

Tracy's Story



We first connected with ECHO through the Facebook group, following advice from the cardiac nurse. From seeing that you're not alone in your situation, to advice from others' experiences, the ECHO group was really helpful! We also took part in an ECHO Cardiac antenatal class online.

We found out about Isabella's diagnosis from the 20-week scan.

The sonographer was unable to measure output flow from the heart and we were referred for further scans. 3 scans later, the Evelina team confirmed the diagnosis of coarctation, as well as a bicuspid aortic valve.

A later scan diagnosed VSD (ventricular septal defect). On hearing Isabella may need surgery soon after birth we were shocked but hearing the words open heart surgery felt even more scary. Admittedly, there were a few tears.

The team was really supportive and reassuring and we've felt this throughout our time with both <u>antenatal</u> and postnatal care.

Apart from a delay to the foetal MRI, we have been lucky with all appointments going ahead as planned. My husband and I went to the main diagnosis scan appointments together, but all follow up scans I went to by myself, which was hard for us both.

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I was due for a planned induction but our little one had other ideas and arrived a few days early.

On arriving at St Thomas, I went into the hospital while my husband, Dean, went to the accommodation. This was nerve wracking but what we expected. I was welcomed by the midwife, taken to my room and in less than 2 hours I was pacing the room with an ever increasing back ache. All I could think was "I can't do this for hours" and found this the hardest time being alone.

Dean made it to me with about 5 minutes to go. I'm so glad he was there, he calmed and encouraged me along with the midwife, Jamie, who was great. Dean cut the cord and told me we had a baby girl (we didn't know the sex of the baby beforehand).

We got a guick cuddle before Isabella was taken off to NICU.

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Throughout our time in the hospital, being able to have only one of us with Isabella at a time was really difficult, especially for support, although all of the staff were wonderful. When our immediate family came to see us, we met them outside for an update and catch up, but again, it was hard for them and us not to be able to go in together to see Isabella.

Our local support postnatally has been limited due to Covid-19, I have struggled at times but the team at the Evelina has been amazing and helped us through further issues, including a tongue tie.

We have been lucky so far and have a fighter on our hands, Isabella hasn't had to have any surgery, she continues to undergo regular reviews but is so far doing well.

We're loving the addition to our family! Her personality is growing and she's becoming more alert and aware with the biggest beautiful smile – we couldn't love her more.