

MYASTHENIA GRAVIS  
**mgmi**  
FOUNDATION OF MICHIGAN

# COMMUNICATOR

## Patient Forward

# MG Health Summit Take-Aways



Dr. Beth Kelley

Myasthenia gravis (MG) has been called the “snowflake disease” because of the uniqueness and variety of patients’ symptoms. The August 9 MG-MI Health Summit and Resource Fair in Livonia highlighted the exceptional challenges of living with MG. Most presenters were MG patients who shared their experiences, setbacks, and achievements.

### **Beth A. Kelley, PhD, FNP-C, CNM**

Sixteen years ago, Dr. Beth Kelley was diagnosed with myasthenia gravis after experiencing fatigue, blurry vision, and weakness. Following surgery and treatment, she adapted to her new circumstances, earned a doctorate in nursing education, and now supports others with MG through public speaking and meditation.

*See Dr. Kelley’s “Life Tips” on page 6.*

**Here are some online resources she suggests exploring.**

- Smiling Minds <https://www.smilingmind.com.au/> – free
- Healthy Minds App - <https://hminnovations.org/meditation-app/> – free
- Insight Timer <https://insighttimer.com/> – has 150,000 free meditations

*HIGHLIGHTS continued on page 2*

## WHAT'S INSIDE

### Page 2

- Health Summit Highlights Continued

### Page 3

- Research News: argenx, Alexion
- Current Treatment Trials
- From our Silver Sponsors

### Page 4

- Ask the Specialist
- Sponsor Ad Alexion
- Michigan State University ad

### Page 5

- Treatment Access Challenges
- Upcoming Special Events
- Sponsor Ad: argenx

### Page 6

- Dan Crandall Joins MG-MI Board
- Dr. Kelley's Tips
- Sponsor Ad: Amgen

### Page 7

- MG-MI Education Conference Oct 11

### Page 8

- Support Meeting Calendar

## Registration Closing Soon! *See Page 7*

**9<sup>th</sup> MG Patient Education Conference**  
 Saturday, Oct. 11, 2025 9:30 a.m. to 3 p.m.  
 Calvin University - Prince Conference Center - Grand Rapids



To Register, use QR code or go to <https://secure.ggiv.com/for/MG-MIConferences/event/mgmipatienteducationconference2025/>

## MG Patient Panel

### ***Been There, Done That, Have Wisdom to Share***

During this session, Southeast Michigan patients, Andrea Fuller, Mickey Bloomberg, and Colette Arnold, discussed the variability of the disease, emphasized self-advocacy, education, and support, and shared strategies for managing symptoms. Topics included medication management, coping methods, and the importance of communicating with healthcare providers. The group also stressed energy conservation suggesting minimizing steps and keeping often used objects within reach.



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*Rebecca Lindemann, MPT*

## **Personalized Physical Therapy Approaches**

Physical therapist Rebecca Lindemann, MPT discussed the value of individualized therapy for muscle weakness and fatigue, incorporating aerobic exercise, strength training, flexibility, and breathing techniques.

She recommended starting gradually, monitoring energy levels, maintaining hydration and rest, and collaborating with a multidisciplinary team. Lindemann encouraged patient involvement and open communication to create an effective care plan.

# **Myasthenia Gravis Treatment Advances**

Dr. Alan Salgado delivered a comprehensive presentation on the history and management of MG, emphasizing the significant reduction in mortality rates, from 80% to just 3 to 4% over the past century. He says it's attributable to advancements in respiratory support and immunosuppressive therapies.

The session reviewed established treatment modalities, alongside recently approved therapeutic options since 2017. Dr. Salgado noted that the choice of therapy should be individualized based on patient-specific factors, including age, comorbid conditions, and antibody status. He also addressed the necessity of vigilant monitoring for adverse effects and the role of lifestyle adjustments.

The presentation concluded with a summary of emerging treatments undergoing FDA evaluation. These investigational agents demonstrate potential for addressing refractory symptoms across different myasthenia gravis subtypes, including seronegative cases, which have historically posed greater therapeutic challenges.



