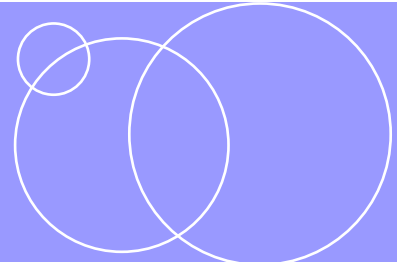




Parent Stories



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This book brings together stories written by parents of babies who have had a neonatal stay in the East of England, with the aim of bringing some hope, comfort and reassurance to those families with babies currently in NICU.

The stories are all from neonatal journeys that took place before the COVID-19 pandemic. The parents whose stories feature in this book would like to share the following message with you:

“We understand the many challenges that a neonatal stay can present and what an emotional rollercoaster the NICU journey can be, but we cannot begin to imagine how devastating it must be to experience all those things during a pandemic. We would like to send strength, love, courage and solidarity to all those families with babies on neonatal units during these heartbreakingly difficult times.”

The East of England Neonatal ODN would like to thank all of the families who have generously shared their stories in this booklet.

The East of England Operational Delivery Network (ODN) is a network of 17 neonatal units and ANTS (Acute Neonatal Transport Service) who work closely together to provide the best care possible for babies who require specialist neonatal services in this region.

www.networks.nhs.uk/nhs-networks/eoe-neonatal-odn/parents-and-carers

Twitter & Facebook: @EoEneonatalODN

There goes my heart

By Anthea Davis Barclay

There you lay, miniature and perfect;
I had not expected our first meeting to be like this;
Separated by: many hours, cables, breathing tubes, monitors, heart-shaped stickers and a heated plastic box.

But as you rested,
Unaware of my presence,
My heart skipped a beat and I knew,
There lay my heart.

The birthing cocktail of drugs and hormones surged through my body;
But this new-found feeling could not be anaesthetised or medicated.

We marvelled at how you were perfectly formed;
Just miniature.

You—
Tangible evidence of our hopes and dreams.

On occasion, when circumstances kept us apart for many hours,
I would sanitise my hands and skip through the wards,
Like a mountain gazelle:
Sure-footed, purposeful, swift.
As I pushed open the door and saw you,
I would feel a rush of endorphins, while barely holding back the tears;
For to touch you *is* to exhale and to hold you *is* to breathe again.

The smallest nappies reached under your armpits,
As if you were clad in borrowed armour.
Darling, we were in a war;
I had no idea how long or fierce the battle would be;
Blood would be spilt in blood tests, cannulas, long-lines, injections, heel pricks,
And then more cannulas;
The battleground spanning three hospitals.

I wished you well, over well-used breast pumps;
Every golden drop of milk was my gift to you.
Longing for the dream of nursing you;
Your warm fluttering lips and delicate baby-breath on my breasts.



Many years from now,
When you will not accept my most ardent kisses so readily,
I will tell you again of these battles,
Show you pictures of:
The nurses.
Those front-line soldiers,
Who many times, went beyond their call of duty and scooped me up in their knowing arms and dried my tears,
When I was too battle-worn to even think of tomorrow.

Doctors, like Generals, reviewed the days progress,
And explained the battle plans.

I will scan through pictures of a barely recognisable you:
Tiny, translucent, tremendous.
I will point out hospitals where our battles were fought,
And convey what happened with strained emotion.
You, may glance at me over your latest tech device,
With little reaction and glazed eyes but smile sweetly.

For, thankfully my dear,
Although the battle beleaguered flag bore your name,
And you are now well,

So You will not remember this first war.
well,

But my heart will.

Yet, life is more than its dawn and there will be many future wars to wage.

So just know:
Wherever you are,
Whenever you may wander,
If ever you are in need,

There goes my heart.

There goes my heart.

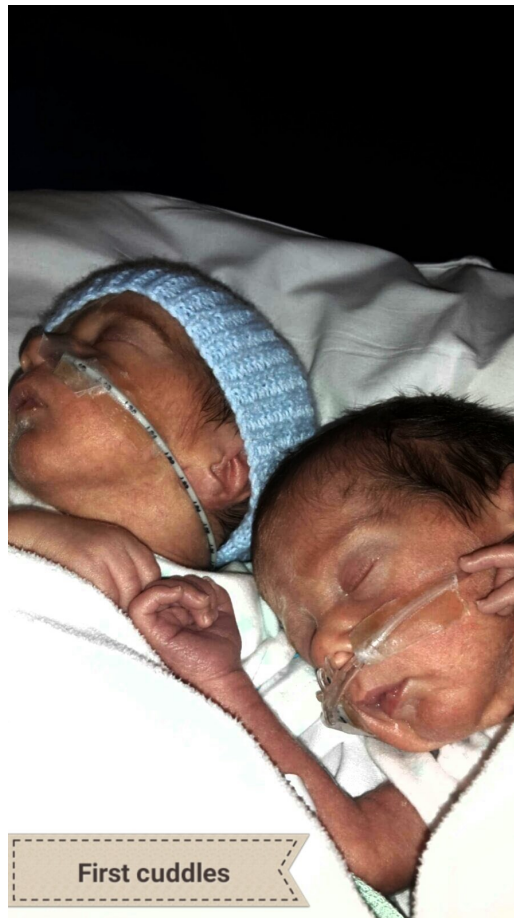
There goes my heart.



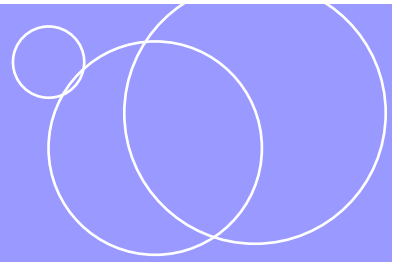
Dedicated to my sons: Elijah and Josiah and all the NHS staff who helped them on their journey to wellness.

Alex & James

My twins were born at 29 weeks and 4 days following a high risk scary pregnancy, numerous stays in hospital due to PPRM and after being discharged from the Homerton after 4 weeks. The twins, delivered by C-section were taken straight to NICU and both intubated. I sadly didn't get to see them until the next day as I need to be monitored. Later that day James was struggling and was taken to the NICU by the ANTs team with suspected NEC. Alex continued to improve, moving onto CPAP. After lots of tests and antibiotics James joined his brother after 10 days and they continued to improve together, gaining weight, learning to feed and gradually breathing unaided.



Alex & James



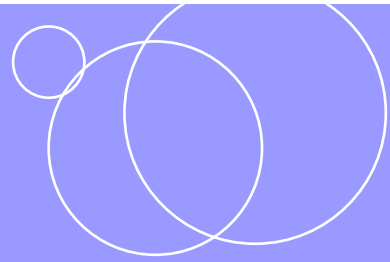
After 7 weeks we got home. We did have a nasty hiccup. After they were discharged they both got bronchiolitis following a cold. Unfortunately they both ended up in intensive care on life support, which was probably the worst time of our lives as we nearly lost one of them.



Anyway, on a positive note the boys are now three and a half and are amazing. They are extremely hard work but they are gorgeous and what we have all been through together has made us stronger and more appreciative of life.



Heath



Heath the Legend

I guess I want to start by saying I wish I knew then what I know now.

I wish I'd known that the fragile little dot in front of me, that arrived so unexpectedly, was a lot more resilient and stronger than we could have possibly imagined. I want to share my journey with you, as his mum, but first I want you to know that you will cope, because there isn't another option.

I really want you to know that you are not on your own and you are not a failure as a parent just because you are feeling completely terrified right now. It really is ok to be totally overwhelmed by the feeling that no one really understands the rollercoaster that you are on. Because they don't.

Back in early October 2015 I met *the* most legendary tiny human that I could ever have imagined. We weren't actually meant to meet until late December.

At 38 I was a fit and healthy excited mum-to-be. We were lucky enough to have had an uncomplicated, quick conception and 'normal' pregnancy. The thought of having a premature baby was so far off my radar that when my waters broke at 30 weeks I didn't really notice - went back to bed for a few hours, just thought I was a bit sweaty! Later that night I knew I wasn't quite right, so decided to go to Lister Hospital for a check up. We left six weeks later with a baby who wasn't due for another month.

When I think back, or try and describe what happened next, it was a bit like being in a trance – or like I was watching this happen to someone else. It was confirmed that my waters had broken but no labour. The 'plan' was to keep me on bed rest until I got to 34 weeks.

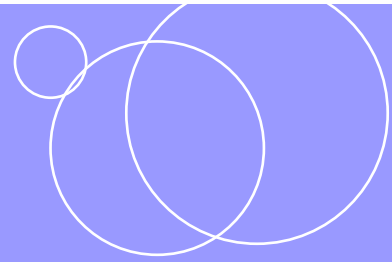
Both mine and my baby's heart rate were being monitored more or less constantly for 24 hours – and then it happened, it felt like slow motion – a nurse hit a red button on the wall and everybody started running, with me on the bed. I can still see the fear on my husband's face – him running behind the trolley, bewildered. The consultant just said 'get the baby out' – as simple as that. And that was it – the best and worst day of my life.

Heath was born, at 8.59am, code red C-section, no labour, 3lb 2oz, breathing on his own. I couldn't hold him, obviously, but I heard him cry and that was the best noise I've ever heard. The NICU team took him away and I had toast and jam and tea. I felt elated!

And then I felt numb.



Heath



I couldn't get warm after the section so it was some time before I could see him – the kindest midwife wheeled me down on my bed to see him in ITU. You shouldn't have to meet your baby for the first time through the side of plastic box. He looked so...I'm not sure I can describe it...delicate, unreal?

We spent the night on the ward – me on the bed not being able to sit up, my husband who was equally as exhausted, sleeping upright in a chair – while, what seemed like, everybody else had a crying baby accompanied by masses of cooing family and balloons.

Being a preemie mum gives you a strength that you never knew you had – and every 4 hours, throughout that night, between us (my husband and I) we methodically tried to get some milk out. I managed 0.4ml on the first night.

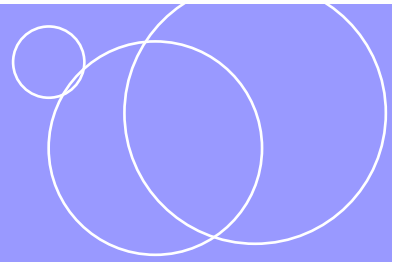
The next day we had our first ward round – I still hadn't showered and was relying on my husband for almost everything. I felt pretty low. Apparently every baby born under 32 weeks gestation gets a brain scan. Heath's wasn't good – he had a 'brightness' on his brain, *'which is evidence of bleed. It's on the area that operates his arms and legs'*. I'd never seen my husband cry before.

We did our best to do our best. A nurse told me *'Mummy, you are no good to him like this. Get some rest'* – so I vowed to look after myself, for Heath. I ate well (brain food), I drank soooooo much fluid and I slept (when my head let me). I had to stay well too.

