

Relieved Parents Share Their Daughter's Happy Outcome | December, 2004

We would love to share our good news story. When Chiari and Syringomyelia first hit our family we, like many others, had never heard of them. We turned to the internet and searched for information. What we found informed us a great deal but frightened us as well because there seemed to be more stories of pain and suffering than success. We hope this story will give optimism to someone who finds themselves in the same place we were only a few short months ago.

In April 2004 our 23 year old daughter, Elizabeth, was diagnosed with a Chiari Malformation and a very significant syrinx. Elizabeth had graduated with a degree in Architecture from the University of Oregon in March and had moved home promising us this was for a few short weeks while she found a job. As she had been in a 5 year program and was still in school after she turned 23 in January, our insurance no longer covered her even though she was a full time student. We debated about letting her risk having no insurance thinking it would only be three or four months with graduation in March and the expectation of a new job with insurance of her own soon after that. At the last minute in February, we made probably one of the most significant decisions of our lives to pick up an individual policy for her from Kaiser Permanente. None of us had ever been to a Kaiser physician before (in fact we didn't even know where it was!) but it was the least expensive option and since we really never expected her to use it we thought it would at least be there in the event that something catastrophic occurred.

On April 7th while home working on her resume Elizabeth experienced a severe headache with numbness in her arm. Elizabeth had been a lifeguard on our local lake for eight years and despite years of training in basic first aid, cpr and emergency procedures she decided that she would call mom at work! When her mom heard of the numbness in her arm she immediately suggested Elizabeth call 911 and she burst into tears. Instead, mom headed home and dad followed shortly. Fortunately Elizabeth was not having a stroke but we were headed for a roller coaster ride we never thought possible.

Over the years Elizabeth had complained of back pain. She had been told she had a slight "sway" back and she was given exercises. Over the last five years in Architecture she had spent as many as 12-15 hours a day in studio bending over models, drawings and computer screens. She had complained several times about blurred vision when working in studio. We had sent her to an ophthalmologist who prescribed reading glasses. She had developed a constant habit of rolling her head in circles and cracking her neck claiming that her neck was always sore because of the hours she spent bent over projects. Honestly, if you polled every student in her studio they would all have complained of almost the same things. Her aches and pains seemed reasonable with what was going on in her life and she never really felt the need to take anything stronger than Advil.

Our first call on that April day was to our family physician that had treated Elizabeth since she moved to Portland, Oregon at 12 years old. By this time the numbness was gone in her arm but a severe headache remained. Our doctor said she was pretty certain it was a migraine and since she would probably be given a shot which was expensive she said "why not take her to Kaiser since the shot can be expensive." Remember...we didn't even know where a Kaiser office was located nearby! We found one and Elizabeth went in that day. We honestly believe because Elizabeth was a "clean slate" to them they looked at her in a way that our physician who knew her well and knew how hard she had been working would not have. Because of the numbness in her arm, even though for a short period, this physician decided she would like to have an ultrasound of her head and a MRI. With Kaiser nothing is ever scheduled really quickly so these took a few days and in the meantime Elizabeth felt back to normal so when the MRI appointment came she went off by herself to what she says was one of her worst days!

They told her the MRI would be of her head and neck only and would take about 20 minutes. Within minutes of viewing the MRI the technicians informed her that "we found something and we need to keep going." A little more than two hours later Elizabeth was still completely in the MRI tube and still knew nothing of what was wrong with her while a full spinal MRI took place. She asked them if she had a tumor and they assured her that she was doing great and "we are finding out what we need to." Then came the 24 hour wait until the doctor's office called and said that she had a "malformation of her brain" and they were making an appointment with a neurologist and with a neurosurgeon. Elizabeth asked, "Are you telling me I have to have brain surgery?" and they simply said "We are telling you that you need to see a neurosurgeon to see if it will be necessary." Later that day the doctor personally called and told her that she had a Chiari malformation and Syringomyelia. She readily admitted that she really knew very little about it and had "looked it up" before calling. She assured Elizabeth that the neurologist that she was being referred to would be able to answer many more questions. Of course, that appointment wasn't scheduled for weeks! So like others do in this age of technology we got a copy of the MRI report and we turned to the internet. As we read the MRI report we had to look up many of the terms but we discovered that Elizabeth had a 15mm Chiari malformation and a significant syrinx occupying 90% of the diameter of the cord and extending from C3 to T4.

