

Emilia's Story

Emilia Di Giovanna was born on 28th October 2014 at St Thomas' Hospital. Emilia was born with half a heart, a condition known as hypo plastic left heart syndrome (HLHS), with an unusual complication of pulmonary vein drainage which is known as Pulmonary Vein Stenosis (PVS).

Emilia's heart condition had been spotted in our 20 week scan at our local hospital. On the same day we were seen by a cardiologist at Queen Charlotte's Hospital and it was confirmed that our unborn baby had a heart condition. We were devastated and in shock as to why this had happened to us, we have two beautiful children that don't have any health issues.

After the scan that day we couldn't get over the shock of what had happened. We knew we had to make a life changing decision as to whether to keep our baby or have a termination, this was the most difficult thing as a mother to deal with.

As the days progressed and we were trying to understand and digest all the info about Emilia's heart condition we knew we had a long road ahead, but we finally made the decision to continue with the pregnancy. It was a joint decision knowing that we had to think of our other two children, but we decided that we could live with the 'we gave her a chance' but not with the 'what ifs'.



Emilia following surgery

We then had more scans at Queen Charlotte's Hospital to determine if there were any other complications. As the weeks progressed and Emilia was growing we were told that there was an unusual kink of the pulmonary vein in the way it drained.

At 32 weeks we were transferred to St Thomas' Hospital for further scans to determine how surgery would prevail. Once we were at the Evelina London Children's Hospital we met Professor John Simpson, Mr Austin and another consultant who talked to us about what the plan for Emilia would be.

On 28th October 2014 our heart warrior arrived looking amazingly well. Soon after I was able to hold her she was taken down to PICU where they looked after her. We decided that Emilia should be christened and the priest based at St Thomas' Hospital, Father Jake, blessed our daughter.

On day 3, Emilia went into surgery to have her hybrid procedure. It was the most nerve wracking and heart-breaking feeling seeing our daughter being wheeled away for her first major open heart surgery, not knowing if we will see her again. Finally, after a painstaking 4-5 hour wait, Emilia was back on PICU and surgery had gone extremely well.

Emilia was recovering well and was progressing until 8 days after her hybrid when she took a turn for the worse and was put back on a ventilator after de-saturating. A further echo was done and it was apparent that more surgery was needed.



Emilia

After 3 months in PICU and six operations later (stenting of the pulmonary vein also included) Emilia finally went up to Savannah Ward with the hope of her going home soon.

Unfortunately this wasn't to be just yet and after a few weeks in Savannah Emilia required further surgery and down to PICU she returned.



Emilia with her siblings

Emilia had her Norwood 1 surgery at the end of January and started having mild seizures. She had coped extremely well after the 48 hour surgery period where on day 3 she had a major seizure causing her to go into cardiac arrest. The consultants and retrieval nurses were on hand performing CPR for 6 minutes, we cannot thank everyone enough for bringing our daughter back.

After this mishap Emilia managed to get back to Savannah Ward and on 26th March she was finally discharged. We had her home for 6 weeks where she put weight on and loved family life.

Emilia then returned to the Evelina London Children's Hospital on 13th May due to her saturation levels dipping. Her Hemi-Fontan was bought forward a week and on 21st May she went for surgery for the 8th time. Whilst in theatre Mr Austin and his team had difficulties getting oxygen into Emilia so a bronchoscopy was

done and it showed that where the stent had been put in the pulmonary vein it had squashed the broncho tube by 90%. A decision was then made that the best port of call was to remove part of the stent, this in turn made the Broncho tube bigger and surgery was then performed.

After 5 long hours Emilia was out of surgery and within 4 hours after being on PICU was

extubated. 24 hours later we were able to start feeding Emilia on solids and on Tuesday 26th May she went up to Savannah Ward and finally was discharged from the Evelina on 29th May 2015.

We are very fortunate to have Emilia - this is all down to the amazing nurses, cardiologists and consultants in PICU and Savannah for their hard work and efforts.

We are eternally grateful and very lucky to have Emilia home, making our family of five truly complete. Our little heart warrior continues to fight for every heartbeat to live.

Emilia our amazing heart warrior we are so very proud of you.

Much love the,

Di Giovanna family



The Di Giovanna Family