

THOMAS' JOURNEY

Thomas was born 10 weeks premature via an emergency c-section after I had gone into labour and due to him being in the breech position on January 9th 2008 weighing only 1470g (3 pound 4 ounces). He spent his first 8 weeks in NICU and Special Care Nurseries in the Royal Women's Hospital and Frankston Hospital. We loved our little man more than we could have ever imagined, so tiny and so perfect.

In Thomas' first 3 weeks, he had many ups and downs, including not gaining weight, jaundice, an infection and many blood tests. Making the trip to Melbourne everyday was exhausting, a very emotional experience and would find myself crying on the way home because I just wanted to be with my baby. Thomas was fed via a nasal gastric tube starting from 2ml every 2 hours but slowly increased over time. He was transferred to Frankston Hospital when he reached a certain weight and we were so excited to have him so close to home, and I could spend more time with him. I was even able to give him his first bath, which he didn't seem to mind.

Spending everyday at the hospital was very tiresome, but I didn't want to be anywhere else but with my baby. We encountered many hospital staff and I couldn't say a bad word about any of them. It was a comforting feeling knowing that Thomas was left in their care whilst I couldn't be there overnight. Thomas was soon known as the "King of the Nursery" at Frankston Hospital as he had been in the Special Care Nursery the longest. But his last day in hospital was soon upon us even though it felt like a lifetime. I remember looking at Trent saying "well what do we do now?" when we arrived home! But we soon settled in to having him home.

Two weeks after we bought Thomas home we had to take to him to Monash Hospital in Clayton to have a hernia operation; it was an overnight stay at the Ronald McDonald House and also an overnight stay in the hospital. The operation was quick and simple, and we were soon home once again.

Before Thomas left Frankston Hospital we were told that he didn't have the routine Newborn Screening Test so we were referred to a place that could do it for us that was just down the road from the hospital, I made and went along to an appointment. Thomas was hooked up to a machine while he was sleeping and I was told that he wasn't responding to the tests and were told to make an appointment with the Integrated clinic in Cranbourne.

Walking away from just being told this news my stomach sank and could feel a knot in my throat, I couldn't help but think was the reason he didn't respond be something that I

had or hadn't done throughout my pregnancy. I called Trent and told him the news and he was speechless, he really didn't know what to say. After wiping the tears away, I put Thomas in the car and we headed home. I just couldn't believe what they were saying, what type of life would our little boy have if these results were also determined by the next test? We told our families of the news and they were heartbroken.

After making the appointment in Cranbourne we were told that Thomas was still not responding to the tests and were then referred to Australian Hearing in Dandenong. Thomas at 4 months old was diagnosed with a Severe to Profound Hearing Loss in both ears. Thomas was measured and fitted for hearing aids, we went back for further appointments and he was fitted with his little blue hearing aids. When they were turned on for the very first time, I said "Hello Thomas" and he looked up at me with a shocked look on his face while tears streamed down mine. It was the first time Thomas had heard my voice.





Over the next couple of months we travelled back and forth to Australian Hearing at Dandenong, every visit Thomas was fitted with new moulds for his ears but we found as soon as the new ones were made he had already outgrown them. Once he turned 6 months old we were told we didn't have to make the 40km trip to Dandenong anymore and that we could go to Frankston Australian Hearing.



At our first appointment at Frankston Australian Hearing we found all the staff lovely and were given some very valuable information that would steer us in the right direction for a better future for Thomas. I was given the name of a School and the name of a lady that may be able to help us. Her name was Liz Levesque and she was a Teacher of the Deaf and a home visiting teacher for an Early Intervention program through the Aurora School. We made contact with the Aurora School and our fortnightly visits with Liz soon begun.