Now the wild ride really began. Between the MRI and the neuro appointments Elizabeth had received a job offer. At first reluctant to take it due to the unknown in her life she decided to go ahead and see what happened. On her third day at work we met with the first surgeon who informed us she needed surgery "sooner rather than later." Despite the fact that Kaiser had been the ones to uncover this we went into overdrive trying to find out about surgeons in the area and elsewhere. Elizabeth was told by the National Institute of Health that she would definitely qualify for a study they were doing but that meant going across the country. We talked to doctors at Portland Providence Medical Center and two neurosurgeons at Kaiser. Eventually, we all decided that we felt very comfortable with a Kaiser neurosurgeon and surgery was scheduled for June 16th.

We arrived at the hospital early Wednesday morning and Elizabeth was taken back to be prepped for surgery. She was happy that they did not shave her head until she was out because in her words "that would have freaked me out!" We were allowed to stay with her until she was rolled into surgery. Four and one half hours later the doctor emerged to tell us that the surgery was "technically perfect" and we could go to intensive care to wait for her to arrive there after recovery. We were elated when another Kaiser surgeon who was a personal friend arrived a short time later to go into Recovery and personally check on her. He came out and said "oh my! She is doing great. She looked at me and called me by my name." What a relief!

Elizabeth stayed in the ICU for 24 hours and her mother, father or boyfriend stayed by her side. She was on heavy pain meds and anti-nausea meds as well. She had not thrown up since she was nine years old and seemed to fear getting sick as much as anything else! Thursday afternoon she was moved into a regular room and a morphine pump was installed. For the next couple of days morphine became her best friend! We were told to be prepared to see her face looking swollen but this never happened. Looking at her laying in her bed you would not have guessed she just had surgery. Her biggest complaint was that she wanted her hair washed!

By Saturday afternoon the doctor said she could go home either that evening or the next morning. After much debate Elizabeth decided that home sounded good so after only 3 ½ days in the hospital she headed home. By this point she had been put on oxycontin and still occasionally took anti-nausea meds. Her biggest complaints were that she needed lots of quiet...no TV, no noise and she HATED everyone asking her questions all the time! Ice packs were needed on her neck 24 hours a day. Her intense part of her recovery lasted weeks and she did end up back in the emergency room twice - once because she had stomach problems as constipation is a huge problem after surgery and taking so many narcotics. And again when she finally threw up for the first time and had a bad headache. This was five weeks after surgery and we have determined that it was most likely caused by a sort of "rebound" effect of all the heavy narcotics she had been taking. She got off all meds and has not had a headache since.

Elizabeth had her first MRI in October, four months after surgery. When we saw the MRI on the screen we all gasped including the surgeon. The cerebellar tonsils had shrunk and most importantly the syrinx had improved dramatically. It now does not start until C5 and extends to T3. At the top it is barely visible and at it's widest it is now 2mm where it once was 9mm. The MRI report says the cervical spinal cord now demonstrates a normal appearance. The results were so dramatic that the doctor has said she does not have to have another MRI for a year. In addition, to the MRI results, Elizabeth went back to work six weeks after surgery and has experienced none of the symptoms she reported prior to the surgery. No headache, no neck pain, no blurred vision. We could not be happier with the results and the experience we had at Kaiser.

The doctors say Elizabeth had probably had this condition her entire life based on the size of this rather large syrinx. In retrospect we can see some indicators that there was something going on but we never put it all together and it was never anything that seemed out of the range of normal. She complained of neck pain and as a teenage used to lie on the floor and say "pull up on my head. It just feels like it would feel so much better if my head was lifted up." Wow! Her body was trying to tell her something! She has some hyper reflexes in her knees and some abnormal reflexes in her feet. She tells us now that she often would take a little extra step to catch her balance. Her balance is not the best but she attributed it to being "clumsy." She never thought anything of these things. She thought everyone was this way.

At our last visit with the surgeon she kept referring to Elizabeth being "like a normal person" and as we walked out she said, "I never really wanted to be a normal person!" The amazing person that she is can now live a "normal" life with little or no restrictions and a great result from a Chiari decompression. We hope this helps those of you who face this road. If there are any questions we can answer, please email us at anneholloway@aol.com.

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