

Kayleigh's Story



This story is about my daughter Kayleigh. She is currently 12 years old and has been battling a brain tumor, a craniopharyngioma to be exact.

It all began in 1999 when Kayleigh's third grade teacher called to say that she noticed Kayleigh squinting while reading and looking at the blackboard. She suggested an eye exam. I thought this a bit strange because just ten months prior, Kayleigh had a complete eye exam with an ophthalmologist and was fine. I really

wasn't alarmed because neither my husband or myself or any of our other children needed glasses. I took her advice and had her examined by an optometrist. He gave her an extensive exam and felt the need to have Kayleigh examined by an ophthalmologist. After an extensive exam with the ophthalmologist, he felt "something" was wrong with her right eye but couldn't be sure because he wasn't used to examining children. He referred us to a pediatric ophthalmologist and diagnosed her with unexplained vision loss in her right eye. Well, after about a ten minute exam by this specialist, I was taken into the hall and told by the doc that Kayleigh was perfectly fine and that she was "faking" -- someone in Kayleigh's class must have just gotten glasses and Kayleigh wanted them too. Case closed, we thought. She was fine. End of story.

Fast forward to December 2000. Kayleigh's 4th grade teacher mentioned that she had noticed Kayleigh having trouble reading while viewing the blackboard. I assured her Kayleigh was fine and was examined by three different doctors and was declared perfect. In the meantime, I had noticed that Kayleigh's grades at school were starting to slip and thought it was probably due to holiday excitement. Just prior to the Christmas break, her teacher again mentioned the vision to me. This time she said that when Kayleigh really focused she noticed her eyeballs bouncing. I watched Kayleigh read and saw the same thing. This sort of validated things for me and I made an appointment with an optometrist (who our insurance made us go to first). He examined Kayleigh and immediately knew there was something seriously wrong. He told me she had something called a seesaw nystagmus and that this is almost never seen by eye doctors.....he said they only learn about in a text book. Still unaware of a tumor, we took Kayleigh to another pediatric ophthalmologist, this one closer to our home. This new doctor examined Kayleigh and immediately knew it was something serious. He told us that she would need an MRI to rule out a tumor. He still never mentioned the words brain tumor. He suggested we go to a facility that he dealt with so that he could get immediate results. On January 23, 2001, Kayleigh had an MRI. I knew it was serious when the technician came in, halfway through the MRI to ask what her symptoms were. My heart sank.

After dropping Kayleigh off at school, I headed straight to work. When I walked into my office my boss told me the doctor had called two times already and he needed to speak with me immediately. The fear and panic that came over me was indescribable. When I phoned the doctor's office he asked me if I was sitting down. He told me that Kayleigh had a brain tumor, a craniopharyngioma. He also said that the radiologist could not believe that Kayleigh did not have any symptoms other than eye problems because the tumor was extremely large and needed to be

removed immediately. The conversation was a blur.....I was sobbing uncontrollably.....I just could not believe that this beautiful little girl had this "thing" growing inside of her. I could barely make rational decisions but I knew that I needed to get her to New York City. We live in upstate New York and knew of many friends and relatives treated by top-notch doctors.

A friend of ours was a nurse at Columbia Presbyterian Hospital in New York City and was able to get us an appointment that very same day. At 2:00 we were in the office of Dr. Neil Feldstein, Director of Pediatric Neurosurgery. He explained this tumor is benign but had all the characteristics of a malignant tumor. Dr. Feldstein explained that Kayleigh's vision was very bad and based on the MRI, the tumor had wrapped itself around the optic nerves and optic chiasm and was crushing her pituitary gland. He asked many questions regarding symptoms and was not too surprised that Kayleigh had no other symptoms other than vision. He did ask about nighttime vomiting and I realized that just weeks earlier she had awoken in the middle of the night and was vomiting, but by the time morning rolled around she was absolutely fine! I had no idea that nighttime vomiting was a symptom of brain tumors!

Feeling as though we were sucker punched and looking like we were in a train wreck, my husband and I had to muster up enough strength to come to terms with what was about to happen. Dr. Feldstein told us that Kayleigh needed emergency surgery. He said that if we did not operate as soon as possible, Kayleigh was in danger of going completely blind. He explained everything that he was going to do and told us to prepare for a 7-12 hour surgery. He also gave us the most valuable piece of advice....he said "You must be strong for your daughter, she looks to both of you for strength. If she senses fear in you than she will be afraid. Don't let her see you cry.....leave the room, do it when she is not with you, but don't let her see you cry." They are words I will never forget. After digesting everything we had been told, I knew that we were making the right choice with Dr. Feldstein. Not only was he brilliant, he was so very kind and compassionate that I knew Kayleigh would be okay.

