



NEWSLETTER

SEPTEMBER 2022

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September's Thursday

Afternoon ZOOM Meetings

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

<https://zoom.us/meeting/register/tJEqfuusrzwoH906VqHOYf4Agv81iRM1pTmF>

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

<https://zoom.us/meeting/register/tJ0rde6orzMoHNa7qmXq1sJEaiTddX-9TSbT>

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

<https://zoom.us/meeting/register/tJApce-orT8oHtLZhRZU6r9DzQIkKfyLq9cM>

When: Sep 22, 2022 03:00 PM Eastern Time

https://zoom.us/meeting/register/tJcofuqgrD4qHNNyfw1Uf_sj1-L2XpyETjnQW

After registering, you will receive a confirmation email containing information about joining the meeting. **See page 2 for special meeting info**



Next In-Person Meeting—

September 17, 2022 1– 3 pm

Parma-Powers Branch Room C/D

Cuyahoga County Public Library

6996 Powers Blvd. Parma, OH 44129

Special Speaker—Dr. Suzanne Ruff will be speaking on “Stress, Anxiety, or Worry? There is a Difference.”

This is information we can all use right now!

Hope to see you there!

Light refreshments will be provided.



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

MG Ohio

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Bobbi Navarra	Vice-President
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Dr. Suzanne Ruff	Secretary
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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.

Ask the MG Expert

Q. I choke a lot when I am weak. Do you have any tips to help when this is happening?

A. There are many things you can do to prevent choking and to help you swallow when choking happens. Below are the best tips we have found:

- Timing is everything. If you are on Mestinon be sure and time your meals for when you feel your strongest. Mestinon (pyridostigmine bromide) usually takes about 20-30 minutes to take effect.
- If you are feeling weak and chewing is a problem, stick to soft foods like casseroles or mashed potatoes. Meals can be blended for an easier consistency.
- Take small sips of cold water or other cold drinks in between bites.
- If you are having a hard time “getting it down” or food feels like it is stuck in your esophagus, sometimes drinking a warm carbonated beverage can help get it down.
- If you are starting to choke—STOP—don’t panic. Bend your chin to your chest. Take small sips of water to help you swallow. (you may have to spit out what you have in your mouth)
- If food is stuck and you have trouble breathing, Do NOT RUN. Motion to someone that you are having trouble with choking.
- If you are alone when you are choking, do the [abdominal thrust](#) on yourself. More info at www.healthline.com/health/heimlich-maneuver

MG Ohio

Northeast Ohio In Person Events and Support Group Meetings:

September 17— 1-3 pm

Meeting @ Parma Powers Library

Speaker—Dr. Suzanne Ruff

6996 Powers Blvd

“Stress, Anxiety, or Worry? There is a difference”

October 8—1:30—3:30 pm

Meeting @ Parma-Snow Library

OSHIIP

2121 Snow Rd

How to choose the best insurance plan for you

October 29—2-4 pm

Trunk or Treat Hybrid Walk Event

Come Celebrate our Cleveland to Cincinnati Walk

Pipefitters Hall 6305 Halle Dr.

November 2 or 3, 2022 TBD

Dinner with Crystal Brown, PEM

December 3 or 10, 2022 TBD

Annual Christmas Party Macaroni Grill

Special Meeting MG 101: with Dr. Yuebing Li

When: Sep 29, 2022 06:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJMud-6gpz4pHtQiSSkuoxp108SCEHi002D1>



Next Parents of MG KIDS Meeting—September 11, 2022

When: Sep 11, 2022 02:00 PM Eastern Time (US and Canada)

<https://zoom.us/meeting/register/tJcucOGupj0sGtJiW6BnxOf-iexC0esqPAMW>

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



Important Things to know about our Support Group Meetings

Our groups are very welcoming and allow for the sharing of helpful hints and tricks for living with MG. However, it should be said that your own doctor is the one who can best manage your care and treatment. Please check any changes in treatments or medications with your physician first.

