

Lyn's Story

My name is Lyn Legge and I am a mother of four, Em, Lisa, Hannah and Tiana. I am also grandma to Zara and Asha. Hannah is 23 years old and has Trisomy 21. Tiana is 15 and has Robertsonian Translocation Down Syndrome.

I had two teenagers when I had a stillborn baby Ellie. I fell pregnant that same year with Hannah. Early blood tests indicated that I was at a higher risk of a child

with Down Syndrome, but we declined an amniocentesis, deciding that we would love this child regardless. It was an emotionally challenging pregnancy, but Hannah was born healthy at 38 weeks gestation. The next day the doctor came to check her eyes, but said nothing. My young nephew visited and commented that she looked Chinese. I later ask the nurse who confirmed that they wanted to test for Down Syndrome. The diagnosis was confirmed by her Paediatrician two weeks later. I think the hospital was concerned for my emotional wellbeing, as they didn't provide me with any information, despite me requesting it. To my husband Glen and myself, we just overjoyed that she was alive and well. We were getting to take our baby home. The midwife who delivered Hannah visited me at home with her 5 year old son who just happened to have Down Syndrome. She had known all along!

Our families all embraced the news and we went to a Down Syndrome get together, making lifetime connections with other families. We have found the vast majority of people accepting of our girls, and for those who struggle, that is their issue.



Hannah attended the local Catholic school and then obtained her Certificate III in Hospitality at TAFE. Her first job was a Saturday morning job at 16, at a Cafe. She now works part time as an office assistant at a Medical Centre, with a wonderful group of coworkers. Hannah enjoys going to the gym, Special Olympics gymnastics and swimming, competing in Triathlons and Ocean Swims. She attends a local drama group and has performed in productions with the local amateur theatre company and choir. Hannah enjoys socialising with her friends and has maintained friendships with many of her school friends. Hannah lives in a "Hanny flat" attached to our house and is enjoying her new found freedom.

Tiana joined our family through adoption at one year old, with a feeding tube and complex medical issues. In her early years we seemed to be in and out of hospitals, often flying to Sydney for hospitalisation. Each year she seems to get more healthy and through it all, she has always been the most happy affectionate child that everyone is drawn to. Like her big sister, Tiana attends the local Catholic high school and is currently in year 10. She is well liked at school by students and staff and her bubbly personality insures she always has plenty of friends. Tiana enjoys Special Olympics gymnastics, Girl Guides, having attended two guide camps. Tiana also attends Groovehouse, a local disability song and dance group. She also likes to Zoom with the Down Syndrome NSW teen dance sessions.





Tiana also has a diagnosis of severe Apraxia of Speech, which is probably her biggest challenge. She uses Auslan sign and LAMP AAC device to assist her, when she can't be understood verbally. Tiana is currently trialling a CPAP machine as she has sleep apnea. She is taking to this as the trouper she is. Tiana maintains a connection with her birth family and I often reflect on how with better support for her parents from a non English speaking background may well have been able to raise her. I am quite passionate about families receiving the support they need to navigate the medical and educational needs of their child.

Anyone who thinks people with Down Syndrome are all the same need to come to our house. Our girls are completely different and one's strength is the other's weakness. We love them both for the joy they bring to our lives, each and every day. We celebrate their achievements, but their worth is not tied to those achievements.

I became involved with Down Syndrome NSW when Hannah was born and we were fortunate enough to have a midwife who was a mum to a six year old with Down Syndrome. She put me in contact with Down Syndrome NSW. Each year I would organise a get together with other local families in Coffs Harbour, to celebrate Down Syndrome Awareness. Hannah went to a local Catholic school with two other students with Down Syndrome. Down Syndrome NSW came to the school to train the staff in including our children.

The following year a few parents and Hannah's teacher travelled to Sydney to attend a three day conference, Our family also attended a family weekend, which was invaluable. I also attended a mother's weekend in the Hunter, prior to NDIS rolling out in our area. For a number of years I was the contact at the hospital for new families. I have handed the reigns over to younger families on a local level and they are doing a great job, running several very popular "Step up" events and starting a Facebook Group.

A couple of years ago I linked in by Zoom to the Health and Wellbeing Workshops, which was a wealth of information and integral in helping Hannah achieve a 10 kilo weight loss. I am currently on the management committee, hoping to make a contribution to an organisation that has only been a phone call away, when I have needed support over the years.

