

AUGUST 2019

Volume 7 Issue 8

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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: 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 **August 10th** at the **MetroHealth November Meeting Room 7800 Pearl Rd., Middleburg Hts., 44130** from **1:00-3:00 pm** **Ice Cream Social**. The ice cream is provided—you may bring a topping to share if you wish. **Friends and family welcome!!**

There will be a special speaker from Alexion with exciting information to share!

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**

Jim Aust from Ohio Senior Health Insurance Information Program (OSHIIP) will be speaking on all things insurance. He will detail the upcoming changes to Medicare for 2020. **Family and friends welcome!!**

LORAIN COUNTY—

Our next meeting will be held on **Thursday, August 15th** 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 August 8th to 216-218-0477 (leave message).**

There will be a special speaker from Argenx who will tell us about the new MG study currently underway. Family and friends welcome!!

Ask the MG Expert—

Question —What is the MG Patient Registry and why should I register?

Answer —These are exciting times in the world of new MG treatments and the MG Patient Registry has a lot to do with that.

The vision of the MG Patient Registry is to support the MGFA vision of “a world without MG”, while aiding in the improvement of care and quality of life for persons with myasthenia gravis and their families.

The MG Patient Registry is designed to:

Offer a confidential means for patients to provide information that will be useful to medical/research communities in assessment of disease course, use of various therapies, and estimation of disease costs.

Provide a system for investigators to gauge the potential for trial recruitment and to communicate with patients directly about potential research investigations, while respecting their privacy.

Educate patients, caregivers, non-expert health care providers, and funding entities about MG through the use of various media. For example, a newsletter with articles about research findings and other topics relevant to individuals with MG will be sent to participants annually.

To register [click here](#)



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)**

August 10* Speaker from Alexion Meeting
1:00—3:00 pm MetroHealth Annual Ice Cream Social

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

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

December 7 Annual Christmas Party—both east and west sides



MEETING NOTES: The **Lorain County Meeting** was held on July 18th and attended by 9 people. The meeting was held at the Sugarcreek Restaurant in Sheffield Plaza, Sheffield Village. This was the second meeting held in Lorain County for the convenience of the people living further west of Cleveland. We welcomed first timers John and Pam G.

The **July 13th Westside meeting** was attended by 27 people. Dr. Bob Ruff gave an interesting presentation on the basics of MG. - Thank –you Dr. Bob!

The **July Eastside meeting** was held on July 20th at the Beachwood Library and attended by 5 people. We welcomed first-timer Sonya M. Hopefully we will get a better turn-out for the September eastside meeting at which a speaker from OSHIIP will present.

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

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

November 16* Speaker Argenx Meeting
12:30—2:30 Mayfield Library

December 7 Annual Christmas Party—both east and west sides

Lorain County Meetings

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

August 15th* Speaker from Argenx Meeting
1:00-3:00 pm

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

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

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.



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!!



2019 MDA Engage Myasthenia Gravis (MG) 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

SAVE THE DATE!!! 3rd Annual MG Clambake October 5, 2019

Local 120 Pipefitters Hall located at 6305 Halle Dr, Valley View, OH 44125

Tickets will go on sale August 10th at the westside meeting and on ticketleap.com



SPEAKERS, we've got speakers, we've got lots and lots of speakers.....

Every regular meeting in August, September and October will have special speakers!!

August 10—Alexion will give a presentation on Soliris and other new drugs

August 15—Argenx will give a presentation on its latest study

September 19—Lorain County OSHIIP volunteer will present on Medicare changes for 2020 and other insurance questions

September 21 and October 12—Jim Aust from OSHIIP will present on Medicare changes for 2020 and other insurance questions

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



Hmmmm Does anyone read the entire newsletter?

No winners last month. This tells me that either I did a great job of hiding the double word (doubtful) or that no one is reading the newsletter. 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**. August'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

UPCOMING 2019 MEETINGS:

WESTSIDE:

Next meeting: **August 10, 2019** MetroHealth Middleburg Hts. Facility
1:00—3:00 pm 7800 Pearl Rd. Middleburg Hts., OH 44130 Ice cream social *Alexion

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: **August 15, 2019 (Thursday)** Sugarcreek Restaurant
1:00—3:00 pm 5196 Detroit Rd, Sheffield, OH 44035 * Argenx

See you soon !

Thank you to our sponsors:

