

MG OHIO NEWS

JUNE 2025

Volume 13 Issue 6

JUNE 21-22, 2025

Southwest MG Ohio will be holding a Regional Walk and Patient Education Conference.

More information on page 3.

MG Ohio

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Dr. Suzanne Ruff President

Dr. Robert Ruff Vice-President

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If we can assist you with medical care referrals, resources, durable

about MG, contact us at 216-218-0477 (leave a message)

You will find a wealth of information at the website:

medical equipment, or information

MGOhio.org

To Donate to MG Ohio, scan

here





MG Ohio Zoom Support Group Meetings

1st and 4th Thursdays

When: June 5, 2025 03:00 PM ET CORRECTED DATE

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

tJcrcO6urTgiGtK3I9I_RXk1QDozODwbXpFs

Dial in: 309-205-3325

Meeting ID: 936 7763 3806 Passcode 586068

When: June 26, 2025 07:00 PM ET CORRECTED DATE

https://zoom.us/meeting/register/ tJUkceCtqj0jHNaMrXHj4XLLH1K4BzKYld U

DOKCECTOJOJI INATVITATIJE

Dial in: 301-715-8592

Meeting ID: 919 6954 6962 Passcode 799908

Saturday night chats weekly at 6:30 pm (ET)

https://zoom.us/meeting/register/ tJOufu6grDsjG9PS1AQG9vWTYeTnNJAZtumm

Dial in: 646-931-3860

Meeting ID: 993 9782 0917 Passcode 730070

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



Celebrate! June Events

June 3: World Bicycle Day.

June 5: World Environment Day.

June 6: National Donut Day.

June 8: National Best Friends Day

June 14: World Blood Donor Day.

June 15: Father's Day.

June 19: Juneteenth.

June 21: International Yoga Day.

JUNE MG AWARENESS MONTH FEATURE ARTICLE

Evolution of the Treatment of Myasthenia Gravis

By Robert L. Ruff, MD, PhD

In observance of June Awareness, I would like to focus on how treatment of Myasthenia gravis (MG) has evolved. The study of MG is in a period where new methodologies for treatment are emerging at an amazing rate. This is an exciting and hopeful time for people with MG and MG-related conditions, their caregivers and loved ones. I would like to talk about past events that increased our understanding of MG and laid the foundation for the emergence of new ways of addressing MG. There are more important people and events than can be discussed in this short, focused article. I will focus on people I knew of or worked with.

Myasthenia Gravis is Treatable

MG has been recognized for several centuries but for most of that time there were no treatments available. The first person to demonstrate a treatment for MG was Dr. Mary Broadfoot Walker (1888 – 1974), a Scottish physician who practiced in Great Britain. In 1934 she noted similarities between MG and curare poisoning. She successfully treated a continued on page 3

2025 MG Ohio Meetings:

MG Ohio Northeast Ohio (NEO) In-Person Support Group Meetings:

June 14, 2025 - 1:00-3:00 pm Metro Health November Campus

7800 Pearl Rd. Middleburg Hts., OH 44130

In celebration of June MG Awareness Month, at our June 14th regular meeting, we will have our Annual Ice Cream Social.

Ice cream will be provided and all are asked to bring a topping to share.

This will be a hybrid meeting broadcast over **Zoom**. Please use the link or call to join:

https://zoom.us/j/95377894109?pwd=NoN8jb0pTRZkrtXEdZkuxfmaja2vdd.1

Dial in: 305-224-1968 Meeting ID: 953 7789 4109 Passcode: 980913

NOTE: This year regular NEO meetings will be BYOW (bring your own water) Coffee will be available. Donations of baked goods always welcome.

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

<u>To Be Determined - 4:30 pm</u> The Dempsey Family Education and Resource Center

at OhioHealth Neuroscience Center Riverside Methodist Hospital

3535 Olentangy River Road, Columbus, Ohio 43214

Parking is free (with vouchers we will provide at the meeting). Park in the

"Red" parking garage.

We plan for this to be a hybrid meeting for in-person support group members and their caregivers/families as well as online via WebEx for those unable to attend in-person. (WebEx is an online meeting platform similar to Zoom) www.ohiohealth.webex.com Please contact Sharon or Cathy at centralohiomg@gmail.com or by phone at 614-334-1140 for the Webex meeting code.

