

MG Treatment SURGE!

C O M M U N I C A T O R

Spring Brings a Deluge of New MG Treatment Options

The medical community has some exciting new tools to treat MG patients. Many of the breakthroughs and refinements revolve around the use of the revolutionary monoclonal antibodies designed to block FcRn and reduce levels of circulating immunoglobulin G (IgG) antibodies that underlie generalized myasthenia gravis (gMG).

IMAAVY

In May, Johnson & Johnson joined the battle against MG with its IMAAVY™ (nipocalimab-aahu) which was approved by the U.S. Food and Drug Administration (FDA). The treatment offers a new option in a proven class with the potential for lasting disease control in the broadest population of people living with gMG. IMAAVY is currently approved for the treatment of gMG in adults and pediatric patients 12 years of age and older who are AChR or MuSK antibody positive. Johnson & Johnson says a program has been created to help patients with treatment costs including a no-cost option for those who qualify during 2025.

Vyvgart/Efgartigimod

The FDA has approved the administration of efgartigimod (Vyvgart; argenx) using a pre-filled syringe. By making the treatment available for self-injection, MG patients have greater convenience and flexibility while cutting down the number of time-consuming trips to infusion facilities.

Continued on page 2

Registration is Now Open! See Page 5



Saturday, August 9, 10 a.m. to 3 p.m., Livonia

MG-MI Regional Health Summit & Resource Fair

Virtual & In-person



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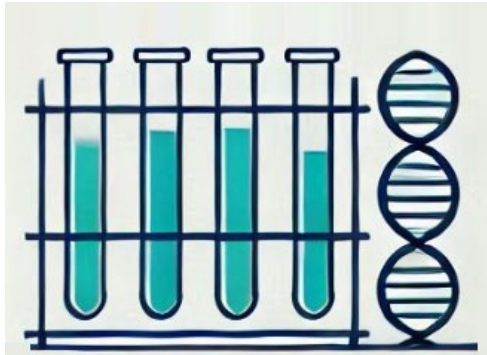
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*This newsletter is
underwritten by
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Soliris

The FDA has approved an expanded application of Alexion's eculizumab (Soliris) to include pediatric patients six years and older who are living with generalized myasthenia gravis (gMG) and who are positive for anti-acetylcholine receptor (AChR) antibodies.

BKEMV

This drug was recently granted status as a "biosimilar" treatment. According to Amgen, the drug's maker, the FDA found BKEMV to be similar in safety and efficacy to Soliris, for use for adult patients with generalized myasthenia gravis (gMG) who are anti-acetylcholine receptor (AChR) antibody positive.

Advanced imaging provides direction for new MG Research

Researchers at UC San Diego's School of Biological Sciences have used an advanced imaging technique called cryo-electron microscopy (cryo-EM) to probe details of human muscle AChRs at high resolution. In an article in the journal *Cell*, researchers said they analyzed the autoantibodies of six different myasthenia gravis patients. They discovered that these antibodies can disrupt the normal receptor functioning in different ways. The findings challenge previous assumptions about how myasthenia gravis antibodies disrupt receptor activity and may eventually lead to developing more personalized therapies.

For details on these and many other news stories on MG treatment and research, go to our new web page: <https://mg-mi.org/resources/mg-news/>



MG-MI Research Grant Update

- Madeline Niblock, a fourth-year Doctor of Osteopathic Medicine student at MSU and recipient of MG-MI's 2025 *Finding Solutions in Myasthenia Gravis* research grant has been investigating the potential of a common therapy that would benefit both myasthenia gravis and rheumatoid arthritis. She has submitted and been approved to present the project outcome at the October AANEM meeting in San Francisco and will also present the outcome at our October 11 conference.
- Additional MG-MI research grants support the Seronegative MG Research at the O'Connor Laboratory at Yale School of Medicine. This investigation continues to define new autoimmune mechanisms in seronegative MG.
- The MGNet research grant supports Dr. Baylor at Yale School of Medicine as she continues to investigate the molecular mechanisms in the pathway of acetylcholine receptor in gMG, and Dr. Sikorski at George Washington University as she explores the hypothesis that differentiation into atypical B cell and dysregulated T cells in the thymus T is stronger in women.

Note: NIH funding cuts will potentially put clinical trials and research funding in jeopardy.



Madeline Niblock, MG-MI grant recipient



Ask The Specialist

Ask the Doctor, is now Ask the Specialist, a change we made to broaden the conversation to include more clinicians who treat MG. See mg-mi.org for answers to questions such as the one shown below. If you have questions to share with others, use the link on the page or contact us at info@mg-mi.org or 616 956 0622.

