

Spring/Summer 2019

Little Bliss

For the families of babies born premature or sick

Defying expectations

Carlyne talks about life since daughter Zoe's spina bifida diagnosis **p5**

Sibling support

Naazia shares how her son's premature birth affected his brother and sister **p17**

Bliss
for babies born
premature or sick



Welcome to Little Bliss



If your baby is on a neonatal unit or has recently gone home, Little Bliss is for you. It's full of parents' stories and practical information to support you, however long your baby spends in neonatal care.

If this is the first time you've heard of Bliss, why not visit bliss.org.uk to see what information and support we offer?

Bliss' information and Little Bliss magazine are available thanks to regular donations from generous supporters. If you support Bliss in this way, or any other way, thank you.

A handwritten signature in black ink, appearing to read 'Caroline Lee-Davey'.

Caroline Lee-Davey, Chief Executive

About Bliss

Bliss is the leading UK charity for babies born premature or sick. We were founded in 1979 and we exist to ensure all babies in neonatal care:



have the best chance of survival



have well-supported parents playing an active role in their decision-making and care



are cared for in neonatal environments that best support their development



benefit from neonatal research that can lead to practical improvements in their care



receive high-quality care within a neonatal health system which is appropriately funded, structured and staffed.

bliss.org.uk

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Little Bliss is reviewed by parents with direct experience of neonatal care.
For information about their role visit bliss.org.uk/parent-panel

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Bliss information for parents

We have information to support you on many different topics:



About neonatal care



Procedures and medical conditions



**Being involved in your
baby's care (family-centred care)**



Looking after your mental health



Weaning your premature baby

Visit [bliss.org.uk](https://www.bliss.org.uk) to find out more

Zoe has defied the
doctors' expectations



Our baby's spina bifida diagnosis

Carlynnne and her husband Paul were delighted when they found out they were expecting their first baby. At the 20 week scan however, the doctors delivered some life changing news.

“At our scan, Paul and I were so excited to see our baby. The sonographer started going over the same part of the baby’s brain again because she couldn’t find the cerebellum – the part of the brain that receives information from the spinal cord.

"I knew then and there that something was wrong and I was already inconsolable.

"The next day, the consultant conducted another scan. When he finished he told us that our baby had spina bifida."

Spina bifida means 'split spine'. A fault in the development of the spinal cord and surrounding bones leaves a gap in the spine. The spinal cord has not formed properly, and may be damaged. Carlynnne's baby was also diagnosed with hydrocephalus – fluid on the brain, which increases pressure and can cause brain damage.

"After we were told about the diagnosis, I felt totally numb. Fortunately, Paul and I both knew we wanted this baby. Every kick made us believe that we were making the right decision and we were more positive than ever.

"We were referred to the Fetal Medicine Unit in Glasgow which was excellent. They were upfront and told us that

no one can really say how this would affect our baby until she was born but that people with spina bifida are known for defying expectations.

"The Bliss volunteers were always very supportive. It was great to know people were there to help us."

"It was the hardest time of our life but it made us a lot stronger as a couple. We took some time off work to get our heads round everything which was what we needed.

"I had a planned induction at 39 weeks of pregnancy. In the lead up to being induced, I just kept busy and stayed quiet. I was overwhelmed with emotions."



Zoe was diagnosed before she was born



Carlynnne cares for Zoe on the unit



Paul bonds with his daughter



Zoe spent 19 days in the neonatal unit

After a long labour, the baby's heart rate started dropping and Carlynnne was rushed in for an emergency c-section. When Carlynnne came round she was told they had a little girl. They named her Zoe.

"Zoe went into surgery at two days old for her back closure. I was still an inpatient myself. Paul was staying at the Ronald McDonald house so he came and collected me in a chair first thing and we went to the ward. We went down to the theatre with Zoe and gave her a kiss before she went in. It was the most heartbreaking thing I've ever had to do. We both sobbed as she was taken away.

"We sat at her empty bed space and waited for her all day."

"The day is really just one big blur because we were filled with worry and nerves. She was in surgery for almost

eight hours. We sat at her empty bed space and waited for her all day. Finally we had good news – the surgery went amazingly well!

