

## **Ollie's story**

When baby Ollie was born in June 2014, he wasn't breathing. So he was resuscitated before being put in the arms of his Mum, Sophie. She and her husband Sean took their precious new-born son home the next day, but for some reason, they knew something wasn't right.

Back at their home in Barry, Sophie found a sacral dimple at the base of Ollie's spine, so at 8 days old he had a scan for suspected spina bifida, which didn't reveal anything. His parents were worried that he wasn't feeding properly or swallowing and he wasn't gaining weight. With Ollie having endless trips back and forth to the doctors, medical experts couldn't pin point the problem but after four long, anxious months, Ollie was eventually diagnosed with Pallister Killian syndrome – an incredibly rare chromosome abnormality that results in complex medical issues.

Sophie explained: "For the first 18 months of Ollie's life, his development seemed reasonably normal but that soon slowed too and he started having more and more seizures. We were referred to Tŷ Hafan by our consultant when he was a year old, but that first time we didn't get a place. Time went on and Ollie continued to be very poorly, with constant, severe chest infections and other illnesses. He was awake all the time at night and I was at the end of my tether with sleepless nights and medical appointment after medical appointment. I really needed some help so I self-referred when he was two years old and this time, we were offered a place".

"Although I knew they were going to help us, I hated the thought of a hospice. Everyone hates that word, don't they? But the moment Sean and I walked through the doors of Tŷ Hafan, we knew we couldn't have been more wrong. It was nothing like you'd expect. The first time we took Ollie there for short break care, we both stayed overnight as I was worried about leaving him, but soon all my worries disappeared. I know now how much the nurses love him and take complete care of him. He's so well looked after I'm happy to leave him there with them".

"It's an absolutely amazing place. They look after Ollie but they look after us too. I was going through a really rough time recently, with a close family bereavement and illness. Tŷ Hafan knew things were bad for me so we were offered a short break there, so we could just step back from things. They were just so lovely, offering us practical help and support and a shoulder to cry on if we needed it. Tŷ Hafan is there for all of us".

Tŷ Hafan takes its support to wherever it is needed: at home, at school or in hospital. We do this completely free of charge for families in Wales that need us. Please help us continue to be there for life-limited children and their families, so they can make the most of the precious time they have left together.

For more information visit [www.tyhafan.org](http://www.tyhafan.org) or call 029 2053 2199.

