



#### Northeast Ohio Area Support Groups

## **MARCH 2020**

Meeting Updates -

Meeting information/notes pg. 2 New MG Trials pg. 3 National Conference pg. 3

## MDA ADDRESS:

#### Valerie Galbicsek

Care & Clinical Services Specialist, Muscular Dystrophy Association

Gemini Towers 1, 1991 Crocker Road, Suite 600, Westlake, Ohio 44145

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: <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 March 14, 2020 at the Parma Library Meeting Room 6996 Powers Blvd., Parma, 44129 from 1:00-3:00 pm

NOTE: NEW meeting place!

## LORAIN COUNTY—

Our next meeting will be held on **Thursday**, **March 19**, **2020 at the Sugarcreek Restaurant located at 5196 Detroit Rd**, **Sheffield**, **OH 44035** in the Sheffield Plaza from **1:00—3:00 pm (regular time)** We will be ordering off the menu and everyone is responsible for their own check. **Please RSVP by March 18th to 216-218-0477 (leave message).** 

#### ZOOM Meeting

Tuesday March 24 7:00 pm—7:00 45 pm

See page 3 for an explanation of what is a zoom meeting meeting and how to join



## EASTSIDE—

Our next *regular* meeting will be March 21, 2020 at the Mayfield Library meeting room 500 SOM Center Rd., Mayfield Village 44143 from 12:30-2:30 pm

NOTE: NEW meeting place!

# Ask the MG Expert—

Volume 8 Issue 2

Question — What do I do to protect myself from contagious diseases like the coronavirus (Co-Vid19)?

**Answer** — Those of us who are immunosuppressed have a weaker defense against any kind of infection. To limit exposure to contagious disease try the following:

- Limit air travel especially outside the U.S.
- If you must travel, ask your doctor about wearing a protective mask.
- Avoid crowds and avoid shopping at peak times.
- Use shop at home and delivery or pick up services to avoid crowds.
- Avoid crowded places like shopping malls, ball games, theaters, etc.
- Avoid sitting next to someone who is obviously ill on public transportation or in church.
- Employ frequent hand washing with soap and water.
- Avoid touching your eyes, mouth, and nose.
- Augment the humidity in your home to prevent your protective mucous membranes from drying out.

NOTE: There are NO *current* cases of Co-Vid 19 in Ohio. The risk of coming into contact with someone infected is very LOW. Use common sense and frequently wash hands!

## <u>Westside Meetings</u>

Meets every 2<sup>nd</sup> Saturday except September, November, and December at various places (see below)

**February 8\***—Parma-Snow Library Meeting Room A, 2121 Snow Rd., Parma, 44134 from 1:00-3:00 pm

March 14—Parma Library Meeting Room 6996 Powers Blvd., Parma, 44129 from 1:00-3:00 pm

**April 11**—MetroHealth Middleburg Hts Campus 7800 Pearl Rd., Middleburg Hts. 44130 from 1:00-3:00 pm

**May 9**—MetroHealth Middleburg Hts Campus 7800 Pearl Rd., Middleburg Hts. 44130 from 1:00-3:00 pm

**June 13**—MetroHealth Middleburg Hts Campus 7800 Pearl Rd., Middleburg Hts. 44130 from 1:00-3:00 pm

**July 11**—MetroHealth Middleburg Hts Campus 7800 Pearl Rd., Middleburg Hts. 44130 from 1:00-3:00 pm

**August 8**—MetroHealth Middleburg Hts Campus 7800 Pearl Rd., Middleburg Hts. 44130 from 1:00-3:00 pm

September 12—MGFA Ohio Walk

October 10-TBD

December 12—Annual Christmas Party 2 pm

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.

MEETING NOTES: February's westside meeting had 27 attendees. Dr. Li gave an interesting presentation about MG 101. February's Eastside Meeting had 15 attendees. (see page 3 for more details) Lorain County meeting had 6 attendees and we enjoyed informal conversation.

Zoom meeting, had 4 attendees. Dr. Robert Ruff answered questions about MG medications.

## Eastside Meetings

Beginning in January meets every 3<sup>rd</sup> Saturday of the month except September, November, and December, at various places (see below)

January 18—Cancelled due to weather

**February 15\***—Gates Mills Library 1491 Chagrin River Road • Gates Mills, Ohio 44040 from 12:30 -2:30 pm

March 21—Mayfield Library Middle meeting room 500 SOM Center Rd., Mayfield Village, 44143 from 12:30-2:30 pm

April 18-TBD

May 16-TBD

June 20-TBD

July 18-TBD

August 15-TBD

September 12-MGFA Ohio Walk

October 17-TBD

December 12—Annual Christmas Party 2 pm

#### Lorain County Meetings

Meets every 3<sup>nd</sup> Thursday at Sugarcreek Restaurant 5196 Detroit Rd, Sheffield, OH 44035 (in the Sheffield Plaza) except November and December

February 20— Sugarcreek Restaurant 1:30— 3:00 pm \*\*new time this month only\*\*

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

What to expect: Regular meetings are open to all

Attendance usually 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.

