PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

Kylie is 19 months old. She was born August 2020. The healthiest baby I had ever seen. At 7 months old, Kylie lost her father in a tragic accident in March 2021. I couldn't work due to grief. This would be the beginning of our series of unfortunate events. By one year old, Kylie had never been sick, not even a cold. She was learning to walk, laughing, playing and experiencing things most babies do.

A couple weeks after her first birthday, Kylie's stomach began to expand. I initially thought she was a normal, potbelly toddler. Kylie's paternal grandmother came to visit and immediately noticed as it was much bigger than the last time she had seen her. Once it was pointed out, I agreed and began to worry.

I immediately took Kylie to a local emergency room where they diagnosed her with a UTI (urinary tract infection). We came home with antibiotics but once completed, there was still no difference in the size of her tummy. I then started noticing bruises on her legs, arms, thighs, head and feet. I tell myself it's probably because she's one and learning to walk, falling and bumping into things.

She began sleeping more than usual. Kylie being my only child, I hoped it was normal but took her back into the ER anyway. Once we arrived at the ER, I noticed tiny red dots on her skin. I told them every symptom and pointed out the bruises.

They took an X-RAY of her belly and diagnosed her with constipation (although I made sure they knew she was having normal bowel movements). They attempted an enema which did not work. The doctor went back out of the room, looked at the X-ray, came back in, felt Kylie's stomach and said it had to be constipation. We were sent back home.

I made a follow up with Kylie's pediatrician where they seemed very concerned and sent us straight to the nearest children’s hospital. The children’s hospital immediately began running tests, blood work, X-rays and ultrasounds. They requested records from the hospital we had been to previously. The previous X-ray reports stated “no constipation” which seemed odd considering that’s what she was diagnosed and sent home with.

The children’s hospital gave me what I thought was the scariest news; Kylie may have a mass or tumor in her abdomen. Further testing was done and showed the “mass” was actually Kylie’s liver and spleen, much larger than they should be. Then the blood results. That’s when I truly got the scariest news. That’s when I began praying it was the simple tumor they initially thought it was. A tumor that could be removed. But no, “Kylie has Leukemia”. Cancer. My baby has cancer. But it can be cured, right? Not necessarily. There are treatments, but not a “cure”.

A normal white blood cell count in a child should be around 6,000-10,000. Kylies was almost 1,000,000. 92% of those cells in her body were cancerous. That was a record in that hospital. And so it began. Tests, procedures, surgeries, medication, chemotherapy. Kylie immediately received chemo, a central line, and a list of a million other things I couldn’t understand or keep up with at the time. Within 12 hours, my baby went from walking, talking and playing; to coming back into the hospital room on a ventilator.

I could go back and count how many chemotherapy medications, lumbar punctures, bone marrow aspirates, blood and platelet transfusions, surgeries, ICU stays, nights in the hospital; but that would take hours or even days.

Kylie's treatment plan was approximately 3 years long. Kylie is almost 20 months old now. 7 months into our treatment protocol. She has failed remission twice and achieved remission once. The chemotherapy she received was supposed to be the best chance of remission and it failed her.

We have had to move on to our next option and she is now in the process of getting a bone marrow transplant. She shouldn't have to get a transplant. No child should. No child should have to go through YEARS of treatment. No child should have to endure poison throughout their body for a CHANCE of remission and HOPE it doesn't come back.

During some treatments, my sweet baby can't play outside, be around flowers, visit family, go to the grocery store or go out to eat. Instead, she has to be quarantined for long periods of time. She has missed so much of her childhood due to cancer.

So many people tell me how strong I am as a parent of a child with cancer. I'm not strong. What choice do I have? I shouldn't have to worry each and every day about how things may turn out for my baby; but I do. I am depending on these treatments. My whole world depends on the research going toward the life of my child.

Cancer is the #1 cause of death by disease in children. In the year 2022 it is estimated that over 15,000 children will be diagnosed with cancer; of them, over 1,750 will die from this disease. Only 4% of federal funding for cancer research goes to children. My child along with any child with cancer is worth more than 4%. This petition is to push the government to raise federal funding for childhood cancer research from 4% to 8%.

The amount of money that Americans spend on Starbucks in 3 days is more than what goes toward federal funded childhood cancer research in a year. Please join me in this fight. Please sign and share the petition everywhere that you can.

MY BABY DESERVES MORE THAN 4!

CLICK HERE TO SIGN PETITION