

The Human Side of Chiari and SM

by Tammi Brown

My name is Tammi Brown. I am forty-three years old and have been disabled for seven years due to the affects of Arnold Chiari malformation, syringomyelia and related disorders. Since I own a Cavalier who is also afflicted with these conditions, I thought it would be of interest to share the human side of these problems with fellow Cavalier owners. For humans, Chiari malformation and syringomyelia can be quite devastating physically, mentally, emotionally and financially on patients, as well as their families. According to the Chiari & Syringomyelia Foundation, over a quarter of a million families are affected by Chiari and/or syringomyelia, and those are just the ones that are properly diagnosed at this time.

My journey with CM & SM began with some burning pain across the middle of my back when I was eighteen years old. After a visit to an orthopedic surgeon I had no diagnosis, but left his office with a prescription to wear an upper body corset for my first year in college.

Over the next eighteen years I struggled with numerous symptoms: severe neck and shoulder pain, migraines, back pain, fatigue, irritable bowel syndrome, vertigo, right arm pain, fluid in my ears, concentration and memory problems. Studies have shown that the average patient can go five or more years before being properly diagnosed with these conditions. The long list of symptoms and the fact that no two patients present the same is what makes it so difficult to diagnosis. With hope of bringing faster diagnosis to Chiari sufferers, a study of 265 patients describing a unique headache that runs up the back of the head with increased pressure into the back of the eye/eyes which increases in intensity with coughing, sneezing, singing, laughing, posture, etc. was published in the March 2004 Journal of the American Academy of Nurse Practitioners by Dr. Diane Mueller, Neurosurgery Nurse Practitioner and Dr. John Oro, one of the country's leading neurosurgeons specializing in CM. This one commonality among Chiari patients is what the Nurse Practitioners and General Practitioners need to be most educated on.

Over the years my quest continued



Tammi Brown and her Cavalier

randomly visiting a doctor in the new city or state which I lived. I would present my symptoms and each time it was insinuated that I was depressed, stressed or basically... crazy. One study of over 300 CM patients revealed that more than 50% had been told at some time by a doctor that they were suffering from mental or emotional problems.

Beginning when I was twenty-four, I started going to the chiropractor two to three times per week to get adjustments on my back and neck to keep me going through my school and/or work week. I continued this for the next twelve years. Eventually, I gave up on conventional medicine altogether and switched to alternative medicine. I go to my General Practitioner only if I need a referral. I started getting massages when I could afford them, taking supplements, eating the best I could and exercising to the point of what my body could handle, although it always seemed to just fatigue me more.

I continued to push along, following my dreams. In 1996, I began a great career with Walt Disney World. My first three years I worked at Disney's Fairy Tale Weddings as an Intimate Wedding Coordinator. Then in 1999, I was promoted to the Creative Costuming Department as an Entertainment Costumer Supervisor. I had the job of a lifetime. It was extremely rewarding, but very stressful, and I needed to be on my toes. Well, I was feeling my absolute

worst. My symptoms were escalating, but nobody I worked with had a clue. I always looked my best and wore a big smile. When I would get home, I was almost dead.

In October of 2001 it all came to an end. My right arm stopped working completely for a week, my migraines were so bad I couldn't get out of bed, and I had an episode with my back that took me out of work for a week. My chiropractor finally realized there was something more going on. I BEGGED him to send me for an MRI. FINALLY, someone listened. I had an MRI the next day. The following day, just over eighteen years from my first appointment, I had an answer. I was diagnosed with Chiari and syringomyelia. My poor chiropractor, who had become a good friend of mine after treating me for six years, gave me the news.

Unfortunately, the saga doesn't end there. I was promptly referred to a neurosurgeon, as I was told I would need brain surgery, more formally known as decompression surgery. From there I sought a second opinion. Over the next four months I saw five other neurosurgeons, not one matching the opinion of the first. I was just beside myself. I realize now I had to go through all of that to meet my angel, Dr. Paolo Bolognese, neurosurgeon at The Chiari Institute. For the five minutes all those other doctors could barely spare this man would give me a lifetime. After sitting with him for two and a half hours in Disney's Grand Floridian Hotel while he was on vacation (which is a whole other story), I decided he was the one to see. I traveled to Long Island, NY for a series of tests: MRI's of brain and entire spine; 3D CT brain scan; lumbar puncture/myelogram; test for Multiple Sclerosis and many more. It was confirmed, I was a mess. Dr. Bolognese agreed, I needed to have the decompression surgery. If I didn't, I would be in a wheelchair within a year. I scheduled the surgery. In May of 2002, I had decompression surgery and they found I barely had any spinal fluid flowing to my brain.

The decompression is the most common surgery done on CM patients, which is the same surgery they are currently doing on Cavaliers. In the Winter 2007 Edition of *Royal Spaniels*, Dr.

Dominic Marino wrote of this surgery on Cavaliers. In combination with my neurosurgeon, Dr. Paolo Bolognese, the two of them worked together to perfect the cranioplasty (placing a titanium mesh and a bone cement cover over the portion of skull bone that is removed). In both humans and dogs, the decompression surgery is designed to create more space in the back of the head in order to restore the proper flow of cerebrospinal fluid, which in return will hopefully reduce the size of any syrinxes. Every neurosurgeon has a different approach to this surgery. Unfortunately, some neurosurgeons, because they are uneducated about Chiari, can do more harm than good.

Research has shown that brain surgery can improve symptoms for about 80% of patients, but fails 20% of the time. I fall in the latter percentile. After about three months, all of my symptoms returned. I was unable to return to work and had to give up my dream job. Over the next five years my symptoms increased. I started having major low back pain, bladder issues, and loss of sexual function, increased headaches and neck pain. Even though Chiari malformation was described back in the 1890's, the in depth research on both CM and SM didn't begin until the introduction of the MRI. To this day, they are both still considered rare conditions and a great deal is still left to be learned.

From 2002 to 2006, a new theory was born regarding the cause of Chiari in several patients. The theory was tethered cord syndrome, a condition where the spinal cord tissue is abnormally attached to the bones of the spine. The filum terminale is a fibrous thread which connects the very bottom of the spinal cord to the coccyx bone. If it is unusually thick, or tight, it can essentially place the spinal cord in traction, pulling it down along with the brain stem. In 2006, Dr. Bolognese diagnosed me with tethered cord syndrome and told me I would need to have more surgery. He told me my brain stem was stretched to its complete maximum. He also told me I had cranial/cervical instability/settling, which means my head is bobbing on top of my spine and my head is settling down into my neck. Many other CM patients have this condition, which can be caused by whiplash or from a condition called Ehlers-Danlos syndrome (a connective tissue disorder). In my case, we believe the cause of this instability is due to the forceful chiropractic adjustments of my head which, for years, brought relief to the very top of my spine and neck.

For this condition, a cranial/cervical fusion is recommended. This surgery is the most invasive surgery of all because rods are screwed into the skull and cervical spine to stabilize and lift the head permanently.

In January 2008, I had my spinal cord un-tethered. The surgery revealed several defects within the lower spine that had been continuing to obstruct the proper flow of spinal fluid throughout my spine. These defects were repaired. Three months after the surgery I began physical therapy, which will be a life long process, in order to keep my neck muscles strong to avoid the cranial/cervical fusion. Six months post-op my MRI's revealed the syrinx in my cervical spine finally getting smaller, meaning the last surgery did its trick in restoring proper spinal fluid flow. Things are starting to look up.

Is there a genetic component to Chiari malformation? No gene has been identified as of yet, but scientists have identified specific chromosomes where genes may be located. There are a number of families in which several members have been diagnosed with CM. In October 2007, Extreme Makeover: Home Edition featured the Carter family from Billings, Montana where the mother and her three daughters are all suffering from the devastating affects of CM and SM. Some have thought the small posterior fossa (the base of the skull), which tends to be abnormal in Chiari patients and Cavaliers, could be the genetic link. However, when studying families such as one of a family with four generations of CM patients published in the January 2008 Journal of Neurosurgery Pediatrics, they showed no such link.

Not a day goes by that I don't continue to have many symptoms. Some days it is hard to get out of bed, especially really rainy, overcast days. When there is a big pressure system moving in the pressure in my head/neck increases, which was much worse before my decompression. Unfortunately, I notice my dog being more lethargic and having a tougher time getting going for his morning walk on those types of days. My symptoms also increase with stress, anxiety, bright lights, loud noise, commotion, reaching, pulling, upward or lengthy neutral head positions, strong smells and even certain foods.

I have made the environment for myself and my dog as non-toxic as possible through using green household products, body products, and as much organic food as possible. Although I do have to take medications, I fill my body

with whole food supplements to counteract the negative effects. I use Young Living therapeutic grade essential oils for all different kinds of remedies: pain relief, stress, energy, migraines, sleep, memory, perfume and much more. I even use an herbal flea collar that is made out of essential oils, as I am concerned with the flea control that requires placement on the spine. With proper knowledge many of the Young Living oils, along with the Young Living Raindrop Technique (a technique designed to bring the body into structural and electrical alignment) can be used safely and effectively on animals. Many other alternative therapies can be very effective for humans, as well as dogs, such as: cranial sacral therapy, massage therapy, acupuncture, reiki, chiropractic/kinesiology (when they know what they are dealing with). Unfortunately, it is the cost that keeps most away, as there is no "one time fix" and most aren't covered under insurance.

Living with Chiari and syringomyelia is a lifelong engagement. It is a long road to acceptance, but the journey brings new friends, greater appreciation for life and the ability to overcome the guilt about the work that isn't getting done while you rest. It teaches you to appreciate every moment, to be thankful for the good days and not take life for granted. As fellow Chiarian Sheila Reilly writes in her Chiarian Creed, "I will not ask, 'Why me?' While Chiari has weakened my physical body, it has strengthened my heart, my soul and my spirit."

Living with a Cavalier with Chiari and syringomyelia is very humbling. He has helped me find JOY. He has brought such laughter and unconditional love into my life. His tail never stops wagging, he never stops smiling, he never admits pain and his life revolves around me walking by so he can tip over in order for me to rub his belly. Who knew living with a Cavalier with CM and SM would be so enlightening. On the days I am feeling my worst, he inspires me to get out of bed. He inspires me to go for a walk and keep moving through my day no matter how I feel. He is always an inspiration as he is so full of life, extreme joy and lives in every moment. We really can learn a lot from our dogs. Mostly, I wish I could learn how to get someone to scratch my belly every time I rolled over.

The following websites can offer more information on the illnesses mentioned in this article: www.CSFinfo.org, www.asap.org, www.conquerchiari.org, www.ednf.org

