Couple whose daughter is one in 10,000 raise nearly £2,000 for The Sick Children's Trust and CHUF

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The family and friends of a little girl who was diagnosed with a rare heart condition at birth have raised nearly £2,000 for charities The Sick Children's Trust and the Children's Heart Unit Fund (CHUF).

Esme Hamlyn was born during lockdown at Friarage Maternity Centre in Northallerton. Her parents, Stacey and Karl, were getting ready to take their newborn home when the midwives noticed Esme's oxygen levels had dropped. She was soon transferred to James Cook Hospital in Middlesbrough for scans of her heart and lungs before being taken to Freeman Hospital in Newcastle where she was diagnosed with Ebstein's anomaly. Ebstein's anomaly, which affects one in 10,000 babies born, affects the valve which directs blood through the right side of the heart and doesn't work properly.

While Stacey was able to stay in the hospital following a negative COVID test, Karl had to make the long journey home to Guisborough not knowing whether his daughter would need major heart surgery. Thankfully, the following morning, the couple were told that Karl could stay at Scott House, run by The Sick Children's Trust, located just a few minutes' walk from the paediatric heart unit. This meant that during Esme's two week treatment in Newcastle, both her parents could be close by even during the coronavirus pandemic. During this time, alongside support from The Sick Children's Trust, the couple received meal vouchers from CHUF, which provides holistic care to children and their families, alongside vital funds for large and small pieces of equipment, facilities, aftercare, salaries and research. **Stacey said:**

"On the day our daughter was born, we were delivered the news she had a lifelong condition and we couldn't stay together. With the restrictions around coronavirus, Karl had to drive all the way home and I was really concerned about him making the 1 hour 15 minute journey, by himself, but this was the reality we were facing until she was allowed home.

"With the support of The Sick Children's Trust, both me and Karl could be there with Esme. We couldn't be together by her bedside, but at least one of us could always be, without the other being far away. Leaving your child in hospital is the hardest thing in the world, but the nurses encouraged us to leave her side to rest so that we would stay strong for Esme. It was the best advice. Scott House made this so much easier though as we only had to walk down a corridor to have an hour to ourselves and sleep in a quiet room, to only have a few minutes' walk to be back at her side. Another charity, CHUF, gave us meal vouchers. Without those vouchers, we would've probably gone without. Instead, we ate regularly throughout the day which really made a difference to our wellbeing.

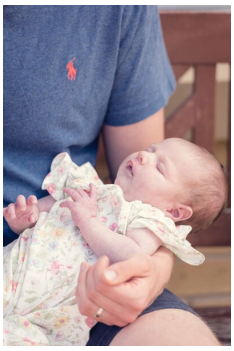
"Esme was given medication to prevent further issues with her heart and give it a chance to grow before any operations are scheduled. Esme might never need an operation, but then again she might. No parent should have to go through what we went through without the support from charities like The Sick Children's Trust and CHUF and so while we were at Freeman Hospital, we set up a fundraising page for them which has raised £1,800. We know that fundraising is hard at the moment and also know that anything helps."

During these unprecedented and uncertain times, The Sick Children's Trust has continued to support families, like Esme's, with a place to stay close to their child. It costs £2.2 million to run The Sick Children's Trust's ten 'Homes from Home' across the country and the charity relies entirely on voluntary donations to meet this cost. **Jane Featherstone, Chief Executive at The Sick Children's Trust, said:**

"We're incredibly grateful to Esme's parents for setting up a fundraising page to support us during their time in hospital. Our 'Homes from Home' help ease some of the concerns families experience when their child is in hospital by giving them a place to stay and this money will go towards helping more families like Esme's.

"It is a worrying and uncertain time for everyone and there are many challenges we are all facing but for families with seriously ill child in hospital there is even more worry and uncertainty. This is why we need your support, whether that's setting up a birthday fundraising page, taking on a virtual challenge or making a donation. Anything you can do to help will go towards supporting a family with a child in hospital."

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Charlotte Campbell, Director of Fundraising and Operations at CHUF, said: “We are beyond grateful and really thankful to Esme’s family for helping to raise these vital funds, especially during these difficult times. Every penny raised contributes towards life-saving equipment, facilities, aftercare, salaries and research for the Children’s Heart Unit in the Freeman Hospital and six district hospitals in the Northern region, and ultimately helps children like Esme and her family through uncertain, scary times. Thank you to Heart Hero Esme and her family.”

To find out more about The Sick Children’s Trust visit sickchildrenstrust.org and CHUF visit chuf.org.uk

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