



Parley

Parents And Relatives
Listening and Empathising
with You

Hannah's Story

At 31 weeks, after noticing that my baby (now known as Elliott!) was not moving as much as normal, we found out that his heart was beating at 250 bpm. The normal rate for an unborn baby is approximately 140-160 bpm.

Because Elliott's heart was beating so fast it was not contracting properly and therefore not pumping blood/fluid round his body properly.

This is a condition called Supra Ventricular Tachycardia (SVT). The SVT had led to a build up of fluid around Elliott's heart and lungs, which was restricting the heart. Elliott was essentially in heart failure. We were later told that the build up of fluid is a condition called Hydrops. The day Elliott's conditions were diagnosed I was told that I would need an emergency caesarean within a couple of hours in order to save his life. The consultant could not give us any idea of Elliott's chances of survival as he did not have any experience of these conditions. Thankfully, the doctors at our local hospital spent some time contacting other hospitals in our area and got in touch with Dr Sailesh Kumar at Queen Charlotte and Chelsea Hospital who is a specialist in fetal care. Dr Kumar advised that Elliott should be treated in-utero by giving me medication which would hopefully lower his heart rate. He also advised that if Elliott was delivered at this stage he only had a 20% chance of survival.

I then spent the next two weeks travelling back and forth to London for regular scans to see if there had been any improvement in Elliott's condition. After nearly 2 weeks we were given the brilliant news that Elliott's heart rate had dropped to below 200 bpm and the Hydrops was resolved. Dr Kumar said we were winning the battle. We left the hospital that day with a plan in place that I would have a caesarean at approximately 38 weeks.

However, that night at 1am my waters broke. We went to our local hospital and were transferred to QCCH the following morning. A scan showed that Elliott's heart rate had increased and the Hydrops was returning. We were told that if Elliott was not delivered within about an hour we could lose him. I was taken straight to theatre and Elliott was born on 29th November 2007 weighing a healthy 5lb 12oz. He was taken to the Neonatal Intensive Care Unit.

I had to wait for my epidural to wear off before I could go and see him, and I was not able to hold him until the next day.

An ECG showed that Elliott's heart was healthy, but when Elliott was 3 days old he had an SVT attack, where his heart starts to beat too fast. If this is left untreated for too long, it compromises his other organs which would not be receiving enough oxygen. He was therefore transferred to The Royal Brompton Hospital, which has a specialist Cardiac Unit. He had 2 more attacks over the next 2 days, while he was started on daily medication. When an attack began we would watch Elliott for an hour to see if his heart returned to normal. This was very traumatic as Elliott would be pale and lay limply in my arms. If it did not resolve Elliott would have an injection at varied doses of a drug to return his heart to normal.

Once his daily medication was in his system it seemed to stop the attacks. After a week we were told that his condition was under control and Elliott could be discharged. However, he had to be transferred to the Special Care Baby Unit at our local hospital due to his prematurity. Elliott spent 3 weeks in the SCBU, and whilst there suffered 3 more SVT attacks. He was started on a beta-blocker to control his heart rate. This meant we had to give him medicine 5 times a day.

Elliott was discharged from hospital on 22nd December 2007, which was the best Christmas present we could have hoped for.

Unfortunately in the New Year we had a week where Elliott was having an attack every day, but this stopped after his medication was increased.

Elliott is now nearly 1 and is a very happy little boy. He is still under the care of the Royal Brompton and has regular checkups. He has not had any attacks since January 2008, and we are in the process of weaning him off his medication. Thankfully, SVT is a condition that most children will grow out of in the first year of their life.

Elliott is due to start nursery in a couple of weeks as I am returning to work.

The fantastic care and support we received from the 3 hospitals that treated Elliott is still continuing as a Cardiac Liaison Nurse from the Royal Brompton is coming to train the staff at the nursery about Elliott's condition so they are able to spot if he is having an attack. This has made the thought of putting Elliott in nursery much more bearable.

The day we found out about Elliott's conditions was the worst day of my life, but I had to remain strong for Elliott's sake. Thankfully, we have come out the other side. My heart goes out to people whose babies have any sort of medical condition. I know there are other people who are not as lucky as we have been. If anyone wants to talk about having a baby with a heart condition, or any medical condition at all, please feel free to contact me.