We were so fortunate to have a preemie who, on the face of it, was well – he could breathe by himself, he was putting on weight, he took all his milk - my milk, he wasn't jaundice – he had the odd 'brady' but the coffee sorted him out. But there was this colossal shadow hanging over us – we had weekly brain scans, some showed improvement, some said no change, some said it was subjective to the person reading the scan. We had to wait until he was discharged to get an MRI to understand the true impact of the bleed.

We did the *cares* and I sat with him on my bare chest for hours – my husband said I'd dent his head with all the kisses I gave him! I read to him, anything I could find, to try and stimulate his damaged brain - I felt so self conscious and stupid (please don't feel stupid, do it – read to your baby). I asked and asked and asked until I understood what I needed to understand and I sought comfort in places I would never have dreamed of – I'm not religious, never have been but the hospital Chaplain let me have a 'hope' which the medical professionals did not allow. It's also ok to laugh in the unit – please don't feel guilty about that.

Heath



Weirdly those six weeks felt so long at the time yet now it feels like an instant. They taught me how fragile life is and how strong human resolve can be. I'm writing this right now with an incredible four year old legend sleeping next to me, who has taught me so much. This is what I would like to pass on:

1. Surround yourself with people who have experienced the same situation as you. No one else will understand. That can be in the unit, Facebook, Bliss etc. etc.
2. Take one day at a time
3. You're going through a trauma. Speak to someone professional. It took me 3 years – and helped so much.
4. You will cope.

Love Kate xx



Leo

We struggled for over 5 years to get pregnant but eventually did via IVF in 2017. Leo was a twin until around 13 weeks when, unfortunately, his sibling did not make it. We were high risk because of this from the beginning. At 25 weeks, at a growth scan, it was picked up that Leo's femur length was much shorter than it should have been. After being referred to foetal medicine we had a scan at 28 weeks where they confirmed that Leo had a placenta restriction causing his growth to slow. Due to poor movement and an even worse monitoring trace I was given steroids and told he would be coming that night.

The monitoring and movements improved and I was put on bedrest in hospital until Leo was born at 29+5 weighing a tiny 2lbs. Leo struggled to breath and turned blue, so was immediately put on ventilation, lines in everywhere – it was somewhat expected as we had some time to prepare for Leo being premature, however it was still a shock to see him like that for the first time.



Leo

Leo suffered a brain bleed, several bouts of jaundice, sepsis, multiple blood transfusions and had severe PDA. He had very under developed lungs, made worse by the amount of blood the PDA was letting into his lungs. Over the weeks he moved from ventilation, to MPAP, then CPAP & eventually VaporTherm. Leo also contracted MRSA while in neonatal care and was moved to isolation which was very tough for us all but after two weeks we were allowed back out into the main units.

One of the other huge struggles for Leo was his weight gain; he would go days and put on no, or minimal, weight. We attempted breastfeeding which did not work out for Leo and getting him to drink from a bottle was also really difficult. He suffered with reflux in addition so often vomited or was in discomfort after feeds.



We bought Leo home 14th Feb 2018, his due date. He came home on 0.9ltrs of oxygen which was terrifying for us. After being in the hospital for so long you start to fear coming home, especially with an oxygen tank and being solely responsible. However, we quickly adjusted to life at home, we used the saturation monitor (that I thought I would never ever take off) for a couple of days and at night but that was it. Within 6 weeks Leo was almost fully weaned off oxygen in the day, we started our first baby group and small outings and I finally felt like I was a mum to a 'normal' little baby.

Leo is now 3 years old, he is still very small and has his PDA which is still under review, however he is thriving and is a happy, cheeky little toddler! It is an experience that will shape myself, my husband and our families forever – but we are so proud of our miracle.



The header features a solid purple background. On the left, the name 'Remi' is written in a large, light blue, sans-serif font with a thin white outline. To the right of the name, there are three white-outlined circles of varying sizes that overlap each other.

Remi was born at 28 weeks in December 2015, just a few days after Christmas. I was loving being pregnant, especially as it had taken a long time to conceive. I felt happy and healthy and at my midwife appointment just a week earlier everything appeared fine with baby, so it was a complete shock when I went into spontaneous labour 12 weeks early. We were in Suffolk visiting my Dad at the time, and I had woken that morning with a weird, uncomfortable feeling and baby was lying in a strange position. Throughout the day the weird feeling became painful cramps. I called my local maternity unit who advised going to the nearest hospital to get checked. On arrival they initially suspected a urine infection but after examination they found me to be 2cm dilated with bulging membranes and confirmed I was in labour.

I was given drugs to try and stop the contractions but they had no effect; my labour was too far progressed. Due to the baby's gestation, I needed to be transferred to a nearby hospital with a higher level NICU. As we waited to secure both a bed for me and a cot on the neonatal unit, my labour intensified. By the time beds for both of us were confirmed, and the ambulance arrived to transfer, it was no longer safe for me to travel; I was 7cm dilated, baby was transverse and his heart rate was increasingly difficult to trace. The baby needed to be delivered as soon as possible. I went straight to theatre for a C-section - the total opposite of my planned water birth.

Our baby was born at 11.40pm and was taken straight to resuscitation, just a few metres away but out of sight. I looked up into the eyes of my husband, the only words I could utter were – "Is it alive?" After a few minutes the answer came "Yes, it is alive. And it is a little boy." They took me to recovery as our son was stabilised and taken to the neonatal ward.

Later that night, I sat wide awake feeling totally lost with a deep sense of something missing – no longer with a baby inside me but no baby in my arms either. A Maternity Care Assistant arrived and asked if I would like her help to start hand expressing. I will forever value the time she dedicated to me in those early hours; careful encouragement, instructions of how to softly massage my breasts, a tiny syringe held up to them, willing them into action. As a few precious little drops of milk arrived I allowed myself to feel hopeful; perhaps my body hadn't completely failed my baby – we may be separated for now but at least he would be able to have my milk.

The next morning I met Remi for the first time. He was a tiny 1.2kg. We got to hold him very briefly and as I looked down into my arms, I could barely see him amongst all the cables. Soon after, they transferred him to the tertiary unit (a cot available for him but no bed for me) and I followed a painstaking 12 hours later.

The following morning at ward round we met his wonderful consultant. She said that whilst Remi was stable his swollen tummy was concerning. She requested another ultrasound which showed a perforated bowel. They needed to operate the next day – New Year's Day. The surgeon came to meet us. He gently gave us the statistics of the laparotomy - a one in three chance he'd die in surgery, one in three chance he'd need further urgent surgery and one in three chance it would go well. We signed the consent forms and spent that evening at our son's incubator whispering messages of strength, hope and love through the little portholes, and sharing a drink of fizzy orange with the nurses to welcome in the New Year.

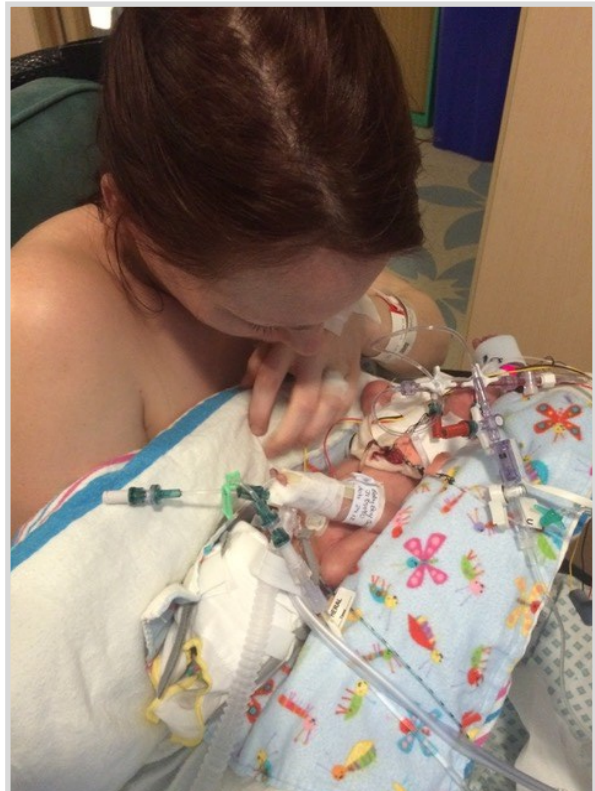
The next day we kissed Remi as he went off to theatre. After the longest and most anxious wait of our lives we were told he was back on the unit and that the operation had gone well. There are no words to describe how relieved and lucky we felt. He now had a stoma which, they explained, would be reversed when he was bigger and stronger.

Remi

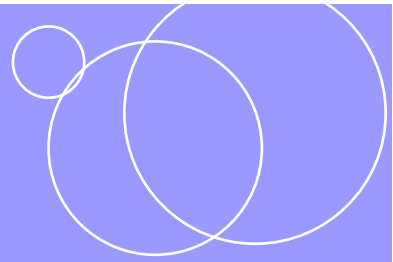
During the first week or so, I devoured all the information booklets I could find on the unit, whilst I sat for hours, expressing milk for my son. I wanted to learn as much as I could about this new world we had found ourselves in and how best to support our son as we navigated our way through it. We quickly got into the routine of life on a neonatal unit and the tight schedule of expressing, attending ward rounds, doing cares, doing feeds, squeezing in some cuddles and then repeating it all again, just about finding time to eat and sleep in between. It was unbearable leaving Remi each night; I still don't know how I, or any NICU parent, manages to put one foot in front of the other and leave their baby who should still be in the warmth and safety of the womb.

On day 8 we got our first skin-to-skin cuddles with Remi. It was an overwhelming feeling; tears rolling down my face, I finally felt like I had my baby and I never wanted to let him go. As Remi got stronger and needed less medical interventions, we became more involved in his cares which we loved; we started to feel like his parents rather than helpless onlookers.

The neonatal staff were almost all brilliant. One of whom shared a crucial bit of insight; that whilst they are the trained clinicians, only we, as parents, are the true specialists of our son. It was our job to learn his cues, what was normal for him and what wasn't, and to use this knowledge to advocate for him. We took this on board with a vengeance and came to ward round armed with a list of questions and concerns each day.



Remi



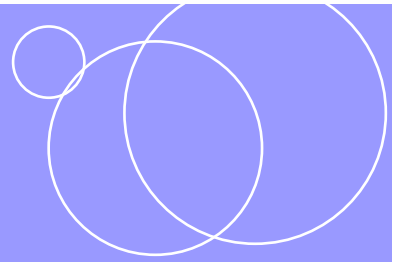
After a month in NICU, Remi was strong enough to be transferred to our local unit. Whilst we knew this was a step closer to bringing him home, we felt very unsettled by the change and adapting to the LNU was difficult; after a month of being in the NICU, we had become institutionalised! But we gradually got used to the new setting where he grew bigger and stronger. Finally, after 53 days in hospital, we were able to bring our son home. It was the best feeling in the world.

