

Northeast Ohio Area Support Groups

For Strength, Independence & Life

NOVEMBER 2020

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November's ZOOM Meetings

Thursday meetings at the following times:

When: Nov 5, 2020 11:00 AM Eastern Time (US and Canada)

Register in advance for this meeting:

https://zoom.us/meeting/register/tJAofutrD4tGNCqlpEaO4Nwi0ASelfTZJfS

After registering, you will receive a confirmation email containing information about joining the meeting.

When: Nov 12, 2020 01:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

https://zoom.us/meeting/register/ tJAqdOmpqT8sHNx8xN44ZeQxh6o5fYIQ948Y

After registering, you will receive a confirmation email containing information about joining the meeting.

When: Nov 19, 2020 03:00 PM Eastern Time (US and Canada)

Register in advance for this meeting:

https://zoom.us/meeting/register/ tJcodu6grjwoHdEqMh0yjNF352Zpf8hmvJF8

After registering, you will receive a confirmation email containing information about joining the meeting.

There will be no 4th Thursday Meeting this month Happy Thanksgiving!

NOTEL We have gone to a registration system for meetings. Please register in advance. If joining by phone and unable to register, call or text me for the phone number and passcode to enter the meeting

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.



Volume 8 Issue 11

Since we have a holiday this month that centers around a big meal, here are some tips for safe chewing and swallow-

Ask the MG Expert

ing:

- Don't eat and talk. Sounds simple but when we gather, we are tempted to hurry through chewing to talk.
- Take small bites and chew carefully.
- Time your Mestinon so that you will be strong during meals.
- Have a drink handy to help wash down food NOTE: Some people prefer iced beverages as the cold helps with muscle strength and some people prefer warm soda. Do what works for you.
- Choose foods that are easier to chew. If you are having an off day, choose things like mashed potatoes and turkey over foods that require more chewing.
- Take frequent rests between bites to give your muscles a chance to recover.
- If you find that your food is hard to "get down", try turning your head to the side while slowly drinking a beverage.
- After a meal, rinse your mouth to be sure you have removed all left over food.

2020 MG Meetings and Events

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Westside Meetings: TBD

Lorain County Meetings: TBD

NOTE: Everyone is welcome to attend any meeting including on ZOOM, regardless of where you reside. Family and friends are welcome too! Hope to see you soon at one of our meetings or events.

NOTE: Due to the coronavirus pandemic, we will not be meeting in person until 2021. Therefore we will be having a Zoom online meeting every Thursday at various times (see page 1).



We have gone to a "share and care" format. We take turns giving updates, asking questions of our MG expert, Dr. Robert Ruff, and in general just connecting with others like us experiencing the same problems and sharing tips and solutions. 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.

We are requiring pre-registration this month. Click on the links provided where you can register. You must register for each meeting separately. You will be sent an email with the link and passcode for each meeting. Zoom has added these extra protections to keep our meetings safe.



Eastside Meetings: TBD

Just a note about Covid-19

We are all getting just a bit weary of this pandemic. But please know that the threat is very real. We have had some of our own fellow MG'rs become very sick with this virus.

Please continue to protect yourself and others by wearing a mask and staying socially distant!

Need a mask? <u>Email</u> me and I will hook you up. We have several people willing to help provide masks to those who can't afford them.

Feeling isolated? Take advantage of our virtual meetings.
They really are the next best thing to being there.

Stay Home and Stay Safe

Introducing the MG Virtual Closet!

Do you need any durable medical equipment?

Do you have some to share?

Email me at clevelandmggroup@gmail.com and I will add it to the closet inventory.

Likewise, if you need some equipment, please state what the item is and your anticipated term of need for the item.

Don't forget to include your name and contact info. Thanks! We can all use a little help now and then.

MEETING NOTES:

We had 50 people join for the October Zoom meeting with Dr. Mei. He gave a great presentation about the neuromuscular junction and the history of MG and his research. We hope he will return next year.

