It allowed us to live a relatively normal life in an utterly abnormal time

Friday 12 August, 2016

Arthur was born seemingly fit and healthy. For all the assessments and tests every new-born goes through, our son was given the thumbs up. There were no suspicions of what was to come.

It was when Arthur was about three months old that he began to let us know things were not as they should be. He began to vomit. Not just ‘spit up’ - it was a violent regurgitation that resulted in all his feed coming back up. This would happen three to four times every day. We were assured several times by our health professionals that this was just reflux. Besides, what else could it be? He showed no other signs and symptoms of it being something more. As Arthur was our first and only child we had no reference as to whether this was a normal experience or not.

Then Arthur began to have significant weight loss and these words of assurance turned into words of doubt. Our son had started to miss his weight milestones, which worried us, but made sense as he was keeping so little feed down.

One morning, a few days after the New Year, Arthur wouldn’t stop vomiting. Something deep inside told my wife and I that the current trajectory of treatments and assessments were no longer appropriate. We took him into our local hospital in Tunbridge Wells.

It turned out Arthur had blood oxygen saturations of 73%. None of the medics could quite believe the reading. The staff even changed the monitor twice as they couldn’t believe Arthur would be as active and smiley as he was. Besides, at 73% blood saturations, there should have been a bluish discolouration of the skin. But it turned out the readings were correct and Arthur was placed on oxygen until his levels returned to normal. It was now up to the consultants to work out what the diagnosis was.

After weeks of going backwards and forwards, and hard work on the hospital’s account, several possible problems were suggested. We were transferred to the Royal Brompton Hospital, and it was there that they speculated that Arthur may have interstitial lung disease.

A Computer Tomography Scan at this incredible hospital was undertaken and from its results a tentative diagnosis of lung disease was confirmed. However there was still something not quite right. Arthur’s T-cell count was worryingly low, meaning that he couldn’t fight off infections.

The medical team wouldn’t let this curiosity go and chased up more results, sending us to Great Ormond Street Hospital (GOSH) for extra tests, where the best people were to find out what Arthur’s complex condition was. When the results came back, we were placed in isolation and the course of treatment turned on its head. GOSH had diagnosed Arthur not with interstitial lung disease, but with Severe Combined Immune Deficiency (SCID). This, quite simply, meant that Arthur was born without an immune system.

We had to leave the Royal Brompton to get Arthur the best possible care available for him. We were transferred to GOSH and placed once again in an isolation ward. GOSH explained the procedure and how this genetic issue can be solved. The re-assurance and explanation of their cutting edge research gave us hope that we had a chance of Arthur making a full recovery even with all the risks which were terrifying. It was clear we would have to be at GOSH for quite some time while Arthur got better and prepared for the bone marrow transplant which could save his life. Amongst all of this stress and worry, we were told that there was only enough accommodation for one of us to stay with Arthur. There wasn’t room for both of us.

Neither of us wanted to be away from Arthur and we lived over two hours away. What were we going to do? We were already very emotional from being in and out of hospital for three months trying to figure out what was making Arthur so poorly and one of us having to return home or use the hospital accommodation. We also had to deal with the news of Arthur’s diagnosis.

When we finally had a definitive cause for his sickness we felt a huge relief. Finally, there was a known condition, something that he could be treated for. But it was only as the hours and days passed that the

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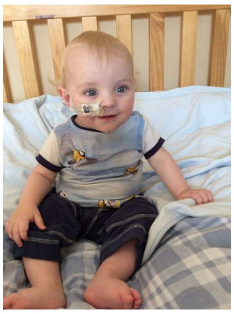

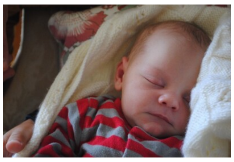

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reality of what S.C.I.D meant diffused through us. The feelings of fear, despair and unfairness began to creep in like a liquid slowly working its way through our core.

It was at this point, in our darkest and most fearful hour, that The Sick Children's Trust came into our lives. They supplied us with a room literally a five minutes' walk away from GOSH, completely free of charge, at a place called Guilford Street House. This benevolence meant that we didn't have to worry about how we were going to make looking after Arthur work. Their kindness reduced the stress dramatically at what had been an already very stressful time for the previous three months. It allowed us to support each other, to wash and dry our clothes and live a relatively normal life in an utterly abnormal time. Not only this, but the kindness and warmth shown to us by Tina, who managed Guilford Street House, was such a boost. On a practical level, the cleanliness and decorative level of the charity's 'Home from Home' was without fault, something which back home you may take for granted, but it made a significant difference to our state of mind.

We have just come back to GOSH for Arthur's bone marrow transplant which went really well, and now he starts chemotherapy. We are currently on the waiting list for Guilford Street House while he undergoes treatment. There's a huge demand for a room in the charity's 'Home from Home' – and to keep Guilford Street House running, alongside The Sick Children's Trust's other nine houses, the charity relies entirely on voluntary donations.

My wife, Alice, Arthur and I would like to thank The Sick Children's Trust for the generosity and care that they gave to us as a family. Guilford Street House had a huge impact to our lives – there are too many things to mention which the charity gave us. The most important though was the gift of peace of mind which allowed us to give more to Arthur, which we believe significantly improved his recovery. Thank you.

Ben, Alice and Arthur Randall

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