

## **Dravet Syndrome**

### What Is Dravet Syndrome?

Dravet syndrome is a rare type of epileptic encephalopathy. Children with the condition will have:

- Different types of seizures.
- Some degree of intellectual disability and developmental delay.
- Abnormal findings on an EEG (a test to see brain waves/electrical activity).

Dravet syndrome begins in the first year of life, and it's a lifelong condition that requires a high level of care.

## What Types of Seizures Happen in Dravet Syndrome?

Children with Dravet syndrome have different seizure types. In addition, they are often sensitive to fever (even a slight increase in body temperature can trigger a seizure).

#### **Generalized tonic-clonic seizures:**

In this type of seizure, a child:

- Has convulsions, or rigid muscles and rhythmic body jerks
- Rolls the eyes back
- Cries out
- May pee or poop
- Can't respond during seizure
- Is confused and sleepy after the seizure

# **Atypical absence seizures:**

In this type of seizure, a child:

- Blanks out or has staring spells that last 5-20 seconds
- May flutter their eyes or look upward
- Is unaware of what is going on during the seizure
- Returns to normal activity and won't remember having the seizure after it's over
- Has lip-smacking, chewing movements

# Myoclonic seizures:

In this type of seizure, a child:

• Has brief muscle twitches or jerks in the upper arms, shoulders or neck

#### **Focal seizures:**

In this type of seizure, a child

 Has rhythmic jerks (clonic movements) affecting only one side of the body

## **What Causes Dravet Syndrome?**

Most patients with Dravet syndrome have a mutation in the sodium channel gene called SCN1A.

# **How Is Dravet Syndrome Diagnosed?**

A pediatric neurologist can diagnose the condition by doing tests such as:

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

## **How Is Dravet Syndrome Treated?**

Dravet syndrome is treated with antiseizure medication. Other treatments that may be considered are VNS (vagus nerve stimulation) or the ketogenic diet.

# **How Can Parents Help?**

Caring for a child with Dravet syndrome can be challenging. Work with your child's care team to set up the 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 one 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, 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