

Hoping A Second Surgery Will Lead To A Normal Childhood

Ed. Note: *The opinions expressed below are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. Anyone with a medical problem is strongly encouraged to seek professional medical care.*

My name is Rachel, I'm a mother of two young girls one (my youngest) was diagnosed with a Chiari I Malformation in 2003. As to be expected my husband and I were completely devastated for our young daughter.

We had spent 6-8 months with our pediatrician trying to figure out what was happening with her. At just two years old she did not know how to point out where the pain was hurting her; so much was left to me watching her every move and guessing-until they became more frequent and more intense and we started to notice the activities were consistently the same every time she had a 'spell'. I pushed our pediatrician to do something more, so we were scheduled with a larger hospital in the nearest metro area for an emergency MRI scan of her head.

The next day we met with the neuro doctor who took one look at her MRI scan and immediately detected her Chiari Malformation. The doctor had the neurosurgeon paged and he explained in great detail her condition and what it would require to help her have a 'pain free' life. I remember leaving the hospital completely numb-our lives and our daughter's life changed forever at that very moment. Now, I was pushed into researching and understanding this unique medical condition to select the best care for our daughter. We were recommended to a University Hospital in our state to a female pediatric neurosurgeon. So, scared and strong we took our then 2 1/2 year old on the beginning of her medical journey.

Gracie's first surgery was a chiari decompression with the dura left intact in December 2003. She also had part of C1 and C2 removed as well to allow more room around the brain and spinal cord. The decision by the ped. neurosg. to leave the dura in tact was due to the amount of immediate flow and movement of the tissues back to position. It was decided that the risk of opening the dura was not necessary at that time. We were advised of the post surgery risks of scar tissue potentially forming and the potential for the necessity of a second surgery if the scar tissue posed more blockage.

Gracie healed perfectly. Within a couple of days she was up, moving and on regular Tylenol. She was truly a different child-even weeks to months after surgery everything was perfect and getting back to normal life was a smooth transition. Then about the 10 month post op we started to notice a headache here and there, then one more and more until we were back to where we had started and seemingly worse at times. I immediately contacted the nsg. office to discuss what was happening with her-truly I felt like I was pushed aside. I remember not receiving a phone call back to have anyone talk with me about what was happening with her, I just received her next MRI schedule for several months out. I was not okay with that, so I returned to the neurology department where she was initially diagnosed with the condition. Not comfortable at all with the change in her headaches they ordered a flow study which showed a syrinx that had formed at C3 through just about C5.

Again devastated and more disappointed I immediately contacted her ped. nsg. who requested the films be overnighted to her office. We were scheduled right away and I was contacted to discuss what was happening now. So, here we were again, back and upset as Gracie was now old enough to understand what was about to happen to her. It was a hard decision to make, a second surgery with a risky invasion into the dura. But our decision was put to ease as Gracie's headaches became more intense and we began to notice her sense of urgency to use the bathroom. Most times, she could not make it to the bathroom like she couldn't tell when she had to go. Along with the sense of urgency she was always saying her toes felt hot and constantly was dropping things. The risk of having her lose sensory or motor control was too much for us as parents to not take the next step in helping her. We talked with Gracie about her surgery and assured her she would heal and feel better.

The second surgery was in May 2005 and was a success again. Post op the nsg talked with us about the thick fibrous bands of scar tissue which had formed and created a lot of pressure in the base of her skull which created the pocket in her spinal cord. This healing was more difficult-at 4 years old she was very aware, vocal and wanted to be home with her big sister. Once out of the hospital her recovery sped up and now nearing 5 months post op is still doing very well. We are scheduled for a flow study again in the coming weeks, so we are trying to be optimistic but cautious of the potential positive or negative.

Gracie starts preschool next week, we are praying for a smooth transition for her. She wants nothing more than to be a normal 4 1/2 year old girl but with her condition I fear she will have some set backs.

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

