LIVING WITH DRAVET SYNDROME A DEVASTATING FORM OF INTRACTABLE PEDIATRIC EPILEPSY

What is Dravet syndrome?

Dravet syndrome is a rare, devastating, and life-long epileptic encephalopathy that begins in infancy and is marked by frequent treatment-resistant seizures, significant developmental and motor impairments that persist into adulthood, and an increased risk of sudden death.[1,2]

Seizures associated with Dravet syndrome[1]

Begin within the first year of life

Present in a developmentally normal infant

Can be repetitive

Can sometimes be prolonged

lasting more than 5 minutes for tonic-clonic seizures (status epilepticus)[3]

Can be triggered by common daily occurrences[4]

Emotional stress or excitement

Sunlight, or flashing lights or patterns

Changes in body temperature

Who does Dravet syndrome impact?

Dravet syndrome affects approximately one in 15,700 infants born in the U.S. and can be devastating in nature, as patients often can not care for themselves.[5] 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.

66% of caregivers experience depression due to the devastating nature of Dravet syndrome[2]

74% of caregivers report concerns about the emotional impact on siblings of children with Dravet syndrome[2]

Dravet syndrome by the numbers

90%
or more of children with Dravet syndrome are not able to achieve seizure-free days[6]

~85%
of children diagnosed with Dravet syndrome carry SCN1A gene mutations[4]

Dravet syndrome has a mortality rate of up to
20%
by age 20[3]

>50%
of all deaths in children and young adults with Dravet syndrome are attributed to sudden unexpected death in epilepsy[7]

How is Dravet syndrome treated?

Most patients with Dravet syndrome are taking combinations of 3+ antiepileptic drugs (AEDs). Despite treatment with multiple AEDs, many patients continue to experience multiple seizures on a weekly or even daily basis.[6] Existing treatment options may not be able to provide the amount of seizure control that patients desire.

Less than 10% of children with Dravet syndrome are able to achieve freedom from their persistent seizures, despite treatment with AEDs based on a recent study[6]

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