

MG OHIO NEWS

APRIL 2025

Volume 13 Issue 4

Special thanks to Rebecca for all her years of doing the newsletter.

Please bear with us during the transition.

MG Ohio

Executive Board

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Dr. Suzanne Ruff

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If we can assist you with medical care referrals, resources, durable medical equipment, or information about MG, contact us at 216-218-0477 (leave a message)

You will find a wealth of information at the website:

MGOhio.org

To Donate to MG Ohio, scan here





MG Ohio Zoom Support Group Meetings

1st and 4th Thursdays

When: April 3, 2025 03:00 PM ET

https://zoom.us/meeting/register/ tJcrcO6urTgiGtK3l9l RXk1QDozODwbXpFs

When: April 24, 2025 07:00 PM ET

https://zoom.us/meeting/register/ tJUkceCtgj0jHNaMrXHj4XLLH1K4BzKYld U

Saturday night chats weekly at 6:30 pm (ET)

https://zoom.us/meeting/register/ tJ0ufu6grDsjG9PS1AQG9vWTYeTnNJAZtumm

After registering, you will receive a confirmation email containing information about joining the meeting.



Celebrate! April Events

- April 1: April Fool's Day, International Fun at Work Day, National Sourdough Bread Day
- April 2: World Autism Awareness Day
- April 7: National Beer Day
- April 15: Tax Day, equality, tolerance and diversity.
- April 16: National Pajama Day
- April 19: Husband Appreciation Day
- April 20: Easter

MG Ohio Educates

Ask the MG Expert

Q. My MG makes me so tired. How can I manage my fatigue?

A. There is a difference between being tired and having muscle weakness due to MG. Muscle fatigability is one of the defining symptoms of MG. It means that, with repeated effort, your muscles are less strong and less able to perform tasks easily or quickly, or even at all. Fatigue – or tiredness is a feeling of exhaustion, loss of energy and sometimes motivation. Fatigue can be both physical and mental. A good way to distinguish between the two is that muscle fatigability is an objective symptom and can be measured by your healthcare provider, and fatigue is a subjective measure and is reported by a patient to their healthcare provider. Both affect day to day tasks.

Muscle fatigability can be measured by using the MG ADL (Activities of Daily Living) Scale to track and report these symptoms to your healthcare provider. It is also good information for your own use. There are many ways of decreasing the impact of muscle fatigue by planning your day and pacing yourself, using "MG life hacks" and giving yourself enough time to complete tasks. We have a good handout on "MG life hacks" and there will be an event in NE Ohio using this as a theme in July. Watch for it!

Fatigue that is not solely due to MG can also be a big factor. Fatigue can be related to many factors: disuse, poor sleep, lack of exercise, medication side effects, depressed mood or anxiety are among the most common. Often,

Continued on page 3

MG Ohio Supports

2025 MG Ohio Meetings:

MG Ohio Northeast Ohio (NEO) In-Person Support Group Meetings:

April 12, 2025 - 1:00-3:00 pm Metro Health November Campus

7800 Pearl Rd. Middleburg Hts., OH 44130

This will be a hybrid meeting broadcast over Zoom. Please use the link or call to join:

https://zoom.us/j/95377894109?pwd=NoN8jb0pTRZkrtXEdZkuxfmaja2vdd.1

Meeting ID: 953 7789 4109 Passcode: 980913

April 22, 2025 - 10:30 am Meet us for Brunch at Marie Scramblers

26435 Great Northern shopping Center, North Olmsted 44070

May 10, 2025 - 1:00-3:00 pm Metro Health November Campus

7800 Pearl Rd. Middleburg Hts., OH 44130

MG Ohio Central Ohio In-Person & Zoom Support Group Meetings:

April 14, 2025 - 4:30 pm The Dempsey Family Education and Resource Center

at OhioHealth Neuroscience Center Riverside Methodist Hospital

3535 Olentangy River Road, Columbus, Ohio 43214

Parking is free (with vouchers we will provide at the meeting). Park in the

"Red" parking garage.

