



Avery's story

by Jesse McNeil

On a warm fall day in 2003 I found out my husband and I would be having our second baby. We were ecstatic; this pregnancy was planned, so in the months prior I lost weight, started pre-natal vitamins and met with my doctor. I did all the things moms-to-be are supposed to do.



In my thirty-second week I was diagnosed with hypertension (pregnancy-induced high blood pressure). I had lots of ultrasounds; the plan was to induce labour as soon as Avery's lungs were ready. There were many remarks about how big my baby was; they thought she would be 10 lbs. when she was born. I didn't care; I just wanted her to be here so I could be healthy again.

An induction was scheduled and on June 12, 2004, at 3:07 p.m., Avery Kaitlin entered the world. I anticipated a tough birth, but one push and she arrived; 6 lbs. 13oz. My ordeal was over but little did I know her ordeal was just beginning. In utero she used my hormones, but each minute outside of me was causing her body to shut down.

With an easy delivery, and the over-crowded health care system, I was essentially ignored. I was bottle-feeding (another story, for another day) so I wasn't a priority to the limited staff. My husband fed Avery and my friend helped me shower and get comfortable. My husband went home for the evening, at my urging, to be with our older daughter. Avery and I both slept 5 hours; a nurse woke me up and said, "She's such an easy baby, we haven't heard

from her all night, but you should wake her up to feed her." No one, me included, could believe what a "good" baby she was. Eighteen hours after Avery was born the doctors asked if I wanted to go home. Yes please!

Alberta Health Services has a Newborn Metabolic Screening Program in place. The program screens for 17 disorders, including congenital hypothyroidism. I remember putting Avery in her car-seat to leave when a lab technician asked to do one more blood test. I thought it was strange, as they had done tests earlier that morning, but I didn't question it.

After arriving home Avery was quiet and slept quite a bit. I went to sleep at midnight, with her in a bassinet beside our bed. I prepared myself to wake up in an hour, instead I woke to my mom knocking on our bedroom door telling me it was 6 a.m. and I should wake Avery up to feed her. What a blessing this easy baby was.

Avery progressively got sleepier and ate less the next day. I didn't want to wake a sleeping baby, any second-time mom would tell you to take advantage of the time to recuperate, but I was starting to wonder why she was so sleepy. The public health nurse came and my blood pressure was down and Avery's vital signs looked fine. The nurse mentioned she looked a little jaundiced; he gave us a blood work form to get her tested. He told us some babies need time at the hospital under special lights to get rid of their jaundice.

The next day we got the blood work done and within hours Alberta Children's Hospital called; perhaps the caller said they were calling from the Endocrine Clinic, perhaps not. Even if they had, neither my husband nor I would have understood what that meant. They asked us to bring Avery to the hospital first thing in the morning, no further information was given.



We arrived at the hospital ready to watch our baby get her tan on! We were approached by a group who introduced themselves as endocrinologists, nurses, psychologists and technicians. Someone asked, "Are you ready for these tests?" I must have looked completely confused; one of the nurses said, "Has anyone talked to you about why you're here?" I replied, "Yes, to put Avery under the lights for her jaundice." At that point we were taken into a boardroom where a doctor started explaining that there was something wrong with our daughter. Maybe she didn't have a pituitary gland (A what gland?) or maybe she didn't have a thyroid (isn't that an adult problem?). Words like: failure to thrive, brain development delay, cognitive disability and death were thrown around. I went into shock, everything became cloudy and I couldn't focus. I was taken to a nurse's office where someone got me a blanket and made me tea.

Avery needed an MRI immediately; I couldn't stand up so my husband went alone. I needed to make phone calls but I couldn't remember phone numbers or what I'd been told. Avery slept through her MRI, and I decided to go to her next test with my husband. I recall sitting in a hallway waiting for her x-ray; she was down to almost 5 lbs. after 3 days of barely eating. My husband could hold her in one hand; we huddled together, both of us sobbing uncontrollably. How could this be happening?

A doctor told us the news was good: our baby had a pituitary gland, but did not have a functioning thyroid, it had not developed and was not in the proper place; however, this could be controlled with medication. It was the best case scenario as far as the medical team was concerned. He told us she would be on medication for the rest of her life; there would be more blood tests and follow up appointments. Both

my husband and I wanted to know "why", we had done everything right! No one could answer the why; it just happens sometimes. A nurse showed us how to give her medication and she mentioned that as the medication started to work her real personality would come through, it was likely our last night of having an "easy" baby. With that we were sent home to absorb everything that had happened that day. Within 12 hours my easy baby was wide awake, wanted to eat constantly and we couldn't change her diapers fast enough! I wanted to curl up and hide in my bed, but this baby was having none of that.



During Avery's first 18 months she had a blood test every six weeks and cognitive development testing. We sat in a playroom with two-way mirrors, a group of psychologists and doctors sat on the other side telling me what to make her do. Little did they know, no one makes Avery do anything! I remember they wanted her to walk a straight line, she had just started walking the week before and there was no way she was going to do it. That day I took control, I decided I would let them know if I thought there was something wrong. The stress of the constant testing was too much.

Avery is now a healthy, thriving, funny eight year old. She knows about her condition and we have recently been teaching her the importance of making sure she takes her medication each day. Most kids learn their phone number, address and parent's names in case they have an emergency; Avery also knows what her condition is called, how much medication she takes daily, who her doctor is and that she shouldn't eat soy or walnuts.

Although some of our experiences could have been better, we are truly lucky that the Alberta Children's Hospital was here and they could run tests quickly.

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Recently, I had an opportunity to perform on Global Television's Canada Sings. My team from WestJet, Cabin Pressure, worked incredibly hard to win a \$25000.00 grand prize to donate, in Avery's name, to the Alberta Children's Hospital Foundation. The best part of performing on this television show is the awareness that has been brought to thyroid issues, affecting all ages, in Canada.

Jesse and Avery live in Calgary with Avery's Dad, Phil, and big sister, Emma.



Avery today – a healthy, thriving, funny eight year old