

# MG OHIO NEWSLETTER

# September 2023

### Volume 11 Issue 9

Supporting the Myasthenia Community in Ohio & Beyond

# MG Ohio

ve Board		
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Dr. Ben Claytor		
Dr. Miriam Freimer		
Dr. Hani Kushlaf		
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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 (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.



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/tJlpciqpiloHNCPaKAHyOFjGu5rbVOrJdlf

The above link is good for the following dates: Sept 14 & 28 Oct 12 & 26 Nov 9 Dec 14 & 28 (No meeting on Thanksgiving)

Weekly Saturday night chats starting at 6:30 pm ET <u>https://zoom.us/j/96504171582?</u> pwd=ODFjbXZGZ1I2V2tJRTNHaFVlcGFRdz09



A very BIG thank you to all who attended the Regional Conference on August 26th and a special thanks to the speakers and sponsors who made it possible!



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

#### Ask the MG Expert

During the last session of the conference, Dr. Hani Kushlaf, Dr. Yuebing Li, and Dr. Robert Ruff answered questions that participants had submitted in advance. Here are some of the questions from the Regional Conference:

**Q.** Does being on Prednisone make one more susceptible to infection?

**A.** Yes. Any immune-suppressant drug will lower your body's ability to fight off infection making you more susceptible to viruses and bacterial infections. Vaccines are encouraged

**Q.** Does living in a rural community and being exposed to agri-chemicals make one more likely to come down with an autoimmune disease?

A. While there is no direct correlation between instances of MG and living in rural communities, there has been an uptick in the number of cases reported perhaps due to the processed foods we eat and the chemicals in those foods. Some patients have felt better by changing to an organic diet. This will not cure MG but following an anti-inflammatory organic diet has been shown to help some patients feel better.

**Q.** Does thymectomy help ocular patients?

**A.** A long dialog ensued about the merits of thymectomy in gMG, but Dr Kushlaf pointed out that unless there is evidence of a thymoma, having a thymectomy for ocular only MG could do more harm than good leaving the patient at risk for certain types of cancer.

**Q.** Are there any alternative medicine options that will treat myasthenia gravis?

A. No. We do not know of any alternative drugs, or vitamins, or supplements that will treat MG.

#### MG Ohio In-Person Support Group Meetings:

## MG Ohio Northeast Ohio In-Person Support Group Meetings:

September 9—1:00-3:00 pmParma-Powers Library Meeting Room C6996 Powers Blvd, Parma, Ohio 44129<br/>(Across from Parma Hospital)<br/>For more info, please contact Rebecca at 216-218-0477<br/>or mgohio@mgohio.org

#### MG Ohio Central Ohio In-Person & Hybrid WebEx Support Group Meeting:

#### Monday September 18-4:30 pm North Columbus

The Dempsey Family Education and Resource Center at the Ohio Health Neuroscience Center at Riverside Methodist Hospital 3535 Olentangy River Road, Columbus, Ohio 43214

NOTE: Parking is free (with vouchers we will provide at the meeting). Park in the "Red" parking garage.

We are hoping for this to be a hybrid meeting with attendees in-person and online using WebEx (an online meeting platform similar to Zoom. This is what the meeting space uses).

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:

<u>September 9 —1:00-3:00 pm</u>

Mayerson JCC

8485 Ridge Road, Cincinnati, Ohio 45236.

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





# Gathering Together Growing Stronger Conference Recap

Here are some pictures from the conference. Thank you to Ty Bryant, photographer!



Conference are now available on the MG Ohio website http://www.mgohio.org under the NEO Presentation tab. Videos of the event will be posted soon.

#### 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 mgohio@mgohio.org

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)



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

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> Resources/Resources-External-Assistance-Programs

U	PCOMING SEPTEMBER 2023 MEETINGS:	
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