

# Rosie's Story



I was told that there was a problem with my baby when I was 20 weeks pregnant. At the routine scan I was told that I needed to go to Guy's as there may be a problem with the heart. The earliest appointment was four days later and, after an hour-long scan, a consultant from Guy's hospital told me that my baby did have a heart problem.

This was my first baby. There hadn't been any problems during the first few months of the pregnancy so the news came as a complete shock. The consultant thought that the baby had Coarctation of the Aorta. This, he explained, meant that there was a narrow section in the Aorta which can restrict oxygenated blood going to the rest of the body. He said that the operation to take out the narrow section was fairly routine - as far as heart surgery can be "routine" - and afterwards the baby should be healthy and lead a normal life.

However, he carried on to say that the scan had shown up another problem. The lefthand side of the heart was smaller than the right and if it could not pump blood around the body then the baby would have to have several complicated operations. If this was the case our child could be very poorly and life expectancy was uncertain.

Finally he said that the heart condition could be linked to a disability and we should consider having further tests to find out if the baby had Down's Syndrome or another "abnormality".

My husband and I sat and heard one piece of bad news after another. He stopped whenever I was crying too much and at the end said he hoped he was wrong and that our baby would be fine. But he felt certain that the baby would need at least one operation.

We went home and spent hours on the phone having to tell people the news. The first reaction was: "Why us?" and then we had to decide whether to have an amnio which could cause a miscarriage. It was awful having to make a decision which could harm the baby. Also what would we do if we had more bad news? However after a couple of days we decided that we had to find out if we were going to be facing more problems.

A week after the heart scan, I met another consultant to talk through an amniocentesis test. By this

time, I was becoming more confident at handling doctors, particularly as I was managing not to burst into tears all the time. I asked him how many amnios he had done and how many had gone wrong. "I've done about 5,000," he boasted. "And none have gone wrong." I told him that I wanted him to do it - nobody else.

The amnio was over in a couple of minutes. It sounds awful - a needle being stuck into your stomach to draw out fluid - but I didn't find it too painful. I was told that, if I was going to miscarry, it would happen over the next couple of days. I felt fine and the next afternoon I had a phone call to say that the first results showed that the baby did not have Down's syndrome. It was a turning point - good news. One chromosome was fine another 21 to check.

A couple of weeks later we were told that all of the chromosomes were normal and when I was 33 weeks pregnant another heart scan at Guy's showed that the lefthand- side of the heart had grown so the baby would just need one operation. From then on we had more of an idea of what to expect. Unless there was a fantastic mistake our baby was going to have an operation in the first week of its life.

At the time there was a lot of publicity about Ulrika Jonsson's baby, Bo, who had had a heart operation. Baby Bo had gone to the same unit at Guy's and was seen by the same consultants and surgeons. This reassured me. I knew that our baby would get the best treatment and it also helped me to speak to other parents whose children had had heart operations.

Most of the time I felt positive about the baby. There was, of course, the occasional "wobble". I would be feeling fine and then someone might say something which would open the floodgates. One occasion was when a doctor from the local hospital joked: "Go away and grow a proper baby next time!" Also most people I spoke to had no idea about "heart babies". Some would say "you poor thing" or "don't get upset, stay positive". But sometimes having someone who would listen to you moan and have a good old cry was the best therapy for me. Luckily my lovely husband, family and friends did this.

Towards the end of the pregnancy, Guy's arranged for us to meet one of the surgeons. I had been worrying about how they were going to get to the heart and what the scar would be like after the operation. Like all of the staff at the hospital, the surgeon told us everything which reassured me that he would not hold back any other bad news. He had come straight from surgery and was dressed in his surgical gear. He told me that he would use a "gentle saw" to cut through the breastbone and because babies' bones are so supple it would mend in days. He would cut away the narrow section from the Aorta and sew the two ends back together. The scar would disappear to a silver-coloured line. He was so matter-of-fact that I felt much better. I thought he was wonderful, he was going to save our baby's life.

Later that day we also went to the children's intensive care unit where we saw a baby who had just had heart surgery. It was heartbreaking to see but helped me to prepare for what my baby would look like straight after the operation.

