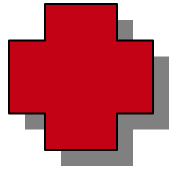


Epilepsy First Aid



- Stay calm and provide comfort
- Protect the person from injury but don't restrain their movements.
- Watch their breathing– turn them on the side to help keep airway open.
- Watch how long the seizure lasts. If longer than _____ minutes, give rescue medication. If it continues for another two minutes call 911.
- Don't put anything in their mouth during seizure.
- Stay with the person after the seizure until they are aware and safe.
- Some seizures will make them frightened or anxious, be calm and comforting.
- Know when to call 911.

Emergency Contact Information

Name _____

Relationship to patient

Phone _____

Alternate Phone

Special Instructions:

Current Medications

Rescue Medication:

Understanding Hypothalamic Hamartomas



For more information go to:
www.hopeforhh.org

What is HH

Hypothalamic Hamartoma (HH) is a rare brain lesion that causes a syndrome characterized by:

1) treatment-resistant epilepsy, beginning with Gelastic (laughing) or Dacrystic (crying) seizures, but later including other seizure types

2) developmental and cognitive deficits

3) behavioral problems, including uncontrollable outbursts of anger followed by remorse or no memory of the event

4) endocrine disturbance including temperature deregulation, growth issues and most commonly central precocious (early) puberty.

It is common for the disorder to progress as the individual ages and the seizures worsen, becoming longer and more involved, and with more seizure types. The seizures are often poorly controlled or completely unresponsive to the standard seizure medications.



What are the symptoms

- *Gelastic seizures are called the “laughing seizure” because they may look like bouts of uncontrolled laughter or giggling. However, the laughter-like sounds are often forced and combined with a facial contraction similar to a smile or smirk.*
- *Cognitive impairments may range from slight to severe. Most prevalent are problems with working memory, long-term retrieval, and processing speed, as well as visual and verbal learning and memory.*
- *Some individuals may experience endocrine or hormonal disturbances as a result of HH.*
- *Precocious Puberty can occur in patients with HH. It is defined as unusually early onset of puberty.*
- *Emotional and behavioral difficulties*

What will you see

- *Individuals may seem easily distracted and not focused. Instructions may have to be given several times because of memory deficits.*
- *Behavior may mimic ADD, ADHD, OCD, Autism or even Aspergers.*
- *Some children have significant difficulties controlling angry outbursts, aggressive tendencies and many have been described as having oppositional-defiant disorder.*
- *These angry outbursts are often referred to as hypothalamic rages. Rages often can be mistaken for temper tantrums however, they usually happen quickly and without an identifiable cause or provocation.*
- *Sensory issues include sounds, touch, textures or smells etc....*
- *Low tolerance to stressful situations.*
- *Some individuals may experience difficulty regulating their body temperature.*