"It was the hardest time of our life but it made us a lot stronger as a couple."

"A week later Zoe had another surgery to fit a shunt to drain the fluid from her brain which had been caused by hydrocephalus. This surgery took around five hours. This shunt will be permanent for her and has been successful so far. However shunts can be temperamental and come with their risks of failure and infection. We know the signs and symptoms of this and always look out for them with Zoe.

"I felt helpless when Zoe was in the neonatal unit. I think because I'm a nurse, I found it hard to switch off.

“I have met so many amazing kids with spina bifida and they are all incredible warriors.”

“I kept looking at the machines and the numbers and this would just make me more anxious.

“The staff and Bliss volunteers were always very supportive and asked if we needed anything. It was great to know people were there to help us.

“When we were told we could go home we were over the moon. I could not wait to get into a home environment and have our baby girl to ourselves.

“Zoe has defied everyone’s expectations. So far there is nothing to show that the lesion in Zoe’s spine has affected any leg or foot movement which orthopaedics and physios are impressed with. She is such a little wriggler!

“She has regular appointments and check-ups with many different specialists and clinics. It is really overwhelming and I struggle at times but Paul is excellent and helps me as much as he can when he’s not at work and our families have been massively supportive.

“Since Zoe’s diagnosis, I have met so many amazing families with kids with spina bifida and they are all incredible warriors. Every single one is different and not every child has the same diagnosis. Some need wheelchairs, some don’t need wheelchairs. Some need shunts, some don’t need shunts. But all of them have defied the expectations of doctors and others around them.

“Zoe has enriched all our lives and brings us incredible joy each and every day; we couldn’t be more proud.”

This is a shortened version of Carlynné’s story – to read it in full visit: bliss.org.uk/story/carlynné-part-one



Zoe’s smile brings joy to everyone she meets



The family enjoying time together

Heroes assemble!

Host a Bliss Little Heroes superhero walk this year



Get your free fundraising pack at bliss.org.uk/littleheroes



Want to do something different?

Join our nation of bakers and be part of Bake for Bliss bliss.org.uk/bake



Look at them now

Every issue we follow the incredible and often miraculous journey of a baby born premature or sick. In this issue, we meet George who was born at 41 weeks with Hypoxic-ischaemic encephalopathy (HIE).



George was born by emergency c-section at Horton General Hospital, Banbury. He was born with HIE and had to be cooled to reduce the risk of brain damage.



George had seizures at just a few hours old and had to have an MRI at nine days old. Mum, Laura, said: "Every day was filled with worry."



George was able to go home after three weeks. "His daddy, Matt, and I were so pleased but the first few months were tough. George struggled to gain weight due to silent reflux."



Laura noticed that George's right hand was always fisted in the bath. He was referred for physio not long after.

Hypoxic-ischaemic encephalopathy (HIE) is a lack of oxygen and/or blood flow getting to the baby from the placenta during birth. For more information, visit bliss.org.uk/medical-conditions-and-procedures



First
birthday

The family celebrated George's amazing progress with a trip to the seaside.



Two
and a
half
years
old

George was diagnosed with epilepsy when he was two. Laura said: "it was hard but he takes it all in his stride, even reminding us to take his medication out with us!"



Family
time



On the
move

It took George a bit longer than his peers to crawl and walk. Laura said: "I worried he wouldn't achieve these things but I'm happy that he's proved me wrong many times!"



Starting
school

George found the long days tiring but received lots of support from the teaching staff.

George is now five and has been diagnosed with right-sided hemiplegia, a form of cerebral palsy. Laura said: "I spend a lot of my time worrying about George's future but he amazes us every day. He loves being outdoors, having a cup of tea and listening to music."



"After overcoming enormous hurdles, small things trip you up"

The twins bond with their dad and brother

After an anxious pregnancy, Peter and Felice welcomed their twin daughters, Olwen and Iona, at 29 weeks. Here Peter shares his experience and tells us why he wanted to be part of Bliss' mental health podcast.

