

Chloe's Story

Chloe was born with a rare liver disease called biliary atresia. We noticed that she was jaundiced a couple of days after she was born. It is not uncommon for some babies to be jaundiced and the doctor recommended we sit her in the sun and that it should go away in a few days.

I think I did not want to admit there was a problem when Chloe was not eating well, was restless and the jaundice persisted. We had a public health nurse visit a few times which is customary with a multiple birth (Chloe has a twin sister named Sydney). She was the one who said I should urgently see a doctor when at two weeks old Chloe had not gained much weight and was jaundiced.

Blood tests and other scans were done. The diagnosis of biliary atresia was confirmed at around 4 weeks. Her pediatrician had never had a patient with biliary atresia before.

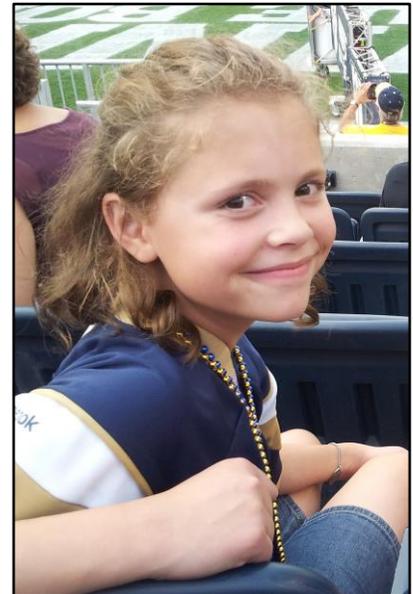
Chloe had her first operation at 8 weeks old – the Kasai procedure. This procedure attaches some of the intestine directly to the liver in an effort to facilitate bile drainage since her bile ducts and gall bladder were pretty much obliterated by this disease. We were at first hopeful this procedure was successful, but Chloe's condition soon deteriorated.

We went for a consultation to London, Ontario when Chloe was around 6 months old and she was put on the waiting list for a liver transplant. We were given a beeper and sat on edge for months watching her condition worsen.

When your liver fails, you don't just get yellow skin. You are unable to absorb fat soluble vitamins and many foods pass right through you. Despite frequent feedings with a fat and protein-rich formula, Chloe was essentially dying of malnutrition. Just like the images of starving children that we see on our televisions, Chloe had a very large tummy and scrawny legs and arms. Her belly would swell uncomfortably with ascites – fluid retention – and her belly button popped out with a hernia. The muscles in her arms and legs atrophied because she was not getting the needed nutrition. It was very uncomfortable for Chloe and she rarely slept through the night, feeding frequently and wanting to be held by her mom or dad.

Since Chloe is a twin, it was sometimes very difficult to watch her twin reach different developmental milestones. Each month, the differences between the two of them was more evident. Sydney crawled, walked, ate solid food and began saying some words by the time she was one year old, but Chloe was unable to do any of that.

By the time Chloe was one year old, she was very sick. The doctors prepared us that she had very little time left. We tried to have a happy celebration with family and friends to celebrate their first birthday. The next day the



beeper went off while we were all at the park. Tony and I went on the life flight with Chloe to London while family stayed with Sydney and older brother Aidan here in Winnipeg.

Tony went home after the first week and I stayed with Chloe for the remaining 5 weeks. It was amazing to see the transformation after the transplant. Immediately afterwards I was struck by how small she seemed – after removing the diseased liver, Chloe only weighed 12 pounds. Within days, the yellow jaundice drained from her and a rosy glow appeared on her skin. A week post-transplant, she smiled the biggest, truest smile I had ever seen. She was no longer in pain.

The months after her transplant, Chloe worked hard, making up for lost time. She tried crawling and started walking when she was around 1 ½ years old. She was happy and enjoyed playing with her twin and her older brother. You can imagine the heartache as we noticed that familiar yellow tone appearing on her skin and her belly starting to swell. We had flown to London and Toronto a couple of times since the transplant for a couple of biopsies and tests. Finally, about 10 months after her transplant (almost 2 years old), Chloe was placed on the waiting list for a liver transplant again. Her transplanted liver had failed – non-specific hepatitis they said.



Chloe was around 2 ½ years old when the beeper went off in the early hours of the morning. This time I went with her alone and Tony stayed home with her brother and sister. We went to Toronto this time, and it was a whirlwind. Chloe was in the operating room within the first hour or so that we arrived at Sick Kids. Before going into the operating room, I was horrified when the doctor informed me that since this was her second transplant, there was a 50% chance that Chloe would not survive. At that moment I regretted coming by myself. To our relief, the operation went well and Chloe recovered quickly. I can't believe we were only in Toronto for 2 weeks before we were allowed to fly home!

Since her second transplant, Chloe has been very healthy and is now a happy 11 year old. She has caught up with her twin sister and is now actually taller than Sydney! Chloe will have to take immune-suppressing medication for the rest of her life, but other than that, she is unlike any other healthy child.