



MICHIGAN On the Move!



COMMUNICATOR

MG-MI Makes a Difference in Michigan

Myasthenia gravis is gaining more attention across Michigan and beyond—and that momentum is bringing new support to our community. The Myasthenia Gravis Foundation of Michigan is helping lead the way through research partnerships with Michigan State University and new statewide care programs.

We've expanded in-person and virtual support groups, and educational events. We're also improving our website to make trusted Information easier to find.

Thank you for the trust you place in us—we're honored to support the MG community and excited for what's ahead.



FDA Approves Expanding VYVGART & VYVGART HYTRULO

The FDA has expanded approval of VYVGART and VYVGART Hytrulo for all adults with generalized myasthenia gravis (gMG), broadening access to treatment across the community.



According to an argenx press release, "VYVGART and VYVGART Hytrulo are the first and only approved treatments for all serotypes of adult patients living with gMG – anti-AChR-Ab positive, anti-MuSK-Ab positive, anti-LRP4-Ab positive, and triple seronegative.

Patients treated with VYVGART in the ADAPT SERON study experienced rapid, significant and sustained symptom improvements that continued with ongoing treatment

The approval is especially meaningful for patients without detectable AChR-Ab, who have historically had fewer targeted treatment options. Advocacy leaders say the decision brings renewed hope and recognition to thousands affected by gMG."

Get the full details here:

<https://mg-mi.org/resources/mg-news/>

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MG Awareness Month

MG-MI is participating in the worldwide "MG Awareness Month" through its social media. Every day on Facebook and Instagram, we post a helpful tip or provide an MG resource hosted on our website. If you're not following us, you can find us at <https://www.facebook.com/MGofMI/> and <https://www.instagram.com/mgofmi/>.



Research News



MSU Medical Students

Returning to Research Initiatives

Not all meaningful medical research requires big budgets or large labs—sometimes it begins with curious students taking a closer look at what’s already known.

By reviewing and analyzing existing studies, medical students can uncover new insights that may help improve care and policy for people living with MG.

That’s the idea behind the *Returning to Research Initiative*, a partnership between the Myasthenia Gravis Foundation of Michigan and Michigan State University. Led by neuromuscular specialist Dr. Amit Sachdev, this year’s program

includes eight second-year medical students exploring important MG topics.

Each student selects a focus area, receives support for their work, and shares their findings at national meetings and the MG-MI Patient Education Conference this October. MG-MI is pleased to invest \$20,000 in student research—helping bring fresh ideas and hope to the MG community.

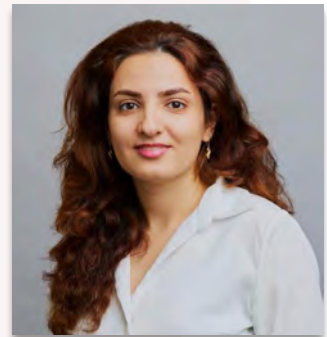
Topics & Researchers

- Muscle Pain** -- Eaman Ahmed
- Muscle Relaxants (Safety)** - Saneh Kaur
- gMG & Anti-Lipid Meds** - Shems Hamdan
- The Underhoused & Underinsured** - Justin Romero
- Pre-existing infectious illness** (screening) - Cynthia Hinderscheid
- Min. Manifestations (MMD)** - Heidi Aguas
- Inebilizumab Transition** - Annie Hoang-Pham
- gMG and Employment** - Emily Myers

MGNet Scholar Named

Fatemeh Khani-Habibabadi, PhD, has been awarded the 2026 MGNet Scholar Award. A postdoctoral researcher at Yale School of Medicine, she is exploring why some immune cells continue to fuel the disease even after therapy.

By analyzing patient samples in a clinical trial, she aims to identify markers that can help predict which treatments will work best. Dr. Khani-Habibabadi’s research is partially underwritten by MG-MI.



Clinical Trial Resources



mgnet.rarediseasesnetwork.org/

clinicaltrials.gov

MG-MI Health Summit Highlights

The MG-MI Health Summit & Resource Fair on May 30 in Kalamazoo brought together MG professionals and patients to focus on health and wellness as essential parts of MG care. The October Patient Education Conference will be centered more on medical treatments and research. Here are a few highlights from the May summit.

