



mg MYASTHENIA GRAVIS
mi
FOUNDATION OF MICHIGAN



COMMUNICATOR

Summer 2022
Issue 2 Volume 45

MG-MI WELCOMES RHONDA WENTWORTH




MG-MI is pleased to welcome and introduce our newest team member, Rhonda Wentworth, as our office administrator.

Rhonda is a retired middle and high school science and math teacher. She has spent the past few years broadening her life experiences through part-time employment,

serving as board member and secretary for the Hudsonville Education Foundation, and volunteering in the Hudsonville and Georgetown Township communities.


Rhonda holds a bachelor's degree from Central Michigan University in biology and mathematics and a master's degree in education from Grand Valley State University. She and her husband, Doug, have two grown children and reside in Hudsonville.



FDA-approved treatment

Talk to your neurologist about VYVGART

[Find out more](#)



VYVGART is a registered trademark of argenx.
© 2021 argenx US-EFG-21-00176 V1 12/2021

SHOP AT AMAZON & DONATE TO MG-MI

If you're looking for a simple, automatic way to continue supporting MG-MI, sign up for the AmazonSmile program at smile.amazon.com.

You shop as you normally would with your account at no extra cost to you. AmazonSmile donates 0.5% of the

purchase price from eligible purchases to a charity of your choice. Amazon does not charge a percentage or fee for this service, so it's a great way to donate to our cause.

Make sure you choose the Myasthenia Gravis Foundation of Michigan as your charity.

OUR MG-MI FAMILY

Welcome

We would like to welcome 15 new members who have joined our MG-MI family this year.



We hope your affiliation with us is mutually rewarding and we look forward to meeting you at one of our upcoming in-person or virtual events soon.

Sympathy

We mourn the passing of David Girton of Sturgis on March 17 and Linda Crane of Norton Shores on March 24.

Linda was active in coordinating support group gatherings for the Muskegon area. Both will be greatly missed by our MG-MI community.

Get Well

Best wishes for a full recovery of two Kalamazoo-area members who were recently hospitalized. They and their caregivers will be in our thoughts.



Helping the
[Indication(s) Communit(y/ies)]

Always Here to Help

To Learn More, Call
1.888.765.4747

Enroll Today at:
www.AlexionOneSource.com



Alexion® and the OneSource logo are registered trademarks of Alexion Pharmaceuticals, Inc.
© 2020 Alexion Pharmaceuticals, Inc. All rights reserved. US/ALL/0111 09/20

10 SUMMER TIPS FOR PERSONS LIVING WITH MG

Warm weather can be difficult for those living with myasthenia gravis. To help better cope with MG symptoms so you can enjoy your summer, consider these tips:

- 1. Stay in air-conditioned rooms** and use fans as much as possible. Keep windows, blinds and curtains closed during the day to keep your home cooler and open windows and doors in the morning and evening when temperatures are lower.
- 2. Stay hydrated** by drinking plenty of water to keep your body temperature cooler.
- 3. Freeze juices**, yogurts and flavored waters for homemade ice pops.
- 4. Prepare and prep meals** that require a heat source in the evenings when its cooler.
- 5. Eat six smaller meals** throughout the day, if preparing or eating a main meal is causing challenges.
- 6. Run cold water** on your wrists, place your feet in a bowl of cold water and use ice packs or a cold towel to cool your body.
- 7. Use ice packs** to help temporarily relieve your ptosis.

- 8. Wear eye protection** such as sunglasses, an eye patch and a hat to help protect your eyes from becoming sensitive to more sunlight.
- 9. Keep bottles of water** and snacks in your vehicle in the case of a breakdown or emergency to take your medication, as heat can cause a sudden flare in symptoms.
- 10. Wear looser-fitting clothes** made from natural fibers, which can offer more comfort during hot weather.



JUNE IS MG AWARENESS MONTH

In recognition of MG Awareness Month, we will host our annual MG-MI Moves MG event on Saturday, June 25 from 9 a.m. to 12 p.m. at Cascade Township Park, 3810 Thornapple River Drive SE, in Grand Rapids (see insert). We hope you will join us for this fun family event!



Also during the month, virtual support sessions are being scheduled via Zoom. In partnership with Argenx and Drs. Melanie Taylor and Christopher Glisson, tentative topics include:

- Introduction to Vyvgart
- Taking Charge of Your Care: Preparing for Your Doctor Appointment
- Taking Charge of Your Care: Managing Your Symptoms
- Taking Charge of Your Care: Real Talk with Your Doctor
- Vyvgart: A Deeper Dive with a Neuromuscular Physician Specialist

Dates and links will be posted on our website events page at mg-mi.org and on our Facebook page, as well as sent out via MailChimp. If you have not signed up for our e-newsletter, subscribe at mg-mi.org/news.shtml to receive the latest MG-MI news.

FDA APPROVES A NEW TREATMENT FOR MG

The U.S. Food and Drug Administration has approved a new medication, ULTOMIRIS™, for the treatment of adult patients with generalized myasthenia gravis, or gMG, who are anti-acetylcholine receptor antibody positive.

The approval was based on positive results from the CHAMPION-MG Phase III trial, in which ULTOMIRIS was superior to a placebo in the primary endpoint of change from baseline in the Myasthenia Gravis-Activities of Daily Living Profile – also referred to as MG-ADL – total score at Week 26, a patient-reported scale that assesses their ability to perform daily activities. The FDA action marks the first and only approval for a long-acting C5 complement inhibitor for the treatment of MG.

“Despite recent advances, managing gMG is complex. Earlier intervention can preserve function and quality of Life,” said James F. Howard, Jr., M.D. of the Department of Neurology at The University of North Carolina School of Medicine, and lead primary investigator in the CHAMPION-MG trial. “This approval offers patients, including those with milder symptoms, a long-acting C5 inhibitor with early onset and reliable efficacy.”

The new treatment was developed by Alexion, a group within AstraZeneca, focused on rare diseases. For more information, visit alexion.com

BOARD OF DIRECTORS



Susan M. Woolner, CPXP
President



Esther Land
Secretary



Priscilla Walden
Treasurer

BOARD OF TRUSTEES

James Booth Burr Jr.
Mallary Cole
Bradford Mathis
Amit Sachdev, M.D., M.S.
Andrew Van Timmeren

MG-MI OFFICE

2660 Horizon Drive SE, Suite 235
Grand Rapids, Michigan, 49546
616.956.0622
myasthenia.info@gmail.com
mg-mi.org



**Myasthenia Gravis
Foundation of Michigan**

2660 Horizon Drive SE, Suite 235
Grand Rapids, Michigan, 49546

616.956.0622
myasthenia.info@gmail.com
mg-mi.org



@MGofMI



MG-MI Myasthenia Gravis Foundation of Michigan

SAVE THE DATES

We are delighted to schedule our **2022 in-person support groups** around the state through August. Most of the gatherings will be held in local parks, allowing us to follow COVID-19 guidelines.

Meetings also give patients and caregivers the opportunity to meet and learn from others who live daily with MG.

“Having people to relate to who have similar stories as mine has been so helpful.” - Ashley, an MG patient.



Please pull out and save the enclosed “2022 In-Person Support Groups Calendar” – and plan to attend a group in your area.