DECEMBER 2025 VOLUME 48 ISSUE 4

MYASTHENIA GRAVIS
mgmi
FOUNDATION OF MICHIGAN

9th Patient Education Conference

Miss It?
A Live
Recording
Is Now
Online!

COMMUNICATOR

Food, Feelings & the Future

There was a great turnout for MG-MI's 9th MG Patient Education Conference in Grand Rapids, featuring experts on living with MG. Speakers served up nutritional guidance, mental health tips, advice for hospitalization and new treatments. You can access speaker highlights and the full conference video via the QR or at mg-mi.org. Quick summaries of each speaker's key points are included below. See the full presentation here

Julie Rowin, MD

Lifestyle Medicine & MG

Medication is still essential for MG patients but by addressing environmental and lifestyle factors, those with MG can significantly improve their quality of life, reduce fatigue, and support immune balance.

Julie Rowin, MD

SUMMARY

Eat the rainbow for a variety of phytonutrients. The Mediterranean diet is recommended.

Mind your gut Avoid unnecessary antibiotics and processed foods that harm gut bacteria.

Exercise can be safe and beneficial for stable MG patients. Start slow and go slow.

Reduce stress Chronic stress and trauma increase autoimmune risk and worsen symptoms.

Stay social Connection and community improve outcomes

See the full presentation here

CONFERENCE *continued on page 2*

Counting Down to Our 50th Anniversary!

50 YEARS
MYASTHENIA GRAVIS
mgmi
FOUNDATION OF MICHIGAN

In 2026, MG-MI will celebrate 50 years of supporting the MG community. Would you share your stories or memories with us? Whether it's an event you attended, a meaningful support group meeting, or what MG-MI means to you, we'd love to hear from you! Please mail your thoughts to our office or email esther@mg-mi.org, who is gathering memories for a pamphlet. Event details will be shared when available.

Fifty Years of Caring for Community & Working for a Cure

WHAT'S INSIDE

Conference Highlights Continued

Louise O'Donnell, NP

Surviving Your Hospitalization

Louise O'Donnell, NP

Preparation, communication, and self-advocacy are the keys to surviving and recovering from a hospitalization.

By staying informed and involved in your care, you can help prevent complications and ensure the safest possible experience.

SUMMARY

Know before you go. Keep a current list of medications, doctor contacts, and known MG triggers. Include your MG diagnosis, neurologist's name, and emergency protocol.

Communicate early and often. Not all healthcare staff are familiar with MG, so advocate for yourself. Ask questions: If something doesn't feel right, alert staff immediately.

Understand your discharge plan. Note any medication changes before leaving.

Follow up. Contact your neurologist soon after your discharge.

Rest! Healing takes time; pace yourself and seek support from your MG community if needed.

See the full presentation here

Melanie Taylor, MD

MG Review & Current Treatment Options

Melanie Taylor, MD

See the full presentation here

Symptoms of MG are highly variable — that's why it's called the "snowflake disease." Therefore, treatment needs to be personalized, balancing symptom control, immune suppression, and side effects. New biologic therapies are transforming care, especially for difficult-to-treat and MuSK-positive patients.

SUMMARY

Know the basics. Most patients have acetylcholine receptor (AChR) antibodies; others may have MuSK or LRP4 antibodies,or are antibody-negative. The thymus gland often plays a role in producing these antibodies.

Most common symptoms. Muscle weakness that worsens with activity and improves with rest. Commonly affects eyes, facial muscles, speech, swallowing, limbs, and breathing. Severe cases may lead to myasthenic crisis requiring emergency care.

Know the treatment options.

- Symptomatic Treatment
- Immunosuppressive Therapy
- Newer Targeted Therapies
    - -FcRn inhibitors
    - -Complement inhibitors
- Biologic & Rescue Therapies
- IVIG and Plasmapheresis
- Thymectomy (surgery)

Know your triggers. Infections, surgery, certain medications, pregnancy, heat, and stress can worsen symptoms.

***CONFERENCE** continued on page 3*

Amit Sachdev, MD, MS

Amit Sachdev, MD, MS

Clinical Trials & Emerging Treatments for MG

Dr. Sachdev provided a comprehensive overview of the current landscape and emerging management strategies for myasthenia gravis, focusing on the role of clinical trials and the importance of disease measurement.