MG Ohio Southwest Ohio In-Person Support Group Meetings:

<u>June 14, 2025 - 1:00-3:00 pm</u> Mayerson JCC

8485 Ridge Road, Cincinnati, Ohio 45236. Lisa Cruz from Argenx will be joining us

(Take the Ridge Road Exit from the Ronald Regan Highway)

RSVP to Erica at amannerica@gmail.com.

This will be a hybrid meeting broadcast over Zoom. Please use the link or call to join:

https://zoom.us/j/97131113585?pwd=r52SrnweJG59pfVbfKgyNCrwelzgZh.1

Meeting ID: 971 3111 3585 Passcode: 974695

June 21-22, 2025 Southwest MG Ohio will be holding a Regional Walk and Patient Education

Conference. See Page 3









WALK A MILE IN OUR SHOES FASTGATE MALL CHECK IN @ 9:30 AM **WALK: 10 AM - 12 PM**

REGISTER NOW! THESE EVENTS ARE FREE!!

www.mgohio.org/southwest-events

CONFERENCE LOCATION: HOLIDAY INN, EASTCATE 4501 EASTCATE BLVD. CINCINNATI, OH 45245

EVENT SCHEDULE AND MORE IS LOCATED ON OUR WEBPAGE! ROOMS ARE AVAILABLE AT HOLIDAY INN FAIRFIELD INN & SUITES RIGHT NEXT DOOR IS GIVING A 15% OF DISCOUNT - USE CODE "KFJ"

THANKS TO OUR SPONSORS

SOUTHWEST MG OHIO PATIENT EDUCATION CONFERENCE JUNE 21-22, 2025

GUEST SPEAKERS



LIZ PLOWMAN, PT, DPT, LMT PHYSICAL THERAPIST **AUTHOR OF** SOME SPOONS ARE WORTH SPENDING TOPIC:

MG & PHYSIO THERAPY



HANI KUSHLAF, MD NEUROLOGY UC HEALTH DIRECTOR OF THE NEUROMUSCULAR MEDICINE, NEUROMUSCUI AR REASEARCH. NEUROMUSCULAR DISORDERS DIVISION

THE BASICS OF MG (MG IOI)



VICKIE PETZ KASPER, MD PODCAST: LIFESTYLE MEDICINE LIFEALTHY LOOKS CREAT ON YOUR TOPIC: THE UNEXPECTED CIFTS OF MC



JUNAID MALIK, MD CRITICAL CARE, PULMONARY, AND SLEEP MEDICINE CERTIFIED DAYTON RESPIRATORY CENTER TOPIC: HOW MG AFFECTS THE DIAPHRAGM AND

BEST SLEEPING MACHINES FOR MC PATIENTS



CHANDLER MURRAY, OTD, OTR/L PELVIC HEALTH OCCUPATIONAL THERAPIST TRI-HEALTH ARROW SPRINGS TOPIC: HOW PELVIC FLOOR THERAPY CAN ASSIST THOSE WITH MC



JON P. WILLIAMS, DO, PH. D. MULTIPLE SCLEROSIS & AUTOIMMUNE **NEUROLOGY** PREMIER HEALTH, THE CLINICAL NEUROSCIENCE INSTITUTE TOPIC: IMMUNOLOGY OF MG



REBECCA MOLITORIS FOUNDER OF MG OHIO PRESIDENT EMERITUS OF MG OHIO **MG PATIENT** TOPIC: SUPPORTING ONE ANOTHER

JUNE 21-22, 2025 Southwest MG Ohio will be holding a Regional Walk and Patient Education Conference. (see flyer above)

The agenda is on the Southwest page on the MG Ohio Website. Registration is NOW OPEN! To register go to: www.mgohio.org/southwest-events

SAVE THE DATES

JULY 20, 2025 **

Northeast MG Ohio is having a Therapy Summit at the Cleveland Zoo - see page 4

SEPTEMBER 7, 2025 **

Northeast MG Ohio will be holding a Regional Walk at the Chalet in the Cleveland Metroparks Strongsville.

