

Rose Blossom

'Rose Blossom Trust' has been set up by the parents of Darcie and Evie Chapman. Darcie and Evie suffer from a very rare form of epilepsy called "**Dravet Syndrome**". This condition affects all aspects of their development.

Imagine how hard it is living with a syndrome that nobody knows about.....uncontrollable seizures, behavioural and development delays, speech issues, sensory disorder, sleep difficulties, balance issues, high risk of SUDEP (Sudden Unexplained Death In Epilepsy), rare and catastrophic epilepsy, regression, diminished quality of life, feeding tubes, ataxia, reduced life expectancy.....This is **Dravet syndrome**

The aim of the trust is to help the lives of not only Darcie and Evie but the lives of others and their families who live each day not knowing if this day will be the last they have with their child. The hope is that the trust will be able to fund items such as, medical equipment, an iPad or even a family break.

There have been approximately 400 people diagnosed with Dravet Syndrome, Darcie and Evie are the only known set of twins that both suffer with the condition.

If you do want any further information you can log onto www.Dravet.org.uk or www.roseblossomtrust.co.uk.

Thank you



