



## LEVI'S STORY

As told by mum, Rebecca

**I was born on the 8th of March, 2012 at 7.26am, weighing 8lb 6oz. I was born at Christchurch Women's Hospital. After I had all my checks and had a good feed we transferred to St George's Hospital. I seemed a happy healthy baby who loved sleeping. It was bliss.**

However, the next day I kept throwing up bright green stomach bile. I wasn't feeding, nor soiling nappies and I became very dehydrated. That night the midwife realised something wasn't right at about 2 o'clock in the morning. She called the Paediatrician to come in. The next thing I know I'm being connected up to the incubator to be taken in an ambulance back to the hospital where I was born.

At about 6 o'clock in the morning I was settled in NICU and the Doctors came to talk to my Mum and Dad. They said they believed I had something called Hirschsprungs Disease and I needed to have a tube put in to help my poo come out, otherwise my tummy was going to burst. This was all very scary for my Mum and Dad who had been up all night and didn't really understand what was happening to me. I was content and warm sleeping in my wee room, I guess the morphine helped.

*My first surgery was at just 4 days old. My parents found it very hard being in NICU and seeing me like this. They had my big brother who was just 16 months old to look after as well.*

The next morning the nurses rushed into my Mum's room upstairs and told them I needed an emergency surgery to attach a colostomy bag so I could poo. I was very sick and bloated. My first surgery was at just 4 days old. My parents found it very hard being in NICU and seeing me like this. They had my big brother who was just 16 months old to look after as well. Mum felt very out of place in NICU, she didn't feel very welcome. It was all very emotionally draining for them, especially my Mum. She just wanted to take me home and start our family life like we all expected was going to happen

after having a baby. She missed our newborn days at home together.

My surgery went well and I was feeling a bit better, I was tube fed for awhile. Before we could go home I had to be able to have more food without throwing it up again. We started with 2mls of milk, slowly went up to 5mls, but 7mls was too much. I eventually got there in the end. I was out of the incubator and in our own room, just Mum and I. I came home when I was 12 days old.

Mum didn't like having to deal with my colostomy bag, it was very stressful. I had my second surgery when I was 1 month old. This surgery was to remove the part of the bowel that had no nerves. We thought the colostomy bag was being removed too but the Doctor said it was best to leave it on for another 2 months. I stayed in hospital for a few days.

**At 3 months old I had, what I thought was, my last surgery to remove the colostomy bag. I was in hospital for another few days. I couldn't wait for this to all be over, I didn't like being away from my Mum, Dad and big brother.**

We still had a long road ahead of us. Toilet training was very hard. There were many hoops to jump through to get where we are today. We had many hospital visits. When I was 3 years old, I had another surgery to open up my rectum, because it hadn't grown with me. This was to help my poo come out properly. We thought then, that it would be easier to toilet train me. I had to avoid certain foods, I saw dieticians to help with my fibre intake and I had to have probiotic balls to help my food digest.

I am now 6 years old and healthy. I can wee in the toilet, I don't wet the bed but sometimes a little bit of poo comes out before I make it to the toilet. I had another hospital visit the other day and the doctor checked my tummy and my bottom. She said I'm doing really well for someone who has hirschsprungs disease, that made me smile.

I might need another surgery in 6 months time if I haven't improved my toileting. The doctor said I can do it, so I'm going to try my best to stay clean every day.