

## Taj's Journey... by Alisha

Finding out we were pregnant for the first time in 2007 was one of the most memorable days of my life. The first appointment with the midwife and dating scan ultrasound, seeing the little flutter of a heartbeat made it all real. Having the ultrasound at 19 weeks we had decided we didn't want to know the sex of the baby.



I love surprises way too much! Was very exciting to see the baby and here I was worrying that it had ten fingers and ten toes intact. Never did I think they were going to find a facial deformity. After the ultrasound the sonographer left the room only to return with a doctor. "Have you heard of a cleft lip and palate before"? the doctor asked. Of course I had heard of it but I don't know anybody personally. They explained what would happen from here on in but I didn't hear a word they were saying. My head was spinning and my heart was breaking.

I cried a lifetime of tears in the following week as we researched all about cleft lip and palate. Blamed myself and tried to find out "why"? But of course now I know it was what they classed as a spontaneous mutation...(horrible word, mutation.)

We had a 3D ultrasound at 22 weeks to confirm it was an incomplete bilateral cleft lip and palate. However they couldn't definitely see the palate but as the baby's lip was quite severe they believed it would most definitely be a bilateral cleft palate as well. On this day we also met with numerous doctors and paediatricians who discussed termination. We had an amniocentesis on this

day to rule out any other possible problems and said no way to the discussion on termination unless this testing turned up anything to do with a life threatening problem.

The amniocentesis results came back fine so we tried to relax and enjoy being pregnant and plan for the arrival of this baby. Made contact with CleftPALS Victoria and bought some Haberman Bottles. I met with the lactation consultant at our hospital and we discussed options for feeding and gave me some good advice. I hand expressed Colostrum and froze it so we had less stress when the baby was born and also organised a double electric pump to make expressing easier. We met with our surgeon David Chong at the Royal Childrens Hospital. He was lovely and helped put our minds at ease with what lay ahead for us and the baby!

On 11 June 2008 I gave birth to a healthy baby boy we named Taj. He was born with an incomplete bilateral cleft lip but his palate was all intact. This was great news as it was not as severe as we had prepared ourselves and family and friends for. It made feeding easy as he could suck from the bottles himself and we didn't need to squeeze the teat for him.

At 11 weeks old Taj was fitted with NAM (Nasal Alveolar Moulding) This was to help stretch the skin around the top part of his lip and shape his nostrils which in turn would make his surgeon's job a little easier to get the best result possible. This meant an appointment every Friday up to the Royal Childrens Hospital to have the NAM adjusted as his face grew. He wore this device right up until surgery.

Spending so much time at the hospital though opened my eyes as to how lucky we were. Our child had a problem that can be fixed, it's cosmetic. There are children in that hospital that I saw who had life threatening illnesses and injuries. We can get through this and we will be ok.



On 11 December 2008 at 6 months old Taj had his operation to repair his lip. One of the most heartbreaking things for me was to be in the room when they put Taj to sleep. I don't think I can ever do that again. His surgery went for 3.5 hours. Waiting was very hard but when we got to see him in recovery it was the best feeling. We were back at home the next day. 4 days later we went back for Taj to have his stitches out, this time my husband went into the anaesthetic room with him. Then we were back at home that afternoon.

Taj is now 3 and it's just remarkable how good he looks. Most people don't even notice his scars. He sees his surgeon David every year at a cleft clinic where there is also a speech therapist, audiologist and dentist. There is talk about maybe fixing his scar as it has obviously widened as his face has grown, this would happen before he starts primary school but it's not a definite yet. Then when he is around 8 he will need a bonegraft as he has "nicks" in his gum where his lateral teeth are. He has all his teeth plus an extra one!

