

# Samantha's Story



At my twenty-week scan, we were told there was something not right with Zach's heart. The sonographer referred us to Fetal Medicine in our local hospital. The Fetal Medicine consultant agreed with the original sonographer that something wasn't right. They thought that Zach perhaps had a hole in his heart. A VSD (Vertical Septal Defect.)

We were referred to the Harris Birthright Centre at King's College Hospital in Dulwich. At the Harris Birthright Centre we met the Consultant in Fetal and Paediatric Cardiology. After a forty-five-minute scan, she confirmed that there was indeed something wrong with our little one's heart.

She explained that there was a 'high suspicion' of aortic coarctation, a VSD and a slightly smaller left

ventricle, and that Zach would need surgery when he was born. He would need open-heart bypass surgery to reconstruct the Arch, the narrow section of the aorta.

The remaining months of the pregnancy felt like they dragged on as I was really drained. I started my maternity leave earlier and focused on setting up the nursery and getting everything organised. By Christmas 2019, I had everything sorted even though Zach wasn't due until late February!

*"We attended an ECHO antenatal class at St Thomas' Hospital, where we found a lot of what was told about applied to us"*

In January, we attended an ECHO antenatal class at St Thomas' Hospital, where we found a lot of what was told about applied to us. The details of the induction and the role-play of a caesarean section helped me to visualise what my birth experience was going to be like. And it was around this point I started to feel 'different' from other mums as I need different birth procedure for my baby's heart defect. Thus, I started to prefer attending my appointments at St Thomas' Hospital. The support from the tower midwife team was amazing.

39 weeks rolled around but Zach was breech. So, after having four External Cephalic Version (ECV) attempts that failed to turn him, I was admitted for a caesarean section. Hearing Zach's cry as he was lifted out of me was the most beautiful moment of my life thus far.

Zach was in the Neonatal Intensive Care Unit (NICU) for two days before moving to the High Dependency Unit (HDU). It was horrible holding my son for the first time with all the wires and lines attached to him. He had pinprick marks all over his hands where the doctors had attempted many cannulas. When I held him in my arms for the first time, I looked past all of that. He was just my beautiful baby boy. My darling Zachary.

*"It was horrible holding my son for the first time with all the wires and lines attached to him ... but I looked past all of that. He was just my beautiful baby boy"*

Zach presented a conundrum to his doctors. He had a large ASD (Atrial Septal Defect.) A hole in his heart between the left and the right side. They could reconstruct the arch to create a wider aorta. However, they were unsure whether they needed to close the ASD. If they did it would put a lot of pressure on the left side of Zach's heart.

Eventually, nine days after Zach was born the decision was made to operate on him. This was all the unknown for us. It was hard; but it was easier by having Emmanuel and my family's support, and secondly, having the Ronald McDonald House to stay in. I would go there in the afternoon to catch up on

some sleep, whilst Emmanuel stayed on the ward before I would come back in the evening for my 'night shift'.

*When the time came to go to the theatre, Emmanuel carried him, and we said a very tear-filled goodbye to him. It was the scariest thing I have ever had to do.*

The operation day came. Zach's surgeon sat down with me, explained exactly what he was going to do, and then I signed the consent form. As he walked away, I burst into tears as I looked over at sweet Zach sleeping soundly whilst I held a piece of paper that said I had just consented to a stranger cutting open his tiny body. When the time came to go to the theatre, Emmanuel carried him, and we said a very tear-filled goodbye to him. It was the scariest thing I have ever had to do.

After having slept for a few hours in Ronald McDonald House, I woke up to my phone ringing. It was Zach's surgeon calling to tell us that the operation had been a success and he was now going to Paediatric Intensive Care Unit (PICU). We got ourselves together and practically ran over to the hospital to see Zach laying there with the tubes and a huge wound on his chest. It was unsettling but not as bad as I thought it would be. He was just sleeping very soundly. We sat by his side and held his hand. His nurse explained all of the various tubes and wires to us in detail.

The next three days Zach was slowly brought round from his medications. It was heartbreaking not to be able to just pick him up and cuddle him. I did everything I could so he knew I was there.

The next two weeks became very blurry. Zach's heart was not performing how the doctors expected. His heart was having to beat faster and faster to get enough blood around his body. He struggled so much when he came off the ventilator that he was put onto CPAP (Continuous Positive Airway Pressure.) On top of this Zach was struggling to breathe on his own. I was exhausted and sore for sitting in uncomfortable chairs all day long.

Glad that the nurses on PICU were amazing and the doctors were equally excellent. Their spirits helped me and Emmanuel get through some of the toughest days of our lives.

Zach was not improving and so the decision was made to operate again. This time to partially close the ASD. Just as his scar had healed, they cut him open again and this time the surgeon went into his heart.

*We were almost there, but then the Coronavirus news was breaking and everything was becoming tense within the hospital. It was all very scary, but all we could focus on was Zach.*

Zach started to recover after his second surgery, and this time, he did make improvements: he cried when his nappy was dirty, cried for comfort and milk. He was looking more and more like a normal baby again. I took charge of all his cares and did everything the nurses would let me. The normality they gave

helped us get through each hour.

Slowly, Zach was getting better, but one day a nurse explained that Zach was just not settled at all. We were then told that due to the surgery Zach had an arrhythmia, which is the electrical signals in the heart had been disturbed. It would need time to sort itself out. During that time Zach would need to be given a beta-blocker drug to slow his heart down and Zach did improve.

*“One morning a wonderful nurse said to us that we can take him off the monitors for some time. For the very first time, I held my baby without anything attached to him (except a feeding tube).”*

We finally said goodbye to the other parents in the neighbouring beds that we had made friends with and made our way to the Savannah ward. The nurses greeted us as if we were a travelling family back from holiday. It was lovely to be able to sleep on the ward next to Zach again. Exhausting but amazing. One morning a wonderful nurse said to us that we can take him off the monitors for some time. I glowed with happiness as I walked around the ward with my baby. For the very first time, I held my baby without anything attached to him (except a feeding tube).

After an echo scan, we were given the all-clear that Zach could be left off his heart monitors. During the day I fed him, and cuddled him, and took a thousand pictures. On the day of my birthday, we were given a private room to ourselves as I needed to ‘establish feeding’—it was the best birthday present ever. I had a full twenty-four hours in that room with just me, Emmanuel and Zach and lots of breastfeeding!

*Coming home was amazing. It was just a joy to be at home together.*

On the 25<sup>th</sup> March, 36 days after Zach was born, we left the Evelina Hospital and went to our local hospital to continue feeding. Zach was severely underweight by this point and needed supervision whilst we fed him back up again. I was one step closer to taking my son home, which we finally came home with him on the 30<sup>th</sup> of March. The UK had gone into lockdown due to the virus and Emmanuel had not been allowed on the ward with me.

Coming home was amazing. We gave him the tour of his bedroom and the living room. We got out the baby bath and gave him his first ever proper bath. He was so small but we didn't even notice that. It was just a joy to be at home together.

There were many times in the hospital when I felt as though we would never get there. Like a dark tunnel that I just could not see the end of. But we did. We finally made it out to and into the real world.



*“There were many times in the hospital when I felt as though we would never get there ... But we did. We finally made it out to and into the real world.”*

Fast forward to July and Zach is a happy five-month-old baby. He has just learnt to roll and to eat pureed food. He brings me more joy than I thought possible. And... he is currently dribbling on my laptop as I type!

Last, to all heart parents my advice would be: talk to the counsellors, make friends with other parents, pack comfortable shoes and clothes, take a backpack to carry things back and forth from Ronald McDonald House to the hospital, talk to the nurses and the doctors, find some moments of normality within the hospital bubble. Find some moments of normality within the hospital bubble. Expect things to

change.

If you would like to read my story in full please check out my blog at [www.graciousmummyblog.com](http://www.graciousmummyblog.com).

All of the highs and lows and the little thing that nobody tells you about. I found these stories such a comfort to read when I was sat next to Zach in PICU. I have loved being able to write about his story and share it in the same way. I hope it brings you a small amount of comfort. If you have any questions you can also contact me via Instagram: [@samantha\\_ava\\_grace](https://www.instagram.com/samantha_ava_grace)