## Myasthenia Gravis

#### **ZOOM MEETINGS**

"I am not fat because I over eat. My medications cause weight gain.

I don't smile because I am sad or angry. My facial muscles are weak.

I am not ignoring you or find you boring. My cognitive skills are diminishing.

I am not drunk or have a drinking problem. My balance and speech are off.

I am not lazy. My muscles fatigue faster than normal.

I am not gasping because of being out of shape. My diaphragm is weak.

I am not weak by choice.

I am stronger than you will ever know.

I am fighting with myself everyday.

I am fighting Myasthenia Gravis.

Please don't judge what you don't understand."

\*Published on an MG FaceBook group

#### What is a ZOOM meeting anyway?

Zoom is a platform that offers an online and/or phone conference meeting. We are currently holding a LIVE Zoom meeting monthly.

#### March's Zoom meeting will be Tuesday March 24, at 7 pm.

Since we are currently testing the Zoom software before we buy into it, we are limited to 45 minutes of meeting time.

Zoom meetings are especially helpful for those of us who have trouble getting out to a meeting or don't want to travel in the winter. To join a Zoom meeting online, watch for the Zoom email blast or go to the local website for a link to the meeting on the 24<sup>th</sup>. A new link and phone is generated for each meeting.

#### www.clevelandmggroup.org

The Zoom site asks you to join and requests that you choose a user name and password. Please allow extra time to follow those steps. You may join Zoom in advance of the meeting. You may also join by phone. The current meeting phone number will be listed in the email blast and online at our website on the 24<sup>th</sup>. Hope to "see" you soon!

BREAKING NEWS \* BREAKING

We will be having another REGIONAL MGFA Conference coming up in October 2020. The Conference will be at the same place, Parma-Snow Library, and will offer a full day of classes and informational meetings about MG. Watch this spot next month for more information

\_\_\_\_\_

#### February's Eastside Meeting Notes

At February's eastside meeting, held at the Gates Mills Library, Dr. Yuebing Li, Dr Robert Ruff, and Dr. Suzanne Ruff were there to answer MG related questions. We welcomed a couple new to the MG experience, the Holzheimers. Also at this meeting, Chris D'Agostino officially took over as the Eastside MGFA Support Group Leader. Thank you, Chris for stepping into this role. Chris became a support group leader after receiving training through the National MGFA Support Group Leader training program. If you feel led to become a MGFA Support Group Leader in your area, contact Rebecca at 216-218-0477. You will receive free training and materials to get you started. We especially need leaders in the Toledo and Canton areas.





# **Caring \* Connecting \* Commitment**

Ft. Worth, Texas | APRIL 5-7, 2020 | Omni Fort Worth

To book your hotel reservation using the MGFA National Conference rate, please see below:

https://www.omnihotels.com/hotels/fort-worth/meetings/ mgfa-2020-annual-meeting-04032020

\*Guests may also call Omni Reservations at 1-800-THE-OMNI and refer to the group name "MGFA 2020 Annual Meeting"

## LOCAL MGFA GROUP WEBSITE

Visit us at <u>www.clevelandmggroup.org</u>

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

Be sure and send in your MG related questions for our Ask the MG Expert column Email at <u>clevelandmggroup@gmail.com</u> Thanks to Laura Lodge for this month's question! Or snail mail it to: Rebecca Molitoris, 9356 Asbury Lane, North Ridgeville, OH 44039

#### Where's the Double Word???

If you would like a \$10 gift card 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**. March'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

NOTE: Meeting cancellations will be posted on our local website AND sent out in an email blast-if you have a question about a meeting call or text me @ 216-218-0477 —Rebecca

#### **UPCOMING 2020 MEETINGS:**

WESTSIDE:Next meeting: March 14, 2020Parma Library6996 Powers Blvd., Parma, 44129 1:00—3:00 pm

EASTSIDE: Next meeting: March 21, 2020 Mayfield Library 500 SOM Center Rd. • Mayfield Village, Ohio 44143 12:30—2:30 pm

LORAIN COUNTY: Next meeting: March 19, 2020 (Thursday) Sugarcreek Restaurant 1:00—3:00 pm 5196 Detroit Rd, Sheffield, OH 44035

ONLINE: Next ZOOM meeting is Tuesday, March 24, 2020 at 7:00 pm (see pg. 3 for details)

See you soon !

Thank you to our sponsors:



