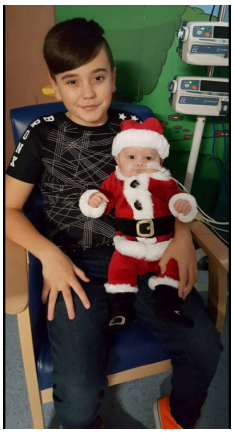
All I want for Christmas is a big family Christmas

Monday 11 December, 2017

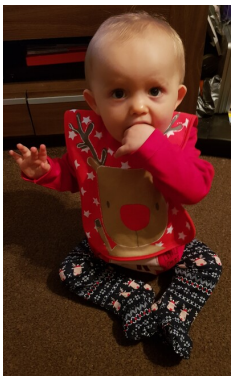
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At just seven weeks old Kobi became seriously ill and was diagnosed with multiple heart conditions, which led to him spending his first Christmas in Leeds General Infirmary. The Sick Children's Trust has supported Kobi's family at Eckersley House ever since his first admission. And as a thank you, Kobi and his family have joined in The Sick Children's Trust's first ever Christmas appeal! Mum Katrina Besley tells their story:

"Kobi was born on 15 August 2016 and at his newborn baby checks the doctor found a little heart murmur – when we returned a week later to have it checked again, the doctor noticed it had gone. We left the hospital reassured and began to settle into life with the newest little addition to our family.

However, everything changed when Kobi was just seven weeks and four days old. He went from taking 24oz of feed to just 9oz in a day and although, at first, we thought it was just very bad wind, we took him to our doctors' surgery just in case. Rather than telling us not to worry and sending us home, the doctor called ahead to Doncaster Royal Infirmary and told them we were coming in.

Looking back it's all a bit of a blur, but I remember being introduced to the same doctor who had detected Kobi's heart murmur originally. This time, as he listened to my son's heart it was clear things were not OK. The doctor found a large heart murmur and all too quickly my baby was wired up to machines, under constant observation and being fed through a tube directly into his stomach. This would be the first of many hospital stays and lasted just under two weeks. We were sent home now knowing Kobi had holes in his heart and a problem with the valve in his left ventricle, which had not formed properly. We knew he would need surgery once he was a little stronger.It felt like we were constantly in and out of the hospital, uncertain of what the future held.

Kobi wasn't happy, he wasn't breathing properly and he seemed agitated. Just weeks later, he crashed for the first, but not the last, time. We were petrified and hysterical. I was by myself in the hospital with Kobi, standing back not able to do anything, I called Moz, my partner, who was at work. He rushed to the hospital to meet me where doctors sat us down and told us the devastating news. Kobi needed to be intubated, but the risk was high. If they intubated him his heart might not cope, but if they didn't try then he would die. Our own hearts stopped – I looked at Moz and I knew we were thinking the same thing – we were going to lose our precious baby boy.

Thankfully Kobi stabilised enough to be transferred to the specialist Sheffield Children's Hospital. The Embrace transport team came to pick him up in Doncaster and we were told to go home and pack a bag and meet the ambulance outside Sheffield Children's Hospital when it arrived. I, Moz and my sisters, Chauntelle and Soraya, raced to Sheffield only to arrive hours before Kobi, because the doctors were struggling to get a line into his body in Doncaster. By the time he arrived late that evening we were exhausted, but grateful to see our baby boy.

We hadn't thought about where we could all stay and one of my sisters began calling in favours from a colleague who had connections to Premier Inn – to no avail. It was at this point that we learnt about The Sick Children's Trust which has since supported my family on three separate occasions. We were given a room in Magnolia House, a free 'Home from Home' run by charity only a few steps from where Kobi was being looked after.

To be so close to my baby meant everything – I was able to leave his side for a few hours, knowing that if anything changed I could be back with him in a matter of minutes. And it was comfortable too. Moz and I were able to shower and make a cup of tea, heat up a meal or simply relax on the sofa away from all the bright lights and loud beeps of the hospital.

We were in Sheffield a week before Kobi was transferred back to Doncaster. Two weeks to the hour after his first crash, Kobi crashed again, but this time it was more serious. This time he was transferred to Leeds General Infirmary (LGI), which is where we would all stay until Kobi came home on 15 March, almost four months later. Thankfully The Sick Children's Trust came to our rescue once again and this time we were given a lovely room at Eckersley House located in the grounds of LGI.

