THE IMPACT OF CARING FOR A LOVED ONE WITH DRAVET SYNDROME

Caregivers and families play a huge role in the health and well-being of children and adults with Dravet syndrome. Due to the need to be “on guard” 24/7, the quality of life for caregivers and families is severely impacted. This commitment can result in physical, psychosocial, emotional, and financial burdens, such as constant monitoring, the need to co-sleep, and fear of death.1

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, and an increased risk of sudden death.1

### The Emotional Toll on Caregivers

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<th>1 in 15,700</th>
<th>approximate number of infants born in the U.S. with Dravet syndrome²</th>
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<td>5–6,000</td>
<td>number of patients diagnosed in the U.S., with ~50 new cases per year²</td>
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<td>40 seizures/month</td>
<td>average number of seizures children with Dravet syndrome experience,³ lasting &gt;20 minutes in up to 49% of patients⁴</td>
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66% of caregivers reported suffering from having depression¹

### Less Time for Oneself

77% of caregivers reported only having 1 hour or less per day for themselves, as being a caregiver takes up a significant amount of time⁵

### Many Parents Experience the Impact at Work

81% of parents stopped working due to their caregiver responsibilities⁶

48 8-hour work days are missed each year⁶

### The Burden Ripples Through the Entire Family

79% of siblings aged 9–12 feared that their sibling might die⁷

35% of adult siblings reported having a history of clinical depression⁸

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THE ADDITIONAL IMPACT OF DRAVET SYNDROME

The lives of Dravet syndrome patients, and those of their caregivers and families, are directly and indirectly impacted by the physical and emotional demands of the disease.

Direct Impacts (i.e., patient care)
- In-home medical care visits
- Doctor visits
- Emergency room visits
- Hospitalizations
- Ground and air ambulance
- Complementary healthcare (i.e., chiropractic services)

Indirect Impacts (i.e., day-to-day effects)
- Missed work due to caregiver responsibilities
- Decline in workplace productivity due to absenteeism and presenteeism
- Loss of leisure time
- Emotional and psychological demands