Dravet syndrome
key facts

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

Dravet Syndrome is a rare and severe form of epilepsy[1,2]

A lifelong condition with significant impact on quality of life (QoL) for patients and families[3–5]

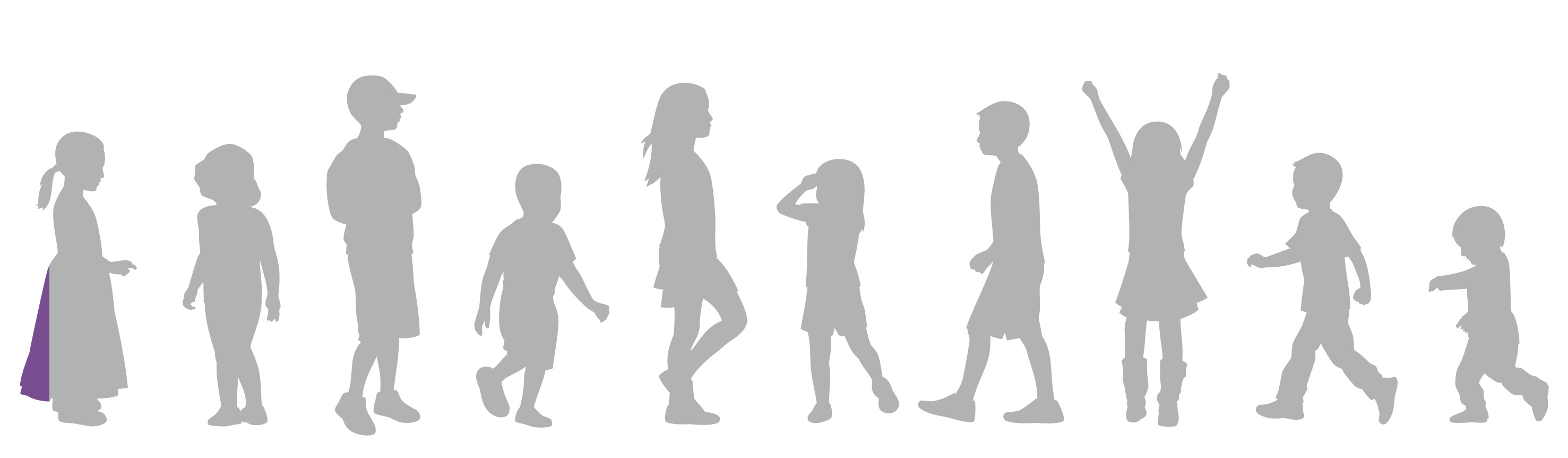
Doesn't respond well to treatment (treatment-resistant)[1,2]

Can affect development[1,2]

Usually starts in childhood and infancy[1,2]

There is no cure for Dravet syndrome[6]

The condition affects **1 in 15,700** to **1 in 40,900** births[7,8]



Dravet syndrome can be misdiagnosed for other epilepsies or go undiagnosed[9]

Diagnosis is based on clinical evaluation and can be confirmed by genetic testing[10]

~85%

of children diagnosed with Dravet syndrome carry a mutation to a gene, known as *SCN1A*[3]

5%-10%

cases are **inherited**[11–15]

90%-95%

cases are completely random[11–15]

15.84 per 1000

person years mortality rate[16]

Seizures in Dravet syndrome

- Are hemiclonic or generalized tonic-clonic in nature
- Begin within the first year of life and persist into adulthood[17]
- Present in a developmentally normal infant[17]
- Can be repetitive[17]
- Can sometimes be prolonged (more than 5 minutes of continuous seizure activity without recovery)[18]
- Seizures are not adequately controlled in **90%** of people with Dravet syndrome[19]
- With age, there is a shift toward nocturnal tonic and tonic-clonic seizures

Seizures can be triggered by daily occurrences[20]

Emotional stress or excitement

Photic stimulation (e.g. sunlight or flashing lights)

Changes in body temperature

Dravet syndrome involves multiple types of seizures including:[3,21–26,*]

Hemiclonic:
Affects only one side of the body

Generalised tonic-clonic:
Begins with stiffness in the arms and legs, followed by jerky movements in the arms, legs, and head with a loss of consciousness

Myoclonic:
Involuntary, brief, jerk-like movements that cause a sudden muscle contraction

Tonic:
Stiffness in the arms and legs

Clonic:
Jerky movements in the arms, legs, and head

Tonic-atonic:
Muscles in the body become stiff and then relax

Focal with clearly observable motor signs:
Affects a limited area of the brain and the affected person remains

**Dravet syndrome seizures are often refered to as convulsive seizures*

There are **four stages** of Dravet syndrome:

Febrile stage (infancy):[27]
High probability of diagnosis within the first year, characterised by long-lasting seizures related to fever, often requiring emergency treatment

Worsening stage (1-5 years):[27,28]
Motor seizures become more common, triggered by environmental factors. Other seizure types may appear, such as myoclonic seizures or absences. Children may show developmental stagnation, lack of coordination, loss of muscle tone, and a decline in dexterity

Stabilisation stage (around 10 years):[27,29]
Seizures become shorter, less frequent, occurring during sleep. Tonic seizures may occur, with milder forms having one episode per year. Patients develop a crouching gait, often leaning on others or using a wheelchair. Cognitive impairment is often present

Adulthood:[27,29,30]
Generalized tonic-clonic seizures are the most frequent seizure type, occuring mainly at night. Progressive worsening in adulthood includes movement disorders, tremors, and symptoms akin to Parkinson's disease. Other seizure types may diminish, but adults may face additional health problems due to Dravet syndrome. About a quarter of patients may also experience loss of bone density with an increased risk of fractures