In Leeds, Kobi had three major operations on his heart. The first, was just ten days before his first

Christmas. It was to fix the holes in the wall of his left ventricle and split his left mitral valve in two. The operation seemed to have gone well and we began to look forward to spending Christmas as a family with Kobi's older brother, Kian, coming to stay at Eckersley House too. The staff at Eckersley were so lovely to him. A 12 year old boy gets bored very quickly in a hospital and so we could sit him in front of the TV in the living room, make him dinner in the kitchen and of course the staff took him under their wing when we couldn't think straight.

We had a lovely Christmas despite being in hospital. We woke up in Eckersley House on Christmas morning and after Kian had opened some presents we went straight over to visit Kobi before breakfast. We even got a smile out of him, which lifted the mood because being in a hospital with your baby when other parents are at home laughing and carefree, is difficult! The nurses on the ward were so jolly, all wearing their Christmas clothing and trying to lift our moods. Even though our lives felt far from normal we felt comfortable to leave Kobi for a few hours and make the journey back to Doncaster for a quick Christmas dinner at my sister's house. Thank goodness this year Kobi will be there with us.

Things began to look like they were on the up in the days that followed, but then Kobi crashed again just three days after Christmas and he was transferred back onto the paediatric intensive care unit (PICU). Kobi was moved between PICU and the high dependency unit (HDU) more times than you can imagine until his second operation six weeks later to repair the leaking left mitral valve. The final operation at the end of February gave him a new valve and the doctors were confident it wouldn't be long until we were allowed home. This day finally came on 15 March and I can't tell you how relieved we all were. It was an amazing feeling to finally take our baby home, but it also felt emotional to be leaving our Leeds home, Eckersley House, after all the support the team there had given us.

Eckersley House amazed me. Having somewhere to cook a meal, which allowed us to look after ourselves so we could be there for Kobi, was without question, an incredible relief. Being able to take ourselves away from the ward when it all got too much helped me keep my sanity and to be strong for my baby. I was also able to talk to other parents which helped me to cope. They acted as a distraction so I didn't feel continuously worried and anxious about Kobi. And then there was the house team, who were fantastic.

Eckersley House enabled us to stay together as a family. Kian would stay at weekends with Moz and I and it was wonderful. It was so important to me to have all my family together.

Kobi is still being monitored very closely and he will need another operation soon, but we are really looking forward to our first Christmas Day with him at home. A 'normal' family day. Kobi was a completely different baby when we brought him home after the third operation and has such a cheeky character so I can't wait to see his excited face on Christmas morning.

We still pop into Eckersley House before his appointments and borrow the kitchen if he needs feeding and catch up with the House Manager Jane and the rest of the team. Last time we visited LGI we went shopping afterwards and bought Kobi some Christmas outfits and his own special stocking, which says 'First Christmas', as last year our baby was too poorly for us to celebrate altogether. Thankfully this year it is a different story and we can't wait – Kobi can try turkey for the first time!

The Sick Children's Trust is a national charity which supports around 4,000 families every year. The charity relies entirely on voluntary donations to keep its ten 'Homes from Home' running, providing vital support to families with children undergoing lifesaving treatment in hospital. This Christmas it expects that every room in every house will be full with families, caring for some of the UK's sickest children.

Jane Featherstone, CEO at The Sick Children's Trust says: "No child should wake up on Christmas morning without their family around them. But this Christmas, many families with a critically ill child in a specialist hospital will face a long journey to be at their child's side."

"A donation of £30 will give a family a place to stay in one of our 'Homes from Home', just moments from their sick child. It costs The Sick Children's Trust £13,140 to run our ten 'Homes from Home' across the country over the Christmas period, keeping families together at one of the most important times of the year. Your donation can make this possible."

To keep a family together this Christmas, please visit: https://www.justgiving.com/campaigns/charity/sickchildrenstrust/alliwantforxmas.

To watch the Christmas appeal film, visit: https://youtu.be/qpgKkZuPWmc.

For more information on The Sick Children's Trust and for other ways to donate, please visit http://www.sickchildrenstrust.org/Donate/.



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