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## Helping Youth Cope with a Medical Condition

Having a medical illness such as epilepsy can be very confusing, overwhelming, and frustrating for our kids. Parents and caregivers often express uncertainty about their ability to help their child cope with the diagnosis. Here are a few suggestions that might help:

**Openly discuss your child's diagnosis and validate their concerns.** Create opportunities for your child to ask questions about his or her diagnosis. Provide honest information that is appropriate for their age. Be understanding as they share their concerns and provide comfort and reassurance. For example, "I know it's hard to take your medicine every day, but remember that this will help keep you healthy!" or "I would be frustrated too if I had to stop playing football. Let's think about other activities that you might be able to enjoy."

**Keep your typical family routine as much as possible.** Try to avoid being overprotective or overly easygoing. It's best to keep daily routines and expectations as similar as what you would follow if your child did not have a medical illness.

**Consider rewards for completing daily medical tasks such as medicine taking.** Examples of rewards include verbal praise, extra time with friends, going to a movie, providing a favorite snack, shopping, or saving for a larger reward.

**Teach Coping Strategies.** The following are tips for coping with stressful situations:

- Positive self-talk—examples: "I'm going to be okay." "I know I can do this." "I'm really good at knowing just what to do to help myself feel better."
- Deep breathing
- Talk to a friend or trusted adult
- Write down feelings in journal

**Seek support when needed.** Caregivers often ask, "When should I reach out for additional help?" Caregivers are encouraged to talk to their child's medical provider at any time; however, it is very important that they talk with their neurology provider if they see any of the following:

- A major shift in mood or behavior
- Problems with school work
- An increase in conflicts with friends or family
- Poor cooperation with medical treatment recommendations
- Withdrawal from others or decreased interest in enjoyed activities

Coping suggestions provided by **Hillary Thomas, PhD**. Dr. Thomas is a pediatric psychologist that provides psychological services to patients in the Epilepsy Center. She is available to assist patients and their families navigate the social, behavioral, and emotional challenges of having a diagnosis of epilepsy. Please talk to your epilepsy provider if you are interested in learning more about this service for your child.

# Summer Safety Tips

Heather Petrie, RN, CPNP- PC

Summer is here! Before the fun can begin, let's review some summer safety tips. Having epilepsy does not mean children should stay indoors, but certain considerations and precautions should be made.

Whether it is lakeside, poolside, or seaside--water safety is very important!

- Children with epilepsy should always swim within reach of a buddy.
- An adult who is familiar with seizure first aid should always supervise a child with epilepsy while swimming.
- If going out on a boat or jet-ski, life jackets are a must!
- All children, including those with epilepsy, should learn to swim.

When riding bikes, scooters, roller blades, or anything with wheels, a helmet should always be worn. This also includes horseback riding.

If traveling by car, boat, plane, or train:

- Always pack extra medication in case some is lost or changes to travel plans extend your trip.
- Medications need to remain in their bottle and stored in carry-on bags when traveling in case you become separated from your luggage.
- Contact your pharmacist about ways to obtain more medication in the event something happens to your child's supplies.
- Be careful about leaving medications in hot cars. Excessive heat could lead to them becoming damaged.
- Don't forget the Diastat or any other rescue medications that are a part of your child's seizure first aid plan.

Keep in mind your child's triggers for seizures. Common triggers include:

- Sleep deprivation--try to maintain a normal sleep routine during the summer, while out of town, or if your child attends a sleep over.
- Missed doses of medication--set alarms or download medication apps for reminders.
- Some children are sensitive to flashing lights—keep this in mind when driving over bridges or past trees when the light is shining through. Have your child close their eyes if this is a trigger.

Here are some considerations for certain anti-seizure medications:

- Sun screen is a must for everyone who ventures outside in the summer sun. However, some medications can cause increased sensitivity to sunlight leading to sunburn. These include **Depakote, Tegretol, Lamictal, and Topamax**.
- Certain medications decrease a person's ability to sweat and cool themselves off. These include **Topamax and Zonegran**. If your child takes either of these medications it is very important that they stay well hydrated especially while outside.

There's nothing like summer vacation for children and this does not change for kids with epilepsy. Follow these guidelines to ensure a fun, happy, and safe vacation!



# Laura Joins the Epilepsy Team



## How long have you worked at Children's and what is your role?

I have been with Children's for a little over 2 years. I just joined the Neurology team as a Scheduler (ASR).

## What is your favorite food?

I would have to say it is authentic Mexican food especially when it is homemade. You can never go wrong with fresh, handmade tortillas.

## Name 3 favorite things you do when not at work.

I enjoy spending time with family. I love to travel and learn about different cultures. I'm not a big fan of flying so I

prefer to drive! And thirdly, I like to cook. I love learning family recipes and the stories that come with them.