SUMMARY

The Evolving MG Treatment Landscape

- **Significant progress (2015 to today)** The field of MG management has seen a "sheer volume of development work" since 2015. There has been a transition from having few options to having multiple treatment avenues.
- **New approvals** Since 2018, there have been six new drug approvals for MG, with a seventh likely expected in December.
- **Improved patient outcomes** Patients with generalized MG have a substantially lower risk of being hospitalized on a breathing machine (ventilator). The high-risk window is understood to be primarily the first year after diagnosis.
- **Ongoing need for development** Despite having options, drug development continues because the work is "not done yet," aiming for better control and outcomes.

Key Recommendations

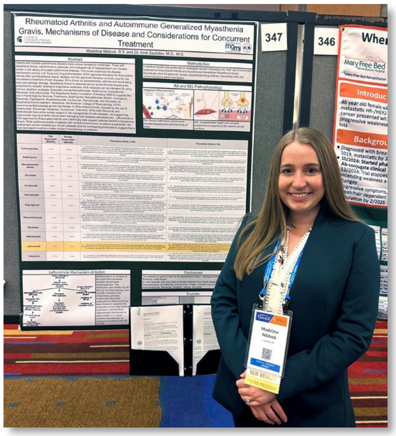
- **Know your MG-ADL**. (An Activities for Daily Living form is at: https://mg-mi.org/wp-content/uploads/2024/12/ADL-chart-1.pdf)

Monitoring Changes: A change of more than three points on the ADL score in a short period signifies a meaningful change in disease state that requires intervention, regardless of the starting severity (e.g., 1 to 4 is treated with the same urgency as 10 to 14).

- **Know your blood work/Marker** Your specific blood marker (e.g., anti-AChR antibody positive) is crucial.

See the full presentation here

Madeline Niblock: MG & RA Comparative Research Project



Madeline Niblock, MSU medical student and MG-MI research grant recipient, presented a poster of her literature review research at the AANEM conference in San Francisco

Madeline Niblock, a 4th-year medical student and MG-MI “Finding Solutions” research grant recipient, presented the results of her literature review on a dozen medications used for myasthenia gravis and rheumatoid arthritis. She investigated FDA approval status, guideline support, theoretical utility, and contraindications. She also identified overlap in treatment potential.

SUMMARY

- **Limited MG research:** Very few FDA-approved drugs; studies dominated by a small number of researchers.
- **Overlap exists**: Many RA drugs target immune pathways also active in MG.
- **Leflunomide** stood out as a promising candidate for further MG research due to preliminary evidence of benefit.
- **Need for more trials** and cross-disease exploration to reduce “polypharmacy” and improve quality of life for dual-diagnosed patients.

See the full presentation here

MG-MI Supports Research

Alongside the “Finding Solutions” grant, we fund major research centers. The O’Connor Laboratory at Yale School of Medicine studies Seronegative MG. Funding for clinical and translational research is provided through the MGNet Scholar Awards, given in February 2026 to MDs, PhDs, clinical fellows, post-docs, or junior faculty. Recipient details and research updates will appear in our March 2026 newsletter, including projects in Michigan.

Ask the Specialist

Ask the Specialist *is a forum for patients and caregivers to ask questions of clinicians who treat MG. See mg-mi.org for a list of topics that have been addressed such as the one below. If you have questions to share with other MG patients, use the link on the page or contact us at info@mg-mi.org or 616 956 0622.*

Question: Can taking a muscle relaxant make you feel worse?

Yes, taking a muscle relaxant may make you feel worse and here's why. The muscles of the people with MG can exist in one of three phases: 1. Active inflammation with muscle activity blocked. 2. Resolved inflammation but still recovering from damage. 3. Recovered from damage but still experiencing muscle de-conditioning. In all three of these phases, loosening up the muscles, the goal of muscle relaxants, can make you feel weaker. The key is globally weaker and not narrowly weaker. Narrow and worrisome weakness of swallowing and breathing, in particular, are the hallmarks of exacerbation requiring hospitalization. This would be unexpected.

Should I take these drugs? You need to talk to your doctor. Many patients try them for a short course, in particular for transient pain. The pain is often disabling in and of itself.

--Amit Sachdev, MD, MS

Find other answers by MG specialists at https://mg-mi.org\resources\ask-the-specialist/

Research Updates

We follow the latest news on MG research and treatments and publish updates at mg-mi.org.

