

MG KIDS

JANUARY 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/>



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:

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

[https://us06web.zoom.us/meeting/register/tZcsdempqjwuE9SmNtLXX7L_xEKfhvLEdOkC](https://us06web.zoom.us/join/https://us06web.zoom.us/meeting/register/tZcsdempqjwuE9SmNtLXX7L_xEKfhvLEdOkC)

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

[https://us06web.zoom.us/meeting/register/tZArD-2trTgqE9VHTcD7nnc-Zgx3QYjgpxpp](https://us06web.zoom.us/join/https://us06web.zoom.us/meeting/register/tZArD-2trTgqE9VHTcD7nnc-Zgx3QYjgpxpp)

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

Volume 2 Issue 1

Ask the MG Expert

Q. My friends don't understand when I can't run and play like they do. How can I explain MG to them?

A. Your friends may be insensitive because they don't fully understand what MG is or how it affects you. Here are a few ideas that can help your friends and relatives to know what MG is like.

Educate them —myasthenia.org is a website where you can download brochures about MG. You can also direct your friends and family to this website where they can read about other MG patients' stories and find out about treatments and medications for MG.

Show them what it feels like—at <https://clevelandmggroup.org/mg-experience> you can download a printable pdf file that contains information and explanations of simple experiments that a person can do to better understand what a neuromuscular disease like MG feels like. With the help of your parents, ask your teacher or school administrator if it would be possible to have an MG sensitivity day in which fellow students can try the different experimentation stations and learn about what MG is and how it affects your strength and endurance.

What if the lack of understanding turns into teasing and bullying?— If your classmates' comments about your MG have escalated to the point of bullying, tell someone. Tell a parent first, then with their help, approach your teacher or school administrator. You should not have to put up with constant comments or teasing.



MGFA



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.

MG Virtual Closet!

Do you need any durable medical equipment?

Do you have some to share?

Email me at clevelandmgroup@gmail.com and I will add it to the closet inventory.

Likewise, if you need some equipment, please state what the item is and your anticipated length of time that you'll need the item.

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

Jan 9th noon and 9:00 pm Times listed are in the eastern time zone (U.S.)

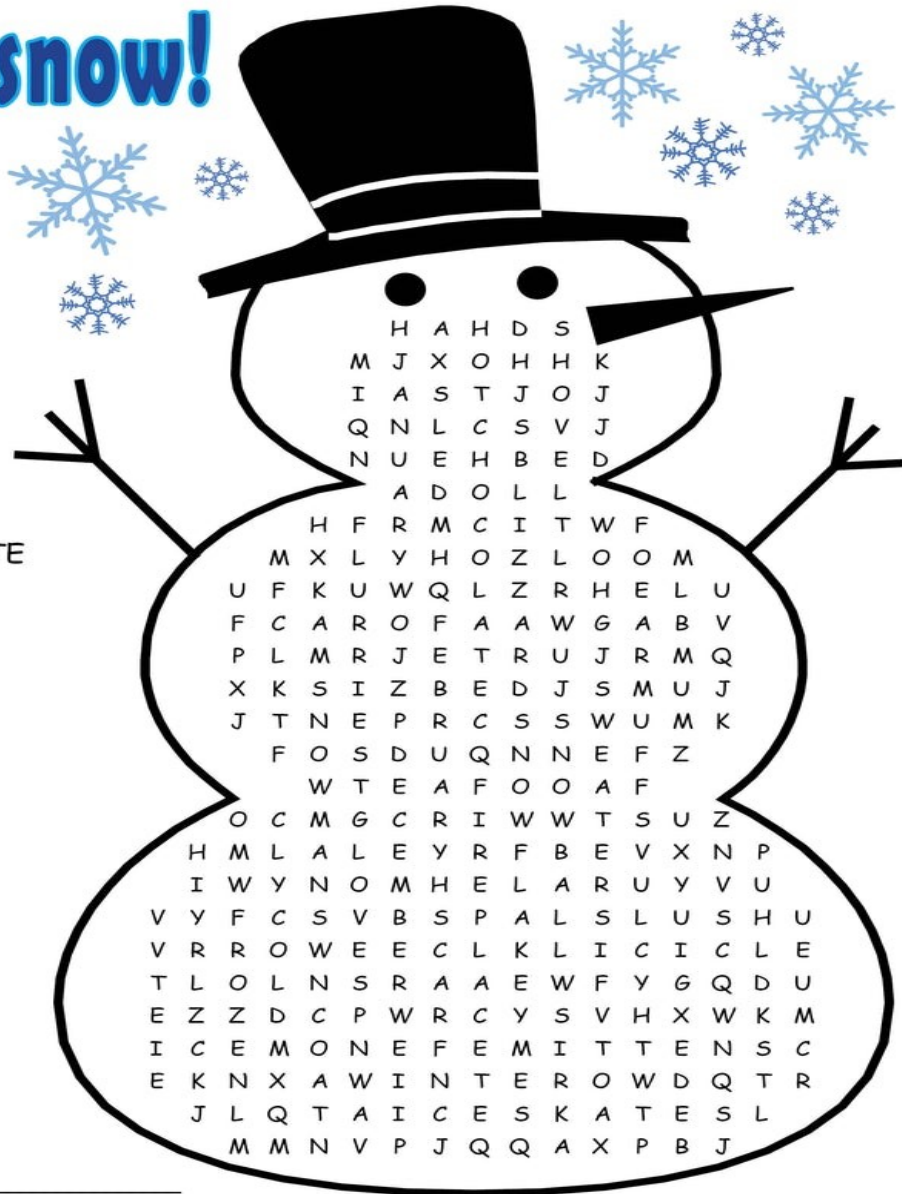
Please adjust the time for your time zone