Question: "What important considerations, including potential adverse effects, should a patient with Myasthenia Gravis be aware of when undergoing a colonoscopy?"

Answer: In general, a colonoscopy is a safe procedure for patients with myasthenia gravis. The medications given during the procedure for sedation are safe but some people may experience a slight worsening of their symptoms afterwards. The preps for colonoscopies often have magnesium in them which can worsen myasthenia symptoms. There are options which do not contain magnesium which you should ask your gastroenterologist about. Most of the time, if your myasthenia is under good control, the magnesium should not cause serious adverse effects. --Paul Twydel, DO

Go to <https://mg-mi.org/resources/ask-the-specialist> for more Q&A's.



Connect With a generalized Myasthenia Gravis (gMG) Patient Education Manager

Understanding your or your loved one's rare disease is important. Your Patient Education Manager (PEM) is here to help along the way by providing education and local community connections.

**YOUR DISEASE IS RARE,
BUT IT'S NOT RARE TO US!**



Scan this QR code with your phone to connect with a local gMG PEM in your area.

ONESOURCE®
Personalized Patient Support from Alexion

ALEXION®
AstraZeneca Rare Disease

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Here's a Handy Chart of Newer MG Treatments

Do you ever get confused with all the hard-to-pronounce medications and treatments for MG?

We've made an easy guide to all the -mabs, -mods and -ases out there. In one simple chart, you can find the drug name (branded and generic), the manufacturer, how it's administered, usual dosing and how it works. We'll keep it updated as new treatments become available.

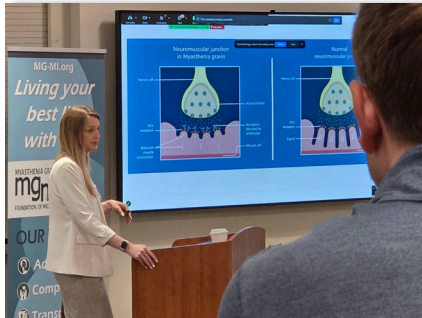
Drug Name	Manufacturer	Indication	How it Works	Usual Dosing	Administration	Comments
Adalimumab (Humira)	AbbVie	MG	Anti-TNF	40 mg SC every 2 weeks	Subcutaneous	Approved for MG in 2023
Abatacept (Orencia)	AbbVie	MG	Anti-CD28	1000 mg IV every 4 weeks	Intravenous	Approved for MG in 2023
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Download it by going to our new MG Toolbox at <https://mg-mi.org/living-with-mg/mg-toolbox/>



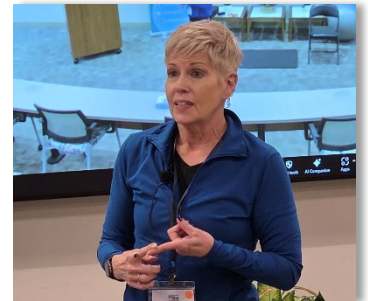
MG-MI In Action!

Health Summit & Resource Fair Gets an “A!”



Margaret Frey, DO

MG-MI's first ever health summit and resource fair was well received by MG patients and family members who attended the event held in Owosso on May 3rd. The event featured presentations by two board certified neurologists from the Memorial Healthcare Institute for Neurosciences which hosted the program, Margaret Frey, DO, Chief of Neurology, and Rosemarie Walch, D.O.



Rosemarie Walch, DO.

Attendees were also treated to a demonstration of low-impact exercise by Jerrell Redwine, MS and myasthenia-friendly yoga by certified yoga instructor, Jill Frieling. Massage therapist Angelica Dye offered shoulder massages during lunch.

In her presentation, Dr. Frey reviewed the medical community's current understanding of MG and other neuromuscular diseases. Rosemarie Walch, D.O. discussed new MG treatments recently receiving FDA approval. She also gave some valuable tips to help patients self-advocate with their clinicians.



Top: Jill Frieling offers yoga instruction. Bottom: Jerrell Redwine demonstrates low-impact exercises.

Self-Advocacy Tips from Dr. Walch

- **Know your diagnosis.** If you have a positive antibody, know which antibody & date that you tested positive.
- **Have a list of clinicians & phone numbers**
- **Maintain an updated medication list**
Know your allergies plus reaction to that allergen.
- **Keep a copy of your vaccination schedule**
Educate yourself about your disease.
- **Go to appointment prepared**
Decide one or two top concerns you'd like addressed.
- **Don't hesitate to take a second person with you for note taking**
- **Therapeutic selection** If the mode of delivery, schedule of medication or financial burden of medication does not work for your life, speak up.



