

MG OHIO NEWSLETTER

April 2024

Volume 12 Issue 4

Supporting the Myasthenia Community in Ohio & Beyond

MG Ohio

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MG Ohio Zoom Support Group Meetings 2nd and 4th Thursdays

When: April 11, 2024 03:00 PM Eastern Time (US and Canada)

https://zoom.us/meeting/register/ tJIIcO6hrDwvHtd61R9VqPmOcl2wqkgs1P1h

When: April 25, 2024 07:00 PM Eastern NEW! Time (US and Canada)

https://zoom.us/meeting/register/ tJwpcu6prT4uEtapOZcjHU8ZtWrkYCAyT3Fs

Saturday night chats weekly at 6:30 pm (ET) Register in advance for this meeting:

https://zoom.us/meeting/register/ tJYvcuytqjgqHdSBm1nwDkGRL5Mi5jXJWKtd



Central Ohio Hybrid Meeting— Monday, April 15th 4:30 pm

ohiohealth.webex.com See page 2 for more information



Ask the MG Expert

Q. I've read about an uptick in MG in people who have had the Covid-19 virus. Is this true?

A. *Viral infection such as coronavirus disease 2019 (COVID-19) can exacerbate and aggravate neurological disorders due to autoimmune etiology like myasthenia gravis (MG). Experimental therapies used in COVID-19 are also factors that can cause the worsening of MG symptoms. This review aimed to assess and conclude the research-based study systematically to analyze the relationship of MG and COVID-19.

Method - This study was conducted in accordance to Cochrane handbook for systematic reviews and the guideline of preferred reporting items for systematic review and meta-analysis (PRISMA) and synthesis without meta-analysis (SWiM) in systematic reviews: reporting guideline. Inclusion criteria in this review were primary studies of every design, articles published in English around January 2000–October 2021, and the study used human as subject. A systematic literature finding was applied in 15 electronic scientific resources. The authors evaluated the study quality and risk of bias of each retrieved article.

Results - The authors found the study through electronic scientific resources that met inclusion and exclusion criteria. The authors evaluated 362 articles identified in literature searching, 22 articles met the criteria for this review and then underwent the evaluation of study quality and risk of bias.

Conclusion - COVID-19 infection can increase the risk of new-onset MG, myasthenic crisis, respiratory failure, and mortality rate due to cytokine storm in MG patients. The management of COVID-19 patients with MG is tailored to each person and based on national guidelines and local expert recommendations.

 Egypt J Neurol Psychiatr Neurosurg. 2022; 58(1): 83.

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We are here for you and your

family to provide help and hope for those living with Myasthenia Gravis in Ohio and beyond.

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

You will find a wealth of information at the website: <u>MGOhio.org</u>

Help out MG Ohio:

Use the link below to sign up for Rare Patient Voice, MG Ohio will receive \$5 for every person chosen to participate. That money goes towards funding our newsletter and our support groups. Click here to sign up.

2024 MG Ohio Meetings:			
MG Ohio Northeast O	hio (NEO) In-Person Support Group Meetings:		
April 13—1:00-3:00 pm	West—Fairview Park Library		
	21255 Lorain Rd., Fairview Park, OH 44126		
<u>June 30—9:30 am - ?</u>	MG Awareness Walk Event		
	Mill Stream Run Reservation - Cleveland Metroparks		
	16200 Valley Parkway, Strongsville, OH 44136		
August 10—1:00-3:00 pm	Central—Annual Ice Cream Social		
	6305 Halle Dr., Valley View OH 44125		
October 12—1:00-3:00 pm	East—Location TBD		
December 7—1:00-4:00 pm	Annual Christmas/Holiday Party—Pioneer Ridge Lodge 9479 Saw Mill Trace, North Ridgeville, OH 44039		

NOTE: This year regular NEO meetings will be BYOB (bring your own beverage) Coffee & water will no longer be available so please bring your own. Donations of baked goods always welcome.

NOTE: Watch this space each month for changes or additions to the in-person meetings

MG Ohio

Central Ohio In-Person & Zoom Support Group Meetings:

April 15, 2024—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.

