



NORTH LINCOLNSHIRE
CHILDREN'S
LITERACY TRUST

Neonatal Book Gifting Scheme

Brought to you by the North Lincolnshire Children's Literacy Trust, with support from Words Count and Scunthorpe General Hospital NICU

Erin's Story

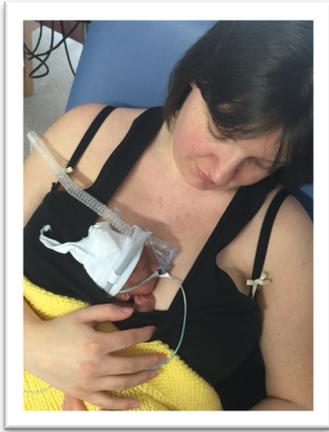
In the words of Erin's mum Katie Taylor

Erin was born at Scunthorpe General Hospital at 28 weeks and 3 days into my pregnancy by emergency C- Section, this was due to pre-eclampsia. I was in and out of hospital for approx. 4 weeks before my blood pressure was made stable and during this period Erin was growing and developing as she should. I wasn't expecting to have my baby delivered this early I had an indication I might not go the full 40 weeks but never expected to have my daughter at 28 weeks. I was unsure how she would look, how developed her features would be and if she was going to have any long term health or learning difficulties just that if she wasn't delivered it was certain that I would lose her.



Erin weighed 801 grams at birth but this was with her breathing tubes attached, I was informed that 800 grams was the cut off weight that Scunthorpe General Hospital were allowed to care for premature babies, so I was pleased that Erin was able to stay in our local hospital. That's 1lb 12oz, Erin did cry (well sort of, but she didn't really sound like a baby.) Soon she started struggling to breathe on her own and so she was whisked off to be fixed up to some breathing equipment. I didn't get to see her when she was born, but I did instruct dad to leave me on the operating table and go with her. Dad wasn't able to see Erin for a few hours until she had been settled in on Neonatal Intensive Care (NICU) and I was stitched back up and put in recovery all the time being congratulated on the birth on my daughter.

As you can imagine this was heart breaking, as I didn't know how poorly Erin was or if indeed she would survive. I was taken onto the maternity ward and luckily it wasn't busy, so I was put in an area where there were no other mothers and babies. I remember being given a photo (Polaroid) of Erin and I was given regular updates on how she was doing.



When Erin had been on the breathing ventilator for 48 hours and showed no sign that she would be coming off it any time soon she had to be transferred to another hospital, one that was more equipped to care for her. Erin was moved to Jessop hospital in Sheffield and when she arrived she was put on a different type of ventilator called the oscillation ventilator (this looks like your baby is being shaken as it vibrates.) I wasn't allowed to go in the special ambulance with Erin and at the point that Erin had been transferred I was still under the care of the midwives at Scunthorpe, luckily they were able to get me a bed at the maternity ward in Sheffield and I was transferred later that day. Erin arrived at Jessop's around 11am and I arrived around 6pm.

Erin slowly improved fighting off infections and after just over 2 weeks in Jessop hospital we were allowed to be transferred back to Scunthorpe General Hospital, where we could be nearer our family.

Erin was 9 days old before I was able to cuddle/hold her and this isn't like when you hold your newborn child, Erin was on breathing equipment called C PAP and hooked up to monitors and it was like breaking out of prison for her I'm sure. It took two nurses and some very good organising from the staff to move her. I was only able to put her down my top and her body temp and stats had to be closely monitored, but it was one of the best feelings in my life!

Morgan and daddy only looked and put their hands in the incubator to get any contact with Erin. Myself and dad were able to change nappies, but these were only being done every 12 hours and again had to be done through the hatches in the incubator and had to be done with sterile water. The nappies had to be weighed and all bowel movements were recorded, all contact with Erin was precious and talking to her helped her know we were there. Erin was 14 days old before she was able to tolerate milk, and then we are talking 5mls upwards. She was also given TPN (total parent nutrition) in her tummy (through her cord) and then moved into a vein in the foot to try and avoid infection. This continued until her feeding was established and when I say established I mean put in a feeding tube, through her mouth or up her nose and that tube then went directly into her tummy.

