

A Great Conversation Starter

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. Anyone with a medical problem is strongly encouraged to seek professional medical care.*

The fact that my brain is too large for my skull is actually a great conversation starter. When I was diagnosed 9 years ago with Chiari Malformation the information out there was very limited. Now, as I look back, it was obvious that Chiari had been a prevalent part of my life for many years. Many mis-diagnosis and a slew of doctors later I was in the process of being tested for MS while taking anti-depressants since the previous doctors had labeled me as "troubled". The family doctor I was referred to after an emergency room visit (I had lost feeling in my right arm and had chest pains) was familiar only because his nurse and her sister had been diagnosed the previous year. He immediately ordered an MRI and took me off of my other medications (none of which were helping anyway). My symptoms were so bizarre. Headaches, sensitivity to light, gagging, vomiting, balance and coordination issues, loss of some motor-skill function in my hands, passing out, not being able to form words even when they were right there in my head, double vision, migraines accompanied by loss of vision, passing out, etc . . . my husband would ask me a question and wait patiently while I gave him a blank stare and tried like hell to form the words. I remember having a conversation regarding sneezing and coughing with a co-worker once. I had thought that everyone had terrible head pain when they sneezed or coughed! I hadn't a clue that this wasn't normal!

When my doctor came to me with the results of the MRI, I was happy. Happy, that isn't a word you would normally use to describe the diagnosis of a neurological disease. When you have suffered for years with something that was dismissed as being "all in your head" (fitting description now) happy is definitely the right word though. I could get help. That was all that mattered.

My recollection of the events leading up to my surgery is less than perfect. We saw several surgeons but decided on one right here in my hometown of Stuart, Florida. My mom flew in and had a brick wall of guilt sitting on her shoulders because she hadn't been able to get me a diagnosis earlier. I explained that she wasn't to blame, if the doctors had never heard of it how were they suppose to help? She did everything she could for me growing up, took me to all of the right doctors. I tried and tried to get her to let go but she couldn't help it. I couldn't understand why she would cry and cry. I was in my late twenties and had a wonderful family that supported me, two amazing kids, and a diagnosis with help on the horizon! I felt she needed to let go of the guilt. The decompression went well and I was out the hospital 3 days later. Since then I have had several symptoms return over the years but I can deal with them now.

I now understand my moms guilt. My daughter had been diagnosed with ACM and now I know where that terrible feeling of guilt comes from. I couldn't believe that I had passed this on to one of my children but just like with my diagnosis we found a wonderful surgeon and got started. My mom flew in again, I apologized profusely for belittling her feelings and we were on our way! She had her decompression surgery when she was seven years old. What a trooper! A six day hospital stay and we were on our way home!

Let me get to the point of my sharing this story. First, the guilt of being a parent with ACM is enormous. My oldest daughter started having headaches this year and we panicked. Two days of absolute hell waiting for the result of the MRI. She's clear! I want all of you parents out there to understand though that you didn't do this to yourself so how could you have possibly done this to your child? Learn with them, give hope to them, let them enjoy as much of you in their childhood days as you can. Try not to dwell but smile, love, share and most of all make them comfortable. She still has headaches and gagging and vomiting on occasion, but we now understand why and how to make the most of that day regardless of whether or not a symptom has reared its ugly head! Even if I am having a bad day, I understand that I have to work through it, my family depends on me and I depend on them. We keep each others spirits up. Everyday is a blessing, with our without a headache!

Second, I truly believe that if you put your mind to it you can do it. I have a successful career and a wonderful group of friends. I am very social and would be in a constant depression if I didn't force myself to get up every morning, say a prayer and get my butt moving. Same with my daughter, Ryanne. She is 11 now and keeping her fit and active has been my goal. She is a competitive cheerleader and an A student! She gets nosebleeds that are real gushers, we have learned to carry plastic bags in the car just in case she starts to feel sick. Many little tricks here and there to help deal with the situation, but we manage. Sure we have days where we would rather stay in bed or a warm tub, and we do on occasion. We have no idea though how long we will be able to do the things we love so we take advantage whenever we can.

Lastly, educate whoever you can! When someone questions me or my daughter about our scars I tell them our brains were too big for our head. That gets the Q & A session in full swing!

-- Wendy Bentley

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

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