"From early on in the pregnancy, we knew that we were having identical twins and that they shared a placenta. This introduced all manner of possible complications, including twin-to-twin transfusion syndrome (TTTS) and we were told there was a high chance that one or both would not make it.

"We endured six months of trying our best to carry on with our lives, including being parents to our three-year-old boy. Then at our 29 week scan, we were told that Olwen had barely grown for two weeks. Our only option was delivery.

"Mundane things like money, food, work and traffic became a colossal effort."

"When Iona was born, we heard a small cry, which was just about the best sound I'd ever heard. A few minutes passed and no one was saying anything about Olwen. Eventually we were told that she was delivered and stable. We named them there and then, as they were both whisked away.

Though the next 24 hours would be critical, the twins had overcome the biggest hurdle – birth.

Peter started to feel optimistic for the first time.

"At this point, there were many reasons to feel happy in this place that everyone seems to fear and avoid."

However, there was a long journey ahead. The twins spent 94 days in the NICU in total.

"We soon settled into a routine and even had a few visitors which was always welcome. The girls seemed to make steady progress.

"However, mundane things like money, food, work and traffic became a colossal effort.

"After overcoming such enormous hurdles – pregnancy, birth, intensive care – it's amazing how it ends up being small things that trip you up."

Peter began to realise that he and Felice were coping in different ways.



Iona and Olwen were delivered at 29 weeks



The family settle in to life on the unit



Iona and Olwen spent 94 days in the NICU



The twins went home on Christmas day

“She became more immersed in the hospital. Meanwhile I became focused on practicalities, like work and preparing the house for their return. When I did arrive at hospital I didn’t want to speak to anyone. I just wanted to hold my girls and go home.

“Just when we thought the girls were nearly ready to come home, they contracted a virus and developed bronchiolitis. I think for me, this was the hardest bit. After months of trying to remain positive, there was just nothing left in the tank.

“Then, on Christmas morning, Felice called from hospital saying the twins could be collected. We drove the girls home and put them under the Christmas tree. We’d made it.”

Over the next year, the reality of what the family had been through started to sink in.

“I would tell people about it like it was the most normal thing in the world and their faces would reflect something very different. Approaching the twins’ first birthday, I found myself getting angry over things that previously wouldn’t have bothered me.

“It's important to know that whatever you're feeling is normal.”

“It was this out of character behaviour that made me think something was wrong. Was it PTSD? Was it ‘burn out’? I didn’t feel like there was an appropriate diagnosis. It was an isolating feeling.

“Eventually I saw my GP who suggested Cognitive Behavioural Therapy (CBT) but it seemed like a big commitment. In the end I tried an app called ‘Headspace’ which teaches mindfulness techniques. It gave me perspective and helped me find acceptance.”

“There is no step by step guide to the NICU.”

Peter was one of five parents to share his experience for the first Bliss podcast – NICU, SCBU and you.

“I wanted to get involved to show my support to other parents but it was also a good opportunity to revisit what had happened.

“When we were in the NICU, I was in survival mode. At the time, it didn’t occur to me to seek support for how I was feeling – or even that there was anything I needed support for.

“There is no step by step guide to the NICU and every parent copes differently. It’s important to know that whatever you’re feeling is normal.

“I would say to fellow parents – be aware of your wellbeing, be kind to yourself and have faith in your baby and in the nurses and doctors caring for them.

“My girls are so full of energy, personality and joy, and while I’m not in a hurry to do it all again, I can say resolutely that they are worth it.”

Listen to Peter talk more about his experience in our podcast, NICU, SCBU and you, at bliss.org.uk/mental-health

You can also read more about our mental health information on page 22.



Iona and Olwen settle in at home

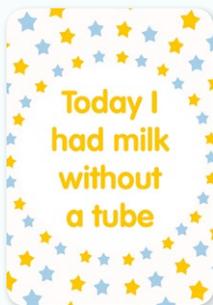


The twins are full of personality and joy



Free Bliss Baby Cards

Celebrate each milestone in your baby's neonatal journey



10 beautiful cards
in each pack:

Each card is 150 x 105mm, is laminated for wipe-clean infection control and includes a space on the back for you to record your memories.

