



### PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

Hayden Lee Jensen was diagnosed with T-cell acute lymphoblastic leukemia on October 25<sup>th</sup>, 2020 at just 20 months old. T-ALL is a rapid-growing type of leukemia and a type of acute lymphoblastic leukemia. It develops from immature lymphocytes, a type of white blood cell. ALL is the most common type of cancer in children. About 10% to 25% of ALL diagnosis are T-cell ALL. Different subtypes of acute lymphoblastic leukemia such as T-cell tend to lead to the same sets of symptoms. These symptoms may include bone or joint pain, night sweats, loss of appetite, weight loss and anemia. In addition, swollen lymph nodes and splenomegaly (enlarged spleen) can occur. By the time children are diagnosed with this type of cancer, the leukemia cells have often spread to their central nervous system which includes the brain and spinal cord. When the brain is affected, T-cell ALL may cause headaches, blurry vision and seizures. The 5-year survival rate for this specific type of cancer is 85%.

I took our daughter to the emergency room on October 24<sup>th</sup>, 2020 for what I thought was a stomach flu but was quickly referred to Loma Linda Children's Hospital. Upon arrival, blood tests were done and by the next day we were given her diagnosis. I was in complete shock and had a difficult time processing what I had just been told. I knew my precious baby girl had a huge battle in front of her and I was terrified. This took place during Covid so I knew I

would have to be by myself with her and was not sure I would even be able to handle that. My baby had cancer and I wanted to scream at the top of my lungs but nothing would come out.

Over the next 11 months Hayden had several chemo holds due to her counts and had more blood and platelet transfusions than I can count. She was put on strong iv antibiotics at various times and was admitted to the hospital at least 15 times. We spent days to weeks for each hospital stay. Hayden underwent many procedures, biopsies and drains. Due to the side effects of the chemotherapy, she suffered multiple infections which resulted in her undergoing major surgery resulting in a colostomy and ureterostomy. She finally reached her long-term maintenance phase and a month later was diagnosed with relapse. She had to be put on a ventilator 3 separate times. We thought she was responding well to the new chemo but sadly she never reached remission again. Her breathing became poor and again she was intubated but after 4 days on the ventilator with no signs of improvement we had to make the hardest decision of our lives. We had her removed from life support and allowed her to rest. I will never be the same nor will I ever forget watching our daughter slip away from us forever. She fought so hard and always wore a smile on her face no matter how much pain she was in.

Cancer is the leading cause of death by disease past infancy among children in the United States. There are approximately 10,470 children in the United States under the age of 15 who will be diagnosed with cancer in 2022. There are an expected 1,050 children who will die from cancer in 2022. The 5-year survival rate for childhood cancer right now is 85%. However, this does not mean that after 5 years the cancer will not return. Childhood cancer is a vicious disease and will destroy anything in its path without warning. This is why we must fight hard to see that 4% government funding rise to 8% for childhood cancer research.

The impact of losing our daughter is indescribable. We miss her every single day and will never understand why this had to happen to her. Her sister who is only 12 months older than

Hayden is autistic and suffered greatly. Being separated from her little sister and her never coming back home from the hospital, played a huge part in her grief. How does a parent explain to a child why their sibling had to die? There is nothing you can say to take the pain of that loss away from them. Cancer robbed us of so much but robbed Hayden of the life she was supposed to have lived. Losing her has made me so passionate about speaking out for her and on childhood cancer awareness. I am determined to make sure that her legacy lives on.

At this time, the federal government is allocating a mere 4% for funding for childhood cancer research. This is absolutely shocking and not nearly enough. By signing this petition, you will help facilitate lobbying and the advance of a healthcare policy that will designate a higher percentage of resources for childhood cancer research. This will allow researchers the ability to do more testing and possibly find a childhood cancer vaccine that would then alleviate so many children from suffering. There is also the possibility that researchers could find a cure for childhood cancer and put a stop to this ugly disease once and for all. We are in need of 12 million signatures to enter the next step in this process. Please stand with us and help make a difference by signing and sharing this petition.

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