

HI EVERYONE!

Happy New Year! I hope you all had a wonderful holiday season. 2018 is full of potential for making a difference. I'm so proud of everything you all did last year. Let's make this one even better!

I would like to introduce the new **Act of Kindness pin!** It is the seventh pin you can earn (check out the back page for more information). Also, we will soon be sharing with you what you will receive if you complete an activity for a second year.

This is the first time the newsletter is being delivered to your house. I hope you take some time to read it and play the games. Now you can put them in a folder and read them in the future, too. Is there anything you would like us to change or add to the newsletter? I would love to hear your feedback! You can send your comments to kids-crew@efa.org.

I want to finish by wishing you a fantastic new year. If you are having a rough time right now, stay strong and have hope! Thank you for joining the Kids Crew and helping your community. Always remember that kids can change the world!

Your friend,



Hailey

Hailey Scheinman
President & CEO
Epilepsy Foundation
Kids Crew



UPCOMING EVENTS



National Walk for Epilepsy

The National Walk for Epilepsy will be on Saturday, April 14th in Washington, DC. This year is going to be bigger and better than ever! The Epilepsy Foundation is celebrating 50 years of serving the



community and we would love to have you join us. We will have music and entertainment and it is a great time to walk together to show support for those living with epilepsy. Hailey will be at the walk again this year with a Kids Crew table. She will have some cool new surprises for you. **If you do attend, make sure to wear your Kids Crew lanyard so others know you are a part of the crew.** Don't forget, if you can't make it, you can join the walk as a virtual walker or you can find another Epilepsy Foundation walk closer to home. If you participate in a walk, make sure you tell us so we can send you your **Walked Together pin.**

TATUMN, AGE 10



Purple Pumpkin Project

Tatumn is 10 years old and was diagnosed with epilepsy when she was 14 months old. Over the years, she has had different types of seizures. She has to take medicine every day to control her seizures, but she doesn't let her "shakies" control what she does. Tatumn is involved in MMA (mixed martial arts) and dance (tap, ballet and hip hop). She also plays soccer and softball and loves to sing.

**SHE BELIEVES THAT
EPILEPSY ISN'T WHO
SHE IS, IT'S JUST A
PART OF WHO SHE IS.**



Tatumn's parents are very supportive of all she does and encourage her to try new things. At the beginning of every school year and summer camp, her mom and dad have meetings with all her teachers and guides to go over her epilepsy emergency plan.

They always attend her doctors' appointments, as well as her MMA and dance classes and recitals. They stand with her no matter what. Tatumn has proven to them that she is a "warrior!" She doesn't let epilepsy get in the way of her goals. In the past, when she wasn't having a good day because of her seizures, she would have a "PJ movie day" with her mom. But even on those days after her seizures, she would not let those "shakies" keep her down.



In October, Tatumn participated in the Purple Pumpkin Project. She went to the store and picked out a white pumpkin and

a big orange one. She also picked out paints and decorations. When she was done painting and decorating them, her mom helped her post the pictures online. When they posted them, all her friends from MMA said they wanted to paint a purple pumpkin next year. So Tatumn asked her mom if they could have a Purple Pumpkin Party in 2018 and she said YES! Tatumn also held an epilepsy awareness event in November during National Epilepsy Awareness Month. At her school, the students wear uniforms



Tatumn likes tap, ballet and hip hop



#MyShotAtEpilepsy

She knows that epilepsy can often be an “unseen medical condition” and she wants to be able to “help people see it.” Living with epilepsy has often been hard for Tatumn but she keeps a positive attitude in all that she does. She believes that epilepsy isn’t who she is, it’s just a part of who she is. For other kids who have seizures,

Tatumn would like to say, “I know it can be hard and you may be tired sometimes but please don’t let epilepsy stop you from doing what you like. I still do the things I like; I just do them differently and that’s okay. I love who I am and I do not let my epilepsy hold me back. A positive mind can take you to really good places.”

and Tatumn thought it would be cool if one day during the month her class could wear a purple shirt to support epilepsy awareness. So she asked her teacher who then went to the principal to get approval. Tatumn’s principal let the whole school wear purple on a day to support epilepsy awareness! Tatumn thinks it’s important for people to learn about epilepsy and create awareness because there are different kinds of seizures. She has more than one type of seizure and not everyone knows what a seizure looks like. She thinks the more someone knows about epilepsy the more they can help people who have seizures.



Mixed martial arts

WILL, AGE 9 AND CHAROLET, AGE 8

Will, now 9 years old, was 5 when he started having seizures. Will's parents took him to the doctor because they knew something was wrong. The doctors told Will that he had epilepsy. Soon, he was having 80-100 seizures every single day.

Will eventually went to a hospital in Ohio where he started the ketogenic diet (a special therapy where people eat a special high-fat, low-sugar diet). After two weeks, his seizures stopped! He didn't like the diet because he had to drink a lot of oils and couldn't have many of the foods he enjoyed. But he thinks it was well worth it because he got to start being himself again and doing the things he loved like riding his bike. Now, he also plays basketball and baseball and loves jumping around doing parkour.

