



COMMUNICATOR

MG-MI Attends Rare Disease Day Event



The Rare Disease Day Gathering at Calvin University was an opportunity to teach and learn for the Myasthenia Gravis Foundation.

The Rare Disease Network recently hosted the Rare Disease Day gathering at Calvin University. MG-MI was there to educate those attending about myasthenia gravis and to learn about the latest advances in treatment and research, as well as the social aspects of living with a rare disease.

MG-MI director Rhonda Wentworth said, "I was amazed by the exponential growth in rare disease research via genetic testing. This testing has become increasingly accessible due to lower costs, equipment portability, and speed of analysis." She said that better diagnoses can help ensure effective

treatment options so patients can live their best lives with their condition. MG-MI founder Esther Land was also staffing the info table along with volunteer Abby Verhoeven. Other event topics included ways to support siblings of children diagnosed with a rare condition, strategies for coping with stress, and exploring careers focused on rare diseases.

The Rare Disease Network is a collaboration project between Calvin University, Corewell Health Helen DeVos Children's Hospital, and Michigan State University.



Speakers at the event presented information on the social and medical aspects of living with a rare disease.



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*Thanks to our
 Platinum Sponsors*



Dr. Stephen TePastte, MD Joins Medical Board



MG-MI is pleased to announce the addition of Stephen TePastte, MD to our Medical Advisory Board (MAB). Upon retirement as a Family Medicine Specialist in the Lansing area and an MG patient himself, he wanted to continue being involved with the MG community. Dr. TePastte contacted our office, where we were delighted to incorporate his medical background and personal experiences with myasthenia gravis into our programs.

Dr. TePastte's involvement has already included the presentation *Living your Best Life with MG* during our virtual 2023 Patient Education Conference in October and shared with patients at a Lansing information and support meeting last fall. He looks forward to rejuvenating the MAB and supporting the office with "Ask the Doctor" Q&A for our website and newsletters. Welcome, Dr. TePastte!

MG-MI Names New Communications Manager

John Bosserman was named Communications Manager of the Myasthenia Gravis Foundation of Michigan. With more than 30 years in corporate and non-profit communications, he will oversee the foundation's website, this newsletter and create social media posts on Facebook, Instagram and LinkedIn. John will also work to encourage health and medical reporters to get the word out that while there is not yet a cure for MG, thousands of people in Michigan are living their best lives with MG. Contact him at john@MG-MI.org.



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COMMUNICATIONS

John Bosserman

It Gets Emotional: Partners in Care

People newly diagnosed with gMG may be tempted to keep it a secret and try to live their lives as if nothing is happening out of the ordinary.

Maryjo Prince-Paul is a Patient Education Manager for Alexion Pharmaceuticals. In a recent virtual support group presentation sponsored by MG-MI, she says the "go it alone" approach is a common early reaction. But she says most MG patients quickly discover that it's better to involve friends, family and other caregivers to provide emotional support.

"Living with gMG is a process," says Maryjo. "It affects you physically, socially, emotionally, mentally, and spiritually." She says that when people with gMG actively plan their support in these areas, they can more successfully "live their best lives with MG."



Maryjo Prince-Paul's Care Tips

- Remember you're better together—don't be afraid to ask for help.
- Be open and honest about your health and your emotions.
- Try to do your best to manage your feelings.
- Use your coping skills and support strategies.
- Keep yourself healthy with diet, rest and appropriate exercise.
- Stay in the know.

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

Follow
 @MoreThanMG



MG-MI Partners with MG Awareness Day & Health Fair

Twenty years ago, Dawn Warner was an energetic businesswoman reveling in her hectic schedule that took her from meeting to meeting and continent to continent. That all ended when doctors pinned a diagnosis onto her jumble of symptoms -- myasthenia gravis.

Dawn's reaction was like many others who were forced to stare down their worrisome MG diagnosis. What am I going to do with my life?

For Dawn, who had always been meticulous about her diet and conscious of her mental and spiritual health, the answer was to help improve the physical and emotional quality of life for others living with MG.

Her quest eventually led her to found the Myasthenia Gravis Holistic Society, a Georgia-based non-profit dedicated to fostering a holistic approach to living with MG. Dawn says, "We operate on the foundational belief that true wellness and improvement come from looking beyond the medical diagnosis of myasthenia gravis and into the whole person—encompassing their lifestyle, environment, and emotional health."



Her organization brings that philosophy to Michigan with the MG Awareness Day and Health Fair May 4 in Southfield. The event is partially sponsored by MG-MI and offers workshops, health education, free chair massages and some fun events. There will also be a free lunch provided, but registration is required at MGAwarenessDay.org.

Dawn says there will be some unique opportunities for event participants. "Through our MyMGLife Experience Challenge, we aim to provide attendees with an immersive understanding of myasthenia gravis, fostering empathy and knowledge that will resonate long after the event concludes."

Registration open

Michigan

MG Awareness Day & Health Fair

**Saturday
May 4, 2024
10AM to 3PM**

**Hilton Garden Inn
26000 American Drive
Southfield, MI 48034**

**Register Now:
www.MGAwarenessDay.org**
Everyone must register for our lunch count

**Free
Community
Event**

*Wellness Options
Health Education
MyMGLife Challenge
Free Lunch
Holistic Health
Free Chair Massage
Workshops*

Drawing for best Star Wars outfit (optional participation)

MG Holistic Society
Vendors/ Questions
info@mgholisticsociety.org

**MYASTHENIA GRAVIS
mgmi
FOUNDATION OF MICHIGAN**

argenx

BACK TO ME

ALEXION
AxinsZarencia Rare Disease

ucb *Inspired by patients.
Driven by science.*

MG-MI Annual Patient Education Conference October 5 in Lansing

The largest conference of its type in the Midwest will be held as an in-person and virtual event in East Lansing on October 5. MG-MI's Eighth Annual MG Patient Education Conference will bring together MG patients, physicians, researchers and pharmaceutical representatives for the one-day event. Those attending will receive information on wellness and the latest treatments currently available, as well as those on the horizon. If MG has touched your life, this is the conference to attend. Look for details from MG-MI in upcoming months.



