



The Annual MG-MI Patient Education Conference is October 5

There's still time to register!



COMMUNICATOR

MG-MI Patient Education Conference Oct. 5

2024 ANNUAL PATIENT EDUCATION CONFERENCE
 For Myasthenia Gravis Patients, Families & Caregivers

Registration Now Open!

- 3 Neurologists
- Panel Discussion
- Pharmacy Reps
- Social Time
- Much More!

In-person & Virtual • October 5, 2024
Register at MG-MI.org
 info@mg-mi.org 616-956-0622

“The More You Know the Better You’ll Do.” That could be the unofficial slogan for the MG-MI Patient Education Conference coming up October 5 in East Lansing. Organizers have assembled a team of Michigan-based experts who will provide a rare opportunity for MG patients, their families and caretakers to learn more and ask questions in a safe and comfortable setting, in-person or virtually via Zoom. Perhaps just as important, persons with MG will be able to meet and have informal conversations with each other.

Scheduled speakers include **Rosemarie Walch, D.O.**, a neurologist and educator with Memorial Healthcare Institute for Neuroscience who will discuss MG basics and how to advocate for yourself. *(More on page 2)*

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FEATURE FOCUS: Research

From Dark Ages to a Brighter Future Of Research and Treatment

By Communicator Staff with review by Stephen TePastte, M.D., MG-MI Medical Advisory Board

There's never a good time to be diagnosed with a rare disease such as myasthenia gravis. But compared to 1672 when Thomas Willis first described it, the prospects of living a good life with MG have never been better.

From the time Willis made his medical notes, it took 150 years for the medical community to learn enough about MG to even begin crude treatments. As amazing as the cellular-level science and immunological breakthroughs are today, they were all on a long history of trial and error, often at the expense of MG patients who had few medical options and even less hope. *(More on page 3)*

Thanks to our
 Platinum Sponsors



Patient Education Conference (continued)

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University of Michigan neurologist **Alan Salgado, M.D.** will give a presentation on the importance of knowing your antibody status. **Amit Sachdev, M.D.**, a neurologist at Michigan State University Department of Neurology and lead clinical trial investigator, will outline some of the latest research efforts and share his thoughts on the future of MG treatments.

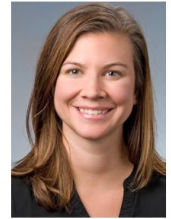
Social worker **Emily Vliek, LMSW** and occupational therapist, **Aimee Smithem, OTL** will host a panel discussion on building coping skills to overcome MG challenges. There will also be opportunities for social connections over lunch, a chance to visit representatives of our sponsors: Alexion, Amgen, argenx, Catalyst, InfuCareRx and others.

The "Coraggio Spirit Award," will be presented to one individual who has demonstrated special courage and set an example for others living with MG. Three additional awards will also be presented.

This year, the conference will be held in-person at the MHSAA Building in East Lansing and virtually via the MG-MI Zoom link. A \$10 charge for the in-person event includes a box lunch, continental breakfast, snacks and beverages. Virtual attendance is free. You may register for either option at mg-mi.org.



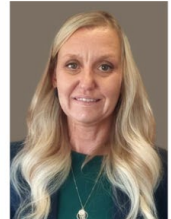
Rosemarie Walch, D.O.



Emily Vliek, LMSW



Alan D. Salgado, M.D.



Aimee Smithem, OTL



Amit Sachdev, M.D.



MG-MI Welcomes Amgen as a Platinum Sponsor!

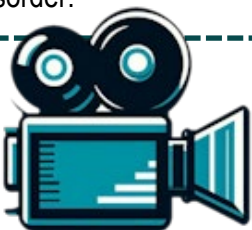
The Myasthenia Gravis Foundation of Michigan welcomes Amgen as its latest Platinum Sponsor. Amgen helped establish the biotechnology industry more than 40 years ago and remains a major pharmaceutical innovator, using technology and human genetic data to create new treatments.

