



PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

On June 2nd, 2021 our lives changed forever. Our rambunctious 4-year-old baby boy Rush was diagnosed with B-cell acute lymphoblastic leukemia. This kind of cancer affects certain cells in the immune system, called B cells and T cells. ALL usually affects B cells in children. B-cell ALL makes your child more likely to get infections because they do not have the protection of those cells. The disease starts in your child's bone marrow. The leukemia cells grow very rapidly and crowd the marrow, so it has trouble making enough normal cells. According to the National Cancer Institute, B-cell acute lymphoblastic leukemia is the most common type of ALL in both children and adults. The NCI estimates about 6,000 new cases of ALL are diagnosed annually. The 5-year survival rate for ALL is 69.9 %.

Rush began getting Petechiae (tiny round brown-purple spots) all over his body. This is caused by bleeding underneath the skin. He complained about having pain in his legs for quite some time. We then took Rush to his pediatrician who felt lab work was necessary. The results of those labs showed that Rush had very low levels. Lab testing was done every 2 weeks for 2 months before we

were referred to an oncologist. Even after seeing the oncologist, she assured us she felt confident that it was not cancer because Rush was a very healthy child.

We went to a family get together shortly after seeing the oncologist. During the get together Rush had gotten bit on his big toe and overnight his toe was infected and he was running a fever. I immediately took him to our local ER and I had to push for doctors to run any other tests. The doctor who saw Rush made a call to have a pediatric oncologist come assess him. At that point I finally had someone willing to listen to my concerns. The oncologist told me Rush needed to be transferred immediately for a bone marrow biopsy. As scary as that was for me, I was relieved that someone had finally made the decision to do more for my son. Test results from that biopsy confirmed our worst nightmare. I was terrified of what would happen to my sweet son. Nothing can prepare a parent or child to hear a cancer diagnosis.

Rush went through chemotherapy and fought hard like a true warrior. The medication my son was being given was intended for an adult. Hearing the doctors say, while administering him his medicine that they are trying to learn more every day, was frustrating to say the least. It was not their fault that they did not have the answers. It is even more frustrating that there is not enough federal funding for research needed for our children. Sadly through it all, Rush has suffered the most. He missed 2 years of schooling at the most important time in a child's life. Not being able to see old friends or make new ones was heartbreaking for both of us.

As Rush's mom, it has been a very hard road for me. Anger, sadness and helplessness are the only emotions I have had through this journey. I could not protect him from the pain he was suffering. I could not stop his fear because I was just as fearful. I did all that I could to take Rush's emotional distress and

carry it on my shoulders. Never knowing what was coming next was terrifying. Every day I prayed that more research could be done to help my son and other children fighting this horrific disease. We have had a wonderful group of doctors and hospital staff beside us the entire way. However, they too are in agreement that more needs to be done for these children.

I am dedicated to doing all that I can to advocate for childhood cancer awareness. Unfortunately, I cannot do this alone. The federal government is currently allocating a mere 4% for funding for childhood cancer research. This is not nearly enough funding. About 10,470 children in the United States under the age of 15 will be diagnosed with cancer in 2022. We have to come together and do all we can to change this and get the funding from 4% to 8%. By signing this petition, you will facilitate lobbying and the passing of a healthcare policy that will designate a higher percentage of resources for childhood cancer research. Our children deserve to have a voice and be heard. Please help us stand together and fight for our children by signing and sharing.

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