

Kieran and Henry's Story

PRENATAL AND NEW BABY

Back and forth, back and forth. I watch Henry's infectious cackle and smile move towards me and away as I push him a little bit higher. I cannot help but laugh with him. Soon his laughter makes the other parents around smile and laugh. It is his first time on a swing by himself at the park and he is loving life. I can't imagine life without him. Recalling the events of his prenatal diagnosis is always difficult. Time and the sharing of stories paves way for healing and making sense of difficult periods in our lives. I hope my experience will be able to help other families to navigate the uncertainty when receiving a diagnosis of Down syndrome.

Three simple words had caused so much heartache and pain. "I'm so sorry". At that point my world froze. The doctor continued and rattled off on medical condition after condition. Each sentence compounded the unease in my mind as he bookended each statement, repeating those same three words.

Each a punch in the gut and an assault on the mind. My wife, Jenny, and I left what we expected to be a routine 12 week scan in tears. We were deflated and broken. What were we to do? We were painted an image where our lives centred around constant medical appointments and chronic health problems. We were told our baby would be extremely sick.

A week went and a follow up test repeated the same result of the pregnancy being high risk.

Again, the words "I'm so sorry" from the same doctor.

Retrospectively, when I think about it, it wasn't the diagnosis that was upsetting. It was having someone speak about your growing child as if they were a burden. Diagnosis or none, the baby was always wanted.



We were able to get a balanced view and gain insight into the reality of lives lived with Down syndrome when Jenny contacted Down Syndrome NSW. The voice over the phone gave us hope and clarity. Miriam shared stories of her parental experiences with her daughter and the array of young people she has worked with. She made it clear there would be some difficulty but it was possible to have the fulfilling family we craved. Our continued contact with DSNWSW and our own research kept us informed of the world of Down syndrome.



Not long after, we found Dr Casikar who understood our situation and what we wanted. Her explanations and recommendations were nonjudgemental and supportive of our decision. More importantly, she provided medical advice neutrally. We understood that we were 'taking the road less travelled'. My wife and I received balanced views on the health of babies and people with Down syndrome. Her considerations to our situation in her practice ensured our baby Henry was getting the best support needed for him to succeed. I remember her saying "we are going to deliver your beautiful boy" after our first appointment. Those were words of reassurance which were much needed. They were a stark contrast to the initial ones received.

At 36 weeks, with a mix of excitement and panic of impending fatherhood, Henry entered the world. I remember feeling very proud but at the same time terrified as I didn't really know how to look after a baby. I had never been a parent before. He was born during the COVID19 lockdown which meant visits to the hospital and home from grandparents weren't allowed. My wife and I had to become experts overnight. The first time I held him I was very stiff and was scared to drop him. I recall him calmly breathing and sleeping on my chest. My fears were allayed. All my little guy wanted was support, warmth, and love. Something my wife and I had strived and fought to give him since his conception.

With Henry's diagnosis, we have had some challenges. At 2 months, Henry had open heart surgery to rectify 2 holes. Being the extraordinary individual that he is, he was back home in half the time we had been told to expect. Since the operation he has become stronger and developed a cheeky personality. Henry constantly defies expectations. He is a little man that does not let his diagnosis define who he is. From sitting, walking, learning to use sign language, to his dedication to practice his waving with every person we pass; he has tackled each milestone in his own way with his signature smile and dance moves.



I am extremely proud of Henry. When I think back, yes, he does not match the initial image of a family my wife and I thought we wanted, but Henry has opened a new world of learning and understanding for us. Henry has made our family extraordinary and more rewarding. He has taught me to be extra brave, to love fiercely, have patience and to embrace everyone's unique self. He is the boy that brings all the family together smiling. He is the boy that makes those stressful days at work seem insignificant. He is the boy that made me realise dancing could be fun. Henry is my perfect little man.

