



ZAKI'S STORY

As a grown up heart-child, Saleha's worst fears were confirmed when her and her husband Al discovered that their unborn baby too had a heart defect...

It was at 6:21am on Tuesday the 11th of October during the special Islamic month of Ramadan that Zaki came kicking and screaming into the world! Eyes wide open, hands balled into fists and ready to strike. This was a good sign though as we weren't quite sure what exactly to expect. Zaki, you see, had been diagnosed prenatally with Truncus arteriosus, a condition where the Pulmonary artery and Aorta are fused at birth and don't connect directly with the proper ventricles. Instead they straddle the two over a VSD. After a brief smile he was whisked off to NICU, father in tow. Zaki was doing well, pink, boisterous and making his presence felt!

As soon as we knew I was pregnant, myself and Al thought about the chances of our baby also having a heart condition, however in the early days we successfully pushed it to the back of our minds and concentrated on enjoying what was shaping up to be a happy and healthy pregnancy. As a patient of Guy's myself I was already being looked after by the Thames team midwives (who take care of the "higher risk" women) and I had been booked in for a foetal cardiac scan scheduled around 20 weeks. At the end of the "normal" scan, I recall the sonographer commenting on the fact that she thought she could see an unusual cardiac outflow tract but, she continued, she thought she could be prejudiced by my history and it was best to wait for the findings of the other scan. Luckily we didn't have long to wait (it was the same afternoon). I can't say what we were feeling at the time, but if Al's face was anything to go by the words "grim determination" spring to mind.

The scan was started and somewhere along the proceedings John Simpson, a consultant that I am sure many fellow parents are familiar with, came in to have a look. That should've set off alarm bells, but unusually for me I remained oblivious. At the end of the scan John broke the news to us and we were ushered into a room to talk things over. As both Al and I have a cardiac background professionally the full weight of his words crashed down upon us and in a few moments all our worst fears had suddenly been realised. Zaki would need surgery in the first few days of life and then again after a few years and possibly a third in his early teens! That first day was so hard I simply couldn't believe what I had been told, I was sure that there was some mistake and they'd tell us so at the next scan. In the days that followed, we prayed hard for a miracle and got on with the business of expecting a child,

although the usual excitement was quenched dramatically. In fact as I recall we bought nothing for Zaki until the 37th week when we felt that we really were cutting it a bit fine. However, when the second scan confirmed the findings made earlier, we had no choice but to confront the situation and somehow deal with it. At that time we arranged with the staff at Guy's to meet with a surgeon and also attend the antenatal day organised by ECHO. We met with David Anderson, one of the surgeons at Guy's, to talk about the surgical plan. He spoke to us at length and explained how essentially Zaki's arteries would be separated, 'replumbed' and the underlying VSD repaired. During our meeting all I kept thinking was "I can't believe this guy is really a surgeon, he's so down to earth and affable". He was really kind and told us to contact him again at any point if we had further questions.

as Guy's paediatric units were shutting up shop and setting up over in the new Evelina children's hospital! As Zaki was fairly stable there was a lot of indecision about what was best to be done. Then one evening, it fell to one of the new consultants to forewarn us that although Zaki would be moved to Guy's with a view to do surgery in the next few days, it would be best to wait awhile to get him into the Evelina! We had spent months preparing for a certain series of events that now seem unlikely to proceed.

Off Zaki went to Guys, Al brought me later as I was still a patient in Tommies following an emergency C-section. We arrived on Rothschild ward to be greeted with half packed boxes and a general sense of mayhem. This was not what we were expecting!!! Later on that evening David came to see us to tell us that the decision had been made to wait on surgery, it was very kind of



Zaki with his Dad

Following that we then came along to the ECHO antenatal day and honestly I can't speak highly enough of ECHO for organising them. It was first time that we had a chance to speak to parents' also expecting heart babies. Luckily the group that we met with were really friendly and we got a chance to speak quite openly to one another. That was also our first encounter with Jo, her experiences and warmth really permeated that day and by the end of it we had resolved to try to get involved and help other parents in the same situation if we could. By the time we had our last cardiac scan we felt that we had built up a good rapport with John and trusted that by God's grace Zaki would be in the best possible hands.

So along came Zaki, our beautiful bundle of joy. There was only one slight snag; he was born just

him to come and talk to us directly, he also said he would be away for two weeks and he anticipated that we would be gone by his return. Further news reached us that Zaki was now going to be transferred to Great Ormond Street the following day. We were assured this was just as a babysitting precaution, and that Zaki would be safer there then on a general ward that was moving premises. Zaki was in PICU when they were getting ready for his transfer. To prepare him for the move one of the doctors had to put a line into his foot, I think I must've cried more than Zaki! I'm sure the poor doctor was doing his best, but it was made worse for me as I couldn't go with him as I was still a patient in Tommies!

Everything had changed and now we didn't know when surgery would be or indeed where. We



ZAKI'S STORY

had initially wanted to have Zaki home in time for Eid, this was clearly not going to happen and I think this was the first point at which I felt I truly desperate. Especially as Zaki was off to GOSH with his father and I was sat in transport for more than 2 hours waiting to go back to the postnatal ward on my own!

Eventually Al came back and told me Zaki was fine and we could see him in the morning. Finally I was discharged two days later and our vacation in GOSH began. I call this week a vacation is because we were given a side room and apart from nurses very occasionally popping in to monitor Zaki we were pretty much left to our own devices. It felt very strange indeed to be there, I knew we were on the exact same ward as I had been on as a child (although they had renamed it). In fact one of the more senior nurses said she had a recollection of me and on hearing her name I knew I had met her before!

Al had decided to go back to work whilst we were there as it was close to where he was, so Zaki and I had a chance to bond, also he begun to breastfeed in earnest (he took to it really well-thank God). It is GOSH policy to let their truncus patients go home if they are stable to wait for the surgery, which normally takes place around 3 weeks after birth. As such we were encouraged to take him round the hospital for lunch and dinner and even to the adjoining square for a bit of fresh air. As we were there, "on-loan" from the Evelina they were happy to let us stay if that's what we felt comfortable doing, but on the last weekend we were to be there, they let us take Zaki home. It was pure bliss to be in our own beds and finally getting Zaki into his own Moses basket. I think the staff at GOS gave Al and I a lot of confidence in ourselves as parents and also in Zaki's own innate strength and for that I will always be grateful to them. However, Zaki's hospital stay was far from over!

We arrived in Camel ward on Savannah floor on the Sunday afternoon. It looked well....cool! A far cry from the sight we had left in Guy's. So we settled into our new "home" and waited for some news. As the hospital wasn't properly up and running the beds weren't all occupied and as such the nurses had let Al stay at night with me on one of the other pull down beds. They were really kind to us; I really needed Al at that time because I was still quite sore from my section. If the truth were told I hadn't really had a chance to rest so I felt like my recovery was slower than it may've otherwise been and I think the staff appreciated that and did their best to help us out.

Zaki was still holding his own and really we felt a little as if we were kicking our heels and watching the clock. Over the next few days we became

properly acquainted with the staff and met some familiar faces in John and Eric. As the move had only just taken place the general consensus seemed to be that there was no need to rush Zaki into surgery without first making sure that PICU etc was running smoothly first. Everyone who came to look in on Zaki remarked on how well he looked, but left looking as if they felt a little sorry for us as our pleas to wait for surgery at home could not be agreed upon. Generally I think Zaki had become rather infamous in the department, as everyone seemed to have heard of him and were well acquainted with our predicament, even prior to our arrival!

In the week we spent waiting for surgery the Evelina had its official opening and there was plenty to keep us occupied; TV crews, X-factor contestants and Halloween parties! We bumped into various ECHO members who were setting up the parents' room (which as it turned out, became our little haven. An oasis of calm in the midst of often noisy and hot evenings-the perfect place to settle a testy newborn!). We also met up with all the parents we had met with on the antenatal day and it was lovely to see their kids.

As Zaki turned 3 weeks news reached us that David Anderson was back from his trip and that they were looking toward surgery in a day or two! When David came to see us prior to surgery he expressed a great deal of surprise at learning of Zaki's still being there, but in truth I think I was really pleased that it was him that would be taking care of our little boy. The night before surgery David came to get consent...it was really happening! The morning of surgery we took Zaki down to the theatre and the last thing I remember was the anaesthetist commenting on Zaki's expanse of lovely dark hair (strange the things one remembers at such a time and what comments then become dear!). Then we were left outside to occupy the hardest few ours of our lives. As Al and I had both worked in Tommies we knew all the surrounding haunts. We headed out down towards Lambeth bridge, crossed over, walked around the houses of parliament and back into Tommies over Westminster bridge. We highly recommend the route, getting out of the hospital was a relief and to see the usual inane tourists doing their usual click...flash...bump...oops...sorry...etc was rather comforting.

Several hours later Zaki was in recovery and we were called down to be with him. The two presiding nurses were absolutely fantastic, they explained everything that was going on and helped us to get hands on with him in those first few precious moments. They really made us feel comfortable and provided lovely cups of tea late into the night! Zaki was doing well we just had to

be patient. The next day was Eid and although Zaki wasn't at home with us it was still a terrific day. I sat by Zaki's bedside and read him poems that he now really loves; The quangle wangle's hat and Old possum's book of practical cats. Zaki had already been extubated and the nurses told us that all being well, they would try to feed Zaki some milk later on in the evening. Although he had an NG tube I realised that he was making his characteristic "sucky" faces and I was sure that almost 3 weeks of breastfeeding would have helped to strengthen his sucking reflex so asked if we might try to bottle feed him first. As if by magic a little over 24 hours after surgery, our little bubba took to the bottle and wolfed down the milk -what a day!

The next day we went back to camel ward and were told that essentially it was just a matter of waiting for Zaki to establish a good feeding pattern and to be putting on weight, before we could finally take him home. That he did and we were told we could take him home on the Tuesday, 4 weeks to the day since he was born. The Tuesday came, but a scan done in the morning showed that Zaki's heart function was not as good as they'd wanted on discharge, and as such they were going to start him on some meds, but the dose would require titration over several days. I think that that was simply one of my lowest days, I remember sobbing like a little girl "I WANNA GO HOME", but with the help of our supportive family and staff we got there in the end.

Zaki is now 14 months old and the time in between has just flown by. He started walking properly just after his first birthday, but he was stumbling around by 11 months!! By the grace of God, Zaki is doing well, health-wise. Just recently he needed to have his homograft stretched by ballooning and that went really well thank God, but we know that he will require further treatment in the years to come. Mostly we don't dwell on it, as we know that God is watching over him and he has blessed the excellent Docs etc, who will hopefully continue to look after him, with some really amazing gifts and skills.

Al and I have tried to stick to our resolution and have gotten more involved in ECHO's work with passing time. I started out in 2006 helping Jo with the antenatal days, to help share my experiences, just as Jo did with us. I think the parents have relished seeing Zaki in all his glory, I am pretty sure Zaki has revelled in all the attention too! I also recently joined the ECHO committee to see if I too can contribute in some way in making their amazing efforts become a reality. [Saleha](#)