Amgen's recent investment in research and development has built a pipeline that expands its existing portfolio of medicines to treat cancer, heart disease, osteoporosis, inflammatory diseases and rare diseases, including myasthenia gravis. Amgen is currently marketing Uplizna, a CD-19-directed cytolytic antibody used to treat patients with neuromyelitis optica spectrum disorder.



Its therapeutic potential is being studied in a phase 3 clinical trial involving adult patients who have MG with acetylcholine receptor (AChR) or muscle-specific kinase (MuSK) antibodies.

MG-MI is grateful for Amgen's dedication to the rare disease community and its support for the Michigan myasthenia gravis community.



MG-MI's video library is at your fingertips!

Have you ever wondered how other people with MG have solved some of the same problems you're facing? Or what leading MG doctors in Michigan have to say about treatment options? MG-MI's YouTube channel is a free video library with patient testimonies, educational conference addresses, and critical research updates.

Go to: <https://www.youtube.com/@MG-MI/videos> Or go to MG-MI.org & select "YouTube" from the menu.

FEATURE FOCUS

MG Research *(continued from Page 1)*

Where have we been?



MG Discoveries

1868-1930s Several therapies were tried including strychnine, mercury, arsenic, potassium, iron, quinine and electrical stimulation. None were very effective.

1930s –1950s The most noteworthy advancement was made with the help of an electric eel that scientists used to isolate acetylcholine (ACh) as the neurotransmitter and began developing some of the first effective therapies for MG.

1970s On the treatment front, doctors were using mechanic ventilation, thymectomy, and immunosuppressive treatments. Researchers discovered anti-MuSK antibodies.

1990s – 2000s New clinical trials and new treatment options were being explored aggressively as pharmaceutical companies begin intensifying their interest in MG.

Where are we now?

Today there are at least five major pharmaceutical solutions available to MG patients, depending on the expression of the disease.

There are several other treatment options available as well, thanks to an explosion of research. Here are some of the major treatment options available today:

- Thymectomy
- Anti-acetylcholinesterase inhibitors (pyridostigmine, Mestinon)
- Corticosteroids
- Immunosuppressant agents: (Imuran, Cellcept, Cyclosporine)
- Complement inhibitors. (C5 Protein inhibitors, IV Solaris and Ultomirus, SQ Zilbrysq)
- Neonatal Fc receptor blockers: (IV Vyvgart, SQ Vyvgart Hytrulo, SQ Ristiggo)
- Anti-MuSK biologic: (Rituxin)
- IVIG
- Plasma exchange (Plasmapheresis, Plasma-pheresis/PLEX)

(Continued on page 4)

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

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FEATURE FOCUS

MG Research *(continued from page 3)*

Where are we going? Ask “The Market!”

Myasthenia gravis is not only a disease but a *market!* Pharmaceutical research, drug development, testing, and treatment all cost money. That money is often provided by the federal government or private investors. Biospace.com reports that the myasthenia gravis market was valued at 1.3 billion dollars in 2023 and is expected to double by 2034.



That’s good news for people with MG. When pharmaceutical companies and investors are excited about their future prospects, that pumps more resources into finding new treatments. Biospace says the focus now is developing targeted therapies and biologics. There’s also a growing interest in personalized medicine approaches and improving diagnostic tools to tailor treatments to individual patient needs.

Patient advocacy groups are also playing a big part in advancing myasthenia gravis research. Collaborating with pharmaceutical companies and research institutions, organizations such as the Myasthenia Gravis Foundation of America support clinical trials and patient registries.

MG-MI is also becoming more active in collaborating with pharmaceutical companies and supporting the research effort to accelerate the development of innovative therapies and ensure that patients have access to the very latest treatments. The organization is also actively involved in advocacy and education within the MG community.

Unanswered Questions

So much has been accomplished during the past few years in the diagnosis and treatment of myasthenia gravis. But there is much more work to be done. First, the association between the thymus and MG has evolving research. Comprehension of immunological mechanisms is in its infancy. And the biggest mystery of all – just what causes MG?



