

# BRAIN SURGERY TO STOP INFANTILE SPASMS



# What are infantile spasms?

## Introduction

Because infantile spasms can be catastrophic to development, surgery should be considered as soon as possible for children with focal brain malformations. If your child has failed vigabatrin (Sabril) and adrenocorticotrophic hormone (ACTH) or prednisolone, and the seizures are coming from a zone of cortical malformation on one side of the brain, or a specific location of the brain – do not delay!

## When to consider surgery

### Your child has failed first-line treatments

No longer considered a last resort, epilepsy surgery is now a viable treatment option to stop seizures when the child's infantile spasms are considered drug-resistant (also known as intractable or refractory). The most recent practice guidelines from the American Academy of Neurology and the Child Neurology Society for the medical treatment of infantile spasms state that adrenocorticotrophic hormone and Vigabatrin are the first line drugs for infantile spasms. There is also some evidence that high-dose oral prednisolone can be an effective treatment as well. If a child has failed these drug combinations, the infantile spasms are considered drug resistant. One third of children presenting with infantile spasms before 36 months of age will be drug-resistant – and the largest group are children with infantile spasms. Children with focal or hemispheric lesions or malformations also carry a high risk of medical intractability.

### Your child has a focal cortical abnormality

The ILAE recommends a surgical evaluation for that infants with drug resistant epilepsy who have focal-onset seizures – particularly those with a unilateral structural brain abnormality, focal cortical abnormalities, tuberous sclerosis, and porencephaly. A presurgical evaluation will attempt to map the cortical abnormality so that the surgeon knows what part of the brain to remove.

### Your child does not have a degenerative brain condition

Children with degenerative brain conditions or metabolic disorders which cause seizures typically are not candidates for epilepsy surgery.

### Your child exhibits delay or developmental arrest

In order to be a candidate for surgery, your child must be progressing very slowly or development has “frozen in time”.

### There is no unacceptable loss of function if surgery is selected

Very difficult decisions must be made – and fast – for parents considering brain surgery to stop their child's infantile spasms. The most sobering decision to make is how much function are you willing to lose in exchange for stopping the infantile spasms? Hemispherectomy, for example, results in partial blindness and partial paralysis; however, this may be acceptable if the infantile spasms have caused or will cause serious developmental regression or arrest and, in many cases, death.

### It is unlikely that your child will “grow out” of infantile spasms

You may be wondering if you should wait and see if your child's infantile spasms go away on their own. It is true that the spasm seizure type stops by three years of age in approximately one-half of children with infantile spasms and rarely continues after age five; however, 50 to 90 percent of patients with infantile spasms will go on to develop other seizure types. In general, patients with infantile spasms caused by stroke, brain malformations, or other known cause more likely to develop other seizure types than those with cryptogenic infantile spasms (57.5 versus 35.3). Approximately 27 to 50 percent of patients with infantile spasms develop a severe form of epilepsy known as Lennox-Gastaut syndrome.

Reading about the long-term consequences of infantile spasms is disheartening for any parent. However, patients with infantile spasms who are also epilepsy surgery candidates are offered a unique opportunity to permanently stop or reduce spasms and future seizure types and lower the number of anti-epileptic medications that they need to take. Seizure and medication reduction can lead to improved development and behavior that can change your child's and your family's quality of life for the better.

*Research shows that surgery should be considered as soon as possible rather than waiting months or years. This is because seizures, especially in infancy, can be catastrophic – this means that they are strongly associated with intellectual disability (formerly known as mental retardation) and poor developmental outcome.*