



## **Developmental and Epileptic Encephalopathies**

### **What Are Developmental and Epileptic Encephalopathies (DEE)?**

It is a group of disorders characterized by drug-resistant epilepsy and abnormal EEG. In these disorders, the epileptiform discharges are very frequent and contribute to cognitive and behavioral impairments. There are many types of DEE, and the most common are:

- Infantile epileptic spasms syndrome
- Lennox-Gastaut syndrome
- Dravet syndrome
- Epilepsy with myoclonic atonic seizures
- Developmental/epileptic encephalopathy with spike-wave activation during sleep

### **What Happens During DEE?**

Children with DEE may have developmental delay, cognitive impairment and drug-resistant seizures, which means that seizures are not completely controlled by medication.

### **What Causes DEE?**

DEE can be caused by multiple conditions. For example, gene mutations, early brain injury from infection or trauma, or problems with the way the brain was formed before birth all can lead to the condition. Sometimes, it has no clear cause.

### **How Is DEE Diagnosed?**

Doctors diagnose the condition based on the description of the seizures, the child's age and development and EEG results.

Patients with seizures might need to see a pediatric neurologist. Other tests done can include:

- VEEG, or video electroencephalography (EEG with video recording)
- MRI
- Genetic testing

### **How Is DEE Treated?**

Seizures in DEEs are typically drug resistant and don't usually respond well to medication. Doctors usually try different combinations of antiseizure medication, according to each type of DEE, genetic mutation and seizure type.

Other treatments include VNS (vagus nerve stimulation) and ketogenic diet.

### **How Can Parents Help?**

Caring for a child with DEE can be challenging. Work with your child's care team to set up medical visits, therapies, and a treatment plan that provides your child with a good quality of life.

Because it could lead to a tonic-clonic seizure, make sure that you and other adults and caregivers (family members, babysitters, teachers, coaches, etc.) know what to do if a seizure happens. Your doctor may prescribe an emergency medicine to give if your child has a long seizure or many seizures in a short amount of time. Be sure to ask your doctor about a seizure rescue plan for your child.

### **What Else Should I Know?**

If your child has epilepsy, reassure them that they're not alone. Your doctor and the care team can answer questions and offer support. They also might be able to recommend a local support group. Online organizations can help too, such as:

- [Epilepsy Foundation](#)
- [CDC – Managing Epilepsy](#)