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MDA ADDRESS:

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Care & Clinical Services Specialist, Muscular Dystrophy Association

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Tel 440.892.3367 ext.1643

We are here for you and your family to provide help and hope for those living with Myasthenia Gravis

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: Myasthenia.org

Easy way to contribute to MGFA:

If you shop at Amazon.com, go to smile.amazon.com next time you shop. Choose MGFA as your charity. It is that simple. Then every time you shop, do it through smile.amazon.com and a portion of your sales will be contributed to the National MGFA.

WESTSIDE—

Our next *regular* meeting will be **October 12th** at the **MetroHealth November Meeting Room 7800 Pearl Rd., Middleburg Hts., 44130 from 1:00-3:00 pm**

EASTSIDE—

Our next *regular* meeting will be **September 21st** at the **Mayfield Library 500 SOM Center Road, Mayfield Village 44143 from 12:30-2:30 pm**

LORAIN COUNTY—

Our next meeting will be held on **Thursday, September 19th** at the **Sugarcreek Restaurant located at 5196 Detroit Rd, Sheffield, OH 44035** in the Sheffield Plaza from **1:00—3:00 pm** We will be ordering off the menu and everyone is responsible for their own check. **Please RSVP by September 12th to 216-218-0477 (leave message).**

IMPORTANT CHANGES TO MEDICARE INSURANCE FOR 2020!!!

Due to significant changes in the Medicare coverage for 2020, we will dedicate the next three regular meetings to learn about these changes and what they will mean to us. We will be getting the most up-to-date information from the **Ohio Senior Health Insurance Information Program (OSHIIP)** experts. This information is free! Come join us for one of the following meetings:

Lorain County—September 19—Sugarcreek Restaurant 1-3 pm

East Side—September 21—Mayfield Library 12:30-2:30 pm

West Side—October 12—MetroHealth 7800 Pearl Rd 1-3 pm

(see above for complete addresses)

Ask the MG Expert—

Question —What is considered a high AChR blood test and are there any other tests that can diagnose MG?

Answer —A positive AChR (acetylcholine receptor antibody) titer is considered anything ≥ 0.002 nmol/L*

Other blood tests to diagnose MG include:

MuSK—(muscle-specific kinase) antibodies

LPR4—Sometimes, antibodies for other proteins such as agrin or LRP4 antibodies are present, signaling that these autoantibodies may be biomarkers of MG

Approximately 10% of people with MG will test negative for any antibodies but still have active MG.

Other tests to diagnose MG include:

Ice Pack tests—Ice Pack tests are examinations performed by specialists to evaluate strength and recovery responses that could be consistent with an MG diagnosis.

Electromyography (EMG)—Repetitive nerve stimulations (RNS) applying electrical impulses are often used to gauge muscle response.

Single-fiber electromyography (SFEMG)—Detects neuromuscular transmission defects by recording action potentials from individual muscle fibers.

* *Clinical Utility of Acetylcholine Receptor Antibody Testing in Ocular Myasthenia Gravis*; Crandall E, Peeler, MD et al *JAMA Neuro*. 2015 Oct; 72(10): 1170–1174.



Don't Forget about the MGFA Walk! Register NOW at mgwalk.org!!

2019 MG Meetings and Events

Westside Meetings

Meets every 2nd Saturday except September, November, and December at **Metro-Health November Meeting Room 7800 Pearl Rd., Middleburg Hts., 44130 (unless noted)**

September 14 9 am **MGFA WALK** @ Chalet Mill Stream Run Metroparks, Strongsville, OH

September 29 10 am **MDA WALK** The Lodge at Allardale (Medina)

October 5 **Annual Clam Bake** Local 120 Pipefitters Hall located at 6305 Halle Dr, Cleveland, OH 44125 (see flyer)

October 12* **OSHIIP Speaker Jim Aust** Meeting 1:00—3:00 pm MetroHealth

December 7 **Annual Christmas Party**—combined for all groups

What to expect: Regular meetings are open to all

Attendance ranges from 8 to 30 or more.

All information shared is confidential.

*Speakers will present information at meetings marked with *

Speakers *usually* present during the second half of the meetings allowing the group to introduce themselves to new patients or catch up with old friends.

Light refreshments are served at the meetings which don't meet at restaurants.

Feel free (but not obligated) to bring a snack to share.

MEETING NOTES: The **Lorain County Meeting** was held on **August 15th** and attended by 14 people including our presenters from Argenx. The speaker gave an overview of MG and details about the new Argenx study now in phase 3 recruitment. (Note Argenx will be speaking again at the east side meeting in November)

The **August 10th Westside meeting** was attended by 27 people. Dr. Rust from Alexion presented about the latest drug Soliris.

We hope to see YOU soon at a meeting near you !

