



NATIONWIDE CHILDREN'S
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Helping Hand™

Health Education for Patients and Families

Seizures: Infantile Spasms

Infantile spasms are seizures that often cause a delay in development. This means that your child may not have the same skills or behave the way other infants do at the same age. It is important to start treatment as soon as possible. Spasms usually begin between 3 and 12 months of age but can sometimes start at an earlier or later age.

There are many possible causes of infantile spasms. Children with different forms of brain disease are at risk. A doctor will make the diagnosis by observing your baby having a spasm and doing an EEG (electroencephalogram) to track brain activity.

After diagnosis, an MRI (magnetic resonance imaging) of the brain or blood tests can often find the cause. The MRI takes a detailed picture of the brain. Sometimes the results of these tests are normal and the cause cannot be found.

Signs of infantile spasms

Infantile spasms:

- Most often appear as a sudden jerk of the neck, shoulders, arms, legs and body.
- Sometimes can be hard to recognize and only involve repeating small movements of the eyes, lower lip or shoulders. The eyes may roll up or the mouth may turn down making it look like your baby may retch or gag. Spasms do not cause throwing up.
- Usually occur while the child is awake and often when first waking up from a nap or from a night's sleep.
- Can cause some children to cry or whimper.
- Often occur in a series, called a cluster. Clusters help make the diagnosis. Spasms within a cluster often have a regular pattern. The time between each spasm can last from 3 to 30 seconds.

What to do during a spasm

There is no treatment to stop a cluster of infantile spasms after it has started. During a

cluster, you can hold your baby or place them on a soft surface (Picture 1).

Also, if possible, you should:

- Take a video of the cluster for the doctor to see. The video will help make the diagnosis.
- Write down what you see.
 - date of spasm
 - one spasm or a cluster
 - how long each cluster lasted



Picture 1 During a cluster, it is OK to hold your baby or place them on a soft surface.

How infantile spasms are treated

The neurologist will discuss 3 medicine options with you. Which one is best for your child will depend on the cause of the infantile spasms and the side effects of the medicine(s).

Prednisolone (Orapred®). For most patients, prednisolone is recommended first. It is a liquid given by mouth and can be stored at room temperature.

If prednisolone does not work, ACTH or vigabatrin may be ordered.

ACTH (Acthar Gel®) is a liquid given by a shot (injection) into the thigh muscle. A nurse or pharmacist will teach you how to give it using a syringe. When giving ACTH, you should switch legs and inject it in a different spot each time. ACTH is very expensive. It must be stored in the refrigerator and never allowed to freeze. Some parents like to rub a small amount of numbing cream on the skin before giving the ACTH shot. Ask your doctor to give you a prescription for this.

Prednisolone and ACTH have similar side effects. The most common are:

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| • weight gain | • increased appetite | • water retention |
| • irritability, fussiness | • increased blood pressure | • trouble sleeping |

Rare side effects are:

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| • electrolyte problems | • stomach ulcer | • high blood sugar |
| • lethargy, weakness | • low blood pressure after stopping | • death (very rare) |
| • infection caused by a weakened immune system | | |

Since prednisolone and ACTH may weaken the immune system, it is very important to tell other health care providers when your child takes either of these medicines. Your child should not get vaccines (baby shots) until these medicines are stopped.

Vigabatrin (Sabril®) might be ordered with or without prednisolone or ACTH. Vigabatrin most often comes in a powder form that must be dissolved and taken by mouth. The nurse or pharmacist will tell you how to mix it and how much to give.

The most common side effect of vigabatrin is sleepiness. This medicine may also cause some babies to have a harder time feeding. After about 6 months of treatment with vigabatrin, 5% (5 in every 100) children may get permanent loss of peripheral (side) vision.

Tips for success

- It is important for your baby to receive every dose of prescribed medicine.
- For prednisolone and ACTH, mark ☒ the medicine calendar after each dose you give to your child. The medicine calendar will tell you when and how much to give.
- Make sure you get a prescription refilled at least 2 days before the last dose is given. That way your baby will not miss any days of treatment. This is very important.
- **Do not stop any medicine suddenly.** This may cause the seizures to increase or to return after they have stopped.

Follow-up care

The neurologist will see your child in about 10 to 14 days to see if the medicine worked. If the spasms stop, an EEG will be ordered to make sure that the brain waves have improved. If the spasms do not stop or the EEG does not improve enough, the doctor may add or change the treatment.

When to call the doctor?

Call the doctor if:

- Your child's spasms
 - have not stopped as expected.
 - become worse after treatment.
 - stop but then come back.
- There is a new type of seizure
- Your child has side effects to the medicine(s)
- Your child
 - has a fever (rectal temperature of 100.4°F (38°C) or higher).
 - looks sick.
 - has poor feeding.
 - is not making wet diapers.
 - is harder to wake up.
 - appears weak.