

Annabelle's Story

Annabelle's story begins on the day of her 20-week antenatal Ultrasound Scan; all previous news from her 12-week scan had been good. The Sonographer was telling my husband James and I that each organ looked healthy when she paused, and said that she couldn't get a good view of our babies heart, but that this could possibly be due to the way she was laying. The Consultant Obstetrician was called in to repeat the scan and after another careful look she explained to James and I that our baby had a serious heart defect. She went on to explain that she would refer us straight away to a specialist Hospital for further investigation.

A few days later we arrived at King's College Hospital for a further lengthy scan, I remember counting the ceiling lights again and again as we waited. The Consultant Foetal Cardiologist then explained her findings to us. Our baby had a very serious defect called Aortic Atresia, this meant that her Aorta was completely blocked. Annabelle was surviving due to the fact that the foetal circulation is different to the circulation of blood around the heart after a baby is born. Our baby would need special drugs to keep her alive as soon as she was born and heart surgery within the first few days of life. Her chances of surviving this first operation were about 70%. We then felt what I can only describe as a roller coaster of emotions from fears to hopes. Due to the seriousness of the heart defect we were told that I would need to have my baby at St Thomas's as they had a maternity unit and a specialist Paediatric Cardiac Care Team.

It was arranged for me to be seen and booked in with a midwife at St Thomas's. I was told that parents of "heart babies" were invited to a special day of talks/information. This was our first encounter with the ECHO organisation. I have to say this was such a relief, to know we would have an opportunity to find out more, and meet someone else who had been through a similar experience. We learned such a lot from the day, which was run by one of the midwives who took us to see what Neonatal Intensive care was like. The day included a vital visit from a parent of a child who had been treated by the team, which is now based at the Evelina children's Hospital. After the talk we filled in our ECHO membership slip and it felt good to be able to do something positive towards Annabelle's future. Soon after I was telephoned by an ECHO member who gives prenatal support and this I found supportive too.

As Annabelle would immediately need an intensive care place, she was induced at around 38 weeks. Annabelle was born on 3rd December 2005 looking well and took her first breath without assistance. She was immediately put on intravenous medication and a N.G. Tube was fitted. Annabelle's birth weight was 2.33Kg (Approximately 5lbs) this we were to learn was a problem in her case.



Annabelle

The operation planned by the Consultant Cardiac Surgeon, Mr Anderson, would require Annabelle going on the Heart -Lung Bypass machine. This was not advisable, as Annabelle was small, under the necessary 2.5Kg weight. Annabelle's heart defect meant that her body was working so hard that weight gain was not expected to occur. This was very hard seeing her loose weight.

After a few weeks of this worrying weight loss and concern over how to treat Annabelle, Mr Anderson and Dr Qureshi her Consultant Cardiologist came to see us and told us about a possible new first stage treatment. There was a new technique that had been carried out in America, where a stent (an artificial tube) could be temporarily fitted in to Annabelle's Arterial duct, to keep her oxygenated blood circulating. The Hybrid operation hadn't been performed in the UK before but Mr Anderson and Dr Qureshi knew it would be Annabelle's best chance of survival. They told us they would be in consultation with their American colleagues and that some of the specialist equipment needed for the operation would be flown in from the USA. The major advantage of this operation was that the patient didn't have to go on the Heart -Lung Bypass machine. This procedure had been named the Hybrid, as the operation involves a Cardiologist and a Surgeon. James and I both agreed to the operation and jumped at the possible chance of Annabelle's life being saved.

Annabelle's operation was planned for 22nd December 2005. Her big day arrived; I felt very scared but also relieved that Annabelle was getting the vital treatment she needed for her continued survival. After waiting with Annabelle until she had been anaesthetised we both gave our darling daughter a kiss. Neither James or I could sit still as we waited while her operation went ahead so we went for a long

walk, we knew as soon as she had had her operation and was back in PICU (Paediatric Intensive Care Unit), one of the nurses would call us on our mobile phone. After about 4 hours the call came, the best Christmas present either of us could ever have, Annabelle was doing well. We arrived by her cot to find her surrounded by Doctors and Nurses our lovely baby girl had come through. After a couple of days Annabelle came off the ventilator and was making steady progress. She did spend her first Christmas Day in PICU. The staff at the Evelina made it so special, fresh Christmas bedding in her cot and Father Christmas had been to the Evelina Children's Hospital too, he had left a present for Annabelle and one for her big brother Thomas. We were offered a Christmas Dinner at the Hospital too. A few days on and Annabelle was well enough to transfer out of PICU and onto Camel Ward we were so relieved. On 29th December Annabelle was transferred to our local hospital and on 1st January 2006 was discharged and could sleep for the first time in her own Moses Basket at home.

All went well until the middle of March, when Annabelle could not seem to throw off a cold and was getting distressed. I was trying to feed her when she collapsed and immediately I could sense she had stopped breathing, fortunately my husband my brother and sister-in law were with me, my husband James quickly took Annabelle and vigorously patted her back and then massaged her chest, my sister-in law phoned 999 and my brother took our son Thomas into another room. Annabelle suddenly started to breath again, I think this all took place in about a minute, it was absolutely terrifying. The Ambulance was with us in minutes, an oxygen mask was put over her face and I went with Annabelle in the Ambulance, as she was blue lighted to the District Hospital. A team met us at the Ambulance doors as we arrived. Annabelle was stabilised and after a few hours and transport had been arranged, Annabelle was transferred up to the Evelina. I was not allowed in the Ambulance with her as there wasn't enough room as a Consultant Paediatrician, Nurse and two Ambulance Crew accompanied her. James and I followed Annabelle up to the hospital in our car, so difficult not being with her. When we arrived at the Evelina Annabelle was having an ECHO (a heart ultrasound). The Cardiologist told us that only half the blood that should be getting through the stent. She was going to need surgery that night. Dr Qureshi was on his way in to the hospital to head up the team. So Annabelle was put to sleep and re-stented. As it was the middle of the night we waited in the parents room next to PICU. A few hours later Dr Qureshi came to see us, all had gone well although as he told us Annabelle had had a degree of heart failure and we needed to wait and see how she recovered. Annabelle was also put on antibiotics to treat her infection. As the days went by she continued to recover, just having one sticky moment in PICU when she stopped breathing again, so scary.

Although Annabelle did have complications after her Hybrid Operation, without it she would not be with us today.

Annabelle then stayed at the Evelina for 8 weeks until the doctors thought she was strong enough to go on the Heart Lung Bypass machine and have the next operation she needed. On 17th May 2006 Annabelle had a combined stage I and II Norwood operation performed by Mr Anderson and his team. We waited for news for nearly 8 hours, longer than anticipated, then the news came Annabelle was out of surgery and in PICU she had bled more than expected and that had delayed things, but the operation had been completed successfully. What an enormous relief we felt as we heard this news and then were able to go to sit by our daughter's bedside.

Annabelle's received fantastic care from so many people, it just goes to show how the care of those with Congenital Heart Disease continues to improve and from the help and support we received, demonstrated to us how caring and wonderful people can be.

Annabelle is now 21 months old and living life to the full. She is a happy toddler who loves charging around with her pram and hiding her brother's toys!

Amanda Gardener