During the time Will was having seizures, the only thing that kept him positive was knowing everyone who loved him was trying their hardest to help. One of those very important people was his 8-year-old sister, Charolet. She was 4 when Will had his first seizure and remembers being with him



Will and Charolet

through most of them and being scared. Every time Will had to stay a long time in the hospital, she would visit him. Charolet said, "I told him I was like his little nurse. I would hold his hand and tell him I would take care of him." When Will started his special diet, it changed how their family ate. But Charolet was happy to help Will feel more comfortable. "I would eat butter with him so that he didn't feel like he was doing it all by himself. I did not like the butter, but it made Will happy to know I cared and would do anything for him".

Their whole family is involved in the epilepsy community. Every year, they organize a team for their local Epilepsy Foundation walk



Parkour

and call it Team Will-Power. Will's family also organizes a big Purple Pumpkin event at his school and another nearby school. This year, they decorated purple pumpkin pails. The event gives Will a chance to share his story and talk with other people who have epilepsy or might know someone with it. "No one in my class knew anything about epilepsy, but now everyone in our school and other schools know what to do when people have a seizure." Charolet also helps with the event and adds, "We went from class to class and talked to kids about epilepsy while they decorated their purple pails. It was really cool to talk to them about why we do purple pails and what they could say to anyone who asks them about their purple pail."

Will and Charolet have become a wonderful team of advocates. Will knows it is important to teach other kids about epilepsy so if they see someone having a seizure, they know what to do. He thinks it is a good idea to start teaching kids about it when they are young so when they grow up, they will talk about it with their friends and their own kids. Charolet feels it is especially important



Purple Pumpkin Project at school

for kids to teach other kids and believes, "Parents and adults feel different than kids, so sometimes kids understand it more when other kids talk about it and not adults. Grownups use too many big words!"

**...THERE ARE LOTS OF PEOPLE
OUT THERE LOOKING OUT FOR
YOU AND TRYING TO FIND A
CURE FOR EPILEPSY.**



Earning their Purple Pumpkin Project pins

Will also has some advice for other kids going through a tough time. He encourages kids to be positive and offers, "Just know that it will be okay and you will get through it. It is not fun to have seizures...It's really scary, but there are lots of people out there looking for you and trying to find a cure for epilepsy. Never give up!" For siblings of kids with epilepsy, Charolet says, "Just stay with your brother or sister and help as much as you can. They are just as scared as you are but knowing you're right there with them makes them feel a lot happier and a lot less scared."

HOW-TO TIPS

Sleep and epilepsy are closely connected. Sleep can affect how often someone has seizures, when they occur, and how long they last. Not getting enough sleep can make seizures worse. Try these tips for getting the right amount of sleep.

Go to bed around the same time each night.

Turn off all electronic devices at least an hour before going to bed.

Make sure your room is dark, quiet, and cool.

Get plenty of exercise during the day.

Use a comfortable mattress and pillow.

These are good rules to follow even if you don't have epilepsy.



EPILEPSY FACTS

What happens during a seizure?

In the beginning of a seizure, some people may have different feelings, become more or less sensitive, or have changes in behavior that can last hours or days. Electrical activity changes in the brain during the middle of a seizure. The end of the seizure is a time people recover from what happened.

You may not see every part of a seizure. It can be hard to tell when one part starts and another begins.

The ways people experience the stages can be different. For example, some people may not even know a seizure is starting.

"IT ALWAYS SEEMS IMPOSSIBLE UNTIL IT IS DONE" - NELSON MANDELA



CREATING AWARENESS TIPS



International Epilepsy Day is coming up on Monday, February 12th and Epilepsy Awareness Day is on Monday, March 26th

Both are days when you can earn your Created Awareness pin. Invite some of your friends over to your house for a purple themed party. Then you can share some epilepsy facts with them. How about making some purple cookies or cupcakes that your parents can take to work? You can make some epilepsy fact cards that go with each treat. You could also earn your Educated Others pin. Either day is a great time to ask your teacher if you can talk to your class about epilepsy.

WINTER WORD SCRAMBLE

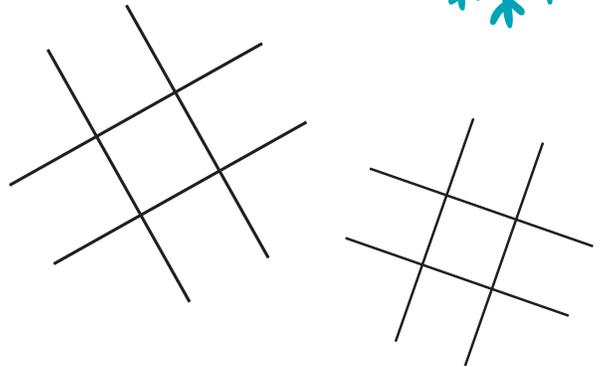
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- gienpnu _____
- sbnowlal _____

Answers: cold, jacket, shovel, skiing, gloves, chilly, winter, fireplace, frozen, penguin, snowball

