



## Next Parents of MG KIDS Meeting—July 10, 2022



When: Jul 10, 2022 01:00 PM Eastern Time (US and Canada) Register in advance for this meeting:

<https://us06web.zoom.us/meeting/register/tZApdu6urT0rG9xp7lCggFCWWhtUJvk6TdV1>

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

### June Awareness Event—June 25th



We had a great time at our annual ice cream social. Thanks to everyone who attended and brought toppings to share. A Special thanks to Bobbi for help in setting up, Jack for the great chocolates decorated with an MG design, and to our servers, Laura and Suzanne.

Another special thanks to our greeter, Eve, and to Mara and Eve for acting as emcees and prize runners.

Thanks too, to my family for the day before preparations and clean-up duty: Melissa, Kelly, Mara, and Jerry.

### 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-uppzspGN2sscHNI1sjg6lbqIOD5ikU>



### Adult Patient Zoom Meetings:

**Our regular Thursday 3 pm meetings**

**continue in July. 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!**

#### In-Person Meeting Notes:

There were 20 people in attendance for our ice cream social on June 25th at the Pipefitters Hall. Thanks to the great conversations, good ice cream and wonderful toppings, a good time was had by all. There were also prizes ranging from an MG awareness bracelet to an MG shirt to a gift card for Panera. Congratulations to all our lucky winners (everyone who attended LOL).

The **MG Experience** was set up for family & friends to walk through and see what it feels like to have MG.

Our next regular meeting will be July 9th in Parma (see pg.1 for details)

Want us to meet in your neck of the woods? Let me know and I'll work to make that happen.

### **Ask the MG Expert cont.**

- A hand-held magnifying glass is good for a quick fix on bad days.
- Another magnifying device such as the one shown below can regularly help blurry doubled print be easier to decipher. There are several different types available. Do a simple Google search.



MGFA introduces a new online community. Once you register, you will be able to interact with the various components of this new community. Here you will find information about the history of the MGFA, view webinars, download information on treatments, and chat with other MG patients on topics like diet and exercise or share helpful hints for handling life with MG.

## **JOIN THE COMMUNITY**

### **MG Virtual Closet!**

Do you need any durable medical equipment?

Do you have some to share?

Email me at [clevelandmggroup@gmail.com](mailto:clevelandmggroup@gmail.com) and I will add it to the closet inventory. Some of the items available for short term use include walkers, wheelchair ramps, and toilet seat raiser.

Likewise, if you need some equipment, please state what the item is and your anticipated length of time that you'll need the item. Don't forget to include your name and contact info. Thanks! We can all use a little help now and then.

### **In-Person Meetings**

As we start to meet in person once again on a regular basis, please keep in mind that Covid is still around. If you feel sick or if you have been exposed to a person who tested positive for Covid, please do not attend a meeting until you are sure you are not ill.

For right now we are having one meeting a month. Soon, we will start increasing the meetings to include an eastside location, a far westside location, as well as a west-central location. If you have an idea for a meeting location or would like to have a meeting in your area, please email me with the suggestion.

Likewise, if you have an idea for an outing for our group, please let me know.



## LOCAL MGFA GROUP WEBSITE

Visit us at [www.clevelandmggroup.org](http://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](mailto: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-](mailto: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.togetherrxaces.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>



We travel, not to escape life—  
But for life not to escape us.

\_\_\_\_ Author Unknown



### UPCOMING July 2022 MEETINGS:

Parents of MGKIDS July 10<sup>th</sup> 1:00 pm via Zoom (see page 2)

Adult MG Patients & Friends—Saturday, July 9<sup>th</sup> 1-3 pm (see page 1)

Zoom Meetings—Thursdays 3:00 pm via Zoom (see page 1)

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

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