SATURDAY ZOOM CHATS—Informal Zoom get together—no agenda— just a time to visit. Register once for a Saturday Chat and use the same link to sign in through December 31, 2022.

When: Saturdays Aug 6 - December 31, 2022 07:30 PM Eastern Time (US and Canada)

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



Meet MG Ohio's Board of Directors—Every month we'll be highlighting a few of your Directors. More information can be found on at mgohio.org Here are the first two Directors, a neurologist and a caregiver—



My name is **Ben Claytor** and I completed training in neurology and neuromuscular medicine at the University of Michigan. I have been practicing neuromuscular medicine at the Cleveland Clinic since 2019. Aside from diagnosing and caring for patients with neuromuscular diseases, I have an interest in physician education and have been named the resident educator of the year twice since becoming a staff member at the Cleveland Clinic. Outside of medicine I enjoy spending time with my family, reading, growing vegetables and foraging for wild mushrooms.



Laura Lodge is a small business owner, with ventures in commercial real estate, property management, and various aspects of the craft beer industry. Experience in event management, hospitality, food & beverage, accounting, and strategic business planning all play a role in her consulting business, Customized Craft Beer Programs. A published author of *Distribution Insight for the Craft Brewer*, Laura currently splits her time between her hometown of Columbia Station, Ohio and residence in Vail, Colorado.

Activities of Daily Life—Why you should be tracking yours. Tracking your ability to complete your daily activities can be very helpful to both you and your neurologist. Here is a link where you can download the tracking tool for yourself:

www.knowyourmgscore.com I'm also sending it by email with the newsletter. If you'd like a copy [contact me](#).

Come Walk with Us From Cleveland to Cincinnati

That's right you DID hear or rather read that correctly. Starting October 1, 2022 we will be lacing up our virtual walking shoes and trekking from Cleveland to Cincinnati. And the best news is that you don't necessarily have to walk to help us get there.

We are excited to share with you an app made just for MG Ohio that will make our walk fun and educational. Every movement or step counts. So if you have a FITBIT, smart phone, or iwatch or other movement tracking device, or if you keep track of your steps on a stationary bike or even just a walk through your house, you can join in on the fun. Watch your email box for more information about how to download and participate. All of our miles will count together so we will help each other get there.

If you don't have a smart device, no problem. On October 29th we will meet at the parking lot of the Pipefitters Local 120 Hall and walk the last few steps together. There we will celebrate with a trunk or treat event. Costumes optional. Friends and family highly encouraged!

What does this cost you ask? All this fun for only \$10 for the app. \$3.50 of it is tax deductible. The trunk or treat event is free for everyone. So join us in celebrating our new united MG Ohio.

Introducing New Evening Zooms with a Doctor—

Starting in September we will be hosting an evening Zoom on various MG topics led by volunteer doctors.

Our first presentation will be **MG 101 by Dr. Yuebing Li**. Come find out what exactly IS this thing called MG, and how it is treated. Presentation starts at 6 pm. Click on the link below to register:

<https://zoom.us/meeting/register/tJMud-6gpz4pHtQiSSkuoxp108SCEHi002D1>

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>



Meet the New LOGO

This LOGO was created by making a cyanotype of snowflake shapes and the outline of Ohio.

The teal color stands for myasthenia gravis which is the color of the MG ribbon. MG is known as

the snowflake disease because each person's MG experience is unique. The snowflakes are extending out beyond the boundary to indicate that MG Ohio helps those outside of its borders.



"Happily we bask in this warm September sun, which illuminates all creatures..." — [Henry David Thoreau](#)

UPCOMING September 2022 MEETINGS:

Parents of MGKIDS September 11 2:00 pm via Zoom (see page 2)

Adult MG Patients & Friends—Saturday, September 17th 1-3 pm (see page 1)

Zoom Meetings—Thursdays 3:00 pm via Zoom (see page 1)

Special Evening Zoom—Thursday September 29th 6:00 pm with Dr. Li (see page 2)

OPEN CHAT every Saturday night at 7:30 pm via Zoom (see page 2)