Eastside Meetings

Meets every other Month on the 3rd Saturday at **various places (see below)**

September 14 9 am **MGFA WALK** @ Chalet Mill Stream Run Metroparks, Strongsville, OH

September 21* **OSHIIP Speaker Jim Aust** Meeting 12:30-2:30 Mayfield Library 500 SOM Center Rd. Mayfield Village 44143

September 29 10 am **MDA WALK** The Lodge at Allardale (Medina)

October 5 **Annual Clam Bake** Local 120 Pipefitters Hall located at 6305 Halle Dr, Cleveland, OH 44125 (see flyer)

November 16* **Speaker Argenx** Meeting 12:30—2:30 Mayfield Library 500 SOM Center Rd. Mayfield Village 44143

December 7 **Annual Christmas Party**—combined for all groups

Lorain County Meetings

Meets every 3rd Thursday at **Sugarcreek Restaurant 5196 Detroit Rd, Sheffield, OH 44035 (in the Sheffield Plaza)**

September 19th* **Speaker from OSHIIP** Meeting 1:00-3:00 pm

October 17th Meeting 1:00-3:00 pm

November 21st Meeting 1:00-3:00 pm

December 7 **Annual Christmas Party**—combined for all groups

We order off the menu and everyone is responsible for their own check.

Of course those living in Lorain county are invited to attend the walks and clambake too! (see above)





MGFA Ohio Walk - September 14, 2019 Registration Opens at 9 am

Mill Stream Run Reservation Valley Dr., Strongsville—Chalet Area

Whether you can actually walk or not - it doesn't matter. You can choose to stay at the Chalet picnic area while our supporters walk for us. Stay after the walk for the family pot-luck picnic. Fun for everyone! Temporary Tattoos, Photo Booth and more! [Click here](#) to register or go to www.mgwalk.org

The **MG Experience** will be making an appearance at this event! Bring your friends and family too!!

Check List for the MGFA Walk:

1. Dress appropriately—We walk rain or shine There is covered shelter for the picnic and registration areas
2. Bring your collected donations—please bring a check if possible made out to MGFA Walk. Can't afford to donate this year? No worries come for the fun and fellowship
3. Pack a picnic—bring enough protein for your family and a dish to share. We will have beverages, fruit and snack items
4. Bring your friends and family too—all are welcome!
5. For those not walking, we will form a welcome line with noise makers to welcome our supporters back.



MDA Muscle Walk for the Greater Cleveland Area

Event Date: **09/29/2019**

Event Time: 10:00 am

Event Location: [The Lodge at Allardale](#) (Medina)

Register NOW by clicking [here](#) or go to <https://www.mda.org/muscle-walk> to find the Greater Cleveland Area walk.

2019 MDA Myasthenia Gravis Symposium

Saturday, November 2, 2019

Registration: 8:30 AM

Event: 9:15am-5:00pm (lunch included)

There will be a social gathering the evening before on Friday, November 1st, from 6:30 - 8:00pm.

Event Location:

Millennium Hotel Durham

**2800 Campus Walk Avenue
Durham, NC 27705**

There is no cost to attend the event, however, registration is required. See <https://www.mda.org/care/mda-engage/disease-symposia/mg-symposium-2019> for more information



**HELP
WANTED!**

Dear Fellow MG'r, recently a milestone passed for me, one I hardly acknowledged. It has been six years since I took over as facilitator of the Greater Northeast Ohio Support Groups due to the passing of our beloved Gloria.

I think she would be proud of the growth we've experienced. I know Sandra, our well loved co-founder who along with Marianne started this group 37 years ago was proud of what we've become. She told me so at the last event I saw her, the MDA walk of 2013. Oh what growth we've had since then. We have more than tripled the amount of people on our roster going from 60 to our current 196. We've also expanded our groups from just 1 to 3 and still growing.

This was never meant to be a one-man show. I along with you, am afflicted with the symptoms of MG. It is getting increasingly harder to do as much as I want to do. So I'm asking for a little help. I could use help in the areas listed below. If you think this is something you could do, please email me at clevelandmgroup@gmail.com or call me at 216-218-0477 and leave a message. There is no monetary reward, but the satisfaction of helping your fellow MG'r is priceless. Thanks so much for considering this!

Help Wanted:

Article Submitter—research local papers in the Northeast Ohio area and submit articles (which I will give you) to their health columns or calendars

Media Liaison—Help get the word out on social media, twitter, Facebook, Instagram , etc. and contact the local news media with PSA's and articles (which I will give you) about our local MG events

Phone Liaison—Help call fellow MG'rs who may not be coming to meetings to check and see if things are ok and if they need our help. This could use more than just one person.

Event Coordinator—To help plan events such as the Annual Christmas Party, Benefit Clambake, and Ice Cream Social as well as special outings during the year.

MG Experience Volunteers—To go to local events and schools and help at the MG Experience (an educational program for school aged children) tables . Those who are FBI/BCI cleared to work with children are especially welcome. You may need to get an FBI/BCI check to work in the schools.

