

# The Impact of Caring

FOR A LOVED ONE WITH DRAVET SYNDROME

Caregivers and families are unsung heroes who play a vital role in the health and well-being of the children and young adults with Dravet syndrome.

The disease not only affects those with the condition, but also the entire family unit - parents, siblings, caregivers and loved ones. This commitment can often result in a substantial financial, physical, psychosocial and emotional burden.



## WHAT IS DRAVET SYNDROME?

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).<sup>1</sup>

Dravet syndrome occurs in approximately



**1 in 16,000** births in the U.S.<sup>2</sup>

## Being A Caregiver For A Child With Dravet Syndrome Can Take An Emotional Toll



**66%** reported having **suffered from depression**<sup>3</sup>



**33%** have moderate to high levels of **anxiety or depression** due to the devastating nature of Dravet syndrome<sup>4</sup>

## Many Parents Experience the Impact At Work



**81%** stopped working because of their caregiving responsibilities<sup>5</sup>



**48** eight-hour **work days missed** per year<sup>6</sup>



**77** eight-hour **work days of lost work productivity** per year<sup>6</sup>

## The Responsibility of Care Consumes Significant Amounts of Time



**1 hr.** or less per day is the only time 77% of caregivers report having completely for themselves<sup>5</sup>



**256** eight-hour **work days of lost leisure time** per year<sup>6</sup>

## The Burden Ripples Through The Entire Family

**83%** of siblings aged 9-12 **felt easily scared and fearful** their sibling will die<sup>7</sup>

**67%** of siblings reported **feeling worried or scared** when their sibling has a seizure<sup>7</sup>

**74%** of caregivers reported having concerns about the **emotional impact on siblings**<sup>3</sup>

**37%** of adult siblings reported having been **treated for clinical depression**<sup>8</sup>



It's important that people who care for children and young adults with Dravet syndrome learn ways to cope.

Many advocacy groups offer tips and parent support groups to connect with other Dravet families.

Visit the Dravet Syndrome Foundation at <https://www.dravetfoundation.org/> to learn more about ways to manage caring for a loved one.

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