

Frequently asked questions about infantile spasms and West syndrome

What are infantile spasms?

Infantile spasms are a specific type of epilepsy syndrome that usually begins in infancy. Infantile spasms are (IS) typically observed between 3-8 months of age. The seizures primarily consist of a sudden bending forward of the body with stiffening of the arms and legs; some children arch their backs as they extend their arms and legs. More than half of children with IS will develop other types of seizures. There appears to be a close relationship between IS and Lennox-Gastaut Syndrome, an epilepsy syndrome of later childhood.

What is West syndrome?

West Syndrome is characterized by three conditions; 1) infantile spasms, 2) developmental regression, and 3) a specific pattern on electroencephalography (EEG) testing called hypsarrhythmia (chaotic brain waves).

What is the treatment for infantile spasms?

A steroid called adrenocorticotrophic hormone (ACTH) is the standard drug that is used to treat infantile spasms. This medication can have serious side-effects and is therefore limited to short-term use. Recent evidence has shown that the ketogenic diet is not only more effective than ACTH but has fewer side-effects and better long-term success. Researchers at Johns Hopkins compared infants with new-onset infantile spasms who were treated with the ketogenic diet to those who were treated with ACTH. The ketogenic diet stopped spasms in nearly two-thirds of cases, and there were fewer side effects and relapses than those treated with ACTH. In addition, the cost of ACTH in 2009 is approximately \$8000 each day. The cost of a ketogenic formula for an infant is less than \$15 each day. The ketogenic diet is now offered as a first-line therapy to parents whose children have been diagnosed with new-onset infantile spasms at John's Hopkins Hospital in Baltimore, Maryland. *Epilepsia, 2008,49(9)1504-09.*

To learn more about infantile spasms and to enroll in a study that will help to better diagnose and treat this syndrome visit: <http://infantilepasms.wustl.edu>