

2023 PATIENT EDUCATION CONFERENCE COMING SOON!

All sessions are virtual via Zoom

Registration will be available soon with notice via MailChimp, a special mailing and on our website—MG-MI.org

Preliminary Program topics include:

October 12, Thursday • 7:00 pm to 8:30 pm

- Focus on MG Patients with Different Types of MG
Gloria Dzielsky, Dave Peterson, Alice White-Kaminski

October 14, Saturday • 9:00 am-Noon

- Generalized MG • Paul, Twydell, MD
- Seronegative MG • Gianviti Masi, MD
- Topic and presenter being finalized

October 15, Sunday • 11:30 am to 3:00 pm

- Awards Presentation
- Topic and presenter being finalized
- Sleep Apnea and MG • Christopher Morgan, MD
- Topic being confirmed • Amit Sachdev, MD

Do not wish to be anything but who you are, and try to be that perfectly.

JANET M. GENTLE JOINS BOARD OF DIRECTORS



We are pleased to announce the addition of Janet Gentle to our MG-MI Board of Directors. She was voted onto the Board this past spring.

Janet received her Masters Degree in nursing from Oakland University in 1981 along with Nursing Administration major. Her nursing career was primarily in staff and management positions in critical care, ER and ICU. Janet retired in 2015 and lives in the Petoskey area.

Janet was diagnosed with MG in 2014 and has had a rocky road related to medication issues and MG complications, but she remains hopeful that the proper treatment plan that works best for her will soon be found.

In addition to her role on the Board, Janet is looking forward to serving our northern Michigan patients through information, support, recruitment efforts and resource sharing. She also anticipates developing partnerships with local/regional physicians who treat MG. She wants to give back to others all the support and encouragement she received from MG-MI since attending her first support meeting in Traverse City shortly after being diagnosed.

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A big
THANK YOU
to our
newsletter
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AMAZING AND GROUNDBREAKING MEDICAL NEWS

The U.S. Food and Drug Administration approved two treatments for MG in June:

UCB announced they received approval for RYSTIGGO (rozanolixizumab-noli) as a treatment for adults who are diagnosed with both generalized myasthenia gravis and who are anti-acetylcholine receptor (AChR) or anti-muscle-specific tyrosine kinase (MuSK) antibody positive. RYSTIGGO is an injection given under the skin and will be commercially available in the U.S. in late summer or early fall. For the official news release from UCB, go to: [UCB announces U.S. FDA approval of RYSTIGGO® \(rozanolixizumab-noli\) for the treatment of adults with generalized myasthenia gravis | UCB](#)

Argenx announced their approval for Vyvgart Hytrulo (efgartugunid alfa and hyaluronidase-qvfc), a subcutaneous injection for adult gMG patients who are anti-acetylcholine receptor (AChR) antibody positive. The drug is delivered via injection instead of through an IV infusion. It combines Vyvgart and a drug delivery technology called Enhance, or recombinant human hyaluronidase PH20 made by Halozyme. The treatment is approved as a single injection administered under the skin once weekly for four weeks by a health care professional. For argenx official release, go to: [argenx Announces U.S. Food and Drug Administration Approval of VYVGART Hytrulo \(efgartigimod alfa and hyaluronidase-qvfc\) Injection for Subcutaneous Use in Generalized Myasthenia Gravis | Argenx](#)

“The ease and convenience of a subcutaneous injectable treatment will undoubtedly be very well received by the patient community because the treatment process fits into the daily lives of patients around the country. Patients have an individualized approach and another important option for managing their unique symptoms.”
 —Samantha Masterson, MGFA president and CEO

Note: Talk with your doctor to discuss if these treatments are an option for you.



Saying Goodbye to a Dear Friend

Ellen Addington, one of our founding members, passed away on August 1, 2023 at the age of 89. She was active on the MG-MI Board of Directors for 26 years. During her term as Treasurer she was proud to say she was never a penny off. Ellen also volunteered many hours in the office and participated at our fundraising events, donating her photography talents that are now being displayed in eight photo albums that give us 35 years of memories! She is greatly missed and lovingly remembered by the MG Community.

