



Our Story

by Sarah Beckwith
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MIGRAINES – A WARNING SIGN!

22 year-old Sarah Beckwith has a complex case of HHT and would like to spread the word about this disorder by sharing her story so that others to understand that migraines may be a warning sign of AVM's in HHT.

It was the day of my second grade line-dancing debut; I had been excited for this day for weeks. We were all lined up and ready to go, when I noticed a strange light show out of the corner of my eye. It got bigger and bigger until it blocked out most of my vision. When the light show ended I was hit with an enormous headache, it was so bad I started to get nauseous. My mom was called to the school and came to pick me up. As soon as I reached her car, the prop hat that I was supposed to wear for the dance became a bucket to be sick in. This was my first migraine.

I continued to get migraines for years, which progressively became worse and worse. As I got older I started to have issues with breathing, which some doctors “diagnosed” as asthma because they had no other explanation. Along with the migraines and breathing problems I would wake up in the morning with an occasional nosebleed.

When high school started my migraines had become such a problem that I would have to go the hospital to get them treated. They would come almost twice a week. So crippling that laying on a pillow felt like my head was expanding. They always started with the light show, followed by the immense head pain, followed by nausea, and at its worst, my migraines ended with the numbing of the right side of my body and tongue.

Needless to say my family and I were starting to get very concerned. We went from doctor to doctor without any real diagnosis or cause to my problems. We had known about HHT on my mothers’ side of the family but didn’t think much of it because we had thought that the most common sign of HHT was constant nosebleeds. In many cases

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this is true. But my nosebleeds were rare; my biggest problem was the headaches.

In my sophomore year of high school my mom decided it was time to get my sister and I checked for the disorder. We found the closest HHT center to us, which was The University of Utah Hospital in Salt Lake City. We went to the Utah HHT Center where they ran several different tests - blood tests, Echo bubble, CT scans, and MRI's.

Waiting for the results felt like it took a lifetime even though the results came extremely fast. We got a call from the geneticist. I remember watching my mom's face as she listened to the person on the other line. It was panic, followed by fear, followed by the “we need to

take action” face.

She told me that I did indeed have HHT, but the good news was that my sister did not. From the tests, they had found an AVM in my brain and several (too many to count) in my lungs mostly in the left lung. I don't remember what I was feeling, just that I was in shock.

We scheduled the brain surgery and lung embolization a couple of weeks later. Both surgeries went extremely well and I can't thank the doctors and nurses at the University of Utah Hospital enough. They saved my life and kept me sane!

I have since been back to the hospital to continue to get more of the AVM's in my lungs treated. I am scheduled to go back again at the end of February 2014 for another procedure.

I now live in Seattle, WA but I will always go back to the University of Utah Hospital because of the bonds and relationships I have made there. I am very lucky to have such an amazing and supportive family to help me through my journey and I don't know where I would be without them.