Treatment of Infantile Spasms

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

- Vigabatrin (marketed as Sabril®) was approved by the FDA in 2009 and is the drug of choice for treatment of infantile spasms associated with TSC. This medication is available in tablet form or as a powder to mix with liquid.
- ACTH (marketed as ACTHar Gel) was approved by the FDA in 2010. This medication is available in an injectable liquid form.

There are risks associated with the use of both of these medications, but the parents/caregivers should discuss the treatment options with the health care provider and determine the risk-benefits for the treatment of infantile spasms for their child.

This brochure is intended to provide basic information about infantile spasms and TSC. It is not intended to, nor does it, constitute medical or other advice. Readers are warned not to take any action with regard to medical treatment without first consulting a health care provider. The TS Alliance does not promote or recommend any treatment, therapy, institution or health care plan. This brochure was reviewed by Elizabeth Thiele, MD, PhD and Martina Bebin, MD, MPA (May 2011).

About the TS Alliance

The Tuberous Sclerosis Alliance (TS Alliance) is the only national organization dedicated to finding a cure for TSC while improving the lives of those affected. For more than 35 years, the TS Alliance has been the leading resource for individuals, families and healthcare providers, helping optimize care and offering experience-based support for anyone affected by TSC. The TS Alliance is also the leading advocate for TSC research and serves as a world-wide clearinghouse for the most current and comprehensive information on TSC.

For immediate assistance, contact:
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What You Need to Know about Infantile Spasms and TSC

Infantile spasms can be a 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 an estimated 40% of children with TSC will start having infantile spasms before the age of 2 years. Onset of infantile spasms can begin at any time after birth and during the first two years of life, and it is very important for the parents and caregivers of children with TSC to know what to look for, and that their children are at risk for this type of seizure. Early diagnosis and rapid treatment can often result in the elimination of spasms and can result in excellent outcomes for the child.

It is important to avoid treating children with TSC with medications that may induce or make infantile spasms worse. Medications such as phenobarbital, phenytoin, carbamazepine and tiagabine should not be used in children and especially in infants with TSC. (Dulac, 2001)

Red Flags — Or, What to Watch For If Your Child Has TSC and You Suspect He/She Is Having Infantile Spasms

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

- 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.
- Unusual jerking 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.
- Infantile 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).

What Infantile Spasms Are Not!

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

What Should You Do?

- The parent/caregiver who suspects that their child is having infantile spasms should get medical attention for their child as quickly as possible.
- Be persistent if the health care provider tells you that there is nothing wrong with your child and/or there is nothing for you to worry about. Don’t stop until you are satisfied that your child does not have infantile spasms, another type of seizure, or is appropriately tested and treated.
- View a free online video produced by the TS Alliance about infantile spasms www.youtube.com/tsalliance.
- Videotape your child while they have the unusual movements so that you can share this with the health care providers.
- Obtain a referral to an epilepsy center, TSC Clinic or a health care provider who specializes in treating children with epilepsy (pediatric neurologist/epileptologist).

What Tests are Needed to Diagnose Infantile Spasms?

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

- Electroencephalogram (EEG): This test uses flat electrodes on the child’s scalp in order to record brain waves.
- Brain magnetic resonance imaging (MRI) may be done 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 Spasms in TSC

There may be a delay in the diagnosis of infantile spasms if the health care 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 that there is something wrong with their child, or if they think the child may be having infantile spasms.

A diagnosis of infantile spasms may be questioned if:

- 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; or
- The spasms occur singly rather than in a more typical cluster.

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