



## MEDICAL TREATMENT OF INFANTILE SPASMS

Infantile spasms are a rare form of epilepsy which begin in children between three to twelve months of age. Infantile spasms are also known as *West's syndrome*. Most of the children who develop infantile spasms do so before one year of age and most stop having spasms by age five. Between infancy and age five, some children with infantile spasms will also have other types of seizures.

A baby with infantile spasms experiences a series—or *cluster*—of brief jerks which can cause a baby to bend forward at the waist with out-stretched arms. If a child is sitting up, the head may fall forward and the arms may bend forward. If the child is lying down, the knees, arms, and head may bend forward.

These episodes are actually clusters of brief seizures referred to as *salaam seizures*. These can be mistaken for colic because the baby doubles up during the spasm and cries afterwards. The spasms are most common in the early morning or when waking from naps. The spasms may occur several times per day.

Even with effective—treatment, most children with infantile spasms have associated developmental delays—such as language and motor skills; and may go on to develop other forms of epilepsy.

Often there is no known cause of infantile spasms, but there are a number of causes thought to be connected such as chromosomal abnormalities, brain malformations, and brain infections.

Neurologists from the American Academy of Neurology (AAN) and the Child Neurology Society (CNS) who specialize in diseases of the brain and central nervous system believe you should know about the options for treating infantile spasms.

The experts decided to look carefully at all of the research about currently available treatments. These experts wanted to find out how safe and effective available treatments were for children with infantile spasms.

### What are the treatments for infantile spasms or West's syndrome?

Treatment of infantile spasms may include corticosteroids,

a hormone called ACTH, and drugs used to manage other forms of epilepsy.

The experts who studied the research found that ACTH is probably effective for the short-term treatment of infantile spasms. However, the most effective dose and best length of use for ACTH therapy is unclear. A number of side effects were reported in studies using ACTH in infants including irritability, severe infection, and high blood pressure. Not every child experiences side effects. Talk to your doctor, nurse, or pharmacist for a complete list of other possible side effects.

The experts found that a medicine called vigabatrin, which is not available in the United States but is available in Canada, is possibly effective for the short-term treatment of infantile spasms. Vigabatrin may cause permanent vision abnormalities as a side effect. Children taking the drug need to be closely monitored for this side effect. Other side effects may include weight gain, irritability, drowsiness, sleep problems, and weakness.

For some treatments, there was not enough information for the experts to decide whether or not the treatment was effective.

For example, the research for oral corticosteroids—or *steroids*—and medicines used to treat people with other forms of epilepsy—or *antiepileptic drugs*—did not prove, or disprove, that the medicines were effective for short-term treatment of infantile spasms.

The experts also found there was not enough research available to prove that treatments improve chances of better, long-term outcomes; including freedom from seizures and normal development.

### Talk to your primary care doctor or a child neurologist

Together you and your child's health care provider can choose the treatments that will work best for your child. A child neurologist can provide more information and resources to help patients and caregivers make the best treatment choices.

This is an educational service of the American Academy of Neurology. It is designed to provide members with evidence-based guideline recommendations to assist with decision-making in patient care. It is based on an assessment of current scientific and clinical information, and is not intended to exclude any reasonable alternative methodologies. The AAN recognizes that specific patient care decisions are the prerogative of the patient and the physician caring for the patient, based on the circumstances involved. Physicians are encouraged to carefully review the full AAN guidelines so they understand all recommendations associated with care of these patients.



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