Elizabeth Michel Camak Counts By Deborah Jacks Camak, MSN, RNC-MNN, FCN, C-EFM

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Author Note

Deborah Jacks Camak, MSN, RNC-MNN, FCN, C-EFM, is the mother of Elizabeth Michel Camak Counts. All correspondence should be directed to: Deborah Jacks Camak, 1601 Nation Road, Hodges, South Carolina, 29653. Email: camakdeborah15@gmail.com.

Abstract

My daughter Elizabeth Michel Camak Counts, was diagnosed with idiopathic scoliosis at the age of 5 years. At age 9 years, she was diagnosed with Syringomyelia, Arnold Chiari with Scoliosis. Through 2 major surgeries and 17 years as a patient of the Shrine Hospitals for Children, she has possessed a positive attitude and a capacity for endurance that most individual's do not possess.

Elizabeth Michel Camak Counts

The prolific author, Helen Keller once said, "Although the world is full of suffering, it is also full of the overcoming of it." This truly defines the life of my daughter, Elizabeth. Through many years of; suffering, pain, living in a brace, enduring surgeries, and various therapies, she has rigidly withstood all with grace truly exemplifying the overcoming of it. First diagnosed at the age of 5 years with idiopathic scoliosis, little did we know that it was just the beginning of a long, winding path that would lead through valleys of fear and mountains of joy.

Elizabeth was born in 1981 of a term pregnancy without complications. First noted during the toddlers' years, she had difficulty with coordination, muscle weakness, swallowing disorders that rendered her unable to take medication dispensed in the tablet form. By her 5th birthday, Elizabeth began to have days in which she would experience headaches, vomiting and nausea without explanation. After her 5th birthday, during a routine medical office visit, it was discovered that Elizabeth had scoliosis with a 22-degree lumbar curve. Within months she was admitted to the services of the Greenville, South Carolina Shrine Hospital for Children. Thus, began a long relationship with the Shrine Hospital System.

After Elizabeth's' 6th birthday, the physicians at the Shrine Hospital placed her in a jacket brace to arrest the scoliosis curvature. Every day, for the next 7 years, she would spend 23 out of every 24 hours in a day in a brace. Within 2 years, she began to develop a thoracic scoliosis curve in addition to the lumbar curve. After her 9th birthday, the physicians decided to try a Milwaukie brace since she now had 2 curves that were continuing to progress in curvature. Many of the children in Elizabeth's' school avoided playing with her because of the Milwaukie brace. Even though, she was treated with misunderstanding and prejudice, she continued to

remain friendly and never retaliated toward them. In conversations regarding the behavior of some of the children in her school, she would tell me," Momma, its ok. Really, its ok".

It was during this time, that Elizabeth was also displaying the loss of her fine motor skills, pain in her arms and legs, some slurring of her words, balance difficulties, and expressed that she was having frequent headaches. One afternoon, she stated that she was experiencing pain in the back of her neck. As she pointed to the back of her neck she said," Momma, it hurts right here," I arranged a visit with her pediatrician, but no symptoms of illness were found.

Within two weeks, during a visit with the physicians at the Shrine Hospital it was discovered that Elizabeth probably had a syrinx in addition to the scoliosis. Three weeks later, after her first MRI, it was confirmed that Elizabeth had Syringomyelia, Arnold Chiari with Scoliosis. Her syrinx was in the fourth ventricle of her brain and she possessed 2 large pockets of cerebral spinal fluid within the central canal of her spinal cord, a pocket in the base of her neck and a very large pocket in her lumbar area. Seven days later, Elizabeth underwent a Posterior Fossa Craniotomy with Plugging of the Obex at Greenville Memorial Hospital in Greenville, South Carolina. Muscle tissue was graphed from Elizabeth neck and used to plug the syrinx located in the Obex (4th ventricle of her brain). It was theorized that overtime, her body would reabsorb the cerebral spinal fluid from her central canal. After her surgery, she began to regain some of her fine motor skills, the headaches lessoned in frequency and her articulation improved. Amazingly, Elizabeth never cried nor complained during her surgery and was running through the Shrine Hospital playing with other children within 3 days postoperative. She was a real trooper!

One year later, Elizabeth was placed in a TLSO brace since both, the thoracic and lumbar curves were continuing to progress and now, it was noted that the vertebral disks were rotating in

a circular fashion due to the loss of placement brought about by the curvatures. At 12 years of age, while wearing her second TLSO brace, Elizabeth decided to run cross country track. During every track meet, she wore the TLSO brace. One afternoon, during a track meet, I overheard a young girl standing a short distance behind me say in a condescending tone," Oh, that's Elizabeth. I don't know what that thing is that she wears on her back!". I did not turn around nor confront the girl, but her words cut to my heart.

At 13 years of age, in 1994, the physicians decided that Elizabeth needed an anterior and posterior spinal fusion with rods to resolve the scoliosis. When the physician explained to Elizabeth that she would need surgery, she smiled and rejoiced over the thought that she could finally do things that she had never been able to do before, such as contact sports and dancing. Her physician was mystified by her delight while facing a 10-hour surgery. Additionally, an MRI was completed revealing that almost all the cerebral spinal fluid had been reabsorbed from the central canal. A few weeks later, Elizabeth underwent an Anterior and Posterior Spinal Fusion with the placement of a Dwyer and 2 Modulock rods at the Shrine Hospital for Children in Greenville, South Carolina. As before, she never complained during the surgery. She only cried once when her wheelchair was bumped by another individual. In fact, she anxiously desired to return to school and made friends with another child undergoing a spinal fusion the day after hers and she would check on her friend daily. Eventually, Elizabeth regained balance and coordination, muscle strength and the pain in her arms and legs ceased to trouble her. Through it all, Elizabeth displayed grace and resilience.

The Shrine Hospital kept Elizabeth as a patient with yearly examinations until she was 22 years of age. Since graduating from high school, she has become a certified nurse assistant and a licensed esthetician. She is also a wife, mother of 4 healthy and active children, is employed with

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a rehabilitation hospital and a beauty supply corporation and she is active in her church. Her love for people and willingness to help others is infectious. Elizabeth frequently has shares her own story with her patients therefore, encouraging them with her experience. She uniquely understands their suffering and struggle since she has walked a similar path. She understands pain, disappointment and the endurance needed to regain health and physical ability. Again, as the author, Helen Keller, said," Character cannot be developed in ease and quiet. Only through experience of trial and suffering can the soul be strengthened, ambition inspired, and success achieved."