*Alan Salgado, MD*





# Research Updates

## Positive Trial Results for Seronegative Patients

Biopharmaceutical manufacturer argenx has announced positive topline results from ADAPT SERON Study of VYVGART in patients with AChR-Ab seronegative gMG. The study's principal investigator, James F. Howard Jr., M.D., says "The results of the ADAPT SERON study, the largest study to date of AChR-Ab seronegative gMG, confirm that VYVGART now has the potential to be a targeted, effective, safe, and necessary treatment for patients living with gMG, regardless of autoantibody status."



argenx 

## New Self-administered Medication on the Horizon



Gefurulumab (AstraZeneca) dual-binding nanobody demonstrated statistically significant and clinically meaningful improvement in functional activities of daily living in adults with generalized myasthenia gravis in PREVAIL Phase III trial. Once-weekly self-administered subcutaneous C5 inhibitor showed statistically significant and clinically meaningful reduction in disease severity at week 26.

ALEXION 

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

## Current MG Treatment Trials

Find out if any current research projects could use your help and perhaps help you, too.  
Go to: <https://myasthenia.org/mg-research/clinical-trial-opportunities/>

## A Word from Our Silver Sponsors...



**UCB** is a global biopharmaceutical company headquartered in Brussels, Belgium, with U.S. offices in Atlanta and six additional research sites nationwide. UCB develops treatments for severe immune and central nervous system diseases, including RYSTIGGO. UCB also supports myasthenia gravis patients through resources and initiatives, including the UCB Myasthenia Gravis Scholarship™, which awarded 15 scholarships in 2025 and will continue funding into 2026. Additionally, UCB's U.S. Rare Diseases Advocacy Team has developed a unique informational resource which includes a new series of 12 short exercises such as warm-ups, mobility work, strength building, and cooldowns, designed to work for individuals living with myasthenia gravis.

Go to: [www.youtube.com/playlist?list=PLX7IQz54GCi-9keRcquiLnA\\_7JUGSjFA1](https://www.youtube.com/playlist?list=PLX7IQz54GCi-9keRcquiLnA_7JUGSjFA1)



**Vital Care of Auburn Hills** provides compassionate and personalized infusion services.

We believe in collaboration between providers, clinical staff, and patients to improve care quality. Our team customizes approaches to meet each patient's needs and offers cutting-edge therapies for MG patients. Our core values—Integrity, Urgency, Quality, Success, Execution, and Team

Commitment—drive our winning culture. While we can't offer better medications than other clinics, our values help us excel for our patients. Patients have a choice in their care. For customized home infusion services, have your provider send a referral to Vital Care of Auburn Hills. We serve patients throughout Michigan.

Visit <https://greatlakesvc.com/> for resources and referral forms. We handle prior authorizations and have contracts with most health insurance plans, including Medicare and Medicaid. We keep providers informed about all aspects of patient services. --Brian Schmitt, President



# 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](http://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](mailto:info@mg-mi.org) or 616 956 0622.

## **Question:** What are the pros and cons of a thymectomy and how would I know if it's right for me?

The surgery is generally deemed safe. There are several scenarios when weighing risk vs benefit.

1. Is a malignant mass suspected? In such a situation, generally surgery is recommended.
2. Is an enlarged but otherwise normal thymus present? In this scenario, you may weigh risk vs benefit, but removal remains generally recommended and early in the disease course is advocated.
3. Is no appreciable mass or enlargement found? Many providers would attempt to optimize a patient first. Optimize means strive to achieve minimal manifestations of disease. This is achievable for a minority of patients (30-40%). The path is most clearly understood with newer therapies. A patient who has achieved minimal manifestations with medication may then weigh the burden of long-term exposure to that medication regimen against risk of surgery. Surgery remains a possible path towards drug free remission.

--Amit Sachdev, MD, MS

**Find other answers by MG specialists at:**

**<https://mg-mi.org/resources/ask-the-specialist/>**



### **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.



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## The Path to New MG Treatments Runs Through MSU

Dr. Amit Sachdev at the Michigan State University Department of Neurology and Ophthalmology has open clinical trials related to myasthenia gravis. MSU has contributed to five FDA approvals.

