

Community in Ohio & Beyond

MG OHIO NEWSLETTER

December 2023

Volume 11 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 (leave a message)

You will find a wealth of information at the website:

MGOhio.org

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 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.



2nd and 4th Thursdays 3:00 pm until December 28, 2023

Register once below and get approved for all meetings.

https://zoom.us/meeting/register/tJlpciqpjIoHNCPaKAHyOFjGu5rbVOrJdlf

The above link is good for the following dates: Dec 14 & 28

Weekly Saturday night chats starting at 6:30 pm ET https://zoom.us/j/96504171582? pwd=ODFjbXZGZ1l2V2tJRTNHaFVlcGFRdz09

LAST CHANCE TO REGISTER FOR HOLIDAY PARTY!

See page 3 for important information!







Ask the MG Expert

Q. What are the best Holiday gifts for someone with MG?:

A. Some of the best gifts for people with muscle weakness are gifts that help conserve energy and make life easier. Here's some of our top picks:

- Jar opener with large grip handle or under counter mounted.
- Electric can opener.
- Smart home device such as Google or Alexa. These can now be paired with most any Bluetooth products including smart blinds, smart ovens, and other smart appliances.
- Smart plugs—can be paired with Google or Alexa device to turn on lights, play music, and more. There are several on the market that you can pair with any electronically controlled device.
- Ring Doorbell or other smart doorbell which allows you to answer the door remotely and to keep an eye on your front door.
- Smart thermostat that can be controlled through a smart device like Google or Alexa or with a smart phone.
- Small waterproof portable pill container with twist off lid. Small enough to fit conveniently in your pocket or on your key
- Home pill container that can hold between 1-4 weeks worth of medicine at a time. Allows you to save time sorting your daily pills.

Continued on pg.3

<u>Upcoming MG Ohio In-Person Support Group Meetings:</u>

MG Ohio Northeast Ohio In-Person Support Group Meetings:

December 9—2:00 pm Annual Holiday Party Romano's Macaroni Grill

25001 Country Club Blvd., North Olmsted, Ohio 44070

For more info, please contact Bobbi at 216-407-4975 or Rebecca at 216-218-0477 or mgohio@mgohio.org

January 13—1:00-3:00 pm Parma-Powers Library

6996 Powers Boulevard, Parma, Ohio 44129

<u>February 10—1:00-3:00 pm</u> Parma-Powers Library

6996 Powers Boulevard, Parma, Ohio 44129

<u>February 17—1:00-3:00 pm</u> Mayfield Library

500 SOM Center Rd., Mayfield Village, Ohio 44143

March 9—1:00-3:00 pm Parma-Powers Library

6996 Powers Boulevard, Parma, Ohio 44129

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

January Meeting—TBD For more information:

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

NOTE: The potluck scheduled for Saturday, Dec. 9 from 11:30-1:30 pm has been cancelled due to the death of our dear friend and fellow MG patient, Joannie Hammond. Please email centralohiomg@gmail.com for details and location of the January meeting.

MG Ohio Southwest Ohio In-Person Support Group Meetings:

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

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Ask the MG Expert

Continued from pg.1

- Smart watch, Fit Bit or other device that can: monitor your heart rate, set a pill timer, and track your steps.
- Cooling vest or cooling towels.
- Rolling stool for kitchen.

New Study—at home participation. If you have myasthenia gravis and have tested positive for the AChR antibody, you may be eligible to participate in a new study using a smart phone and application. The study lasts 12 months and pays \$500 at the end of the year. You use and evaluate the application and provide feedback about your experience monthly to the sponsor.

Interested? Contact Rebecca at mgohio.org for a study link to see if you qualify.

Annual Holiday / Christmas Party

Saturday, December 9, 2023 2:00 pm

Door Prizes! Romanos Macaroni Grill Door Prizes!

Food! FUN!! Food! FUN!!

North Olmsted, OH

Food! FUN!!

Bring a white elephant or other gift (\$5 or under) for gift exchange.



Menu cost—\$15/person

Caesar Fresh Greens Salad

Entrée Choices—(choose one)

Chicken Parmesan Penne Rustica Mushroom Ravioli

Mom's Meatballs & Spaghetti Fettuccine Alfredo w/ Chicken

(gluten free available too)

Desserts

New York Style Cheesecake Decadent Chocolate Cake

Last Chance!! R.S.V. P. by December 2nd

(we need to provide an accurate head count)

Email: mgohio@mgohio.org or call Bobbi at (216) 407-4975 or Rebecca at 216-218-0477

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

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 out-of-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: Enrollment has closed for 2023. Be sure and sign up in January for 2024



Peace on Earth. Goodwill towards Men.

Wishing you and your family a wonderful Holiday Season

MG Ohio

Need help paying for your meds? Check out the following 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/what-we-do/ -for patients living in Indiana, Illinois, and Wisconsin

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



UPCOMING JANUARY 2024 MEETINGS:

In Person—

January 13— 1:00-3:00 pm Northeast Ohio—Parma-Powers Library

6996 Powers Boulevard, Parma, Ohio 44129

<u>January 13—1:00-3:00 pm</u> Southwest Ohio—Mayerson JCC

8485 Ridge Road, Cincinnati, Ohio 45236.