We plan for this to be a hybrid meeting for in-person support group members and their caregivers/families as well as online via WebEx for those unable to attend in-person. (WebEx is an online meeting platform similar to Zoom) www.ohiohealth.webex.com Please contact Sharon or Cathy at centralohiomg@gmail.com or by phone at 614-334 -1140 for the Webex meeting code.

MG Ohio Southwest Ohio In-Person Support Group Meetings:

April 12, 2025 - 1:00-3:00 pm Mayerson JCC

8485 Ridge Road, Cincinnati, Ohio 45236.

Madison, Paul, and Erica will be sharing what they learned from

attending the MGFA Conference at the end of March.

(Take the Ridge Road Exit from the Ronald Regan Highway)

RSVP to Erica at amannerica@gmail.com.

This will be a hybrid meeting broadcast over Zoom. Please use the link or call to join:

https://zoom.us/j/97131113585?pwd=r52SrnweJG59pfVbfKqyNCrwelzqZh.1



Hello. I'm Jack and I will be taking over the MG Ohio Newsletter from Rebecca.

Please be patient with us during the transition. Feel free to contact me at news@mgohio.org

A Special Thank You to Rebecca and Jerry Molitoris for all their work and dedication.

They have decided to step down after many years of leading the MG Community on many levels. We honored them at the Christmas party - here are the awards given at that time.

Lifetime Achievement

Rebecca Molitoris

In recognition and appreciation of lifelong leadership and extraordinary service to the Myasthenia Gravis community, with special dedication to educating and improving the quality of life for all MG patients, families, and caregivers. Your compassion shines through everything you do. The Myasthenia Gravis community has also benefitted enormously from the inspiration, education, and encouragement you extend to health care providers and medical/pre-medical students, resulting in a more knowledgeable medical community as well as students pursuing clinical and research studies involving MG.

Outstanding Service

Jerry Molitoris

In recognition and appreciation for your dedication to supporting the Myasthenia Gravis community through technical expertise and facilitation. Meetings, conferences, newsletters, and all manner of community events have been possible as a result, thereby improving communication, education, and quality of life for Myasthenia Gravis patients and caregivers.



Ask the Expert continued from page 1

your control. As always, we are not look

but an improvement.

fatigue is caused by more than one factor.

These factors respond to lifestyle changes that are under

ing for a perfect solution - that probably does not exist! -

your sense of fatigue or exhaustion and also give you a

for your general overall physical and mental health.

Planning your day with your MG in mind is crucial to

Focusing on factors under your control can help in reducing

boost of accomplishment. An exercise program designed by

a physical and occupational therapist is an excellent place to

start. It is important to get and remain as active as possible

conserving your energy. Pace yourself to get your priorities

done when your energy levels are higher and muscles and

nerves are playing nicely at the neuromuscular junction!

Getting good sleep may be one of the most important

(at a minimum). Avoid caffeine and alcohol 4-6 hours before bedtime. If naps are necessary, set an alarm for 20

minutes so that your nighttime sleep is not affected.

your heart. That is what is important in life.

aspects in caring for yourself in general and your MG in

particular. Have a set bedtime with a routine a half hour

beforehand. Do not use electronic devices in that half hour

Finally, be sure to save enough energy for what matters to



SOUTHWEST MG OHIO PATIENT EDUCATION CONFEREN



CONFIRMED FEATURED CUEST SPEAKERS



LIZ PLOWAN, MD **AUTHOR OF** SOME SPOC TOPIC: MC & PHYSICAL THERAPY



HANI KUSHLAF, MD NEUROLOGY UC HEALTH DIRECTOR OF NEUROMUSCULAR DISORDERS



VICKIE PETZ KASPER, MD PODCAST: LIFESTYLE MEDICINE HEALTHY LOOKS GREAT ON YOUR TOPIC: THE LINEXPECTED GIFTS OF MG



JUNAID MALIK, MD AND SLEEP MEDICINE CERTIFIED DAYTON RESPIRATORY CENTER TOPIC: HOW MG AFFECTS THE DIAPHRAGM AND BEST SLEEPING MACHINES FOR MC PATIENTS

AND MORE TO COME!

