

Freya's Story

When Freya was born at the beginning of December 2006 she seemed to be a perfectly healthy baby. No one had any idea she had congenital heart disease. We took her home from hospital the day after she was born and began adjusting to life as first time parents.



Freya

When Freya was two weeks old we took her to the doctor as she was lethargic and wasn't feeding well. Our GP examined her and told us that she had a heart murmur. Our Doctor was very reassuring and told us not to worry as it is quite common in newborn babies. She referred Freya to our local children's hospital straight away and we spent the rest of that day there. The consultant we saw there was also very reassuring, the chest x-ray and ECG had not shown any problem with Freya's heart and he was sure it was not the cause of her lethargy or feeding problems. He thought the murmur was probably due to a small hole in the heart that would close up by its self in time. We were told that Freya would be referred to the Evelina Children's Hospital for an echocardiogram just to make sure it was not something more serious.

We had a lovely Christmas at home and as the New Year started Freya seemed to be thriving, her lethargy had gone and she was gaining weight well. We were convinced she was completely healthy and that there was nothing serious wrong with her heart.

In mid April when Freya was 4 and a half months old we went to the Evelina for the first time. We were not feeling particularly anxious or worried about her having the echocardiogram or what they might find, she seemed so happy and healthy we were sure they wouldn't find anything. Dr Miller and Emma Symonds broke the news to us that Freya had Tetralogy of Fallot and would need to have open heart surgery within the next 3 months. It was such a shock and so unexpected. We just couldn't believe there was anything wrong with her as she had no symptoms at all! To be honest I had never even heard of

congenital heart disease and the prospect of such a serious operation terrified me. We went back to the Evelina 2 weeks later for a sedated echocardiogram and Dr Miller decided that as Freya was doing so well and wasn't showing any symptoms they would wait until she was a little bigger before surgery.

We went home and tried to carry on with life as normal. We contacted ECHO and Jessica put us in touch with a local family whose little boy had the same condition. He was only 6 months older than Freya and had recently had his surgery. It was a great comfort for us to meet them and see how well he was doing. We all got on really well and became good friends. Eventually after a couple of months of waiting the appointment arrived in the post.

Freya was admitted on the 24th of July 2007 to have her surgery the following day. I hardly slept at all that night, I felt so anxious, but the staff on Camel ward were tremendously reassuring and calming. The next morning at 8.00am I carried Freya down to the pre-op room and held her as they put her under general anaesthetic. Laying her down and leaving her was the hardest thing I have ever done, but I knew she was in good hands. We walked straight out of the hospital and walked through the streets of London for the next 4 hours trying to keep our minds off what Freya was going through. The time seemed to pass so slowly but eventually we had the news that Freya was in PICU and doing well.

As the nurse took us down to see Freya I remember feeling elated that she had come through the surgery and was doing well but also anxious about seeing her with all the tubes and monitors attached to her body. To be honest through, the moment I saw her I hardly noticed anything except for my beautiful daughter and all I felt was relief.



Freya after her surgery

Freya only spent 48 hours in PICU and by the day after her surgery she was propped up in her cot

eating custard! It was amazing to see how quickly she recovered. The staff in PICU were truly wonderful and did everything they could to make Freya comfortable and to make us feel at ease. Two days after her surgery Freya was moved back to Camel ward where we stayed for a further 5 days before she was discharged. We were home within a week, which I still think is incredible.

Ten months post surgery Freya is still doing wonderfully, she had a check up recently with Dr Miller who was very pleased with her progress. She will now be seen annually by him. The whole experience of being in the Evelina now feels like a distant memory. Freya is so full of life and energy that some days I find it hard to believe she has had open heart surgery at all. Looking back at the whole ordeal the hardest times for us were the day Freya was diagnosed and the day she had her surgery. ECHO and the wonderful staff at the Evelina were there for us offering their support at both of those times which has been a huge help to us - Thank you!

Florence Embden-Kane