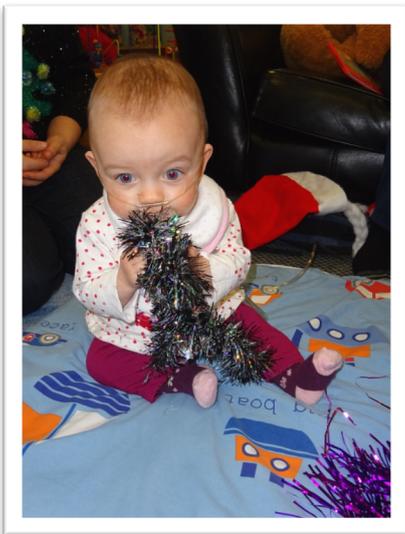
This time wasn't just difficult for my husband and myself but for her big sister Morgan as well. I remember Morgan going to see Erin for the first time (with dad as I was on strict bed rest and just had my operation) and she described it to my mother. Morgan said to her *"Gran I have a baby sister and she is this small, she has to live in a plastic box until she is big enough to come home"* and to this day I still think that is one of the best ways to describe Erin and the whole situation.

It was hard as I felt guilty for not spending time with Morgan but I didn't want to leave Erin in the hospital, as I knew how important it was for her care and development to be near me and be able to hear my voice as after all she should have still been growing and developing inside me hearing my heart beating and muffled voices. We decided that what we needed was to read in the hospital all together (Erin, Morgan, daddy and myself.) This was actively

encouraged by the staff on the neonatal ward and at times Morgan would colour in (for a 3 year old staying at the hospital all day was not their idea of fun!)

We went to the shops to look for an appropriate book and found **Guess how much I love You**, I had never heard of the story of big and little Nutbrown hare, but instantly loved it and decided that this was the book for us. Erin would come out of her incubator and have cuddles with mummy every day and on one occasion Morgan had asked if she could have a sister cuddle! Erin was doing well and so the nurses helped get her out of her incubator and put cushions on Morgan's knees and wrapped Erin up so she would stay warm and we sat together and read our story **Guess how much I love you**. It was truly a magical moment in my life with my two previous daughters...one that will stay with me forever!

After 12 long weeks in NICU we were able to bring Erin home, she would have been due three days prior to us leaving and weighed 5lb 5oz at exactly 12 weeks old, however our journey didn't stop there. Erin still wasn't able to breath on her own and required several different types of medication. I had to have some training on how to inject Erin with a special medicine should she require it, she had vitamin K, D and E supplements, multi vitamins and a phosphate medication that had to be dispensed by the hospital on a weekly basis and kept in the fridge. Along with home oxygen that Erin had to be connected to 24/7. This meant we had to have the fire station come out to the house to check that it was safe to store oxygen cylinders, we had to have the oxygen come and install the cylinders and give me training on how to use them. I had to practice changing Erin's nasal cannula on her face, as these had to be secured down, so she didn't pull them out of her nose and therefore not receiving the oxygen she required. I had to disconnect Erin from the main cylinders to the portable ones if we wanted to go out or if I wanted to bath Erin.

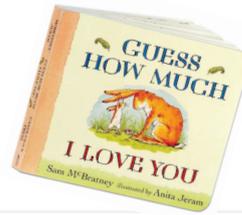


These were normal everyday tasks that required a lot more planning from me. However I was determined not to let the oxygen put me off doing this, granted I was very careful to avoid crowded and public places due to the germs as Erin had a very weak immune system (the baby gets a lot of its immune system from the mum via the placenta during the last trimester of

pregnancy and Erin was born just into this trimester as she was 12 weeks early so didn't get any from me.) I made calculated risks and always made an effort to take Erin to the premature support group that was on every 2 weeks, as I was able to meet other mums in similar situations to mine and luckily they also put on baby massage and wiggle and giggle groups. This helped Erin in her development and I didn't feel as though people would look or ask questions about her tubes (oxygen).

