

Rory's Story

It was at the routine 20-week scan that we first heard the words, 'I think your baby has a problem with its heart.' Having a healthy, boisterous 15-month old boy already, it hadn't even crossed our minds that there would be a problem.

We were sent to the Evelina the next day to meet Professor Simpson who carried out the cardiac scan and confirmed our baby had a condition called Truncus Arteriosus. He carefully explained to us this is a rare condition where instead of having a separate pulmonary artery and aorta, a baby with Truncus has only one great blood vessel or trunk leaving the heart. The result of Truncus is usually that too much blood is going to the lungs and too little red (oxygenated) blood is reaching the body. He told us it can also be associated with certain genetic conditions.

Sitting in the meeting room, trying to absorb all this information felt so overwhelming. This is not how we had anticipated our pregnancy would be. After much contemplation we decided to have an amniocentesis to see if there was anything else we had to prepare ourselves for. After a long 2.5 week wait, we received a call from the specialist midwife telling us they had found a problem...

After a sleepless night we went to meet a geneticist at our local hospital. She explained to us that although the 22q deletion test had come back negative, they had found a microdeletion of chromosome 16, which could indicate learning difficulties and a higher incidence of autism and behavioural difficulties. Equally it could just be an anomaly and mean nothing. Our heads whirling, we decided to put this information to the back of our minds and just continue dealing with the immediate issue of the baby's heart condition. At this point we also found out we were having a boy. We decided we had had enough surprises for one pregnancy!

The rest of the pregnancy passed in a bit of a blur, with regular cardiac scans at the Evelina to check nothing had changed dramatically. We did attend the ECHO antenatal day which we can't recommend highly enough. It gave us the opportunity to see where our baby would be born and spend the first part of his life, and also speak to other parents in a similar situation. When you find out your baby has CHD it can be very isolating and knowing you are not alone in the rollercoaster of feelings you are experiencing is a comfort.

I was booked in for an induction the Monday before the Easter weekend. When we rang, they told us the unit was full and to ring back the next day when we were told the same thing. On Wednesday we got a call to come in. I remember bursting into tears on the way to the train station. The time had finally come!



Rory Caird

But on arrival at St Thomas', we were told a set of triplets had taken our bed in NICU! We stayed for a few hours in case the situation changed, but eventually went home later in the evening when the staff told us it was unlikely I would be induced that day. Finally, at 10pm on Easter Sunday, we got a call to go in. We dropped our son, Noah, with his grandparents and headed back to St Thomas'.

Finally, at 00:39 on 8th April 2015, Rory was born by emergency c-section. He was whisked off to PICU with Ben to be checked over and I was stitched up and taken back to my room. About 2 hours later there was a knock at the door. I had a visitor! Ben was wheeling Rory in a double buggy, our tiny baby wrapped up on one side and the SATs monitor on the other! Jenny, the wonderful sister in PICU, had wheeled him across the Evelina and St Thomas' at 3am to meet his mummy properly. Am not sure who was more surprised, me or the Tower Team midwife!

The next few days all passed in a bit of a blur. Rory was moved from PICU to NICU and finally to SCBU while waiting for his operation. I spent a lot of time in the expressing room! We met the amazing Professor Anderson who explained the procedure to us and told us Rory was booked in for the operation at 5 days old.

Seeing Rory after his first open heart surgery was a massive shock. Although we had seen pictures, no one can prepare you for the reality of seeing your baby hooked up to a multitude of machines, their bodies full of wires and tubes. It is amazing how soon you become acclimatised to this though and realise that it is still your precious baby and all this machinery has a job to do!

Rory recovered remarkably well after his operation, spending a week in PICU and a week on Savannah. We were then transferred to our local hospital to establish feeding. This was a slow process and we finally took Rory home with an NG tube four weeks after he was born.



Rory in hospital

We had our first consultant appointment in May 2015, where Dr Gareth Morgan confirmed he would need a procedure in the cath lab shortly to widen his narrow pulmonary arteries. I have to say, this was a massive shock to me. Although we had known that he had narrow PAs, in the blur of those first few weeks, I think we had chosen to not focus on this information! A date was booked in July and we prepared ourselves for his next procedure.

