

JUNE 2022

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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: Myasthenia.org

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/>



June's ZOOM Meetings

When: Jun 2, 2022 03:00 PM Eastern Time (US and Canada)

https://us06web.zoom.us/join/6vqDkqG9B39G_iTjvLUDsBG7ghxYsd

When: Jun 9, 2022 03:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/join/tZwvde2hrTgvE9DmL73LPKOtxVdN2K8RRiEi>

When: Jun 16, 2022 03:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/join/igri4rHdaWMXjV0oyu4u5ijhczUE4>

When: Jun 23, 2022 03:00 PM Eastern Time (US and Canada)

https://us06web.zoom.us/join/tZwrceirj4uGNVpUQK_OD6ZeqbA-7OoQg5B

NOTE: No meeting June 30th (5th Thursday)

Volume 10 Issue 6

Ask the MG Expert

Q. How do I keep from getting weak in the heat this summer?

A. Many people with MG get weaker in the heat Here are some ways to keep cool :

- Apply ice at pressure points (back of neck, wrists, behind knee, at temple)
- Use cooling towels. You can buy some that are specially made to retain coolness or you can make one yourself with a strip of cloth keep cool in a jar of water in the fridge.
- Stay hydrated. Drink lots of water and use ice.
- Stay indoors during the middle of the day when it is the hottest—in the air-conditioning, if you have it. If not, use fans, shade, and ice.
- If you must be outdoors, consider buying a cooling vest to help keep you cool.**
- If there is no shade outdoors, consider bringing your own by using an umbrella to block the sun.
- Try to plan strenuous activities during the early morning or evening hours when it isn't as hot.

** For an article about cooling vests, how they work, and which ones work best, visit :<https://www.rehabmart.com/post/do-cooling-vests-really-work-4-types-how-they-cool-you-down>



June is Myasthenia Gravis
Awareness Month



Celebrate with our
Annual Ice Cream Social! (see pg. 3)



Next Parents of MG KIDS Meeting—June 2022



When: Saturday, June 11, 2022 02:00 PM Eastern Time (US and Canada) Register in advance for this meeting:

<https://us06web.zoom.us/meeting/register/tZAtf-gqrzkiG9E3rkvxi7HLQCKgwDVt5S54>

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

June Awareness Event—June 25th 1-4 pm

We will be meeting at the **Pipefitters Local 120 Hall**

6305 Halle Drive, Cleveland, OH 44125

This is our annual ice cream social (see page 3) Bring your friends and family!

Please R.S.V.P. with the number in your party so we have enough ice cream for everyone.

Call me at 216-218-0477 and LEAVE A MESSAGE or email me at clevelandmggroup@gmail.com

Important Things to know about our Support Group Meetings

Our groups are very welcoming and allow for the sharing of helpful hints and tricks for living with MG. However, it should be said that your own doctor is the one who can best manage your care and treatment. Please check any changes in treatments or medications with your physician first.

FREE CHATS CONTINUE SATURDAY ONLY—Informal Zoom get together—no agenda— just a time to visit. Register once for a Saturday Chat and use the same link to sign in through October.

Saturdays Apr 2, 2022—October 29, 2022 07:30 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/meeting/register/tZEkf-uppzspGN2sscHNI1sjg6lbqlOD5ikU>



Adult Patient Zoom Meetings:

Our regular Thursday 3 pm meetings continue in June. See pg. 1

Our informal chat nights will continue on Saturdays only at 7:30 pm. This is in addition to our structured Zoom meeting. It's a chance for those of you who are homebound to visit with fellow MG'rs in a friendly chat. Registration is still required but you only need to register once for Saturdays. You will be given a link that will be good until the end of October. See above.

Family, friends, and caregivers welcome!

Meeting Notes:

There were 17 people in attendance for our meeting on May 15th at the Parma-Snow library. While we had the same number of people as the last meeting, the participants were different.

A BIG thank-you to Bobbi who provided great coffee and snacks and a thank-you to Nancy for the gluten-free muffins.

