



COMMUNICATOR

Highlights from the MG-MI Patient Education Conference



We've all heard that knowledge is power. When it comes to rare diseases—especially if you're the one who has been diagnosed with one—knowledge can bring hope and improve the quality of your life. That's why education is one of the fundamental missions of the Myasthenia Gravis Foundation of Michigan.

On October 5, 2024, MG-MI presented the 8th Annual Patient Education Conference in East Lansing, the first in-person event held since Covid-19 forced conferences into a virtual-only mode.

The conference would not have been possible without the generosity of our sponsors. Major Platinum partners were Alexion, Amgen, and argenx. Our Bronze partner was UCB and Contributing partners were Catalyst, InfuCareRx and Soleo.

On the following pages, we include highlights from conference presentations.

We are excited to host our first Regional Health Summit and Resource Fair this spring featuring educational presentations by Dr. Rosemarie Walch and Dr. Margaret Frey, and Wellness Center demonstrations on electrophysiology, Pilates, balance, massage and nutrition. Resources, including treatment options, will be available. Registration coming soon.

SAVE THE DATE!

May 3, 2025

MG-MI Regional Health Summit & Resource Fair

Memorial Healthcare Institute for Neuroscience, Owosso, MI

Connecting the Michigan MG Community to local medical experts and resources to support patients and caregivers on their MG journey



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WHAT'S INSIDE

Page 2

- Know Your Antibody Status
- Self-advocacy: You & Your Physician

Page 3

- Founder's Award
- Volunteer of the Year Award

Page 4

- Coraggio Spirit Award
- Appreciation for Dr. Glisson

Page 5

- Dealing with Grief
- Winter Weather Tips
- Sponsor Ad: Alexion

Page 6

- MG-MI Research Support
- Clinical Trial Resources
- Calvin Rare Disease Day
- Sponsor Ad: argenx

Page 7

- Welcome Dana Green!
- We're Looking for Board Members
- PCs for People
- Sponsor Ad: Amgen

Page 8

- Support Meeting Calendar

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Know your antibody status

AChR antibodies in MG

The first antibodies associated with MG to be discovered were those affecting the acetylcholine receptors (AChR). Then, other antibodies were discovered, including muscle-specific kinase (MuSK) and low-density lipoprotein receptor-related protein 4 (LRP4). Each antibody binds to a membrane protein. The antibodies are present in 80% of patients with generalized MG and 50% of those with purely ocular MG.

Muscle-specific kinase (MuSK) antibodies

MuSK antibody is present in 5-8% of MG patients and 40% among AChR negative patients.

MuSK-MG clinical characteristics

Observations include predominant bulbar involvement with slurred speech, difficulty swallowing, generalized weakness, and shortness of breath.

LRP4 MG clinical characteristics

In an observational multicenter study, LRP4 MG patients had more severe symptoms compared to seronegative patients, however response to standard treatment was good.

Other antibodies

Other antibodies have also been described in the setting of MG:

- Agrin •Voltage-gated potassium channel α -subunit Kv1.4 •Rapsyn •Cortactin •AChE •ColQ •Collagen XIII

Thymoma-associated MG

MG attributed to thymoma constitutes 10% of all MG cases.

What if an antibody test is negative?

Consider rechecking within 6-12 months. Studies have found up to 15% of patients who initially tested negative for antibodies become "seropositive" in later testing.



Rosemarie Walch, D.O.

SELF-ADVOCACY: You and Your Physician

Patient self-advocacy is gaining interest in medicine and neurology, especially in the MG community. One of the topics attendees found especially valuable was preparing for a doctor appointment.

Be Prepared

- Go to appointment prepared
- Educate yourself about your disease
- Don't hesitate to take a second person with you for note-taking or someone else to provide a second set of ears
- Therapeutic selection (medications)
- If the mode of delivery, schedule of medication or financial burden of medication does not work for your life, then speak up; there are non-steroidal agents as well

Monitor MG Symptoms and Treatment Goals: ADL

A scale is used to assess the impact of MG on daily function. It focuses on various activities of daily living (ADL):

- Eating • Dressing • Grooming • Mobility
- A higher score indicates worse functioning
- An improvement of 2 points is considered clinically significant.

[Download an ADL Form Here](#)

MG-MI In Action!



