

## Sahara's Story by Emma

Sahara's cleft lip and palate was discovered at my 20-week scan. The sonographer spent a lot of time looking at her head and I remember thinking that the scan process must have changed since my son's scan two years before. Looking back I was clearly affected by baby-brain that day as I never thought anything was strange, even when the sonographer said she needed to check the scan were clear enough for the doctor.

After she left the room, my partner Darren took our son Mitch outside and I waited for the sonographer to return. When she did, she entered with another woman who introduced herself as a doctor and suddenly it clicked that something was wrong. I rudely interrupted her and said "There's something wrong with my baby's head isn't there?" She then confirmed that Sahara had a cleft lip and suspected cleft palate and I would need to go to Melbourne for further testing.

Like many people, Darren didn't know what a cleft lip was (I had heard of them and knew they could be repaired) and immediately Googled clefts when we got home. Anyone who has Googled clefts knows the type of images that come up and there was a lot of anger in the house that day. I did a little more research and discovered just how common clefts are and was relieved to find the Royal Children's Hospital had its own cleft clinic – it meant that Sahara would be in good hands with people who deal with this every day.

Three weeks later I went to the Royal Women's Hospital for scans. What a disaster! The two sonographers kept everything to themselves and kept complaining that they couldn't get a clear view of Sahara's hands. In addition, they spent a lot of time scanning her face, spine and heart. At the end of the scan I was told I needed an amniocentesis done 'right then'. I immediately began thinking the worst, especially when the sonographer said they needed it to confirm their diagnosis. Following the test I spoke to a doctor who explained that cleft children often have many other problems and that I should seriously consider my options for the continuation of the pregnancy.

The following week was torture as Darren and I tried to come to terms with everything. There were a lot of fights and discussions and in the end, after a lot of tears and consideration we decided that, depending on the results, if Sahara had any serious problems – as was suggested – we would terminate the pregnancy. Going to my antenatal appointment the day before I was to get the results from Melbourne was difficult. I told the doctor what had happened and he was shocked as the scans in Ballarat only showed a cleft. A quick call to

Melbourne confirmed Sahara ONLY had a cleft. Initially we felt relief before anger washed over us – we were about to terminate a healthy little girl because of bad advice.

The night before her birth, I realised Sahara wasn't moving. The next morning she still hadn't moved and while I was in the shower I began having mild contractions. Packing my bag while Darren called my parents, I tried not to panic. Dad drove me to the hospital and I was placed on the CTG machine and thankfully saw a heartbeat. I was monitored for half an hour and the nurse was concerned that while Sahara's movements were showing on the monitor I still couldn't feel anything. The doctor initially decided to wait an hour before inducing me but after reviewing my file decided to take me straight to the theatre.

Sahara was born at 2pm on Australia Day 2011 with a full head of jet black hair. She was taken straight to the Special Care Nursery and it was almost 12 hours before I saw her. When I first held my beautiful girl I was shocked that her cleft was so severe as I didn't realise a cleft lip could be so big. I then felt guilty that I had somehow done this to her.



Sahara at 1 week

The hardest part of bringing Sahara home was feeding her with the Habermann. As other parents are aware, trying to put it together properly is tricky, not to mention it would often leak. Initially it would take up to an hour and a half to feed Sahara, which was trying for all of us.

Sahara's lip repair was scheduled for the end of May 2010 and I didn't want it done. I honestly thought I was sending her the wrong message, telling her she wasn't beautiful or perfect the way she was. But I now know it was the best thing to do because we unfortunately live in a society that would not accept her as she was.



Sahara at 3mths

Handing her to David Chong for her surgery was difficult but not as difficult as seeing her in recovery. I wanted to scream at David “What have you done to my daughter? Take it back!”

The weeks and months that followed her lip repair were hard and I felt so alone. In an attempt to vent my feeling I wrote a poem for Sahara to explain how beautiful she had been and how different she was now treated.

In February 2011, Sahara underwent her palate surgery. Darren and Mitch came with us to Melbourne which helped so much. Seeing Sahara post-surgery harder but watching her reach out to Darren the next day is something I will never forget.



In recovery



Two days post palate

Sahara is progressing well, although she still can't talk yet. Mind you, it doesn't stop her from getting her point across quite clearly. She is very close with Mitch and it is clear how much they love each other. Darren and I are constantly amazed that we were advised to terminate this gorgeous little girl who has so much attitude. We have often been questioned by our families over the decisions we make, including having a large photo of Sahara pre-lip repair on the wall. They think we should put her cleft behind us, but it is who Sahara is. We are proud to have a beautiful cleft child and we have learnt so much about ourselves and our families from having her in our lives.



Sahara today