

Parent letter of support, written by members of the parent advisory group for the
COLLABORATE Study.

22 May 2025,

Dear Healthcare Professionals,

As parents of preterm babies, we know first-hand the worry, stress, and emotions that come with caring for a tiny, vulnerable baby. In those first days and weeks, we relied on healthcare professionals to guide us and help us make the best decisions possible, often in situations filled with uncertainty.

The COLLABORATE trial is designed to answer important questions that directly affect the care and outcomes of babies like ours, specifically around how best to feed preterm babies when there is not enough breastmilk from the mother. We understand there are strong opinions and emotions around donor milk, formula, and fortifiers. It is confusing and anxiety provoking to know that feeding practices are not evidence based and that practises vary across the country. We want evidence about which approach is safest or best for our babies' long-term health.

Some concerns have been raised about whether parents can make informed decisions about taking part in research like this. We respectfully disagree. With clear, honest, and compassionate communication, we believe parents are perfectly capable of making thoughtful choices about their baby's care, including whether to join a study.

We are concerned by reports that some staff may be discouraging participation or limiting access to information about the study. We believe this denies families the opportunity to make their own decisions and risks reinforcing inconsistency in care. That's why we support the COLLABORATE study.

We want to be part of improving neonatal care, not just for our children, but for future babies and families. We urge you to support the COLLABORATE study, to share information openly with all parents, and to trust us to make informed choices.

Kind regards,

A handwritten signature in black ink, appearing to be 'Curie Freeborn', written in a cursive style.

Curie Freeborn on behalf Ellie, Edvige, Rebecca, Curie, Kirsten, and Fiona from
COLLABORATE's Parent Advisory Group.

Voices from Parents:

“My twins were born at 24 weeks and my son passed away at 8 days. My daughter weighed 500g at both and was still only 700g 6 weeks later – growing her in order to grow her lungs was of the utmost importance. I was shocked and un-nerved by the clear lack of consensus on how to achieve this. I was producing enough milk but when fortifier was suggested as well, nobody was able to tell me whether or not this would be for the best – that unknown added significantly to my anxiety and kept me awake at night. If the experienced medics didn’t know, how could I be expected to make a decision? I was terrified of making the wrong choice. Please please please buy into this study – it is so overdue. Why, when there is the opportunity to find out what works best wouldn’t you take it? The answer to these questions is so important and within reach.” (Mother of preterm born twins)

“I’m really sad that staff are discouraging people in such a way”. (Adult born at 26 weeks)

“Day after day we are present at our child’s cot side, and work in a collaborative manner with staff. We partake in dialogue during ward rounds and think long and hard about what is presented. This is modern NICU life. Moreover, in 2025, parents demand and deserve total transparency from medical staff. It is not acceptable to obfuscate clinical research and findings in a way that is possibly to the detriment of our children and their futures.” Parent of a baby born at 24 weeks in 2023

“It’s confusing and anxiety-provoking to know that feeding practices are not evidence-based, and that even within the same unit, healthcare professionals sometimes have different opinions about them. We understand that if a healthcare professional strongly believes a certain type of feeding is not optimal for their patients, it can feel quite nerve-racking to introduce it in their unit. But the point is, this belief isn’t currently supported by evidence. We should aim to resolve this uncertainty” Parent of a baby born at 26 weeks, Year 2016.

“My Mum was given no information or choice and was just given formula for me when she was able to feed me. She and I support this study as she wished to have all the information and options given to her but she was felt that they were taken away unnecessarily.” Adult born preterm