
ALTERNATING HEMIPLEGIA OF CHILDHOOD INTERNATIONAL ALLIANCE

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 collective voice grows.

ALTERNATING HEMIPLEGIA OF CHILDHOOD

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. It ranges from simple numbness in an extremity to full loss of feeling and movement. The attacks may last for minutes, hours or even days.



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

ALTERNATING HEMIPLEGIA OF CHILDHOOD

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AHCIA

AHC INTERNATIONAL ALLIANCE

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

AHC

Symptoms

Children with AHC exhibit a wide range of symptoms. These include tonic attacks (lack of muscle tone), 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), along with 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 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.

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, and 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 developmental achievements.



AHC

Diagnostic Criteria

1. Onset of symptoms prior to 18 months of age
 2. Repeated attacks of hemiplegia that alternate in laterality (meaning that the paralysis alternates from one side of the body to the other)
 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. Relief from symptoms upon sleeping, which may later resume after waking
 6. Evidence of developmental delay and neurologic abnormalities that include choreoathetosis (a type of involuntary continuous and flowing movement), dystonia, or ataxia
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