**To learn more about ongoing and planned MG clinical trials at MSU, contact Aubrey Alexander at [alexaub@msu.edu](mailto:alexaub@msu.edu).**





# MG-MI in Action!

## Facing Treatment Access Challenges Together

Since the FDA approved Soliris for generalized Myasthenia Gravis (MG) in 2017, nearly ten new treatments have emerged. However, high costs and insurance challenges remain major obstacles for many. A 2022 AARP survey found 60% of Michigan voters over age 50 worry about affording needed medications. In our MG-MI community, these concerns are increasing due to funding cuts and rising drug prices—making proper treatment harder to obtain and putting patients at risk of serious complications.

## We Hear You—and We're Taking Action

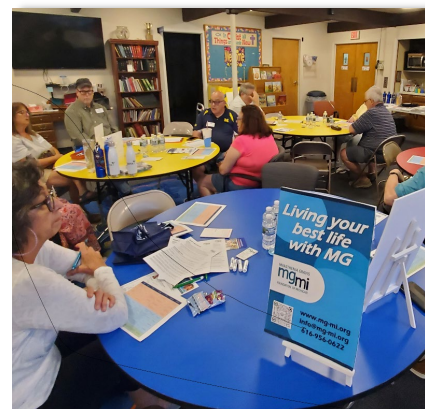
MG-MI is responding by inviting experts to support meetings and providing resources on:

- New MG treatments
- Insurance authorization and step therapy
- Treatment advocacy programs
- Appealing insurance denials
- Resources for assistance
- Research trial information

Find these resource documents at our events, meetings, website, or by contacting us.

## Community Engagement

If you have helpful experiences, including veterans affairs claims, please share—they could benefit others. To advocate for better access, contact your state legislators. Together, we can work for improved care and affordability.



## Upcoming Assistance Events

**Virtual Wednesday, September 17,  
3:00 – 4:30 p.m. & November 19, 6:00 – 7:30 p.m.**  
Free, empowering caregiver support event sponsored by Alexion Charitable Foundation and Amgen.

**Virtual Tuesday, September 23, 11 am - noon**  
National Disability Institute's Financial Resilience Center help you maximize financial security while maintaining essential benefits

**To register for either program, go to:**  
<https://mg-mi.org/upcoming-events/>

## New Online Resource Documents Available

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](mailto:info@mg-mi.org) or call 616 956 0622.

**VYVGART Hytrulo\***  
(efgartigimod alfa and hyaluronidase-qvfc)

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**Self-injection**  
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# MG-MI in Action!

## Dan Crandall Joins the Board



Daniel Crandall

At its June 18 meeting, MG-MI welcomed Dan Crandall to its Board of Directors for a three-year term. Diagnosed with MG in 2024, Dan initially had little information about the disease, but gained valuable support through MG-MI, inspiring him to get involved and help others newly diagnosed.

With over 30 years as a television engineer and currently Chief Engineer at WILX-TV in Lansing, Dan brings strong analytical skills to the board and service to patients. When applying for a position on our board, Dan stated, "The opportunity to participate in these activities seems both exciting and rewarding to me." Welcome, Dan!

### We Need Your Help

The Myasthenia Gravis Foundation of Michigan is a non-profit organization guided by a volunteer board of directors. With Zoom and other efficient technologies, volunteering with MG-MI is more accessible than ever. If you want to make a difference for those affected by MG, consider joining the Board or volunteering in another role. Contact [info@mg-mi.org](mailto:info@mg-mi.org).