- **COUR Pharma Secures FDA Orphan Drug Designation for CNP-106 in Generalized Myasthenia Gravis.**
- **RemeMG is seeking volunteers for its RemeMG Study, which will test how safe and effective a study drug called telitacicept is in adults with MG.**

Get the full articles published at https://mg-mi.org/resources/mg-news/

MG-MI in Action!

2025 by the Numbers

This year has been a remarkable year of growth for MG-MI. We have seen growth in our sponsorship and individual support and, as a result, have been able to expand our services to the MG community. Here's how 2025 "shakes out."

750	Number of patients we serve
3	Major events presented: two new Regional Health Summit and Resource Fairs, and our 9th Annual Patient Education Conference
4,000	Quarterly newsletters distributed via email with another 2400 by mail
5	Partner awareness events – Rare Disease Day and NOWINCLUDED-UCB/Acclinate events
182	Individual patient concerns addressed, including 48 new patients
60	Patient packets distributed with 15 patients being newly diagnosed
2	Major conferences attended: AANEM and MGFA
13	Partner webinars: Give an Hour Caregiver series, NDI ABLE account & SSI & SSDI, Identity Theft & Scam Prevention, Alexion treatment information dinner & webinar, and treatment trials
2,616	Facebook followers with 372 on Instagram and 125 on LinkedIn
304	YouTube followers**: check out our 15 new videos!**
27	Support/Information meetings: 13 in-person (3 new in Berrien Springs), 11 virtual, 3 hybrid

Board of Directors Highlights

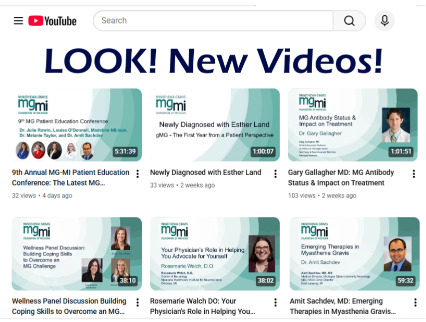
At the November meeting of the MG-MI Board of Directors, Lynn Huls was elected to a three-year term. She is a retired healthcare executive and consultant. Lynn was diagnosed with MG in 2022. She is thankful to be medically stabilized and is now ready to give back to the MG community by helping others cope with the disease. Lynn is a resident of Saint Joseph.

Jim Booth Burr, Jr., was reelected to serve on the board, extending his more than 40-year involvement with MG-MI.

Board member Dan Crandell was elected to serve as vice-president, who will serve along with Susan Woolner, who was reelected president; and Esther Land, who now serves in the role of secretary-treasurer.

MG-MI in Action!

15 New MG Videos Just Released!



LOOK! New Videos!

9th MG Patient Education Conference
Dr. Julie Rowin, Louise O'Donnell, Madeline Niblock, Dr. Melanie Taylor, and Dr. Amit Sachdev
5:31:39
9th Annual MG-MI Patient Education Conference: The Latest MG...
32 views • 4 days ago

Newly Diagnosed with Esther Land
gMG - The First Year from a Patient Perspective
1:00:07
Newly Diagnosed with Esther Land
33 views • 2 weeks ago

MG Antibody Status & Impact on Treatment
Dr. Gary Gallagher
1:01:51
Gary Gallagher MD: MG Antibody Status & Impact on Treatment
103 views • 2 weeks ago

Wellness Panel Discussion: Building Coping Skills to Overcome an MG Challenge
38:10
Wellness Panel Discussion Building Coping Skills to Overcome an MG...

Your Physician's Role in Helping You Advocate for Yourself
Rosemarie Walch, D.O.
38:02
Rosemarie Walch DO: Your Physician's Role in Helping You...

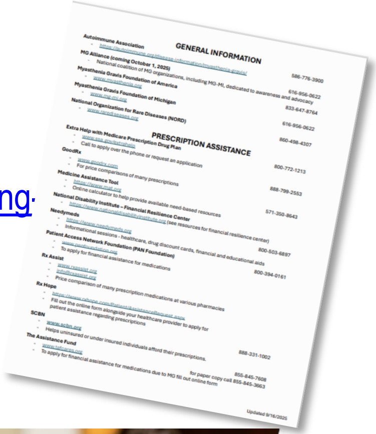
Emerging Therapies in Myasthenia Gravis
Dr. Amit Sachdev
59:32
Amit Sachdev, MD: Emerging Therapies in Myasthenia Gravis...