AMGEN

At Amgen, we stand with the gMG community and are committed to supporting patients on every step of their journey.



MG-MI Regional Health Summit & Resource Fair

Saturday, August 9, 2025 10 a.m. to 3 p.m.
Vistatech Center - Schoolcraft College – Livonia, MI



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Our Next MG-MI Regional Health Summit & Resource Fair is August 9!

Join us at Schoolcraft College in Livonia for this event which builds on our successful program in Owosso in May. Our health summits are designed to bring the MG community the latest updates in research and treatments from Michigan neurologists.

We also address some of the other crucial aspects of wellness, including exercise, breathing and insurance coverage. Networking and meeting others living with MG are extremely important benefits of in-person attendance. The health summit will be live-streamed for those who are not able to attend in person.

Register: <https://secure.qgiv.com/for/MG-MIConferences/event/aug2025/>

Schedule of Events

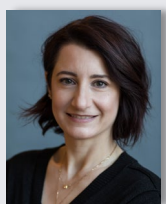


10 AM Beth A. Kelley, PhD in Nursing Education, Family NP and CNM, MG Patient
"Personal MG Journey and the Benefits of Mindfulness Breathing Techniques."

11 AM Patient Panel – "Been There, Done That, Have Wisdom to Share!" Southeastern Michigan MG patients share their MG journeys and answer questions from patients and loved ones. Featuring Yolanda Arnold, Mickey Bloomberg, Andrea Fuller.



NOON - Lunchtime conversation and time to visit MG-MI sponsors, virtual MG experience, health insurance approval tips resource table, and Aimee's adaptive clothing table.



1 PM Rebecca Lindemann, Master of Physical Therapy
Director of Rehabilitation Services at The Recovery Project
"Better Living Through Exercise: PT and Exercise Prescription for MG."



2 PM Alan Salgado, M.D., Neurologist at the University of Michigan
"Current and Future MG Treatments for Successfully Managing MG."

In-person & Virtual

MG-MI Patient Education Conference

Saturday, Oct. 11, 2025 9:30 a.m. to 3 p.m.

Calvin University - Prince Conference Center - Grand Rapids

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MG-MI Patient Education Conference October 11 in Grand Rapids



MG-MI's **Ninth Annual Patient Education Conference** is set for October 11 at the Prince Conference Center on Calvin University's Grand Rapids campus. MG patients and others attending the conference will learn about topics ranging from lifestyle issues, surviving hospitalization, MG basics, and an up-to-the-minute update on the MG treatment and research environment. MG-MI grant recipient, Madeline Niblock will also be presenting.

There will be plenty of time for all-important networking and socializing. Conference sponsors will also be available.

Be sure to save the date and look for more information on registration coming soon.



EXPLORE THE POSSIBILITIES

Ask your doctor about VYVGART Hytrulo (efgartigamod alfa and hyaluronidase-qvfc) and VYVGART (efgartigamod alfa-fcab)

VYVGART[®] Hytrulo
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Subcutaneous Injection
180 mg/mL and 2000 U/mL vial

VYVGART[®]
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Injection for Intravenous Use
400 mg/20 mL vial



Scan the QR code or visit
[VYVGART.com](https://www.vyvgart.com) to learn more

Questions? Call 1-833-VYVGART (1-833-898-4278)

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Tentative Schedule

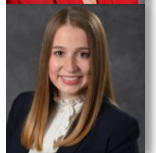
Julie Rowin, MD, ABIHM, FAAN
Lifestyle Medicine & MG - Living Your Best Life



Louise O'Donnell, RN, MS, NP
Surviving Hospitalization - Planned and Emergency



Madeline Niblock, MSU research recipient, gMG and RA - Mechanisms of Disease and Considerations of Concurrent Treatment



Melanie Taylor, MD
MG Review and Treatment Options



Amit Sachdev, MD
Clinical Trials and Emerging Treatments for MG



We've Remodeled Our Website!



If you haven't visited mg-mi.org lately, you'll notice a few changes. We've made the site more informative by collecting current articles about MG research, assembled some "tools" to download such as an MG-ADL form, brochures, and a chart outlining newer MG treatments.

We've also combined our events list and support group calendars into one "MG-MI Calendar." Events, such as conferences and health summits, also have a page of their own. We'll be including specific page links for articles and resources featured in this newsletter that are too large or detailed to include in their entirety.

Don't worry if you're not able to access our website. Just call our office at 616 956 0622 or email us at info@mg-mi.org and we'll be happy to mail you printed copies of whatever you need.



mg-mi.org

We're upgrading our database system, too. Some MG-MI emails and mailings may have a different look.

