

Juggling Five Kids & Chiari by By Ann M Colabufo | February, 2004

It was a Monday morning in March after the hockey state championship weekend. I was sitting in my family doctor's office wondering why they were ordering a MRI of my brain. I thought I would come in and describe my symptoms and go home with a prescription for medicine. On Saturday, the high school team my husband coaches was playing and I stood up to cheer and almost passed out. I had a severe headache. I woke up the next morning and still had the headache and couldn't move my legs. I gradually got up and moving. I shared this with my doctor as well as other strange symptoms that had started since the birth of our son: pain in the back of my head whenever I bent over; back of the head pain before and after a bowel movement; an increase in my migraines which I have had since I was a teenager; and a feeling of pressure and pain in the back of my head when I would go up and down the stairs. A few days after my MRI, my doctor called and said I had a Chiari malformation. Thus, my journey with Chiari began. I was 36 years old. We had 4 children under the age of 7. Three of them adopted from Korea and a 9 month old.

When I became pregnant after 12 years, my gynecologist considered it a medical miracle! I had severe endometriosis and had surgeries due to quality of life reasons because of the pain and also in hopes to become pregnant. A month before beginning a medication to put me in menopause, we received the amazing news! I was pregnant! After a normal pregnancy, I had a long and difficult delivery. We had decided beforehand to try to go natural and we did. Twenty-four hours after labor first began, I was screaming for an epidural but it was too late! Our son was born in June 2001. A few months after he was born, I started having these strange feelings in the back of my head. I kept dismissing them as something that must happen after you have a baby for this was all new to me! I had always had migraine headaches so that was nothing new and could be hormonal I thought. Now, nine months after our son's birth we were dealing with a diagnosis of something we had never heard of before. What was this thing called Chiari?

My family doctor sent me to a neurologist who explained a Chiari malformation to my husband and me and decided the best way to begin treating it was to put me on Topamax. I was still breastfeeding so I had to wean our son first before I began the medication. I constantly searched the Internet for answers about Chiari, what to expect in the future and how to deal with my ever-increasing symptoms. I only found information I didn't really understand - or want to at the time - or read about testimonies that scared me.

A doctor friend of my husband recommended I go see a surgeon in our area known for brain surgery. We made an appointment and left there more confused than ever. In his report and in speaking with him, he acknowledged that the MRI indicated a "4 or 5mm tonsillar ectopia" but just because it said I had a Chiari malformation in a MRI report did not mean that I was symptomatic. He said that many people are probably walking around with the same thing and never need surgery or even know they have it. He told me that I did not have a "symptomatic Chiari malformation." He felt my symptoms were "myofascial" and recommended a migraine medication and that I allow my body to get back to normal from my pregnancy and breast-feeding. He also told us that the tonsils could not drop any further. I never wanted to have surgery anyway so this was a relief but his information about Chiari contradicted what we had read and had learned from my neurologist. My neurologist dismissed the report and continued to treat me with Topamax and monitored my Chiari symptoms.

Dealing with the symptoms was difficult as I tried to maintain my life as a stay at home Mom with a new baby and three children, one of which has special needs. The Topamax seemed to be helping a little I thought and I just kept trying to ignore what was happening even though the pressure and pain were increasing and my ability to do my daily tasks decreasing. I couldn't drive if I did too much bending or going up and down the stairs. I needed to lie down frequently. It was frustrating me and I felt more and more unable to care for the family I had waited and prayed for. I just kept wondering and praying: Who was right-the surgeon or neurologist? Can this get any worse? Will it just stay like this forever? I continued to seek information on the Internet and reading other's experiences but none seem to be just like mine. How would I know what to do?

After an August vacation to visit my parents, I started having some breathing difficulties-kind of like what they describe asthma to be. A trip to the doctor indicated all was fine as far as not having asthma and the question arose as to whether it was related to the Chiari-more than likely the neurologist felt. That was the beginning of when my Chiari symptoms began to become even worse. In September, I increasingly became more bedridden and could not drive at all. We had to move our bed to our living room from upstairs. We also had to have family and friends help with the care of our children.

At this point, my neurologist said he needed to send me to a neurosurgeon familiar with Chiari malformations. The neurosurgeon did not mince words when he told me that I needed surgery and soon. He requested another MRI and then said, "I'll give you the weekend to think about it (the necessity of the surgery)." The following week, he did not back down from the urgency in the situation especially with the MRI results and my symptoms. The MRI indicated that the tonsils had dropped to 9mm. What I was told by another surgeon wasn't supposed to happen did. They had dropped 5mm in 7 months. My neurosurgeon indicated that he could easily make a case for why this should have been done sooner which would have prevented such severe symptoms and the unfortunate possibility that some of those symptoms may even remain despite the surgery. The decision I had felt was so uncertain now became very clear.

I had surgery October 22, 2002. Upon waking, I remember feeling that there wasn't any pressure anymore. When I asked the surgeon who assisted how it went, he said, "We cut the tissue and the brain just popped back up!" The healing process wasn't easy especially since two weeks after the surgery our 5th child, our daughter from Korea who is the biological sibling to our third son, arrived home! I wanted to hold her and care for her and in the process strained the muscles that were cut and trying to heal from the surgery. I had to go to physical therapy for a few months and "not allowed to be the primary caregiver" of my children as per my surgeon's orders! It was difficult but necessary. We had also begun the waiting game to see what symptoms would remain. My experience with Chiari was challenging me physically, emotionally and spiritually from when we first found out to the patience required in the healing process after surgery.

Sixteen months later, I am back to caring for my five children! Am I more limited than before I became Chiari symptomatic? Yes, but we are adjusting and are grateful for what I can do for it is so much more than what I could do before the surgery. After a year, some symptoms have remained and appear to possibly be permanent. Only time will tell. We have had to make adaptations to our home; our bedroom is now on the first floor so I don't have to go up and down stairs and can lie down in the afternoon if necessary. My family continues to be such a blessing to me as they are adjusting to what I can and cannot do and I am trying to adjust to that as well! I am currently receiving vestibular rehabilitation in physical therapy in hopes that my brain will learn to compensate for the damage done to it from the pressure put on it from the Chiari. It is difficult and causes nausea and headaches but I am gradually enduring more.

An unexpected and shocking diagnosis of a Chiari malformation has been life changing but I have learned so much about what is important. I am still learning to adjust my lifestyle and responsibilities, and to accept the pain and limitations so I can enjoy my family. I hope that with this perspective it may help another person who is seeking answers, looking for hope and feeling confused about what is happening to their body and life, as they knew it. There is help- the right kind of help from knowledgeable medical professionals. There is hope after surgery. There are blessings abounding when we step out of the confusion and fear and learn to trust.

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