Baby born with life-threatening condition celebrates first birthday

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A little girl who was born with her organs outside her body celebrates her first birthday next week, after a year of lifesaving medical treatment.

Sophie Tarling spent the first four months of her life in the neonatal intensive care unit (NICU) far away from home in The Rosie Hospital, Cambridge. Being born prematurely at 34 weeks, Sophie needed urgent medical attention after being diagnosed with a congenital overgrowth syndrome found in just one in 15,000 babies. The condition - Beckwith-Wiedemann Syndrome – affects the growth of the body, and for Sophie caused her bowels and part of her liver to be on the outside of her body.

At just 24 hours old, Sophie underwent intensive surgery to save her life. While Sophie was on NICU, her parents – Rachel, 34, and John, 30, - were supported with free 'Home from Home' accommodation run by The Sick Children's Trust, so that they could be just minutes from their daughter. **Rachel, a primary school teacher, says:**

"When your child is so ill it's incredibly scary – we were lucky enough to be given a room at The Sick Children's Trust's Chestnut House, which is just below NICU. Being supported at Chestnut House meant we could be with Sophie before she went into theatre and be there for her once she came out. As a mother your natural instinct is to be with your child, not far away while they lay in hospital in a critical condition. Chestnut House made it possible for me to be with my daughter at the time she needed me the most.

"Due to complications, for the following four months, she remained in NICU at The Rosie Hospital and we were fortunate to be supported by Chestnut House during some of this time. Travelling to the hospital every day was nearly a two hour round trip and made this time ever so more difficult for John and I. It was very draining emotionally and physically and made us appreciate Chestnut House so much – it made a huge difference to our experience. We could make meals in the kitchen and build our strength up for Sophie, and there was a communal living room so we'd chat to parents who were in a similar situation to us which made us realise we were not alone."

Over the last few months Sophie's family have been fundraising and raising awareness of The Sick Children's Trust's 'Homes from Home' including her auntie, Hannah Lockwood, 20. Earlier this year Hannah did a skydive which raised £1,250 for the charity. **Hannah, a catering supervisor, says:**

"Rachel was travelling to and from The Rosie Hospital for a number of weeks so she could be with Sophie and it was clear this was having a significant impact on her emotional and physical well-being. When Rachel and John were given free 'Home from Home' accommodation by The Sick Children's Trust I was so relieved. I felt comforted to know that they had Chestnut House, as it was somewhere they could get some respite and be near their daughter."

The Sick Children's Trust runs ten 'Homes from Home' across the country supporting families with seriously ill children in hospital. Every year, the charity supports over 4,000 families with free 'Home from Home' accommodation, enabling them to remain close to their loved ones. **Chestnut House Manager, Abi Abdelaal, says:**

"Sophie and her family called into Chestnut House to present us with the cheque from Hannah's fundraising earlier this week and we were delighted to see how well Sophie is!

"We'd like to thank Hannah very much for fundraising for The Sick Children's Trust; this money will benefit so many families and help them to stay by their child's hospital bedside. Although our 'Home from Home' accommodation is free for families, it costs the charity £30 to support a family for one night. Thanks to Sophie's family, many families will be able to stay together during the toughest of times."

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