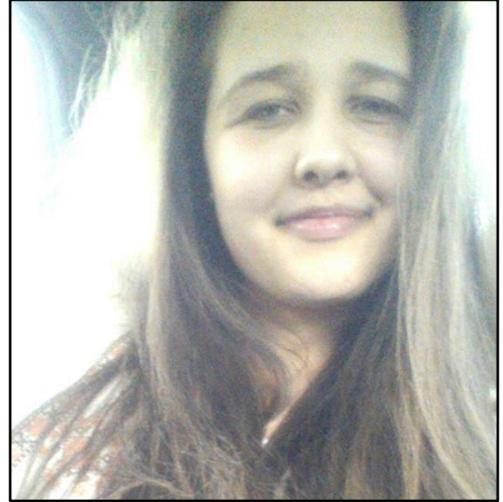


Natalie's Story

When Natalie and her twin sister were born, they were a few weeks premature but otherwise healthy. The first weeks at home were a chaotic but happy as Natalie's parents learned how to deal with the demands of twins. It wasn't long however before Natalie stopped growing and gaining weight. Her stools turned white and her eyes and skin started turning yellow. She vomited after every feeding so her parents fed her twice as often as her sister but she still lost weight. Desperate for answers, Natalie's parents repeatedly took her to their family doctor who kept insisting she was fine. The doctor finally accused them of being paranoid and over-protective so they stopped bringing Natalie to the clinic.



Natalie post-surgery

At nine weeks, a midwife saw Natalie's very jaundiced skin and she was immediately taken to the children's hospital near her home. After multiple tests, scans and procedures, she was eventually diagnosed with biliary atresia, a condition that affects the bile ducts and leads to severe, life-threatening liver damage. Just a few days later, Natalie underwent a surgical procedure called the 'Kasai' which helps re-establish bile flow. When successful, the Kasai allows a child with biliary atresia avoid having a liver transplant – often for several years.

Fortunately for Natalie, the Kasai worked. After three weeks in the hospital, she was able to go home and her health dramatically improved. Life finally became 'normal' – something her family never would have thought possible.

When she was seven years old, Natalie's family moved from England to British Columbia. One of the deciding factors when choosing a province to settle in was the availability of medical experts who could manage her disease. She was lucky that Dr. Rick Schreiber, a leading expert in biliary atresia, was based at BC Children's Hospital and he took over her care.

For the next six years, Natalie's life was like that of any other kid except for annual doctor's visits, blood tests and procedures to monitor her health. She was strong, healthy and had no fears about her future.

All that changed when Natalie turned 13 and she began to suffer complications brought on by her disease. Portal hypertension and an enlarged spleen triggered severe abdominal pain. She had to start taking multiple medications to keep her body stable and to manage her symptoms.

Frustrated by her own declining health and angry about the lives of babies being lost to biliary atresia, Natalie and her parents founded their own organization to help spread awareness and raise funds for biliary atresia research. The Biliary Atresia Awareness and Research Society (BAAR) developed an international profile reaching hundreds



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of thousands of people in over 49 different countries all over the world. Through BAAR and her partnership with the Canadian Liver Foundation, Natalie has helped many families coping with biliary atresia and helped educate the medical community and the public about this disease.

Today Natalie is 18 and has been told that she will soon need a liver transplant. Her portal hypertension has gotten progressively worse and she has consequently developed varices. Her immune system is compromised and she is often admitted to hospital with infections that her body cannot fight.

Despite her health, Natalie remains both positive and resolute. She credits her experience living with biliary atresia for making her into the person she is today.



Natalie & her twin sister



Natalie & Dr. Schreiber

“I will never forgive biliary atresia for taking away my health,” says Natalie, “and more importantly taking away some of the most precious souls I’ve had the privilege of knowing. But although it sounds odd, I am quite thankful because without this disease, I wouldn’t be living the life I know and love today. In the future, I will continue to work on making the world aware of biliary atresia, and am determined to find a cure before I die. I am now enrolled in pre-med working toward one of biggest dreams which is to become a doctor.”