



COMMUNICATOR

June Awareness Month Kick-Off

MG-MI MovesMG

After an early morning rain on Saturday, May 25, the skies cleared at Cascade Township Park and about 50 runners and walkers headed out to promote *MG-MI MovesMG*! Adding entertainment to the event were Scoop the Balloonatic who delighted children and adults alike as he twisted balloons into a variety of animals. Corey the Caricaturist drew some amazing and humorous "likeness" pictures of singles, couples and families.

Kayla was on hand to offer snow cones, and Mike made sure everyone was given a box of popcorn. Everyone likes a prize and this event was a highlight not overlooked by attendees. *(More on page 2)*



Esther, Cheryl and Kayla get ready for the auction



FEATURE FOCUS: *Ocular Myasthenia Gravis*

By Esther Land & Stephen TePastte, M.D.

The first symptoms of Myasthenia Gravis often involve the eyes. Ocular MG specifically impacts the muscles responsible for eye movement and eyelid control.

Double vision (diplopia) and eyelid drooping (ptosis) are the most common symptoms. Diplopia is weakness of the muscles that move the eyes together in balanced alignment. This weakness leads to double vision (seeing two images rather than one) or blurred vision. Ptosis ("toe-sis") occurs when the levator muscle (the muscle responsible for eyelid elevation) is affected, resulting in the eyelid drooping. It can occur symmetric or asymmetric, and can be unilateral (one eye) or bilateral (both eyes). People that have only ocular MG symptoms for five years or more (about 15%) will rarely develop generalized MG. *(More on Page 3)*

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Remembering Jack Sheehan

On April 17 the oldest member of our MG Community, John "Jack" Sheehan, moved on to Glory at the age of 102. We first heard from Jack soon after he was diagnosed with MG in 2007. Wanting to learn everything he could about this puzzling disease, he educated himself to understand how he could "live his best life with MG."

He lived in Lansing at the time, and became a faithful attendee at our information and support meetings – always learning and wanting to know the latest research being done toward finding a cure! For his courageous determination despite challenges, we were honored to award Jack the MG-MI "Coraggio Spirit Award" during the year of his 100th birthday. Such a remarkable man with a sharp memory and endearing personality! We are thankful for these fond memories – he is greatly missed!



MG-MI MovesMG (continued from Page 1)

Two of our corporate partners, Alexion and argenx, were on hand to answer questions about Ultomiris and Vyvgart. Both recently released treatment options for MG. Other sponsors include Amgen, Eenhoorn LLC, and Land & Co.

Through the efforts of team members, sponsors, general donations and our partners, the event raised \$17,000 that will enable MG-MI to continue informing, educating and providing services to over 730 MG patients throughout Michigan.



Upper Left: MG patients Pricilla, Esther and Brandie. Lower Left: Lewis snagged a caricature AND a balloon octopus! Above: The early rain kept several "top down" MG car owners away but Dave and Rod proudly displayed their trophy cars.

FEATURE FOCUS

Ocular Myasthenia Gravis *(continued from Page 1)*

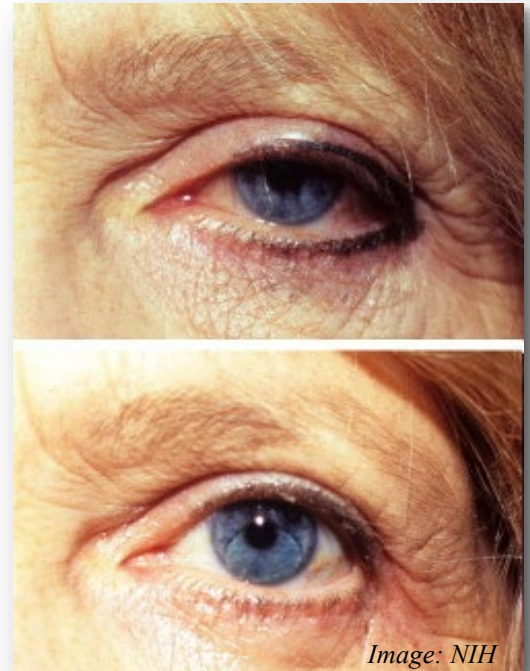


What is Ocular MG?