Our next stop was to the endocrinologist. Dr. Sharon Oberfield, Director of Pediatric Endocrinology was waiting for us. She explained what the pituitary gland was and what its function was. We also learned that people can live without one and that medications can replace what the pituitary can't make. We were told by Dr. O that Kayleigh would be on replacement hormones the rest of her life. She also told us that 90% of people diagnosed with craniopharyngioma will become overweight and in some cases become obese. We thought that we could live with all of these problems just as long as we had Kayleigh.

January 25, 2001 at 7:00AM Kayleigh was taken down to the operating room. We were allowed to go in with her. This brave, brave little girl never ever complained about all the testing she endured the prior day, nor did she cry about the surgery. Little did I know then that her courage would get me through the day. Twelve grueling hours later, Dr. Feldstein told us that the surgery went well, but he was only able to remove 70% of the tumor because of the way it was wrapped around the optic nerves. If any more had been taken, she would have lost her vision. He said that her optic nerves were stretched so much that they were "clear" and nearly severed! She was down to only tunnel vision prior to and after the surgery but had learned to adjust to the loss before the tumor was discovered.

Kayleigh was awake when they brought her up from recovery and was talking to everyone. She hated the foley catheter and all the IV's. After two days, Kayleigh was walking around without help and was released from the hospital ten days later. She had developed diabetes insipidus but quickly recovered. All was well with Kayleigh and she continued to amaze the medical staff, friends and family with her quick recovery.

A routine MRI July 2001 revealed that the tumor had grown completely back. Dr. Feldstein did not want to operate again and felt we should consider radiation. After speaking with Dr. Sharon Oberfield, Dr. Jeffrey O'dell, Kayleigh's eye doctor and Dr. Feldstein again, it was decided that he would operate again instead of radiation due to the fact that Kayleigh was only ten years old. Dr. Feldstein felt that the condition of her optic nerves were not strong enough to stand another surgery and had prepared us for the worst; Kayleigh could very well come out of surgery blind! We prayed for the best and prepared for the worst.

On July 25th, 2001 Kayleigh underwent a second craniotomy. This time the surgery was longer and her recovery was longer. She did come out with her vision intact! Dr. Feldstein explained that when he got inside, he was able to see that her optic nerves had healed and that they were pink and thick and had blood flowing thru them! It was because of this that her vision was spared. A small miracle I am sure. The doctor was able to remove 99% of the tumor this time because he was able to be a little more aggressive around the optic nerves. Ten days later Kayleigh was home and enjoying the remainder of the summer.

Her pituitary was damaged during the second surgery and she did develop diabetes insipidus, thyroid problems and the inability to make cortisone. She was declared panhypopituitary. Again, she took this in stride. We thought we were on easy street, that was until a routine MRI in July 2002 revealed that a new tumor had appeared. This tumor was cystic in nature and was in addition to the 1% left behind after the second surgery. Again, we felt as though we were sucker punched. Why her, we thought? I just could not bring myself to tell this child after her life was just settling down. Again, this brave child took the news in stride. It was determined that she would undergo radiation treatments as opposed to another craniotomy. Dr. Feldstein felt that another surgery would only offer a 65% cure rate with the possibility of serious damage. Dr. Oberfield and Dr. Odell felt that radiation was too harmful for an 11 year-old child and Dr. Jeffrey Wisoff at NYU Medical Center felt he could do exploratory surgery but could only offer a 65-70% cure rate. We were told that the tumor was aggressive and due to her age, it wanted to grow. Ultimately, my husband and I were left to make this medical decision. After agonizing over it and researching radiation treatments we decided that she would have proton beam radiation treatments under the care of Dr. Nancy Tarbell at Mass General Hospital in Boston, MA.

Kayleigh started radiation treatments on 12/02/02 and received six weeks of radiation. The only short term side effect that she experienced was fatigue. It lingered for close to a year after treatment -- it was very severe a month after and began to improve with time. Her tumor continued to grow during treatment and her final day we were told she would need a shunt or another surgery because the radiation may not start working for six months to a year. Again, we prayed for the best and prepared for the worst. Dr. Feldstein said that he would wait until a critical stage in hopes of the radiation "kicking in." A CT scan a few weeks later showed the tumor shrinking!! It continued to shrink the entire year. It is one year post-radiation and Kayleigh's tumor is completely gone. It went from 3.0 cm X 3.0 cm on 1-31-03 to 1mm X 1mm on 12-19-03!! We could not have asked for a better Christmas gift.

Kayleigh is still the same child she was prior to the diagnosis. She has a magnetic personality and her smile can light up any room. Kayleigh is an amazing child and it is her incredible disposition that fuels the strength of those around her. Life for Kayleigh will always be a challenge, but for now, she is just enjoying being a kid.

Written for the Childhood Brain Tumor Foundation by Lisa Brunet, Kayleigh's Mom, an Independent Bank and Title Closer.