Iyla's Story



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

Iyla 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. Iyla 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, Iyla is the bubbliest and brightest soul one could meet. She is truly a fighter.

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