Esther M. Land Founder's Award – Susan M. Woolner

This award is presented to a person who displays the characteristics of initiative, courage, passion and fortitude in promoting the purpose for which our organization was founded – serving and supporting with compassion myasthenia gravis patients through information and educating them on living a quality life with MG.

Susan was honorably presented this award for her initiative and passion in promoting and leading MG-MI to a higher level of service and awareness. As Neuroscience Patient Support Coordinator / Neuroscience Community Manager at Trinity Health Hauenstein Neurosciences she is very much aware of myasthenia gravis and the challenges it can present. Her compassion for those living with MG stimulated her vision for our annual Patient Education Conference which began in 2017. Through her fortitude it has become the largest forum for myasthenia gravis patient education in the Mid-West.

Susan's professional connections have also introduced MG-MI to partnerships in the medical arena. During the past two years, her leadership skills encouraged the Board to develop a three-year Strategic Plan, and her IT skills were an asset in updating our MG-MI logo and launching our new website. Susan's vision, initiative, determination and compassion are advancing MG-MI into a new and improved era of service to the MG community. Our sincere appreciation and thanks, Susan!



MG-MI board president Susan Woolner

Volunteer of the Year Award – Janet Gentle

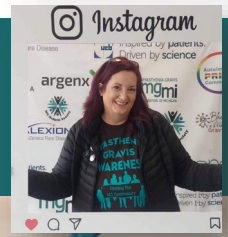


MG-MI board member Janet Gentle receives the Volunteer of the Year Award from founder Esther Land

Janet was diagnosed with MG over ten years ago, but unstable MG limited her involvement with MG-MI. As a Northern Michigan resident, her desire has been to develop a more active representation in the "Up North" region. In the spring of 2023, she responded to a *Communicator* newsletter article seeking members to our Board of Directors.

Her desire to support MG patients coupled with her nursing administrative background resulted in her joining our Board (she remotely attends meetings) and serving as our "Up North" volunteer ambassador. During the past year, Janet has organized and led six support sessions in as many locations and has renewed contact with medical professionals in the region. Janet is a kind and compassionate patient-oriented asset to MG-MI. We were honored and pleased to present her with the 2024 Volunteer of the Year Award. Our grateful thanks, Janet, for your involvement with and service to our Northern Michigan MG community.

Living Your Best Life With MG



Coraggio!

Eva Schmucker Receives Coraggio Spirit Award

The Coraggio Spirit Award is annually given to a person who embodies the Coraggio theme: that with courage, you can persevere and resiliently lead a life of purpose and joy.

Eva Schmucker was presented the *Coraggio Spirit Award* during our 2024 Patient Education Conference. Since childhood Eva has worked alongside her family on household and farm chores in her Amish community. When she was about 4 years old, she and her parents noticed muscle weakness in her arms and legs. Also, at times her speech sounded different, or it was difficult to pronounce words. The family traveled from Indiana to receive specialized neurology care at the Michigan State University Myasthenia Gravis (MG) Clinic. The Schmucker's did not know anyone else diagnosed with the condition. To learn more, they attended several conferences and became actively involved in MG-MI activities and support meetings.

Eva exemplifies the Coraggio principle of believing there are aspects of MG over which you can take charge to enhance well-being. She continues to seek natural methods or modifies the types and number of activities she performs that allow her to have the energy for a productive day.

Upon receiving the award Eva said, "I want to thank you all for the help and inspiration we received from our Michigan friends, my grandparents, parents and family. I feel very blessed (through God all things are possible) when I consider all my blessings and what Jesus did for me that makes each day possible through Faith and Grace."

Eva's determination to live each day with purpose and courage while being actively engaged with family, community, and work through gratitude and faith exemplifies the Coraggio Spirit. She is an inspiration for others living with MG. Coraggio, Eva!



MG-MI board member Lisa Gigliotti announces the winner of the Coraggio Spirit Award, named for her grandmother

In Grateful Appreciation Award – Christopher Glisson, D.O.



We respectfully presented Dr. Glisson an award remotely for his 15 years of service to MG-MI and our MG community. In 2008, he came to Grand Rapids as the first Neuro-ophthalmologist at Hauenstein Neurosciences Center. His interest in myasthenia gravis brought him into a mutually rewarding relationship with MG-MI. His involvement included leading our Medical Advisory Board, serving on our Board of Directors, and writing articles for our "Ask the Doctor" newsletter column.

