









December 2014



My name is Jessica Schenkman, I was diagnosed with a Chiari Malformation with a Basilar Invagination when I was fourteen. I had a decompression surgery and a fusion of my skull to my c2 vertebrae on April 6, 2011. Before my surgery I had been training for 7 years in martial arts in order to earn my black belt. When I was diagnosed it seemed impossible that I would ever be able to reach this goal. But I underwent the surgery and six months after my surgery I was clear to start to training again. Two years after my surgery I was able to compete and earn my black belt. Since my surgery I have been able to climb the grand Teton, backpack in Alaska and run a Spartan race as well. The chiari has been a huge part of my life and I want to do as much as I can to give back to the chiari community and help others with chiari malformations. Please let me know if there is anything more I can do. I would like to also share my story with the chiari community.

I have two scars. These scars are not ancient like one that has faded on a war veteran's face or fresh like the scraped knee of a child who just learned to ride a bike. My scars are old enough to reflect upon but not so old as to be forgotten. One scar, smooth to the touch and faintly elevated, resides on my right hip. This scar is deep red with a curve which

resembles the sun grazing a hill on the horizon at sun rise. The other scar extends from the crest of my head down to the base of the back of my neck. Bumps and lumps surround this scar and it is barren— the hair that once grew there grows no longer. These external marks appear as fleshy defects but they are so much more as they are a reflection of the deeper me.

I felt my heart stop when I first heard the words, "Your MRI came back and it was irregular." Tears welled up inside my eyes as my mind flooded with questions. Why me? Am I going to be okay? What even is a Chiari Malformation? "Well," My Doctor started, "Your condition is very rare, it is when part of the cerebellum is located below the opening at the bottom of the skull putting pressure on the brain stem, He explained, "You also have a Basilar invagination which means your skull is unstable. "This is a very rare condition."

"Can I continue with my training?" I asked nervously half knowing what he was going to say, I had been practicing martial arts since I was eight years old and, at fourteen, I had devoted nearly half my life to my dream of earning a black belt. A dream that was slowly moving farther away from reach as the doctor explained. "I don't think that training is such a good idea, as your head is too unstable." Tears spewed out of my eyes as I struggled to breathe. The doctor started to speak again, "Although we could do a decompression and a fusion which will stabilize your head and relieve the pressure caused by the chiari." The pressure on my lungs was relieved slightly as I saw hope.

Months were devoted to researching my condition and my options. My parents dragged me to countless neurosurgeons. Two options emerged: treat my condition with this surgery with the hope that I would return to life as it was or avoid the operation - with no assurance it would not be vital later - and lead a life of inactivity and insecurity. Agony, over whether to act now or wait and see, filled our home for weeks.

After one particularly distressing discussion with my parents about my circumstance, I took a walk and considered the big decision. What should I do? Should I have surgery? Should I wait and see? I gradually came to a decision. I must take the leap and now. The surgery terrified me but I felt I would slowly wither away in the alternative life of fear and uncertainty. Soon my steps grew mighty carrying me farther away from my doubts until I was forcefully marching down the street with fire in my eyes. I will overcome this. I will get the surgery. I will heal. I will ski. I will get my black belt. At that moment, my mind became a one way freight train, full of resolve, on a journey of conviction.

My week at Columbia Presbyterian Hospital and the following six months were a blur. Nevertheless, I felt I was slowly but surely swimming toward the surface of my ocean of despair. Then, one day I was told, "You are clear for all physical activity Jess." The words danced out of my doctor's mouth like the first note of the most beautiful symphony I have ever heard. I wasted no time. I biked, hiked, swam, and trained that week. It was slow process at first. I had to be eased back in to training and then competitions and at last preparation for my black belt. After I came home from practice, dripping in sweat and satisfaction of a hard work out, I look down at my right I hip and smile. I could finally see the sun coming over the hill at sunrise.

I was now training my hardest and although I had to do things differently because of my chiari. There were moments of frustration and doubt but I knew I had had to try my best. I had almost lost my chance at my black belt, so, I had had to give it my best shot. Two years earlier, I was sitting in a doctor's office wondering if even returning back to karate was even plausible. Then sitting in a hospital bed wondering how I could become the same fighter I was before. The truth was I wasn't the same fighter the chiari had made me stronger. I was more motivated, confident, fearless, and proud of where I had come from. As I walked in to the black belt test, I was ecstatic just to be there, it felt like a breath of fresh air. I fought and I earned my black belt. One week later I received my black belt surrounded by my friends and family. Two years earlier this moment seemed impossible but as I looked around at my family and friends, I was filled with relief and joy.

I have two scars. While others may view my scars as unattractive imperfections, I see them differently. The bumpy road on the back of my head is a badge for the struggles - physical and emotional- that I have travelled on my journey to pursue my dreams. It reflects my strength and endurance. The sun grazing a hill on my hip represents the promise of wonderful things to come. They define who I am in a way that no other feature ever could. It's been a long road but I wouldn't change any of it for the world. Never give up. Anything is possible.

~Jessica E. Schenkman~

Please Note: The opinions expressed above are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. Sports with or without decompression surgery are a controversial topic, anyone with Chiari wishing to engage in contact sports, should do so with caution and only after discussing it with your doctor.

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