

Cleveland Area Support Group



OCTOBER 2019

Meeting Updates -

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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: <u>Myasthenia.org</u>

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 Jim Aust from **OSHIIP** will be the guest speaker. Come with your insurance questions!

LORAIN COUNTY-

Our next meeting will be held on **Thursday**, **October 17th 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 October 10th to 216-218-0477 (leave message).**

EASTSIDE—

The meeting originally

scheduled for November

cancelled due to losing

both our venue and our

meet in November, please

email or call me at 216-218-

0477 and leave a message

and I will schedule some-

thing at a local restaurant.

speaker. If you wish to

16th from 12:30-2:30 pm is

Are you unable to come to meetings because of your health or the distance to drive? We are going to be starting a virtual online meeting in January. One in which you may call in or join online from your computer. Watch this space for more info.



Volume 7 Issue 10

Ask the MG Expert—

Question — Is caffeine helpful or harmful to someone with MG?

Answer — Caffeine found in chocolate and beverages such as coffee, tea and soda has been found to have an effect on the cholinergic system*

While the biological effect of caffeine on the cholinergic system is not completely understood, caffeine seems to play a role in releasing extra acetylcholine (Ach), thereby making more Ach available at the neuro-muscular junction, which in turn may make your muscles stronger.

While the release of too much Ach can be as symptomatic as too little Ach (causing some muscle weakness), many people with MG find that caffeine gives them a boost in energy level and strength.

As in all things, moderation here is key. However, you may choose to experiment with caffeinated beverages or foods and see if you get the desired strengthening effect.

If you are making significant changes to your diet or regimen, or if you notice any ill effects from adding caffeine to your diet, please consult your doctor. If you choose to experiment with caffeine, it may be helpful to keep a diary of what you consumed and how it made you feel and share this information with your doctor.

*Reference:

(1) The effects of caffeine on the cholinergic system. Pohanka M. Mini Rev Med Chem. 2014.

<u>Westside Meetings</u>

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 see page 4

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 September 19th and attended by 10 people including our presenter, Andrea Zimmer from OSHIIP. She was able to explain which Medicare plans are currently the best and how to choose the best drug plan for 2020.

The **September 21st Eastside meeting** was attended by 9 people, including Jim Aust from OSHIIP who presented about insurance and Medicare.

The **Westside meeting** for September was pre-empted by the MGFA walk that was scheduled the same day. See page 3 for more information about the walk

<u>Eastside Meetings</u>

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 cancelled unless requested

December 7 Annual Christmas Party combined for all groups see page 4

Lorain County Meetings

Meets every 3nd 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 see page 4

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

NOTE: Everyone is welcome to attend any meeting regardless of where you reside. Family and friends are welcome too! Hope to see you soon at one of our meetings or events.





MGFA Ohio Walk -

September 14, 2019 The walk as held at Mill Stream Run Reservation Valley Dr., Strongsville—

Chalet Area with about 100 people in attendance.

This year's walk raised approximately \$13,800 so far. There's still time time to contribute. Go to mgwalk.org and search for the Cleveland area walk to donate.



Help Wanted: The following Volunteer positions are needed in our MGFA Northeast Ohio Area:

- 1. Article Submitter
- 2. Media Liaison
- 3. Phone Liaison
- 4. Event Coordinator
- 5. MG Experience Volunteers
- 6. Co-Leader
- 7. Conference Planner

A lot of these positions can be done from home while in your pjs. Please consider getting more involved and email me if you are interested at <u>cleve-</u> <u>landmggroup@gmail.com</u>

Thanks! - Rebecca

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



For email newsletter recipients this is tomorrow! It's not too late to register!!

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 <u>here</u> or go to https:// www.mda.org/muscle-walk to find the Greater Cleveland Area walk. **Annual Christmas Party**

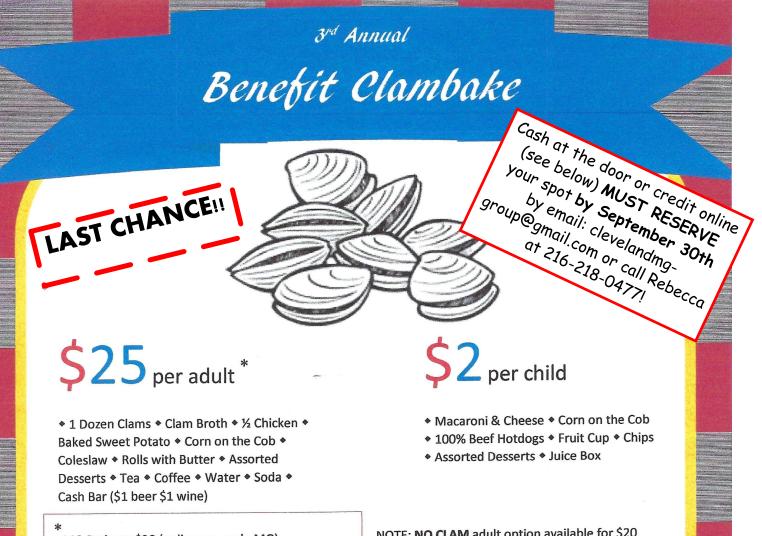
Saturday, December 7, 2019

2:00 pm

Romano's Macaroni Grill 25001 Country Club Blvd. North Olmsted, OH 44070 R.S.V.P. 216-218-0477 or email <u>clevelandmggroup@gmail.com</u> by November 23rd

Please bring a \$5 (or less) gift for the gift exchange

Family and Friends Welcome!



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



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 <u>clevelandmggroup@gmail.com</u>

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

No Newsletter Winner for September!

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, <u>email me</u> with the answer and if you receive the printed version, **call me and leave a message**. October'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

THURLES A

A special thank-you to everyone who helped set-up, cleanup, and work for the MGFA Walk. This wouldn't be possible without all of you!

UPCOMING 2019 MEETINGS:

WESTSIDE:Next meeting: October 12, 2019MetroHealth Middleburg Hts. Facility1:00—3:00 pm7800 Pearl Rd. Middleburg Hts., OH 44130 *0SHIIP

EASTSIDE: November meeting cancelled unless requested contact Rebecca if you want to meet

LORAIN COUNTY: Next meeting: October 17, 2019 (Thursday) Sugarcreek Restaurant 1:00—3:00 pm 5196 Detroit Rd, Sheffield, OH 44035

See you soon !

Thank you to our sponsors:



