

# MG KIDS

**FEBRUARY 2022**

**Volume 2 Issue 2**

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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](http://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](http://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/>



## International Parents of MG KIDS Zoom Meetings—

We will hold two meetings this month on the 2nd Sunday for parents of children with MG. Please click on the links below to register for the meetings:

**Feb 13, 2022 12:00 PM Eastern Time (US and Canada)**

[https://us06web.zoom.us/meeting/register/tZMsf-tqT4vHtLiz\\_cvzToq4kLRcIsRcmtE](https://us06web.zoom.us/meeting/register/tZMsf-tqT4vHtLiz_cvzToq4kLRcIsRcmtE)

**Feb 13, 2022 09:00 PM Eastern Time (US and Canada)**

<https://us06web.zoom.us/meeting/register/tZYqdOChpz0qH9Gq9Rsi9iT6ZFfOCPDdygoR>

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

**Please adjust for your time zone**

**Hope to see you soon on Zoom!**

## MG KIDS CONNECT

Want to connect with other MG KIDS? After considering many options, the best way for MG Kids to connect will be a Zoom meeting set up just for kids to talk and share. These Zoom meetings will require a registration to protect the participants. If your MG Kid would like to join in, please send me the best times for them to meet on Zoom and I will set something up that will work for most. [clevelandmg-group@gmail.com](mailto:clevelandmg-group@gmail.com)



## Ask the MG Expert

**Q. Why is it that some days I'm weaker than others?**

**A.** If your MG is under good control and you experience a bad day seemingly out of nowhere, there may be a few things that could cause your sudden weakness.

**Illness**—Any oncoming illness like a cold or the flu can cause you to feel weaker a full 24 hours before you experience any symptoms like a runny nose or fever. This is because your body is ramping up antibody production to fight off the germs in your body.

**Lack of Sleep**—Getting adequate and restful sleep is essential in keeping you at your strongest. Be sure and develop a good sleep hygiene that includes preparing for bed with some quiet time and staying off screens for an hour or two before bed. Sleeping in a cool, quiet, and dark room also helps promote restful sleep.

**Stress**—Worrying about an upcoming test, field trip, or even the anticipation of a fun event may place extra stress on your body and cause you to feel weaker. Try using some breathing techniques (see page 3) to stay in the moment and help with anxiety.

**Temperature Changes**—Even small changes in your environment, including changes in temperature, may cause undo stress on your body and cause you to have more weakness. Most people with MG experience more weakness with heat but some also find that if the weather is too cold, they will get weaker too.

**Moderation is key**—Try to maintain a schedule that plans for rest periods during the day. If you feel weaker, listen to your body, tell an adult, and take of yourself by getting more rest and doing "downtime" activities.



## 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. **There is a special session on Thursday at 3:20 pm (central time) about pediatric myasthenia.**

**[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](mailto:dlevin@myasthenia.org) or call us at 1-800-541-5454.

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

**I SUPPORT  
RARE DISEASE DAY  
28 FEBRUARY 2022**  
#RAREDISEASEDAY RAREDISEASEDAY.ORG



February 28th is Rare Disease Day. This is a day set aside to bring awareness to more than 300 rare diseases including myasthenia gravis. Find out how you can help bring awareness to your community, school, or business by clicking on the link above. There you will find Rare Disease Day events and downloadable files such as banners to place on your FaceBook page to help you celebrate the day.

### Parents of MG KIDS Zoom Meetings:



We have been averaging about 3-15 people per meeting. It is a great time to connect with each other and share tips and hints for parenting a child with MG

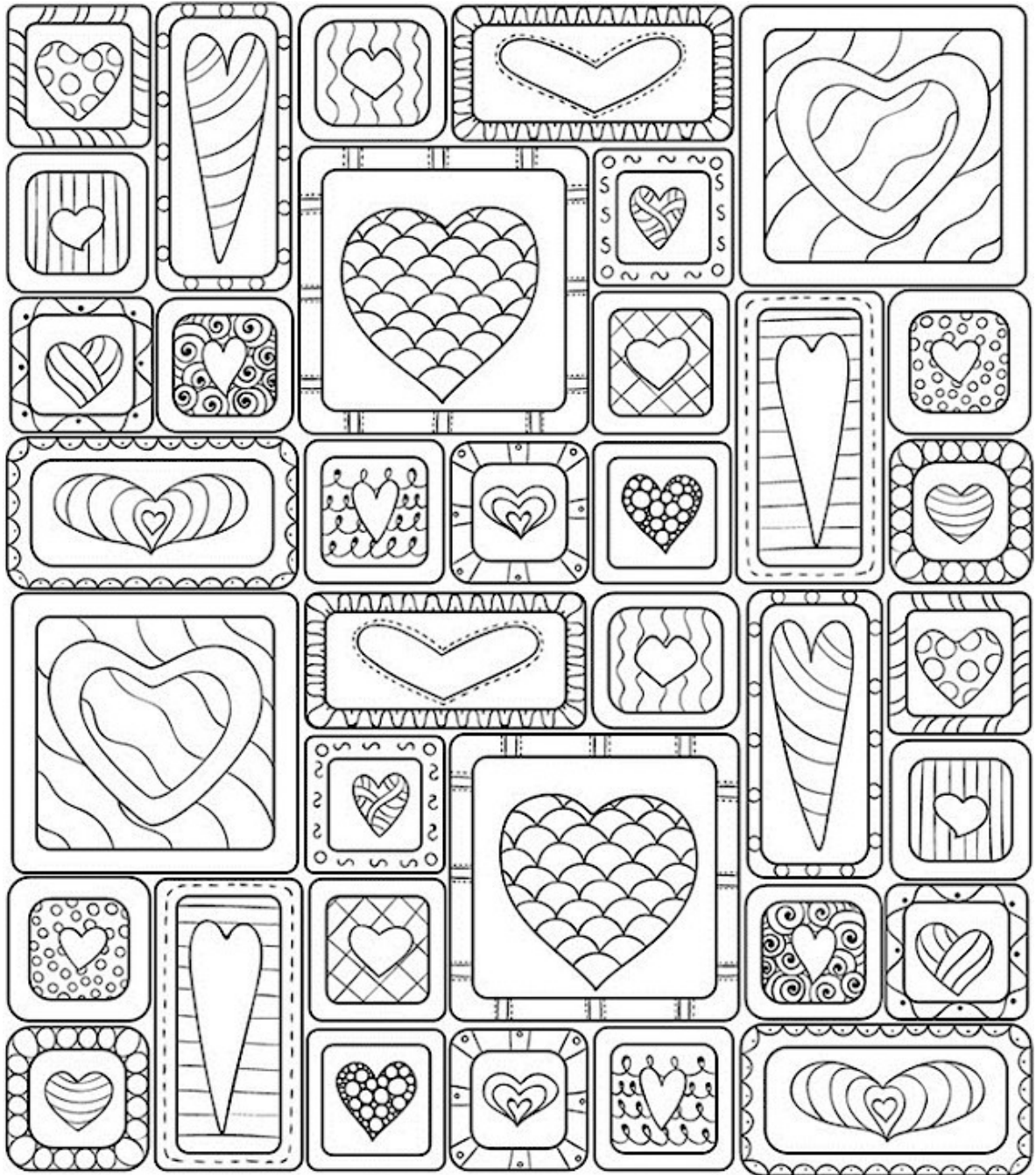
We are usually joined by Dr. Robert Ruff, a retired neurologist/MG specialist who is happy to answer your questions

**Next meetings—Feb 13<sup>th</sup> noon and 9:00 pm (ET U.S.& Canada)**

Please adjust the time for your time zone

**Family and friends welcome!**

**Come and get your questions answered or share what works for you!**



**FUN  
FACT!**

**Did You Know?** Stress of any kind good or bad can make you feel weaker. To help you control your weakness, get plenty of sleep, drink water throughout the day, try and eat a healthy diet, and take a few minutes during the day to clear your mind and just relax and breathe.

Try this simple relaxation technique—breathe in slowly as you count to 4 expanding your belly as you breathe. Hold for a count of 4, then breathe out for a count of 4 returning your belly to its normal position. Repeat for 1 minute.



LOCAL MGFA GROUP WEBSITE  
Visit us at [www.clevelandmggroup.org](http://www.clevelandmggroup.org)

Be sure and send in your MG related questions for our Ask the MG Expert column

Email at [clevelandmggroup@gmail.com](mailto:clevelandmggroup@gmail.com)

**RECIPE CORNER—**

**Chocolate Fudge Cake in a Cup\***

**Ingredients:**

3 tablespoons all-purpose flour  
3 tablespoons sugar  
2 tablespoons cocoa powder  
1/4 teaspoon baking powder  
Pinch of salt, optional  
3 tablespoons milk  
3 tablespoons vegetable oil  
Splash vanilla extract, optional  
3 tablespoons chocolate chips

**Directions:**

In a 12 oz cup, put the flour, sugar, cocoa powder, baking powder and salt if using in a 12-ounce microwave-safe ceramic mug. Blend thoroughly with a fork. Add the milk, vegetable oil and vanilla if using and blend until smooth. Stir in the chocolate chips.

Microwave on high for 90 seconds. Do not overcook or the cake will be dry.

Let cool for 2 to 3 minutes before eating.

\* Recipe from [foodnetwork.com](http://foodnetwork.com)

**Northeast Ohio MGFA Support Groups Website**

We've updated our website. There you can find past and present newsletters, downloadable brochures, and other helpful information including the MGFA Wellness Series and other presentations by MG professionals. There is also a special section just for MG KIDS. Click on the "more" tab to find it.

Check out all of the resources available on [clevelandmggroup.org](http://clevelandmggroup.org)



**UPCOMING FEBRUARY MEETINGS:**

**MGFA National Virtual Conference February 10<sup>th</sup> & 11<sup>th</sup> (see page 2)**

**International Parents of MG KIDS February 13<sup>th</sup> at 12:00 pm and 9:00 pm ET (see page 1)**

Thank you to our sponsors:

