

Infantile or Epileptic Spasms and Tuberous Sclerosis Complex



Treatment of infantile spasms

Two drug treatments for infantile spasms are approved by the Food and Drug Administration (FDA) in the USA.

- Vigabatrin, approved by the FDA in 2009, is the drug of choice for treatment of infantile spasms associated with TSC. This medication is available in tablet and powder for oral solution.
- Adrenocorticotrophic Hormone (ACTH) was approved by the FDA in 2010. This medication is available in an injectable liquid form.

Risks are associated with the use of both medications, so parents/caregivers should discuss treatment options with the healthcare provider to determine the risk-benefits for the treatment of infantile spasms.

Other treatment options

Other hormonal therapies, such as high-dose corticosteroids (e.g., prednisolone or prednisone) may be options in countries where vigabatrin and ACTH are not available. Less effective therapies include zonisamide, topiramate, clonazepam, and valproic acid. When drug therapy does not control the spasms, surgery to remove the seizure-causing area of the brain or the ketogenic diet may help. It is important to discuss the potential benefits versus risks of any treatment with a healthcare provider who specializes in treating children with epilepsy.

Additional resources

- TSC Alliance: tscalliance.org/infantilespasms
- Infantile Spasms Action Network: infantilespasms.org
- The Infantile Spasms Project: infantilespasmsproject.org
- Epilepsy Foundation: epilepsy.com/learn/types-seizures/epileptic-or-infantile-spasms
- Vigabatrin Patient Assistance Programs: tscalliance.org/vigabatrin

Disclaimer

This brochure, which was reviewed by E. Martina Bebin, MD, MPA, Director of the TSC Center of Excellence, University of Alabama Birmingham, is intended to provide basic information about infantile or epileptic spasms and TSC. It is not intended to, nor does it, constitute medical or other advice. Readers are warned not to take any action about medical treatment without first consulting a health care provider. The TSC Alliance does not promote or recommend any treatment, therapy, institution or health care plan.



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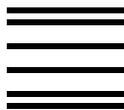
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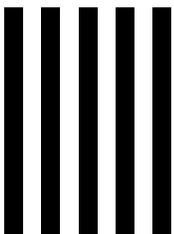
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What you need to know about infantile or epileptic spasms and TSC

Infantile spasms or epileptic spasms can be devastating type of seizures for infants and young children with tuberous sclerosis complex (TSC). Children with TSC are at risk for developing this type of seizure as approximately one-third will start having infantile spasms before the age of 2 years. Onset of infantile spasms can begin at any time after birth and usually during the first two years of life, but uncommonly may be later, when it is referred to as epileptic spasms. It is very important for the parents and caregivers of children with TSC to know what to look for and that their child is at risk for this type of seizure. Early diagnosis and rapid treatment can often result in the elimination of spasms and can result in optimal outcomes for the child.

It is important to avoid treating children with TSC with medications that may worsen infantile or epileptic spasms. These include carbamazepine, oxcarbazepine, phenytoin, and phenobarbital. (infantilepsasmsproject.org)

Red flags – or, what to watch for if your child has TSC and you suspect infantile or epileptic spasms

The following signs and warnings should alert you that your child may be experiencing infantile or epileptic spasms or other types of seizures associated with TSC:

- Movements that occur in clusters – several of the same movements occurring in waves that are seconds apart.
- Sudden jerks involving all or part* of the body in a forward (flexor) or backward (extensor) motion.
(*In some cases, only one side of the body may be affected.)
- Falling asleep after these movements and jerks.
- Feeding difficulties and/or reflux after eating.
- Infantile or epileptic spasms may precede any change in the child's EEG (brain waves), and children with TSC may not ever develop hypsarrhythmia (abnormal EEG pattern associated with infantile spasms).
- Failure of the infant/child to meet developmental milestones.
- Loss of developmental milestones once they have been achieved.
- Loss of interest in people and objects in the child's environment.
- Social interaction may diminish, smiling may cease, sleep may become disrupted, and the child may seem irritable or indifferent to the surroundings.

What infantile spasms are not

- Bad parenting
- Cranky baby
- Startle reflex
- Acid reflex
- Colic
- Pain or digestive problems/cramping
- Nothing to worry about – minor seizures that have no consequences.



What to do if you suspect infantile or epileptic spasms

- Parents/caregivers who suspect your child is having infantile or epileptic spasms should get medical attention for your child as quickly as possible.
- Be persistent if the health care provider tells you there is nothing wrong with your child and/or there is nothing for you to worry about. Don't stop until you are satisfied your child does not have infantile or epileptic spasms, another type of seizure, or is appropriately tested and treated.
- View online educational videos produced by the TSC Alliance about infantile spasms at tscalliance.org/infantilepsasms.
- Videotape your child while he or she has the unusual movements so you can share this with the health care providers.
- Obtain a referral to a TSC Clinic, epilepsy center or a health care provider who specializes in treating children with epilepsy (pediatric neurologist/epileptologist).

Tests needed to diagnose infantile or epileptic spasms

Health care providers will perform the following tests to determine if a child is having seizures:

- A prolonged video electroencephalogram (EEG) with recording of awake and sleep cycles. This test involves applying flat electrodes on the child's scalp to record brain waves during his/her awake and sleep cycles.
 - An overnight video EEG may be recommended to confirm diagnosis of epileptic or infantile spasms. This test includes a video recording of your child's activity at the same time as the EEG.
- Brain magnetic resonance imaging (MRI) may be performed to determine if the child has TSC. If the child has already been diagnosed with TSC, a new MRI may or may not be necessary.

Overcoming obstacles to diagnosis of infantile or epileptic spasms in TSC

A delay in the diagnosis of infantile or epileptic spasms may occur if the healthcare providers are not familiar with this type of seizure. The unusual seizure can easily be overlooked by parents and health care providers who are unaware of its significance. Thus, getting a timely and accurate diagnosis may sometimes call for active advocacy on the part of the parents who suspect something is wrong with their child, or they think the child may be having infantile or epileptic spasms. A diagnosis of infantile or epileptic spasms may be dismissed because:

- The child's EEG does not show hypsarrhythmia.
- The child is considered too old for spasm onset.
- The spasms (seizures) are asymmetrical, one-sided or atypical in appearance.
- The spasms evolve from or into another seizure type.
- The spasms occur singly rather than in a more typical cluster.

None of these conditions is sufficient to rule out a diagnosis of infantile or epileptic spasms in children with TSC.

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Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ E-mail address: _____

Connection to TSC:

- Parent/caregiver. My child with TSC was born in _____ (year).
- Adult with TSC. I was born in _____ (year).
- Grandparent Sibling Relative
- Healthcare professional Educator
- Other: _____



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