

Alexander's Story

As told by Sarah, Alexander's Mum

Our son Alexander was born on Monday 28th June 2010, at our local hospital in Kent. It was a long, four day labour - but everything seemed fine. The doctors suspected I might have pre-eclampsia but at no point did we have any warning that something might not be right with the baby, nothing had been diagnosed during my pregnancy.

Alexander was born weighing 2.6 kilos, and again everything seemed okay to begin with - no problems were immediately picked up. I spent that night on the ward with Alexander by my side learning how to be a mummy. But the next day as we were undergoing the various usual discharge tests, the paediatrician thought she could hear a murmur in Alexander's heart.

We were fortunate that the head of paediatrics at the hospital had a special interest in cardiology and after performing an echo test she immediately recognised there was a problem - suspected Truncus Type 2. At this stage Alexander went into complete organ failure, and was transferred straight into NICU.



Alexander in PICU

It was immediately clear Alexander's condition was so serious that he needed to be transferred to the Evelina London's Children Hospital. Unfortunately we had to wait nearly six hours for emergency transportation to become available, much of this time was spent watching the doctor's trying to stabilise Alexander to ensure he was fit to travel.

My partner Gary and I could not travel in the ambulance and so had to make our own way there separately by car - a very hard journey considering I had just undergone a difficult labour with little time to rest. I felt completely disorientated walking through this enormous hospital at 8:30 pm that night, but as I arrived at PICU I knew immediately where Alexander was as I could see a small crowd of 8-10 medical staff huddled together.

It's hard to describe the levels of confusion and despair my partner and I were experiencing at this moment in time - I had never even heard of the Evelina London Children's Hospital and here I was standing in their Paediatric Intensive Care. It was simply terrifying and the next four days felt like four months.

Alexander was experiencing multiple-organ failure, he was heavily sedated and on morphine. The problems in his heart - Truncus 2 - mean that there is no separation between the oxygenated and nonoxygenated blood and that he doesn't have enough oxygen going into his blood to service his organs.

As my partner is from London his family were able to get to the hospital quite quickly and so was my brother. Unfortunately the difficult task of phoning my parents had to be done. It was so hard telephoning them to tell them that all was not well. Both my parents had to get last minute flights to London because we didn't know how much time Alexander had left. Within two days of his birth we had a small army of people gathered in the family room waiting for news.



Alexander in PICU

On the Wednesday the medical team decided to wake him up to see how he behaved, and fortunately he was quite brilliant and it was lovely to see him awake. We thought our kisses were making him open his eyes only to discover it was because our heads were blocking the bright sunshine coming in the windows on Lambeth Palace Road. The doctors said they had to sedate him again to do an MRI scan. The scan showed good brain function and it was decided that he could be stabilised for surgery.

Not only did he have Truncus and a faulty Truncal Valve, but there was also a hole between the two atriums, and with the additional chance he would not survive the surgery. Professor Anderson told me he believed he could re-plumb Alexander's heart and the consent form was signed without hesitation; we had spent those 4 days fighting to get Alexander into a stable enough state for surgery so there was no question of changing our minds if the Professor would agree to perform it.

On Thursday afternoon we gathered family around his bedside and had him baptised, with the help of Nurse Emily's organisational skills, by the Evelina's chaplain. To say this was a difficult time does not do it justice.

On Friday afternoon Alexander underwent nearly seven hours of surgery, led by Professor Anderson and

Cardiologist Dr Bell. Unfortunately following the surgery Alexander's chest drain continued to leak and there was lots of blood left in his chest cavity.

That night at 9.30pm the medical team called Professor Anderson back in and had to set up an emergency operating theatre at Alexander's bedside, which we understood was a desperate situation to be in. We were sent away to sit in the parent's room where we sat in the dark, not knowing what to think. And then Dr Anderson came to find us. He appeared like an apparition in the early hours to tell us that he had found the leak and managed to close it.

Could we possibly be on the road to recovery?



Little Alexander in his cot

Unfortunately two weeks later we were still in PICU. Alexander had developed DVT (deep vein thrombosis) in his leg. He was put on deltaparin to thin the clot but I knew something was not right when he was not reacting to things as he normally would, especially when he had a lung x-ray and barely reacted. This was a baby that screamed so much having his nappy changed that the doctors would come from the other side of PICU to see what was wrong.

An ultrasound was done on his head and we discovered that he had had a clot in the sagittal sinus vein; Alexander had had a stroke. The medical team couldn't tell us whether this was a result of the DVT, of surgery, or of being immobile.

After further blood tests we discovered that Alexander also had a blood condition called Factor V Leiden, an inherited illness which causes blood to clot, though neither of us have the condition, and which can cause DVT.

In total Alexander spent 27 days in PICU. He slowly got his lung, kidney and liver function back and the doctors were pleased with his progress. After 5 days in Savannah and two weeks in our local Hospital establishing feeds, we were allowed home where Alexander continued to do well.

I continued to administer deltaparin subcutaneously for 2 months which meant regular blood tests to keep his levels in check as well as heart and kidney needs. As he became more mobile it was obvious that he was favouring his left side from very early on and at 18 months another MRI of his brain showed the stroke on the left side.

Thankfully for him he began to regain use and by the age of 2 he was using both hands although his left side is still his preferred one.

As awful as the experience was I have say we were so well looked after by all the staff, who consistently kept checking on us and asking if we were okay. They would check my blood pressure to keep an eye on the levels after childbirth and always encourage us to eat and rest.



Alexander in recovery

We were also very grateful to receive an ECHO Comfort Pack when we first arrived, containing little

useful bits and pieces like shampoo etc. We were miles from home, and having had no prior warning we had barely anything with us. I was so touched to think someone had taken the time to put this together – the whole situation felt so surreal. I was getting excited about a tube of toothpaste.

Truncus is a condition which requires further surgeries as children grow, which meant we returned to the Evelina London Children's Hospital nearly five years later, in March 2015.

The medical team repeated the original surgery and repaired the Truncal Valve, as well as repairing the hole between his atriums.

In the immediate aftermath of the operation Alexander lost the power in his right hand again and also had a slight tremor. No cause could be found so it is believed to possibly be as a side effect of the operation in conjunction with what his body had experienced following the stroke he had had as a baby. Fortunately after 8-10 weeks Alexander had movement in his hands again.



Alexander today

I am delighted to say that Alexander has recovered very well from his last surgery, his energy levels are

increased, as is his weight, though his diet is still supplemented. He is a strong willed young boy and we believe it was this determination that got him through his difficult early days and it is what will get him through the future, whatever that may bring. Once again we are hugely appreciative of the care we received at the Evelina London Children's Hospital.