

# Our TRANSPLANT story



Ellie (in blue) with sister, Grace, and brother, Monty, at the back



**Ellie Bleiker, 13, was diagnosed with Biliary Atresia as a baby and six months ago a liver transplant saved her life. Almost 50 years since the world's first ever liver transplant, her mother Anna shares their family's story to highlight the importance of research into digestive diseases.**

“ Ellie was our first child, and things were absolutely fine to begin with. But when she was four weeks old, a visiting nurse noticed Ellie's urine was yellow, which led to major tests including a liver biopsy and eventually a diagnosis of Biliary Atresia (BA) – something neither I nor my husband D'Arcy had heard of. **Ellie's Kasai operation, to create a new bile duct, was relatively successful but it was the start of a slow journey.**

We always kept Ellie as well informed as her age would allow. We were unsure for many years how long her liver would hold out for – the doctors predicted that she would probably need a new liver around the age of eight. The problem was that Ellie's Kasai really had taken a bit of time to kick-in and her liver was scarring until it did. Irreversible damage was done, and although it would work well enough for the time being, it would almost certainly not last a lifetime. **As Ellie got older, the word 'transplant' was mentioned more frequently and we were listed for transplant in October 2016.**

On the day we found out a liver had become available, we got the call at midnight and the ambulance arrived within seven minutes. We were on the ward by 5am, waiting expectantly, but Ellie didn't go to theatre until 12 hours later. We subsequently found out that our donor was on life support, and they were going to turn it off once everyone was ready and in place for the incredible multiple transplants that had been arranged following the family's consent to do so.

This was a terrifying day and night and nothing prepared us for how Ellie looked afterwards. She was utterly dwarfed by the technical equipment around her. **She had so many tubes connected to her that we could barely see her amongst it all.**

Amazingly, we were home just 12 days after the operation – testament to our brilliantly strong little girl and to the incredible work done by the NHS.

It has been six months since the transplant now, and things are remarkably different. **We saw the whites of Ellie's eyes for the first**

**time after just 24 hours - which in itself was a special moment.**

The itchiness that has plagued her stopped immediately, her appetite changed and she actually became nicer! The sleep deprivation had taken a huge toll on her well-being, her daily moods and her capacity to think. She had been sleep-deprived her whole life.

**We are all very aware of the debt we owe to an incredible young woman who tragically lost her life, but was able to save our daughter and others. We continually thank the NHS for their incredible care and support. We owe them our family.** ”

## **£190,000 Research Grant, Dr Neil Henderson explains:**

*“Biliary Atresia is a devastating condition which causes inflammation and destruction of children's bile ducts and can lead to scarring of the liver, liver failure and death. In 2014, Core provided a three-year research grant with the Children's Liver Disease Foundation to me and my team at the University of Edinburgh to help investigate new treatments. When biliary fibrosis becomes severe, the liver begins to fail and currently our only available treatment for end-stage liver scarring is transplantation. However, a shortage of donor organs means many patients die on the waiting list, and patients undergoing liver transplantation have to take immune system suppressing drugs for the rest of their life. Therefore, effective new treatments for biliary atresia and fibrosis are urgently required.”*

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