THIS EVENT IS FREE! FOR MORE INFORMATION EMAIL AMANNERICA@CMAIL.COM OR VISIT OUR WEBSITE WWW.MCOHIO.ORC/SOUTHWEST-EVENTS

THANKS TO OUR SPONSORS

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THE PURPOSE OF THIS CONFERENCE OFFERS ATTENDEES A CHANCE TO CONNECT WITH THE ORGANIZATION'S MISSION, LEADERSHIP, AND INITIATIVES. OUR CONFERENCE WILL BE AN EXCITING OPPORTUNITY TO ENGAGE, LEARN. AND CONNECT. JOIN US FOR AN INSPIRING LINEUP OF INTERACTIVE SESSIONS DESIGNED TO EMPOWER PATIENTS, CARECIVERS, AND HEALTHCARE PROFESSIONALS ALIKE. DIVE INTO THE LATEST BREAKTHROUGHS IN TREATMENT AND MANAGEMENT OF MG. CAIN VALUABLE INSIGHTS FROM EXPERTS, AND SHARE EXPERIENCES WITH OTHERS WHO UNDERSTAND YOUR JOURNEY.

SAVE THE DATE JUNE 21 -22, 2025 LOCATION HOLIDAY INN, EASTCATE 4501 EASTCATE BLVD CINCINNATI. OH 45245

ROOMS WILL BE AVAILABLE AT A DISCOUNTED CROUP RATE UNDER THE NAME MG OHIO - MORE INFO TO COME



JUNE 21st EASTGATE MALL **EVENT IS FREE!** ADULT T-SHIRTS \$25 YOUTH T-SHIRTS \$15

CHECK IN @ 9:30 AM WALK: 10 AM - 12 PM

SAVE THE DATES

JUNE 21-22, 2025

Southwest Ohio will be holding a Regional Walk and Patient Education Conference. (See flyer to the left) SEPTEMBER 7, 2025

Northeast Ohio will be holding a Regional Walk at the Chalet in the Cleveland Metroparks Strongsville

See the MG Ohio.org website for more information about the walk: https://mgohio.org/southwest-ohio

MG Ohio Website: Visit us at www.mgohio.org

For all the latest local MG news, upcoming events, and newsletters

Is there a topic or subject that you would like to see covered in the monthly MG News?

Email us at news@mgohio.org and let us know!

Did you know that at www.mgohio.org you can view educational videos, download newsletters and brochures, and get all the latest information about our in-person and online meetings?

Check out our MG Alliance Partners Page https:// mgohio.org/mg-alliance for information about other MG groups in different parts of the country that hold online meetings. Just click on their logo and you will be taken to their site. You are always welcome to attend any online meeting wherever you may live.

Need help paying for your meds? Check out the following sites:

https://www.needymeds.org/

Good Rx.com

http://www.themedicineprogram.com/

http://www.togetherrxacces.com/p/prescriptionsavings

https://mat.org/ (Medication Assistance Tool)

http://www.rxhope.com/Patient/ AssistanceRequest.aspx

Order MG Ohio T-Shirts - order by April 11

Option to purchase t-shirt to wear to represent each group.

This t-shirt would be purchased at the cost of the shirt, with no one making extra money from it.

Why SHOULD you purchase a MG Ohio Group T-shirt?

- 1. It helps spread awareness about our support groups when you where it.
- 2. When we have a group outing or event we look more unified wearing them.
- 3. They would be great to wear to wear on the second day of the Patient Education Conference In Cincinnati this June.
- 4. It gets people to ask questions about MG that may not be aware, so again, you are bringing more awareness to MG.

T-Shirts cost \$15 each plus \$1 shipping cost for Central or Northeast Members Available sizes: S, M, L, XL, 2XL, 3XL, 4X

Order here: https://docs.google.com/forms/d/e/1FAIpQLSf9Od241t9j-CrIDqEzlAeE58de-M4ndB4Nh8ZBvn-QLOkvdw/viewform?usp=header





Northeast Ohio

April 12 - 1:00-3:00 pm **Metro Health November Campus**

7800 Pearl Rd. Middleburg Hts. OH 44130

Southwest Ohio

April 12 - 1:00-3:00 pm **Mayerson JCC**

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Central Ohio

April 14 - 4:30 pm The Dempsey Family Education and Resource Center

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