



### **Kirby – Cerebral palsy (and mum Jackie)**

Eleven-year old Kirby, who has cerebral palsy, tends to bring out the best in everyone who comes in contact with her.

Testament to this is the remarkable actions of the Nelson Bay community where Kirby and her family lived for seven years.

Jackie and a small group of friends, supported by the Air Force family liaison officer, organised a fund raising night which raised the incredible sum of \$50,000 to modify the family's vehicle so that it could carry Kirby's wheelchair. Invaluable financial management was provided by the Nelson Bay Rotary Club's Treasurer to handle all monies.

Six years later, Kirby's mum Jackie is still in awe of the community's remarkable generosity.

"It was just spectacular. What a community. They will always have such a really special part in our lives."

As a mother to four boys under the age of five, there had been no warning that Kirby's birth was going to be difficult. Jackie's pregnancy had been uneventful up to the time when she walked into Katherine Hospital in labour, when she felt what she thought was her waters breaking.

"I looked at the nurse and my husband, and they were both pale. I looked down and discovered that I was gushing blood."

Jackie was experiencing a placental abruption, which left baby Kirby starved of oxygen.

"I had an emergency caesarean and Kirby was airlifted to Darwin before I had even woken up.

"As they were putting Kirby in the plane one of the nurses grabbed a Polaroid camera from her car and took a photo for me so that I had a picture of her."

Jackie, who was forbidden to fly due to low haemoglobin levels from loss of blood, remained in hospital in Katherine. Then, three days after her birth, Kirby started having seizures.

"When I found out Kirby was fitting I said to the hospital: 'Look, if you don't transfer me up to Darwin I'm going to discharge myself and drive'. They sent me."

Following Kirby's fit she was given an MRI scan to look for any signs of brain damage.

"We got the results back about three days later and they told us 'you've been very lucky, there's no damage'.

"But because she was our fifth child we knew that things weren't quite right. We had decided that if we didn't talk about it, then it wouldn't be true, and things would be ok.

"But it wasn't ok."

The family moved from Katherine to the Blue Mountains when Kirby was a month old.

"We went to a paediatrician who asked about the MRI scans. He rang Darwin and found out we had been given someone else's results by mistake."

With Kirby given a diagnosis of cerebral palsy, the family had some idea of what to expect. Two years later, they moved again, this time to Nelson Bay on the NSW North Coast, where they began seeing a local neurologist who became a great support.

“Poor Kirby wasn’t sleeping. She was having spasms and was in constant pain. There was nothing we could do.

“Kirby doesn’t have an intellectual disability, it’s all totally physical. Because she was such a bright child our neurologist didn’t want to put her on a benzodiazepine drug to sedate her, so he started her on an oral anti-spasticity drug.

“It was a godsend. Our life started again because she was out of pain and she was finally sleeping. Life became good.”

While oral anti-spasticity drug made life much easier and less painful for Kirby, she began to need larger and larger doses of the drug for it to be effective.

“We got to the point where Kirby was actually taking 150mg of the drug a day. There are adults that aren’t on that. Kirby is a very little girl. Even now she’s nearly eleven and she’s only 21 kilos.”

Their neurologist told Jackie about ITB (intrathecal baclofen) therapy and she agreed that it was a good solution.

As per standard practice, Kirby was first given a trial of the drug intrathecally. The test requires that oral drug be suspended for a day, so that doctors can see if intrathecal delivery is going to be effective.

“That day she was off the anti-spasticity drug just reminded me why we were doing this thing in the first place. It was a horrendous 24 hours until they did the lumbar puncture and then she was fine again.”

Kirby had surgery to implant a 10ml pump, because the 20ml version was not available in Australia at that point. It was replaced with a 20ml pump two years later.

“We chose to do that because Kirby is still on quite a high dosage of the drug and her refills were getting to be only three weeks apart. Now we’re back to every seven weeks, which is much easier to manage.”

The family has not looked back since Kirby has started ITB therapy.

“I dread to think what our life would be like if we weren’t on the pump.

“ITB stops 90 percent of her spasms. Previously she would have them 24 hours a day. She was having them in her sleep. So she was always in pain and she couldn’t sleep.

“Then my husband and I were exhausted as well, which makes everything worse. And we still had 4 other children to look after.”

Today, with five children ranging in age from 17 to 11, the household is a busy one. Kirby’s older brothers are fiercely protective of her, at the same time, refusing to treat her like she has a disability.

“They do everything with her. Cross country wheelchairs is just a fact of life.

“If one of the boys gets rollerblades they’ll put them on Kirby and roll her around the house. They lay her on the skateboard and push her around.

“When she does funny things they’ll joke to her ‘Kirby, stop being a spastic’ – but if anyone else called her spastic they’d probably hit them!

“They are lovely boys. They are very much boys, but she has turned them into very caring people. She’s had a very large impact on their life. It’s the same with everyone in the family.

I have 17 nieces and nephews from the age of 18 down and she's changed all of their lives."

While Kirby has very little purposeful movement, she uses her eyes to communicate.

"Kirby looks at her right hand to say 'yes' and her left hand to say 'no'.

"And like any 11 year old girl she likes to say 'whatever'! So when she wants to say that she raises her eyes to the roof. We see that a lot lately!

"I've been blessed with Kirby, and I'm not the only one. So have my whole extended family and our friends and everyone who comes in contact with her.

"She just brings so much joy into our lives."