AMGEN

Sources: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8214743/>

<https://www.biospace.com/myasthenia-gravis-market-size-to-reach-usd-2-1-billion-by-2034-impelled-by-the-emerging-popularity-of-plasmapheresis-therapy>

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



Medical/Research

Highlights & Late-breaking News



The Latest News in MG Research

Dr. Henry Kaminski from the Department of Neurology & Rehabilitation Medicine at George Washington University is in the forefront of research into myasthenia gravis and similar diseases. His department has published several articles which present the latest perspectives on MG research and treatment protocols. Here are two that are especially important in the MG community.



Henry Kaminski, M.D.

A Deeper Understanding of MG Opens Doors to New Treatments

In the past few decades, scientists have gained substantial knowledge of the underlying pathophysiology of MG, leading to the discovery of distinct subcategories within MG. Those include MG linked to AChR or MuSK antibodies as well as age-based distinction, thymoma-associated, and immune checkpoint inhibitor–induced MG. Dr. Henry Kaminski and colleagues from MGNet have published an article outlining how this new understanding has paved the way for the development of more precise and targeted therapeutic interventions. Read the full article here: <https://www.jci.org/articles/view/179742>

Another look at thymectomy

Surgical removal of the thymus gland has been a treatment for myasthenia gravis for more than a hundred years. Recently, concern has been raised about negative consequences for patients who undergo thymectomy for MG or resection of a thymoma. This scientific review by Dr. Henry Kaminski adopts a multidisciplinary approach to scrutinize the evidence concerning the long-term risks of cancer and autoimmunity [post thymectomy](#). The study concludes that for patients with acetylcholine receptor antibody-positive MG and those diagnosed with thymoma, the removal of the thymus offers prominent benefits that well outweigh the potential risks. Read the full article here: <https://www.neurology.org/doi/10.1212/WNL.000000000209482>

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 ↗

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Clinical Trial Resources

Click on the links below for online information about current MG clinical trials.



Myasthenia Gravis
Rare Disease
Network



National Institute of
Health Clinical Trials



Ravulizumab IV Clinical Trial (NIH)



MG Clinical Trial Article



Living Your Best Life

With MG



A Personal Story From Randy Kaeding

Randy Kaeding says he was living a “normal life.” He was 71 years old and took a retirement job at an electronics lab.

“Then, one morning in 2016, I suddenly had a hard time communicating because my tongue seemed to be much larger than normal. I assumed that the problem would go away on its own.

Then I started having sleep problems and trouble swallowing. I almost suffocated three times when something would get stuck in my throat. During one of these times, my daughter was with us and knew how to clear the obstruction.

I went to my regular doctor and explained the problems I was experiencing. So, he sent me for MRIs, EKGs, blood tests, swallowing tests. The results all came back as normal. Still without a diagnosis, my doctor also sent me to a speech therapist for help with my speech problem.

In the meantime, I lost about 60 pounds and was miserable for several months. My doctor then sent me to his older partner, Dr. Troy Thompson. He listened to my story and considered my symptoms.

He referred me to a local neurologist, Dr. Robert Ward. It took another couple of months to get an appointment with Dr. Ward due to the limited number of neurologists in my area. He took one quick look in my mouth and told me I have myasthenia gravis.

He wrote a prescription for Pyridostigmine (Mestinon) and directed me to take one-half to one tablet, three times a day at mealtimes.

My diagnosis took almost a year, but two nights after I started taking the medicine, I slept like a log. With no food restrictions, I started to gain weight. As long as I remember to take my medication, I have been completely symptom free. I credit Doctor Ward for essentially saving my life”



Randy Kaeding

Traverse City Support Group

Munson Medical Center offers Plasmapheresis Services

At MG-MI’s August 22 support meeting in Traverse City, Dr. John Stanifer, a Nephrologist with Munson Medical Center, explained the processes involved in conducting plasmapheresis treatments.

