Parents of baby given just 20% chance of survival back charity campaign

Monday 19 September, 2016

The parents of a baby who was given just a 20% chance of survival are asking the nation to support The Sick Children's Trust's Pyjama Party after the charity supported them with free 'Home from Home' accommodation.

14 month old Ruby Callaghan, Northern Ireland, was born with a serious heart condition – dilated cardiomyopathy - where her heart was three times larger than usual. Not long after she was born, Ruby was transferred to Belfast Royal Hospital where her parents, Jo-Ann McCullough and John Callaghan were told that there was no cure and Ruby would die without a new heart.

Ruby was eventually transferred to Newcastle upon Tyne's Freeman Hospital for a heart transplant. Before a heart became available, while she waited, Ruby had three cardiac arrests and her parents had to make the heart-wrenching decision to not resuscitate should another happen. While Ruby was treated at Freeman Hospital, her family were supported with free 'Home from Home' accommodation run by The Sick Children's Trust and finally after a 76 day wait, Ruby received her new heart. **Mum Jo-Ann says:**

"For weeks I couldn't pick up my daughter because she was ventilated in the incubator with so many different medicines feeding into her tiny body. She made a slight improvement, but quickly went downhill again as her heart began to fail. It became clear that our brave baby couldn't fix her heart herself. She needed help and what she needed was a new heart. Without a transplant we would have to let her go.

"When things looked at their bleakest, a bed finally became available at Newcastle's Freeman Hospital. This was one of only two places in the UK where Ruby could be fitted with a Berlin Heart device, which pumped her blood for her before a transplant organ became available.

"It took 76 days for Ruby to receive her new heart after officially being put on the waiting list, but due to her various complications, it felt like years. I remember going down to the ward to see her with my partner and our eldest daughter, Lily, and we knew something was happening because a few of the nurses couldn't stop smiling. Finally we were told that there was a heart available and it was Ruby's if it matched. I couldn't stop smiling and crying. I was so happy! It was like a massive weight had been lifted."

Ruby is now back at home and doing really well. Her parents Jo-Ann and John are calling for the nation to help raise funds for The Sick Children's Trust by getting involved with the Pyjama Party. Pyjama Party is a fun filled day where children are sponsored to come to nursery or playgroup dressed in their favourite pyjamas and take part in various activities. **Jo-Ann continues:**

"We were miles away from home and didn't know where we were going to stay.

"Luckily, on arrival we were offered free 'Home from Home' accommodation at The Sick Children's Trust's Scott House, which was just a few minutes' walk away from the hospital. This meant that we could visit Ruby at any time of the day as she waited for her life-saving donor heart.

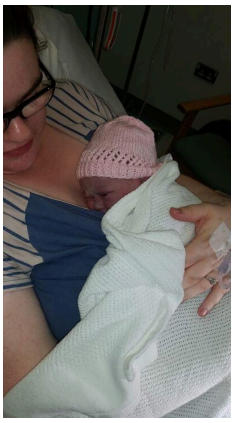
"Ruby is now doing really well and we want to thank The Sick Children's Trust for giving us a room to stay in so we could be nearby our daughter as she underwent lifesaving surgery. Scott House provided us with a space of our own to process things quietly, away from the wards, and not have to worry about anyone else. It really was a lifeline. So if you can support the charity by getting involved in Pyjama Party, please do."

The Sick Children's Trust runs ten 'Homes from Home' two of which are located in Newcastle upon Tyne. **Scott House Manager, Andrew Leadbitter, says:**

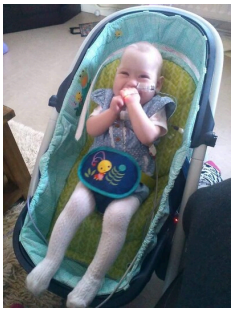
"It's wonderful to hear how well Ruby is doing since her heart transplant. The Sick Children's Trust helps families from all over the UK who have to travel miles to get their loved ones life-saving treatment. When your child is so seriously ill, it's an incredibly difficult time. Scott House - along with the charity's other 'Homes from Home' - helps ease some of those worries by keeping families together."

The Sick Children's Trust's Pyjama Party takes place from Monday 17 October to Friday 21 October.

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For more information on The Sick Children’s Trust’s Pyjama Party, please visit: http://bit.ly/2bpm0ls or email fundraising@sickchildrentrust.org.

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