

## Eli's story

### *Lucy, a paediatric nurse and her partner Shaun from Salford share their story about their experience of their son, Eli, taking part in research at the Neonatal Intensive Care Unit (NICU).*

I found out I was pregnant at the end of 2016; and we (me and my partner Shaun) were over the moon. It was early March when I had my 20 week scan and we were so happy to find out we were having a healthy little boy. Seeing his movements on screen made everything feel real, we hadn't even thought about names yet.

One morning a few weeks later I woke up with pain in my stomach. At first I didn't think much of it and thought it was just cramps, so got ready to go to work and text my ward manager to say that I might be a little late in. As I started driving to work the pain got worse so to be on the safe side, I went to Saint Mary's Hospital just to reassure myself that everything was ok.

Once I got to the hospital I realised that something wasn't quite right and within an hour I was on the labour ward. One of the midwives rang Shaun and he rushed to the hospital, but not having had much information he was stunned to find me in labour when he arrived. The next 30 minutes went by in a blur, my labour was very quick and before we knew it Eli had been born.

At just 23 weeks and 6 days, Eli was very premature weighing only 730g. He needed specialist care immediately and was rushed to the Neonatal Intensive Care Unit (NICU). After two hours we were able to go and see him for the first time.

We felt so helpless, what should have been one of the happiest moments of our lives was marred by seeing Eli hooked up to so many machines and multiple tubes and wires on his tiny body. The staff at the unit were brilliant and kept us informed about his progress, but we knew we had a long journey ahead.

It was about a week after Eli was admitted to NICU that we were first approached about taking part in a research study. The midwife explained that the unit was part of a study investigating the best time to give blood platelet transfusions to babies with low platelet counts. As Eli needed a transfusion they asked if we would be interested in taking part in the study, but there was no pressure or expectation for us to do so.

*After speaking with Shaun, we both agreed that we wanted Eli to take part. If there was anything that we could do to help improve the care and understanding of premature babies, we wanted to help. With Eli being so poorly, being part of the study helped us feel we were contributing to helping babies in Eli's position in the future.*

Being a nurse I know that medical research is important to advancing care, and that without research the care Eli has received during his time at NICU might not have been available. That is why we decided that we would take part in a number of other studies whilst at NICU, to help as much as we could. Eli has been part of a study looking at immune systems of premature babies, one evaluating the different types of capillary tubes and one looking at the effectiveness of antibiotics in treating infections.

All the studies we took part in were linked in with Eli's standard clinical care, so if the research study needed a blood sample this would be done at the same time that Eli would normally have blood samples taken for his monitoring. This meant there were no added demands on Eli or us, which was all explained when the nurses took us through each study.

**If someone was in a similar position and were asked about research, I'd say give it a go. The research nurses are always on hand to talk you through anything you don't understand and answer any questions. In the future we plan to tell Eli about how he's helped doctors and nurses improve treatment for premature babies, and we hope it's something that he'll be really proud of.**