The ocular manifestations of MG are characteristically variable, with the frequency of diplopia and ptosis affected by environmental, emotional and physical factors.

Cholinesterase inhibitors like pyridostigmine (Mestinon) are helpful in patients with mild ocular symptoms. They are effective in alleviating ptosis but not very effective for diplopia. Mestinon can be prescribed in varying doses depending on the clinical response and how well it is tolerated. Common side effects include nausea and vomiting, diarrhea and stomach cramps.

Oral steroids are frequently used for diplopia or ptosis with diplopia. Oral steroids can be effective, but they have



There are several surgical options to address ptosis, often with good results

many side effects and can be difficult to tolerate.

Non-medication treatment options include wearing dark glasses in bright light, using eyelid tape or crutches, applying a patch to one eye, or using eyeglass prisms.

Surgical treatment for ptosis can be beneficial for reducing ptosis in older people who also exhibit noticeable dermatochalasis (excess skin and drooping of the upper lids). Surgical correction of diplopia works best for people who have a stable, fixed, non-fluctuating diplopia. Surgery to correct diplopia or ptosis should be done by an ophthalmologist who has experience treating people with MG.

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FEATURE FOCUS

Ocular Myasthenia Gravis

Surgical Options for Ocular MG

By Adam Hassan, MD

One of the muscles commonly affected in Myasthenia Gravis (MG) is a muscle in the eyelid called the levator muscle. This muscle is responsible for the lifting of the upper eyelid. Several surgical options are available for correcting eyelid ptosis, including frontalis sling suspension, levator muscle advancement, and conjunctival Müller resection. Each procedure has its own benefits and considerations:

1 Frontalis Sling Suspension

Procedure Involves attaching an implanted material to the eyelid and the frontalis muscle in the forehead, thus using the frontalis muscle's strength to lift the eyelid.

Pros Uses the frontalis muscle to lift the eyelid, compensating for weak levator muscle. Works well for patients with particularly weak levator muscle function.

Cons May lead to forehead fatigue. There may be reduced eyelid closure and blink. Risk of sling material visibility or extrusion. Can contribute to dry eyes due to increased exposure.

2 Levator Advancement

Procedure: Involves repositioning and tightening the levator muscle to improve eyelid elevation.

Pros: Directly addresses the weakened levator muscle, maintains normal eyelid anatomy, and does not require an implant.

Cons: Risks of over- or under-correction. Limited effectiveness in severe cases of muscle weakness. Can contribute to dry eyes due to altered eyelid function.



Some surgical options to address ptosis can be minimally invasive

3 Conjunctival Müller Resection

Procedure: Involves removing a small portion of the conjunctiva and the Müller muscle, which are present on the underside of the eyelid. This can improve eyelid elevation.

Pros: Minimally invasive procedure. No skin incision required. Effective for mild to moderate ptosis.

Cons: Limited effectiveness in severe cases of ptosis. Risk of under-correction or over-correction.

The choice of surgical approach depends on factors such as the severity of muscle weakness, patient anatomy, and treatment goals. A thorough discussion with a surgeon is essential to determine the most appropriate surgical option for each individual with MG and eyelid ptosis.

Adam S. Hassan, M.D. is qualified in facial, cosmetic, reconstructive and functional surgery. He received his medical degree at the University of Michigan Medical School where he completed a residency in ophthalmology followed by an intensive fellowship in eye plastic, orbital, and facial cosmetic surgery. He is board-certified and a member of the American Society of Ophthalmic Plastic and Reconstructive Surgery, the American Academy of Facial Plastic and Reconstructive Surgery, the American Academy of Cosmetic Surgery, and the American Academy of Ophthalmology. He practices in Grand Rapids, MI.