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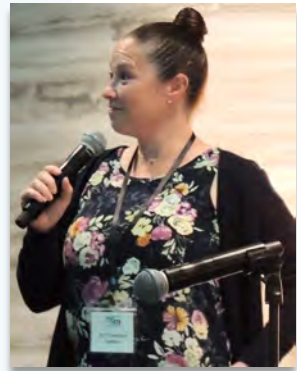
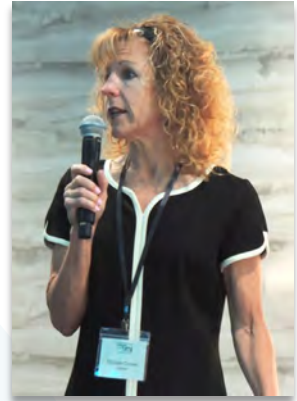
Living With a Chronic Condition

Michelle Crooks, MD

Living with a chronic condition can feel overwhelming, but small, steady steps can make a meaningful difference. Start by educating yourself about your diagnosis so you can make informed decisions. Keeping a notebook of what you learn, along with questions, symptoms, and progress, can help you prepare for appointments. Support groups can also provide encouragement and practical advice from others. It may help to enlist an accountability buddy who can check in, offer motivation, and support healthy habits. Remember that managing a chronic condition is a marathon, not a sprint, and progress often comes one day at a time.

April Davenport, MS

Effective management starts with self-care: healthy eating, regular activity, adequate rest, and consistent medication use. Equally important is building a strong support system of family, healthcare providers, and community resources. Healthy coping strategies such as mindfulness, counseling, and support groups help manage the stress and emotional toll. Social workers play a key role in connecting individuals with resources and advocacy. With the right tools and support, living well with a chronic condition is achievable.



April's Tips for Living With a Chronic Condition

- Focus on strengths and abilities
- Set realistic goals
- Celebrate small successes
- Maintain hope and resilience
- Seek support when needed

FREE ONLINE WORKSHOP

Dr. Crooks suggests looking into **PATH -- Personal Action Toward Health**. This is a free 6-week online class offered for those with chronic conditions by Michigan State University.

<https://www.canr.msu.edu/PATH/CHRONIC-DISEASE-path>



Amgen is proud to support the Myasthenia Gravis Foundation of Michigan.

MG & Speech Pathology Health Summit Continued

Dr. Laura Lenkey, PhD., CCC-SLP & Olivia Buckhout, M.S. CCC-SLP



Dr. Laura Lenkey and Olivia Buckhout discuss speech and language pathology and MG

Myasthenia gravis (MG) affects far more than muscle strength. Up to 80% of patients develop bulbar symptoms, including slurred speech, swallowing difficulties, and voice changes that worsen with fatigue. Speech-language pathologists (SLP) help manage these challenges through assessment, meal pacing, voice amplification, and caregiver education. Ask your neurologist about an SLP referral.

No-Cost Speech and Language Therapy

Dr. Lenkey and Ms. Buckhout oversee VPEd (Virtual Patient Education), an organization that provides quality speech services to adult patients while also preparing future speech-language pathology graduate students for their future in the profession. Patients can receive services at no cost. This is also an option for those who have previously received speech services but stopped because of cost, insurance or transportation.

<https://www.vpeddesign.com/>

Thank You Patient Panel!

The knowledge that researchers, physicians and practitioners bring to the MG community is crucial. But so is personal experience. At the Health Summit, our popular Patient Panel featured host Lisa Gigliotti, Brandie DeHaan, Wallace Fu & Lynn Huls who told their own MG stories and described their journeys of diagnosis, treatment and daily life. Our panel also fielded questions from both the in-person audience and those who were streaming live.



MG-MI extends its sincere thanks to our panelists and our admiration for the courage!

What could your days look like with IMAAVY™?

Scan to learn more

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Are You a Medical Zebra?

Ever felt like a medical zebra because your symptoms were either invisible or your medical condition was difficult to diagnose? Myasthenia gravis was recently highlighted by the Life as a Zebra Foundation with the help of writer, lawyer, MG-MI board member, and MG patient, Lisa Gigliotti.



Lisa Gigliotti

In April's Zebra Nation spotlight, Lisa shares an inspiring glimpse into life with myasthenia gravis. She opens up about invisible symptoms such as double vision, trouble swallowing, shortness of breath, and facial weakness, while also highlighting the daily practices that help her move forward with strength and purpose.

Through resilience, gratitude, rest, nourishing food, and exercise, Lisa's story reminds us that even the hardest-to-see challenges can be met with courage (coraggio!), and that a meaningful, positive life is always possible. Here's a link to the full article:

<https://zebration.org/blogs/april-2026-zebra-spotlight-lisa-gigliotti/>



Is there a link? **FOREVER CHEMICALS & MG**

Wallace Fu is a retired Hope College chemistry professor who also lives with MG. Dr. Fu recently spoke to a group of MG patients in Holland about what he calls "Forever Chemicals," which include common chemicals known as PFAS or PFOS. These chemicals have been used as waterproofing agents, in cosmetics and firefighting foam.

Potential Exposure to Forever Chemicals

- Meat and dairy
- Cosmetics and waterproofing products
- Carpet and upholstered furniture cleaning agents
- Drink carbon-filtered water, change filters often
- Know and test water quality

For more information, contact wally.fu@gmail.com

**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.



Personalized Patient Support from Alexion



AstraZeneca Rare Disease

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Hot Weather Safety Tips

Warm weather can be difficult for those living with myasthenia gravis. To help better cope with MG symptoms so you can enjoy your summer, consider these tips.

