

Trust Board Paper D

Meeting Title	Trust board				
Date of the meeting:	13 th November 2025				
Title:	Patient story – Jacob’s Neonatal Journey				
Report presented by:	Julie Hogg, Group Chief Nurse				
Report written by:	Sharon Wilkinson, Senior Nurse patient Experience & Kerry Johnston, Head of Nursing				
Action – this paper is for:	Decision/Approval		Assurance		Update X
Where this report has been discussed previously	None				

To your knowledge, does the report provide assurance or mitigate any significant risks? If yes, please detail which
None

Impact assessment
N/A

Purpose of the Report

Shared by Emma Rawlings, Jacob’s mum from Northamptonshire

Jacob was born at 25 weeks and 1 day on Easter Sunday 2024 after several scans revealed growth restriction. His birth weight was just 11b 2oz.

Before Jacob’s arrival, Emma and her husband Adam were given a tour of the neonatal unit, which Emma described as “brilliant,” though nothing could truly prepare them for life as neonatal parents.

Emma likens their experience to riding a “Neonatal Wave,” full of highs and lows. During his short life, Jacob underwent numerous interventions, including ventilation, multiple lines, infection treatments, and blood transfusions. As parents, Emma and Adam faced difficult decisions, weighing the risks and benefits of each treatment.

Emma speaks warmly of the staff, describing them as “almost like family,” with nurses often staying beyond their shifts to support babies. Doctors and nurses shared a common goal—giving every baby the best chance. Yet, Emma also reflects on how traumatic the experience can be, as circumstances can change so quickly.

Jacob’s condition improved enough for transfer to a Level 2 unit closer to home, but sadly, he deteriorated and had to return to Leicester for further intensive care.

Emma highlights the support available for parents, including an excellent counselling service and a parents’ room where families can share both pain and joy. She also mentions practical facilities such

as the milk store, noting how she helped orientate other parents because nurses were so busy caring for babies.

Emma concludes: “Amongst all the pain, there are moments of joy.”

Actions Taken on the Unit

- Virtual Tours: Developed for Leicester Neonatal Units, accessible via the Health for Under 5s website for parents unable to visit in person.
- Improved Facilities: Breastfeeding rooms on each site have been upgraded and redecorated.
- Equipment Availability: Additional breast pumps purchased and donated; loan process streamlined.
- Milk Storage: Expressed breast milk now stored in milk-safe boxes in fridges within each room for easier access.
- Parent Orientation: All parents receive a full orientation on their first visit; information in parent rooms has been enhanced.

Recommendations

The Trust Board is asked to:

- Listen to Jacob’s neonatal journey and reflect on the experiences shared.
- Participate in any discussions arising from the story, considering how these insights can inform improvements in care and family support.