Living Your Best Life

With MG



A Personal Story From Alice White-Kaminski

I have had random vague muscle weakness my whole life. I would stumble and fall a lot as a child. There were other odd symptoms as well but pediatricians never suspected that I had myasthenia gravis and certainly not a rare form of the disease! That took until I turned 45. Then, I had every symptom of MG but the blood work tested negative for eight months.

My neurologist started me on meds and treatments immediately. Things improved but then declined rapidly. I would feel a little stronger after plasmapheresis but within hours, I was weak again. Due to my negative blood tests, my neurologist was skeptical that I had MG. He wanted to test for something else but I urged him to wait for my bloodwork from Los Angeles.

My condition was getting dire. My doctor wanted to intubate but I resisted. The next day, my test results came back positive for the antiMuSK protein! The Mestinon was stopped and after the next three plasma exchanges, I was much improved!

For a dozen years, plasmapheresis worked to control my symptoms. There were many ups and downs with brief periods when I was feeling pretty good. After nearly 200 line placements, the plasmapheresis was becoming too difficult. In June of 2023, Efgartigimod (Vyvgart) saved my life!

My weakness has been replaced by strength. My speech is clear and I am articulate again! I have started to build myself back from that hole I was in. Volunteering with the Myasthenia Gravis Foundation of Michigan has been a goal for over a decade. I am so happy to be a motivated – *and reliable* – member of our team. I hope to be an asset for years to come.

I was so desperate to find a helpful doctor before I died, that I contacted a friend in L.A. who suggested I consult with her functional medicine doctor by email and phone. The doctor had me complete an extensive medical history along with numerous blood and sputum tests. While waiting for the test results, I was hospitalized.



Alice White-Kaminski

Southeast Michigan in the Spotlight

A dozen people worked for months to organize and plan the first MG support group in the Macomb County area in many years. With the guidance and support of MG-MI, the first meeting was held June 10 in Warren and 21 people attended, making it a big success.

Organizers were thrilled with the results and are already planning to set up a schedule for the next event in Southeast Michigan. One of the meeting planners was Alice White-Kaminski. She said, "We had a wonderful mix of attendees all across the Detroit area. We met people from Bloomfield to Grosse Isle and Detroit to Harrison Township." Other organizers were Mark Hosking, Andrea Fuller, and Lisa Gigliotti, who is on the MG-MI Board of Directors and lives in the area.

Amazing Grace Lutheran Church in Warren graciously donated meeting space. The group is planning to meet quarterly.

MG-MI has a goal of expanding support groups and activities throughout Michigan. The Macomb Regional Support Group has demonstrated that with a lot of hard work and planning, something really valuable can be created for the MG Community.



Macomb County Regional Support Group meeting June 10



Medical/Research

Highlights & Late-breaking News



Got MuSK MG? A New Study Needs Your Help

By Anosha Khan, MGNet Project Manager & Sr. CRC

The MuSK Myasthenia 1000 study aims to collect saliva samples from 1000 patients with laboratory documented muscle specific antibody positive myasthenia gravis. These samples will then be used in a special DNA study called a genome-wide association study (GWAS). GWAS will identify genetic risk factors for MuSK myasthenia.

With this understanding, we hope to develop better treatments for MuSK MG. GWAS has been used in other forms of MG to understand the disease, but never in MuSK MG.

The study is organized by the Myasthenia Gravis Rare Disease Clinical Research Network, MGNet by its lead investigator Henry Kaminski, M.D. at George Washington University.

Please visit:

<https://musk1000.smhs.gwu.edu/>

email musk1000@mfa.gwu.edu for more information.

SUPPORT FOR MYASTHENIA GRAVIS (MG)

Find what makes you

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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.



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LOOKING FOR MG CLINICAL TRIALS?

Click here for the NIH clinical trial website

CLINICAL TRIAL TERMS TO KNOW

Double-blind

Neither researchers nor participants know which participants are taking the drug or placebo.