This month's meeting will be a celebration of June MG Awareness month. We will have lots of games, prizes, ice cream and fun! (see pg. 3)

The **MG Experience** will be set up for your family or friends to go through and see what it feels like to have MG.

Everyone Welcome Bring the whole family!! R.S.V.P. by 6/20

Dr Robert Ruff recently attended the International Scientific Symposium on Myasthenia Gravis. Here are some of his notes from that symposium. To view his complete notes, go to : www.clevelandmggroup.org

Tuesday, May 10, 2022

8:15 – 9:05 **Session 1- Rationale for Therapeutics in Development Chair: Nils Erik Gilhus, MD, PhD, University of Bergen, Norway**

8:15 – 8:35 **Complement Inhibition: From Basics to RCT Data**, Saiju Jacob, MD, PhD, University of Birmingham, UK

An important observation was the recognition that complement is deposited on the damaged muscle membranes of muscle from people with MG and animals with experimental MG induced by antibodies (Abs) to AChR. Complement is a collection of chemicals that functions as the enforcer of the immune system by attacking and destroying autoimmune targets. Early studies in animals demonstrated that disrupting complement activation would prevent tissue damage in animal models of MG. The trick has been to find ways of safely inhibiting complement so that this strategy can be used to treat people with MG. Current effective strategies employ 1) using antibodies to target components of the complement system, for example eculizumab, or chemical agents that interfere with the complement activation such as zilucoplan.

8:35 – 8:55 **FcRn: Mechanism and RCT Data**, Sally Ward, MD, University of Southampton, UK

Immune modulation in disorders such as MG needs to balance tamping down the immune system without rendering the patient excessively susceptible to infections and other complications of immune suppression. Antibodies (Abs) are circulating chemicals produced by B-cell lymphocytes especially the group of B-cells called plasma cells. Abs bind to specific targets and in so doing can mark their targets for destruction. There are several classes of antibodies. The pathogenic antibodies in MG are the class IgG. Treatments that wipe out all antibodies can render an individual excessively immunosuppressed. Therapeutic strategies for MG include selectively targeting IgG. A recent strategy is to lower the concentration of IgG without eliminating IgG. This strategy is based on the observation that portions of the IgG molecules are recycled by immune cells. Disrupting the recycling of IgG will lower, but not eliminate, circulating IgG. Vyvgart is a recently FDA approved treatment for AChR+ MG that acts by compromising IgG recycling. The lifetime of IgG is short, which enables Vyvgart to have a relatively quick clinical onset. Other agents that act on IgG recycling are being evaluated.

ANNUAL ICE CREAM SOCIAL & MORE!

June is Myasthenia Gravis Awareness Month

To help celebrate June MG Awareness Month, we will be having our annual ice cream social+ a little early.

Saturday June 25, 2022

1– 4 pm

Pipefitters Local 120 Hall

6305 Halle Dr, Cleveland, OH 44125

Not a fundraiser but a FUNraiser!

FREE Games Prizes Food Photo Booth FUN!

Take your family & friends through the [MG Experience](#)

Ice cream (regular, sugar-free, and vegan) supplied. Bring a topping of your choice.

R.S.V.P. to Rebecca at clevelandmggroup@gmail.com by June 20th



LOCAL MGFA GROUP WEBSITE

Visit us at www.clevelandmggroup.org

Have questions or comments? Send in your MG related questions to our **Ask the MG Expert** column

Email at clevelandmggroup@gmail.com

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 COVID19assis-

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

<https://www.needymeds.org/>

[Good Rx.com](http://www.goodrx.com)

<http://www.themedicineprogram.com/>

<http://www.togetherrxaccess.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 June 2022 MEETINGS:

Parents of MGKIDS June 11th 2:00 pm (see page 2)

Annual Ice Cream Social—Saturday, June 25th 1-4 pm (see page 3)

Zoom Meetings—Thursdays 3:00 pm via Zoom (except June 30th see page 1)

OPEN CHAT every Saturday night at 7:30 pm via Zoom (see page 2)

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