We had been home for 3 months when we were given a date for his stoma reversal. Despite being supported by a brilliant stoma nurse and dietician, managing Remi's stoma was a total nightmare and his weight gain was very slow, so finally getting a date for the surgery was a huge relief. The operation was successful thanks to his incredible surgeon and almost immediately everything felt easier. No more leaky stoma bags, no more top up feeds and after months of pumping, Remi finally became exclusively breastfed and started gaining weight like a champion! Remi is now a happy, healthy, confident and cheeky three year old with such a strong and determined spirit. He is our miracle and we couldn't be prouder of him. We will never forget how lucky we are, and always remember those babies we met in hospital for whom the fight was too much and who devastatingly grew their angel wings.

We will be eternally grateful to those amazing people who cared for Remi and supported us as parents from the minute he was born; and one group of people without whom I don't think I'd have survived, was our fellow preemie parents. We helped each other through each of our baby's ups and downs, day and night, both in hospital and after discharge, and after almost 4 years we are all still firm friends.



Remi



The NICU journey is an emotional rollercoaster, full of unbearable pain, but also where small milestones feel like momentous achievements. To watch your tiny baby fight for his life is heartbreaking but equally, seeing such fight and determination come from such a small human is extraordinary. Whilst I will never fully recover from the traumatic way our son entered our lives, seeing him grow into the most amazing little human being certainly helps to heal the wounds.

When I fell pregnant with my second son, the joy and excitement I felt was quickly overshadowed by a fear of history repeating itself. I desperately wanted to enjoy my pregnancy but my anxiety levels were so high; every niggles I experienced had me wondering if I was going in to premature labour again. I sought out support from a specialist pre-term surveillance clinic in London that I visited regularly in my second trimester and which offered exceptional care and vital reassurance. Whilst I continued to feel anxious, passing 28 weeks was a huge milestone and I started to relax a little and feel more hopeful of making it to term.

I had Jonah at 37 weeks and he arrived healthily kicking and screaming! I was able to hold him almost immediately and we were discharged after 24 hours; I felt overwhelmed with happiness. I will always hold the scars from having Remi so early but Jonah's birth and being able to experience the newborn period at home has been an incredibly healing process. Remi is now a brilliant, proud and loving big brother.



Conor & Cody

We found out we were expecting identical twins at our 12-week scan. At 18 weeks we were told our twins were showing early signs of Twin to Twin Transfusion Syndrome (TTTS) and at 28 weeks we were told the TTTS had deteriorated significantly and the babies needed to be delivered within the next 24 hours. I was given the steroid injections to help mature their lungs and the twins were delivered by emergency caesarean. Conor was delivered first weighing 732g and Cody was born a minute later weighing 850g. They were whisked away from me by the NICU nurses in their little plastic bags.

I first saw them in their incubators when they were over 24 hours old. It was only then that it hit me that they were so small and so poorly. They had so many tubes coming out of them, machines beeping all around me and Conor was on a ventilator. It was heart breaking. The following day, Cody's blood pressure could not be stabilised, and he was transferred to a NICU. We asked the hospital chaplain to baptise him before he left, I honestly thought I would never see him again. By some miracle, the first of many we would experience, Cody stabilised overnight, and Conor was taken off the ventilator. Things were looking up, but it didn't last long. Conor's kidneys were not working, and they started treating him for sepsis. Cody came back to the unit after 10 days and luckily after a few more days Conor's kidneys started working. But then we were told Conor had a strangulated hernia and suspected NEC. He was transferred back to a NICU where they successfully managed to push the hernia back, without surgery. After 4 weeks of treatment he came back to the LNU. Again, we started to get our hopes up, but when we visited one day, Cody's head looked an odd shape. It turned out he had developed hydrocephalus from the brain bleed he suffered at birth. The Drs performed a lumbar puncture to relieve the pressure on his brain, with the intention for transferring him to have neurosurgery. But our next miracle came when the lumbar puncture had a permanent effect on the flow of the fluid and the hydrocephalus was resolved. 11 weeks after Cody was born, he was ready to come home, on oxygen, but he was coming home! In his second week at home he caught a cold and was suffering from bronchiolitis which resulted in a 2 week stay in a PICU. I think of all we had been through, this was the most terrifying of all. Meanwhile, Conor was still in our local LNU trying to master feeding and gain weight, but on day 103 he was allowed home, on oxygen, and with an NG tube.

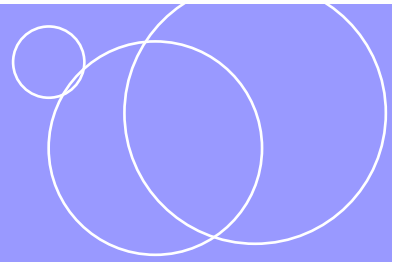


Cody



Conor

Conor & Cody



103 days after our worst nightmare began, we had our twins home, both on oxygen. Getting out the house with 2 babies and 2 oxygen tanks was a challenge but manageable. Over the first year we had multiple hospital admissions, but they have grown so much stronger and now, at nearly 4 years old, I hope those days are mostly behind us. They are both behind developmentally, but they are such happy little boys. They are incredible, and I could never thank our local unit enough for everything they did for them.



Oliver

My story may be a little different to some but we still had our four weeks of NICU life. After being in a relationship with Oliver's father for five years we had tried for a baby but with no success. Until at 11 weeks I discovered I was pregnant. All was going well with my pregnancy until my 20 week scan which revealed that baby number 5 was a boy with feet deformities. The extent of the deformities was unknown but we were assured that as soon as he was born he would have them corrected. My pregnancy continued well with regular scans because I was an older (38 years old in fact) and a bigger mummy who had had a heart attack at the age of 36 so a close watch on my health was taken to ensure this pregnancy would go smoothly. I had 4 other pregnancies which went quite smoothly and natural births.

