



Chiari: My surgical miracle

■ How a rare diagnosis and a risky surgery gave me back my life

By Dee Ann Campbell
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GILBERTOWN — “This has to be happening to someone else,” I remember thinking. “This can’t be me.”

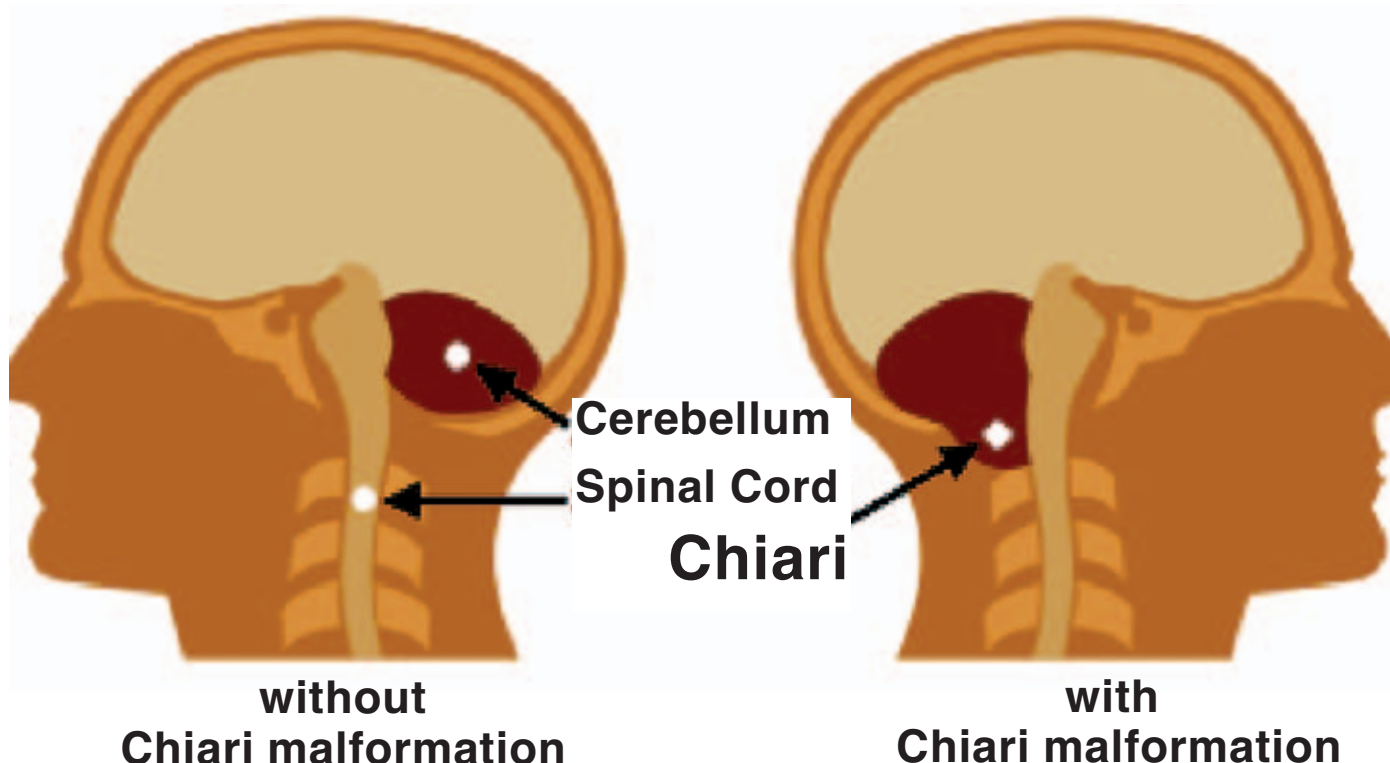
I remember watching my family walk into the amusement park ready to spend the day riding rides and having fun on our short vacation. Any other time, I would have been right there with them, thrilled to ride the tallest roller coaster and charging through the park like one of the kids.

But not anymore, I remember thinking as I sat in the motorized wheelchair. Not today. Not now, and probably not ever.

It had been a long time, it seemed, since I had been able to walk for more than a few steps, a long time since I’d been able to go to the grocery store or clean my house or walk to the mailbox. It had been a long time since I was able to stay awake for more than a few hours at a time, or spend a day without pain, or walk through the yard with my husband.

It had been a long time, it seemed, since I’d been able to do the simplest task without exhaustion, or control the movements of my legs and arms, or just think without fading into fuzziness — so long since I’d done all those simple things that had once been a part of my life.

And it had been so long since I’d been able to do all those fun things with my children. In fact, more often than not, when they asked me to play the simplest game or help with the simplest



Graphics courtesy of the C&S Patient Education Foundation

task, my response was a dejected, ‘I can’t.’

Looking back, I remember the day when the symptoms began. That walk through the mall on a spring Saturday in 1999 had seemed unusually long, and I was unusually tired — or so I thought. Before the shopping trip was an hour old, my daughter Brandi had to hold me up as I made my way slowly, hesitantly, awkwardly to the car — walking on legs that seemed not to be my own, with arms that seemed hundreds of pounds heavier, and a head that seemed too far too heavy for my shoulders.

Over the next few days, my symptoms grew worse. From crippling fatigue to intense pain to blurred vision, my list of ailments grew and grew until I could no longer function, no longer go to work, no longer even hold my head up.

There were those days that I spent in bed, days when I lost hours of memory, days when I could barely speak without slurring, barely

walk, barely think. There were times when my legs hurt so much that I cried, and days when I could barely move my left foot. There were days when I would wake up unable to control my right arm, or prompt movement in the fingers on my left hand.

Eating required too much effort, it seemed, so I stopped. Three weeks and 20 pounds later, I found myself lying in bed yet again, wondering how much longer until I would feel like me again.

I went to doctor after doctor, endured test after test after test, but no one could give me the answer. I was labeled with every ailment imaginable, from Multiple Sclerosis to arthritis to Lupus, but none were proven, and none seemed right.

I was treated for migraines, for hypothyroidism, for arthritis, and even for depression. Finally, after exhausting all other possibilities, I was diagnosed with Chronic Fatigue Syndrome and Fibromyalgia and told to go home and

live with it.

Two years after my first symptoms, I still had no real answer, and no real solution.

I simply had to resign myself to my bed, to my wheelchair, and to my life without doing all those things that I had taken for granted.

And my children had to resign themselves to a mother who always said, “I can’t”.

But one last trip to a doctor, one more MRI, one more test, changed everything.

The diagnosis was strange — something uncommon, something rare, something I’d never heard of. But it was something that could be corrected.

When I first learned about Chiari Malformation, I was frightened. To think that I had a structural defect at the base of my brain was more than a little daunting.

Normally the cerebellum and parts of the brainstem sit in an indented space at the lower rear of the skull, above the foramen

magnum — the opening to the spinal column. Part of my cerebellum was located below the foramen magnum. The space was smaller than normal, causing the cerebellum and brainstem to be pushed downward into the foramen magnum and into the upper spinal canal. The resulting pressure on my cerebellum and brainstem had affected functions controlled by these areas, blocking the flow of spinal fluid to and from my brain.

No one could tell me exactly what caused the malformation, but a neurosurgeon in Birmingham could tell me how to fix it — surgery.

The surgery was risky, he had told me. To have someone open the back of my skull from the mid-point half way down my neck was not something I looked forward to doing, and there were possibilities of severe, even fatal problems during surgery.

But when I weighed the options, my choice was simple: live as I had

been living for the past few years, or risk the surgery to gain my life back.

In late July of 2001, I woke up in the recovery room in a Birmingham hospital with a new life.

It’s been six years now since I had the surgery that changed everything. For six years, I’ve walked and ran. I’ve jumped and laughed and shopped and worked.

I’ve bought groceries and had enough energy to put them away. I’ve worked long hours and lay awake at night pondering my day, only to get up the next morning with energy enough to do it all again.

I’ve even gone to amusement parks — without my wheelchair.

Since that time, I’ve realized that the problem that caused my symptoms is not so rare after all. In fact, estimates are that about 20% of people — primarily women — who have been diagnosed with fibromyalgia and chronic fatigue syndrome have at least a mild form of Chiari Malformation instead.

They are, no doubt, living lives filled with pain and struggling, just as I was — just as I would still be — if not for that one last MRI, if not for being pushy and bold and vocal and insistent that someone, somewhere simply listen to my problems and find a way to fix them.

Now, when I think about the events of six years ago — when I remember the wheelchair, the pain, the fatigue, the struggles, and the surgery — it still seems as if it happened to someone else, someone from another time and another place, and I guess, in a way, it was.

Those memories ARE of someone else, someone without hope for a normal future, someone with only a wheelchair, a life filled with struggles, and a life of saying, “I can’t.” But today, I’m not that person anymore, thanks to a medical miracle and the surgery that gave me back my life.



Choctaw Sun photo by Dee Ann Campbell

New officers chosen for 2007

BUTLER — The Choctaw County Health Council elected new officers for 2007 during their meeting on Tuesday. Officers are: Linda Turner-Gaines — treasurer; Georgia Dozier — vice-president; Barbara Shoemaker — president; and Dora Whitted — assistant secretary. Not pictured is secretary Vivian Heartfield. The council is made up of healthcare workers and other concerned citizens who work to provide health-related informational workshops, health fairs, and other events in order to address health concerns in the area.

Sisters needed to help find the causes of breast cancer

RESEARCH TRIANGLE PARK, N.C. — The National Institute of Environmental Health Sciences (NIEHS) needs 19,000 more women to join the Sister Study, the nation’s largest research effort to find the causes of breast cancer. Researchers still don’t know what causes the disease. NIEHS hopes to enroll a total of 50,000 women whose sisters had breast cancer. The Sister Study must meet its enrollment goal by the end of 2007.

Since its national launch in Oct. 2004, The Sister Study has successfully recruited more than 31,000 participants — women whose sisters were diagnosed with breast cancer. Recruitment is far from over.

Available in English and Spanish, the Sister Study requires very little time from its volunteers. The 10-year observational study begins with participants answering questions about diet, jobs, hobbies, and things they’ve been exposed to throughout their lives to determine what may influence breast cancer risk. Later, at a convenient time and location for the participant, a female health technician collects small samples of blood, urine, toenail clippings, and house dust, which

will also help give researchers a better picture of the woman’s environment and genes.

Women in the U.S. and Puerto Rico, ages 35 to 74, may be eligible to join the Sister Study if their sisters (living or deceased) had breast cancer. Women who join the Sister Study must never have been diagnosed with breast cancer themselves. Breast cancer affects women from every walk of life, so the Sister Study is seeking women of all backgrounds, occupations, ages, and ethnic groups.

African-American women and women of all races from Alabama are especially needed for the study.

The Sister Study follows sound, ethical research practices, and keeps all personal data safe, private and confidential. Women who join are not asked to take any medicine, visit a medical center, or make any changes to their habits, diet or daily life.

To volunteer or learn more about the Sister Study, visit the web site www.sisterstudy.org. A toll free number is also available, 877-474-7837. Deaf or hard of hearing persons may call 866-889-4747.