JOKES & RIDDLES

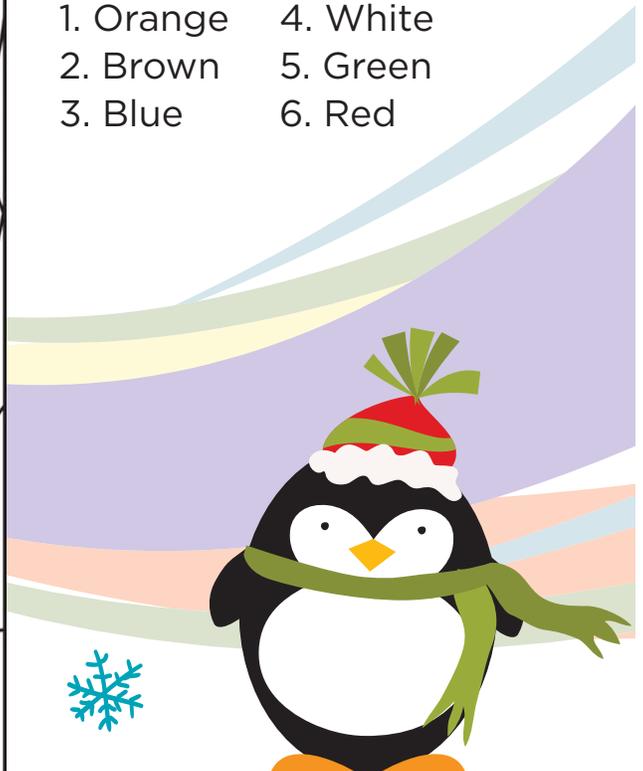
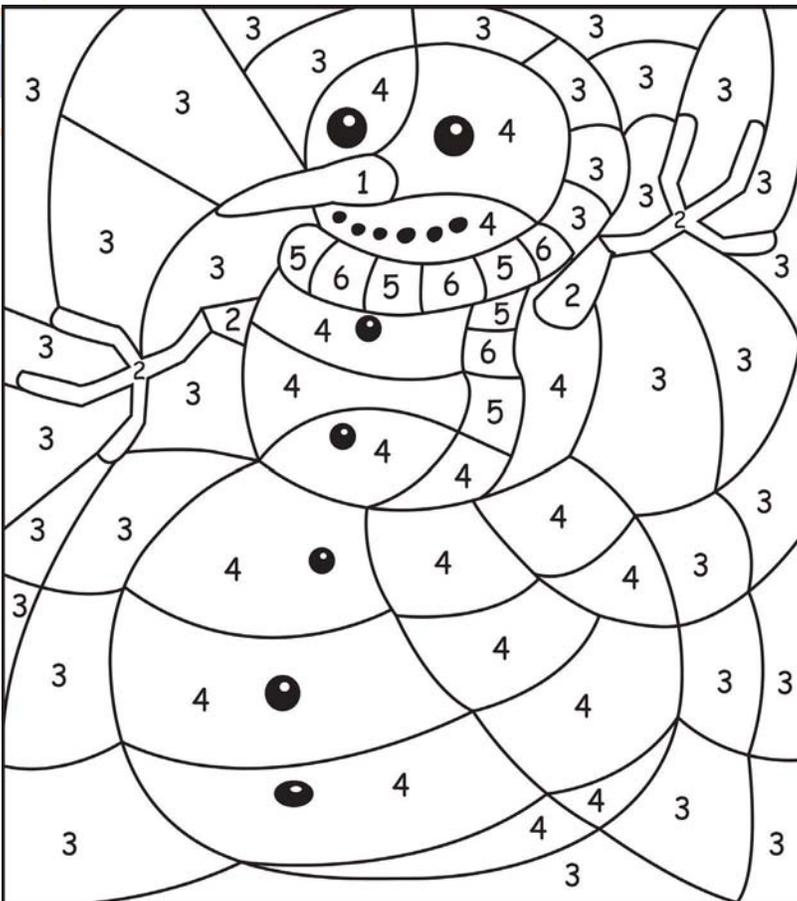


- Q:** What did Frosty call his cow?
- A:** Eskimoo!
- Q:** Which one is faster, hot or cold?
- A:** Hot. You can catch cold!
- Q:** How do snowmen greet each other?
- A:** Ice to meet you!



COLOR BY NUMBER

- 1. Orange
- 2. Brown
- 3. Blue
- 4. White
- 5. Green
- 6. Red



NEW

ACT OF KINDNESS PIN!



How to Earn Your Pin:

- Do something nice for a person (kid or adult) who has epilepsy or who is taking care of someone with epilepsy.
- Complete a project for a bunch of people with epilepsy, that's even better!

Some ideas are to paint a picture with an inspiring message and deliver it to the person, make cards to take to hospitals for kids being treated for epilepsy, or make a meal for a family going through a difficult time with seizures.

To earn your Act of Kindness pin, complete your activity and tell us what you did. Pictures are always great!

