Perspectives | 9.12

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Kristen Checking In

September, 2012 - It’s amazing how things can change so drastically and yet so much remains the same. Last June I wrote and submitted a perspectives piece on how my struggle with Chiari did not and would not define who I am as a person. In my piece, I discussed my battle with Chiari up until that point and mentioned that after 3 previous surgeries, one of my biggest fears was that my surgical journey would not be over. On February 21st of this year, I confronted that fear when I was told that the existing syrinxes in my cervical spine had increased in size and that a long, but thin syrinx had developed in my thoracic spine. Unfortunately, I had been experiencing symptoms for a few months before that and somewhere deep down, knew what to expect when I met with my surgeon that day.

Although I have never felt “normal,” starting in January of this year I felt that something was different. Since my last surgery in 2003, I had been meeting with my neurologist routinely as scheduled. Within that time, I discussed various symptoms and concerns I had over the years which I later learned had been dismissed by my neurologist. The symptoms got to the extent that on one particular day in January while I was at work and I knew I was having neurological issues, I called my neurologist pleading for an appointment that day and was told that my doctor was “not convinced that I did not have a cold and should see my primary physician.” This was the first time since being diagnosed with Chiari that I ever reached out to my neurologist for a same day appointment and I was hurt, frustrated and angry with the lack of sympathy and regard by my neurologist. I was not even able to speak with the doctor himself, despite my request and simply was relayed the message via a nurse. I was told that I would not be able to meet with the neurologist for another 4-6 weeks. However, as instructed, I made an appointment with my primary physician that day who concurred with me that my issues were neurological; a fact that an MRI in early February confirmed. I have since decided not to remain a patient within that neurological practice and re-established myself as a patient with my original neurosurgeon in Philadelphia that I respect and admire.

On June 13th, I underwent my fourth surgery, a “Shunt Revision.” After making the incision into the site of the original shunt placement, my surgeon noticed that the original shunt had “slipped” from its attachment and was nowhere to be found. At this point, it is believed that it may be within my chest cavity; however we are not certain. While fundamentally the surgery went well and one syrinx collapsed completely and one shrunk in size, 7 weeks later I am still struggling with neuropathy where the light sensation in both of my legs has been affected. My feet especially feel as if I have permanent pins and needles. We are hopeful that the majority of feeling will return, yet I have been warned that there may always be spots of numbness within my legs.

What has struck me most throughout this ordeal is that although it has been 9 years since my previous three surgeries, the procedure almost mirrored that of 9 years ago. While technology, cell phones, computers, tv’s and most of our daily lives have been impacted and improved upon within the past 9 years, medically speaking, I was back in the same position I was 9 years ago. After my release from the hospital, even the home visiting nurse that was assigned to my case had never even heard of Chiari, yet was trying to reassure me that my healing process was going well and I was making progress. Although I mean no disrespect, I cannot understand how I can be told that I am making progress by someone who does not understand and has never heard of the initial concern and reason I required surgery. The feeling of being “brushed off” by my neurologist of 5 years also brought back many of the frustrations and resentment I had felt before I was finally diagnosed with Chiari and in the time it took me to find the right surgeon. Once again there is such a lack of awareness and research in this field that it baffles and disappoints me that we are no further along than we were 9 years ago.

Having had to confront one of my biggest fears this year, I pray to God that the other fear, of my daughter being diagnosed with Chiari, never comes to fruition. And God forbid it does, I plan to make sure that I will do whatever I can to increase awareness so that her experience does not involve the 4 neurosurgeries, untold permanent damage to her back and spinal cord, possible permanent nerve damage, and the mental and emotional struggles that I have had to deal with. It has upset me enough that I had to explain to my four year old daughter that I needed surgery and what exactly that meant. She has had to visit her mother in the hospital during a four day stay (two of which I was not able to get out of bed) and had to see staples in the back of her mothers’ neck and on a second incision on my mid-back. For almost 2 months, my daughter was not able to be picked up by her mother. No mother and daughter should have to experience that and it makes me even more incredibly grateful that I have the amazingly strong daughter that I have. When she visited me in the hospital the day of my surgery, my husband placed her in bed next to me and she looked at me and said “Mommy, you look pretty.” Although I am still frustrated, resentful and angry at what myself and my family has had to endure (and I can’t help but wonder if things would have been different with a different neurologist), I think of that moment often and realize that I am still an incredibly lucky person and I am still determined not to let this disorder define who I am. There are too many other blessings that I would prefer to focus on, including my family, my friends and my amazing little girl.

-- Kristen C. Grim

Would you like to share your perspective? Submit to: director@conquerchiari.org Type "Perspectives" in the subject line.