We just added 15 new videos to the MG-MI Video Library! The latest uploads cover almost every topic related to MG, focusing especially on talks by doctors and patients from Michigan. For example, there's a complete live video from our October conference with each speaker's remarks indexed for easy access. Another features MG-MI founder Esther Land discussing what it's like to be newly diagnosed. There's also a video where a Michigan neurologist talks about self-advocacy, and a panel of MG patients shares tips on developing coping skills.

Go to: https://www.youtube.com/@MG-MI/video to see the new content.
Be sure to subscribe to our YouTube channel to be notified whenever we add something new.

New Online Resources

MG-MI maintains updated directories of medical contacts, assistance agencies and informational resources for MG patients. You can find them at https://mg-mi.org/ living-with-mg/mg-toolbox/ If you are unable to access our website or need assistance, please email us at info@mg-mi.org or call 616 956 0622.



GENERAL INFORMATION

Autoimmune Association 586-776-3900
- https://autoimmune.org/disease-information/myasthenia-gravis/

MG Alliance (coming October 1, 2025) 616-956-0622
- National coalition of MG organizations, including MG-MI, dedicated to awareness and advocacy

Myasthenia Gravis Foundation of America 833-647-8764
- www.myasthenia.org

Myasthenia Gravis Foundation of Michigan 616-956-0622
- www.mg-mi.org

National Organization for Rare Diseases (NORD) 860-498-4307
- www.rarediseases.org

PRESCRIPTION ASSISTANCE

Extra Help with Medicare Prescription Drug Plan 800-772-1213
- www.ssa.gov/extrahelp
- Call to apply over the phone or request an application

GoodRx 888-799-2553
- www.goodrx.com
- For price comparisons of many prescriptions

Medicine Assistance Tool 571-350-8643
- https://www.mat.org
- Online calculator to help provide available need-based resources

National Disability Institute – Financial Resilience Center
- https://www.nationaldisabilityinstitute.org (see resources for financial resilience center)

Needymeds 800-503-6897
- https://www.needymeds.org
- Informational sessions - healthcare, drug discount cards, financial and educational aids

Patient Access Network Foundation (PAN Foundation) 800-394-0161
- www.panfoundation.org
- To apply for financial assistance for medications

Rx Assist
- www.rxassist.org
- info@rxassist.org
- Price comparison of many prescription medications at various pharmacies

Rx Hope
- https://www.rxhope.com/Patient/AssistanceRequest.aspx
- Fill out the online form alongside your healthcare provider to apply for patient assistance regarding prescriptions

SCBN 888-331-1002
- www.scbn.org
- Helps uninsured or under insured individuals afford their prescriptions.

The Assistance Fund 855-845-7608
- www.tafcares.org
- To apply for financial assistance for medications due to MG fill out online form for paper copy call 855-845-3663

Updated 9/16/2025

Stronger Together

Announcing the MG Alliance

The MG Alliance is a new national coalition uniting organizations dedicated to supporting the myasthenia gravis community. MG-MI is proud to participate in this collaborative effort, which aims to expand educational, social, and support opportunities for individuals affected by MG.

Benefits of the MG Alliance:

- Access to information on nationwide MG-related conferences
- A directory of resources
- Opportunities to connect with diverse communities, including LGBTQ+, Black, Hispanic, caregivers, teens, and holistic wellness groups.

Learn more at www.theMGalliance.org

2025 Annual Awards

Each year, MG-MI honors those who have contributed their extraordinary gifts of time, talent, and expertise to the organization. Many of our award recipients face their own daily struggles with myasthenia gravis but still find the energy and drive to give to others so that all our lives are enriched.

Esther M. Land Founders' Award – Amit Sachdev, M.D., M.S.

Susan Woolner, presents Dr. Amit Sachdev with the Esther M. Land Founders Award Oct. 11, 2025

In August 2015, Dr. Sachdev became the director of the first Division of Neuromuscular Medicine at Michigan State University, where he has improved neuromuscular research, education, and clinical services. That month, he invited our MG-MI office to join a myasthenia gravis clinic linked to the Muscular Dystrophy Care Center. He actively participates in clinical trials, especially for myasthenia gravis, helping bring new treatments that enhance patients' lives.

