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Ed. Note: *The opinions expressed below are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. The procedure described below may not be suitable for everyone. Anyone with a medical problem is strongly encouraged to seek professional medical care.*

My struggles with Chiari probably go back about 20 years. I always ignored the symptoms because they were very sporadic and so unusual that no one understood what I was trying to explain. The past two years, however, I could no longer ignore the "head rushes" - the sudden acute pain that would shoot up from the back of my head sending excruciating throbbing pain in my head, then a tingling sensation throughout my body, which always ended with nausea and muscle weakness.

I also had balance problems, trouble swallowing at times, and chronic migraines that were different from the head rushes. These symptoms became more and more frequent and interfered in every aspect of my life. I no longer could cough or sneeze without pain, could no longer exercise, could no longer raise my voice in any way, good or bad. Chiari had taken all enjoyment from my life. Even simple things like not being able to go upside down while swimming or on a roller coaster, or not being able to cheer for my son at his soccer games because screaming when he made a goal would trigger the painful head rush that has altered my life. I'm an eighth grade teacher so "cold season" was the absolute worst.

Since the Chiari head rush is triggered by coughing, I literally would have to leave my classroom to get help so I wouldn't collapse in front of my students when all I had was just a common cold. I have been lucky in that my colleagues have been very supportive, but ignorance on the part of the general public is yet another challenge in the daily life of a Chiari sufferer.

In time, I learned to control my Chiari triggers the best I could so that I could avoid the pain, but it left me with a life without emotion. I couldn't laugh, I couldn't cry, I couldn't be angry, I couldn't feel anything that might set off a Chiari head rush. Finally, I decided to see my family doctor who had no explanation for my symptoms. Unfortunately, that's a truth for most Chiarians. Luckily, my doctor referred me to a neurologist who was able to diagnose the Chiari malformation after two MRIs. He referred me to Dr Xiao Di at the Cleveland Clinic. It took me about 7 months to mentally prepare myself for the decompression surgery.

The main reason I want to write my perspective is because Dr Di specializes in an endoscopic procedure that must be more readily known to Chiari sufferers as a viable option. My surgery was a delicate 5 hour surgery, but only a 2 cm incision was made, the dura was split and cerebellar tonsils were left in tact. Dr Di removed two bones to create more space for CSF. I was only in the hospital for 3 days and I was up walking around on the first day. Three days post-op, I was already out shopping around town. It has now been ten days since the surgery and I'm off all medication and have not had one occurrence of the dreaded "head rush." The surgery is amazing. The only mild pain I'm still having is from the incision site and I still have limited motion in my head and neck. I plan to return to work after three weeks, but that's only because we're on spring break. I could have returned sooner. The moral to my story, of course, is that I am a fellow Chiarian; I am not however a "zipperhead." No longer should Chiarians be out of work 6-8 weeks and endure such an invasive surgery. I am writing to all Chiarians considering decompression surgery to encourage them to research all their options and know that with the right specialists, there can be relief to their symptoms. Dr Di has been my miracle worker. I know I have conquered Chiari!

~Traci L. Schmidt~



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