Alternating Hemiplegia of Childhood

Actively Helping Children and Families with AHC

Symptoms of AHC

Children with AHC exhibit a wide range of symptoms. These include tonic attacks (lack of muscle tome), dystonic posturing (stiffening of muscle tone), ataxia (lack of coordination when performing voluntary movements), nystagmus (fast, uncontrollable movements of the eyes that may be side to side, up and down, or rotary), and other ocular motor abnormalities (eye disorders), developmental delays, and seizures. Some children with AHC develop 'true seizures' sometime during the course of their disorder. Currently the cause and cure for AHC is unknown. In addition, medicinal treatment options are extremely limited. The incidence of AHC is estimated in roughly 1 in 1,000,000 births; however, the true incidence may be higher since the disorder is commonly misdiagnosed due to the lack of awareness about AHC and the variability of its clinical features.

Diagnostic Criteria

1. Onset of symptoms prior to 18 months of age

2. Repeated attacks of hemiplegia involving either side of the body

3. Other paroxysmal disturbances, including tonic or dystonic spells, oculomotor abnormalities and autonomic phenomena, during hemiplegic bouts or in isolation

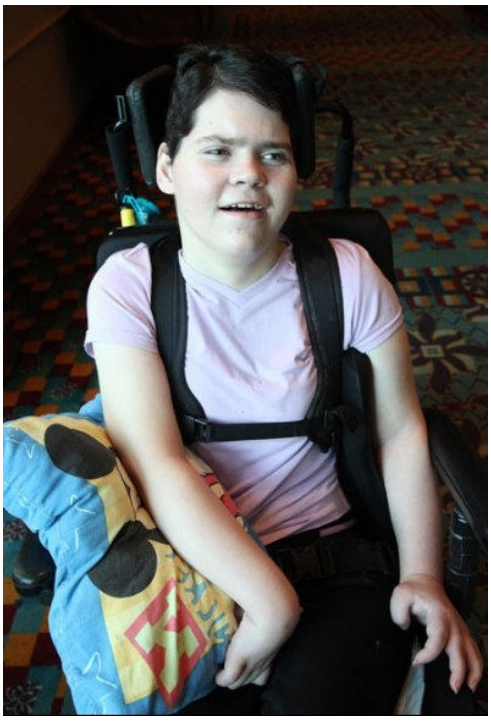
4. Episodes of bilateral hemiplegia or quadriplegia as generalization of a hemiplegic episode or bilateral from the beginning

5. Immediate disappearance of symptoms upon sleeping, which later may resume after waking

6. Evidence of developmental delay and neurologic abnormalities including choreoathetosis (involuntary continuous and flowing movements) , dystonia, or ataxia

What is AHC?

AHC is a rare neurological disorder in which repeated, transient attacks of hemiplegia (paralysis of a portion of the body, including the face) occur, usually affecting one side of the body, or the other, or both sides at once.



Why AHC is Unique

AHC is an orphan disorder, a condition so rare that there are fewer than 600 known cases. Due to the rarity of the disorder, it is not uncommon for patients to travel great distances to find knowledgeable experts. AHC is also a progressive and disabling disorder that requires multidisciplinary care. While AHC patients are frequently treated by neurologists; the vast majority of orphan disorders are genetic, typically arising from an abnormal genetic mutation. With geneticists still searching for a cause, neurologists are left with few treatment options. While the sheer lack of scientific information can make the isolation and loneliness felt by AHC families very palpable; it is the compassion and dedication of the AHCF community that provides support and hope for the future.

Triggers of AHC Episodes

AHC episodes are often associated with triggers that precede or induce the attack. Triggers for AHC episodes may include—but are not limited to—environmental conditions (such as temperature extremes or odors), water exposure, physical activities (exercise, swimming), lights (sunlight, fluorescent bulbs), foods (chocolate, food dye), emotional response (anxiety, stress, fright), odors (foods, fragrances), fatigue, and medications.

AHC: Long-Term Effects

Although the disorder is named "of childhood" those affected by AHC do not grow out of the disorder. The AHC episodes may change and sometimes even decrease in frequency as a child gets older. Every person with AHC is unique, and they can be mildly or severely affected. However, as children get older, developmental problems between episodes become more apparent. These developmental problems may include difficulties in fine and gross motor function, cognitive function, speech and language, even social interactions. There is developing evidence that AHC may cause ongoing mental and neurological deficits with a progressive course. Early intervention for such children is extremely important to help maximize their developmental achievements.

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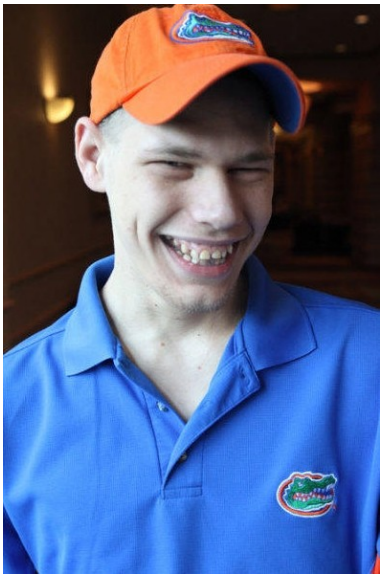

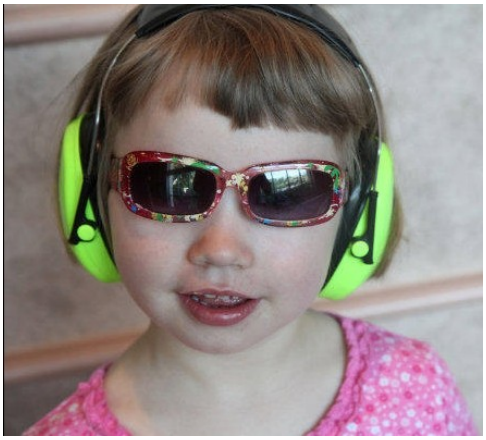

For more information on AHC or the AHCF, including press releases, resources, research, or fundraising information, contact the AHCF at:
ahcfoundation@ahckids.org

Our mission is to find the cause(s) of AHC, develop effective treatments and ultimately find a cure, while providing support to the families and children with AHC by funding research to accomplish these goals. Secondarily, we strive to promote proper diagnosis, educate health professionals, the public, and related organizations, encourage the worldwide exchange of information and advance the development of an international database of all AHC patients.

The AHCF is run almost entirely by volunteers which allows us to keep our administrative costs to a minimum.

The AHCF has a medical advisory board of medical professionals who have experience with the disorder.

As a charitable organization we are classified as a non-profit, tax exempt organization 501c (3).

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