Dr. Glisson's compassionate care and medical expertise are highly respected by MG patients throughout Michigan. In January of this year, he accepted a position to direct an emerging neuroscience institute in Tulsa, OK. Our sincere best wishes, Dr. Glisson, as you embark on this new role in your medical career, and our gratitude and thanks for your services in Michigan!



Living Your Best Life With MG

Dealing with Illness and Grief

By Emily Vlieg, LMSW - Patient Education Conference Presenter

Acknowledging grief can release emotions patients tend to feel as they grapple with a new diagnosis and live with chronic illness. Often, once this grief is acknowledged and felt, we can more easily be in the present to focus on challenges and joys at hand.

- Validate your experience and the process it took to arrive at the diagnosis. Feeling anger/sadness/rage doesn't make you weak. You're not "giving in" to negative thinking to sit with these feelings. It's important for caregivers to acknowledge your own feelings as well. It's often just as difficult to watch someone you care about going through something challenging when you yourself can only observe.

- Be gentle with yourself. It's easy to become impatient and think, "all I'm doing is fulfilling tasks like everyone else." Except that for you, it may take five more pre-planning steps just to get in the car. So, praise yourself for being careful with your body and your time. Remember that you're doing something that is NOT easy.

- Remember that grief can re-appear just when we think we've conquered it. Feelings can be different depending on where we are in life. Something that may not have seemed difficult or frustrating at one point may suddenly become very emotional. It just means you've grown and changed and now you need to look at something again from a new angle and process it again.



Emily Vlieg

Winter Weather Tips

Living in Michigan, we all have to deal with winter winds and snow. If you have MG, you may need to be a little more cautious about frigid conditions. And remind ourselves it's just a season; it will pass!

- Keep your home at a comfortable temperature.
- Dress in layers -- try and keep your core temperature around 95 degrees Fahrenheit.
- If it is raining or snowing outside, make sure you are wearing shoes with good traction.
- Be mindful of the surfaces you are walking on and try to avoid the icy and snowy patches.
- Avoid going out on days where there is a 'Winter Weather Advisory'.
- Perform strenuous activities during peak medication times.
- Schedule rest periods while shopping, or try shopping online.
- Plan when and learn how to safely shovel snow.

SUPPORT FOR MYASTHENIA GRAVIS (MG)

Find what makes you



MORE THAN MG

Join the community of patients, caregivers, and other advocates

Whether you're looking to hear more about MG, find a friend with the same diagnosis, or receive some motivation, there's a place for you in the More Than MG community.



[MORETHANMG.COM](https://www.morethanmg.com)

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Medical/Research

MG-MI Supports Research in 2024

Much of our work at MG-MI focuses on providing education and emotional support for MG patients, their families, and caregivers. We also support scientific research endeavors aimed at making discoveries to improve the lives of those with MG. We were honored to support two research endeavors during 2024.

Seronegative MG Research - MG-MI has continued to support Kevin O'Connor, PhD at Yale School of Medicine and the team conducting research on Seronegative MG (SNMG). SNMG is a disease subset of MG defined by the absence of detectable autoantibodies to neuromuscular junction targets.

MGNet Scholar Program - This project provides individualized training and mentorship in one of two tracks, Clinical Research or Biomarker Development Research. MG-MI is supporting two recently awarded scholars.

Alexandra Wilder Bayer, a postdoctoral associate with Dr. O'Connor at Yale School of Medicine, proposes to investigate the molecular mechanisms through which autoreactive IgM may contribute to the pathway of acetylcholine receptor antibody-positive MG.

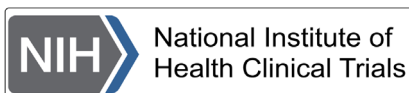
Patricia Sikorski is a postdoctoral associate at George Washington University in the Laboratory of Myasthenia Gravis under the direction of Linda Kusner, PhD. Dr. Sikorski's project investigates the hypothesis that bias toward a stronger immune response in women drives enhanced differentiation into atypical B cell and dysregulated T cells in the thymus.

As MG-MI grows, we will continue to support vital research efforts by providing funding, and inform patients about studies.