Over the next 7 months we continued our visits with Liz, she taught us how to communicate with Thomas by using Auslan, which made our day to day life just that much easier. It was lovely to have someone come to us and really become a part of our life and family. And Thomas always looked forward to her visits. Liz would arrive with Teddy Bear in hand and a stack of activities she wanted to get through with Thomas, but he always had other ideas. But always persisting she eventually got something out of him. Her support throughout Early Intervention was amazing, her knowledge and understanding of our situation was exactly what we needed. We had many problems with Thomas' hearing aids, he swallowed a mould, pulled them apart, he went through a phase of not wanting to wear them, they would whistle when they weren't sitting in right, it used to drive us crazy! But we persisted.....



Through Aurora's Early Intervention we also attended a fortnightly Early Learning Group and Mother Goose session at Lynbrook, which were run by Linda and Jina and Anne and Heather. Thomas enjoyed these groups very much although he would never sit still in story time; he loved the different activities set up and started to interact with other children. It got us both out of the house, and it was great for me too, to be able to chat to other parents in similar situations.



With continual appointments at Australian Hearing we were referred to the Eye and Ear Hospital to see if Thomas was a candidate for the Cochlear Implant. After an MRI and CT scan, and an overnight stay at the Royal Children's Hospital, it was found that Thomas has abnormal shaped cochlears and more importantly he was a candidate! So the next decision was "do we go through with the operation, one ear at a time, or both together. Would it make a significant difference having one over two or vice versa?" We thought and thought about the decision, we attended appointments to discuss it with the surgeon and luckily we had Liz with us to be there, and to also listen to our thoughts as we found the surgeons didn't have very good bedside manners! And one in particular didn't really know how to talk to parents! We were very upset.

After lengthily conversations with Liz, Family and Friends we decided to go ahead with the operation and were booked in to the Royal Children's Hospital. Thomas was only 14 months old. The operation was going to be roughly 5 hours. We stayed overnight at the Ronald McDonald House before the operation and Thomas went in at 7am. Once I had taken Thomas to the room where he was put under anaesthetic, one of the volunteers had to escort me from the room, because as they put him under, he screamed a horrible scream and I just froze. Thoughts were rushing through my head "What are we doing?", "Is doing this the right thing?", "Will it work?", "What if it doesn't work?", "Will they get all 22 electrodes in?", "Should we be doing this?" After calming down and meeting up with Trent again we went to the waiting room. And waited..... and waited.....



After a few hours Trent had to leave to go to work, so I continued to wait. Finally after about 4 hours the surgeon appeared around the corner with the news that the first implant was a success, all 22 electrodes had gone through! Now for the next one, more waiting.... After another 2 and half hours the operation was over with the results for the second ear the same as the first. A complete success, I could have danced around the hospital. As we were told that they would be lucky to get only 9 electrodes in both ears. Thomas was then moved to recovery and soon was put in the ward. We only had an overnight stay, I had a sleepless night only sleeping on a window type ledge and keeping an eye on Thomas. Morning came and he sat up in a high chair and had a weetbix for breakfast with a smile on his face!

Two weeks later, Thomas' implants were switched on, we didn't really notice a big difference with him at first and we started attending mapping sessions at the Eye and Ear Hospital with Gabrielle and they were turned up over time. We continued to work with Gabrielle and Liz on Thomas' sounds and communication, it was a very rough road, and we had ups and downs, including Thomas losing his implants, pulling them off his head, hiding them under the slats on our beds and days spent looking for them seemed endless. We had good weeks and bad! But I knew that we had support behind us in Liz, and we could contact her at anytime.

At the end of 2011 it was time to say goodbye to Liz, as Thomas was ready to start the School based program at Aurora in Blackburn. Saying goodbye to Liz was one of the hardest things that I have done, she had been our rock, sounding board, teacher, friend and family member since Thomas was 6 months old. Without her I don't know where we would have been or how we would have got through it all. We are truly grateful for all of her help, and "Thank you" just doesn't seem enough. But "Thank you Liz, you will always be a part of our family and hold a special place in our hearts". And Thank you to Linda and Jina, Anne and Heather for the Early Learning Group and Mother Goose Sessions, Thomas loved all the activities and time spent with you.

