



Supporting the Myasthenia
Community in Ohio & Beyond

MG OHIO NEWSLETTER

August 2023

Volume 11 Issue 8

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.



Thursday Bi-weekly
Zoom Meetings for August:

Aug 10, 2023 03:00 PM ET

[https://zoom.us/j/91053589626?
pwd=aW1cUtoaGdmLzRkZSsyUmVndIQ0QT09](https://zoom.us/j/91053589626?pwd=aW1cUtoaGdmLzRkZSsyUmVndIQ0QT09)

Aug 24, 2023 03:00 PM ET

[https://zoom.us/meeting/register/
tJUld2rrjMqG9yFFXgu59Wcm4wySNfVN7ic](https://zoom.us/meeting/register/tJUld2rrjMqG9yFFXgu59Wcm4wySNfVN7ic)

NOTE: We will be meeting via Zoom the 2nd and 4th Thursday of the month until further notice.

Weekly Saturday night chats starting at 6:30

pm ET [https://zoom.us/j/96504171582?
pwd=ODFjbXZGZ1I2V2tJRTNHafVlcGFRdz09](https://zoom.us/j/96504171582?pwd=ODFjbXZGZ1I2V2tJRTNHafVlcGFRdz09)

Argenx Announces—

The Food and Drug Administration (FDA) has approved a subcutaneous formulation of efgartigimod (Vyvgart; argenx)—officially known as efgartigimod alfa and hyaluronidase-qvfc—as a **treatment for adult patients with generalized myasthenia gravis (gMG) who are antiacetylcholine receptor (AChR) antibody positive**



Ask the MG Expert

Q. With Covid restrictions no longer an issue, is it safe for someone with MG to travel? Any travel tips?

A. The answer is a little complicated. With some preplanning, you can enjoy your summer trips:

Use Caution—If you are currently on immunosuppressants such as Prednisone, Imuran, Cellcept, or one of the monoclonal antibodies like Rituximab, Vvgart, or Soliris, you should continue to protect yourself by avoiding crowds, wearing a mask, and practicing social distancing when you go out.

Public Transportation—Masks are not required when you fly, take a train, or ride on a bus. However, when you are traveling using one of these methods, you may want to continue to wear one. Try and distance yourself from others while using these forms of transport.

Driving—If you decide to drive yourself, take frequent breaks about every 2-3 hours. These breaks give your eyes a rest and allow you to stretch your legs.

Plan Ahead—Be sure to pack extra medication in case you need it. Other essential items may include hand sanitizer, extra masks, and sanitizing spray.

Research—Know which hospitals are closest to your destination and if they accept your insurance. Consider buying medical travel insurance.

Conserve Energy—Don't be afraid to use the free transport at the airport or a scooter at a store. Build in some rest periods in your itinerary. Even doing fun things like sightseeing can be physically taxing. Be sure and plan some down time.

Relax and enjoy your summer.

MG Ohio

August 25, 2023

Ohio In-Person Support Group Meetings:

Meet & Greet 5:00 pm—7:00 pm

Impulse Lounge—Holiday Inn Express

6001 Rockside Rd., Independence, OH 44131

August 26, 2023

Regional Conference 9:30 am—4:45 pm

Sari-Feldman Auditorium

Parma-Snow Library

2121 Snow Rd., Parma, OH 44134

Famous People with MG

Here is a list of famous people who were diagnosed with MG:

Amitabh Bacchan (actor)

Aristotle Onassis (millionaire)

Connie Haines (singer)

David Niven (actor)

Doris Lilly (author)

Sleepy (Walt Disney character)

Heine Toerien (radio personality)

Henrique da Costa Mecking (chess champion)

Wilma Mankiller (Cherokee Chief)

Hjalmar Gullberg (poet laureate)

John Spencer (snooker player)

Lamar Lundy (football player)

Sir Lawrence Olivier (actor)

Leland Brewsaugh (artist)

Leonas Leitas (poet)

Linda Darnell (actress)

Christopher Robin Milne (inspiration for his father's Winnie the Pooh books)



Lucianno Pavorotti's daughter

Phil Silvers (actor)

Suzanne Rodgers (actress)

Roger Smith (Ann Margaret's Husband)

Roque Carbajo Rayna (Mexican Songwright)

Sir Peter Wright (ballet director)

Weeb Eubank (football coach)

Rondell Jones (football player)

James Carter (2005 Olympic athlete)

Stephen Garrett (Hip Hop Artist)



Final Opportunity!

