

## Teresa and Ben's Story

PRENATAL AND NEW BABY

**Congratulations on the birth of your precious new baby! You may be exhausted and feeling a bit overwhelmed as many new parents feel especially when they are sleep deprived. I hope you are enjoying some cuddles too and the warmth of your little one.**

I'm a mother of three children, one girl and two boys. I wanted to share with you something about our amazing Ben who is 13 years old and our story. I'll begin with what I admire about Ben, his independent streak, his confidence to dive off the swimming blocks at Homebush for a big race, his love of performing, ability to memorise lyrics and rhythm, perseverance in the face of challenges, cheeky smile and his French accent.

I was a mother of a lovely one year old girl when I became pregnant with our second child soon to become the amazing Ben. Similar to my first pregnancy I had my regular checks and ultrasounds and unexpectedly some different results came up. The 12 week ultrasound showed my baby's nasal bone was missing and my blood test showed a high probability of having a child with Down syndrome. It took a little while to process the information. I had never met anyone with Down syndrome and didn't know much about it. I had previously worked as an economics researcher and in my typical habit started researching almost straight away. I found helpful information about all the things people with DS were capable of doing and the DS NSW Association website. I contacted them and they sent me a great welcome pack.



➤➤➤ **I was excited to be having my second baby and also concerned if he or she would be okay health-wise. Having more thorough ultrasounds, we picked up at hole in the heart at his 16 week scan. This was definitely more concerning than the initial diagnostic news. However, having the information helped us to plan ahead and see a Paediatric Cardiologist who has taken excellent care of Ben prenatally, and even until this day. We are very fortunate that he had successful surgery at 9 months old and has been a healthy, thriving boy ever since. His heart surgeon was caring and wonderful.**

Some of the medical staff were not always positive, only telling us many of the difficulties and health issues we might face. I made sure we chose a supportive Paediatrician who was on board with us. When Ben was born 4 weeks early and spent the first two weeks in the special care nursery, the midwives were excellent and one supported me in my desire to breastfeed him. Some doctors said not to worry about even trying as I would have enough concerns but having the confidence of a second time mum and researching the Australian Breast Feeding Association's resources I was able to give him that start in life.



Down Syndrome NSW put me in touch with other families over the years and they are great sources of information about schooling and different stages of life. They also put me in touch with a mum in the area with a child with DS who was around five years old. It was lovely meeting her and her daughter and she has been a wealth of knowledge and inspiration along the way.

Through the Association I heard about the benefits of early intervention and a local provider Lifestart. Being an over enthusiastic parent Ben was attending their playgroups starting his therapy journey from 6 weeks old. This was a great place to meet other families in a similar situation. Now some of our children are teens and we are connecting again seeing them begin to enjoy more socialising and joining local sporting clubs and going on camp like most other teenagers.

Family support and good friends have been key and meeting others in a similar situation. Ben has also benefited from some great therapists over the years who really care about him and helping him progress. They are some of the hardest working people I've met. We've regularly worked as a team with the school to try and support Ben forge ahead as he becomes a young man.

Primary school and preschools were on the whole really positive experiences. Ben had some wonderful teachers who thought outside the box and amazing teachers' assistants whose care and support were boundless. There were also those who seemed to have outdated views. He went on school camps, performed in music concerts and drama performances, began learning French and went on a Year 6 trip to Canberra.

One highlight was the sports teacher encouraging Ben to pursue competitive swimming through the multiclass classifications system. We applied for his classification through Sports Inclusion Australia and Swimming Australia. Athletes can compete in different environments and be grouped according to their classification. Ben has been able to represent his school and compete in multiclass races at regional and state events, and in high school has joined a swim club and races at club meets. Ben and our family have always loved the water, he loves performing be it going off the diving blocks and smiling at the crowd as he swims or on the stage in drama which he also loves. Swimming has been a family sport with his siblings also training and a great way to keep healthy and active.

Ben is now in the second year of high school. The transition was a big jump with so many students on campus and some being double in height. Ben showed a willing attitude, sense of belonging and wanting to be a teenager and included just like his peers. Having experienced, supportive and flexible learning support staff has been so helpful. We have continued to meet with our team of therapists face to face or online during the year to help tackle challenges that crop up.

**Barriers still exist and can be frustrating and exhausting but I am grateful to those older parents and adults with Down syndrome who have worked hard to bring some of them down. Making progress on inclusion requires some thinking outside the box, learning from support organisations and agencies, building in support to make things happen, a lot of patience and a can do attitude. We will continue to work on our vision and goal for Ben to be an independent and happy person contributing to society – I'm sure he wouldn't have it any other way.**