With Thomas starting Aurora, I was very nervous as the school was an hours' drive from home. We had been told of a taxi service that Thomas could travel on to school but I just couldn't bring myself to let him go. So for the first school term we drove him to and from school. In the last week of Term 1, Thomas travelled on the taxi for the first time because he now has a baby brother and had my hands full. But I had nothing to worry about as Thomas loved his taxi ride, although he would often sleep on his way home after his busy day.

Beginners at Aurora in 2012 with teachers Linda and Kathy was just fantastic. They are very devoted and just lovely ladies. Thomas at the start of the year was always very shy, not really playing with or interacting with the other children. But soon found a friend in Hugh, Thomas would wait for him to arrive. With the different activities throughout the day Thomas' speech soon developed. He learnt the routine of the day, and just loved playing with the trains. He loved all of the new experiences and would often look through his communication book at home of what he had done in the day and show us.

Thomas was very visual and to help him with his words, to also help him to communicate with us at home, a PECS folder was made; he had photos of places, people, items, food, emotions etc. We found this a fantastic resource to use with Thomas; it prevented him from getting frustrated. Thomas had his first experiences of attending many school excursions, and was very excited to tell us where he had been. Thomas had help with Andi in toilet training, which we found a challenge. Thank you Andi.





In 2013, Thomas attended the Kinder Program with teachers Cynthia and Kathy. Another fantastic year at Aurora! Thomas was very excited to have Kathy as his teacher again, Thomas was just fascinated by her signing and he too started to sign with her to communicate. I found that Cynthia and Kathy were just so dedicated to their students, the success of the children they teach really are a credit to them. Communication using the communication book was just fantastic; a great way to get messages back and forth. Thomas also had Speech Therapy sessions with Karen and Erin; he especially loved using the iPad.

Over the school year Thomas learnt so many new things and gained so much confidence we couldn't be prouder. He was becoming so confident and independent in many different aspects. This year Thomas learnt about many things including Australian animals, different countries, enjoyed cooking and learnt about how to care for animals with having pets in the classroom. As part of the school program the kinder class visited the Mt Pleasant Kindergarten so they could interact with other children their age. Reading back through Thomas' school reports one sentence really stands out is "Thomas loves to communicate with staff and always has something to say!"

Then comes this year, 2014, Thomas' last year at Aurora. He is attending Auroras' Foundation (Prep) Program with teachers Stacey and Kaylene. He also has been seeing Speech Therapist Sue. Thomas, since starting with Aurora has gone from strength to strength. He has gone from a little boy that barely said a word to a little boy that just doesn't stop talking. He even kept the kids up talking/signing on the sleepover at the school! Poor Stacey thought she would have a quiet night!

The Foundation (Prep) Program has taught Thomas to become even more confident and independent, he really is growing up. His speech is becoming so much clearer. He loves his daily readers and has developed a love of books. As part of the program he has been attending Orchard Grove Primary School which he enjoys. He is almost ready for the next chapter in his life.

We have made the decision that Thomas will attend a local Primary School, it is a small school and they teach Auslan. This is fantastic as Thomas does rely on Auslan when he is learning new words, and also helps him to spell words and names too. To make this decision we visited a couple of schools and chatted with the Principal and Acting Principal. We followed the process of discussing Thomas' needs and filled out tons of paperwork. Although I am completely terrified of him leaving what we call the Aurora bubble, I know that the school we have chosen will be supportive of Thomas and his needs.

Thomas' appointments at the Eye and Ear Hospital are now once a year unless we feel he needs an appointment. It really has been amazing watching him become such an independent little boy who surprises us on a daily basis. Another thank you goes to Gabrielle and team at the Cochlear Implant Clinic. Your support is fantastic.

As I finally come to the present time in Thomas' journey I would like to thank everyone at Aurora both through Early Intervention and the School itself. You have all made this journey an enjoyable one, Thomas is so confident, happy, very determined and animated in his day to day life. I know that without you all in our life, it would have definitely been a different one. Thank you again for your continued support, incredible kindness, and understanding and for making this chapter in our lives a memorable one.

We will never forget everything that you have done for our little man.
"Thank you, Thank you, Thank you!"
From The Holden Family