These will be hybrid meetings 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.) **ohiohealth.webex.com** Webex Call-In Phone Number -650.479.3208 Please contact Sharon or Cathy at <u>centralohiomg@gmail.com</u> or by phone at 614-334-1140 for the Webex meeting code.

MG Ohio

Southwest Ohio In-Person Support Group Meetings:

The Southwest Ohio MG Support Group will meet the following months in 2024: Jan. ,Mar., May, Jul., Sept., and Nov. The exact Saturday we meet during these months will be added as soon as our meeting place confirms the dates.

<u>May 11 —12:00 pm</u>	Bravo! Italian Kitchen	NEW!
	9436 Waterfront Drive, West Ches	ter, Ohio 45069
Special Speakers LeeJean Beringer, Patient Education Manager, Alexion		
	Jon Durrani, MD)
	See Special Flyer Insert for regist	ration information.

June is Myasthenia Gravis Awareness Month

We plan to celebrate it with two family friendly walks, June 22nd in Southwest Ohio, and June 30th in Northeast Ohio.

The walk paths are both fully accessible. Walk as much or as little as

you want, or cheer on other participants and teams. There will

be sponsors to visit, food, drinks, and more. The MG Walk is an

amazing day of friends, togetherness, and fundraising.

When we come together; we create a powerful force for good.

Gather your team and get ready to participate in one or both of our annual walk events.

REGISTRATION BEGINS APRIL 15th





Transitioning into a new era -

Rebecca Molitoris will be stepping down as President and transitioning to President Emeritus. New Date for this transition is July 1st due to the upcoming MG Walks. Robert Ruff, MD and Suzanne Ruff, PhD, will be heading up MG Ohio starting in July.

We will still be holding both Zoom and In-person meetings during this transition (see page 2). Rebecca will continue as a member of the MG Ohio team – just not as involved.

We are looking to expand our in-person meetings to include the Canton and Youngstown areas. If you would like to see an in-person meeting in your area, please let us know by calling or texting 216-218-0477 or emailing us at <u>mgohio@mgohio.org</u>.

We will be holding Support Group Leader training this month (April). Please contact us 216-218-0477 and LEAVE A MESSAGE if you would like to become a support group leader or co-leader in your area.

A BIG thanks to those of you who have stepped up and offered your services during this transition period.

MG Ohio Website: Visit us at <u>www.mgohio.org</u>

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

NOTE: The assistance fund is accepting applications from patients with myasthenia gravis to help with the following outof-pocket costs:

- Prescription drug assistance (copays, deductibles, and coinsurance) on FDA-approved treatment
- Health insurance premiums
- Therapy Administration costs
- Physician co-pays
- Treatment related travel costs

The Assistance Fund (tafcares.org)

NOTE: Important!! Be sure and sign up NOW for 2024

Your mind is a garden. Your thoughts are the seeds. You can grow flowers or you can grow weeds.



<u>Need help paying for your meds? Check out the fol-</u> lowing sites:

https://rarediseases.org/patient-assistance-programs/ financial-assistance/?search=myasthenia%20gravis accepting new applications

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

http://www.myastheniagravis.org/we-can-help/whatwe-do/ -for patients living in Indiana, Illinois, and Wisconsin

More info at: <u>https://myasthenia.org/Community-</u> <u>Resources/Resources-External-Assistance-Programs</u>

	APRIL 2024 IN- PERSON MEETINGS:
<u> April 13— 1:00-3:00 pm</u>	Northeast Ohio
	Fairview Park Library 21255 Lorain Rd., Fairview Park, OH 44126
<u>April 15—4:30 pm</u>	<u>Central Ohio</u>
	The Dempsey Family Education and Resource Center at OhioHealth Neuroscience Center Riverside Methodist Hospital 3535 Olentangy River Road, Columbus, Ohio 43214
<u>May 11 —12:00 pm</u>	Southwest Ohio
	Bravo! Italian Kitchen
	9436 Waterfront Drive, West Chester, Ohio 45069