Dad on fundraising mission to thank charity who helped family after birth of seriously ill daughter

Monday 13 November, 2017

The father of a baby girl who was born unable to swallow and had to undergo multiple surgeries starting from her first week of life is on a mission to raise money for The Sick Children's Trust to thank the charity for supporting his family whilst his daughter received lifesaving treatment in hospital.

Dr Simon Hill, 30, a De Montfort University lecturer from Bedworth, has raised £303 so far for the charity by organising weekly 5km runs around the Miners Welfare Park. The runs, which are held every Sunday at 9am, are for runners and walkers who want to get fit and meet others from around the local area. With a weekly turnout of up to 90 participants, the runs have been a resounding success and have raised vital funds for The Sick Children's Trust, a charity close to Simon's heart.

Simon and his wife, Jennifer, 28, were devastated when their daughter Emilia was born on 2 June 2016 with a rare congenital condition of the oesophagus, trachea-oesophageal fistula (TOF). TOF is when the bottom end of the baby's oesophagus is joined to its windpipe and not connected to the mouth. Within a few hours of being born with this life-threatening condition, Emilia had to be rushed by ambulance to The Rosie Hospital in Cambridge, over an hour and a half away from home. **Dad, Simon, who has organised ten 5km Sunday runs to date and has planned nine more in the coming months, says:**

"We were shocked when Jennifer went into labour five weeks early and we just didn't know how to react when we were told that Emilia was seriously ill. The labour is meant to be the most traumatic part, but for us there wasn't the time or space to come to terms with what the doctor was telling us about our baby's condition. All of a sudden our lives were being turned upside down and we were being told that Emilia needed to be immediately transferred from George Eliot Hospital in Nuneaton to The Rosie Hospital in Cambridge for lifesaving surgery.

"Two hours after Emilia was whisked away in an ambulance Jennifer was discharged and we rushed home to pack a bag each and then raced to The Rosie Hospital. Jennifer was so brave. We hadn't had time to think about where we might stay or how long we would be away from home. It was mentioned that some accommodation might be available before we left, but little did we know that we would be sleeping only the floor below Emilia's intensive care cot for 45 days. All of this courtesy of the generosity of The Sick Children's Trust."

During Emilia's first treatment in Cambridge, The Sick Children's Trust gave Simon and Jennifer free 'Home from Home' accommodation at Chestnut House, which is located just below the neonatal intensive care unit (NICU), minutes from their daughter's intensive care cot. **Simon, who, as part of his fundraising endeavours, is preparing for the Outlaw Triathlon in Nottingham in July 2018, continues:**

"Being given a room at Chestnut House when Emilia was in The Rosie Hospital meant that we were never more than a few minutes away from our baby. There was a direct phone line in our room straight to NICU where she was which helped with the anxiety of leaving her each night, as the nurses could contact us 24 hours a day. It was so comforting to know that if anything changed during the night we could be with our daughter in a couple of minutes. Chestnut House was absolutely amazing. When we were told that the room was also free of charge we couldn't quite believe it!

"We had no idea that The Sick Children's Trust existed to help families like us. When we were desperate they gave us a home as well as emotional support and comfort. We were there for 45 days and it became a 'Home from Home' for us both. Family members could come to visit Emilia and we were able to take them to Chestnut House to sit, enjoy a cup of tea and chat. It was so comfortable and homely. There was even a playroom full of toys for children who were also staying there to play with."

The Sick Children's Trust also supported the Hill family earlier this year at its Acorn House, the charity's other 'Home from Home' in Cambridge, when Emilia needed further treatment at Addenbrooke's Hospital. **Simon continues:**

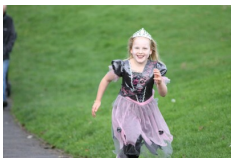
"The weekly 5km run was an idea I had a while ago. We time everybody and then share times on the Facebook group, but it is not a race, more of a personal challenge. It is designed to help people improve their health and meet socially. So far we have 457 registered runners and hopefully we can attract many more. If people donate just £1 or what they can every time they run we will be able to raise so much

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money for The Sick Children's Trust and other charities we are supporting who have helped us since Emilia was born. We recently held a Halloween themed run and it was such a fun morning, with Alli Norman and Lacey Arnold taking the prize for best costumes!

"Emilia still needs regular procedures to help widen her oesophagus at Addenbrooke's Hospital every six weeks, but now she is stronger we can do the journey there and back in a day.

"We still pop in to see Abi and the team at Chestnut House when we can. They all became good friends in our time of need. Even though we spent so long in Cambridge we met other parents going through terrible ordeals and realised how lucky we were that Emilia was recovering and growing stronger – even though she still struggles with certain foods. Jen and I are getting braver as she gets older and it seems like a lifetime ago when our baby was born unable to swallow and The Sick Children's Trust first came to our aid."

The Sick Children's Trust runs ten 'Homes from Home' across the country, giving families with seriously ill children free accommodation just minutes from their child's hospital bedside. The charity relies entirely on voluntary donations and it costs the charity £30 to support a family for one night. **Chestnut House Manager, Abi Abdel-aal, says:**

"Simon has done such a great job, it's fantastic that he's organising these events that not only benefit so many people on a personal level, but hundreds of families with seriously ill children in hospital that need a 'Home from Home'.

"Simon and Jen were with us at Chestnut House for quite a while and we really got to know them and their family well. I am so pleased that Emilia is getting better every day and it is nice to see them when they drop in to say hello. I can't believe Simon is also going to take on an Ironman Triathlon – what an amazing thing to do!

"As a charity, The Sick Children's Trust relies entirely on voluntary donations so we can continue to run our ten 'Homes from Home' across the country, supporting families with seriously ill children in hospital. The money Simon and his family have and will raise is going to make a huge difference to many families who need our support."

To get behind The Sick Children's Trust and take part in the weekly 5km run in Bedworth, please visit the facebook page https://www.facebook.com/bedworth5k/

To sponsor the weekly Bedworth 5km runs, please visit https://mydonate.bt.com/fundraisers/simonhill5

To sponsor Simon's Ironman Triathlon, please visit https://mydonate.bt.com/fundraisers/simonhill4

For further information about The Sick Children's Trust, please visit http://www.sickchildrenstrust.org/

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