

W. DREW SCHRAMM JOINS BOARD OF DIRECTORS



Drew Schramm was diagnosed with ocular MG in 2009. In 2011 his MG became generalized. Learning about MG-MI, he reached out and became acquainted with Esther Land. Through her diligent coaching, Drew was able to find a path to managing his MG.

When Drew retired as president of World Resource Partners in Byron Center, MI, he was looking for ways to keep active and give back to the community. This search led him to joining the MG board in early 2023.

Drew holds a BS from Rutgers University in business administration and a MBA from Lake Forest Graduate School of Management. He has held executive positions in supply management at World Resource Partners, Spartan Motors, Herman Miller and Abbott Laboratories.

His current endeavors are woodworking, sailing, renovating a cottage built in 1941, and helping his two married children with projects at their homes in the Grand Rapids area. He and his wife, Kathy, have been married for more than 40 years and enjoy traveling to historic sites.

SUPPORTING SOMEONE LIVING WITH MG

To “walk” in someone else’s shoes means before judging someone, you must understand their experiences, challenges, thought processes, etc. Living with MG can be challenging and frustrating for the patient. Here are a few ways that you can support and empathize with someone diagnosed with MG:

- **Flexibility:** Be prepared for the unpredictable ups and downs of MG. There may be times when an awaited social outing or planned day of shopping may have to be canceled at the last minute due to weakness that comes on suddenly and unexpectedly. Know this change of plans deeply affects the patient. Encourage him/her with understanding and set plans for a later date—with a “next time will be better” attitude (even after several tries).
- **An Assumption—“But you look so good!”:** A patient may look the picture of good health, but be aware that symptoms of muscle weakness and rapid fatigue are not always visible to the eye.
- **Be Yourself:** Don’t abandon family activities, normal conversations, affection and laughter. A hand touch or a quick hug can convey more comfort than words or advice ever could. Remember, before you became a part of a “support system” you were—and still are—Sister Jane or Uncle Bob!!

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A big
THANK YOU
 to our
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(See ad on Pg 2 & 3)

ALEXION
 AstraZeneca Rare Disease

argenx

FDA Authorizes Additional Omicron Covid Booster for Seniors and People with Weak Immune Systems

CNBC Press Release, Spencer Kimball, April 18, 2023

BOARD OF DIRECTORS

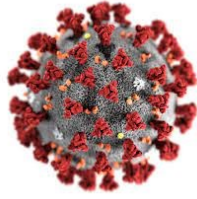
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The Food and Drug Administration authorized an additional dose of Pfizer and Moderna's Covid 19 vaccines targeting the omicron variant for seniors and people with weak immune systems.

Seniors who are 65 years of age or older and who have already received a vaccine targeting the omicron BA.5 subvariant are now eligible to receive another dose at least four months after their last shot according to the FDA. People with weak immune systems can receive another omicron shot at least two months after their last dose and receive additional shots at the discretion of their doctor.

"Covid-19 continues to be a very real risk for many people, and we encourage individuals to consider staying current with vaccination, including with a bivalent Covid-19 vaccine," said Dr. Peter Marks, who heads the FDA department responsible for vaccines.

The FDA first authorized the omicron BA.5 shots last August, but that subvariant has long since been displaced by a version of omicron called XBB.1.5. In June, the agency will likely update the variant that the Covid vaccines target, ahead of the fall respiratory virus season.

Note: Talk with your doctor to discuss if this booster is right for you.

June is MG Awareness Month



Organizations and individuals affected by Myasthenia Gravis (MG) will be participating in a variety of activities to promote awareness of this neuromuscular condition.

MG is a rare and non-contagious autoimmune condition that affects an estimated 100,000 people across America.

To promote awareness, MG-MI will host virtual information sessions (see page 3) and our major summer fun fundraising event, *MG-MI MovesMG* (page 5). Help spread awareness about MG by being involved at our sessions and the event.

Other ways you can help promote these events and awareness:

Create a *MG-MI MovesMG* fundraiser page at:

bit.ly/3o56SkU

- Make and wear a teal awareness ribbon
- Share this information or create an event on your Facebook page

Don't let what you cannot do interfere with what you CAN do. - John Wooden

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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2023 IN-PERSON SUPPORT GROUPS CALENDAR

We are delighted to announce the following informative support group gatherings. There is no charge to attend and you are invited to attend multiple locations. Each meeting will have time for Q&A and sharing, but topics may change. Watch our website and MailChimp emails for any additional sites or updates. NO POST CARD REMINDERS WILL BE MAILED—SO MARK YOUR CALENDAR NOW.

Snacks, water and brochures will be available at each gathering. Look for the MG-MI signs. An RSVP would be appreciated for planning purposes, but is not required. We look forward to seeing you again—to meet you for the first time!