Order at bliss.org.uk/baby-cards

With thanks to our supporters whose donations make it possible to provide these cards free to families with a baby in neonatal care.

For information and support from Bliss email hello@bliss.org.uk

Bliss
for babies born
premature or sick

Naazia is so proud of Hamza's progress



Splitting time between my children

When Hamza arrived 16 weeks early, his mum Naazia was faced with the struggle of having one child in hospital and two older children at home. Here she tells us how this affected the whole family.

“We were all excited that I was pregnant, especially my daughter who couldn’t wait to have a new baby to play with. Everything looked fine at the 20 week scan so my husband and I thought we could relax.”



Naazia gave birth to Hamza at 24 + 4 weeks



Hamza had to be transferred after birth

Then at 24 + 4 weeks, Naazia's waters broke and Hamza was born at City Hospital in Birmingham later that day, weighing 765 grams. As he was so small, he had to be transferred to the Women's Hospital which meant Naazia wasn't able to see him until she was discharged from hospital a day later.

"Salmaa said 'don't worry mummy, he'll be fine.'"

"When I first saw him in the incubator, he looked dark red, not quite like a baby at all.

"I saw other mums with their babies and just wanted to be able to cuddle mine. I started to question myself, why had this happened to my baby?"

Naazia then faced the difficult task of explaining to fifteen year old Yaseen and eight year old Salmaa that their baby brother was poorly.

"When I got home, I told the children that Hamza had been born much earlier than he should have been and we didn't know what would happen. Salmaa said 'don't worry mummy, he'll be fine.'

"We all went to the hospital and the children's faces dropped. Even though we'd told them how small their brother was, it was a shock for them to see him.

"Being older, my son took in a lot more of what the doctors had told us and kept telling me not to worry, but I think he was just trying to be strong for us."

Over the coming weeks, Naazia dropped Salmaa off at school before making the one hour trip to the hospital, and then back again in time to pick Salmaa up.

"I took the bus during the week when my husband was at work and we travelled to the hospital together at weekends.

"I felt like he was supporting me when I should be supporting him."

"It was hard as I'd come home too tired and upset to do much with the children during the week. I felt guilty if I didn't cook them a healthy meal and I was always on edge, expecting the hospital to ring to say something had happened.

"Looking back, I didn't really ask other family and friends for help as much as I could have because I just didn't think anyone would understand what we were going through and I didn't want to have to explain."

Naazia received a lot of support from her eldest son but this added to her feelings of guilt.

"Yaseen learnt how to do everything at home by himself but I felt like he was supporting me when I should be supporting him.

"He also started to ask what was going to happen with Hamza and I didn't have the answers."

Naazia drew comfort from going to the hospital's prayer room and also spoke to the psychologist on the unit who told her to have more time to herself.

"The hospital was so supportive. I was feeling quite down and it was good to hear someone tell me that I needed to stop putting so much pressure on myself. She helped me to understand that it wasn't helping anyone if I was exhausted all the time."



Hamza spent 182 days in hospital



The family enjoy spending time together



Hamza went home on oxygen



Salmaa loves having a baby brother

In total, Hamza spent 182 days in hospital. Now at home, his doctors are happy with his progress but there are still lots of appointments.

“It’s really important that we spend time together as a family.”

“My daughter will say to me ‘mum, you’re always at the hospital’.

“I have to tell her that Hamza is still little and needs more of my time right now.

“It’s really important that we spend time together as a family as much as we can so we’ll play board games and watch movies, and talk about what a year it’s been. It’s been hard but it’s changed us too.

“My husband used to say that I needed to be more confident. Now I talk to strangers on the bus who ask why Hamza is on oxygen.

“When they are surprised to hear that he was once so small it reminds me how far he has come.

“My older children have learnt so much too. They do so much for themselves now and it makes me so proud to see how they are with their brother.”

Bliss has a series of videos about what happens on a neonatal unit which can help older children to understand the environment. Visit [bliss.org.uk/about-neonatal-care](https://www.bliss.org.uk/about-neonatal-care)

Parent-to-parent: expressing

We know not every mum is able to or wants to express breast milk but, for those who do, it can take time. Here, parents share their tips on expressing and supporting their partners.

Rebecca says: "Having my baby's blanket and being able to smell her made a huge difference to my supply. If I was at home I would get comfortable and snuggle into her blanket whilst expressing."

"Use it as a bit of time for you. Take some music, TV or a book."

Sarah

Lauren says: "I would see other mums with more than triple what I could manage, and I would get so disheartened. Other mums need to know that there's nothing wrong with them. If you can't manage, don't blame yourself."

Nat says: "Relax, eat plenty, drink plenty and ask for support if you need it."

Kirsty says: "I used to sit with one of the other mums while expressing and have a good talk about everything we were going through."

"Helping with little things like cleaning pump equipment can go a long way."

James

Catrin says: "My partner fully supported me. It was the little things like making me feel relaxed, reassuring me when I thought I was failing and making sure I was eating and drinking properly, that made all the difference."

Michael says: "I helped as much as I could by getting everything ready as well as staying up with her through the night while she was doing it."

Laura says: "If I went to express, my husband would always sit with our son so he wasn't alone, and I liked to know that his daddy was there."

Read more tips online at
bliss.org.uk/expressing

You asked, we answered

Is it common for parents to struggle with their mental health on the neonatal unit?

We surveyed almost 600 parents and 80% said their mental health became worse after their experience. Here are some ways that you can help support your mental health on the unit.



Have a cup of tea or coffee



Get fresh air and natural light



Have a long shower, or bath



Keep comforting routines, like getting ready in the morning



Read, watch TV, or listen to music if you enjoy these things



Do exercise that you enjoy, like going for a short jog, or taking a class



Spend time with your other children, if you have them



Spend time with your partner, friends or family



Make a diary or memory book

Whatever you're experiencing, you're not alone. Find more information about how you might be feeling, who to talk to, and what support is available via our website – bliss.org.uk/mental-health



Listen to our podcast – NICU, SCBU and you. Hear parents talking openly about their mental health on the unit, how they faced challenges, and how you can get more support from health professionals.



How can I be involved in care on the neonatal unit?

You and your family can be involved in caring for your baby on the neonatal unit and you should be supported by healthcare professionals to do this. This is called family-centred care. It can help you to connect with your baby, feel more confident as a parent and is linked to better long-term outcomes for babies' development.

You might like to go through this checklist with a healthcare professional and see what they can help you to do.

Find out more about family-centred care and how it can help you and your baby by watching our video at bliss.org.uk/family-centred-care

Family-centred care checklist

Tick the ones you've done

- Feeding your baby
- Washing your baby
- Dressing your baby
- Changing your baby's nappy
- Watching and learning from your baby
- Skin-to-skin with your baby
- Feeling informed
Visit bliss.org.uk/parents for more information
- Asking about any help with money, like free parking or food vouchers
- Asking which family members can visit
- Creating a memory book
- Being involved in talks about your baby's care
- Comforting your baby during difficult procedures
- Getting emotional support for you and your family
Visit bliss.org.uk/mental-health for more information

Q&A: the hospital chaplaincy service

Many think that chaplaincy services are only for people with a religious belief, but actually chaplains in hospitals are there for everyone – religious or not. We talked to a chaplain about their work, and some parents who found support this way whilst on the neonatal unit.

Mark, a hospital chaplain at Sheffield Teaching Hospital, tells us more about his role, how having a baby in neonatal care can affect your mental health, and what you can do to take care of yourself.

How would you describe chaplaincy to someone?

Mark: “Words like ‘spirituality’ and ‘chaplaincy’ can sound off-putting to some people. However spiritual care is simply one way of thinking about how we experience the world around us. Having a baby on the neonatal unit can make it difficult for families to do those things which give life meaning

or help them relax – whether that’s prayer, meditation, dancing or going to the gym.

“Hospital chaplains provide a listening ear and help people make sense of their experiences to help them to find hope.”

Do you support mostly religious people, or is there a mix?

Mark: “I would say a complete mix; people who have strong beliefs or contact with their own faith community, people who might describe themselves as spiritual, people who don’t have set beliefs – anyone or everyone who



wants to talk to someone. We have members of the chaplaincy team who are of different faiths, as well as representatives from other faith and belief traditions we can contact.

Why might a parent on the unit talk to a chaplain?

Mark: "I often introduce myself as someone who is there for a normal conversation. Unlike other hospital staff on the unit, I don't make any decisions about a baby's care as I'm not medically involved. It's common for parents to talk about how their baby is doing but often it can help them to have a normal conversation that doesn't focus on their baby."

When do you support parents on the neonatal unit?

Mark: "I am there for people throughout their experience, which can include helping parents to mark significant events such as a christening, or it can be co-creating something more personal that feels right for their child."

What suggestions do you have for parents on the neonatal unit?

Mark: "It might be worth thinking about whether there are simple routines that can help you cope. It might be helpful to talk to someone who has the time to listen and who will create space for you to work through the things on your mind."

If you would like to speak with a hospital chaplain for support, speak to a member of staff on your unit who can give you more information.

What parents say about the chaplaincy service

Donna, mum to Beatrice born at 25 weeks

"The chaplain in our neonatal unit always accompanied the parent volunteers on their visits. As soon as I met her, I said I didn't want to hear about God as I do not follow any religion. She never mentioned God to us. She came every week, sometimes more than once, and chatted to me and offered me support."

Lori, mum to Otis born at 24 weeks

"The chaplain was such a positive presence on the ward, knowing all parents by name.

"She gave us a knitted tortoise and said our journey will be that of a tortoise's – very slow, but hopefully steady. I still have that tortoise by my bed and the message is still as relevant now, even though the NICU days are over."

For more information and tips on supporting your mental health while on the neonatal unit, visit our website at bliss.org.uk/mental-health

it's the small things that matter

new premature baby clothing and blanket
all developed with the help of Bliss -
sizes start from 2lbs



- ♥ the new collection is now available in 41 stores across the UK and online
- ♥ designed in conjunction with neonatal units and Bliss
- ♥ sleepsuits and bodysuits open flat for easy dressing and to allow access for special care
- ♥ soft-touch hook and loop fastenings

to find out more visit [mothercare.com](https://www.mothercare.com)

mothercare
is proud to support

Bliss
for babies born
premature or sick

Bliss updates

Mothercare's new premature baby clothing

Our partner Mothercare have released a new premature baby clothing range! We're so proud to have been involved in the creation of this line that was based on feedback from nearly 800 parents and health professionals, to ensure the clothes work best for babies from 2lbs to 10lbs. They hope the pieces will make those early days at home, or in neonatal care, that little bit easier.

Caroline Lee-Davey, Chief Executive said: "We are delighted with this new range which not only comes in sizes suitable for the smallest babies, but has also been designed with fabrics and fastenings to support ease of use with any tubes or wires that babies may need in hospital. We know that parents will welcome having clothing that is specifically designed for their premature baby, and we're thrilled that the range will be available for all parents online as well as in Mothercare stores."

Bliss Baby Charter accreditation for Royal Devon and Exeter Hospital

This year the Royal Devon and Exeter Hospital became the first hospital in South West England to receive Bliss Baby Charter accreditation. Bliss awards the accreditation to neonatal units that deliver high quality family-centred care to babies and support for their families. The Bliss Baby Charter was developed by Bliss to help hospitals caring for premature and sick babies to assess the care they provide and identify areas for improvement.

Louise Rattenbury, Matron on the neonatal unit said: "The Bliss Baby Charter Accreditation Scheme has supported the neonatal team to focus on what really matters to families. This has made a vital difference every day to all the babies we care for, as well as to parents and families. I am so proud of the Exeter neonatal team and their dedication to putting babies and their families at the heart of everything they do."

Pregnacare®

UK's
No 1
PREGNANCY
SUPPLEMENT
BRAND*



Proud to support Little Bliss

With you every step of the way



BEFORE CONCEPTION
Carefully balanced formulation with folic acid recommended for all women trying to conceive.



ORIGINAL
19 vitamins and minerals, with folic acid and vit. D as recommended by the Department of Health.



LIQUID
Great tasting orange liquid for those who prefer not to swallow tablets.



BREAST-FEEDING
Includes 10mcg vitamin D and 300mg DHA for mums during lactation.‡



NEW MUM
With biotin and zinc to help maintain normal hair and skin.

BEFORE

DURING PREGNANCY

AFTER

From Boots, Superdrug, Holland & Barrett, supermarkets, chemists, health stores & www.pregnacare.com

Bliss
for babies born
premature or sick

Made in Britain

The ONLY vitamin company to twice receive The Queen's Award For Innovation



VITABIOTICS
SCIENCE OF HEALTHY LIVING

*UK's No.1 pregnancy supplement brand. Nielsen GB ScanTrack Total Coverage Unit Sales 52 w/e 8 Sept 2018. ‡ A beneficial effect can be obtained from a maternal daily intake of 200mg DHA in addition to the recommended daily intake of 250mg DHA / EPA for adults - Annex of Commission Regulations (EU) No. 440/2011.

Do something amazing

Our fantastic fundraisers get involved with all sorts of wonderful activities to help Bliss support more babies in neonatal care. Here are just a few examples of how you can join them this year.



Host a ball

Raise some dough

Calling all bakers! Host a sale and ask friends, family and colleagues for a donation for your tasty treats.

Find out more about organising your own event at bliss.org.uk/community



Bake for Bliss

A true inspiration

Bliss supporter Marie Bailey's daughter, Lily, was born prematurely in 2006. Over the last ten years, Marie has raised a phenomenal £100,000 from cake sales, quizzes and an annual 'Lily's Ball'.

We are so grateful for Marie's continued support.

Inspired to organise a ball like Marie? Or are you more of a quiz master? Our website will help you plan your own event to help babies born premature or sick. Find out more at bliss.org.uk/community

A parent's soothing touch

It is shocking to think that around 30 years ago, surgical procedures were routinely performed on premature babies without adequate pain relief. At the time, it was believed that a premature baby's nervous system was not mature enough to process pain. It is now widely accepted that babies born early do experience pain and so they are routinely given pain relief during surgery.

But babies in hospital have many routine procedures, such as heel pricks for blood tests, intubation and injections, which are known to cause them discomfort and distress.

This is why Bliss has chosen to fund a pioneering research project to find accurate and reliable ways to measure babies' pain, and to investigate whether a parent's touch during a procedure can reduce their baby's pain.

"Many people do not realise just how many medical procedures a premature baby goes through during their hospital stay, and just how new the area of pain measurement and reduction is", said Bliss Chief Executive Caroline Lee-Davey.

The researchers from the University of Oxford will study babies born between 24 and 37 weeks' gestation using a specially designed electroencephalogram (EEG) template to track brain patterns. The study will seek to investigate reliable and accurate ways to measure pain in premature infants. This will give them





the knowledge to enhance clinical care and refine procedures to minimise babies' pain.

Parents will be closely involved in the three year project and will be consulted throughout in order to ensure they understand what the results could mean for babies in the future. It is hoped that the research will give us even more evidence that parental involvement is essential to bring about the best outcomes for babies.

Andy Greeves and his wife Cathryn chose to support Bliss by fundraising to support research after their eldest son Toby was born premature and sadly died at 23 days old from necrotising enterocolitis (NEC).

"As parents we want our interaction with a neonatal baby to be the same as with other babies. We need to know how to offer comfort. To an outsider,

the world of neonatal care can seem dehumanised. It is only by studying what distresses the baby that we can be sure we are giving the right care.

"I hope that by the time my son Henry, who is now three, becomes a parent, treatments and pain management will be more advanced."

Bliss needs to raise £148,000 over three years to support this pioneering research. To make a donation or find out about other ways to support our work, please visit [bliss.org.uk](https://www.bliss.org.uk)



Join the family

If your baby is on a neonatal unit, you're not alone. Find practical information, emotional support and a community of families with a neonatal experience at bliss.org.uk

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Bliss
for babies born
premature or sick