



Empowering Children. Supporting Families. Building Brighter Futures.

Resource 060 | Brain, spinal cord, and seizure conditions

Dravet syndrome

What it means

Dravet syndrome is a rare developmental and epileptic encephalopathy that usually begins in infancy. Early development may appear typical before recurrent seizures and later developmental difficulties emerge. Seizure types and support needs change over time. Early specialist recognition helps guide medicines, safety planning, and developmental support. [1]

Causes and risk factors

Many cases involve a new change in the SCN1A gene, affecting how nerve cells regulate electrical signals. The change is often not inherited from a parent. Fever, illness, and overheating can trigger seizures in susceptible children; these triggers do not explain the underlying genetic condition. [1,2]

General family education. A concern deserves assessment, but this guide does not diagnose a child or prescribe treatment.



Signs and everyday impact

An infant may have prolonged seizures with fever, sometimes affecting one side of the body. Later, additional seizure types, movement or balance difficulties, and slower language or learning development may appear. Early EEG and imaging can be normal. This pattern needs specialist interpretation rather than self-diagnosis from a single febrile seizure. [1,2]

Assessment and diagnosis

A pediatric epilepsy specialist assesses age at onset, seizure pattern, development, EEG, and family history. Genetic testing can support diagnosis and counseling. Results must be interpreted with the clinical picture. Ongoing assessment tracks seizures, mobility, communication, sleep, feeding, and learning needs. [1,2]

Treatment and therapy

Treatment uses medicines selected for Dravet syndrome; some medicines used for other epilepsies can worsen seizures. Families should not change treatment without specialist advice. Selected children may receive specialist dietary or other treatments. A rescue plan, illness guidance, and coordinated developmental therapy are central. Medication availability and age eligibility vary by country. [1,2,3]

Support at home

Keep rescue medicine available as prescribed and train regular caregivers in the written plan. Discuss managing fever, illness, heat, and activities with the team. Support hydration and regular routines according to medical advice. Adapt learning and communication to the child's strengths, and review mobility and safety needs over time.

When to seek help

Follow the individualized emergency plan, which may require action before five minutes. Call emergency services for prolonged seizures, repeated events without recovery, breathing difficulty, or a child who remains unusually unresponsive.

Questions for your care team

- Does the clinical pattern support Dravet syndrome?
- Which medicines or triggers need specific guidance?
- What rescue plan should home and childcare follow?



Podcast preparation

Use this outline to develop a later podcast script.

Suggested opening

Welcome to Mariel Early Intervention. Today we discuss Dravet syndrome. Dravet syndrome is a rare developmental and epileptic encephalopathy that usually begins in infancy. This is general education; each child needs individualized care.

Opening: Define the topic and its developmental context.

Understanding: Explain causes and signs without inviting self-diagnosis.

Assessment: Describe evaluation and distinguish screening from diagnosis.

Support: Discuss treatment, therapy, and practical family supports.

Closing: Explain urgent signs and one clear next step.

Misconception to address: Myth: normal early tests rule out Dravet syndrome. The developing seizure pattern and genetic findings can be important.

Before recording: update clinical references and local service details, arrange clinical review, and use fully consented or fictional examples.

Terms in plain language

- SCN1A: a gene involved in nerve-cell electrical signaling.
- Febrile seizure: a seizure associated with fever; many are unrelated to Dravet syndrome.
- Rescue plan: written instructions for urgent seizure treatment and help.

Sources and further reading

Sources accessed 3 October 2026. Numbered references support the clinical overview. Treatment availability and referral routes vary by country.

[1] Dravet Syndrome

<https://www.ninds.nih.gov/health-information/disorders/dravet-syndrome>

[2] 6 Treating childhood-onset epilepsies

<https://www.nice.org.uk/guidance/ng217/chapter/treating-childhood-onset-epilepsies>

[3] First Aid for Seizures

<https://www.cdc.gov/epilepsy/first-aid-for-seizures/index.html>