

Lyla's Story



I hope that her journey will help others understand the challenges that children with Dravet syndrome and their families face.

Lyla is almost two years old and has a severe gene mutation in the SCN1A gene, resulting in Dravet syndrome. Dravet syndrome is a rare and severe form of epilepsy that usually starts in infancy and can cause lifelong difficulties. Lyla has already experienced 18 status epilepticus episodes, which are seizures lasting over one hour each time. She has been admitted to the hospital numerous times and unfortunately is resistant to most daily and rescue drugs, which makes her condition even more challenging.

Despite all the hardships, Lyla is the bubbliest and brightest soul one could meet. She is truly a fighter.

Recently, Lyla underwent surgery to have a portacath, commonly known as a port, inserted in her chest to avoid failed IV access attempts and IO lines during her trips to Resus. Although it has been a saviour for the family, it hasn't shortened the length of her seizures. I hope that her journey will



0800 37 45 37



national@epilepsy.org.nz



www.epilepsy.org.nz

help others understand the challenges that children with Dravet syndrome and their families face.



0800 37 45 37



national@epilepsy.org.nz



www.epilepsy.org.nz