



PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER AWARENESS

William was experiencing constant constipation and he would spit up his bottles frequently. When speaking with his doctor, we were told he was lactose intolerant and that this was normal. He then began experiencing other symptoms such as throwing up in the mornings, random fevers, extreme fatigue and loss of appetite. One week before his 2nd birthday, we found a lump in his upper quadrant of his abdomen. My husband and I fought hard with his pediatrician to look at why he was always constipated. Within 2 weeks of finding this mass, finally testing was done and we were told William had stage IV liver cancer. Hearing the word cancer was hard enough but to hear stage IV was an even harder blow. The day of his diagnosis was the worst day of our lives. I will never shake the feeling of complete helplessness.

William Candelario was diagnosed with Stage IV hepatoblastoma at the tender age of 2 years old on September 21st, 2021. Hepatoblastoma (Liver Cancer) is the most common liver cancer in children, however it affects only 2 to 3 children in a million. It usually presents as an abdominal mass which causes pain and discomfort. A large

percentage of these tumors occur in children who are born premature. It is estimated that a fifth of hepatoblastoma tumors may require a liver transplantation. Also, it now accounts for 7.5% of all liver transplants in children compared with less than 3% for other pediatric liver cancers. Stage IV means that the tumor has spread through the bloodstream to other parts of the body. While stage IV liver cancer has low survival rates, some patients may live for years after their diagnosis. A 5-year survival rate of 88% has been reported for children with posttreatment extent of stage III and IV hepatoblastoma who underwent resection after neoadjuvant chemotherapy.

Chemotherapy began on September 24th, 2021. In October on day 15 of his first cycle, his bowels began to die. He ended up having emergency surgery on October 5th, 2021 to clean and try to save them. We had been told we should begin the planning process of his funeral as they did not feel he would live. We were absolutely devastated. The day of surgery when they began and went in; they said the rest of his bowels were saved. He did not have to have a liver transplant as many children do but he did have 60-70% of it removed. He lost 1/3 of his large intestine and 1/3 of his small intestine which resulted in him needing an ostomy bag. This will hopefully be reversed once he finishes his chemotherapy treatments. After his first introduction cycle he would not eat so he was put on TPN which is IV nutrition. He also had a NG tube for a short period of time but he did not tolerate the feeds well. He was extremely sick with the irinotecan (anti-cancer chemo drug) after his right lung surgery but has been doing well since then.

Each year in the United States there are an estimated 15,780 children between the ages of birth and 19 years of age who are diagnosed with cancer. Globally there are more than 300,000 children diagnosed with cancer each year. On average, about 16% of children die within 5 years of diagnosis. Despite advances in medicine, some types of cancer remain incurable. Even with a more “curable” diagnosis, too many children in the United States do not have access to the medical care they so desperately need.

Although treatments have advanced and mortality rates have decreased, it is quite surprising to hear that cancer is still killing more children in America than any other disease. This is why it is so crucial to see the federal funding rise from 4% to 8% for childhood cancer research. Our children deserve a fighting chance which is why I am so passionate about advocating for childhood cancer awareness.

The hardships of cancer alone are devastating. I had to quit working immediately after William's diagnosis and was out of work for 6 months. This put a huge strain on us financially. William has handled all of this in strides although he struggles with the pokes of needles constantly and not being allowed to go out and do things while actively getting treatments. He has been such a brave boy and continues to amaze us daily. Sadly, our older son's behavior has gotten out of hand. He cries every time we have to leave to take his brother to his treatments. He struggles being away from William for days and sometimes weeks. Cancer affects everyone in our family. I am now finally able to work again but only part time as my husband also has to work. Cancer has forever changed our family and it has caused such heartache.

The federal government right now is only allowing a measly 4% for federal funding for childhood cancer research. This is not nearly enough funding to make a difference. By signing this petition, you will help facilitate lobbying and advance of a healthcare policy that will designate a higher percentage of resources for childhood cancer research. This will allow researchers additional funding to potentially find a childhood cancer vaccine or possibly a cure so that our children will be able to live a normal childhood. We are in need of 12 million signatures to advance to the next stage in making this happen. Please stand with us by signing and sharing this petition to do all we can to make sure these children and families are heard.

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