

## Girl who had 70% of Lung Removed Starts School

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A little girl who had 70% of her lung removed before she turned one, and a kidney removed at three years old, is now packing her bag ready to start school for the first time this September.

Four year old Emily Norris was born with congenital cystic adenomatoid malformation, a rare condition which meant her right lung was made up of cysts. It was also discovered that Emily had a multicystic dysplastic kidney – something which is extremely rare to see combined with Emily's other condition.

Since her first operation on her lung, Emily has undergone three more – one of which was to remove her diseased kidney. Now, as Emily prepares to take a big step into school, Mum Nicol is nervous but excited to wave her off at the school gates. **Mum Nicol Pybus says:** 

"Emily is doing really well. And although she still struggles to grow at the same rate as other children and has her feeding tube, she can't wait to start school and has been asking constantly through the summer holidays if she can go to school yet. She has never let her medical issues stop her and just sees herself as a normal four-year-old.

"I'm nervous like any mum whose child is starting school for the first time but also anxious as she still has unresolved issues with her health and can't eat normally like her classmates. She has come a long way since her operations and stuns me with her determination and confidence."

During Emily's treatment at GOSH, Nicol was supported by The Sick Children's Trust. The Sick Children's Trust supports families with seriously ill children in hospital by giving them free 'Home from Home' accommodation. Nicol was supported by the charity's Guilford Street House for ten days while Emily was in hospital. The 'Home from Home', located just minutes from Emily's hospital bedside, meant Nicol could be with her daughter throughout her treatment. Without the room, Nicol would have had to make the two hour journey daily to be by her daughter's side. **Nicol continues:** 

"I have no idea what I would have done had it not been for The Sick Children's Trust. Because Emily was so poorly and being treated first on the intensive care unit and then on the high dependency unit, I couldn't even sleep in a chair beside her.

"I suppose I would have had to return home and leave Emily alone until she was well enough to leave. I certainly couldn't afford to stay in a London hotel and I don't even have any family or friends in the south east who could put me up for the time she was in hospital. So The Sick Children's Trust really came to my rescue and helped me stay with my daughter and the most important time."

Every year, The Sick Children's Trust supports around 4,000 families with seriously ill children. It costs around £30 to support a family for a night in one of the charity's ten 'Homes from Home'. **Guilford Street House Manager**, **Tina Thake**, **says**:

"Nicol has kept us up to date on Emily's progress over the years and we have got to know her very well – she's a little star.

"It is families like Emily's that really need the charity's support so that they can be kept by their loved one's hospital bedside. Nicol lives over 100 miles away from Great Ormond Street Hospital and it would have been a huge amount of stress and worry to have left Emily's side, or travel back and forth every day. By having a 'Home from Home' it eases some of those worries and allows families to focus solely on their child."

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