

## LEO'S STORY

### *Leo was born with cleft lip (intact palate)... by Susannah*

This is a word I never again want to hear at the start of a sentence from a medical professional: “Unfortunately”.

We were at the 20 week scan for our first baby. So excited. She told us the baby was a boy – a boy! Then she scanned his face – again – and again – and paused – and again. “I thought she was just trying to get a good picture of his face to print out for us”, said my husband sadly, later.

But instead when she finally spoke, what she said changed our world. “Unfortunately, it looks like your baby has a cleft lip and probably palate.” The rest faded away. Something inside me froze. I wanted my baby to be perfect, to be healthy, to have a happy life, and in that instant I knew he would be different and have a path that wasn't easy.

We went home, googled, cried, rang family, hugged each other and went back for more scanning.

We had more scans – anomaly scan, heart scan, discussions about amniocentesis, warnings about possible other problems. We held tight. We'd had a good nuchal scan at 12 weeks so held onto that result and declined an amniocentesis – I couldn't face the chance of losing a healthy baby. It made for a stressful pregnancy, as you can imagine.

I went to a CleftPALS playdate to meet other parents and cleft affected children while I was pregnant, which was really helpful for me to understand what was coming.

Leo arrived at 36 weeks (nothing to do with his cleft). He was so beautiful. I was instantly in love. I knew as soon as he was born that I was the luckiest mother in the world. Still am!



My lovely smiley baby



Three months old



The day after his lip surgery

Leo's palate was intact, and to my surprise, we were able to breastfeed. It took a lot of help from BESS at the Royal Women's Hospital, a lot of wiggling and an unusual position, but it worked. We also tried 'normal' bottles but he didn't have the strength in his lip so we used a squeezy (Queensland) bottle with the Pigeon teat.

His lip surgery was the worst day of my life. He was fine. I still feel sick thinking about it. But he was fine.

After the surgery, we had to learn how to breastfeed all over again as his lip had changed. He still couldn't use a 'normal' bottle.

As he was cleft lip only, he's only had one surgery so far. His hearing tests were always fine. He has had ongoing speech and language issues and we've had some years of speech therapy to get his talking up to speed. His teeth are crooked around the cleft line, and he has an extra tooth.

Leo is 6 now and we've started to talk about his cleft lip. Through CleftPALS we've made some great friends so he has buddies of similar age who are also cleft affected, and that's very reassuring to him – to know that he's not the only one. As he gets older I look forward to getting him into Cleftstars, the support group for older kids.

He's a normal kid. He likes trains and Hot Wheels and Lego. He started school this year and is getting on well. He's a sweet and loving boy and I'm so proud of him.



Leo at 18 months



Leo at 6