

MG OHIO NEWSLETTER

January 2024

Volume 12 Issue 1

Supporting the Myasthenia Community in Ohio & Beyond

MG Ohio	
Executive Board	
Rebecca Molitoris	President
ТВА	Vice-President
Dr. Robert Ruff	Treasurer
Dr. Suzanne Ruff	Secretary
Laura Lodge	Event Coordinator
Board of Directors	
Dr. Elsheikh Bakri	Dr. Daniel Benson
Dr. Ben Claytor Larry Dix	Amanda Cordrick Dr. Miriam Freimer
Dr. Bashar Katirji	Dr. Hani Kushlaf
Dr. Yuebing Li	Sharon Rastatter
Amy Shaper	Saul Wiener
Dr. Kylie Sramek	



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

2nd Thursdays at 3:00 pm (ET) beginning January 11

Register in advance for this meeting:

https://zoom.us/meeting/register/ tJllcO6hrDwvHtd61R9VqPmOcl2wqkgs1P1h

4th Thursdays at 7:00 pm (ET) beginning January 25

Register in advance for this meeting:

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

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

Register in advance for this meeting:

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

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

NOTE: New Time! The 4th Thursday group meets at 7:00 pm



Ask the MG Expert

This month's column is from your MG Ohio President Rebecca Molitoris—

If this is your first time here, welcome. MG Ohio support groups offer safe spaces both in-person and via Zoom to discuss your experience with myasthenia gravis (MG).

Whether you have had MG for many years or are just beginning your MG journey, our support groups offer friendly faces, open minds, and the kind of understanding that one can only find with a another who has "been through it" too.

We can provide you with the best resource and educational tools possible. The best defense against this neuro-muscular disorder is knowledge. If we don't know the answer to your question, we will consult with one of our MG specialists to get you the information you need.

While we don't offer medical advice, people often share in meetings hints, and tips of things that have worked for them in their own MG journey.

The best source of advice is your own doctor and we encourage you to ask your health care team. We can help you prepare for your doctors appointments so you go in armed with your list of questions about your specific situation.

We would like to serve you better. So look for an email soon with a survey about our support groups. How can we be better? What other services can we supply?

We look forward to receiving your answers. —-Rebecca

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 Rebecca at 216-218-0477 (leave a message)

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

Want to donate to MG Ohio?

Contact us to find out how.

Help out MG Ohio:

Use the link below to sign up for Rare Patient Voice, MG Dhio will receive \$5 for every person chosen to participate. That money goes towards helping to fund this newsletter and run our support groups. <u>Click here</u> to sign up.

2024 MG Ohio Meetings:

MG Ohio Northeast Ohio (NEO) In-Person Support Group Meetings:	
January 13—1:00-3:00 pm	West—Parma-Powers Library
Speaker Suzanne Ruff, PhD—Top changing illness	6996 Powers Boulevard, Parma, Ohio 44129 ic: Dealing with Depression and Anxiety when diagnosed with a life-
February 10-1:00-3:00 pm	West—Parma-Powers Library Celebrating Rare Disease Month
February 17—1:00-3:00 pm	6996 Powers Boulevard, Parma, Ohio 44129 East—Mayfield Library Celebrating Rare Disease Month
March 9-1:00-3:00 pm	500 SOM Center Rd., Mayfield Village, Ohio 44143 West—Parma-Powers Library
<u>April 13—1:00-3:00 pm</u>	6996 Powers Boulevard, Parma, Ohio 44129 East —Location TBD
<u>May 11—1:00-3:00 pm</u>	West—Location TBD
June 30—all day event	Central—MG Awareness Walk Event Cleveland Metroparks Zoo
July 13—1:00-3:00 pm	3900 Wildlife Way, Cleveland OH 44109 East—Location TBD
August 10—1:00-3:00 pm	Central—Annual Ice Cream Social
	6305 Halle Dr., Valley View OH 44125
<u>September 14—1:00-3:00 pm</u>	West—Location TBD
October 12—1:00-3:00 pm November 9—1:00-3:00 pm	East—Location TBD West—Location TBD
December 7—1:00-4:00 pm	Annual Christmas/Holiday Party—Pioneer Ridge Lodge

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.

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

2024 Meetings—TBD For more information:

Please contact Sharon or Cathy at <u>centralohiomg@gmail.com</u> or by phone at 614-334-1140

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.

Plan to meet on Saturday, January 13 from 1-3 PM for our 2024 Kick-Off meeting.

Family and Friends Welcome!"

January 13 — 1:00-3:00 pm

Mayerson JCC

8485 Ridge Road, Cincinnati, Ohio 45236.

(Take the Ridge Road Exit from the Ronald Regan Highway) RSVP to Sharon Meyer slmeyer1954@gmail.com



MEET THE BOARD 2024 This year we welcome 3 new Board Members. Each month will feature a new member. This month meet: **Amanda Cordrick, MS**

I received both my Bachelor of Arts (major: Speech and Hearing) and Masters of Arts (major: Communication Sciences and Disorders) degrees from Cleveland State University, graduating this past spring. My

graduate program clinical experience includes internships at Dentzler Elementary School (grades K-4); Brentwood Healthcare (Skilled nursing and assisted living); Stars and Stripes Extended School Year Camp (ages 4-15); Cleveland State University Clinic (adults); and Washington Park Community School (children). I am currently completing my clinical fellowship year at the Achievement Centers for Children in Westlake as a speech-language pathologist, serving children and adults with a variety of needs.

Thank you to everyone who donated cash or donated items for the regional conference or one of the awareness events held during 2023: Philip L & Rosyln L Headington, Rebecca & Jerry Molitoris, Bobbi Navarra, Carolyn M. Osmialowski, Jack Peterson, Bob & Suzanne Ruff, Laura Ann Tomco.

Thank you to those who gave a donation in Honor of Marjorie C Crow: Myrna J and Richard J Hugh, Jennifer N. Kingsley, William R and Connie J Loy, Melvin D. & Jennifer Marie McMullen, Grace D. Michaels , David R. and Donna B. Quist.

If you would like to donate to MG Ohio, send a check or money order to: MG Ohio, c/o Robert Ruff, Treasurer, 935 Richmond Rd., Lyndhurst, OH 44124

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

2024

• Treatment related travel costs

The Assistance Fund (tafcares.org)

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

Man Contraction of the second second

<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>

> "WHAT THE NEW YEAR BRINGS TO YOU WILL DEPEND A GREAT DEAL ON WHAT YOU BRING TO THE NEW YEAR."

 JANUARY 2024 MEETINGS:

 In Person—
 January 13— 1:00-3:00 pm
 Northeast Ohio—Parma-Powers Library
6996 Powers Boulevard, Parma, Ohio 44129

 January 13—1:00-3:00 pm
 Southwest Ohio—Mayerson JCC
8485 Ridge Road, Cincinnati, Ohio 45236.