Noah

LIVING WITH SEVERE OBSTRUCTIVE LARYNGOMALASIA, SLEEP APNEA, SCOLIOSIS, CHIARI MALFORMATION AND 16P11.2 DELETION

We are so happy to have our little boy who we were told would not survive. He fought so hard to be here.

"His future is uncertain but we take every day as a blessing."

Noah was born in 2017 in Limerick maternity hospital. Over the 8 weeks after birth he was failing to thrive and deteriorating a lot. After spending a lot of time in hospital we finally had answers as to why he was failing to thrive and struggling to breathe. His sats were dropping every day and we nearly lost him a few times.

Noah was later diagnosed with a heart condition after he went into heart failure, he had severe obstructive laryngomalasia which is a blockage of the airway, severe sleep apnea, scoliosis,chiari malformation of the brain and he has a rare deletion which is 16p11.2.

Noah has had open heart surgery , surgery on his airway. He is tube dependent as he aspires and vomits daily for the smallest reason. He also wears a cast for scoliosis.

His rare deletion means he is non verbal and will have learning difficulties, delayed development, behavioural issues and maybe seizures. Although he doesn't mark all these symptoms he is classed as severe as geneticist has never come across a child as sick as Noah is with this deletion which made him think there had to be another reason but more genetics were done and he was tested for 2 things in particular which came back negative so we were non the wiser.

We decided to stop testing him as we are just so happy to have our little boy who we were told would not survive and that the reason 16p is so rare is because these kids are usually miscarried so to have our little miracle with us is all we need. He fought so hard to be here. He still has good and bad days and he does go through alot but he does so with a big smile on his face. His future is uncertain but we take every day as a blessing.