WHAT IS A HYPOTHALAMIC HAMARTOMA (HH)?

Hypothalamic Hamartoma (HH) is a rare, non-cancerous brain tumor/lesion that can cause a syndrome characterized by:

- treatment-resistant epilepsy
- developmental delays
- cognitive deficits
- behavioral problems including uncontrollable outbursts of anger followed by remorse or no memory of the event
- 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. The seizures can worsen, last longer and be more intense, and may result in more seizure types developing. The seizures are often poorly controlled or completely unresponsive to the standard seizure medications.

EMERGENCY CONTACT INFORMATION

Name_____

Relationship to patient

_____

Phone_____

Alternate Phone

_____

Special Instructions:

_____

_____

_____

_____

_____

Current Medications

_____

_____

_____

_____

Rescue Medication:

_____

_____

_____

_____

A CAREGIVER'S GUIDE TO HYPOTHALAMIC HAMARTOMAS

Hypothalamic hamartomas (HH) are a rare, non-cancerous brain tumor/lesion that occur in the brain during fetal development and are present at birth.

Hypothalamic Hope Hamartomas

Giving Hope. Getting Answers.

Hope for HH provides information and support to hypothalamic hamartoma patients, caregivers, and healthcare providers and promotes research toward early detection, improved treatments, living with HH, and cure.

www.hopeforhh.org info@hopeforhh.org

COMMON SYMPTOMS

- Gelastic seizure, the “laughing seizure”, 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, smirk or grimace.
- 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.
- Individuals may experience endocrine or hormonal disturbances
- Precocious Puberty, unusually early onset of puberty, can occur in patients with HH.
- Emotional and behavioral difficulties, which may include depression, anxiety, rage behaviors, OCD, autism spectrum

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.

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.