up future meetings in the Upper Peninsula and schedule sessions in the Traverse City and Gaylord areas. Janet also served on our MG-MI Board of Directors where her compassion provided gracious insight into board decisions.

At our Annual Patient Education Conference last October, we were honored to present the *Volunteer of the Year* award to Janet for her many hours of dedicated service to our organization and MG patients.

Janet is deeply missed by our MG community. Our thoughts and prayers go out to her family during this season of sorrow and loss.

MG-MI board member Janet Gentle received the 2024 Volunteer of the Year Award from founder Esther Land

2025 Calendar

In-Person & Virtual Events

Click to Connect

Thurs., April 24 In-Person Support Meeting, E. Lansing,11:30 a.m. to 1:30 p.m. Coral Gables Restaurant, front meeting room, lunch on your own. 2838 E Grand River Ave, East Lansing

Tues., April 29 Virtual Support Meeting, 6:30 p.m. to 7:30 p.m. Join us for a virtual MG support group meeting. Open discussion of "Living your best life with MG."

Sat., May 3 Regional Health Summit & Resource Fair 10:00 a.m. to 3:00 p.m. In-Person and Virtual, Memorial Healthcare Institute of Neuroscience – NOW Building, 819 N Shiawassee St, Owosso *(See P. 6)*

Tues., May 6 In-Person Support Meeting, Berrien Springs 6:30 p.m. to 7:30 p.m. Kathy Morris, PT, Corewell Health Rehabilitation-Royalton, with student physical therapist, Belle Miller from WMU, will be presenting on Physical Therapy and Myasthenia Gravis. Berrien Springs Community Library, 215 W Union St, Berrien Springs

Tues., May 20 Virtual & In-Person Support Meeting, Livonia 6:30 p.m. to 7:30 p.m. Speaker - Maryjo Prince-Paul, Alexion: "Productive Conversations with your Healthcare Providers." Livonia Civic Park Senior Center, 15218 Farmington Rd., Livonia

This newsletter is underwritten by Great Lakes Vital Care

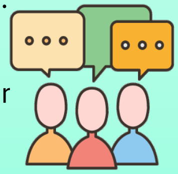
Virtual meetings allow for Q&A

Watch our website & MG-MI emails for updates

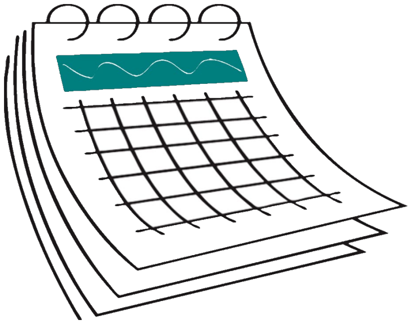
Virtual link
https://us02web.zoom.us/j/6169560622
Meeting ID: 616 956 0622
By phone 1 309 205 3325
Enter meeting ID 616 956 0622
when prompted.

In-Person Meetings

Look for MG-MI signs. Please join us at one or more location. We hope to see again—or to meet you for the first time!



We appreciate you! Click HERE to donate to help us provide services throughout 2025.



Save the Dates!

Sat., Aug. 9: Health Summit & Resource Fair – Livonia

Sat. Oct. 11: 9th Annual Patient Education Conference – Grand Rapids

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Our Mission: The Myasthenia Gravis Foundation of Michigan is committed to our MG Community by providing patient support, community connections, education, and advocacy.

Our Vision: Living your best life with MG