Erin continued on home oxygen from June 15 to April 16 and we haven't had to have any help with breathing since. As a safety precaution it was left in the house until July 16 in case Erin caught a cold or got poorly as it isn't uncommon for babies to relapse. We went on our first family break in Oct 15 and had to arrange for the oxygen to be put in our hotel room and portable oxygen cylinders to be delivered to the hotel but we managed and this year we are returning to the same hotel but without the oxygen and we can't wait!

Guess How Much I Love You...



Whilst Erin was in NICU we frequently read her the story *Guess How Much I love you*. We found reading was a fantastic way to talk to Erin so she could bond and build relationships with us as well as start to recognise our voices. Her older sister Morgan really enjoyed sharing the story with her whilst we spent a significant time on NICU.



The tale of the Nutbrown Hares competing to measure their love for one another, and Big Nutbrown Hare's heartwarming declaration to Little Nutbrown Hare, "I Love you right up to the moon and back", has helped this story become a way of saying I love you all over the world.

The Neonatal Book Gifting Scheme - This pioneering initiative which has been successfully rolled out in Middlesbrough and Bradford Hospitals with the support of the National Literacy Trust, aims to highlight the importance of communicating and reading with babies, as studies show that sharing stories and rhymes with babies from an early age helps families to bond. Hearing their parents or siblings telling stories or singing support a baby's wellbeing, let's them get to know their voice and stimulates their brain development. Many parents feel that reading, singing, talking and recording their voices helps the parents and other family members such as siblings, feel like they have something meaningful to do which will support their babies development whilst they are in hospital.

Parents whose babies are being cared for on neonatal units are given carefully selected book packs, which include a quality copy of the award winning book ***Guess How Much I love You***. Parents will also be given information from trained volunteers and be provided with leaflets, support and resources which explain the importance and benefits of reading and singing to their baby.

The North Lincolnshire scheme will be a standalone scheme and therefore we can add a more localised personal touch, which will include an additional resource in the form of our **'Singing Together'** songs and song words booklet. This carefully put together song list includes familiar songs and rhymes which parents and staff can sing to their babies.

What the research Says... **It's bonding time!**

A recent study in the Journal of Development and Behavioural Paediatrics found that reading to babies in NICU can help parents develop the same feelings of intimacy that parents of healthy new-borns cultivate in the days and weeks after a baby's birth. The study also found that it helps parents to feel more in control of their situation and promotes future reading. By providing a meaningful noise (voice) they recognise, will also help them to practise listening and develop language skills they need.

For more information about how this scheme has worked in other authorities you can view details of the Middleborough scheme by visiting the link provided below. The Middleborough scheme was shortlisted for a Charity Times Ward.

http://www.literacytrust.org.uk/news/7300_middlesbrough_hub_shortlisted_for_charity_times_award

There is also published information about the Bradford Scheme, which can be found via www.ourstories.org.uk/node/94

The gifted book pack - Our packs will include:

- Hard Back Copy of Guess How Much I love You by Sam McBratney
- Singing Together Song Booklet
- Singing Together CD or Downloadable Songs
- Gift Bag
- Practical guidance, leaflets and resources i.e. Wiggle and Giggle Baby Play Booklet

In addition to the above, North Lincolnshire Council Education Officers will provide staff and volunteers with training, ensuring that families receive the best guidance and support when they receive their gift pack.

Funding – In the first instance we would love to provide a year’s worth of book gifting packs this would be approximately 600 packs, at a cost of £5 per pack this would be roughly **£3000 a year.**

To date we have submitted four bids for funding to support this project, which we are waiting to hear a response from, these, are:

- 1) Ongo Community Grants Fund
- 2) NHS/Trust Ward Charitable Funds
- 3) Rotary Club Lunch Time Group
- 4) British Steel

If this pilot is successful we hope to continue to raise additional funds, so that we can look to continue this scheme into the foreseeable future and support more babies and families – just like Erin’s.



Thanks you for taking time to read Erin’s story and how we can all make a difference.

For further information please contact aisla.leggott@northlincs.gov.uk, alternatively call Ailsa on 07717586411

