

BREAKING BARRIERS FOR CYSTIC FIBROSIS

TODAY'S DEDICATION

DAY 30: SATURDAY 30th SEPTEMBER 2023



JESSIE

Meet Jessie, a 20-year-old strong-willed, resilient young man who takes everything in his stride as best he can. Has a love for animals, gaming, fishing, and playing the guitar.

Jessie was born in 2002 6 weeks Premi and diagnosed with CF shortly after birth when his routine heel prick came back abnormal. Jessie is also a twin fortunately his twin sister isn't a carrier of the CF gene. Soon after Jessie was diagnosed, he was then transferred to RCH for the best possible care. We were guided on the best care that Jessie was going to need, and the support we also were going to need especially being new parents.

It sure was a lot, but we took in as much as we could in those first few weeks.

Finally, the day came to take Jessie home. We were so excited! When we arrived at the hospital, the doctor was in with Jessie, and he said I'm afraid you can't take him home today he has Pneumonia!

Jessie ended up being in hospital for nearly 2 months from the time he was born. From that moment onwards Jessie spent more of his life in hospital than he did at home in his first 5 years with multiple chest infections. Jessie was not expected to live past 5 years old, but here he is today about to turn 21 in just a few months' time!

When Jessie was 2yrs old he was diagnosed with CF-related Liver disease, and it has slowly progressed over the years causing multiple problems along the way. I remember the doctor telling us it's like waiting for the train to come, but you just don't know when it's coming.

Jessie also had a port a cath placed in just under his arm when he was a toddler as he was having so many hospital admissions and blood tests his poor little veins just weren't coping. The port a cath lasted for about 5 years before it stopped working and then had to be taken out, by then thankfully Jessie didn't end up needing another one in.

Over the years Jessie has always battled weight issues and had so much trouble keeping his weight on which resulted in him getting a peg put in for night feeds, to help gain weight. This has been in place for around 10 years now and has been a huge help in stabilizing his weight.

For Jessie, the hospital has been like a second home over the years for many different reasons due to his CF and Liver Disease. Nurses become like family you see them so much, and most are always so kind. It has been a tough journey for him, over the years but he deals with what comes as best he, can with his family by his side every step of the way.

When Trikafta came out we didn't have much hope, as Jessie had previously done a trial for Orkambi and his liver didn't react very well, causing his liver levels to skyrocket to dangerous levels. Sparking an urgent admission to get those levels down to a safe zone and cease all Orkambi medication. But

again, we asked all the questions, and this was a decision that wasn't taken lightly but, unfortunately, due to Jessie's liver complications, he cannot have it at this time. In time we hope this might change. What I can say is we are thankful that Trikafta is helping so many others with Cystic Fibrosis.