At the beginning of June, we went for a routine check-up at the Evelina. Rory had been very unsettled the previous few days and we had taken a trip to our local hospital. During the ECHO he was inconsolable, and the doctor did struggle to get pictures. From what she did get, it was obvious Rory's heart was under a lot of pressure and the procedure couldn't wait. We were admitted to Savannah there and then and Dr Morgan came to talk to us to tell us he would have the procedure in two days' time.

The morning of the procedure, we went down with Rory to the anaesthetic room. I find this is one of the worst parts of the process, handing him over and saying goodbye. After getting some breakfast, we

headed back to the room on Savannah and waited to hear any news. About 3 hours after we left Rory, Dr Morgan came to see us. They had had to stop the procedure as Rory had become so unstable and they were concerned he was going to go into cardiac arrest. They couldn't just stabilise him and bring him round as something needed to be done to relieve the pressure in his heart now.

An emergency surgical meeting had been held about how to proceed and a plan had been formed. They were going to put Rory on ECMO (a mini heart and lung bypass machine) and try to do the procedure with this support. They were very clear about how high risk this was but we knew there was no other option. We have always had the upmost faith in Dr Morgan and Professor Anderson and we took some comfort from the fact we knew Rory had the best possible chance with them.

Four hours later, Gareth came to tell us Rory had made it through and was in PICU. They had inserted stents to widen the arteries and this would be sufficient for the meantime. We knew by now the days following the operation were key and we all waited for him to come off the various support and see how he would cope.

Bar a chest infection, Rory recovered remarkably well. I think everyone was surprised at how quickly he had bounced back after all he had been through!

We were told after the operation that this was the first time a child had been put on ECMO whilst already in the Cath Lab, so he was a bit of a celebrity while in PICU! Two weeks later we were home and hoped that Rory would now finally get a break, unfortunately it wasn't to be.

Although it was amazing to have our little boy home, these months were tough. He has bad silent reflux which causes him a lot of discomfort. Although we no longer NG fed him, feeding has always been a challenge. We had a few mini hospital stays with bronchiolitis and breathing difficulties. He also never sleeps for longer than 45 minutes to an hour at a time! Dealing with all this plus an energetic 2 year old was difficult!

Luckily we have amazing family support which certainly helped. After starting reflux medication Rory did settle and started to put on weight, and with Dr Morgan's permission we went on holiday to France and had some much needed family time.

The 26th October was the date for his next cath lab procedure. Dr Morgan explained they would try to either widen the stents or crack them completely to widen the arteries further as the narrowing was still substantial. Once again, we took him down to the anaesthetic room and started the wait. After about 3 hours, the first we heard was that Rory was being taken to PICU. We knew this wasn't a great sign, as if all had gone according to plan he would have come straight back to Savannah.



The Caird family on holiday

A little while later Dr Morgan arrived looking pretty exhausted. Once again, they had been unable to proceed as Rory's heart hadn't been able to cope with the drugs.

He would need another OHS in the next few days. I think at this point we were both fairly numb. We knew Professor Anderson would be doing the procedure which gave us confidence. We made our way to PICU to see our brave little man. The next 24 hours were very hard. Overnight Rory became very

unstable. He was in a lot of pain and from the ischemic changes on his ECG this was probably angina. It was pretty horrendous seeing our baby like this and the doctors made the decision to ventilate and sedate him.

We finally made our way to bed at midnight. Rather bizarrely, an hour later I got a call from someone on the surgical team telling me Rory had a suspected twisted testicle! At 2am we received another call from PICU telling us Rory was very unstable and we should go over. We found him with lots of people around his bed (by now we knew this wasn't a great sign). There was lots of discussion about the best way to stabilise him, as the worry was he'd need an emergency operation in the middle of the night. We'd been told this would be a very bad situation to be in.