1. Stay in air-conditioned rooms and use fans as much as possible. Keep windows, blinds and curtains closed during the day to keep your home cooler and open windows and doors in the morning and evening when temperatures are lower.
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 when its cooler.
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 such as sunglasses, an eye patch and a hat to help protect your eyes from becoming sensitive to more sunlight.
9. Keep bottles of water and snacks in your vehicle in the case of a breakdown or emergency to take your medication, as heat can cause a sudden flare in symptoms.
10. Wear looser-fitting clothes made from natural fibers.

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VYVGART[®]
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argenx



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

Have you moved recently? Do you have a new email address or phone number? Make sure you're getting the regular mailings and invitations by updating your contact information.

- Go to our contact page at: <https://mg-mi.org/about/contact/>
- Email us at: info@mg-mi.org
- Call 616 956 0622

Mark Your Calendars!



MG-MI 50th Anniversary Celebration!

We're excited to be celebrating our 50th year serving the MG community. Plans are underway for a celebration gathering on Thursday, August 20, 2026, from 5-8 pm at the Grand Rapids Art Museum.

We're gathering memories, quotes from patients and caregivers, fun facts, and lots of photos from fundraising events, Christmas parties, conferences and more. A program during the gathering will include persons who have traveled the MG-MI journey with us, and we'll launch a new "Fueling the Care" endeavor that will propel MG-MI into the future.

A commemorative brochure is in the works that will include ads from companies and individuals who wish to honor or pay tribute to someone. Contact our office to learn more about how you can be involved. "Save the Date!"

In-Person & Virtual

10th MG-MI Patient Education Conference

Saturday, Oct. 10, 2026 • 9:30 am to 3 pm
Hilton Garden Inn Detroit/Novi – Novi, MI



Michigan MG patients will have an opportunity to get the latest research and treatment information from leading MG researchers at the MG-MI Patient Education Conference in October in Novi. Our keynote speaker is Kevin C. O'Connor, PhD who is Professor of Neurology and Immunobiology at Yale School of Medicine. Also presenting will be Amanda L. Hernandez, MD, PhD, Assist. Professor, Neuromuscular Medicine & Neuro-

Immunology, University of Connecticut, and Amit Sachdev, MD, MS, Director, Neurology & Ophthalmology, Michigan State University. Dr. Sachdev has been supervising second-year medical students conducting literature review research on MG (see related article on page 2). Their findings will also be available. Signup information for both in-person and virtual attendance will be available soon at www.mg-mi.org.

2026 Support Calendar



2026 VIRTUAL SUPPORT MEETINGS

10 am	NOON	6:30 pm
Aug 18	Jul 16	Sept 1
Nov 17	Oct 15	Dec 1

7/16 - Maryjo Prince-Paul, Alexion patient advocate
 8/18- Candis Fansher – Amgen patient advocate
 9/1 - Lisa Gigliotti – Using AI for MG Well-Being Hazards to Avoid

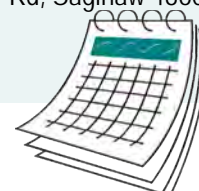
To better protect privacy, we now ask for your name and contact information before sending the link for virtual meetings. We will never share personal or identifying information. If you prefer not to register, email info@mg-mi.org and we'll send the link directly.



For more, go to MG-MI.org or use the QR Code above

2026 IN-PERSON SUPPORT MEETINGS

Berrien Springs Tue., July 21, 6:30 – 7:30 pm, Lynn Huls hosting, Berrien Springs Community Library, 215 Union St, Berrien Springs, 49103
Saginaw Wed, August 5, 6:30 – 7:45pm, Zauel Memorial Library, Dr. Kuremety Meeting Rm - 3100 N Center Rd, Saginaw 48603.
East Lansing Wed., August 12, 6:00-7:30 pm, MHSAA, 1661 Ramblewood St., 48823 *Box lunch provided.*
Rockford, Tue., Sept 22, 6:30-7:45 pm – Rockford Reformed Church, 4890 11 Mile Rd, NE, Rockford 49341



MARK YOUR CALENDAR!

Tenth Annual Patient Education Conference – Saturday, October 10, 9:30 am – 3 pm Hilton Garden Inn Detroit, 27355 Cabaret Dr, Novi, MI



50th Anniversary Celebration of

Myasthenia Gravis

Foundation of Michigan

Thursday, August 20, 2026
Grand Rapids Art Museum



MG-MI 50th Anniversary Celebration - Thursday, August 20, 5 pm – 8, Grand Rapids Art Museum,
 An evening of history, hope and launching "Fueling the Care" fundraiser. [Get tickets here!](#)



MYASTHENIA GRAVIS
mgmi
FOUNDATION OF MICHIGAN

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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