He further elaborated on the treatment’s role in the management of MG for both urgent and maintenance care. Established in late 2021 to make accessibility of this specialty treatment available locally, the Munson Healthcare Kidney and Hypertension center has administered over 275 treatments for a variety of medical conditions that benefit from this procedure.



MG-MI host and MG-MI board member Janet Gentle and Dr. John Stanifer



MG-MI in Action!



MG-MI's Strategic Plan is a Roadmap to the Future

The Myasthenia Gravis Foundation of Michigan got its start in 1975 when 18 MG patients decided there needed to be a formal organization to educate patients, their families, and the public about their illness, and support medical research into myasthenia. This was a time when receiving an accurate diagnosis sometimes took years and effective treatments were in their infancy.

Through the decades, MG-MI has grown into a busy non-profit organization, sustained by donations and fundraising activities. Its goal is to provide Michigan patient services, awareness, education and research support to more than 700 patient members. With a part-time director, and additional part-time and volunteer staff, MG-MI is guided by an elected board of directors and medical advisory board. Many of those who serve on those boards are MG patients or are actively involved in research and treatment of MG.

A carefully developed strategic plan serves as the framework for expansion and ensures those who contribute to MG-MI that there is responsive leadership, full financial transparency and dedication to providing valuable services to the MG community.

In the next few issues of *Communicator*, we will be highlighting some of the features of the 2024-2026 MG-MI Strategic Plan. Our hope is that you may discover new benefits of the organization, be inspired to share new ideas, and become involved in your own MG community or statewide.

OUR VISION

“Living your best life with Myasthenia Gravis”

STRATEGIC PLAN



OUR MISSION

The Myasthenia Gravis Foundation of Michigan is committed to our MG Community by providing patient support, community connections, education, and advocacy.

Our Values

Advocacy - Our patients come first.

Compassion - We will treat everyone with dignity, kindness, and respect, ensuring every individual has a sense of belonging.

Transparency - We will be transparent with the clarity of our purpose.

Integrity - We will adhere to the highest ethical standards by being a cost-effective organization and good stewards of what we receive.

Collaboration - We will listen and learn from each other to increase our understanding, partnerships, resources and connections.



Support

In-person & Virtual Scheduled Events

mgmi
Connect



October 5 MG-MI Patient Education Conference 10 a.m. to 3 p.m.

Patients, family, caregivers, educators and physicians will get in-person and on-line support and information about myasthenia.MHSAA Building, East Lansing and virtually via Zoom.

October 10 Ann Arbor Partner Event 6:30 p.m.

Alexion Hosted Dinner - Find out about a treatment for anti-acetylcholine receptor antibody-positive generalized myasthenia gravis from speaker Julie Burnham, D.O. Free event. Carlyle Grill, 3660 Jackson Rd., Ann Arbor

October 15 Virtual Support Meeting 6:30 p.m. to 7:30 p.m.

Vyvgart, an MG Treatment.” A presentation by argenx.

October 24 Kalkaska Support Meeting 3:00 p.m. to 5:00 p.m.

Discussion of 2024 conference sessions and Living Your Best Life with MG. Kalkaska County Library, 247 S. Cedar St., Kalkaska

November 20 Virtual Support Meeting 6:30 p.m. to 7:30 p.m.

Dietician Sarah Smith discusses the benefits of the Mediterranean Diet in a virtual presentation. Free of charge. All are welcome to attend.

December 9 Macomb County Regional Support Group 7 p.m. to 8:30 p.m.

Learn more about MG and share your story with other MG patients. In-person meeting will be held at Amazing Grace Lutheran Church in Warren.

December 16 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 10:00 a.m. - 3 p.m.

In-person and virtual - Memorial Health Care Institute of Neurosciences Wellness Center, Owosso

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

Virtual meetings allow for Q&A

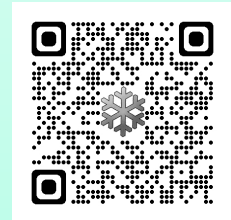


Watch our website & MG-MI emails for updates

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!



MYASTHENIA GRAVIS
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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