SUDEP (sudden unexpected death in epilepsy)

Is a constant fear for parents and caregivers of people living with Dravet syndrome and the risk should be discussed with a healthcare professional[31,32]

The risk of SUDEP in children living with Dravet syndrome is estimated to be **30 times greater than** other childhood-onset epilepsies[33,34]

Current treatment options

1. Antiseizure medications[35]
2. Ketogenic diet[36,37]
3. Trigger avoidance[35]
4. Vagus nerve stimulation (pacemaker-like device that sends electrical impulses to the vagus nerve in the neck)[38]

Aspects of patients' daily life affected by Dravet syndrome:[39]

Sleep - Sleep difficulties worsen seizures, and more seizures lead to less sleep, creating a vicious cycle

Feeding - Individuals tend to experience feeding problems

Gait disturbance - Can impact patient's independence and ability to walk

Toilet training - Patients tend to be late to learn and are sometimes incontinent

School - Individuals require additional support and seizures can cause missed school days

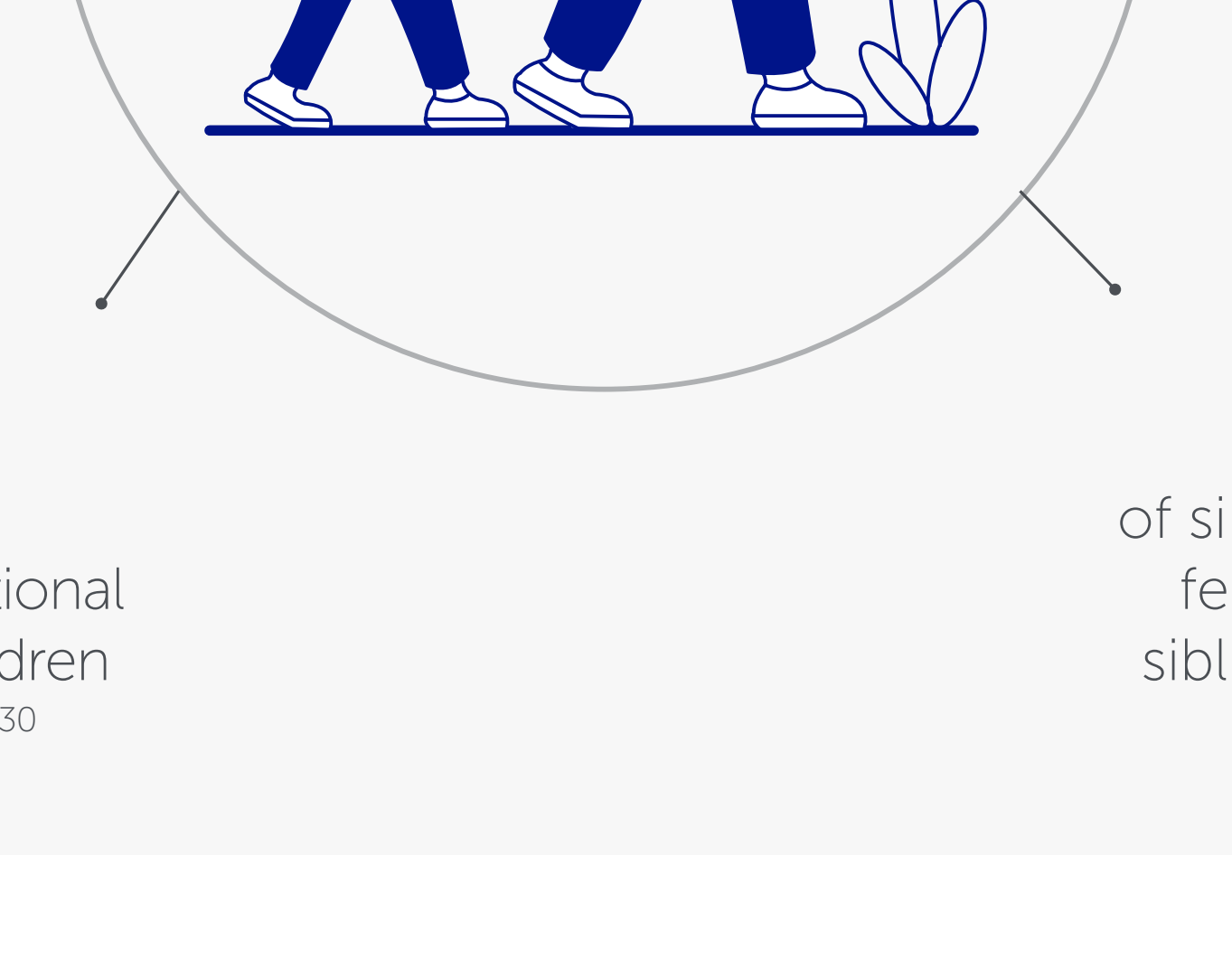
Cognitive challenges

Motor and behavioural disorders increasing with age

Impact on family and caregivers

The responsibility of care can have a significant impact on day-to-day life.[4]

The lives of Dravet syndrome patients, and those of their families, are directly and indirectly impacted by the physical and emotional demands of the disease[40]



35%

of adult siblings report a history of treatment for clinical depression[41]

66%

of caregivers experience depression due to the devastating nature of Dravet syndrome[30]

81%

of caregivers stopped working because of their responsibilities[4]

58%

of siblings aged 9-12 reported feeling worried or scared when their sibling has a seizure[41]

74%

of caregivers report concerns about the emotional impact on siblings of children with Dravet syndrome[30]

79%

of siblings aged 9-12 feared that their siblings might die[41]

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