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May 31, Wednesday—SAGINAW—6:15 to 7:45 pm

Zauel Memorial Library—Dr. Kurumety Meeting Room • 3100 N Center Rd, Saginaw 48603
Topic: General Discussion on Living with MG; lead by Ashley Boucher

July 13, Thursday—KALAMAZOO—1:45 to 3:15 PM

Oshtemo Branch Library—Meeting Room • 7265 W Main St, Oshtemo 49009
Topic: Living your Best Life with MG; lead by Esther Land

July 27, Thursday—HOLLAND—2:00 to 3:30 pm

Herrick District Library—North Branch • 155 Riley St, Holland 49424
Topic: Living your Best Life with MG; lead by Esther Land

August 23, Wednesday—SAGINAW—6:15 to 7:45 pm

Zauel Memorial Library—Dr. Kurumety Meeting Room • 3100 N Center Rd, Saginaw 48603
Topic: TBD; lead by Ashley Boucher



VYVGART®
(efgartigimod alfa-fcab)
Injection for Intravenous Use
400 mg/20 mL vial

You're invited to VYVGART (You)niversity

An educational series
sponsored by argenx

Wednesday, June 21
at 6:30 PM ET

DoubleTree by Hilton Hotel Detroit
42100 Crescent Blvd
Novi, MI 48375

Also available as a virtual event



Reserve your virtual
or in-person spot today!

VYVGARTyouiversity.com
(844) 4-VYV-YOU



Learn about VYVGART, get resources, and more.

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UPCOMING VIRTUAL SUPPORT SESSIONS

June 6, Tuesday at 2:00 pm

June 27, Tuesday at 6:30 pm

July 20, Thursday at 2:00 pm

August 10, Thursday at 6:30 pm

We currently have four virtual support sessions scheduled for the summer. Session content is being finalized, but will include guest speakers and informal discussions on living with MG.



Go to our website (mg-mi.org) to get the most current information on meeting content and to see if additional sessions have been added. To receive a Zoom link, email your RSVP to info@mg-mi.org with Subject: Virtual Sessions.

OFFICE UPDATES

Keeping Cool—MG Tips for Summer

- Wear loose-fitting, light weight clothes
- Stay in air conditioning (home, car or mall) during extreme heat and humidity
- Perform outdoor tasks/activities during coolest time of day
- Carry ice pack or neck cooling collar
- Keep hydrated by drinking plenty of fluids; carry ice water
- If drinking products that contain electrolytes, read label carefully to avoid magnesium. High magnesium levels can cause muscle weakness.

Support Groups - 2023

May 31—Saginaw—6:15 pm
July 13—Kalamazoo—1:45 pm
July 27—Holland—2:00 pm
August 23—Saginaw—6:15 pm
Other dates and locations TBD

MG-MI MovesMG

Sat, June 24
9:00am—Noon
Cascade Park

Virtual Support Sessions:

June 6—2:00 pm
June 27—6:30 pm
July 20—2:00 pm
August 10—6:30 pm
Additional dates TBD
Check website

SAVE THE DATE:
7th Annual Conference
Oct. 12, 14 & 15, 2023
Via Zoom

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 Myasthenia Gravis

Save a Tree

Sign up to receive your newsletter via email. Contact us at:
info@mg-mi.org

Spartan-Nash Cash Register Receipts

Spartan-Nash's *Direct your Dollars* fundraiser has been discontinued. Our sincere THANK YOU to our MG community members who helped us earn \$500 from this project.



Myasthenia Gravis Foundation of Michigan
2660 Horizon Dr. SE, Ste. 235
Grand Rapids, MI 49546

www.mg-mi.org

Phone: 616-956-0622
email: info@mg-mi.org

Find us on Facebook
Search
Myasthenia Gravis Michigan
You will see our logo!



**Saturday, June 24, 2023
9:00 a.m. – Noon
Cascade Township Park, 3810 Thornapple River Dr. SE, 49546**

Join us on Saturday, June 24, 2023, at beautiful Cascade Park for a morning of fun activities while raising funds for the Myasthenia Gravis Foundation of Michigan (MG-MI). Funds raised will provide awareness by updating our website, education via print and online resources, community connections through support groups, and advocacy by providing one-on-one patient support.

Activities throughout the morning include:

- 9:00 – Noon – Yard games
- 9:00 – 5K run (untimed, around the loop 3 times)
- 9:15 – 1-mile walk, bike, or rollerblade
- 9:00 – 11:00 am – Magic Bob (with Magic Show at 10:00 a.m.)
- 9:00 – 11:00 am – Face Painting with SuZie
- 9:00 – Noon – MG car show – West Michigan “Old Speckled Hen” MG Car Club
- T-shirts available for a minimum donation of \$10
- Raffle – purchase tickets to win your favorite prizes. The more you buy, the better your chance of winning!
- Network with other patients and caregivers
- Water, snacks, and literature provided

How can you help MG-MI? Collect donations!

- Use the give lively donation link <https://bit.ly/3o56SkU> to give online and/or create a team to raise funds and help achieve our event goal of \$15,000.
- Donate via PayPal/Credit Card or Facebook, mg-mi.org/donate.shtml
- Set up your own fundraising page on Facebook.
- Cash and checks, payable to MG-MI, may be brought to the event or mailed to address below.

We hope you will join us in helping us to deliver resources and services to our Myasthenia Gravis community! For more information or to volunteer, please contact us: **616-956-0622**; info@mg-mi.org

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**Myasthenia Gravis Foundation of Michigan
2660 Horizon Dr SE, Suite 235
Grand Rapids, MI 49546**

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