



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

Kaelynn Rae was born on July 10th, 2016 in Oklahoma City, Oklahoma. Weighing in at 9lbs 6 ounces, she was quickly given the nickname "Chunky Dunk." At 2 days shy of turning 3 months old, Kaelynn began showing signs of Petechiae (pinpoint bruises) on her hands and legs. This is caused by having no platelets which we found out later on. She was seen by her Doctor who misdiagnosed her with Hand, foot and mouth disease and we were sent home. Within a week Kaelynn's symptoms became much more severe. She had a high fever; severe vomiting and she was very lethargic and pale. We took our daughter to the Emergency Room on a Saturday and within hours she was flown to St. Francis Hospital in Tulsa, Oklahoma. That is where she was diagnosed on October 8th, 2016 with Acute Lymphoblastic Leukemia. I'll never forget how hearing those words felt. I could literally feel my heart shatter into a million pieces. Her Father and I were terrified and knew nothing about this disease. You never think it will happen to you until it does.

Acute Lymphoblastic Leukemia is the most common childhood cancer. A type of cancer of the blood and bone marrow that affects white blood cells. It occurs when a bone marrow cell develops errors in its DNA. The American Cancer Society's estimates for Acute Lymphoblastic Leukemia (ALL) in the United States for 2022 (including both children and adults) are: About 6,660 new cases of ALL (3,740 in males and 2,920 in females).

We were given the option to have Kaelynn treated at OU Hospital in Oklahoma or St. Jude Research Hospital in Memphis, Tennessee. By the following Monday at 12:00 am, we were landing in Memphis and she was put in the ICU. By 8:00 am that same day her central line was placed and we were signing plans and consents to start treatment. It happened so quickly that we literally had no time to even let what was happening sink in. That's what happens with

Cancer. It doesn't allow you to breathe for even a moment. In the blink of an eye our world changed forever.

Treatments were very difficult. Even more difficult was trying to explain to her brother Jayce who was only 5 years old at the time, why she was being given medicines that were ultimately making her sicker. After all, isn't medicine supposed to make you feel better? Imagine a 5-year-old having to watch his sister going through this battle. How can a child understand what the word cancer really means? It weighed so heavy on both myself and Kaelynn's father not being able to take away her pain and fear. Not to mention trying to deal with our own fear, as well as our sons.

At 9 months of age Kaelynn underwent a bone marrow transplant. She was in remission for a very short period of time. Not even long enough to be considered remission. She fought so hard and with a vengeance. Kaelynn was very matter of fact. When the Nurses would come in to take her vitals, she would simply tell them "NO!" There was no attitude with it, it was just who she was. She loved her blankets or "bwankies" as she called them and stuffed animals. Anything soft comforted her. Sadly, after only 50 days, Kaelynn relapsed. Kaelynn never left the hospital after her bone marrow transplant. But she continued to fight hard in true Kaelynn style. Our home or as we called it our "safe place" was in Memphis at the St. Jude Target House. We then had to enroll our son Jayce into Kindergarten in Memphis so we could be close to Campus if anything should happen to Kaelynn. During that time, we lost my Mother unexpectedly to diabetes, which only added to our stress and grief. We were not even given the chance to see her before her passing. We still tried to keep our faith and hope strong. It's all we had left.

During the next almost 12 months, treatments continued for Kaelynn. You'd have never even known she was sick much of the time. She often wouldn't show us she was sick, to keep us from worrying even more. Sadly, after almost 12 months of fighting, on July 4th, 2018 Kaelynn lost her battle to Cancer. Nothing can ever prepare a parent to lose their child. The devastation of losing Kaelynn weighed heavy on our hearts and Kaelynn's father turned to drug use, to cope with the loss, which led to us no longer being together. Not only did I lose my precious Kaelynn, I lost the father of both of my children. My son lost his sister and father. Childhood cancer does not discriminate. It can destroy anything or anyone in its path. My family is living proof of that. We will never be the same. Our grief will never go away. We are only left with memories, many of which are of her battle. Memories that haunt me sometimes.

Her brother Jayce has been dealing with the loss fairly well or as well as can be expected but children are resilient. I worry that as he gets older, his grief may be much more difficult for him to navigate through. I worry about him and Kaelynn's father, who chooses not to come around and how that is affecting my son Jayce, now and in the future. Almost 4 years have passed since we lost Kaelynn and not a single day of those years have I not thought about Kaelynn. I still have all her blankets and stuffed animals set up in her crib. She is on my mind constantly. I often find myself thinking about what could have been. Thinking about all the things I won't get to do with her or for her. I think about my son Jayce, not having his best friend any longer or the things he and Kaelynn would have shared. The firsts are the hardest but no matter

how hard you try it doesn't get any easier. Just when you think "this may be the year that it's a little bit easier" it just isn't. I miss Kaelynn's sweet spirit and her beautiful smile. I will always remember how soft her head felt and how it felt like velvet, as she never really grew much hair due to the treatments. I will never forget how, towards the end she always smelt like pancake batter with a hint of sweet syrup. I remember like it was yesterday. I will miss her lovies the most. She gave the very best lovies. I will miss Kaelynn forever! We will miss Kaelynn forever. Oh the places she could have gone.

It is my hope and mission as Kaelynn's Mother to do all I can to help raise awareness of this devastating disease. These children deserve a fighting chance. These families deserve it too. The only way that can happen is by signing the petition. These children and their families deserve to be heard. Too many families are being affected by this disease every single day. Not only do these children go through hell, the families do as well.

The federal government right now is only allowing 4% for funding, for research on childhood cancer. That is not nearly enough for these children. Signing this petition gives a higher chance for passing a new Healthcare policy or law, that will call for a higher percentage of national resources. While our sweet Kaelynn lost her battle, there are still so many children left fighting. What a child goes through because of these treatments is the most devastating thing I have ever seen. Treatments that are meant to be used on adults are the only option given to these children and families. By signing this petition, you are giving these children and families more hope.

I will never stop fighting for these children or their families. I will never stop fighting to make sure Kaelynn's story is heard and her memory stays alive. Our Chunky Dunk deserves to never be forgotten. Please sign this petition and help us make a difference for these children and for their families. Let's all stand together to fight to raise the percentage. Together we can give these children the chance they deserve. A chance to have a normal life and do the things these children were born to do.

**[CLICK HERE TO SIGN](#)**