Gathering Together Growing Stronger MG OHIO Regional Conference

Saturday, August 26, 2023



Sari-Feldman Auditorium
Cuyahoga County Public Library
Parma-Snow Branch
2121 Snow Road Parma, Ohio 44134

- **Have you ever wanted to explain to someone what MG feels like?** Invite them to the Regional Conference where they can walk through the **MG Experience** and find out first hand what it feels like to have a neuromuscular disease.
- **Do you have a question that you'd love to ask a researcher or a doctor but seem to forget when you're at the doctor's office?** We'll have a Q & A session where researchers and other MG medical professionals will answer your questions about any MG topic.
- **Want to learn if your symptoms are age or MG related?** Dr. Yuebing Li will be presenting about MG and Aging and what it means for you.
- **Are you new to your myasthenia diagnosis and want to understand more about it?** Dr. Ben Claytor will be presenting about MG 101—everything you need to know and then some!
- **Want to know how to pick a physical therapist who knows how to treat MG?** Dr. Kylie Sramek and Dr. Christine Morgan will present PT and the MG patient.
- **Need to know how to get insurance to pay for your meds?** Donna D'Amico from KAZ Insurance will be here to answer your questions.
- **Worried about swallowing and chewing with MG?** Dr. Amanda Cordrick will present with helpful hints and tips for safe eating.
- **All this and more—much more:** Staying Positive with MG with Dr. Suzanne Ruff, Preparing for Emergencies with Rebecca Molitoris, Learn about the Latest Treatments straight from the researchers.
- Free Continental Breakfast and Free Lunch—Dietary Restrictions heeded—list them during registration

To register click or go to :<https://mgohio.org/regional-conference-1>

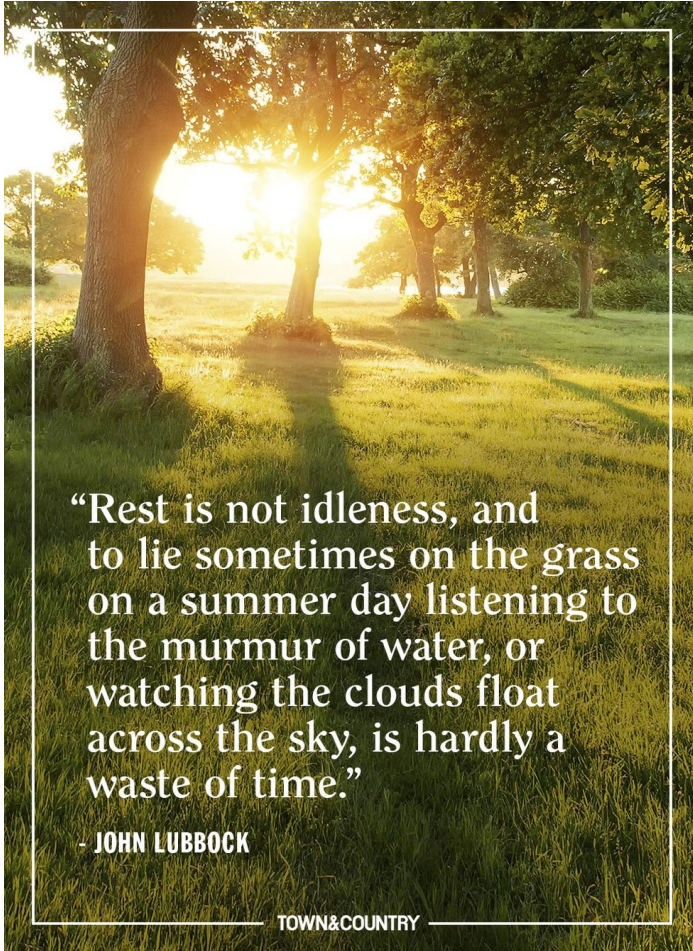
August 25th—5:00 pm—7:00 pm (the evening before the conference) Join us for a Meet & Greet event and meet fellow MG patients from across Ohio and beyond at the Impulse Lounge located at the Holiday Inn Express-S 6001 Rockside Rd., Independence, OH 44131 Appetizers provided, BYOD (buy your own drinks) Please RSVP for this event mgohio@mgohio.org or call 216-218-0477 and leave a message.

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



“Rest is not idleness, and to lie sometimes on the grass on a summer day listening to the murmur of water, or watching the clouds float across the sky, is hardly a waste of time.”

- JOHN LUBBOCK

TOWN&COUNTRY

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.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/> -for patients living in Indiana, Illinois, and Wisconsin

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

UPCOMING AUGUST 2023 MEETINGS:

In Person—

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Pre-Conference Meet & Greet Impulse Lounge Holiday Inn-S

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RSVP mgohio@mgohio.org

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Register online at <https://mgohio.org/regional-conference-1>