

# Sofia's Story



For my birthday this year, I asked for donations to the Evelina Children's Heart Organisation Ltd. (ECHO).

I chose this charity because they deserve and need every bit of help they possibly can.

I'd also like for them to be more recognised as I'm sure many people aren't even aware they exist and we need to raise more awareness for Congenital Heart Disease (CHD) - it's the most common birth defect, affecting just under 1 in 100 children.

To give you a brief outline of why I've chosen ECHO, this is how have they helped us in the past, continue to do so now and how we will need their help in the coming future:

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Our son Finch, was born with a rare heart condition called Ebsteins Anomaly and has severe regurgitation of the tricuspid valve.

At our most recent cardiac appointment (February 2019), we were advised by Finch's consultant that Finch is most likely going to need open heart surgery in the next 18 months - 2 years, so we need to start discussing our options and preparing ourselves. This breaks me but I know the consultant will do whatever is best for Finch's future, I have so much trust in him. We will stay strong for our fighter,

along with the help and support from ECHO if and when the time may come, as this isn't going to be easy for us.

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This led to an urgent referral (the following day) to see a specialist Fetal Cardiologist at Kings College, London.

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Due to it being in the early stages of pregnancy, the consultants couldn't diagnose what the problem was as they basically said it was like looking at a grain of rice. However, after returning back for lots of further scans they diagnosed Finch's condition as Ebstein's around 18 weeks.

We were monitored very closely with scans every 2 weeks, I can remember like it was yesterday, when being scanned by the fetal cardiologist - the room was silent and you had 2 or 3 trainees in the room all making notes. Once the scan was finished we would then be taken into a consultation room to find out what the findings were. Unfortunately on one of our scans we got told our baby's condition had deteriorated and that serious medical intervention would be needed as soon as he was born. This is then when we were introduced to ECHO and transferred over to the Evelina Children's Hospital, London for all future scans.

This was an extremely hard time for us, if it wasn't for the support we had from ECHO, friends and family then there is no way we would have remained as strong as we did throughout the pregnancy and the start of Finch's life. ECHO helped me from the very first meeting we had with them.



They support families at every stage, connecting a community of heart children, young people and their families. They arranged an antenatal day at St Thomas' Hospital, London for all expecting parents whose babies had heart conditions - they went through every step of the way of what will happen during our birth and showed us around the Intensive Care Unit, which is where our babies would be taken as soon as they were born. This made it very real, and I can speak for myself and all the other parents that we never really expected to see what we saw.

It was an extremely emotional experience for all, and even the dads couldn't hold those tears back. It also in a weird way gave us comfort as we knew our poorly babies were going to be in the best place.

There is a Facebook group where we all can ask for advice and just support each other as a community, I post on this Facebook page fairly regularly just asking for advice - even if it's the smallest things like the best place to get travel insurance as obviously Finch can't just have standard insurance. There were pregnant mummies on there who I spoke with that were expecting the same time as me, one who even lived in Scotland that had to travel to London to have her baby.

We all built such a nice relationship beforehand which gave us all such comfort and made the hospital not such a scary and lonely place, and are all still in contact today.

The Evelina midwives are there to support us and be there for us - I remember just popping up to their station whilst still in hospital even just for a chat, little things like that just to clear your head, have a 'normal' conversation, have a 5 minute break from the constant bleeping noises off all the machines and just give yourself a break from sitting there feeling helpless not even being able to pick up your baby for a cuddle.

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When Finch was born, he wasn't stable and needed immediate care from the resus time who were already in the delivery room on standby. I got to hold my baby for a matter of seconds before he was taken away from me and taken straight to intensive care. This is where he stayed for nearly the first 3 weeks of his life.

Our lives changed from that moment on - nothing else mattered other than getting our new baby son better. We spent hours upon hours just sitting at Finch's bedside just staring at him, I was there from very first thing in the morning until the very last thing at night. I felt helpless; not being able to hold your new baby was such a hard thing. All I could do was just sit there and let him know I was there with him and hold onto his little hand. I would wake up in the night at all hours and phone the hospital to make sure our boy was ok. I took anything I could which had his smell on to bed with me to cuddle at night just to give me that extra comfort. When you lay down in bed all you can hear is the constant bleeping from the machines which you have sat there watching and listening to all day. We were extremely fortunate enough to have a room at the Ronald McDonald House which was round the corner from the hospital. This house saved us, it was our safe haven. Once again they are such an amazing charity that truly deserves more recognition.

We had a very scary and emotional start - Finch was intubated from the very beginning and sedated for his first couple of weeks of life. He had wires coming out of him left right and centre and was only fed sugar water for the first week. They tried desperately to get an IV line into him so they could give him nutrients but every time they attempted his little veins just couldn't cope. I remember the fear of always walking up to the room and asking one of the nurses if it was ok to go in, and as I couldn't bear to see him with the blue cloth over him whilst they were doing little procedures on him. Even when his lung collapsed and he had to have physio that was distressing enough to watch, let alone them making little incisions on him. I just had to keep telling myself that these doctors and nurses were doing whatever they could to make our son better and stronger!

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In Finch's second week he was transferred from NICU (Neonatal Intensive Care) to PICU (Paediatric Intensive Care) in the Evelina. NICU mainly had premature babies in whereas PICU was a children's Intensive Care ward - being in these units opened our eyes to a lot of things and we saw / heard some very distressing and upsetting things. Even the move wasn't an easy process, they had to call for a special team to come and move him as he was hooked up to a lot of machines and on lots of drips for medication. They moved Finch to PICU as I believe they were preparing us and Finch for surgery. The nurses and doctors were very more hands on in PICU and worked in a different way to NICU. As soon as he got onto the ward, they changed his intubation and shaved his head to put the IV lines and cannulas in his head. From that moment forward his saturation levels started to go up so they then said the next step was to gradually take him off the sedation and see how he comes round. Well that was it from that moment forward our boy improved every second of the day! He pulled through without having to have surgery, like we all thought he would have to.



Another week went by of further progress and we then got transferred to the high dependency ward - this was an amazing thing but unnerved and unsettled me. I had gone from someone sitting at the end of Finch's bed 24/7 to it being an open ward and there being 3 nurses to 6 children. This was the time for us as parents to become more hands on and start to have more involvement in the care of our children i.e. feeding them through the tube, giving them their medication, changing nappies without assistance (assistance beforehand was required because of all the wires and tubes etc.), picking them up and finally being able to have cuddles.

Once again, he showed signs of improvement every second of the day and we were eventually allowed to take him for a walk around the hospital in the pram, this was such a proud moment. Even if it was only around the hospital, our son was off all the wires and constant monitoring and we were free and able to enjoy him just us. Once we were able to do this then I knew it wouldn't be long before we were allowed home, and we were right.... a few days later we got discharged!

We've certainly got a fighter in our family! Finch has shown such strength and is stronger than I'll ever be!

Being a parent is one of the hardest things you'll ever do, but in exchange it teaches you the meaning of what love really is.

*We are and will forever be so thankful for the NHS and ECHO! If it wasn't for all their amazing teams us as a family wouldn't be the strong family we are today.*



If it wasn't for ECHO along with all our family and friends, we wouldn't have got through this hard time and remained as strong as we did. It really does make you realise life is too short – health, love, happiness, friends and family is all you really need as you do not know what is around the corner.

Our boy is now 19 months old and has brought happiness and love to our lives that we never knew existed. To look at him you would never know what he has been through and would never know that underneath it all he does have a heart that is working hard and getting stronger each and every day.

We are and will forever be so thankful for the NHS and ECHO! If it wasn't for all their amazing teams us as a family wouldn't be the strong family we are today.

ECHO are an amazing charity, they prepared us for exactly what to expect and like I said if it wasn't for the support of them along with friends and family then I truly believe we would have hit rock bottom.

To all at the ECHO team, you should be SO proud of yourselves! **THANK YOU!!!**