## What is your favorite tv show or movie?

Sherlock Holmes movies are my all time favorites. I enjoy mystery shows because they keep me on the edge of my seat!

## Tell us about your family.

I come from a family of 4 with me being the only girl out of 3 brothers. I just recently married and am enjoying time with family.

## What is the best part about working at Children's?

Learning something new everyday. You come across so many different situations so everything is a learning experience.

### Keto-friendly Roll-Up

#### Ingredients:

- 21g whole iceberg lettuce leaf, choose an outer leaf that is flexible
- 17g genoa salami, Applegate Farms Organic was used for calculation
- 18g Marie's Creamy Italian Garlic Salad Dressing
- 14g oil, use a mild flavor oil such as safflower or canola



#### Directions:

- 1) Rip off one outer leaf of iceberg lettuce. Trim to 21g. Avoid using the hard stem close to the core.
- 2) Lay the salami on top of the lettuce leaf. Fold in the edges of the leaf so it is the same width as the salami. Roll the leaf around the salami. Secure it with a toothpick or a fun shaped bento pick.
- 3) In a small bowl, combine the salad dressing and oil. Use a small fork to stir the dressing until it is completely combined with the oil.
- 4) Use the dressing as a dip for the roll-up.

#### Notes:

- Commercial salad dressing is very flavorful. It is a great option to add more fat to since the flavors will hide most of the oil taste.
- The salad dressing and oil will separate as it sits. Just stir again to combine.

### KetoCal Mock Baked Potato Soup (4:1)

#### Ingredients:

- 120g Formula: KetoCal 4:1 LQ (measure in mL) Nutricia
- 50g cauliflower, raw
- 2g Bouillon, Wylers Instant-Beef/Chick granules
- 19g oil, olive
- 3g cheese, Kraft Cheddar (mild, medium, sharp)
- 4g onions, spring or scallions (tops and bulb)-raw
- 4g bacon, cooked crisp-Oscar Mayer



#### Directions:

- 1) Steam or boil the cauliflower until soft, then blend using a hand mixer or food processor. Add a small amount of water if needed.
- 2) Add KetoCal, oil, pureed cauliflower and bouillon (dissolved in 15g water) to pot on low heat.
- 3) Cook bacon to crisp in microwave, add half (2 g) to soup mixture and save other half for garnish.
- 4) Add black pepper and poultry seasoning, if desired.
- 5) Let simmer for 10-15 minutes to allow to thicken slightly.
- 6) Just prior to serving, top with shredded cheese, chopped green onions and remaining (2 g) of bacon.

**\*\*Please note: These recipes are intended for children on the ketogenic diet.**

# Upcoming Epilepsy Events

## Family Epilepsy Camp

—Camp EEG is for families that have a child or children with epilepsy; will take place October 13-15, camp is held at Camp John Marc in Bosque County, TX

## Wacky Winter Weekend Camp

—Camp for children with epilepsy and their siblings ages 6-17 that takes place in January, camp is held in Anna, TX

\*\*Applications will be available online at [eflx.org](http://eflx.org)

## Teen Group

Fall Session Begins October 7th  
Saturday from 10:30am-12:30pm

Texas Star Conference Room at Children's Specialty Center

\*\*Info on how to attend the group online go to Epilepsy Foundation Texas page on Facebook

## Grupo de Apoyo de Epilepsia

28 de septiembre  
5:30 a 7:30pm

Ambulatorio Pabellón de Children's  
Sala de la Independencia  
2350 N. Stemmons Freeway  
Dallas, TX 75207

## Calling all Teens!

**What:** Bowling, Food, and Fun

**Where:** Main Event in Grapevine, TX  
(407 W. State Hwy 114 Grapevine, TX 76051)

**When:** Saturday, August 12 11am-1pm

**Who:** Teens living with Epilepsy  
age 12 and older

**Cost:** Free!

Please RSVP at  
[epilepsyprogram@childrens.com](mailto:epilepsyprogram@childrens.com)

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## Epilepsy Word Search

- **Medicine** (what people take to keep from having a seizure)
- **Trigger** (something that causes a seizure)
- **Sleep** (important for your body)
- **Nervous system** (system that sends messages back and forth from the brain to different parts of the body)
- **VNS** (small device placed under the skin that can stop a seizure)
- **Action Plan** (a way for others to know how to help you during a seizure)
- **Clinic** (where you go to visit your doctor)
- **CT scanner** (machine)

Comprehensive Epilepsy Center

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Would like to share your story in our newsletter? Email suggestions to Lauren Suttle at

[epilepsyprogram@childrens.com](mailto:epilepsyprogram@childrens.com)

