Living with Dravet syndrome, a devastating form of intractable pediatric epilepsy

Dravet syndrome is a rare form of intractable (treatment-resistant) epilepsy that begins in infancy and is associated with potentially life-threatening, frequent and severe seizures, developmental delay, cognitive impairment, and an elevated risk of sudden unexplained death in epilepsy (SUDEP).1,2

What is Dravet Syndrome?
The seizures in children with Dravet syndrome:1,2

<table>
<thead>
<tr>
<th>Event</th>
<th>Description</th>
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<td>Begin within the first year of life</td>
<td>Develop many different types of seizures with aging</td>
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<td>Can be repetitive</td>
<td>Can be prolonged – sometimes lasting more than five minutes.</td>
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Dravet syndrome by the numbers

- ~85% of children diagnosed with Dravet syndrome carry SCN1A gene mutations.2
- Dravet syndrome has a mortality rate of up to 20% by age 20.1

Children and families with Dravet syndrome live in constant fear of seizures, which can be triggered by common daily occurrences, such as:2

- Emotional stress or excitement
- Sunlight, or flashing lights or patterns
- Changes in body temperature, such as hot weather or warm baths or fever

SUDEP accounts for ~50% of all deaths in children and young adults with Dravet syndrome.9
Who does Dravet syndrome impact?

Dravet syndrome affects approximately **one in 15,700** infants born in the United States.  

Dravet syndrome doesn’t just affect those with the condition, but also their parents, caregivers and loved ones. According to a survey of 256 parents and caregivers conducted by the Dravet Syndrome Foundation:

- **66%** of caregivers experience depression due to the devastating nature of Dravet syndrome.  
- **74%** of caregivers report concerns about the emotional impact on siblings of children with Dravet syndrome.  

Many caregivers experience sleep deprivation due to the constant worry of when their child’s next seizure could occur.

How is Dravet syndrome treated?

Most patients with Dravet syndrome are taking combinations of **3+ antiepileptic drugs**. Existing treatment options fail to control the frequent and severe seizures that children with Dravet syndrome experience, which means physicians and caregivers desperately need access to new medicines with proven efficacy.  

In addition, most of the currently prescribed anti-epileptic medications cause significant side effects, such as slowed thinking, and many have potential adverse events such as liver toxicity.

Less than 10% of children with Dravet syndrome are able to achieve freedom from their persistent seizures, even though more than 20 anti-epileptic drugs are currently on the market.

To learn more about Dravet syndrome, visit the [Dravet Syndrome Foundation](https://www.dravet.org).

Zogenix is committed to developing and commercializing transformative therapies for people living with rare diseases that can dramatically improve the lives of patients and their families.

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