

# MG KIDS

**MARCH 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](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:

When: Mar 13, 2022 12:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/j/84461212693>

When: Mar 13, 2022 09:00 PM Eastern Time (US and Canada)

<https://us06web.zoom.us/j/84461212693>

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

NOTE: The Zoom will be broadcast in the eastern daylight savings time zone as we are shifting ahead one hour.

Here is a helpful link to figure out the meeting time in your time zone:

<https://www.timeanddate.com/worldclock/converter.html>

**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)

NOTE: So far only 1 response, please let me know if this is something your child would like to do.

**Volume 2 Issue 3**

## Ask the MG Expert

### Got those winter Blues?

A lack of sun in the wintertime, especially for those of us living in the northern U.S., can lead to low vitamin D and seasonal sadness. Kids are not exempt from feeling blue due to circumstances or low light levels in winter.

While severe clinical depression may need medication and therapy to alleviate its symptoms, there are several things you can do now for seasonal or situational blues and help yourself feel better:

Get out of your normal pattern. If you eat the same thing every day, go to school the same way, and do the same things each day shake it up a little:

Take a new path to school or to the store.

Try a new food.

Watch a funny video.

Learn a new skill or read a new book.

Spend some time under a full spectrum light each day to increase your vitamin D absorption

Play some happy music. *Three Little Birds* by Bob Marley is a good choice.

Contact a friend or family member and ask them how they are doing.

Retrain your brain. Every time you catch yourself thinking about how bad it is, tell yourself to STOP.

Be kind to yourself. Conquering the blues takes time and practice, but by learning some new skills to help you cope, you'll get there.

## So, What's up with St. Patrick's Day anyway?

The real St. Patrick wasn't even Irish.\*

He was born in Britain around A.D. 390 to an aristocratic Christian family with a townhouse, a country villa, and plenty of slaves. What's more, Patrick professed no interest in Christianity as a young boy, Freeman noted. At 16, Patrick's world turned. He was kidnapped and sent overseas to tend sheep as a slave in the chilly, mountainous countryside of Ireland for seven years. "It was just horrible for him," Freeman said. "But he got a religious conversion while he was there and became a very deeply believing Christian." According to folklore, a voice came to Patrick in his dreams, telling him to escape. He found passage on a pirate ship back to Britain, where he was reunited with his family.

The voice then told him to go back to Ireland. "He gets ordained as a priest from a bishop and goes back and spends the rest of his life trying to convert the Irish to Christianity," Freeman said. According to St. Patrick's Day lore, Patrick used the three leaves of a shamrock to explain the holy trinity: the Father, the Son, and the Holy Spirit. After he died on March 17, 461, Patrick was largely forgotten. But slowly, mythology grew up around Patrick. Centuries later he was honored as the patron saint of Ireland, Freeman noted.

Until the 1970s, St. Patrick's Day in Ireland was a minor religious holiday. A priest would acknowledge the feast day, and families would celebrate with a big meal, but that was about it. "St. Patrick's Day was basically invented in America by Irish-Americans," Freeman said. Timothy Meagher is an expert on Irish-American history at Catholic University in Washington, D.C. "Eighteenth-century Irish soldiers fighting with the British in the U.S. Revolutionary War held the first St. Patrick's Day parades. Some soldiers, for example, marched through New York City in 1762 to reconnect with their Irish roots. Other parades followed in the years and decades after, including well-known celebrations in Boston, Philadelphia, and Chicago, primarily for flourishing Irish immigrant communities." Today we still celebrate St. Patrick's Day by holding parades and wearing green shamrocks.

\* Source <https://www.nationalgeographic.com/animals/article/100316-st-patricks-day-facts-shamrocks#:~:text=According%20to%20St.,a%20shamrock%20out%20of%20tradition>.



# I SUPPORT

## RARE DISEASE DAY

### 28 FEBRUARY 2022

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FREE BOOK from  
RARE PATIENT DAY  
2022!

<https://clevelandmgroup.org/for-mg-kids-%26-parents>

To download a copy of the free book *A Friendship Story* by Danijela Knez and Ivan Drajzl click on the link above and scroll down to "Helpful Pamphlets" and click on *A Friendship Story*.

### 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—MARCH 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!**



Myth has it that if you can catch an Irish Leprechaun, he will have to give you all his gold.

What would you do with a pot of gold?

Write me and let me know. I will post your answers next month:

[clevelandmg-group@gmail.com](mailto:clevelandmg-group@gmail.com)

## **FUN FACT!**

**Did You Know?** You can assess how well you are breathing by doing a fun exercise. Take a glass of water and a straw. Blow into the straw to create bubbles in the water. If you can do this for 20–30 seconds, you are breathing well.

In fact, this is a good way to strengthen your diaphragm (the muscle you use to breathe). Practice this technique a few times a day when you are feeling strong to help maintain strength in this muscle. Have an adult time you to see how long you can blow the bubbles. Record the times to keep track. Do not do this exercise to the point of weakness or when you are feeling weak overall.

## 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—

#### Irish Soda Bread

##### Ingredients:

3 1/2 cups all-purpose flour (I use gluten-free flour)

3/4 cup sugar

1 tablespoon baking powder

1 teas baking soda

1/2 teas salt

1 + 1/2 cups milk

2 tablespoons butter

1 cup raisins

1 beaten egg

##### Directions:

Preheat oven to 375 °F

Grease two 9 inch round cake pans and set aside

In a large bowl, mix dry ingredients until well blended

Place milk, raisins, and butter in a microwave safe bowl

Microwave on high for 60 seconds or until butter is melted

Let a cool a few minutes then add to dry ingredients

Add egg and stir until well combined

Divide dough in half and spread each half into prepared cake pans

Sprinkle top of dough with a little sugar

Bake in a 375 °F oven for 20-22 minutes until golden brown

Let cool 10 minutes then remove from pans. Enjoy!

#### 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 MARCH MEETINGS:

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

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