Multiarm

Comparing several different experimental treatments against a common control group within a single study.

Multicenter

The trial is completed at more than one site.

Randomized

Participants are assigned at random to groups taking the drug or placebo.



MG-MI in Action!



MG-MI Patient Education Conference

One of the biggest days of the year for the MG community in Michigan is the MG-MI Annual Conference. The October 5 event will be held in-person in East Lansing and virtually via Zoom.

This year's conference will feature at least four MG related presentations on various medical topics by Michigan physicians. There will also be a panel discussion on ways to cope with chronic illness. Topics will include emotional health, lifestyle adaptation, and wellness.

MG-MI sponsors will play a part in the conference. Alexion and argenx will be updating attendees on the treatments offered by their companies, as well as vital updates on MG related medical trials and research progress. A new MG-MI sponsor, Amgen, will make their first appearance at the statewide MG-MI conference.

Vendors will feature MG-related information, resources, and merchandise. Registration information will be coming soon.

If you've never attended one of our conferences, please visit our YouTube channel for featured speaker videos.

[Click here for the 2023 MG-MI conference.](#)

SERVING & SUPPORTING THE MICHIGAN MG COMMUNITY

MYASTHENIA GRAVIS
mgmi
FOUNDATION OF MICHIGAN

**2024 ANNUAL
PATIENT
EDUCATION
CONFERENCE**

**SATURDAY, OCT. 5, 2024 9 AM TO 3 PM
EAST LANSING, MI & VIRTUALLY**

Those living with MG, caregivers and medical professionals are invited to attend the **2024 MG-MI Annual Conference**. This year's conference will be in-person in East Lansing as well as via Zoom.

Check for updates!

PRESENTATIONS

- Focus on Wellness
- Panel: Coping with MG
- Know Your Antibody Status
- Research Updates
- Discussions with Sponsors

MORE INFORMATION

616-956-0622

WWW.MG-MI.org

MHSAA Building, 1661 Ramblewood Dr., E. Lansing, MI

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Join Us!

Saturday, October 5, 2024 9:00 pm – 3:00 pm
MHSAA Building 1661 Ramblewood Dr. East Lansing, MI 48823



Support

In-person & Virtual Scheduled Events

mgmi
Connect



July 15, Monday, Holland - In-person - 2:00-3:30 pm

Herrick District Library—North Branch 155 Riley St, Holland 49424
Guest Speaker, Elizabeth Scott, DNP, CNRN, with Trinity Health Neurosciences
Topic: Neuromuscular Disorders and Sleep Apnea

August 1, Thursday – Livonia - In person - 2:00-3:30 pm (Tentative)

Livonia Public Library, 3277 5 Mile Rd, Livonia, MI 48154 Topic: TBD

August 21, Wednesday - Berrien Springs - In person - 6:15-7:45 pm

Berrien Springs Community Library, 215 West Union St, Berrien Springs 49103
Topic: TBD

September 9, Monday – Macomb County Regional Support Group - 7 pm

Amazing Grace Lutheran Church
29860 Dequindre Rd., Warren, MI 48092

September 12, Thursday – Saginaw - In person - 6:30-7:45 pm

Zauel Memorial Library—Dr. Kuremety Meeting Room
3100 N Center Rd, Saginaw 48603
Guest Speaker: Maryjo Prince-Paul of Alexion will present
“The Power of Partnership” followed by Q&A.

October 24, Thursday – Kalkaska - In person - 3:00-5:00 pm

Kalkaska County Library, 247 S Cedar St, Kalkaska 49646
Topic: 2024 Conference Sessions discussion and living your best life with MG.

Virtual meetings allow for Q&A

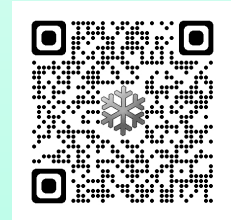


Watch our website &
MG-MI emails for
updates

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!



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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