At 32 weeks, on a Friday afternoon, I had a scan and other appointments at the hospital and all was ok with me and baby. On the Sunday night I felt sick and dizzy but put it down to me trying to clear my allotment and I had overdone it. On the Monday morning I woke up with a tummy pain but didn't think much of it and took my medication and tried to rest. The pain gradually got worse. I had no other signs there was a problem, no bleeding, nothing just a pain that wouldn't go away. The pain got to the point I was worried, so I rang the maternity unit at Hinchingbrooke and an ambulance was sent: I was in too much pain to drive myself and my husband was working over an hour away and I didn't have time to call him. My daughter who was 16 at the time jumped in the ambulance with me and off we went to the hospital.

When I got to hospital my baby's heartbeat was near non-existent and within 15 minutes of arrival, I was rushed for a cat 1 section due to placental abruption. I was given a general anaesthetic and that's the last I remember. When I was opened up the placenta had completely come apart and was just blood and clots. The cord was also wrapped really tightly around Oliver's neck twice. Oliver was on CPAP for several days and then moved to oxygen. I didn't get the first cuddle with the newborn smell which I had so longed for; I was just handed a photo. I was too poorly so I didn't get to meet my baby for 3 days and when I did there were tubes and wires on every part of his tiny body; I was shocked to see Oliver and very upset and angry that my body had failed me and I didn't get to see him first. I finally got a 5 minute cuddle on day 5. Oliver spent 3 weeks in the NICU then he was moved into the nursery where he spent a further week. I was allowed to stay on the labour ward for 3 days then I was moved over to the maternity ward and placed in a side room. I felt because I didn't have my baby with me I was forgotten and walking over to the NICU was excruciatingly painful, but I managed it several times a day to sit next to my baby, only being able to touch his tiny head. I can remember the worst part was hearing other babies cry without having my baby with me. I was told 'at least he's here and healthy'; not what I wanted to hear.



Oliver

Oliver weighed 5lb 7oz and was a good healthy size, but I couldn't get my head around why he was there if he was a big baby. I didn't understand how poorly he was. The only way I could get through the pain of leaving him on the NICU after each visit was to emotionally remove the thinking of him being my baby. As cruel as it may sound I was just visiting him and with visits you say goodbye, love you, seen you soon. You don't leave your baby behind!! I know he was getting the best care and was in the best place but it is heart breaking knowing that someone else is looking after him when it should be me. The staff on the NICU were angels; they kept my baby safe and would update me with his daily progress. I went home after a week without my baby. I couldn't get to visit as much as I wanted as my partner had to work. But when I did visit I made sure I had as much contact as I could with Oliver. I didn't want him forgetting me but again leaving him behind was tough. He came home with a feeding tube which I had to juggle but after a week he had pulled this out and we didn't ever use it again.



Oliver

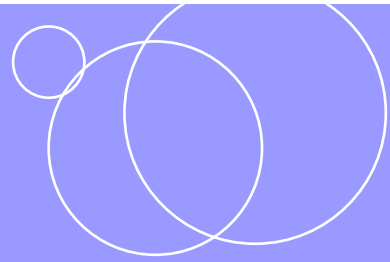
Oliver is now 3 and a half years old. He has a lot of physical and developmental delays. He spent roughly 6 months of his first year in plaster casts to try and prepare him for an operation. Weekly visits back and forwards to Addenbrookes really took a toll on me mentally and physically. After a second opinion from Chelsea and Westminster hospital, we finally got his diagnosis: Oblique talus left foot, vertical talus right foot, and hypermobility. Along the way other tests and appointments revealed Oliver had a collagen disorder, developmental delays, drooping of his left eye, and a whole host of other problems.



I was pregnant again 8 weeks after having Oliver which I was mortified by. All the what ifs came - what if it happened again? Removing all emotions and having weekly rewind and counselling sessions the pain of the traumatic birth faded a little and again I began to focus on Oliver and his needs. What would his future be like with his feet? As weeks, months & years passed I noticed more problems Oliver was having. He didn't seem to be as forward as other babies of his age or what my other four had been. With this began the still ongoing process of fighting to get Oliver a diagnosis. But he doesn't let his difficulties bother him. He still has his feet deformities after a failed attempt to correct the position of them. Oliver now attends pre-school and loves playing with his younger sister who is 2. He will be staying a year behind until a space becomes available in 2022 at a special needs school. He is a ray of sunshine and lets nothing hold him back.



Lillianna & William



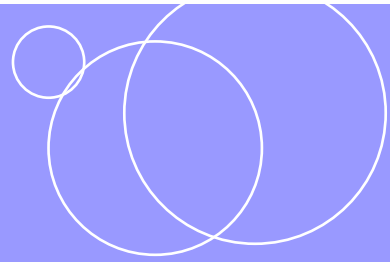
Our journey started at Luton and Dunstable Neonatal Intensive Care Unit after having a 23+5 weeker 1lb 30z in 2010. We then had another brief preemie encounter at Watford General Hospital SCBU after having a 35+2weeker 5lbs 3oz weeker in 2015.

