Mum runs to raise money for charity after keeping family together

Thursday 17 August, 2017

The Mum of two children diagnosed with a rare life-threatening condition is running the Great North Run to thank The Sick Children's Trust for keeping her family together during the toughest of times.

Jessie Leggett, 32 from Ipswich, is lacing up her trainers to raise money for The Sick Children's Trust which supported her and husband Ryan with free 'Home from Home' accommodation when her children were rushed 57 miles away from home to Addenbrooke's Hospital, Cambridge, for lifesaving treatment.

During 2016, both of Jessie's children – Esmae (three years old) and Dexter (ten months old) – were rushed to Addenbrooke's Hospital with respiratory problems which were later discovered to be a rare inherited disorder called glycogen storage disease type 4 (GSD type 4) – an abnormal accumulation of glycogen which can lead to liver and heart failure.

When Jessie was pregnant with Dexter, her daughter Esmae was treated for swelling around her heart. And when Dexter was just six weeks old, he was admitted to the specialist hospital after contracting the rhinovirus. Dexter was the first to be diagnosed with GSD type 4, and Esmae's diagnosis followed shortly afterwards. On both occasions, Jessie and husband Ryan were supported at The Sick Children's Trust's Acorn House, located just a few minutes' walk from the hospital. **Jessie says:**

"When Esmae was poorly, and I was pregnant with Dexter, only one of us was allowed to stay on the ward. We decided I would sleep next to Esmae's hospital bedside, but we had no idea where Ryan would stay. Thankfully, The Sick Children's Trust came to our rescue and told us we had a room in Acorn House, which is one of the two 'Homes from Home' the charity runs in Cambridge. I remember Ryan coming back to the ward after dropping his bag off and being over the moon. He was just amazed that such a place existed. A place that was there to support families with seriously ill children.

"When we left Acorn House that first time, we never thought we'd be back there just eight months later when our baby son Dexter was fighting for his life. This time it was ten times harder since we had to leave Esmae behind with our parents as we travelled to the hospital with our poorly baby. When we arrived at Addenbrooke's Hospital, I was told I couldn't sleep next to Dexter but we were handed a set of keys for Acorn House once again. I cried with mixed emotions – I didn't want to leave my baby but I was so relieved that I could just be a few minutes from his bedside because of The Sick Children's Trust.

"We were soon given the news that Dexter had GSD type 4 and it was recommended that Esmae was tested for it too. When they told me Dexter had it – I thought he was going to die, and then when it was discovered Esmae did too I honestly thought I was going to lose both my children. We were told to go home and make memories with them as the only information about this condition was that it was life-limiting. I was utterly heartbroken.

"It was at that time, when we tried to take everything in, that it was so important to have The Sick Children's Trust's support. Acorn House gave me and Ryan somewhere to escape every night - to talk, cry and chat to parents in similar situations. We felt like our world had ended."

Dexter remained in hospital for four weeks before becoming strong enough to be discharged home for the first time. And despite the siblings' diagnosis, both Esmae and Dexter are doing really well and are happy, healthy children. **Jessie, who is running the Great North Run with her mum Jane Eustace, adds:**

"I was so worried and fearful for Dexter that I thought I would never sleep, even though I was shattered. But after leaving his hospital bedside, I walked over to Acorn House to have a shower and when I got into bed I drifted off and had the best night's sleep.

"The littlest things in life, like washing your clothes and sitting down for a homemade meal made all the difference. It made me and Ryan stronger for our children. The Sick Children's Trust was there for us – through all the emotional turmoil - and it continues to be there for us.

"Acorn House allowed us to be a family when we needed to be, to give our daughter Esmae a bit of normality – like by making cakes and playing with her when her little brother was seriously ill. And most importantly it gave us a place to rest on both occasions, giving us the peace of mind that our children

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were just minutes away. I dread to think how I would have coped without it."

Jessie and her mum Jane are hoping to raise £1,500 for The Sick Children's Trust which relies entirely on voluntary donations to run its ten free 'Homes from Home'. **Campaign & Appeals Manager, Caroline O'Doherty, says:**

"It's so lovely to hear that Esmae and Dexter are doing well, and we are so pleased that we could be there on more than one occasion to support Jessie and Ryan.

"We're wishing Jessie and her mum the best of luck with the Great North Run and would like to thank them for fundraising for The Sick Children's Trust. Our 'Homes from Home' are provided free of charge to families with seriously ill children in hospital, but it costs the charity £30 to support a family for one night, so their support really means a lot to us."

To support Jessie, please visit her fundraising page:
https://www.justgiving.com/fundraising/Jessie-Leggett

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

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