

Brandon

Sudbury, Ontario

As a lab technologist working in a hospital, I thought I had seen it all – but my son’s diagnosis proved me wrong. In the summer of 2014, we noticed that my eight-year-old son Brandon was drinking more than usual and peeing a lot. Since I work in the hospital lab, I brought him in one day to test his urine expecting that he might have a urinary tract infection or even the beginnings of diabetes. While all the results that I was expecting were negative, one result indicated possible anemia or liver damage. After making an urgent call to our family doctor, my son underwent bloodwork that day. The doctor called us back the next morning to explain that I was right about the potential liver damage.



We had to wait 10 days for the results of all the follow-up bloodwork and it showed that my son had autoimmune hepatitis. The day we received the diagnosis we were sent to Sick Kids Hospital in Toronto. At Sick Kids, he had many more tests including a liver biopsy to confirm both the diagnosis and the stage of the disease.

At this point, the panic set in. I cried a lot and somehow felt guilty because I had been the one to discover it but yet had never heard of it before.

Today Brandon is 10 and his whole life is now centred on his meds. He’s taking multiple medications to not only treat his autoimmune hepatitis but also his overlapping condition, primary sclerosing cholangitis or PSC. I do his bloodwork at home and bring it in to work, so he doesn’t have to miss as much school but we still have to take frequent trips to Sick Kids to see his specialist. It’s a five-hour drive one way and we often need to stay over.



It’s been hard watching him have to deal with his disease. His activity levels have changed drastically due to weight gain from the steroids and he tires easily when active for extended periods of time. He hasn’t been responding as well to treatment as the doctors expected so he may need a liver transplant if his liver gets worse.

Brandon pretty much knows everything I know about his disease. He is very intelligent and very proactive at educating everybody who will listen. He does a presentation on rare disease day at school to teach his peers and teachers about his condition and why he doesn’t “look” sick.

If I had one piece of advice for parents, it would be ‘always trust your instincts’. We knew something was up and we followed our instincts to get it checked out. We do not know what the future holds but we’re taking it day by day.



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