► Summer Tips for Persons Living with MG

1. Stay in air-conditioned rooms and use fans as much as possible. Keep windows, blinds and curtains closed during the day.

2. Stay hydrated by drinking plenty of water to keep your body temperature cooler.

3. Freeze juices, yogurts and flavored waters for homemade ice pops.

4. Prepare and prep meals that require a heat source in the evenings.

5. Eat six smaller meals throughout the day, if preparing or eating a main meal is causing challenges.

6. Run cold water on your wrists, place your feet in a bowl of cold water and use ice packs or a cold towel to cool your body.

7. Use ice packs to help temporarily relieve your ptosis.

8. Wear eye protection as much as possible.

9. Keep bottles of water and snacks in your vehicle in the case of a breakdown.

10. Wear looser-fitting clothes made from natural fibers, which can offer more comfort during hot weather.

Here's the Skinny on QR Codes

QR codes can transport you to a web page using your smart phone's camera. We use them because it's a quick way to bring you to an article that may have an internet address that is too long to easily type into your phone or computer. If you're not used to using QR codes, here's an easy guide.

iPhone Open the camera and point it at the QR code. Tap the link above the code to open it.

Android Open the camera. Point the camera at the code and click the link that pops up. Older phones may require you to tap the cog icon and toggle on "Scan QR codes". You may need to download a free app. <https://mg-mi.org>

Windows Open the Camera app. Click the down-arrow and select "Barcode" mode. Hold the QR code to your webcam until it scans.

If you aren't able to access the website, you can always contact our office and someone will be happy to get the information to you by email or standard mail.



2025 Calendar

In-Person & Virtual Events

[Go to the MG-MI Calendar](#)



Virtual - June 24 - Tuesday 6:30 p.m. - 7:30 p.m.

Patient Check-in: "Living your best life with MG"

Berrien Springs - July 15 - Tuesday 6:30 p.m. - 7:30 p.m.

Lynn Huls hosting, topic "Living Well with MG" Berrien Springs Library: 215 W Union St, Berrien Springs, 49103

Virtual - July 22 - Tuesday 6:30 p.m. - 7:30 p.m.

Maryjo Prince-Paul, Alexion "Advocating for Yourself"

Grandville - July 24 - Thursday 11:30 a.m. - 1:30 p.m.

Private room, lunch on your own Russ' 4440 Chicago Dr SW, Grandville 49418.

Topic: "Lunch and Learn" – Q&A session

Regional Health Summit & Resource Fair August 9 – Saturday 10:00 a.m. - 3:00 p.m.

Vistatech Center, 18600 Haggerty Rd., Livonia MI 48152 ([Details on Page 5](#))

Traverse City - August 18 - Monday 3:30 p.m. - 4:30 p.m.

Maryjo Prince-Paul, PhD MSN RN FPCN, Alexion: "Advocating for Yourself" 20 Fathoms, 10850 E. Traverse Hwy, Ste. 4400 Traverse City, MI 49684

Saginaw – Hybrid – August 21 - Thursday 6:30 p.m. - 7:45 p.m.

In-person & virtual. Zauel Memorial Library, Dr. Kuremety Meeting Room, 3100 N. Center Rd, Saginaw 48603. Ken Bush, RN MHS, argenx "Access to Insurance"

Virtual - August 26 - Tuesday 6:30 p.m. - 7:30 p.m.

Maryjo Prince-Paul, PhD MSN RN FPCN, Alexion: "Navigating Stress & Cultivating Wellness Workshop"

Virtual meetings allow for Q&A



Visit our website & look for MG-MI emails for updates

Virtual link

<https://us02web.zoom.us/j/6169560622>

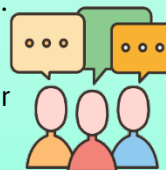
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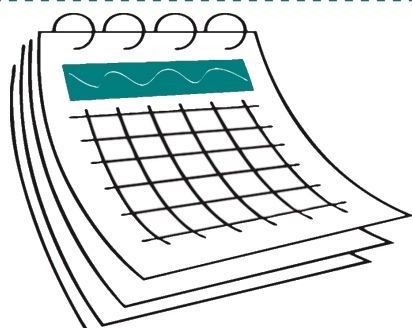
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In-Person Meetings

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



Myasthenia Gravis Foundation of Michigan

2660 Horizon Dr. SE, Ste. 235
Grand Rapids, MI 49546-7933

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<https://www.facebook.com/MGofMI>

<https://www.instagram.com/mgofmi/>

<https://www.youtube.com/@MG-MI/videos>

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