** There will be Basket Raffles at both Northeast MG Ohio events. The Event Committee is asking for donations. If you, your family members, or friends have a business, or personally can donate, we are looking for the following things. Gift cards, tickets to events, or other items to be put into the baskets. We appreciate it very much. You can reach Gina at 440-225-2069 or email at goradini@dettoregroup.com. Thank You.

person with MG using a drug similar to pyridostigmine (Mestinon). Dr. Walker showed that MG was a disorder in the neuromuscular junction (NMJ, the connection point between nerve and muscle fibers).

MG is an autoimmune disorder

Serendipity led to early advances in MG. James Patrick and Jon Lindstrom wanted to isolate the acetylcholine receptor (AChR) by making antibodies against the AChR. In their work, rabbits developed muscle weakness that resembled MG. Treating the rabbits with a Mestinon-like agent temporarily reversed the weakness. Doug Fambrough, Dan Drachman and Luke Kao showed that the NMJs of people with MG were abnormal in structure and had a deficiency of AChR. Andrew Engel demonstrated that complement was deposited at the NMJ in MG. Dr. Vanda Lennon showed, in animal models of MG, that complement activation was critical for the development of NMJ damage associated with MG. Research showed that several types of lymphocytes contributed to both MG development and progression, which led to many types of immune-based treatments for MG. AChRs were linked to several other important proteins, including MuSK, LRP4, and agrin. Antibodies against newly-recognized NMJ proteins produced variants of MG and led to new treatment strategies.

Greater understanding of the immune system led to new ways to treat MG. Using manufactured antibodies that target different parts of the immune system enable clinicians to tailor more effective treatment for each MG patient.

The past ten years has seen a veritable explosion of research in MG. It is truly an amazing time of frequent breakthroughs and new therapies. More and more people with MG can live fuller lives with more treatment choices and more hope for the future.

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

For all the latest local MG news, upcoming events, and newsletters

Is there a topic or subject that you would like to see covered in the monthly MG News?

Email us at news@mgohio.org and let us know!

Did you know that at www.mgohio.org you can view educational videos, download newsletters and brochures, and get all the latest information about our inperson and online meetings?

Check out our MG Alliance Partners Page https:// mgohio.org/mg-alliance for information about other MG groups in different parts of the country that hold online meetings. Just click on their logo and you will be taken to their site. You are always welcome to attend any online meeting wherever you may live.

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



SAVE THE DATE

Northeast MG Ohio Sunday, July 20 - 10am - 2pm Therapy Summit at the Cleveland Zoo

RSVP by July 1 to events@mgohio.org or call Gina at 440-255-2069

- ▶ Spend the day at the zoo with our MG Ohio community!
- ▶ We have rented the Rising Waters pavilion for a special day of connection and education around physical and speech therapy.
- ► Zoo admission & lunch complimentary for MG patients & caregivers. Family also welcome & can reimburse MG Ohio for admission.
- ▶ Our day will include life hacks, best practices, group exercises, and the opportunity to visit individually with Dr. Kylie Sramek, Amanda Cordrick, and members of the Synergy Physical Therapy & Wellness team. (plus time to explore the zoo)
- ► Visit with our sponsors. (Alexion, Argenx, possibly UCB)
- ► Fantastic Gift Basket Raffle.

Note that no regular meeting will be held in July due to our gathering at the zoo.

DID YOU KNOW?

- You can find the latest clinical trials for myasthenia gravis by going to: www.clinicaltrials.gov
- MG Ohio has formed an alliance with other independent MG Support Organizations across the country. Go to https://mgohio.org/mg-alliance to find such virtual groups as Black with MG, Muscle Makers (for crafters), Young Adults, and LGBTQ+
- MG Ohio offers one-on-one mentoring in our MG Friends program. Contact us at mgohio@mgohio.org to participate.

IN PERSON - JUNE 2025 MEETINGS:

Northeast Ohio

June 14 - 1:00-3:00 pm **Metro Health November Campus**

7800 Pearl Rd. Middleburg Hts. OH 44130

Southwest Ohio

June 14 - 1:00-3:00 pm **Mayerson JCC**

8485 Ridge Road, Cincinnati, Ohio 45236

Central Ohio

To Be Determined The Dempsey Family Education and Resource Center

3535 Olentangy River Road, Columbus, Ohio 43214