Living with **Dravet syndrome**

Dravet syndrome is a rare, devastating, and life-long developmental and epileptic encephalopathy that begins in infancy and is marked by frequent treatment-resistant seizures, significant cognitive, developmental and motor impairments that persist into adulthood, and an increased risk of Sudden Unexpected Death in Epilepsy (SUDEP).[1,2,4,7,9]

Seizures associated with Dravet syndrome[1]

- Begin within the first year of life[1]
- Development is normal before seizure onset [1,4,8]
- Can sometimes be prolonged
  lasting more than 5 minutes for tonic-clonic seizures (status epilepticus)[3]
- Are drug-resistant[1,3]

Can be triggered by common daily occurrences[4]

- Emotional stress or excitement[8]
- Sunlight, flashing lights, or patterns[8]
- Changes in body temperature[4,8]

Who does Dravet syndrome impact?

Affecting **one in 15,700** live births in the U.S. and approximately one in **20,000 to 40,000** live births in Europe, the impact of Dravet syndrome can be devastating in nature, as people often cannot care for themselves.[3,4,10] Dravet syndrome is associated with lifelong deficits in cognition and behavior, as well as a constant need for monitoring due to the high frequency of seizures, motor impairments, and risk of death. Thus the disease doesn't just affect those with the condition, but also their families and caregivers.[2,5,11]

66% of caregivers experience depression due to the devastating nature of Dravet syndrome.[11]

74% of caregivers report concerns about the emotional impact on siblings of children with Dravet syndrome.[11]

Dravet syndrome by the numbers:

Up to **20%** mortality rate with Dravet syndrome by age 20[3, 12]

~85% of people diagnosed with Dravet syndrome carry *SCN1A* gene mutations[3,6]

Less than **10%** of people with Dravet syndrome are able to achieve freedom from their persistent seizures, even though more than 20 anti-seizure medications are currently on the market [5,8]

How is Dravet syndrome treated?

Most people with Dravet syndrome are taking combinations of 3+ anti-seizure medications (ASMs).[5]

Despite treatment with multiple ASMs, many people continue to experience multiple seizures on a weekly or even daily basis that can persist throughout their lifetime.[2,9,14] Existing treatment options may not be able to provide the amount of seizure control that people desire.[9]

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Inspired by **patients.**
Driven by **science.**

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