We will continue to hold weekly Thursday meetings at the following times:

1st—11:00 am 3rd 3:00 pm

2nd—1:00 pm 4th 7:00 pm

NOTE:

There will be no 4th Thursday meeting this month due to the Thanksgiving holiday

MG Clinical Trials Now Recruiting

1. <u>Official Title</u>: A Phase 3, Randomized, Double-Blind, Placebo-Controlled Study Evaluating Efficacy and Safety of Rozanolixizumab in Adult Patients With Generalized Myasthenia Gravis

Recruiting site: Columbus, Ohio 43210

To learn more about this study, you or your doctor may contact the study research staff using the contact information provided by the sponsor.

Please refer to this study by its ClinicalTrials.gov identifier (NCT number): NCT03971422

Contact: UCB Cares +1844599 ext 2273 <u>UCBCares@ucb.com</u>

2. <u>Official Title</u>: A Phase 2, Randomized, Placebo-Controlled Study to Evaluate Safety, Tolerability, and Efficacy of TAK-079 in Patients With Generalized Myasthenia Gravis

| Experimental: TAK-079 Dose 1 | Drug: TAK-079 subcutaneous injection |
|--|--------------------------------------|
| TAK-079 dose 1 injection, subcutaneously, once weekly for 8 weeks. | |
| Experimental: TAK-079 Dose 2 | Drug: TAK-079 subcutaneous injection |
| TAK-079 dose 2 injection, subcutaneously, once weekly for 8 weeks. | |
| Placebo Comparator: TAK-079 Placebo-matching | Drug: TAK-079 placebo-matching |
| TAK-079 placebo-matching injection, subcutaneously, once weekly for 8 weeks. | subcutaneous injection |

Please refer to this study by its ClinicalTrials.gov identifier (NCT number): NCT04159805

Contact: Takeda Study Registration Call Center +1 877-825-3327 medinfoUS@takeda.com
Locations:

United States, Florida

SFM Clinical Research, LLC Recruiting Neurology Associates PA Recruiting

Boca Raton, Florida, United States, 33487 Maitland, Florida, United States, 32751

3. Official Title: A Long-Term, Single-Arm, Open-Label, Multicenter, Phase 3 Follow-on Trial of ARGX-113-1704 to Evaluate the Safety and Tolerability of ARGX-113 in Patients With Myasthenia Gravis Having Generalized Muscle Weakness

Experimental: ARGX-113 Biological: ARGX-113 Intravenous administration of ARGX-113

Other Name: efgartigimod

To learn more about this study, you or your doctor may contact the study research staff using the contact information provided by the sponsor.

Please refer to this study by its ClinicalTrials.gov identifier (NCT number): NCT03770403

Contacts

Contact: Antonio Guglietta, MD 329-310-3471 clinicaltrials@argenx.com

Investigator Site 18 Recruiting

Cleveland, Ohio, United States, 44195

For more MG Trials, go to ClinicalTrials.gov and search on myasthenia gravis



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 $\pmb{\mathsf{Ask}}$ the $\pmb{\mathsf{MG}}$ $\pmb{\mathsf{Expert}}$ column

Email at clevelandmggroup@gmail.com

Or snail mail it to: Rebecca Molitoris, 9356 Asbury Lane, North Ridgeville, OH 44039

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

Need help paying for your meds? Check out the following sites:

https://www.needymeds.org/

http://www.themedicineprogram.com/

http://www.togetherrxacces.com/p/prescription-savings

https://mat.org/ (Medication Assistance Tool)

http://www.rxhope.com/Patient/AssistanceRequest.aspx

http://www.myastheniagravis.org/we-can-help/what-we-do/

More info at: https://myasthenia.org/Community-Resources/ Resources-External-Assistance-Programs



UPCOMING 2020 ZOOM MEETINGS:

3 Local ZOOM meetings in November! (see inside for details)

Hope to see you soon on Zoom!



Thank you to our sponsors:

