The Sick Children’s Trust was there for us when we didn’t think our precious baby girl was going to make it; without them I don’t know how we would have survived.

Tuesday 3 April, 2018

Finding out I had cytomegalovirus (CMV) at our 20 week scan was absolutely devastating. Neither my partner, Zak, nor I had ever heard of CMV so when the doctor explained what it was, we were terrified for our unborn baby. CMV is a common virus, similar to the virus that causes cold sores and chickenpox, and is usually harmless, but we were stressed and confused to learn it could cause problems in babies if a mother catches it during pregnancy.

The not knowing was the most traumatic part – even though I had been diagnosed with the CMV infection it didn’t necessarily mean my baby, to be called Luna, had the virus too. Then at 22 weeks when I had an amniocentesis (a procedure where a sample of fluid is taken from the sac around the baby) and suddenly started to feel stomach pains and then contractions, I was rushed into hospital. It was too early for my daughter to be born.

Thankfully, after three days in hospital and many more tests, the pains and contractions ceased, but by this point we knew the virus had been passed onto Luna. We tried to cling on to the hope that around four out of five babies born with CMV don’t have any health problems, but nevertheless for the remainder of my pregnancy I had fortnightly growth scans at The Rosie Hospital in Cambridge, an hour away from home, and also two MRI scans.

Twelve weeks later, I had a familiar feeling. I started getting awful pains. Again Zak rushed me to The Rosie Hospital and this time Luna was safely delivered early the next morning. Our daughter was very small, weighing just 3lb 4oz and was unable to breathe on her own. Whilst we watched on petrified, the doctors intubated Luna and hurried her away to the neonatal intensive care unit (NICU). I was inconsolable.

The first two weeks of Luna’s life rushed by and she seemed to be doing well and, because she was such an amazingly strong and brave little baby, she was transferred to our local hospital, West Suffolk. It was a great feeling to be told we should start preparing for bottle feeds as it wouldn’t be long until she was home. That night Zak and I left Luna in hospital feeling so happy and excited, but early the next morning we received the worst phone call of our lives. The nurses had found blood in her nappy and Luna had become critically ill, deteriorating fast. We rushed back to the hospital, but there was little West Suffolk could do for Luna and she was blue-lighted back to The Rosie Hospital by ambulance and rushed into NICU and intubated once more.

Luna had necrotising enterocolitis (NEC), a serious condition more common in premature babies, where tissues in the bowel become inflamed. It can cause a hole in the intestinal wall and a life-threatening infection of the abdomen. The consultants initially tried to treat the infection with antibiotics and observed our baby through the night – Zak and I stayed in the hospital’s emergency accommodation, but when we woke up the next morning it was to more bad news with a call asking us to get to Luna’s bedside as quickly as possible.

Our baby was wired up to all sorts of monitors with tubes in and out of her tiny body. Her tummy was so swollen and things were not looking good. The only thing that would save Luna now was a lifesaving emergency operation, but she was so fragile that the consultant warned us there was a high risk she might not make it. As they took our baby down to surgery neither Zak nor I knew whether we were ever going to see our baby alive again. We waited for three hours whilst doctors performed surgery to remove 10cm of her bowel and create a stoma, or opening, on the surface of her abdomen, to divert the flow of faeces. When Luna came back from theatre she was still seriously ill. We live almost an hour away from the hospital and there was no way we could’ve ever left her there alone. This is when The Sick Children’s Trust stepped in and offered us a room in a ‘Home from Home’ just minutes from where she was recovering in NICU. The ‘Home from Home’ was called Chestnut House. It was amazing, and literally two minutes from our baby girl. There was also a phone in our bedroom with a direct line to NICU, so at night when we did leave Luna’s side to get some much-needed rest, it was a comfort to know that if anything changed we would know immediately.

Over the next three weeks Chestnut House really did become a ‘Home from Home’ for Zak and me. It was somewhere to retire when it all got too much on the ward and a place of sanctuary at night when we needed to rest in order to be strong for Luna the following day. We could even cook meals in the

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well-stocked kitchen to keep ourselves nourished. Thankfully after five days the consultant felt confident to extubate Luna, and she began to breathe on her own again. It was a huge relief and we shared this amazing news with the very kind and supportive staff in Chestnut House, who were always asking after Luna whenever we bumped into them.

The next few weeks flew by as our miracle girl grew stronger and stronger. She was no longer one of the sickest babies on NICU and so we packed our things and left Chestnut House so that a family with a baby more poorly than Luna could have our room. After three weeks of being so close to Luna at all times, it was really hard to leave her each day and make the 90 mile round trip to and from the hospital and home, but we knew it wouldn’t be too long until she came home with us.

Finally, after the longest seven and a half weeks of our lives, our amazing baby came home! It was a memorable day for everyone and very emotional. Since then, however, things have not been straightforward – Luna has battled pneumonia, been declared profoundly deaf, which means she cannot hear a thing, and had a stoma reversal surgery. When she had her second round of surgery, we stayed at Acorn House, another ‘Home from Home’ in Cambridge run by The Sick Children’s Trust. Once again we were right there with Luna, just minutes from her side. Again, this was incredibly important for us all and, again, I don’t know what we would have done without the charity’s help.

I’ve never been so thankful to anyone in my life and The Sick Children’s Trust has been a lifeline though an incredibly traumatic time – without them I just don’t know how Zak or I could have survived, especially when we thought we were going to lose Luna. We needed to be on site during that time, so that we could be by her bedside right away and if we had been back home, it might have been a very different story. Luna still has many hospital appointments and monthly physio, but she is now six months old, beautiful, and growing stronger every day.

Rhainnon Hutcherson, Luna Riley’s mum.

About The Sick Children’s Trust

The Sick Children’s Trust is working to a future where every family with a seriously ill child in hospital will be able to stay together, just minutes from their child’s bed during their treatment.

We believe keeping families together significantly improves the recovery of seriously ill children. We provide free, high-quality ‘Home from Home’ accommodation, as well as emotional and practical support, to families with sick children in hospital in the UK.

The Sick Children’s Trust was founded in 1982 by two paediatric specialists Dr Jon Pritchard and Professor James Malpas. Today we have ten ‘Homes from Home’ at major hospitals around the country where families can stay free of charge.

Big Chocolate Tea campaign

Big Chocolate Tea is The Sick Children’s Trust’s biggest annual fundraising event for chocolate, tea and baking lovers! It encourages people to get together with friends, family, colleagues or neighbours and raise money to support families with seriously ill children in hospital. Big Chocolate Tea will run for a month from **Tuesday 1 May – Thursday 30 May.**

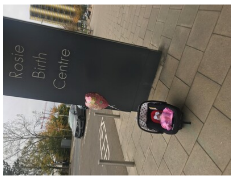
It costs The Sick Children’s Trust £30 to support a family for one night in a ‘Home from Home’ and every penny raised makes a huge difference.

Big Chocolate Tea is backed by The Sick Children’s Trust celebrity ambassadors, Sian Welby and Jen Pringle.

For the fourth consecutive year, we are delighted that Valrhona will be sponsoring Big Chocolate Tea.

This year’s fundraising pack includes cake cards, balloons, bunting and much more!

To take part in Big Chocolate Tea and receive a fundraising pack, please email bigchoctea@sickchildrenstrust.org or visit The Sick Children’s Trust’s website: www.sickchildrenstrust.org/bigchoctea/.



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