Infantile Spasms

This handout explains infantile spasms and what to expect. Infantile spasms are a type of seizure that occurs in the first year of life, often between 4-8 months of age. It is a seizure type that can harm development. Early testing and diagnosis are very important.

What does it look like?
Infantile spasms have a typical look. During a spasm the infant may quickly bend forward at the waist or neck. The arms and/or legs often become stiff. Some spasms may occur with arching of the back. The spasms are brief, often lasting one or two seconds. They tend to occur in clusters where the infant may have several spasms over a few minutes. Spasms often occur when the infant is falling asleep or waking up from sleep. They rarely occur during sleep.

How is it diagnosed?
The history you provide to your health care provider is important. Do your best to describe your infant's movements and when they occur. If you can, record video of the movements and show them to your infant's health care provider.

If the provider suspects infantile spasms or another seizure type, your infant will have an EEG, a brain MRI, and blood tests. In infantile spasms, the EEG shows a pattern called *hypsarrhythmia*. This term describes a chaotic brain wave pattern with abnormal discharges called spikes.

If a diagnosis is made or suspected, an EEG is often repeated at regular times. This is done to see if treatment is helping.

What causes it?
Infantile spasms are not common. It affects around one out of three thousand infants. In about 20 percent of cases, the cause is not known. These infants most often develop normally.

In the other cases, the cause of spasms may include:

- Brain defects
- Brain injuries or infections
- Chromosome and genetic defects
- Metabolic disorders
- Syndromes that involve the brain, skin, and heart

How is it treated?
The treatments for spasms include hormone shots (ACTH), steroids by mouth, or other seizure medicines. ACTH is often used as the first treatment. It is a hormone made by the pituitary gland. It tells the adrenal glands to make and release more cortisol, which acts like a steroid. ACTH is given as a shot once daily for the first few weeks. It is then slowly tapered until it is stopped.

ACTH and steroids do have side effects that can be safely managed. Side effects may include:

- Irritability
- Increased appetite and weight gain
- High blood pressure
- Kidney problems
- Increased risk of infection
- Increased risk for bleeding in the stomach
- High glucose level in the blood

Some infants will need seizure medicine such as Vigabatrin®, Depakote® or Topamax® along with the steroids.

What effect will this have on my child's future?

The future course of the disorder and how your infant develops depend on the cause of the spasms. Even with treatment of the spasms, most infants will have delays in speech and motor skills. Many infants also develop other seizure types. Some infants may later have autism or a syndrome called Lennox-Gastaut.

Development outcomes improve when an infant has developed normally before spasms occur. In these cases, there is a better chance of normal or mild delayed speech and motor skills. Studies have shown that infants have the best chance at improved development outcomes the sooner the spasms are treated and controlled.

To learn more, please visit the website **www.efa.org**.