

Northeast Ohio Area Support Groups

JANUARY 2022

Meeting Updates

New MG Treatment FDA approved pg. 2

Assistance Programs pg. 4

MDA NOTES:

While the MDA Clinic at MetroHealth is still in operation for MG patients, there is no longer a physical MDA liaison present at the Clinic. You can reach MDA at the national level by calling 800-572-1717 or online at MDA.org

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>

Help our Local Group: If you use the following link to sign up for Rare Patient Voice, our local group will receive \$5 for every person chosen to participate. That money goes towards helping to fund this newsletter. Sign up at : https://rarepatientvoice.com/ MGFANortheast/



January's ZOOM Meetings Thursday meetings at 3:00 pm:

When: Jan 6, 2022 03:00 PM Eastern Time (US and Canada) <u>https://us06web.zoom.us/meeting/register/</u> tZwoduytrD8qHdRj 8c2Mtv4LZPi -Ufe5q

When: Jan 13, 2022 03:00 PM Eastern Time (US and Canada)

https://us06web.zoom.us/meeting/register/ tZ0vcOGhrTsqHNVkwOgZEcw0MYt7agDPScYF

When: Jan 20, 2022 03:00 PM Eastern Time (US and Canada)

https://us06web.zoom.us/meeting/register/ tZUucuyuqDMjG9b7ACrcYlGWnY7KjW4-ZPAp

When: Jan 27, 2022 03:00 PM Eastern Time (US and Canada)

https://us06web.zoom.us/meeting/register/ tZIIfumorTktG9LPRxCsdAPcTqxyZGqTluZk

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





Volume 10 Issue 1

Ask the MG Expert

Q. I'd like to toast in the New Year, is it safe to drink with MG?

A. If your MG symptoms are stable and you are not experiencing a lot of weakness, then drinking in moderation should be ok. The key is moderation 2 drinks for males and 1 drink for females.

If however, your MG is not well controlled, then it is best to avoid any alcoholic beverage as it acts like a mild muscle relaxant.

Q. My New Year's resolution is to lose some weight. Is there a recommended diet for MG patients?

A. Many people find some relief from their MG with an antiinflammatory diet such as the Mediterranean Diet or the DASH diet. This is a way of eating that is rich in macro nutrients and eliminates processed foods, red meats, and excess sugars from your diet. Click here to find an explanation of antiinflammatory diets: <u>https://</u> www.medicalnewstoday.com/ articles/320233

Other MG patients find that their symptoms get better with a modified KETO or Paleo diet. This is a diet that eliminates most sources of sugar and starches from the diet. Click here for more information about these types of diet: <u>https:// www.healthline.com/nutrition/</u> <u>paleo-vs-keto</u>

Q. My New Year's resolution is to get more exercise. How do I start with MG?

A. Before starting any exercise program, be sure and ask your doctor if it is ok for you. When starting any new exercise regimen, start SLOW. You can gradually build up to more as your body tolerates. Here's a good video for beginners: <u>https:// www.youtube.com/watch?</u> <u>v=FeliggiF6Ss&list=PLvJ7HXj75I1qN-YjbhjfDf9npBaEOAK &index=1</u>

Parents of MG KIDS Meetings – January 2022

When: Jan 9, 2022 12:00 PM Eastern Time (US and Canada)

https://us06web.zoom.us/meeting/register/tZcsdempqjwuE9SmNtLXX7L xEKfhvLEdOkC

When: Jan 9, 2022 09:00 PM Eastern Time (US and Canada)

https://us06web.zoom.us/meeting/register/tZArd-2trTgqE9VHTcD7nnc-Zgx3QYjgpxpp

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

NOTE: The Parents of MG KIDS Meetings are open to any family, friends, or caregivers of a pediatric MG patient. However, if you are an adult patient who has had MG since childhood and can provide some helpful insight and encouragement to the pediatric patients currently living with MG, we would welcome you to join us and share your experience.

2022 COVID-19 UPDATE

Due to the fact that the omicron variant is so prevalent right now, we will continue our distance meetings via Zoom. I wish I could tell you when it will be safe to meet again. I really miss seeing you all in person and miss all the events we've shared together. It is most important though that we remain this way to keep everyone safe. You can help! Please follow the guidance given to us by the CDC and local health officials. Regardless of your politics, we are truly all in this together so please follow these simple rules to bring this terrible pandemic to an end.

1. Get vaccinated AND boosted—it is still the most effective way to protect yourself and others and to prevent more variants from forming. **2.** Wear a mask when indoors with others. This includes that quick trip to the store. **3.** Distance yourself. Try and limit your close interactions with strangers. **4.** If you feel sick, STAY HOME! Don't take the chance that you could infect others. **5.** If you think you have covid, call your doctor and arrange to take a test. DO NOT go to the ER unless you are critically ill. Our hospitals are currently overtaxed and some have had to turn patients away.

Adult Patient Zoom Meetings:



We have been averaging about 9-20 people per meeting. It is a great time to connect with each other and share tips and hints for living well with MG
We will continue to hold weekly Thursday meetings at 3:00 pm ET (pg. 1)
Come and see old friends or make new ones.
Family, friends, and caregivers welcome!



VYVGART is a new FDA approved treatment for adults with anti-AChR* antibody positive generalized myasthenia gravis (gMG)

*AChR=acetylcholine receptor

VYVGART is the first treatment of its kind for adults with anti-AChR antibody positive gMG

VYVGART Improved daily abilities:

68% (44 of 65) of participants on VYVGART achieved significant improvement in their ability to perform daily activities

Reduced muscle weakness:

63% (41 of 65) of participants on VYVGART achieved a significant reduction in muscle weakness⁺

VYVGART is the first and only FDA approved treatment that uses a fragment of an IgG antibody to treat adults with anti-AChR antibody positive gMG

VYVGART is a fragment of an IgG antibody

Learn more about VYVGART by clicking HERE

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# Register Today for the

# **2022 MGFA National Patient Conference**

The Myasthenia Gravis Foundation of America has announced that its annual National Patient Conference will be hosted virtually in 2022. This premier event for the MG patient community and caregivers will take place on Thursday, February 10, and Friday, February 11, 2022.

Registration is now open! We are so excited to see members of the MG Community from around the world attend this important annual event.

# **REGISTER HERE**

The conference will feature research information, patient stories, updates on MG treatments and discoveries, and many exciting and informative topics to help you and your family navigate your MG journey – and you can experience it all from the comfort of your home or office. Can't wait to talk with you soon.

If you have questions, please contact Dova Levin at **dlevin@myasthenia.org** or call us at 1-800-541-5454.

### LOCAL MGFA GROUP WEBSITE

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

Be sure and send in your MG related questions for our Ask the MG Expert column Email at <u>clevelandmggroup@gmail.com</u>

#### 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/ Good Rx.com 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

"There are better things ahead than any we leave behind."

- C.S. Lewis.

"The bad news is time flies. The good news is you're the pilot."

- Michael Altshuler

"I hope that in this year to come, you make mistakes. Because if you are making mistakes, then you are making new things, trying new things, learning, living, pushing yourself, changing yourself, changing your world. You're doing things you've never done before, and more importantly, you're doing something."

- Neil Gaiman

#### **UPCOMING JANUARY 2022 MEETINGS:**

Adult MG Patients, Family, Friends, Caregivers—Jan. 6th, 13th, 20th, and 27th at 3:00 pm via Zoom (see page 1)

Parents of MG KIDS Zoom Meetings Jan. 9th at 12:00 pm and 9:00 pm ET (see page 2)



Thank you to our sponsors:



