

Meeting Updates →

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WESTSIDE—

Our next *regular* meeting will be **sometime in June** watch this space for info in May

EASTSIDE—

Our next *regular* meeting will be **sometime in June** watch this space for info in May

LORAIN COUNTY—

Our next meeting will be **sometime in June** watch this space for info in May

ZOOM Meetings

Thursdays at the following times:

- 1st Thursday April 2—11:00 am**
- 2nd Thursday April 9—1:00 pm**
- 3rd Thursday April 16—3:00 pm**
- 4th Thursday April 23—7:00 pm**

Go to www.zoom.us and click join meeting

Then enter meeting ID 374 115 6227

Hope to see you soon.

Ask the MG Expert—

Question — What do I do to protect myself from the coronavirus (Covid-19)?

Answer — Those of us who are immunosuppressed have a weaker defense against any kind of infection. To limit exposure to Covid-19 try the following (updated!):

- **Stay Home!**
- Use shop at home and delivery or pick up services to avoid crowds.
- Have the delivery driver leave your items on your porch or outside your door.
- If you must leave home, wear gloves and a mask.
- Maintain a 6 foot distance between yourself and the next person. (except for those with whom you live)
- **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.
- If you feel ill, call your doctor first to get instructions before heading to an ER or Urgent Care facility.
- Watch the following video for instructions on bringing items into your home <https://clevelandmgroup.org/covid-19>

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.

PLEASE WASH YOUR HANDS OFTEN!

Especially before eating!!



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Click here to get on MGFA's mailing list:

<https://interland3.donorperfect.net/weblink/WebLink.aspx?name=E248489&id=25>

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—cancelled

April 11—cancelled

May 9—cancelled

June 13—TBD

July 11—TBD

August 8—TBD

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: Due to the coronavirus pandemic, the National MGFA is asking us to not meet in person at *least* through May maybe longer depending on circumstances. Therefore we will be having Zoom online meeting every Thursday at various times (see page 1)

Zoom meeting, held on Thursday March, 26, 2020 had 14 attendees. Dr. Robert Ruff answered questions about MG and the Corona virus. Dr. Suzanne Ruff presented on stress during this unprecedented time

Thank you both!

And Thank all of you who attended.

Hope to see everyone soon online

Our Zoom Meeting ID is:

374 115 6227

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—cancelled

April 18—cancelled

May 16—cancelled

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: TBD

What to expect at in-person meetings:

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.





2020 NATIONAL CONFERENCE

PROMISE

Caring ★ Connecting ★ Commitment

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

Breaking News!

Due to the Corona Virus, the in-person conference has been changed to an online conference and YOU are invited. This is a FREE conference.

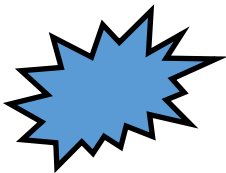
You can view the entire letter from MGFA at our website: <https://clevelandmgroup.org/upcoming-events>

No special downloads are needed—just an internet connection. You can attend as much or as little as you like—and we have large capacity to accommodate all who want to participate. Watch for registration information coming early next week to your email box and mark your calendars now for:

Sunday, April 5, noon- 5:30 ET (opening session at 1:00)

Monday, April 6, 10 – 4:30 ET (opening session at 11:00)

Tuesday, April 7, 10—5:00 (opening session at 11:00)



MDA Sponsored Clinical Trials:

Myasthenia gravis (MG)	Amifampridine phosphate	Phase 3	Catalyst Pharmaceuticals
Myasthenia gravis (MG)	Eculizumab	Phase 3	Alexion
Myasthenia gravis (MG)	nipocalimab	Phase 2	Momenta Pharmaceuticals

The following information is now found on our website at <https://clevelandmgroup.org/covid-19>

1. Video that shows new grocery handling guidelines
2. Guidelines for Covid-19 and MG Patients provided by Dr. Yuebing Li
3. Stress Management Guidelines by Dr. Suzanne Ruff
4. Sign to post on your front door for people at high risk

You can safely download each pdf from our website

I'm hoping that we will be able to meet once again beginning in June. June is National MG awareness month. It would be nice to have another pot-luck get-together at the Pipe Fitters Union Union Hall, but we will see what it looks like closer to the end of May. In the meantime, please stay safe, stay home, and wash those hands!

Rebecca

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**. 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: TBD

EASTSIDE: TBD

LORAIN COUNTY: TBD

ONLINE: ZOOM meetings every Thursday in April (see pg.1 for details)

See you soon !

Thank you to our sponsors:

