

## ***Finlay's story***

Upon being informed I was pregnant, my husband and I were over the moon. Having experienced a miscarriage some four months earlier, this news served to lift our spirits once more, as we both really desperately wanted a second child.

My pregnancy started out really well. I was never sick and didn't have any problems chasing after our first child Riley, who is a very inquisitive and active three-year-old.

It was at the 18/20-week ultrasound we first found out there was a problem with our baby. The ultrasound indicated a thickening in the back of the baby's neck and my husband and I both knew all too well that this is a sign that the baby may have Down's Syndrome. We were referred to the Canberra Hospital, Foetal Medicine Unit, where some further testing was conducted. Fluids were taken from my placenta, to test baby's chromosomes. This would then either confirm or expel our concerns that our baby had Down's Syndrome.

The week in which these tests were performed was the precursor to many emotional and traumatic times to come. The results of these tests took one agonising week to return, and we were lucky, for the staff rushed them through for us. Sometimes people wait 14 days, which must seem like an eternity. The result was negative to Down's Syndrome, however there was more bad news to come.

The professor attending us also performed ultrasound, checking all the major organs. When he was examining our baby's heart, we noticed he was really studying the scan extensively. It was at this point, we both knew there was a problem. On completion of the ultrasound we were guided to another room where the scan results, once related, confirmed our fears. The scan had confirmed that our unborn baby had Congenital Heart Disease. A condition referred to as Tetralogy of the Fallot. I just stared at the doctor and burst into uncontrollable tears while my husband asked all the questions he could think of.

We were referred to a Cardiac Specialist at Westmead Children's Hospital in Sydney. The experience of attending the Children's Hospital was a very scary and even more traumatic occasion, as Westmead is such a large and formidable place. The doctors told us more in relation to our child's problem and explained that our baby would need some form of heart surgery soon after birth. This would need to be performed to help the baby's circulation and respiration, as this condition is one that affects the amount of oxygen in the blood.

My choice of treatment, as far as my birth plan, was now completely out the window. We returned to Canberra with so many questions running through our heads. Questions there just did not seem to be answers to. We did not know how our child was going to cope with birth, the operation, having open-heart surgery. And what of post-operative trauma?

Canberra Hospital conducted follow up treatment and all my blood tests and scans were now conducted at their Foetal Medicine Unit. I had regular scans and it was at 22 weeks, we found out that our baby was a little boy. Again we were overjoyed. I have always wanted two boys.

I had fortnightly scans as the birth got closer. The scans were to make sure that the baby was growing well, as babies with heart problems can stop growing during the pregnancy.

As baby had such an acute problem, we were informed he would need to be born at Westmead Hospital, then transferred via a corridor connecting the two hospitals, to the Neo Natal Intensive Care Unit at the Children's hospital. Also due to this severe problem, we were referred to the best obstetrics and gynaecology unit in Australia. The professor assigned to our case, delivers high-risk babies all the time. We felt we were in the best possible place to give our baby the best chance of life.

As my confinement date drew closer, I was starting to get really worried and scared. I should now mention that my due date was the 26<sup>th</sup> of Dec 2003, Boxing Day of all days. How difficult is it to get a medical team together at that time of year? So when my water began to leak about 4:30 am a month before my due date, you can imagine my concern. We had no real plan in place, however luckily we have a good friend just next door. This dear friend took my older child while my husband and I went across to the Canberra hospital to see what had to happen next. If this was the beginning of labour, our baby would be arriving 4 weeks early.

By the time we travelled the 35-km's to the hospital, my waters were leaking even more. Unsure about what was really going on, I was very scared and frightened for the health of our baby. We did not know it at the time but we were about to embark on the biggest nightmare of our lives to date. By 5 p.m. that very day, I was being prepared for a flight in the Air Ambulance to Sydney. By 7 p.m. I had arrived in the labour ward of Sydney's Westmead hospital. I was in a place I had never seen before. I felt alone and was very frightened. My husband had to drive our car up to Sydney from Canberra. He actually set off for Sydney with our other boy, about the same time I was being transported to Canberra airport, and arrived at Westmead at about 9 p.m..

The drugs the hospital staff had given me to slow my labour finally kicked in a few hours after arrival at Westmead, I didn't know if that was good or bad. We were taken to a ward upstairs to rest, little did I know how the situation was about to change. At 2 am I awoke very quickly and in a great deal of pain. The labour had started again. Baby was determined to come into this world as fast as he could. At 6:58 am our second son was born. Finlay Scott weighted in at only 2.190 kg. Our tiny bundle of joy had arrived. He was transferred immediately to the Children's Hospital where he was placed in an intensive care ward and equipped with all these machines to monitor every aspect of his life systems.

The nursing staff were very attentive to his every need, they were amazing. I am sure you form a special bond with some staff, either due to them being of a similar age or maybe it is just that they are so genuine in their desire to help.

On the 13<sup>th</sup> of Dec 2003, Finlay's condition took a turn for the worst. There was no warning. He just seemed to be in great difficulty. A meeting of all the concerned took place, and it was determined that Finlay could not go on the way he was, and surgery would have to be performed to increase his chances of survival. The surgery was to take place in the 17<sup>th</sup> of Dec 2003. We had the best surgeon anyone could ever wish for. He explained every detail so clearly and even drew pictures for us to better understand what was going to happen. He explained that on a percentage basis 98% of cases survive without complications and only 2% of babies die after such operations. So although still somewhat concerned, we were convinced our baby must have this operation.

At 1200 p.m. on the 17<sup>th</sup> of Dec 2003, with family and friends at our side, Finlay was conveyed to the operating room and after a very long and emotionally draining 3 ½ hour wait, we were called back to the Grace Ward's Intensive care unit. Finlay had a cut right down the front of his chest at the end of which was a chest drain to allow the fluids to drain from the site.

There was no one arm or leg that didn't have something on it or in it. It is so frightening to see your own baby this way. Our surgeon told us that all had gone well. The operation was a complete success and had gone to plan, in a day or two Finlay would be taken off the ventilator. In the mean time he would not be awake for at least 8 hours, they have to keep them very still and quiet after such a traumatic ordeal. We left the hospital that night feeling better and reassured that tomorrow would be a better day. Brighter things will come.

At about 4:30 am our phone rang. The hospital needed us to come in straight away. Finlay's condition had taken a turn for the worst and he had been placed on the critical list. We left in a hurry, calling family on our way. When we arrived at the hospital our worst fears were about to come true. We were told that our little boy's heart had stopped and that the doctors had been trying to revive him for an hour. They told us if he were to come out of this situation now, owing to the length of time he had not been breathing, there would be no way of knowing just how much brain damage he had suffered.

At 6:30 am on the 18<sup>th</sup> of Dec 2003, nearly 3 weeks to the day of his birth, we were forced to make the most difficult decision a parent could ever make. We turned off the ventilator and set him free. Sadly our beautiful little boy was statistically in the 2% of patients who suffer from post-operative complications and unfortunately he died that morning. He is now in God's hands, some would say.

It has been nearly two months now since our nightmare. Only time will heal our hearts but we do hope that one-day we can have another baby to complete our family.

**In Memory of Finlay Scott Cavanagh  
28 Nov 2003 to 18 Dec 2003**