HOW DO YOU EXPLAIN YOUR RARE DISEASE TO A LOVED ONE?

Take a page out of *Klara’s Talent*, a free children’s book all about generalized myasthenia gravis(gMG), sponsored by Alexion Pharmaceuticals!



REQUEST A FREE COPY OF KLARA'S TALENT AT KLARASBOOK.COM

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UPDATED 2023 IN-PERSON AND VIRTUAL SUPPORT GROUPS CALENDAR

- August 30, Wednesday—ELK RAPIDS—2:00 to 4:00 pm • In Person**
 Jack Blesma Pavilion, Isle of Pines Dr, Elk Rapids 49629—Topic: Open discussion
- September 13, Wednesday—LANSING—6:00 to 7:30 pm • In Person**
 East Lansing Public Library, 950 Abbott Rd, East Lansing 48823
 Guest Speaker: Stephen TePastte, MD • *“How to live your best life with MG”*
- September 14, Thursday—VIRTUAL—2:00 to 3:00 pm • Topic: Vyvgart Hytrulo—Speaker: TBD**
- September 20, Wednesday—GRAND RAPIDS—2:00 to 3:30 pm • In Person**
 Gaines Township Library, Community Room • 421—68th St SE, Grand Rapids 49548
 Guest Speaker: Anu Allington, LMSW, Christian Counseling Center • *Living with a Chronic Condition*
- September 25, Monday—LIVONIA—6:00 to 7:30 pm • In Person**
 Livonia Senior Center—15218 Farmington Rd, Livonia 48154
 Guest Speaker: Nikita Lyons Murry, Alexion® • *It’s gMG, Now What?*
- September 27, Wednesday—CADILLAC— 4:00 to 6:00 pm • In Person**
 Munson Cadillac Hospital—Missaukee Room, 400 Hobart St, Cadillac 49601
 Topic: *Understanding, Living and Thriving with MG* • Margaret Frey, DO (video=2020 Conference)
- October 18, Wednesday—(tentative) GAYLORD • In Person**
- November 14, Tuesday—VIRTUAL—12:00 to 1:00 pm • Topic—TBD**

Each meeting will have time for Q&A. Topics are subject to change. Watch our website and MailChimp emails for updates. Register for Sept. 14 and Nov. 14 virtual sessions via email to: info@mg-mi.org.
Subject line: Virtual Support Groups. Link will be emailed back to you.

MG-MI MovesMG Raises \$20,000!

We are thrilled with the results of our family fundraising event held June 24 at Cascade Township Park. Thanks to pre-event solicitations from MG patients and corporate partners, proceeds from the event totaled \$20,000! A 5K run, walk, bike ride, yard games, a donut truck, and donations for prizes all contributed to a fun and successful event. Thanks also to Magic Bob for the magic show, SuZie for face painting, and the MG Car Club for again displaying their beautiful MG sports cars. A sincere thanks to all who volunteered, donated and helped make the event a BIG success!



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BULLETIN BOARD

Go Green with an email NEWSLETTER

We're conserving resources, saving trees and being more technology savvy. YOU CAN HELP! Call or email us and future newsletters will be sent to you via email. We and the world appreciate it.

REGISTER FOR 7th Annual Conference

Oct. 12, 14 & 15, 2023
Via Zoom

Board of Directors Meeting

Our next Board meeting will be in person and via Zoom on September 20 at 6:30 pm. Contact our office if you are interested in attending or learning more about our Board.

"People can be divided into three groups: those who make things happen, those who watch things happen, and those who wonder what happened."
— John W. Newberr

In Person Support Groups

Aug 20—Elk Rapids—2:00 pm
Sept 13—Lansing—6:00 pm
Sept 20—Grand Rapids—2:00 pm
Sept 25—Livonia—6:00 pm
Sept 27—Cadillac—4:00 pm

Virtual Support Sessions

Sept 14—2:00 pm
Nov 14—12:00 Noon

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 our best life with MG

Snippets from MG-MI MovesMG



Myasthenia Gravis Foundation of Michigan
2660 Horizon Dr. SE, Ste. 235
Grand Rapids, MI 49546-7933
616-956-0622 • info@mg-mi.org • www.mg-mi.org

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