

# Let's Talk About...

## Infantile spasms

Infantile spasms (IS) is a seizure disorder in babies. The seizures (or spasms) make muscles in the arms and legs stiff and bend the baby's head forward. They look very much like a startle. These type of seizures can effects infants younger than 2 years old. Most infants who have IS are 3–7 months old.



Babies also might have slowed development or loss of skills (like babbling, sitting, or crawling). Although the spasms usually go away by the time a child is 4 years old, many babies with IS will have other kinds of epilepsy later in life.

### What Do Infantile Spasms Look Like?

Spasms start suddenly and last a second or two. They often come one after another in a cluster that lasts several minutes. They happen most often just after waking. They're often mistaken for colic, reflux, or hiccupping.

A baby having a spasm might have:

- the head bent forward with arms flung out and the knees pulled into the body (described as “jackknife”)
- the head bent back with the arms and legs straightened
- small movements in the neck or other parts of the body

### What causes infantile spasms?

IS can be caused by many different brain disorders or neurologic diseases. These may include:

- Metabolic problems (how the body processes its own chemicals)
- Abnormal brain development
- Genetic disorders (such as Down syndrome and tuberous sclerosis complex)
- Extreme difficulties at birth or very early in a baby's life

If your child's healthcare provider can figure out what is causing the infantile spasms, it is called symptomatic IS. In four out of 10 children with IS, the cause cannot be found. If healthcare providers cannot find what is causing the spasms, the disorder is called cryptogenic (crip-toe-JEN-ick) or idiopathic (ih-dee-oh- PATH-ick) IS.

### What kinds of infantile spasms tests are there for my child?

At first, your child's healthcare provider may test some of your child's blood. Then your healthcare provider may refer you to a pediatric neurologist (nurr-OLL-oh-jist).

The pediatric neurologist will want to know what is causing your child's IS so your child can be treated quickly. Every child is different, so the doctor will choose the right tests and decide the best treatment. In general, the doctor might want to know the following:

- **Medical history:** The doctor may ask about your child's health and the types of seizures they have. Tell the pediatric neurologist as many details as you can, even if you've already told the story to other doctors. Sometimes videos of the seizures are helpful.

- **Physical exam:** The physical exam helps the doctor learn about your child's general health, especially about their nervous system.
- **Developmental exam:** The doctor will ask questions about your child's development, such as when they started to roll, sit, hold toys, and make eye contact. The doctor will also see how well your child performs some simple medical tests. These tests are not painful and help the doctor understand your child's nervous system.
- **Lab tests:** Your child might have blood, urine, and spinal fluid tests to look for problems that cause spasms. The doctor may choose some of these tests:
  - **Electroencephalogram (EEG):** A healthcare provider will attach small disks to your child's head. Little wires are attached to the disks to measure electrical brain waves. The EEG does not hurt at all, and there is no risk of injury. The EEG takes about two hours. The doctor is looking for brain patterns that are not normal.
  - **MRI scan:** The MRI scan uses magnetic energy to make a picture of the brain and takes about 30 minutes to 1 hour. Trained healthcare providers give most infants medicine to make them sleep and lie still for the MRI. Because MRIs use magnetic energy, there is no radiation and it does not hurt at all.

## How do healthcare providers treat infantile spasms?

You and your child's pediatric neurologist will decide the best treatment for your child. Usually, treatment begins very quickly after diagnosis. The goal of therapy is to stop the spasms and abnormal brain waves as soon as possible. The healthcare provider may recommend the following medicines for your child:

- **Prednisone:** Is a steroid pill or liquid taken by mouth once a day. It is usually very safe and different than the steroids athletes use. The doctor will recommend a small amount of prednisone at first. If your child still has IS after one week, the

doctor will increase the amount of prednisone. Possible side effects include weight gain, high blood pressure, difficulty sleeping, and irritability.

- Take your child to their pediatrician regularly while they are treated for IS. If your child receives steroid medicine, the pediatrician will need to check your child's blood pressure twice a week.
- Your child may not have their vaccines on schedule because steroids change the body's ability to respond to the vaccine. The pediatric neurologist will give you a letter explaining your child's treatment and diagnosis for the pediatrician.
- If the steroid medicine does not stop your child's spasms, the pediatric neurologist may prescribe another steroid called ACTH (Acthar® gel).
- If your child is taking steroid medicine, they should not be around anyone who has chickenpox or has recently had a chickenpox shot. Infants should not get a chickenpox shot while taking steroids.
- **Vigabatrin (Sabril®):** Is an anti-seizure medicine used to treat infantile spasms. Some children with IS have tuberous sclerosis (TOO-burr-us sklurr-OH-sis), a brain disorder. If your child has this, your doctor may have them try vigabatrin first. The pharmacy will ship vigabatrin, a powder you mix with water, to your home. You'll give your child the medicine by mouth twice a day. One possible side effect of vigabatrin is losing peripheral vision, but this is very rare. Have your child's vision checked regularly by an eye doctor while they are taking vigabatrin.

## What will happen to my child later in life?

Many children with IS have difficulty learning and developing. Spasms usually stop by the time your child is 5 years old, no matter how they are treated. Up to 6 out of 10 children who have infantile spasms will develop other types of seizures after the spasms stop. Treating IS quickly is important. The earlier your child is treated, the better chance they have of developing more normally.

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