

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: 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—

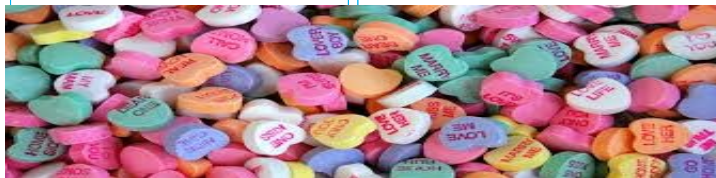
Our next *regular* meeting will be **February 8, 2020** at the **Parma-Snow Library Meeting Room 2121 Snow Rd., Parma, 44134** from **1:00-3:00 pm**

NOTE: NEW meeting place!

EASTSIDE—

Our next *regular* meeting will be **February 15, 2020** at the **Gates Mills Library meeting room 1491 Chagrin River Road • Gates Mills, 44040** from **12:30-2:30 pm**

NOTE: NEW meeting place!



LORAIN COUNTY—

Our next meeting will be held on **Thursday, February 20, 2020** at the **Sugarcreek Restaurant** located at **5196 Detroit Rd, Sheffield, OH 44035** in the Sheffield Plaza from **1:30—3:00 pm** We will be ordering off the menu and everyone is responsible for their own check. **Please RSVP by February 13th to 216-218-0477 (leave message).**

NOTE: New time this month month only!

Can't Leave Home? Join our Zoom Meeting

Topic: Drugs to Treat MG
Time: February 18, 2020
01:00 PM Eastern Time

Click the link below to join the meeting:

<https://zoom.us>

When prompted to join a meeting, enter **Ohio MG** to join

The following is a list of famous personalities who are known to have MG:

Connie Haines (1921-2008), big band singer co-starred with Frank Sinatra.

John Spencer (1936-2006), snooker player

Leland Brewsaugh (1935-2003), sculptor, designer, and painter.

Roque Carbajo Reyna (1936-1996), Mexican musician and songwriter.

Wilma Mankiller, former Chief of the Cherokee Nation (Oklahoma, U.S.A.)

Harold P. "Chuck" Klein (California, U.S.A.)

Amitabh Bachchan, Indian actor, public figure.

Leonas Letas Lithuanian poet (1924-1998)

Henrique da Costa Mecking (Mequinho) in Brazil.

Linda Darnell (1921-1965), Hollywood actress who starred in more than 30 Fox films.

Heine Toerien, radio personality in South Africa and first Chairman of the Myasthenia Gravis Foundation of South Africa.

David Niven actor and writer.

The late Aristotle Onassis - Greek business tycoon and husband of Jacqueline Bouvier Kennedy

Roger Smith - husband of the movie actress Ann-Margret

Lamar Lundy - formerly a football player with the Los Angeles Rams

Rondell Jones. Defensive back Denver Broncos

Hjalmar Gullberg former poet laureate of Sweden.

Doris Lilly, (1922-1991) author of "How to Marry a Millionaire"

Suzanne Rodgers, actress in "Days of Our Lives" soap opera

Sir Peter Wright - former director of the Royal Birmingham Ballet -

(Sir Lawrence) Olivier - actor and film star -

Phil Silvers (actor - Sgt. Bilko)

Noah Deitrich, right hand man for Howard Hughes.

Weeb Ewbank (former coach of the NY Jets and Baltimore Colts) (U.S.A.)

Luciano Pavarotti's daughter has MG



2020 MG Meetings and Events

Westside Meetings

Meets every 2nd 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: January's westside meeting had 20 attendees and lively discussion. Eastside Meeting was cancelled due to weather. Lorain Cty meeting had 9 attendees and we enjoyed informal conversation.

1st online Zoom meeting, had 4 attendees including myself. There were some flaws and I had to change the meeting password 1/2 hour before the meeting began. We'll try again this month and hope for the best. "See" you there :)

Eastside Meetings

Beginning in January meets every 3rd 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 3rd 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****

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.

Clinical Trials in Northeast Ohio—

The following MG clinical trials are currently recruiting in our area:

A Phase 3, Multicenter, Randomized, Double Blind, Placebo-Controlled Study to Confirm the Safety, Tolerability, and Efficacy of Zilucoplan in Subjects With Generalized Myasthenia Gravis

Click link below for more information:

https://myasthenia.org/Portals/0/MGFA_Research_Announcement%20Form_RaPharma_RAISE.pdf

Catalyst Pharmaceuticals Clinical Trial for Firdapse in MuSK MG

Study to Evaluate Amifampridine Phosphate in Patients With MuSK-MG

<https://www.clinicaltrials.gov/ct2/show/NCT03304054>

Safety and Efficacy Study of Ravulizumab in Adults With Generalized Myasthenia Gravis

<https://clinicaltrials.gov/ct2/show/NCT03920293>



Dr. Yuebing Li from the Cleveland Clinic will be speaking at our Westside & Eastside February meetings.

Dr. Li is an expert in the diagnosis and treatment of myasthenia gravis and is a past recipient of the National MGFA Physician of the Year award

INTRODUCING - A New Leader! Starting in February there will be a new leader at the Eastside meeting. Come and meet the new leader on February 15th at the Gates Mills Library. I'll still be around for a while during the transition, but I think you'll like this guy! All will be revealed at the February meeting. See you then!



2020 NATIONAL CONFERENCE

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>

PROMISE

Caring ★ Connecting ★ Commitment

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

*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 www.clevelandmggroup.org

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 clevelandmggroup@gmail.com

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, [email me](#) with the answer and if you receive the printed version, **call me and leave a message**. February'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: **February 8, 2020** **Parma-Snow Library**
1:00—3:00 pm 2121 Snow Rd., Parma, 44134 Speaker Dr. Yuebing Li

EASTSIDE:

Next meeting: **February 15, 2020** **Gates Mills Library 1491 Chagrin River Road •**
Gates Mills, Ohio 44040 12:30—2:30 pm

LORAIN COUNTY:

Next meeting: **February 20, 2020 (Thursday)** **Sugarcreek Restaurant**
1:30—3:00 pm 5196 Detroit Rd, Sheffield, OH 44035 *New Time this month only

ONLINE:

Next **ZOOM** meeting is **Tuesday, February 18, 2020 at 1:00 pm** (see pg. 1 for details)

See you soon !

Thank you to our sponsors:

