

# The Emily Harris Foundation: ensuring a legacy continues at King's Mill Hospital



**Clare Harris** Emily's Mum and Foundation Manager for the Emily Harris Foundation

**F**inding out you are pregnant is one of the most exciting times for a parent-to-be. The expectation is that all will be well – 40 weeks of pregnancy followed by a birth just as you described it in your birth plan. Imagine giving birth four, five or even 14 weeks before you were expecting to or giving birth to a term baby who is ill. A whirlwind of fear, stress and uncertainty; emotions all over the place, no idea what is happening. Your baby is taken to the neonatal unit before you get to see it and here begins the journey of a family whose baby begins life in neonatal care.

For us, we had the advantage of knowing that Emily would be ill at birth, which gave us the chance to visit the neonatal unit at Queen's Medical Centre (QMC), Nottingham, where she was born. Emily was progressing better than expected a week after her birth and we were told we were being transferred back to our local unit at King's Mill Hospital in Mansfield. This set me back to those first anxious moments – I'd spent a week learning how to tube feed, change a nappy with my arms through the holes of an incubator (I've never been able to change a nappy without the baby sideways since) and I was confident in the care she was receiving.

Despite our protests, we were whisked back to Mansfield and arrived at what was then the neonatal unit and is now a car park. The run-down look of the place made us wish we were back at the QMC; how wrong we were. Arriving in an emotional state and leaking breast milk, I was taken to the expression room while Emily was settled into her cubicle. I couldn't get the breast pumps to work – they were different to the ones at the QMC – and it felt as if things couldn't get any worse. At this point, I was approached by two nurses who exclaimed: "Are you Mr Harris' wife; he teaches our sons?" With a boob hanging out and in floods of tears, the appropriate response was to laugh!

Emily spent 12 weeks on the unit before moving to Birmingham Children's Hospital, back to the children's ward at King's Mill and then home for three weeks over Christmas. We received the best care we could from all the staff but unfortunately Emily picked up an infection and despite fighting in intensive care at Leeds General Infirmary for four weeks, she passed away on 1 February 2007.

We were so grateful for the care given to us throughout our journey that we wanted to do something to show our appreciation following Emily's death. We spoke with staff on the unit to see if there was a way we could offer ongoing support and from those discussions the Emily Harris Foundation was launched on 5 September 2008, which would have been Emily's second birthday.

The objectives of the charity as set out in our constitution are:

1. To provide financial support for King's Mill Hospital neonatal

unit staff members who wish to undertake further training but have no funding from the NHS.

2. To provide financial relief in cases of hardship for families with babies receiving care on the neonatal unit.

In practice, this means very many different things. Over the years we have developed ways of offering regular support as well as funding one-off provisions. The following gives a flavour of what we have done and what we continue to do in Emily's name.

## Regular support for parents

All families who arrive on the unit are provided with a welcome pack containing a packet of nappies, a blanket, bibs, cotton wool, a scented heart and a diary in which to record their baby's milestones. Staff often tell us how great it is to be able to hand something so practical to a parent who is feeling incredibly stressed. Any parents who are travelling to the hospital to visit their baby via bus will also be offered transport tokens that cover the cost of their journeys for as long as they are in the unit. It is vitally important that parents remember to look after themselves, especially a breastfeeding mother, and the Emily Harris Foundation provides vouchers for lunch in the hospital café as well as vouchers for parents to go for a meal at the local pub if they have been on the unit for a few days.



Welcome packs given to families arriving on the unit.

In order to make the unit more comfortable for families, we have contributed to the refurbishment of the flats, providing new crockery, cutlery, kitchen equipment and furniture. To date, we have also provided seven nursing chairs within the unit bays and are in the process of ordering five more. We receive many positive comments about how amazing these chairs are, allowing parents to cuddle their baby in comfort. Staff tells us when they move a baby they are invariably told by the parents that the chair must come too.

### Support for staff training

One of the first things the foundation funded pertaining to staff development was to pay for a consultant and a nurse to visit a neonatal unit in Uppsala, Sweden, in 2011. This gave them an insight into the use of kangaroo care and its benefits for babies and parents. The feedback we received from this trip was wonderful and from that a number of initiatives were introduced to the unit in King's Mill. Kangaroo care is now regarded as a normal part of everyday life in the unit and the staff recognise the impact this has. We have funded staff to attend annual neonatal conferences, including the two-day REaSoN meeting, all of which have been met with positive feedback and changes to practice. We also provide every member of the nursing staff with a book, *Pocket Neonatology*; to date we have provided over 50 of these books and again, the nursing staff are incredibly grateful as the book aids their practice.

In 2013, we were approached by the infant feeding co-ordinator at King's Mill who wished to undertake a trial on the use of donor breast milk on the unit. The foundation agreed to fund this trial to enable parents to have a wider choice around feeding their baby. As a result of the positive outcome the use of donor breast milk, funded by the NHS, was introduced to the unit.

### Number crunching

Since we launched the charity in 2008 we have raised more than £100,000. This milestone was celebrated at the hospital in August. Since September 2014 (when we first began keeping records) up until the end of June 2017, we have provided:

- 496 welcome packs (276 for boys and 220 for girls)
- 217 meal vouchers for the local pub
- 364 sets of transport tokens for local buses.

### Feedback

We are always delighted to hear back from families who have found our support beneficial to them. It is also great to receive feedback from staff regarding the courses they have attended and how their learning has gone on to benefit the unit. These are just a few of the comments we have received over the years:

*"I just want to say a huge thank you for making it possible for me to attend the REaSoN conference. It was such an incredible learning experience, it was just amazing. I am so grateful and I have some great family-centred care ideas for the unit. And also a big thank you for my neonatology book. Saying thank you does not seem enough."*

*"These [nursing] chairs were amazing – so comfortable for cuddling babies and big enough so I could hold both my babies at the same time."*

*"Thank you for the great work you have been doing for our neonatal unit over several years now. Many families on our unit have*



The Chair of Sherwood Forest Hospitals NHS Trust, John MacDonald, presents a certificate of appreciation to the Emily Harris Foundation for raising £100,000 for King's Mill neonatal unit.

*benefited a lot with your continuing support and they do appreciate it. Very grateful to you."*

*"I loved those [wax] melts – that moment I opened my bag and was greeted by a beautiful baby smell – wonderful touch."*

*"It [arriving on the unit] was such a whirlwind we really appreciated your pack, it was so kind. The diary gave me something positive to do rather than biting my nails."*

*"The welcome pack we got with my daughter was a life-saver especially the nappies because it's really not something you think about when your baby's lying in an incubator, so thank you so much for taking some of the pressure off."*

### What does the future hold?

The Emily Harris Foundation is now heading into its tenth year of working with the neonatal unit and things are going strong. We are in the process of funding a counselling service on the unit and are looking to begin a coffee morning to enable me, as Foundation Manager, to meet parents and chat about their experiences. We don't know what the future will hold but while we continue to have fantastic people willing to raise money for us and while the unit continues to need and value our support, we will continue to do everything we can to make life a little easier for parents and staff and ensure Emily's legacy carries on.

For more information about the Emily Harris Foundation visit:

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