



AHCIA

AHC INTERNATIONAL ALLIANCE

Alternating Hemiplegia of Childhood

*Welcome to AHCIA - Gateway to the AHC Community
Help Us Change the World of AHC!*

Symptoms of AHC

Children with AHC exhibit a wide range of symptoms. These include tonic attacks (lack of muscle tone), dystonic posturing (stiffening of the muscles), 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.

Recently, the first gene (ATP1A3) was identified as the cause of AHC in 70% of the cases. Much work needs to be done to identify the remaining gene/s and develop medicinal treatment options. The incidence of AHC is estimated at 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 choreo-athetosis (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 800 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 disabling disorder that requires multi-disciplinary care. While AHC patients are primarily treated by neurologists; like the vast majority of orphan disorders it is genetic, arising from an abnormal genetic mutation. And although research is progressing, currently, neurologists are left with few treatment options.

Many other medical disciplines are required to control and help alleviate some of the symptoms of AHC.

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, or 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.

AHCIA

In 2012, leaders from worldwide AHC organizations decided to join forces and form an International Alliance. We share a common vision to help those patients who suffer from AHC and their families who care for them. There are 27 countries represented currently.

The AHCIA website serves as a portal to countries where there are formal AHC organizations, AHC support groups or individual AHC contacts, in the hope they will connect with other AHC families in their country. It also provides a starting place for those families from around the world whose children have just been diagnosed with AHC.

AHCIA supports and encourages collaboration and an exchange of ideas to promote awareness of AHC while guiding research towards effective treatments and ultimately a cure for AHC. We welcome all AHC families from around the world to join us as our voice grows.

For more information on AHC, including press releases, resources, research, or fundraising information and events in each country, please contact the AHCIA at: www.ahcia.org