***OUR VISION: Living Your Best Life With MG***

### Dr. Kelley's Tips for Living Your Best Life

- **Connect with others at MG events.**
- **Participate in support meetings.**
- **Accept your limitations for any given day. Say no when necessary.**
- **When you're having "one of those days," maintain your mental health by journaling or conversing.**



**AMGEN**

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



# 9<sup>th</sup> MG 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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**Saturday, October 11, 2025 • 9:30 a.m. - 3:00 p.m.**

Calvin University • Prince Conference Center  
1800 East Beltline SE, Grand Rapids, MI 49546



- 8:45 a.m.** Registration / Continental Breakfast / Visit Sponsors
- 9:25 a.m.** Welcome – Susan Woolner, MG-MI President, Board of Directors
- 9:30 a.m.** Julie Rowin, MD, ABIHM, FAAN – Keynote Speaker *Lifestyle Medicine & MG – Living your Best Life:* Supporting conventional medicine management with holistic approach in treating adult neurological conditions
- 10:30 a.m.** Louise O'Donnell, RN, MS, NP – *Surviving Your Hospitalization*  
Guidelines for practical preparedness when hospitalization is part of your health journey.
- 11:30 a.m.** Madeline Niblock, MSU, Research recipient – *gMG and RA Mechanisms of Disease & Considerations of Concurrent Treatment:* Sharing the outcome of research project to locate a common therapy for MG and RA.
- 12:00 noon** Lunch, socializing, networking, and visiting sponsors
- 12:45 a.m.** Awards Presentation
- 1:00 p.m.** Melanie Taylor, MD – *MG Review and Treatment Options:* The etiology of MG and the role of treatment management with recent options.
- 2:00 p.m.** Amit Sachdev, MD – *Clinical Trials and Emerging Treatments for MG:* The role of clinical trials in developing new therapies and emerging treatment options.
- 3:00 pm** Closing – Susan Woolner

REGISTER NOW at no charge for in-person or virtual attendance at MG-MI.org by contacting the office. Donations are always appreciated.

<https://secure.qgiv.com/for/MG-MIConferences/event/mgmipatienteducationconference2025/>  
**Please Register by September 29, 2025**

For a Conference Center hotel room, visit <https://calvin.edu/prince-conference-center>. Click Reserve a Room; click Rate Option then type the code: **ICMGMI**. Click room type picture and click Book It. A credit card is required to pay the room fee of \$115/night. **Block closes Friday, September 21, 2025**



# 2025 Calendar

## In-Person & Virtual Events

[Go the MG-MI Calendar](#)



### Virtual September 23, Tuesday Monthly 6:30 p.m. – 7:30 p.m.

Dr. Beth A. Kelley PhD, FNPC, CNM “Myasthenia Gravis from a Patient/Provider Perspective”

### Berrien Springs September 30, Tuesday 6:30 p.m. – 7:30 p.m.

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

### Virtual October 21, Tuesday 6:30 p.m. – 7:30 p.m.

Dr. Omar Sinno, UCB Medical Lead, will present on the MG treatment “Zilbrysq”

### Virtual November 18, Tuesday 6:30 – 7:30 p.m.

argenx speaker will discuss “Managing Symptoms”

### Macomb County Regional December 8, Monday 7:00 p.m. – 8:30 p.m.

Amazing Grace Lutheran Church, 29860 Dequindre Rd, Warren 48092.  
General discussion of *Living your best life with MG*.

### Virtual December 16, Tuesday Monthly 6:30 p.m. – 7:30 pm

argenx speaker will address “MG & Emotional Health.”

### Seronegative MG (SNMG) Patient Webinar | Monday, October 13, 6:30 p.m. – 7:30 p.m.

Join Amit Sachdev, MD, MS as he discusses SNMG. Q & A to follow. Topics include:

- The Immunovant Study – FCRN
- The Cladribine Study
- The Seronegative dataset coming from Vyvgart study

Go to: <https://mg-mi.org/upcoming-events/>.

### 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!

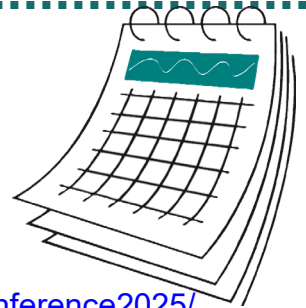


We appreciate you! Click [HERE](#) to donate to help us provide services throughout 2025.

**Register  
Now!**

## Sat. Oct. 11

### 9th Annual Patient Education Conference Grand Rapids



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