

## PER'S STORY

*Per's story was written by actress and writer, Tania Lacy. Per is now ready to conquer the world!*

Our son Per was born on 29 December 2005. When my water broke at three in the morning, I woke my husband Ole, crazy with excitement and nerves. We were finally going to meet our baby! But as I noticed the colour drain from Ole's face I wondered if he'd ever considered that this baby did have to come out at some point.



As we drove to the hospital my mind flashed back to a moment two weeks prior when in a shopping mall, and travelling down an escalator, my mother asked me if she felt my baby had ED. ED is short for Ectodermal dysplasia, a genetic disorder that has affected my brother and his daughter, and that had a one in four chance of affecting our child. While it had been a big concern for my husband and I, we were willing to take the risk based on the fact that my brother and his daughter enjoyed an excellent quality of life despite the challenges of their ED. So I remember saying to my mother, 'I don't think he has ED but I feel like there is something wrong.' It was just a feeling, an uneasiness, but I felt it.

And so back to the birth. My 'this is so exciting' vibe soon gave way to screams of 'bring me the head of the mid-wife who suggested aroma-therapy oils and relaxation music!' Anyway, long story short - after a good seven hours of pushing it became apparent to the doctor that Per was stuck and a forceps birth was going to be necessary. I was rushed off to theatre (operating, not Shakespeare), husband in tow. By now he was as white as the sterile suit they had put him in. A spinal epidural, a couple of pushes later and Per arrived. Suddenly he was on my chest and I looked at him, my baby!

A rush of emotions - joy, excitement, relief, love and then he was whisked away. 'Hang on, did I just see a Hare Lip?' I asked myself. (And yes, I remember very clearly I said 'Hare Lip'.) No, it was just the way the blood was smeared on his face I told myself. But then Ole was called over by the doctor. I could see them chatting quietly. What was going on? Why

wouldn't anyone tell me? Was my baby okay? Whose legs are they in the stirrups? Oh mine! Ole arrived back at my side and I still think of this moment with the greatest adoration for my husband. He had this funny, weird half-smile on his face. He looked so vulnerable. He had something to tell me and he was nervous. But when it came down to it, he told me what I already knew - Per had a cleft lip. In fact it turned out Per had a unilateral incomplete cleft lip and incomplete palate - to be precise.

As I lay in recovery waiting for the feeling to return to my legs, dozens of questions ran through my mind. How did this happen? Was this my fault? Had I somehow failed everyone - my husband, my parents, who were all expecting a "perfect child". Of course, my fears proved to be completely unfounded. When I was taken to the ward, my husband and family were nothing but supportive. 'He's got a cleft,' I said, almost as an apology, as they wheeled me into the ward. 'It doesn't matter,' came the swift response from everyone, 'He's beautiful.' And he was. But we all had a little ways to go yet before we could all come to grips with what was going on, what the future held for Per and how we would all come to deal with this situation.

My first hurdle arrived on the second day after Per's birth. I was in my ward, listening to other parents talk excitedly about their baby's perfect nose, or cupid's bow lips or any other number of perfect baby features. I found myself, suddenly, once again, overwhelmed with this sense of failure - and I wept. I wept that I was continually apologising to people about Per's condition. I realised every person I spoke to, I started the conversation with an explanation so that they wouldn't be shocked when they saw him and more importantly, they wouldn't blame me. I wept because I couldn't talk about my baby's perfect face like the couple next to me. I wept that I couldn't breastfeed Per, an experience I had been looking forward to. I wept because I was worried about what people would think.

And then I realised, this wasn't about me. It would be the first and last time I would indulge myself in relation to Per's condition because ultimately this was about Per and the life he was going to lead, the future he was to have, and right now that future was in my hands. If I was going to be of any service to my beautiful gorgeous baby boy, I needed to get my sorry-ass out of his way and do all I could for this child and his self esteem. And as far as I was concerned that was going to start right now, in the hospital, on his second day of life. Don't get me wrong. I wasn't making a pact with myself to become cold and heartless about all this, I was making a decision to not be the victim. That wasn't going to help Per, it would only serve to keep us all in a cycle of defeat. And trust me, I have cried since that day - the surgeries were hard, and we've

all been there, some of us more than others. No parent likes to see their child suffer and I cried when I saw Per suffer pain. But I have not, and will not, ever cry because Per's situation is hard for me.

Why is this so important? What is the difference between crying for my son's suffering or crying for my son's situation. I believe there's a big difference. The first sends a message that says 'I love you so much but it's hard to see you suffer', the second says 'your condition is the reason why I suffer' and that's the one that's not fair - on any child and it's definitely not the message I wanted to send to my son. Having a good blub in the hospital two days after giving birth was possibly the best thing I could have done for myself and for Per. I left feeling strong, understanding that there were more hurdles to face, but I knew where I stood in all of this. Yes, I was the parent of a baby who was born with a cleft lip and palate, but ultimately I was a parent of a beautiful baby boy - and this was a time to celebrate.