



Supporting the Myasthenia Community
in Ohio & Beyond

MG OHIO NEWSLETTER

DECEMBER 2022

Volume 10 Issue 12

MG Ohio

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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 Rebecca at 216-218-0477

You will find a wealth of information at the website:

MGOhio.org

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. [Click here](#) to sign up.



December's Thursday Afternoon ZOOM Meetings

When: Dec 1, 2022 03:00 PM Eastern Time

https://zoom.us/meeting/register/tJlkceqtrjMrG9YRbdDjZ_hc5NDcysdcpBWf

When: Dec 8, 2022 03:00 PM Eastern Time

<https://zoom.us/meeting/register/tJclceyupj4tG9EPCY1z8q6ZFievaSigmk7M>

When: Dec 15, 2022 03:00 PM Eastern Time

<https://zoom.us/meeting/register/tJwkd-gqpzwqGdEbhzAZ4VCLoBwEDxUmi01Rw>

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

NOTE: No Meeting on Thursday, December 22nd or December 29th Merry Christmas & Happy New Year!



Next In-Person Meeting Westside—

January 14, 2022

New Middleburg Hts. Library 15700 E. Bagley Rd.
Middleburg Hts., OH 44130

1:00—3:00 pm



MG Ohio is a 501(c)(3) designated non-profit

Ask the MG Expert

Q. I'm on immunosuppressants. How do I keep myself safe during the Holidays?

A. It is important to protect yourself from the triple threat of viruses making the rounds this season, Covid, influenza, and RSV. Here are some helpful hints for traveling and Holiday get-togethers:

- Wear a good mask in crowds— it's one of your best defenses against air-borne illnesses
- Don't be afraid to ask if the others attending are taking precautions too
- Try meeting in well ventilated areas— or those with HEPA filtering systems
- Tell everyone that you cannot attend if someone else is attending sick. Don't expose yourself to unknown germs
- When traveling, going by car is preferable to using public transportation (planes, trains, etc.)
- Use caution when using public facilities always wash hands thoroughly with soap

Q. What should I keep in the car when traveling?

A. You should keep the following things in your car in case of emergency:

- A list of current medications you're taking & allergies
- A list of medications contraindicated for those with MG
- Contact information for your attending doctor and your emergency contact (ICE)
- Extra Mestinon (pyridostigmine bromide) in water tight vial.

MG Ohio

Northeast Ohio In Person Events and Support Group Meetings:

December 10—2:00 pm

Annual Christmas Party Macaroni Grill cost \$15
25001 Country Club Blvd, North Olmsted, OH 44070
RSVP Required 216-218-0477 (leave Message)

January 14—1:00-3:00 pm

New Middleburg Hts. Library
15700 E. Bagley Rd
Middleburg Hts., OH 44130

February 11—1:00-3:00 pm

Olmsted Falls Library
8100 Mapleway Dr.
Olmsted Falls, OH 44138

March 11—1:00-3:00 pm

New Middleburg Hts. Library
15700 E. Bagley Rd
Middleburg Hts., OH 44130

MG Ohio

Cincinnati Area Support Group Meetings:

January 14 —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](#)

March 11 —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](#)



MG Ohio—National

OPEN CHAT every Saturday night at 7:00 pm ET via Zoom (click bellow to register)

<https://zoom.us/meeting/register/tJ0qduytrT4jH9KSiOgggP8G0xHTCjcYC6b1>

NOTE: A new link will be sent out next month for the Saturday chats.



ANNUAL CHRISTMAS PARTY

DECEMBER 10, 2022—2:00 PM

Romano's Macaroni Grill

25001 Country Club Blvd, North Olmsted, OH 44070

NOTE: We will be ordering off a special menu

Bring a small gift \$5 or under for the fun gift exchange

Everyone is invited but you *Must RSVP* cost \$15 /person

Text or leave message at 216-218-0477

Or email mgohio@mgohio.org



MEET YOUR MG OHIO BOARD



Miriam L. Freimer, MD, Director

Miriam L. Freimer, MD is a professor of Neurology at the Ohio State University. She has been the director of the Neuromuscular Division for over 9 years. She attended the Ohio State University College of Medicine, receiving her MD degree in 1985. She was both a neurology resident and neuromuscular fellow at Johns Hopkins from 1986 -1992. She returned to Ohio State to join the faculty of the Neurology Department in 1992. Over the past 30 + years she has been involved in the care of patients with many neuromuscular disorders. However, the one area that she has devoted much of her time has been to the care and development of clinical treatments for patients with Myasthenia Gravis. In her role as the lead for the Myasthenia clinic, the Neuromuscular Division has participated in numerous clinical trials over the past 30 years including the seminal trials which have led to the approval of 3 medications for the treatment of MG. She continues to be involved in the development of new and innovative treatments for MG.



Sharon Rastatter, Director

Sharon Rastatter is a Central Ohio native and graduate of The Ohio State University, where she earned a B.A. in Journalism. She worked as a reporter for daily newspapers in Ohio and West Virginia before transitioning to software marketing. She has since served in several volunteer roles, including civic leadership roles with the city of Columbus. She has served as Co-Facilitator for the Central Ohio Myasthenia Gravis Support Group since 2017. In her spare time, she enjoys gardening (she started a native pollinator patch last year), listening to music, traveling, and playing with her family's two dogs. As someone living with MG, she looks forward to helping others learn more about MG, how to live their best lives with this autoimmune disease, and to offer additional patient support through MG Ohio.

Clinical Trials now Recruiting—Click on links below for more information:

MG Momena/ Jansenn with Nipocalimab <https://clinicaltrials.gov/ct2/show/NCT04951622> now recruiting at Cleveland Clinic, The Ohio State University, and University of Cincinnati

Vielo Bio MINT trial with inebilizumab

<https://clinicaltrials.gov/ct2/show/NCT04524273> now recruiting at Cincinnati, Ohio, 45267 & Columbus, Ohio, 43210

MG Ohio Website:

Visit us at www.mgohio.org

Have questions or comments? Send in your MG related questions to our **Ask the MG Expert** column

Email at mgohio@mgohio.org

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.goodrx.com)

<http://www.themedicineprogram.com/>

<http://www.togetherrxaccess.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 2023 MEETINGS:

In Person—January 14 Mayerson JCC 1:00-3:00

8485 Ridge Road, Cincinnati, OH 45236

In Person—January 14 Middleburg Hts. Library 1:00-3:00

15700 E. Bagley Rd. Middleburg Hts., OH 44130

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)

<https://zoom.us/meeting/register/tJ0qduytrT4jH9KSiOgggP8G0xHTCjcYC6b1>