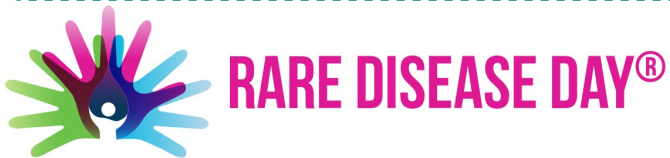
Clinical Trial Resources



<https://mgnet.rarediseasesnetwork.org/>



<https://clinicaltrials.gov/>



Calvin Rare Disease Day Event

MG-MI will be hosting an informational table at the Rare Disease Network's 6th annual Rare Disease Day on Saturday, February 22, 2025, from 9 a.m. to 4 p.m. at the Prince Conference Center on Calvin University's Grand Rapids campus. The event is free to the public.

Information is available at <https://calvin.edu/events/rare-disease-network>



EXPLORE THE POSSIBILITIES

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

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MG-MI In Action!



MG-MI welcomes Dana Green to our Staff!

MG-MI is pleased to introduce and welcome our newest team member, Dana Green, Administrative Assistant.



Dana Green

Dana has had many roles since graduating from Grand Valley State University in 2008. Upon graduation, she worked for an insurance company for ten years as a commercial account manager. After the birth of her third child, she left the business and focused on her family.

In 2019, Dana was diagnosed with breast cancer and as a result of her battle she developed a passion to support people through their health journeys. Dana volunteers at Beautiful You, a non-profit for women going through cancer treatment, as well as at her kids' school. She is on the PTO board, coaches Girls on the Run, and works as a paraprofessional. Dana and her husband live in the Rockford area with their three children.

When they aren't busy driving their kids to after-school activities, their family enjoys exploring events in and around Grand Rapids and Michigan on day trips.

MG-MI is Looking for Board Members!

Want to have an impact? Our MG-MI Board meets five times throughout the year with three virtual meetings and two hybrid (in-person and virtual options). The meetings are open to anyone interested in learning more about our operating structure. If you are interested in joining our Board of Directors, please contact the office for an application or with questions.

No-Cost Technology Now Available



<https://mg-mi.org/no-cost-technology-available/>
or call 651-354-2552
Coupon Code: mgmi100



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



2025 Support

In-Person & Virtual Events

mgmi
Connect



January 28 Virtual Support Meeting 6:30 p.m. to 7:30 p.m.
Join us for a virtual MG support group meeting. Topic to be determined.

February 22 MG-MI Partner Event Calvin University Rare Disease Day Event
MG-MI hosts an info table at the event from 9:00 a.m. to 4:00 p.m. at the Prince Conference Center on the Calvin University campus.

February 25 Virtual Support Meeting 6:30 p.m. to 7:30 p.m.
Join us for a virtual MG support group meeting. Topic to be determined.

March 10 Macomb County Regional Support Group 7:00 p.m. to 8:30 p.m.
Learn more about MG and share your story with other MG patients. In-person at Amazing Grace Lutheran Church in Warren.

March 18 Virtual Support Meeting 6:30 p.m. to 7:30 p.m.
Join us for a virtual MG support group meeting. Topic to be determined.

March 20 Grandville Lunch and Learn 11:30 a.m. to 1:30 p.m.
In-person meeting at Russ' Restaurant, 4440 Chicago Dr. SW, Grandville. Private room reserved but lunch is on your own.

April 29 Virtual Support Meeting 6:30 p.m. to 7:30 p.m.
Join us for a virtual MG support group meeting. Topic to be determined.

May 3, 2025 MG-MI Health Summit & Resource Fair 10:00 a.m. – 3:00 p.m. (Details P.1)
In-person and virtual - Memorial Health Care Institute of Neurosciences Wellness Center, Owosso.

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.

Welcome UCB!

We thank UCB for joining us as a Bronze Partner for the 2024 Annual Conference and presenting on Rystiggo, an MG treatment option, at a virtual support meeting in November. UCB is a Belgium-based biopharmaceutical company active in researching new treatments for myasthenia gravis. We look forward to working together!



UCB Scholarships available!

UCB has launched the UCB Myasthenia Gravis Scholarship™ program to help individuals living with myasthenia gravis and their immediate family members pursue educational opportunities. Find out more at www.UCBMGSCSCHOLARSHIP.com. Hurry, the last day to apply is Feb. 5!



Myasthenia Gravis Foundation of Michigan

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

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

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