

## My journey with my little boy Mason.....

### About Mason

Mason was diagnosed at the age of 7 months with "Dravet Syndrome", which is a rare debilitating condition that can cause pro-longed seizures, developmental delay and sadly SUDEP (sudden unexplained death in epilepsy). He first started having seizures at the age of 4 months. Despite everything life has thrown at him, he is a very happy, fun loving courageous little boy!!

### Zoë's!!!!

Zoë's Place (aka our extended family), has enabled my family to function how we do. Firstly, Zoë's input has allowed me to have quality time with my eldest who also has the same condition as Mason. Secondly, I cannot express how I feel knowing Mason is loved & cared for at Zoë's like he is. The peace of mind is second to none!! Which means when mason is at Zoë's, I can breath and totally enjoy my time with Jake knowing Mason is so happy, interacting with new friends in a very safe environment & medically he is looked after too.

If I could sum up Zoë's in a sentence it would be "they give so much, yet take so little".



## Dravet Syndrome

Dravet syndrome, also known as Severe Myoclonic Epilepsy of Infancy (SMEI), is a rare and catastrophic form of intractable epilepsy that begins in infancy. Initial seizures are most often prolonged events and in the second year of life other seizure types begin to emerge. Development remains on track initially, with plateaus and a progressive decline typically beginning in the second year of life. Individuals with Dravet syndrome face a higher incidence of SUDEP (sudden unexplained death in epilepsy) and have associated conditions, which also need to be properly treated and managed. These conditions include:

- behavioral and developmental delays
- movement and balance issues
- orthopedic conditions
- delayed language and speech issues
- growth and nutrition issues
- sleeping difficulties
- chronic infections
- sensory integration disorders
- disruptions of the autonomic nervous system (which regulates things such as body temperature and sweating)

## Children with Dravet syndrome do not outgrow this condition and it affects every aspect of their daily lives.

Unless a cure or better treatments for Dravet syndrome and related epilepsies are found, individuals with these disorders face a diminished quality of life. Current treatment options are extremely limited and the prognosis for these children is poor. The constant care and supervision of an individual with such highly specialized needs is emotionally and financially draining on the family members who care for these individuals.

## Meggie Feeney ~ Mother of Mason age 5 years

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Baby Hospice