Since 2016, he has served on our Board of Directors and Medical Advisory Board, regularly sharing MG updates at conferences, contributing to our newsletter, and leading webinars.

He also proposed a grant supporting grassroots research, enabling Madeline Niblock's work to be presented at MG-MI's October conference and at a major neurology conference. Dr. Sachdev's dedication and compassionate care make him an exceptional doctor who inspires hope.

Coraggio Spirit Award – Yolanda Colette Arnold

This annual award honors someone who lives the Coraggio theme: that *With Courage You Can* persevere and resiliently lead a life of purpose and joy. Yolanda Colette Arnold has lived with myasthenia gravis (MG) for 30 years. When her ophthalmologist couldn't diagnose her symptoms, she took charge by seeking answers until she was diagnosed. Her determination helped her maintain her job, raise her son, stay active in her church and with family, and inspire others. She often thanks God for her health and embodies Spirit through her faith, gratitude, and refusal to let MG limit her meaningful life.

MG-MI's Esther Land, Collette Arnold and Coraggio presenter Lisa Gigliotti

Kristine Fey-Paiz

Volunteer of the Year Award – Kristine Fey-Paiz

Kristy joined MG-MI three years after her diagnosis. In 2004, she saw our Walk-A-Thon on the website and created the "Thymectomy Scar of Courage" team, raising over $600. After retiring in 2023, she began volunteering regularly, mainly handling our newsletter mailings. Kristy is a quick and efficient help, ensuring timely and attractive mailings. We appreciate her dedication to MG-MI and the patients we support.

Volunteer of the Year Award – Alice White-Kaminski

Since her MG diagnosis in 2011, Alice has been a dedicated advocate for MG awareness. In 2014, she led a campaign distributing MG information to local medical facilities in Warren. That summer, she gained recognition by participating in a Detroit Public TV segment on MG. This year, Alice volunteered at our MG office and actively supported the Macomb County Regional Support Group by sharing materials and promoting engaging meetings. Despite challenges, she remains a positive and valuable member of our MG community.

Alice White-Kaminski

2026 Support

In-Person & Virtual Events

mgmi Connect

Our full schedule is in progress.
Go to https://mg-mi.org/upcoming-events/
for updates.

2026 IN-PERSON SUPPORT MEETINGS

Macomb County Regional

Quarterly on the 2nd Monday, 7:00 – 8:30pm.
Tentative dates: 3/9, 6/8, 9/14, (12/7)
Amazing Grace Lutheran Church, 29860 Dequindre Rd, Warren 48092

2026 VIRTUAL SUPPORT MEETINGS

(RSVP to the office is encouraged, but not required)
Quarterly on the 3rd Thursday at 12:00 noon ET on 1/15, 4/16, 7/16, 10/15
Quarterly on the 3rd Tuesday at 10 am ET on 2/17, 5/19, 8/18, 11/17
Quarterly on the 1st Tuesday at 6:30 pm ET on 3/3, 6/2, 9/1, 12/1

NEXT BOARD OF DIRECTORS MEETING

Virtual Wednesday, January 21, 6:30 – 8:00

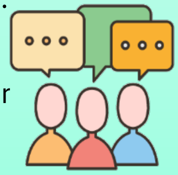
Virtual meetings allow for Q&A

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

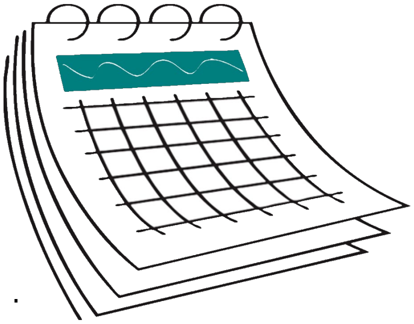
Virtual link
https://us02web.zoom.us/j/6169560622
Meeting ID: 616 956 0622
By phone 1 309 205 3325
Enter meeting ID 616 956 0622
when prompted.

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 2026.



Save the Dates!

Regional Health Summit and Resource Fair – Saturday, May 30, 9am – 1pm.
Delta Marriott Kalamazoo Conference Center. 2747 S.11th St., Kalamazoo, MI

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

MYASTHENIA GRAVIS mgmi FOUNDATION OF MICHIGAN

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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