



mg MYASTHENIA GRAVIS
mi
 FOUNDATION OF MICHIGAN

COMMUNICATOR

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INAUGURAL MG-MI MOVES MG EVENT RAISES \$9,000

Drawing approximately 100 participants from toddlers to seniors, the Myasthenia Gravis Foundation of Michigan held its first ever MG-MI Moves MG event July 24, raising more than \$9,000.

Held at Cascade Park in Grand Rapids, participants walked, ran, pushed strollers and roller skated along a 1-mile trail to continue MG-MI's mission to find a cure for Myasthenia Gravis by providing information and support to those living with the disease through research, education, community programs and advocacy.

The event also included yard games, a cardio drumming session and an opportunity for kids to decorate their bikes and add safety flags, courtesy of Riding for Ryan, a West Michigan nonprofit organization aimed to promote the safety of young bike riders through visibility and awareness. The event concluded with participants enjoying cake to celebrate MG-MI's 45 years of serving those living with MG in Michigan. MG-MI would like to thank event fundraisers Esther

Land, Brandie De Haan and Kristine Fey-Paiz for all their great work to make this event run smoothly.

Additionally, MG-MI would like to thank Eenhoorn LLC for its continued support of MG-MI, golf outing sponsors who donated to this event in lieu of participating in this year's golf outing due to COVID-19 restrictions, Land & Co., Georgetown Waterproofing, Van Laan Construction Supply, Grand Rapids Glass & Door, event photographer Bob Kopen, and all of the volunteers who made this event amazing.



THREE EASY WAYS TO CHANGE LIVES WITH MG-MI

Your donation to MG-MI can change lives. Here are three easy ways you can make an impact:

a **Amazon Smile.** Visit smile.amazon.com and choose Myasthenia Gravis Foundation as your charitable organization. When you shop, Amazon will donate 0.5% of eligible purchases to MG-MI at no cost to you.

P **PayPal.** Make a recurring donation via PayPal at mg-mi.org and select "Donate" to set up a monthly donation. Payments are tax deductible.

f **Facebook.** Visit facebook.com/MGofMI and click "Donate" or set up your own fundraiser and link it to the MG-MI page.

MG-MI WELCOMES TWO NEW MEMBERS TO BOARD OF TRUSTEES

MG-MI has added Paul Copeland and Andrew Van Timmeren to its Board of Trustees for a three-year term.

Copeland joined the Board in November 2020 and brings more than 30 years of health care knowledge as a registered nurse, serving in the intensive care unit, emergency room, surgery, care management and clinical reimbursement disciplines.



Diagnosed with MG two years ago, Copeland's goals as a Board member are to promote MG awareness, share his life's experiences and resources and be an advocate in the MG community.

Copeland earned his associate degree in nursing from Grand Rapids Community College and bachelor's degree from Cornerstone University in business management. He and his wife reside in the Grand Haven area and are the parents of three adult children and two grandchildren.

Van Timmeren joined the Board in March after serving in the U.S. Air Force as an F-22 Raptor pilot.

In 2019, when ocular MG symptoms began and eventually could no longer be ignored, Van Timmeren reached out to MG-MI for information and support.



Being appreciative of the services MG-MI provided, he reached back out again upon returning to Michigan.

The Jenison High School graduate's goals as a Board member are to give back to others living with MG with the same support and care he had received.

He is looking forward to meeting others with MG and sharing his MG story of resilience.

He and his wife live in Jenison and are the proud parents of two young boys.

BAY CITY BROTHERS' LEMONADE STAND HELPS SUPPORT MG-MI

What do you do when life hands you lemons? You open a lemonade stand and donate proceeds to MG-MI.

That's what brothers Xander and Jaxson Dehmel did in front of their home in Bay City.

The two opened a lemonade stand and pledged 25% of their profits to MG-MI to help people living with Myasthenia Gravis and raise awareness.

Their inspiration for the idea came from their mother, Jessica LaBerge, who was diagnosed with MG seven years ago.

Xander and Jaxson have observed the challenges she and their family have faced living with MG and wanted their efforts to help her and others.

During MG-MI's Aug. 26 support meeting in Saginaw, the brothers surprised meeting organizer and MG-MI Board of

Directors Secretary Esther Land with their donation of \$45.

MG-MI would like to thank Xander and Jaxson for their efforts to support their mother, others living with MG and MG-MI.



OUR MG-MI FAMILY

2020 Coraggio Award

Mathew and Vicki Mikolajski of Saginaw were both named recipients of the 2020 Coraggio Award. This mother and son team exemplified the spirit and courage of Lisa Gigliotti, who created the award in 2011.



Born with cerebral palsy, Mat was diagnosed with MG at age 25. Vicki, his loving and resolute advocate, sought the best neurology care while staying informed about the latest therapies to provide the best quality of life possible for her son. The resilient determination Mat and Vicki showed as they fought the challenges of the physical limitations from CP and MG were inspiring.

Mat continued his Coraggio spirit right to the end, and on July 3, the MG-MI family was saddened to learn of Mat's death.

Our sincere sympathy to Vicki and family as they mourn and adjust to their loss.

“My father has been approved for Gammagard infusions in the home, and Optum RX has approved his financial hardship application. He is covered 100% for one year and we feel very blessed! This never would have happened without MG-MI. My dad is so grateful! Thank you for leading us down a path that will help our dad! It has been three months since his last infusion. He only had three, but he hasn't declined very much at all. Our hearts are filled with joy and hope! Thank you again!”

Karmen Kraft

2020 Volunteer of the Year Award

After retiring from Dematic a few years ago, Marilyn Moorman of Ada became one of MG-MI's tireless volunteers. She's logged more than 300 office hours, assisting with filing, record keeping and preparing the newsletter, meeting notices and other mailings. One of the large projects she enjoys is coordinating the cash register receipts for the Spartan-Nash Direct Your Dollars fundraiser. She has tallied \$40,000 of the \$150,000 needed for us to receive a \$1,000 check from SpartanNash.



Welcome

A warm welcome to 21 new MG-MI members who have joined this year. We are privileged to now serve 732 members.

In Memoriam

Our sincere sympathies to the families and caregivers of our MG-MI family who have passed away in this year:

Larry Fox of New Era (Feb. 4), **Mat Mikolajski** of Saginaw (July 3) and **James Frohm** of Marshall (May 25).

CELEBRATIONS



Congratulations, Jack Sheehan, on your 100th birthday on May 31! You are an awesome and inspiring member of our MG-MI community.



ANNUAL CONFERENCE

OCTOBER 2-3, 2021

Virtual

REGISTER TODAY!

The **Myasthenia Gravis Foundation of Michigan** will once again hold its annual conference virtually this year via Zoom at no cost to registrants on Saturday, Oct. 2 beginning at 10 a.m. and Sunday, Oct. 3 beginning at 1 p.m. Those living with MG, medical providers, caregivers, advocates and anyone interested in educating themselves about MG are invited to tune in. Industry leaders will unpack the complex – and ever-changing – nature of this rare disease. Speaker topics will include:

- Existing treatments for MG
- Emerging treatments and research
- Critical care management and anesthesia
- Ocular MG diagnostics

Register online by Monday, Sept. 30 at mg-mi.org.

Unable to tune in virtually or want a copy of this year's conference? Order a flash drive by mail with all of this year's presentations.

The Myasthenia Gravis Foundation of Michigan
2660 Horizon Drive SE, Suite 235
Grand Rapids, MI 49546

Please consider a donation to MG-MI
\$25 \$50 \$100

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