Baby Who Spent First Year Of Life In Hospital Celebrates First Birthday At Home

Friday 10 February, 2017

The family of a baby girl who spent the majority of her first year of life in hospital are delighted to be celebrating her first birthday at home.

Little Emma Gulliver, from Beccles, spent her first Christmas and New Year in Great Ormond Street Hospital (GOSH), but is celebrating her biggest milestone at home today.

Just a week after Emma was born last February, she was diagnosed with Hirschsprung's disease a nerve condition which causes serious chronic constipation. Her family's lives were turned upside down when a week later doctors suspected Emma had a breathing condition called congenital central hypoventilation syndrome (CCHS), which caused her to take shallow breaths and hypoventilate. Her parents Claire and Chris were told she needed to be transferred to Great Ormond Street Hospital (GOSH) for a lifesaving tracheostomy and ventilation. For the following four months, Emma was treated in GOSH – over 125 miles away from home. During this time, Emma's mum Claire was supported with free 'Home from Home' accommodation provided by The Sick Children's Trust. In November, Emma underwent further surgery at GOSH and although the procedure went well, she has had numerous infections and remained in hospital until January**.**

Mum Claire says: "It's been lovely having Emma home and settling into a routine with her. The boys have loved having their mummy and sister around again and have been playing with Emma a lot more now she can sit up and interact with them! We've invited friends to join us for tea and cake to celebrate her birthday today and to say thank you for their support, then we have a big family celebration planned on Sunday."

Looking back on the year, Claire adds: "We had to wait a month at the Norfolk and Norwich Hospital before we could be transferred to GOSH. The thought of going to another hospital so far away from our home was very scary. We knew we could be there for months and I worried about how our family would be able to support each other during this extremely difficult time. My husband Chris is a businessman, and could not take time off work for months on end, and our little boys, aged just five and two, needed to stay at home to go to school. I knew I would have to go with Emma to London alone. Miles away from home and with a very sick child, I felt very lonely, upset and confused. I couldn't bear the thought that our family would have to spend months apart, but we couldn't afford to keep the whole family together in central London hotels either.

"Thankfully, it wasn't long before I was offered a room at Guilford Street House – free 'Home from Home' accommodation run by The Sick Children's Trust. Having a room at Guilford Street throughout Emma's treatment was amazing; it enabled me to be near Emma so I could be trained in her care and bond with her. It also meant the rest of the family could visit her regularly and her brothers could understand her condition and get to know their little sister better.

"Although Emma has spent the majority of her first year in hospital, we really are hoping that she makes some great improvements this year."

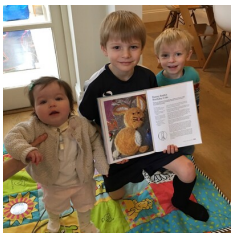
The Sick Children's Trust runs ten free 'Homes from Home' across the country supporting over 4,000 families with seriously ill children in hospital. **Guilford Street House Manager, Tina Thake, says:**

"We wish Emma a very happy first birthday at home! We're so pleased we could be there for her family when they needed to be just minutes from her hospital bedside.

"The Sick Children's Trust will support thousands of families in its ten 'Homes from Home' across the country, helping them stay close to their seriously ill child. Although the accommodation is provided free to families, it costs the charity £30 to support a family for one night, and we rely entirely on kind donations from individuals."

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

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