



PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

Kelsey Christensen was diagnosed with Pineoblastoma at the tender age of 2 years old. This is a rare, aggressive type of cancer that begins in the cells of the brain's pineal gland. Due to their position these tumors often cause hydrocephalus, a build-up of pressure within the skull. This happens because the tumor, usually located near the third ventricle blocking the Cerebro-spinal fluid surrounds the brain from draining. As well as headaches and nausea due to the hydrocephalus, symptoms often also include abnormalities in eye movement. In many cases, a biopsy is required to determine the tumor type. The overall 5-year survival rate for children with this cancer is 60%-65%.

Along with her diagnosis, Kelsey also suffered complications of Diabetes insipidus which is a disorder of salt and water metabolism marked by intense thirst and heavy urination. This occurs when the body cannot regulate how it handles fluids. The condition is caused by a hormonal abnormality and is not related to diabetes. This can result in severe complications such as confusion, seizures, brain damage, or death. It can also cause weight loss. The condition takes two main forms: central diabetes insipidus and nephrogenic diabetes insipidus. Those who suffer from this often urinate up to 3 liters in 24 hours which is extremely abnormal.

Kelsey began rapidly losing weight and she was always very cold. She also started throwing up frequently. It took several doctor's visits to get a someone to do any kind of testing on my daughter. I knew something was severely wrong with Kelsey but no one would believe me and at one-point doctors

were convinced that I suffered from Munchausen's syndrome because I continually would bring her in to see a doctor even when telling us she was fine. Finally at another visit, she suffered a pain fit where her body became very stiff and she would scream. She spent 24 hours in the hospital for evaluation. That next morning, she suffered another pain fit. We were immediately transferred to Legacy Emanuel Medical Center and once we were there, Kelsey seemed to be doing better. After a few hours she had a rash from head to toe. The doctors were baffled so they called in a Dermatologist. Once again, we were given no answers.

I was aggravated and after a bit of time the doctors finally decided to do a CT scan. Once the results came back, we were given the worst news imaginable. My daughter had several tumors on her brain that were cancerous. The doctors actually apologized to me for not believing me when I continually tried to tell them Kelsey was very sick. This type of cancer typically is not found in children but instead in adults between 18-24 years of age and more so found in males. Sadly, after her diagnosis my husband began using methamphetamines to try to cope. I had no choice but to make him leave our home and because he refused to get help, he never returned. Thankfully I had both my mother and my father who stepped in and helped as I had 3 other children to take care of. My Dad stayed with us and my mom who lived in Alaska would travel as often as she could to be by Kelsey's side when I could not handle going to every treatment Kelsey had.

Treatments began with 3 rounds of chemotherapy. Once finished she then went through 3 more rounds of a more intense chemotherapy treatment which ended up killing almost every cell in her body. She then had to undergo a stem cell transplant at Doernbecher Children's Hospital after her chemotherapy treatments were finished. My Mom was there through it all because I had such a difficult time watching my daughter suffer due to treatments. Not being able to take away my daughter's pain was almost unbearable for me. I can honestly say I am not sure what would have happened had my mom not been there. I was unable to spend much time with my other 3 children who stayed with their father's parents much of the time. That was also very traumatic for me and extremely hard on them.

As a parent you always worry that after remission the cancer might come back. You pray it does not but there is no guarantee it will not return. Kelsey was in remission from August of 2008 until March

of 2009. In March after a visit to the doctor for a checkup, we once again received the news we had prayed we would never hear again. The cancer had returned and the tumors were not only located on her brain but had spread down her spine. She underwent 30 rounds of radiation to try to shrink or get rid of the tumors. Another CT scan was done in September of 2009 and while waiting on the results I decided to take my children on a short trip. While traveling I received a phone call from the doctor who told me the results of the CT scan had come back and that the tumors had grown again and that there was nothing more they could do.

The doctors suggested Hospice care but I knew that was not where I wanted my daughter to spend her last days on this earth. I brought her home and did everything I could to make her comfortable. I spent every waking moment with her. I laid down with her and her hand was on my heart and within minutes she took her last breath. My sweet Kelsey died in my arms on December 12th, 2009. I cannot remember much from that day as I was in complete shock. The loss of my daughter was the most painful thing I have ever gone through and her siblings had a very difficult time processing the loss as well, especially her twin Lacey.

Childhood cancer happens everywhere. Each year, more than 17,000 children are diagnosed with cancer in the United States. Globally, it is estimated that 400,000 cases of cancer affect children each year. However, this number may be vastly underestimated due to large numbers of undiagnosed cases. Despite all these facts, childhood cancer research is consistently underfunded. This is why it is so crucial that we see the federal funding rise from 4% to 8%. There are too many children fighting this ugly disease and far too many parents losing their children to cancer.

I have not only lost my husband to drugs but I had to bury my daughter and, in the process, I also lost my relationship with my other 3 daughters. They are now 16, 17, and 18 and have removed themselves from my life. They are very resentful of all the time I spent with Kelsey and feel I loved her more than I did them. Cancer has literally taken everything from me. At one point I was even homeless. It has taken years to get myself in a better place and through this journey I have had several opportunities to speak in front of hundreds of people about my loss and to spread awareness on

childhood cancer. I am passionate about advocating and will do everything in my power to make sure my daughter is remembered for who she was and not just a statistic.

The federal government is allocating an alarming 4% for federal funding for childhood cancer research. This is not enough to make a difference for our children. By signing this petition, you will help facilitate lobbying and the advance of a healthcare policy that will reserve a higher percentage of resources for childhood cancer research. This will give researchers more opportunities to do more testing and research to potentially find a childhood cancer vaccine which would ultimately shorten the time children will have to suffer and fight for a normal life. Please sign and share this petition and help give these children a fighting chance.

[CLICK HERE TO SIGN PETITION](#)