

## Charlotte's Story

I was 25 years old when I had my first child. I was overwhelmed with happiness when I first laid eyes on her. A daughter, Charlotte Rose. I never imagined that anything could go wrong. After all, my husband and I were young, healthy and had no history of illness in either family. Little did I know my world was about to crash down on me.

When the doctors initially told me that Charlotte had jaundice, I didn't worry. They didn't seem to worry- and said it was common in newborns. But as the weeks went on and her jaundice got worse, the doctors - and I - began to think something more was going on.

It was difficult to watch my infant go through numerous blood tests, but I told myself each time that soon they would figure it out. Soon the doctors would give Charlotte that magic pill and her jaundice would disappear.

At two and a half months of age, Charlotte underwent a procedure to figure out whether or not she had "biliary atresia". I had never heard of this disease, and although the doctors did their best to explain it, I couldn't wrap my head around what exactly it meant.

I went home and Googled it. Biliary Atresia: rare Liver disease with no known cause and no cure. What? That was impossible. I kept reading. To treat it an infant must undergo major surgery before 3 months of age which involves attaching the intestines to the liver. Vast majority of those diagnosed with biliary atresia need a liver transplant, many before they are one year old.

There was NO way that my baby, my sweet innocent little Charlotte, had this disease. No way.



A few days passed and the results were in. I remember the phone call. Yes. Charlotte has biliary atresia. Pack your bags & head to Children's Hospital, she will undergo major surgery in a few days.

Charlotte was sleeping when I got the call. Peacefully resting in her bed. I walked to my bed and collapsed. I have never cried so hard in my entire life. I sobbed until I didn't have the energy to sob anymore.

It crossed my mind more than once that my baby could die. I couldn't let that happen. Yet, all of this was completely out of my control.

Charlotte had her surgery. When I was allowed to see her in the intensive care unit for the first time she had more tubes coming out of here than I care to remember. She had a large surgical cut on her abdomen which I was not prepared for. She was fussing and looked uncomfortable. She was so tiny. I asked the nurse to give her





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something to ease her pain because she seemed to be in distress. Instead the nurse picked her up and handed her to me. Instantly, Charlotte stopped crying and fussing. She nestled in to my arms and closed her eyes to rest.

“That’s all you mom,” the nurse said to me. For the first time since Charlotte’s diagnosis, I felt some peace. We would get through this, there was no other choice.

Charlotte’s surgery was a success. Her jaundice slowly disappeared. But that was not the end of her struggles.

Over the next few years, Charlotte had numerous infections, blood tests, spinal taps, ultrasounds, various medications. We stayed in the hospital many times. There were many days Charlotte felt unwell. Charlotte was diagnosed with bile lakes, pools of bile that do not drain from the liver and cause infection. Her liver is permanently scarred. Her spleen is large, working harder than it should.

Through it all Charlotte remained a kid. Happy. Fun. Energetic. With a twinkle in her eye and a giggle you can’t help but laugh along with.

Charlotte is now 8 years old. Thankfully, her health is good. Stable. She is a fantastic dancer. She plays soccer, swims, skates, does gymnastics. She is a big sister. She is a fighter.

Odds are that Charlotte will need a transplant in the future. My hope is that we find a cure before that happens. Please remember Charlotte’s story and support liver health research. Liver disease can happen to anyone.