Co-Leader—Train to be a co-leader or get trained to lead a group of your own. Now recruiting for new groups forming in our area. (NOTE: For new groups, you will not have to do this on your own. You will be given help and support to get your group up and running)

Conference Planner—Help to plan local conference events—similar to but not on the scale of the October 2018 conference.

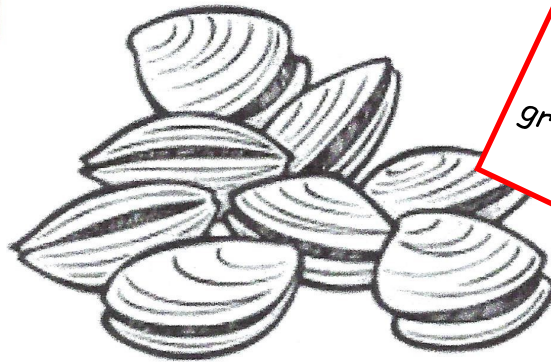
A lot of these positions can be done from home while in your pjs. Please consider getting more involved.

Thanks! - Rebecca



3rd Annual

Benefit Clambake



Cash at the door or credit online
(see below) **MUST RESERVE**
your spot by **September 28th**
by email: [clevelandmg-
group@gmail.com](mailto:clevelandmg-group@gmail.com) or call Rebecca
at 216-218-0477!

\$25 per adult *

\$2 per child

◆ 1 Dozen Clams ◆ Clam Broth ◆ ½ Chicken ◆
Baked Sweet Potato ◆ Corn on the Cob ◆
Coleslaw ◆ Rolls with Butter ◆ Assorted
Desserts ◆ Tea ◆ Coffee ◆ Water ◆ Soda ◆
Cash Bar (\$1 beer \$1 wine)

◆ Macaroni & Cheese ◆ Corn on the Cob
◆ 100% Beef Hotdogs ◆ Fruit Cup ◆ Chips
◆ Assorted Desserts ◆ Juice Box

*
MG Patients \$20 (online use code MG)

NOTE: **NO CLAM** adult option available for \$20

Saturday • October 5th

Doors Open at 2:00 pm • Meal served at 3:00 pm

Pipefitters UA Local 120 Hall, 6305 Halle Dr., Valley View, OH 44125

• Music • Raffle Items • Corn Hole • Lots of Family Fun!

All Proceeds to Benefit the Myasthenia Gravis Foundation of America (MGFA)

See www.clevelandmggroup.org for more information



For Tickets Contact Rebecca Molitoris @ 216.218.0477 or clevelandmggroup@gmail.com

Or go to ticketleap.com and search MGFA Clambake

NEW!

NEW LOCAL WEBSITE!!

Visit us at www.clevelandmggroup.org

There you can get all the latest local **MG** news, see upcoming events, download any newsletter from this year, and sign up for the newsletter email edition.

Be sure and send in your **MG** related questions for our **Ask the MG Expert** column

Email at clevelandmggroup@gmail.com

Or snail mail it to: Rebecca Molitoris, 9356 Asbury Lane, North Ridgeville, OH 44039

This month's question was sent in by Jeanne Coppola, Thanks Jeanne!



Yes! You do read the newsletter!

Thanks for all of your feedback and support. It's great to know that the newsletter is making a difference. August winners were **Susan Penko and Jeanne Coppola**. If you would like a \$10 gift card to Subway just for reading the newsletter and finding the **double word** this month, be the **first** person to email or call me and win. Since the newsletter goes out in both email and printed form, there will be one winner from each category. If you receive the email version, [email me](#) with the answer and if you receive the printed version, **call me and leave a message**. September's winners will be listed in next month's newsletter. You can only win once every 12 months so if you have already won, let someone else have a chance (family members or friends can play too!) and thanks for playing—Rebecca



A special thank-you to everyone who helped set-up and clean-up after the Ice Cream Social especially Russ and Barb Lockyer and Dr. Bob and Dr. Suzanne Ruff who kept the food and other items safe and secure!

UPCOMING 2019 MEETINGS:

WESTSIDE: Next meeting: **October 12, 2019 MetroHealth Middleburg Hts. Facility**
1:00—3:00 pm 7800 Pearl Rd. Middleburg Hts., OH 44130 *OSHIIP

EASTSIDE: Next meeting: **September 21, 2019 Mayfield Library**
12:30—2:30 pm 500 SOM Center Rd., Mayfield Village, OH 44143 *OSHIIP

LORAIN COUNTY: Next meeting: **September 19, 2019 (Thursday) Sugarcreek Restaurant**
1:00—3:00 pm 5196 Detroit Rd, Sheffield, OH 44035 * OSHIIP

See you soon !

Thank you to our sponsors:

