

## One of Those Happy Stories



May 1st, 2013 - When I think of a happy story I think of a fairy tale, the whole guy gets the girl and they live happily ever after shebang. Well not this one, all though this is a happy story. This story is my journey with Chiari and how one can overcome the worst, to see how the grass is greener.

In 5th grade, I would come home complaining of a headache that I had, but when mom asked, it was always gone before I came home. I never used to get headaches so the pain, I thought, is what everyone gets as a headache. I had just started swimming competitively a lot and it was June, so my Mom and Coach Rod, my new swim coach, just thought I was dehydrated and getting used to the new training level. I never went to the nurse, not worth it I thought. The headaches, back then, only lasted 5-15 minutes plus I didn't want people to think I was weak. When I would get a headache at school I would be playing kickball or basketball, whatever the sport of the "month" was. The pain was so bad I would just lie down on the ground and grab my head. When friends asked what I was doing I said "It's just a headache, nothing more". Although some teased me when I lay on the ground saying "Ew you're lying on the ground gross", the ground and floor, at school become my new best friend.

Six months later, in September, I was carrying groceries up from the car and I got in to the kitchen and a headache came on. I grabbed the counter and tensed on my neck. Immediately my mom asked "What's wrong?" and when the pain died down "I told you mom, I've been getting headaches". A worried look came across her face, "That's not a headache, Hun". The next day she dragged me to the doctors. "I'm fine, Mom! I don't need to see a doctor," I was complaining the whole ride to Sand Point Pediatrics, little did I know. Dr. Ben Jackson asked me three questions: where the pain was, how long did it last and does it wake you up at night. If that was a test, I would have failed. Two days later we were seen at Children's Hospital for an MRI. Me, being a fifth grader was more worried about missing school rather than the outcome, "But Mom, it's Friday! Can't I go tomorrow? Today we have the last hour of school outside!" She said no, this had to be done immediately.

The day after the MRI, we got a phone call. It was Dr. Jackson, and Mom knew something was up. First off, doctors don't call that soon after unless it's bad news, also they don't call after hours. Two months later Andy, my stepdad, Mom, Dad, Maura, my stepmom and I saw Dr. Richard Ellenbogen at Seattle Children's Hospital. We got the scoop on Chiari, we also got a surgery date, May 25th 2010, which is one of the most indented dates of my life. There were lots of ice cream for the next week and lots of different emotions.

May 25th, 4am wake up call, which if you know me; I hate mornings and did not get my dad's genes of waking up early! We stopped by the drive-thru Starbucks because mom needed her morning coffee especially for today. I don't remember much from that day but one thing I do remember is the barista asking us what we were doing today and kept asking over and over again. We obviously didn't want to say I'm having brain surgery, that's a major downer! So we just kept quiet. I had my surgery and got out of the hospital in two days. Dr. Ellenbogen was impressed "fastest I've ever seen" he bragged. Coach Rod and Coach Bryan, the two most important and influential guys in my life, came to visit me when I was admitted out of ICU, which is about the only thing I remember from the hospital days. They brought flowers, movies, books, M&M's and a "book" filled with get well wishes from the team, which is still hanging in my room. Once my friends started to visit, it was not as I expected. It was awkward and quiet, with people looking for the right words to say. The truth is there were none. There was nothing they could say to make me feel better. Those awkward visits were enough alone to make me want to feel normal ASAP!

In August I started swimming again. Right away I felt in tune with the water, but felt like a rock. I got back into it with Brenda, another one of my swim coaches, best friend, and role model, in September was able to start up with the team as a senior. By December I dropped ten seconds from May, which is crazy even if you don't take swimming off. Chiari was at bay for about two years, still getting the occasional headache here and there, but manageable. We ran some tests, saw some specialist doctors but no one knew what was wrong with me. After some reading my mom found that allergies can cause some of the same symptoms I have been having. We saw a naturopathic physician; they informed us I was allergic to three main food groups, wheat, dairy and eggs. Go figure! They said: your allergies on top of your Chiari will bring up symptoms, which normally wouldn't be present. So I did the must needed but hard to do diet of no wheat, milk and eggs and it worked. My symptoms increasingly decreased and I was healthier and happier.

It has now been three years since surgery; I am swimming every day for three hours or more, attend one of the most vigorous private schools in the USA and enjoying life. I am able to place second in the region for my one hundred butterfly, attend school every day and help my family with chores and cooking. A dream of living without pain, three years ago, was untouchable. Now that dream has shifted to helping others live without pain and raising awareness. So yes this is not your sad story of how I never got better, this is your joyful, hope raising, story of how one girl is living close to pain free and happy.

-- Sami Robbins

**Disclaimer:** This publication is intended for informational purposes only and may or may not apply to you. The editor and publisher are not doctors and are not engaged in providing medical advice. Always consult a qualified professional for medical care. This publication does not endorse any doctors, procedures, or products.

© 2003-2020 C&S Patient Education Foundation