

View From Montana, By Julie Carter

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.*

Here in Montana, Chiari is virtually unheard of. It is not like we are living in teepees and covered-wagons, although there are actually people who still think we are that far behind, in every way, not just medically. Montana is one of Americas most "rural" states, with 147,138 square miles of geographically diverse land, but only 883,000 people living here, according to the 1999 U.S. Census estimates. If you divide that up, we have only about 6 people per square mile; not exactly New York. Luckily for me, I live right outside of Billings, the largest city in the state, and definitely the Medical Metropolis for this entire region. We have two Hospitals here in Billings, St. Vincents and Deaconess, and these two hospitals are serving Montana and Wyoming and outlying areas, a region of about 500,000 square miles. We are fortunate to have many highly trained specialists, and yet, the challenges in healthcare are tremendous in this vast, rural region.

I was diagnosed with the Chiari Malformation in December of 2001. I had never heard of it, and neither had anyone else I knew. Fortunately, a few of the medical professionals I came in contact with, had heard of Chiari. I had symptoms all my life, and had been misdiagnosed with many other conditions along the way. It was not until I had turned 40, and my symptoms were literally crippling me that I was diagnosed correctly. Really, do you remember how you felt when you first heard the words? Arnold who? My husband and I were totally speechless after seeing the MRI's showing the brain where it is not supposed to be. Many times I have felt as if I fell off of the planet Mars, the looks I get when I try to explain this to people.

I had the great fortune to be placed in the hands of a very competent brain surgeon who knew how to do the decompression. I have to say that I was absolutely terrified, but he had a sense of confidence that I trusted immediately. Besides, I had never met a Surgeon who wore cowboy boots with his scrubs, and I knew that he must be very sure of himself. Dr. John did an excellent job, and I made an amazing recovery. I could not remember feeling that good, not since I was in grade school. All was well, and I had started my life over, literally.

I returned to work in the garden center, I was the "plant lady". Just 84 days after my surgery, as I was loading mulch for a customer, her car-hatch dropped on my head. Things began to unravel quickly, as the numbness in my face and left side returned almost immediately. I began to stumble over words, I could hardly make a complete sentence. My short-term memory was about 1 second long. My head was throbbing, and my left leg started to drag again. My boss wanted me to get back to the brain surgeon immediately, but I was having none of that. Secretly I thought that the head injury had knocked my brain out of the bag and I would have to go through the decompression again. I was thoroughly discouraged and definitely in denial, maybe I thought I could "will" myself to heal.

When I did finally get back to see the doctor, he sent me to Headway. I was so angry, I was not working again and now I had to go to brain rehabilitation. But it was the best thing that could have happened to me. The folks at Headway were not only total professionals, but some of the kindest, most patient people I had ever met. There was only one thing...not one of them had ever heard of Arnold Chiari Malformation. It seems that the information about ACM just has not reached Montana yet. They were fairly fascinated with my condition and tried to understand exactly what had happened to my brain, but it was definitely frustrating, especially for the Physical Therapist. It seemed that no matter what we tried, I could not even hold my own head up, the neck just would not do its job. I guess the head injury happened so soon after the brain surgery that my neck muscles had not had enough time to heal thoroughly.

Because I had been injured at work, I was a Workman's Comp. case. This proved to be a heartbreaking situation that I still wish I could undo. Work/comp. had never heard of Chiari, and I was just not healing fast enough for them. Many doctors did not want to take me as a patient, possibly because of the red tape and paperwork involved in Work/comp. I ended up getting sent from one doctor to another, and none of them seemed to know what Chiari was. The Neuropsychologist at Headway felt that I was slipping through the cracks, but Work/comp. wasn't interested in Headways opinion. So I was sent to a Psychiatrist, apparently he was supposed to figure out what was going on with me. I truly felt sorry for this man, and he could not help me. He diagnosed me with ADD and put me on Ritalin. I had a bad reaction to Ritalin and ended up in the Emergency Room with what appeared to be a stroke. When a stroke did not show up on the Cat Scan, Work/comp sent me to a Psychologist, who, after hearing my story, diagnosed me with Chronic Delusional Disorder---for making up all these symptoms since I was a child. The Psychologist actually sent out a report stating that he felt that I should have no more medical care, but that I obviously needed regular Psychiatric care and medication management.

I could not help but wish I lived in New York, where Chiari is not only known and understood, but researched and studied. I believe if this had happened to me and I lived in New York, or Chicago, I would not have to deal with this stigma. I cannot help but wonder how many others who live out in rural areas have had to deal with this frustration. It seems as if I am constantly having to defend myself and my symptoms; who could make this up, and why would they? One thing I have noticed about myself, since the head injury, is that I have become an isolationist. Me, the extrovert who sang and danced my way through life, no matter how much pain I was in, have found myself shut up in my house. Partly because of the physical pain, but partly because I am so tired of explaining this Chiari to people who cannot seem to understand, or maybe they don't want to. They don't have it, why should they care?

You know, you really cannot see Chiari. It's not as if my brain has slipped out of my head and is sitting on my shoulder; I look pretty normal. To have a TBI, (Traumatic Brain Injury) on top of Chiari is like sentencing a person to a life of frustration and misunderstanding. Sometimes on bad days, I tend to sway and weave a bit when I am trying to walk. Sometimes people look at me and I know they think I am drunk. I don't drink, I can't imagine drinking when I am already like this. I am thankful that my family loves and supports me, even though they do not understand all of this, and it seems as though we have been hit by a never ending storm. I know that eventually all the research and work

done by the specialists in New York and Chicago and other places will reach Montana, and then, I will be treated normally.

Until then, it appears that it has fallen on me to try to get this information out to the Doctors here. When you're feeling like the lone stranger, the best thing to do is to seek out support. I have found this in an on-line Chiari Support Group. I am in the process of trying to start up a local support group in my area. The thing I am finding out about Chiari-people is that once they have been diagnosed and corrected, they are so happy to get on with their lives again that they seem to want to put this behind them and be "normal". I know I did. Truthfully, had I not ended up with the TBI setback, I am not sure I would want to be involved in the problems Chiari causes. It can be so painful, physically and mentally. We all know what a terrifying and frustrating journey this can be. Nothing like a good dose of frustration and anger to get me to stand on my feet and take up this cause. So here I stand, way out here in Montana, and waiting patiently for the good news to come west. It will be as good as gold when it finally arrives. If there is one thing I have learned living here in Montana, it is patience. As I wait, I study Chiari, as if it is my enemy; it can't be my friend. I study my enemy so I can learn how to overcome it, and bring it into submission. I am so grateful for technology. Can you imagine where we would be without the internet? Especially those of us in rural areas. If I had to be born with Chiari, I am glad it was in this Century.

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

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