Family and friends welcome!

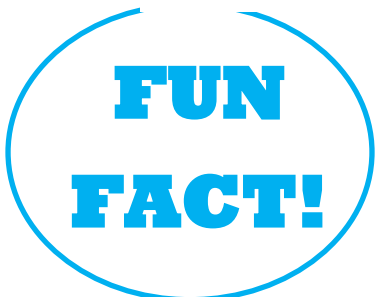
Come and get your questions answered or share what works for you!

Let it snow!

BLIZZARD
 COAT
 COLD
 DECEMBER
 EARMUFFS
 FEBRUARY
 FIREPLACE
 FLURRIES
 FROZEN
 GLOVES
 HOT CHOCOLATE
 ICE
 ICE SKATES
 ICICLE
 JANUARY
 MITTENS
 SCARF
 SHOVEL
 SLED
 SLUSH
 SNOWBALL
 SNOWFLAKE
 SNOWMAN
 SWEATER
 WINTER



Name: _____



Did You Know? If you start to choke while eating, tilting your chin to your chest will sometimes help you to breathe until you can swallow again. If the choking is bad and you are alone, there is a self-Heimlich maneuver that is worth learning.

Check out how to perform this here. <https://www.youtube.com/watch?v=FEr9jjZ6fi8>

LOCAL MGFA GROUP WEBSITE
 Visit us at www.clevelandmggroup.org

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

Email at clevelandmggroup@gmail.com

RECIPE CORNER—

Quick and Easy Chicken Stew:

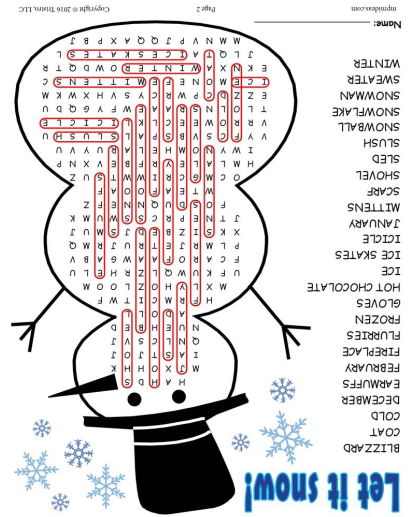
Ingredients:

- 4 chicken thighs or 2 chicken breasts
 - 1 can diced tomatoes
 - 1 can tomato paste after spooning out, use to fill with 3-4 cans water and add to pan
 - 3 stalks celery cut up into small pieces (I peel my celery first to remove strings that may cause choking)
 - 1 cup cut-up carrots
 - 1 cup diced green or red bell peppers
 - 1 diced onion
 - 3 cups cubed potatoes or fingerling potatoes
- Add a pinch of salt, some garlic salt or garlic powder and Italian seasoning to taste

Directions:

Place all in an oven safe dish and bake in a 375 °F oven for 60-90 minutes until the chicken is thoroughly cooked. Chicken is done when it has reached an internal temp of 165°F

“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



Key to puzzle on page 3

UPCOMING JANUARY MEETINGS:

International Parents of MG KIDS January 9th at 12:00 pm and 9:00 pm ET (see page 1)

Thank you to our sponsors:

