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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.

May's ZOOM Meetings

Thursdays at the following times:

1st Thursday May 7—11:00 am

Register in advance for this meeting:

<https://zoom.us/meeting/register/tJAodeCrqzorEtNkQdqKNcxdQglwRVY08oZV>

2nd Thursday May 14—1:00 pm

Register in advance for this meeting:

<https://zoom.us/meeting/register/tJwucupqTsjHtEpFWp0QsrqDzAg5BLmMF4L>

3rd Thursday May 21—3:00 pm

Register in advance for this meeting:

<https://zoom.us/meeting/register/tJctdemrrDluG9HOtgEjzPfmW572rRSkbr2v>

4th Thursday May 28—7:00 pm

Register in advance for this meeting:

<https://zoom.us/meeting/register/tJ0vcuytrz4jH9ws9yFM-bnc3CrYITruOR3y>

You can register right up until meeting time. You will be sent a clickable link and the meeting ID and password.

See page 3 for more information on how to use Zoom.

Ask the MG Expert—

Question — What do I do now during this pandemic?

Answer — If you're like me, this is getting a little old. It is a little scary and downright frustrating at times. Here is some advice for trying to get through this hard time. Take what works for you and disregard what doesn't. After all we are all snowflakes.

- Be kind to yourself and cut yourself some slack. The house doesn't have to look magazine cover ready. You can always use a virtual background for Zoom meetings.
- Be kind to others. Give grace where you can and don't sweat the small stuff. —And everything is small stuff.
- Try to do something fun everyday. Read a book, watch movie, go for a walk, listen to music, play a game.
- Reach out to others. Everyone is feeling a little low right now. Hearing your voice could cheer them up.
- If you need to go to the doctor's office for a blood test or other procedure, don't be afraid to go. They have it handled and you will feel safe there.
- Keep in mind that "This too shall pass" The only thing that's constant in this world is change. I look forward to the day we can meet again in person.

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)

The average attendance at April's Zoom meetings was about 8 people per meeting. The last meeting of the month was the most popular with 12 people attending a presentation by Dr. Kylie Sramek from Synergy.

Dr. Sramek gave us access to a pdf of simple home exercises to help us keep strong while at home.

Dr. Robert Ruff and Dr. Suzanne Ruff have given generously of their time and expertise and have attended the Zoom meetings regularly.

I would highly recommend that if you have the time, give Zoom a try. It is a great way to connect and learn more about MG and each other.

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

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.





2020 NATIONAL CONFERENCE

PROMISE

Caring ★ Connecting ★ Commitment

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

Although the conference has ended, you can view the conference's presenter's pdf's by going to

www.clevelandmgroup.org

and click on the Upcoming Events Tab

OK, so what is Zoom anyway?

Zoom is an online platform developed to enable multiple people to see and hear each other in a meeting setting. The only equipment you actually need to participate is a phone with long distance capabilities. However in order to get the full experience, a computer, tablet, or smart phone is best.

Did you know that our Zoom meetings are now more secure?

Every meeting is now protected with a password.

To join us just click on the link below each meeting listed on page one. Each meeting has a unique code so the meeting on week one will NOT be the same as week two, etc. If you misplace this newsletter, don't worry, I'll send out the new meeting info every week before the meeting. Please allow enough time for the code to be sent, by registering *at least* 24 hours prior to the meeting. Especially if you are joining for the first time. After you register with your name and email, You will be sent a clickable meeting link and an ID and password via the email you provide.

Joining a Zoom meeting is easy. Just click on the link in the email. You may be asked to download the app.

Then the meeting appears on your computer, laptop, ipad, tablet, or similar device, or smart phone.

NOTE: Please insure that your device has a working camera and microphone.

Don't have any of these? No problem. You can still join the meeting by calling in using one of the phone numbers that will be sent to you following your registration. Can't register? Call me and I'll give you the call-in info. Rebecca 216-218-0477. Please leave a detailed message as I often don't hear my phone ring.

I hope you will join us on our next call. While nothing is as good as meeting in person, until that can happen, this is a good substitute. Hope to see you at our next Zoom meeting.

Has COVID-19 Left You Financially Strapped?

The National Organization for Rare Disorders (NORD) has opened a financial assistance program for people in the rare disease community including those with MG, who are affected by the COVID-19 pandemic in the U.S. Called the NORD COVID-19 Critical Relief Program, the effort will provide up to \$1000.00 annually to those eligible to support critical non-medical needs. The program is designed to help rare disease patients and their families who may be facing monetary hardships due to the outbreak. The funds are exclusively for living expenses such as utility bills, internet service, car repairs, rent and mortgage. Applicants must have income levels at or below 4 times the poverty level or experiencing financial difficulties due to the pandemic. Examples include: job loss, inability to work due to local stay-at-home orders, and school closures.

For further information about eligibility or how to apply, call NORD at 203-242-0497 or send an email to COVID19assistance@rarediseases.org

—Submitted by Ana Colic Thanks, Ana!

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

You are **Braver**
than you believe,
Stronger
than you seem,
and **Smarter** than you
think.

__Winnie the Pooh



UPCOMING 2020 MEETINGS:

The National MGFA Support Groups are following local and National guidelines concerning the COVID-19 pandemic. We will not be meeting in person until given the ok to do so. Therefore, please join us on the Zoom meetings that run throughout May. Stay home. Stay safe.

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

See you soon (online)!

Thank you to our sponsors:

