

A Battle to Conquer the Unknown



Shillingburg's scar almost two years after surgery.

May 3, 2016 - Shelby Shillingburg spent most of her 19 years battling with her brain. Now, one of her greatest pains in life is a distant memory.

She was a surprise to her young parents. Her mother took on the role as her primary caretaker. "I think we are a lot like Rory and Lorelai from the Gilmore Girls," said Shelby's mother, "we are just that close." According to her mother, Shillingburg was a very smiley child. She had very few tantrums, and always followed the rules. "My Shelby was a very well-behaved little girl," her mother said.

Despite being such a good child, Shillingburg encountered many obstacles. Around the age of four, "I would tell my mom I was seeing two of her," Shillingburg said. "She thought I was playing around until I persistently insisted I wasn't."

Shillingburg's mother took her to the doctor where he informed her that she had strabismus, a condition where the eyes cross. "In the end, this led me to get correctional glasses to stop my eyes from crossing," Shillingburg said.

According to Shillingburg, when she was little she developed chronic headaches often. "If I told my mother I had a headache she knew she only had about three minutes to get me to a bathroom because I was going to throw up," Shillingburg said.

As Shillingburg got older, that sickness came under control while the headaches remained.

When Shillingburg entered middle school she developed a love for swimming. "I was so good that I would beat all the boys, swimming became my passion," Shillingburg said. "I developed really bad shoulder pain that I attributed to the repetitive motion of swimming. Unfortunately, because of the severity of this pain, I had to give up swimming, which really broke my heart."

One day in high school, Shillingburg awoke to a pain in her left arm. "It felt like my wrist was broken, so I alerted my mother," Shillingburg said. Over the course of a week the pain had spread up her arm and down her fingers. "With the symptoms getting worse, my mom took me to see a neurologist," said Shillingburg.

The neurologist recommended an electromyography (EMG) to test for nerve damage and carpal tunnel. Based on family history, the neurologist thought Shillingburg had dystonia, which causes pain in muscles due to a lack of dopamine in the brain. He prescribed her a medication to supplement dopamine.

Though the medicine the neurologist prescribed Shillingburg successfully reduced her arm pain, it also brought with it side effects. "The medication made me feel weird," Shillingburg said. "I got dizzy easily, and I would feel numb and clouded."

Shillingburg returned to the neurologist and he gave her a different prescription. Over the course of a year, Shillingburg returned to the neurologist insisting the different medications he prescribed her had different negative effects. Eventually, the neurologist decided he to recommend her to go to the University of Virginia Movement Clinic because he felt he no longer could help her.

The new UVA Movement Clinic neurologist tested her to see if she had the symptoms of dystonia. "He made me do various exercises to see if I had any of the movement problems associated with dystonia, which I did not," Shillingburg said.

Realizing Shillingburg moved fine, the neurologist recommended she receive a MRI. "After about a year and a half, I felt like I was finally going to get some answers," Shillingburg said.

After several months of waiting for her appointment, Shillingburg was finally able to get a MRI. The MRI was supposed to look at her neck and brain without the use of gadolinium contrast. "I was in the MRI machine for about an hour, when suddenly it turned off," Shillingburg said. "The radiologist came in and informed me I would need to use the gadolinium contrast to further look at my neck and simultaneously measure my heart rate."

Shillingburg states that she knew something had been found on the MRI when the radiologist informed her the contrast was needed.

"It took a month before the doctor got back to me," Shillingburg said.

The doctor told Shillingburg's mother over the phone that she had Chiari.

"It took five years, from the beginning of my arm pain to the phone call, to finally knowing what was wrong with me," Shillingburg said. According to the [C&S Patient Education Foundation](#), Chiari Malformations are located at the base of the skull. Part of the brain, the cerebellum, descends out of the skull into the spinal area. This results in compression of parts of the brain and spinal cord, and disrupts the normal flow of cerebrospinal fluid.

"Of course, when I first searched the Internet for Chiari I psyched myself out," Shillingburg said. "But, once I read the symptoms of Chiari it felt nice to have validation for what was going on with me."

According to the [National Institute of Neurological Disorders and Stroke](#), symptoms of Chiari include dizziness, muscle weakness, numbness, vision problems, headache and problems with balance and coordination.

"After I read about the symptoms of Chiari everything made sense," Shillingburg said. "All my life I had struggled with various symptoms, ranging from my strabismus, my shoulder pain and endless headaches. Now I finally knew that there were other people like me out there." The next step in Shillingburg's journey was making an appointment to meet with a neurosurgeon at the University of Virginia.

"I went into my appointment with the neurosurgeon hoping to find solutions for Chiari," Shillingburg said. "However, I left disappointed because he dismissed my symptoms. This left me again confused and wondering if I did or did not have Chiari."

Shillingburg attended her first Conquer Chiari Walk Across America on September 21, 2013. It was at the walk that Shillingburg met many other people with Chiari. She engaged with the various individuals and learned more about the condition.

"While at the walk I became more aware of the fact that the neurosurgeon was not as informed as he should have been about Chiari," Shillingburg said. "With this in mind, I decided to look for a neurosurgeon with more experience with the condition."

After researching neurosurgeons in Virginia, with experience with Chiari, Shillingburg finally found one she thought might work. "I came across a doctor who worked for the Virginia Commonwealth Department of Neurosurgery," Shillingburg said. "He has performed over 60 Chiari decompression surgeries."

Shillingburg arranged for a consultation with this new doctor. He went over Shillingburg's MRI with her, explaining the extent of her overlap of spinal cord and cerebellum. "He told me that it was my decision whether I wanted to have surgery," Shillingburg said. "He informed me that he believed surgery could help my symptom."

Shillingburg had plenty to think about following her consultation. "The concept of having surgery on my brain was a big concern," Shillingburg said.

"After weighing the pros and cons of surgery, I decided to try it," Shillingburg said.

Shillingburg chose to have her surgery done the summer after graduating high school. "I chose this timing because I didn't want Chiari interfering with my life anymore," Shillingburg said. "Also, there was also a nine-week recovery period that went along with the surgery." The surgery took four hours, with a six-day hospital recovery. "My stay at the hospital was filled with a lot of pain and sleeping," Shillingburg said. "The nine weeks following surgery were dedicated to working myself up to the state I was in prior to surgery."

Although Shillingburg feels like she missed out on many summer activities during that time, she believes it was worthwhile. "I believe the surgery was successful. Now, most of my symptoms are gone or under control," Shillingburg said. "This has made my life a lot more enjoyable and the nine-week recovery worth it."

"Chiari is a big part of my life and who I am," Shillingburg said. "I continue to go to walks for Chiari and try to connect with as many people as possible in the Chiari community."

The two-year anniversary of Shillingburg's surgery is approaching fast. Only the faded scar on the back of her neck is a visible reminder of it. "When the scar was fresh I never pulled my hair up. I felt embarrassed and uncomfortable," Shillingburg said. "I felt like it was the only thing people were going to notice about me."

"Now I have come to embrace my scar," Shillingburg said. "It is not a reminder of something nasty in my life, instead it is a symbol of what I have overcome and I am proud of that."

When people approach Shillingburg about her Chiari she plays it off. "I like to say my brain is just too big for skull, and just note it's one of the things that makes me unique," Shillingburg said.

-- Emily Knee *Feature Story*

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

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