

# MG OHIO NEWSLETTER

# **NOVEMBER 2022**

# Volume 10 Issue 11

Supporting the MG Commun in Ohio & Beyond

MG Ohio		
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Dr. Yuebing Li	Jerry Molitoris	
Sharon Rastatter	Saul Wiener	

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** 

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

### Help out MG Ohio:

If you use the following link to sign up for Rare Patient Voice, MG Ohio 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.

# Zoom

# <u>November's Thursday</u> <u>Afternoon ZOOM Meetings</u>

When: Nov 3, 2022 03:00 PM Eastern Time https://zoom.us/meeting/register/tJlkd-2srD8uEtSJop3MagVxetM2krO8CS\_Q

When: Nov 10, 2022 03:00 PM Eastern Time https://zoom.us/meeting/register/ tJcudeqtqzlvHNTjEhV-t3rduLXP1VaUMyK3

When: Nov 17, 2022 03:00 PM Eastern Time https://zoom.us/meeting/register/ tJwkde2qrD0sEtze5gXG-dVN5mE05zdx5E5b

When: Dec 1, 2022 03:00 PM Eastern Time https://zoom.us/meeting/register/ tJlkceqtrjMrG9YRbdDjZ\_hc5NDcysdcpBWf

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

NOTE: No Meeting on Thursday, November 24th Happy Thanksgiving!



Next In-Person Meeting Eastside-

November 19, 2022 Mayfield Library 500 SOM Center Rd. Mayfield Village 44143 1:00-3:00 pm



# Ask the MG Expert

Q. Why do I need a support group? Don't you all just sit around and complain? I'm doing fine on my own.

A. A support group is so much more than people gathering to complain, it is a community that allows you to ask questions about MG and provides the following:

- Important tips and tricks for living well with MG
- Information on how to avoid MG flares and crises and when to call the doctor
- Information about what lifestyle changes have helped in managing MG
- A group of ready made friends who understand why your smile is crooked or that you need to just listen while closing your eyes
- A community willing to provide hope when you are feeling hopeless
- A group of friends who won't judge you if you can't show up all the time
- A community who gets what you are experiencing
- People to talk to about life's daily challenges and yes, allow you to vent when you need

Even if you are in remission, you are welcome to join our support groups. Let your prior experience count for something. Come and give others the hope you have found during your MG journey. We are adding newly diagnosed patients to our midst every month. Come virtually or in person and share your story.

MG Ohio Nor	Northeast Ohio In Person Events and Support Group Meetings:	
<u>October 29—10 am –2 pm</u>	FREE MG Ohio Awareness Event and short 0.7 mile walk	
	South Central Park—Pavilion 1	
	7565 Avon-Belden Rd., North Ridgeville 44039	
	Lunch Provided—RSVP mgohio@mgohio.org	
November 3-6:30 pm	FREE Dinner with Crystal Brown, Alexion PEM	
	Corleones Restaurant 5669 Broadview Rd, Cleveland, OH 44134	
	Must RSVP—See flyer attached to this email	
	NOTE: This is not sponsored by MG Ohio	
November 19—1:00—3:00 pm	Eastside Support Group Meeting	
	Mayfield Library—Medium Meeting Room	
	500 SOM Center Rd., Mayfield Village 44143	
December 10-2:00 pm	Annual Christmas Party Macaroni Grill	
	25001 Country Club Blvd, North Olmsted, OH 44070	
	See page 3 for more information	
MG Ohio Cin	cinnati Area Support Group Meetings:	
November 12-12:30-3:00 pm	FREE Light Lunch at 12:30—Meeting at 1:00 pm	
	Mayerson JCC 8485 Ridge Road, Cincinnati, Ohio 45236.	
	(Take the Ridge Road Exit from the Ronald Regan Highway)	
	We'll follow with discussion on our opportunity to participate in	
	MG OHIO, an organization created for Ohio MG Support Groups to	
	share ideas, friendships and information. RSVP to <u>Sharon Meyer</u>	
	MG Ohio—National	
C	PEN CHAT now every Saturday night at 7:00 pm ET via Zoom (click bellow) to register)	
<u>h</u>	ttps://zoom.us/meeting/register/tJ0qduytrT4jH9KSiOgggP8G0xHTCjcYC6b1	



# MEET YOUR MG OHIO BOARD

This month we get to know two more of our MG Ohio Board Members:



# Bobbi Navarra, Vice-President

Bobbi Navarra relocated to the Cleveland area from her native western Pennsylvania in 1987 to continue her career as a Human Resources professional. Bobbi semi-retired in 2009, renewed her teaching certification, and began a second career working with special needs students. Bobbi has served on the boards of Power of the Pen, Northcoast Food Rescue and the Cleveland Food Bank. Diagnosed with MG in 2020, She credits the Northeast Ohio MG support group with guiding her to the best resources for treatment and for providing valuable ongoing support.



### Saul Wiener, Director

Saul Wiener received a Masters degree from Temple University in Plant Physiology in 1965 and a Masters Degree in Landscape Architecture from University of Pennsylvania in 1973. He worked in the Department of Environmental Protection for the State of New Jersey, The US Heritage and Conservation Service, The Montgomery County Planning Commission and for John Rahenkamp Consultants. In 1989 he founded the Urban Tree Connection, a nonprofit that worked with underprivileged children in West Philadelphia, transforming vacant land into farms which fed the underserved population in West Philadelphia. Saul retired to Ajijic, Mexico in 2016 and relocated to Cincinnati in late 2021 due to his Myasthenia Gravis.



### What are you thankful for?

A great app to help you focus on the positive and count your blessings is **3 Good Things** - a free downloadable app for your smart device.

Check it out and start recording what you're thankful for. Thank you, Dr. Suzanne Ruff for this suggestion.

# MG Ohio Website:

# Visit us at <u>www.mgohio.org</u>

Have questions or comments? Send in your MG related questions to our Ask the MG Expert column Email at <u>mgohio@mgohio.org</u>

#### Has COVID-19 Left You Financially Strapped?

The National Organization for Rare Disorders (NORD) has opened a financial assistance program for people in the rare disease community including those with MG, who are affected by the COVID-19 pandemic in the U.S. Called the NORD COVID-19 Critical Relief Program, the effort will provide up to \$1000.00 annually to those eligible to support critical non-medical needs. For further information about eligibility or how to apply, call NORD at 203-242-0497 or send an email to COVID19assistance@rarediseases.org



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/prescription-savings https://mat.org/ (Medication Assistance Tool) http://www.rxhope.com/Patient/AssistanceRequest.aspx http://www.myastheniagravis.org/we-can-help/what-we-do/ More info at: https://myasthenia.org/Community-Resources/ Resources-External-Assistance-Programs



UPCOMING NOVEMBER 2022 MEETINGS: In Person—November 12 Mayerson JCC 12:30—3:00 <u>8485 Ridge Road, Cincinnati, Ohio 45236</u> In Person—November 19 Mayfield Library 1:00 –3:00 <u>500 SOM Center Rd. Mayfield Village 44143</u> Zoom Meetings—Thursdays 3:00 pm ET via Zoom (see page 1) OPEN CHAT now every Saturday night at 7:00 pm ET via Zoom (click bellow to register) <u>https://zoom.us/meeting/register/tJ0qduytrT4jH9KSiOgggP8G0xHTCjcYC6b1</u>