



“Life as Xavier’s mum is a constant battle and is full of appointments and therapy. There are no words to describe the anxiety and fear I live with every day”.

As parents, we encourage our children to dream big and live large. We tell them that if they work hard and apply themselves, that anything is possible. When my son Xavier was five, he told me he wanted to be an AFL player and my heart broke just a little bit more knowing that it would never be possible.

Xavier was born with the genetic disorder, Neurofibromatosis (NF) Type 1. It is a condition that has been passed down through many generations of my family; a condition that I knew we had a fifty percent chance of passing onto any children we had.

My partner and I discussed the possibility of having a child with NF and what that would mean, but **my family only ever experienced mild complications**, so we decided it was a risk we were willing to take. I don't think I really understood how variable and serious NF could be...until I had my son.

Xavier has learning difficulties and developmental delays. He has a severe speech impairment, a brain tumour and an invasive tumour that has wrapped itself around multiple nerves in his spine, hip and thigh.

"NF HAS ROBBED SO MUCH OF MY SON'S CHILDHOOD AND HAS DIMMED OUR EXPERIENCE OF BEING PARENTS. THE GUILT I FEEL FOR PASSING THIS FAULTY GENE ONTO MY SON SOMETIMES THREATENS TO SWALLOW ME WHOLE".

Despite not meeting all of the diagnostic criteria, I suspected that he had NF from a very early age, but every doctor I visited disregarded my fears.

When he was almost three, Xavier became clumsy and exhibited signs of in-toe walking. I took him to specialist-after-specialist begging for someone to listen, but was told it was “unlikely” that he had NF and that his leg “appeared fine”.

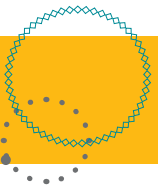
When a doctor finally agreed to do an ultrasound it showed a mass in his leg. **I thought finally someone would take my concerns seriously**, but was told to do nothing but “watch and wait”. The complete lack of urgency highlighted a vast lack of understanding of NF, even amongst medical practitioners.

Desperate for answers, I called the Children's Tumour Foundation and all but begged them for help. I am so grateful that I did. Within one week Xavier was admitted to the Royal Children's Hospital in Melbourne and referred to a Neurologist who ordered an urgent MRI. The news was worse than anything I had prepared myself for.

Xavier had a **plexiform tumour** (a tumour that is vascular and has its own blood supply) which covered the entire lumbar region of his spine. It had wrapped itself around the nerves in his hip and finished 7cm above his knee. They also found a hamartoma tumour in the hypothalamus of his brain.



YOU DON'T HAVE TO GIVE A LOT TO MAKE A BIG DIFFERENCE.



In May of 2018, two years after his original diagnosis, **Xavier's previously straight spine was at a 28-degree angle and just 12 months later it had progressed a further 10 degrees.**

Now at a 38 degree angle, Xavier has been fitted for a back brace to prevent his scoliosis from worsening. He was initially thrilled that he would resemble a turtle, but for me it represented a definite shift in his treatment and quality of life.

Our options are to do nothing as the tumours make their menacing advancement through his body or risk him bleeding to death in a surgery to remove them.

IF WE DO NOT FIND A CLINICAL TRIAL SOON, HE COULD END UP WHEELCHAIR BOUND – OR WORSE.

I worry about his tumour and his spine, I worry about his development, his speech, his behaviour and his inability to articulate when something is wrong. I worry about the brain tumour that is currently lying dormant and I worry because I know this will be the first of many. I worry about Xavier's experience in school, the potential for bullying and the social isolation his situation will have on him.

"I OFTEN FIND MYSELF IMAGINING WHAT A LIFE WITHOUT NF WOULD LOOK LIKE FOR XAVIER. IN THOSE MOMENTS, I SEE HIS LITTLE LEGS TAKING OFF ACROSS THE AFL FIELD IN SEARCH OF GLORY".

As a Mum, I want to tell Xavier that life is too short to wake up with regrets, so if you want something, work hard and it will happen.

Just last month, he played his first game of Aus Kick. An avid Richmond Tigers supporter, he wore his signed jersey with pride as he took off onto the field and **just for a moment, my heart soared.**

I am well aware of the limitations that NF will place on his life, but that doesn't mean we won't put up one hell of a fight first.



Xavier's older sister Chantelle also has NF1.

Diagnosed at just 3 months old, she has a plexiform neurofibroma in her arm and chest, scoliosis and mild learning difficulties.

Unfortunately, she may also require surgery on the growth plate in one of her legs to help prevent further curving of her spine.



LEFT TO RIGHT: Xavier, Chantelle, Zalia and Owen