I am from a nursing background and work under extreme pressure; hence I have for a long time enjoyed de-stressing at my local gym. So I'd say I was pretty healthy and was just losing a few pounds when I fell pregnant. To my surprise within the first month of pregnancy, the GP confirmed that I was suffering with high blood pressure at a level normally found in second trimester. I thought, 'ah will just cut out salt from my diet and I will be fine'. 8 weeks on in my pregnancy and I experienced a near miss miscarriage but my little fighter soldiered on. My GP acted promptly and referred me to the early pregnancy centre for an internal scan to confirm all was well. By this time I was referred to Consultant Care at my local hospital to keep an eye on the blood pressure. Being a nurse I thought I knew the treatment plan: Plenty of rest, including bed rest, feet up etc... But I was directed otherwise; carry on with the gym as I was a regular except for tummy exercises. So I plodded on with Aqua Aerobics, Pedal X, and Treadmill doing an hour each time. At the 12 week scan all was honky dory minus the blood pressure. I was seeing the consultant every week. By 21.6 weeks the consultant thought it was best to be seen every two weeks. I was slightly concerned as the protein in the urine was increasing from one plus to three plus, but I was reassured.

Before my next appointment which was held on Wednesday; I started feeling achy in my back from the Friday night. By the early hours of Saturday I felt severe constipation but thought; that's just the change of stage in the pregnancy. Having breakfast I felt the worst pain ever, but thought to continue to work and seek help whilst there. I did take peppermint tea and asked my colleagues about this experience and they all teased me 'first time mum' relax.

I took it easy by letting my hospital team know of this complication and they felt I was on the right track but if I felt worse I should call again. I work in the community so after my three home visits which I sailed through until the end, I felt the aches come on again. I took myself to Tesco to get real peppermint from the pharmacy. Only then did I realise it was serious when a gush of blood came. I knew I had to get to hospital. I was very near my work hospital but because of the negative issues that I had heard regarding premature births, I decided to sail homeward bound and called an ambulance to meet me somewhere local to my area. I did alert my husband to meet me at a car park near our home; and when he got there I didn't show how much pain I was in as he does sometimes think I go on...anyhow the paramedics came, and did I let loose! The pain was more severe and I was desperate to get to the hospital there and then. Paramedics did try to calm the situation by saying it was Braxton Hicks...my BP was through the roof.

Lillianna & William



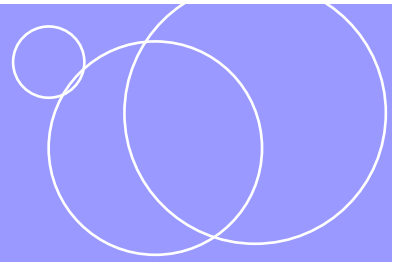
The assessment unit in the maternity department gave me steroids on arrival and found I was 2cm dilated. The Neonatal Team attended and did counsel me and my husband as they believed that the baby was keen to make an appearance soon, but would not be viable at all, having a 6% survival rate. We were resolved with the predicted outcome and just let nature take its course. The midwives really kept me going especially a lady called Paula. She always looked glam and worked for the two days I was there. To slow down the contractions and the bleeding I was tilted upside down and felt that was the little that I could do to keep my baby inside, IV fluids to stop the haemorrhaging. It was very uncomfortable but knew I had to bite my tongue. By Monday night at 19:00 contractions became serious and there was not turning back. The SCBU team were ready, and at 19:55 baby Lillianna was born viable at 540g but needed an incubator. I observed that to find an incubator was not an easy task, before baby could be intubated then a cot had to be found, this process seemed to last forever.

My husband was brilliant, until this day I ask if he might have felt like fainting, as it was a gruelling experience. He followed our baby to SCBU whilst I went to theatre to have the placenta removed. I was having black outs and felt the end was nigh. When I was back on the ward, my hubby confirmed that the baby was well and would be going to another hospital to stay in a Neonatal Intensive Care Unit. I felt so relieved but knew the journey would be a long dragged out one. It took three days before I could leave hospital let alone drive to the NICU being the sole driver in our home. I would check on baby every day; feeling detached as this was all I could do for my baby, being so unwell myself with Chronic BP. When we began the daily commute to the NICU each day got easier. I guess being from a nursing background I went into clinical mode when I walked into the NICU. But this knowledge also was damaging when things went wrong and this was a regular occasion in the first month. Christmas of 2010 was the worst time ever as a family; after spending a week at Great Ormond Street to close the hole in her heart (PDA ligation) my daughter went into renal failure 2 days before Christmas and survived just by a fine line resulting in vascular tissue damage.

I must say that through this journey I rediscovered my faith which has restored me. Once Lillianna got to 1kg she was transferred back to our local unit where it all began, and we stayed there until over two weeks past her due date and having spent 133 days in NICU....but it was all worth the roller coaster journey.

Four years on I decided to request a preconception appointment via my GP, thinking its best to see the reason for having such an early labour first time round. No answers were given in that regard by the consultant team, just possible keep on the healthy side and it didn't sound a great concept to conceive with my history but they changed my BP medication to safe for conceiving anyway. Within the month of this appointment as I enjoyed the last of the summer sun, I discovered I was already pregnant. I took a deep breath and felt I just got to soldier on. My pregnancy lasted well under consultant care until 31 weeks, where I had a show which I got checked out and was told no more work. I became a weekly lodger on the maternity wards until my son was discovered as breech but needed to be delivered as my BP was dangerously high. William was born at 35+2 5lbs 3oz via c-section thriving but whisked off to SCBU while I spent 7 days in ICU before I joined him in Transitional Care

Lillianna & William



During our NICU journeys we have made friends along the way and realised our dream to give back to such a service that took us from being vulnerable to confident parents and supporting others through establishing HertsPrem's, a charity that I set up with a fellow preemie mum who I met at my local hospital in 2010. HertsPrem's offer parents and families affected by premature birth, illness or disability in babies as much practical and emotional support as we can in and around Hertfordshire, Buckinghamshire and Bedfordshire. We invest our time, not for personal gratification but for the benefit of others who are walking our journey.





Robyn

At my 20 week scan we had found out that my placenta was low so any bleeding meant I needed to go to hospital and if it didn't move then I would need a caesarean. I had a small bleed around 30 weeks but by the time I got to hospital it had stopped and after a few hours I came home. I had another larger bleed at 31 weeks but again it had stopped by the time I arrived at hospital, I was sent for a scan following this which showed the placenta was still low and there was also a placental lobe. I remember talking to a friend two days later on the Thursday and telling her what had been happening and she suggested that I pack a bag in case it happened again, I said this was a good idea and planned to do it the next day as I was off.

Unfortunately I never got to do this as in the early hours of the Friday morning I had another even larger bleed and although it had again stopped when I arrived I was admitted to hospital. I was given steroids to help with the baby's lungs and advised to stay in hospital until the second dose was given 24 hours later.

At just after 1 am Saturday morning I started bleeding again and was rushed across to the delivery ward, where even at that time of day a room full of Dr's, nurses, midwives and anaesthetists were waiting. They tried to find the baby's heartbeat and found a heartbeat but were unsure if it was mine or the baby's. The decision was quickly made to take me to theatre for an emergency caesarean, I knew things were serious when the Dr's kept saying things such as 'we don't have time to wait for that'. Within half an hour of me pressing the buzzer and before her dad, who was at home with our 3 year old, could arrive our rainbow baby was delivered at 32 weeks weighing 4lb. She started crying when she was born which was the biggest relief ever, she was taken to the side of the room and looked at for a few minutes and then brought over so that I could see her before being taken to SCBU.

When her Dad arrived he went over to see her and said that she was receiving some oxygen but otherwise seemed to be doing well. When we both went to see her later in the morning she had been put onto CPAP and was in an incubator receiving photo therapy and with lots of wires and monitors attached to her, it was a very overwhelming experience.

A few hours later the Dr came and advised us that she was still having difficulties with her breathing and they were going to put her on a ventilator and transfer her to NICU. After such a promising start it seemed like things were going rapidly downhill.

We were both transferred to the NICU later that day and the first trip over to see her in NICU was another very over-whelming experience, after the small environment of SCBU there just seemed to be machines and tubes everywhere and constant alarms and beeps.

I was discharged after 48 hours and leaving Robyn in the hospital by herself was so difficult even knowing that she would be looked after so well.

Fortunately Robyn wasn't intubated for long but still required CPAP. Everything seemed so strange and unnatural compared to the experience with our first child who had been born healthy at full term. I remember the nurse talking to me about expressing and the process involved in this and becoming very upset as it seemed so clinical and different but I was keen to do whatever I could and this seemed to be one of the things that I could do to help our baby when so much was out of our control.



Robyn

On the Monday afternoon I finally got to hold Robyn for the first time, an experience which was both lovely but also scary as she had so many tubes and wires attached to her and seemed so small and fragile.

After a week Robyn was discharged back to SCBU in the middle of the night, phoning the hospital the next day not knowing which hospital she was in was a weird experience. At this stage she was breathing by herself and just needing feeding support. On her second day back at SCBU I was having skin to skin with her and she started to desat, one of the nurses said she thought that this was as she had been over handled, I felt like I had done something to hurt my baby even though we had been sat in a quiet, dark room and I had just had my hand resting on her. If she couldn't manage this how was she ever going to manage coming home to a loud, bright home with a lively 3-year-old sister? The next day the nurses reassured me that it was nothing that I had done. This started a pattern of several weeks of being on oxygen and one-minute de-sating and the next her sats being too high, watching the monitors and listening to the beeps became a bit of an obsession.

She seemed to be doing well otherwise and progressed to a cot in the nursery but then we got a 2am phone call saying she had been moved back to an incubator and they thought she had an infection. Her dad rushed to the hospital to see her while I stayed at home with our daughter, she looked poorly and was back to having a cannula for anti-biotics and having her incubator covered, it seemed like a massive set back. The next day she was allowed out for some skin to skin, however she had ideas of her own and manoeuvred herself in position for a feed, the first signs of the determination and independent streak that she continues to show to this day. Fortunately she recovered well and was moved back into a cot after a few days.

Amongst the constant monitor watching, blood tests, weighing's, photo therapy and other ups and downs were moments of pleasure, such as when we were first told we could try breast feeding her and she took to it straight away.

The day before she was due to be coming home I remember cuddling her and walking round the room looking at some of the posters on the wall, it felt so lovely and I couldn't think initially why it felt so special, but then I realised that after 5 weeks this was the first time that I had been able to walk around with her. Prior to this we had always had to stay by her cot as she was attached to oxygen tubes or monitors, it was something that I had so taken for granted with my first child.

Robyn



One of the most difficult things about our experience with Robyn was also trying to balance the needs of our 3-year-old, who didn't understand why the baby we had talked about her being a big sister to was in hospital and she just wanted her Mummy and Daddy. Having to share our time between the home and hospital meeting needs of both our children was very challenging. Having a baby in special care is difficult and stressful at a time when you are already tired and emotional so be kind to yourselves and do what you need to do to look after yourself, whether that is taking some time away from the hospital or taking something to do at the bed side so you don't become too fixated on numbers and beeps.

No one expects you to be able to be at the hospital 24 / 7 and no two families are the same, you need to do whatever is right for you, your baby and the rest of your family. Try not to compare yourself to others and don't feel guilty, it is a situation no one would ever want to be in and you can only do your best.

Robyn is now a healthy, happy, cheeky and determined 2.5 year old who you would not know had spent the first 5 weeks of her life in hospital.





East of England Neonatal

Operational Delivery Network

Collaborative working to deliver high quality care to our babies and their families

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