Luckily, the amazing PICU staff managed to stabilise him until the morning when Professor Anderson and some elusive homograft tissue (apparently there is a national shortage of this tissue) were available. Professor Anderson explained he would try and widen the branch arteries by snipping them and applying the homograft tissue to widen them. He also said it was very difficult to predict what his chances were but he would estimate it was roughly 50/50.

Rory went down about 1pm and, once again, we started the long wait. At 7pm, we were told Rory was on his way back to PICU. We rushed there, but by the time we arrived we were told he had become unstable once again and had to be put back on bypass. We headed to the parents' room and waited in silence, unthinkable thoughts running through our minds until Professor Anderson arrived at 11pm.

After 10 hours in theatre, this amazing man and his team had managed to widen the pulmonary branch of his arteries with the homograft tissue and had inserted a hole in his VSD patch to relieve the pressure on the right side of the heart. This means if the right side of his heart comes under too much pressure, it shunts from right to left. Obviously we knew he wasn't out of the woods yet and the next few days would be key.

This time Rory did not recover so quickly from the operation. This was most definitely the hardest time we had in hospital. He still seemed to be in a lot of pain and would spend hours screaming. He was put back on milrinone to help his heart recover.

He had to go to theatre again to have a pic line inserted, as he was so difficult to cannulate (the dodgy PICU haircut came out in full force during this stay!) He was on high doses of morphine to help manage the pain.

On top of all of this, he contracted the norovirus! After being in PICU for 3 weeks, we moved to Savannah. He didn't cope very well with coming off morphine suddenly and we had many nights of pretty much constant crying! He was put on a weaning plan, although this didn't seem to particularly help. We had another mini visit to PICU, as everyone was concerned about how his heart was coping. By now all the PICU staff knew him very well! It really did feel like one step forward, two steps back and we had to dig very deep to get through this difficult time.

Amid all the tough times, we did have some chinks of light during this stay including Rory's first pantomime and a visit from Father Christmas!

We were finally discharged three weeks before Christmas and we looked forward to Rory's first one at

home...or so we thought. On our return home, I had purposefully kept Rory in all week to avoid him contracting any illness. Unfortunately, having a 2-yearold at nursery means our house is not bug free! A week after being at home Rory started struggling with his breathing. An ambulance took us to our local, where he continued to deteriorate and we were retrieved back to PICU.



Smiling Rory Caird, aged 9 months

It was reassuring to see familiar faces Ben & Karen from the retrieval team coming to pick us up, but we were so disappointed that we were heading back to hospital again. Rory had contracted a bad case of RSV and needed to be ventilated and on milrinone again. After 10 days in PICU, Rory's first Christmas was spent on Mountain ward. We were discharged on Boxing Day and, once again, our family was reunited.

We have now been home for 2 weeks and we really hope it will stay this way for a while! Straight after Rory's second OHS, we were told he would need another operation in a matter of weeks. We are all really hoping that this can now be stretched out further as a CT scan showed his arteries are looking better than they initially thought.

We see Dr Morgan every 4-6 weeks to monitor how Rory's heart is coping. We all desperately hope he will continue to improve, so this will give him time to put on weight and be in a better position for the

next procedure. Rory is now 9 months. Feeding and sleeping is still a bit of a challenge and unfortunately the only solids he is keen on are chocolate buttons and wotsits! Hopefully this will improve if he gets some time at home and a chance to experience life as a normal baby.

We continue to be amazed at what a resilient and brave little boy we have and it is just wonderful to see him happily bouncing away in his jumperoo, while his brother smothers him in kisses (with the odd poke in the eye). From spending a lot of time at the Evelina, we have witnessed the enormous love parents have and how we all find a strength we never realised we had. Although nothing could have prepared us for how complex Rory's heart condition would be, and we have no idea what the future holds, we celebrate what a remarkable little man he is daily.

The patience, kindness and support our little boy (and us!) have received from all the staff at the hospital, when we were all at our most fragile and vulnerable, we will be forever thankful for. We really could not wish for him to be under better care.