Rosie arrived on Friday 18th May 2001 at 5.30 in the morning. She was 7lb 7oz and two weeks overdue. Even after I was induced, it took another 30 hours to persuade her to come out. No one suggested a caesarean as we were told that heart babies cope better with a natural delivery as it's less of a shock. Throughout the labour, a heart monitor was strapped to my stomach to make sure that she was OK. During the labour I had the works: gas and air; a drip to speed up contractions; an epidural and finally a ventouse.

As soon as she was born she was put on my chest and after a quick look the doctors, midwife and my husband took her away to the special care unit. I was able to see her a couple of hours later. It didn't feel as though she belonged to me and the nurses encouraged me to hold her. She looked perfect. Later, the surgeon came to see us and said that he would operate on the Monday. We spent the next couple of days getting to know our beautiful daughter.

The day before the operation was awful. I felt treacherous because I was going to let doctors cut her open when she looked perfect and so healthy. There were moments when I was tempted to run out of the hospital with her. Also I was staying on the maternity ward and it was difficult seeing other mums with their new babies.

On the Monday morning, my husband and I followed a porter and nurse to take Rosie to the operating theatre. The porter was wonderful and left us saying: "She'll be fine, I will pray for her." I was allowed to give her a final cuddle before they gave her anaesthetic. Within seconds her body went limp and we had to leave. For me this was the worst moment. We went outside, hugged each other and cried.

We sat on a wall by the river and waited. After a couple of hours we went back to the hospital to see if there was any news. There wasn't and we were sent to a waiting room with plastic flowers and a box of tissues. I couldn't bear the wait and we went to the hospital cafe for a coffee. While we were queuing for drinks I saw the surgeon chatting to our consultant. He saw me, came over and said: "She's absolutely fine."

After the operation Rosie was moved to the intensive care unit along with two older children who had been operated on the same day. Our three-day-old baby had all sorts of tubes and wires coming out of her tiny body, a scar ran down her chest and she was surrounded by equipment and monitors. A ventilator, helping her to breathe, was attached to a tube which had been put down her mouth. This was taped across her forehead and was hiding most of her face. I didn't feel too shocked at seeing her like this as I knew what to expect. She had got through the operation and from now on she was going to get better. We sat by her cot, talked to her and the nurses gave us jobs, like cleaning her eyes and mouth, which helped the hours go by. Also I was expressing milk which was poured into her feeding tube.

On the Wednesday morning we had a set back. The previous day the doctors had said that because Rosie was doing so well they were going to take her off the ventilator. But at four in the morning I went down to see her and found yet another awful tube stuck down her nose. The nurse said that Rosie had had problems breathing on her own so they had decided to keep her on the ventilator. Also she was wearing eyeshades and was lying under bright lights because she had Jaundice. She kept grabbing the shades and was trying to cry but couldn't because of the tube down her throat. I couldn't do anything except tell her that she could yell as loud as she wanted when she was off the ventilator. Later a consultant said that the last heart scan had shown up further problems.

It's amazing how things can change so quickly in hospitals – particularly with babies. On the Wednesday we felt that everything was going wrong. The other children had gone to the recovery ward and we were wailing to find out if we were facing more bad news. However later in the day another scan showed that there wasn't a problem after all and the following morning the ventilator finally came off. Then she was moved to the recovery ward where, apart from nurses measuring her oxygen levels and taking the occasional blood test, I was left alone with Rosie for the first time.

We were sent home on the Monday afternoon when she was ten-days-old. It was very scary not having a nurse around. I was worried that she wasn't feeding enough and felt incapable of looking after her - normal baby stuff!

Throughout the whole experience the hospital staff were fantastic. From the surgeons and consultants who saved her life, to the nurses who cuddled and talked to her around the clock, and the porter who took her down to theatre who we kept bumping into and always asked after Rosie.

Today Rosie is five-years-old. She is very active - runs everywhere and loves to swim and go to gym. She had her last check-up over a year ago. If the repair to the Aorta doesn't grow with her then she may have to have another operation but we'll deal with that if it happens. She's just like most children her age - into everything, is very active, throws the occasional tantrum but, of course, absolutely gorgeous.

**Jenny Follett**