

## Ariana Struwe Story

Being pregnant felt so wonderful, knowing I have a little mini me growing inside. Every gynecologist visit was exciting just to see our little girl and to hear little heart beat and see that she still growing, until 36 weeks when the gynecologist noticed something when listening to her heart beat but wasn't sure. He sent us into hospital for them to just monitor the baby for a few hours, and then everything was fine again. Just a 4 days later I felt this uncomfortable feeling and went into hospital, where nurses confirmed that I am in labor.

The next morning our beautiful baby girl Ariana was born, but I only held her for a few minutes before doctors took her away. A little bit later that morning the NICU doctor came to tell me they will be doing a scan of our little girl's heart. We said okay, and I started praying softly in my head. Later that evening the NICU doctor returned and I would never forget his first words "There is Big problems with your baby heart". My heart felt like it was breaking into a million pieces as he explained everything her little heart is missing. He started drawing a picture that showed no chambers and no pulmonary artery. My thoughts went straight to, I won't be taking my baby home.

The next day the NICU doctor came again to update us on our little girl, he said he lowered her oxygen to see how she does and will be doing that until she doesn't need it anymore, so that she can go home, those words brought a little bit of hope. I remember seeing her for the 1<sup>st</sup> time in NICU all covered in wires and tubes. The days following she started breathing better and the oxygen intake was lowered and the tubes were no longer needed and I started getting more faith and hope.

After two weeks she was released and then the real journey started of keeping her safely away from germs and family and friends who was sick. Our lives now consisted of lots of doctor visits, from cardiologist, pediatrician, dietitian to physio visits. But we would do anything to help our little girl live the best life, no matter how much it cost.

Every cardio visit was the same results, her report read - she has a complete atrioventricular septal defect of the Rastelli C type, with an enormous central defect in the heart, and free communication between all four cardiac chambers. Dextro-transposition of the aorta is also demonstrated and complete absence of the pulmonary artery and valve. The lungs are supplied via two MAPCA's which originate from the descending thoracic aorta. Her results were discussed with another two cardiologist who confirmed that there are no surgical options available.

Ariana is three years old now and just finished here first year in crèche. Her teachers describe her as someone who is lovable, caring, enthusiastic, full of energy, passionate and always in a happy mood with a smile on her face. We don't know how long we have with her, so until then we will love and enjoy each day with her. She is one of the bravest little girls we know and has brought so much love, joy and lots of crazy moments into our lives.