MEDICAL/RESEARCH

Highlights & Late Breaking News



Low-Dose Rituximab Effective Against MuSK-Positive MG in New Analysis (AJMC)

Following implementation of low-dose rituximab as standard of care for muscle-specific kinase–positive myasthenia gravis (MuSK-MG), a hospital evaluated the treatment’s efficacy over a 2-year period. For patients who have muscle-specific kinase–positive myasthenia gravis (MuSK-MG), low-dose rituximab was proved effective. View the full article by clicking [here](#) or using the QR code at right.



Serum fibrinogen may be a universal biomarker for MG (Scientific Reports)

High levels of serum fibrinogen were found to be a sensitive and specific biomarker to identify people with myasthenia gravis (MG), according to a recent study. The plasma protein was observed in all 31 MG patients in the study. View the full article by clicking [here](#) or using the QR code at left.

Many Autoimmune Disease Patients Struggle With Diagnosis, Costs, Inattentive Care

Despite their frequency, finding help for many autoimmune diseases can prove frustrating and expensive. getting diagnosed can be a major hurdle because the range of symptoms looks a lot like those of other medical conditions, and there are often no definitive identifying tests. View the full article by clicking [here](#) or using the QR code at right.



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Coming Up



May 4 - *Southfield* - MG Awareness Day & Health Fair
(Partner Event) 10 am to 3 pm
Register at: mgawarenessday.org

May 25 - *Grand Rapids* - MG-MI MovesMG
(See article on page 5)

June 10 - *Warren* - In-Person Support Group Location & speaker to be confirmed

June 15 - *Grand Rapids* - In-Person Support Group Julie Burnham, DO “Take on Your Tomorrow with gMG”
Lunch program, location and time to be confirmed

October 5 - *MG-MI Eighth Annual Patient Education Conference* East Lansing, MHSAA Bldg. 9 am – 3 pm



SAVE THE DATE!
MG-MI MovesMG
Fun Summer Event
Saturday May 25, 2024
Cascade Township Park
9 am to Noon

MG-MI MovesMG Kicks Off June MG Awareness Month

By Esther Land, MG-MI



To kick off 2024's annual MG Awareness Month, we are planning our annual *MG-MI MovesMG* fun summer event. Come spread the word about MG while helping raise funds for our MG-MI programs. Join us on Saturday, May 25, 2024 at Cascade Township Park from 9 am to noon.

This event is for you and your family! There will be a 5K fun run, 1-mile walk, yard games, special invited guests who will be roving around to entertain us, food truck, snacks and more.

Our friends from the MG car club will also have their personal cars on display. More details will be coming soon but put this exciting event on your calendar now.



Thank You!

We thank **John Twist** and **University Motors Limited** for again supporting MG-MI with a 50/50 drawing at their 49th Birthday Party on January 20. This event allows us to promote both of our MG causes. Also attending the party were representatives from the *Old Speckled Hen MG Car Club*. Individuals from this club will again have their MG cars on display during our *MG-MI MovesMG* summer event.



YOUR GIFT HELPS US HELP OTHERS



WWW.MG-MI.ORG



SUPPORT

In-Person & Virtual Scheduled Events



April 10, Wednesday - Lansing - Hybrid (In-Person and Zoom) 5:00 - 6:30 pm

MHSAA Building, 1661 Ramblewood Dr, East Lansing, 48823

Guest speaker: Ken Bush, *argenx*—Topic: **“Navigating MG Treatment Coverage”**

Sandwiches and beverages available for in-person attendees—MUST RSVP to info@mg-mi.org or 616-956-0622

May 9, Thursday - Saginaw - In person - 6:30 pm

Zaue Memorial Library, Quiet Study Room - 3100 N Center Rd, Saginaw 48603

Hosted by Ashley Dudek (Boucher) Topic: TBD

May 14, Tuesday - Muskegon - In-Person - 12:00 noon - 1:30 pm

Pizza Ranch - 1848 E Sherman Blvd, Muskegon 49444 Topic: **“Lunch and Learn”**

General discussion

June 19, Wednesday - Kalamazoo - In Person - 2:00 pm

Oshtemo Branch Library, 7265 W Main St, Oshtemo 49009 - Guest Speakers

Michelle Crooks, MD, Bronson Healthcare-Neurology, & April Davenport, MSW

Topic: **“Living with a Chronic Condition”** followed by Q&A

June 20, Thursday - Mount Pleasant - in Person - 4:00-6:00 pm

McLaren Central Michigan Hospital - FDJ Board Room

1221 South Dr, Mt. Pleasant 48858 - Hosted by Janet Gentle - Topic: TBD

Virtual meetings allow for Q&A

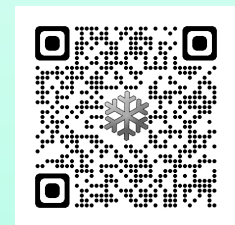


Watch our website & MG-MI emails for updates

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 Foundation of Michigan

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616-956-0622 • info@mg-mi.org • www.mg-mi.org

<https://www.facebook.com/MGofMI>

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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