



PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

Tiera Ortega-FitzGerald was diagnosed with Stage 4 Alveolar Rhabdomyosarcoma at the age of 15 years old. ARMS typically affects all age groups equally. It makes up a larger portion of RMS in older children. It most often occurs in large muscles of the trunk, arms, and legs. Stage 4 means the tumor can start anywhere in the body and can be at any size. It has spread to distant parts of the body such as the lungs, liver, bones or bone marrow. There are many symptoms that can occur, but the most common are persistent lump or swelling in the body that may be painful, headache, nausea, blood in the urine, and constipation. When the cancer becomes high risk, (Stage 4) spreading widely in the body, the 5-year survival rate ranges from 20% to 30%.

In late December of 2020, Tiera began complaining of pain in her left thigh that she attributed to her brother kicking her a few days earlier. She was our “hypochondriac child” so we just thought she was worrying too much, as she often thought something was wrong with her medically. By early March of 2021, her pain appeared to be more in her knee and she was having pain onsets that we were unable to see or narrow down, based upon her activities. We took her to the emergency room and at the time she weighed 140lbs. The doctors stated that it was growing pains in her knee and told us to get her a knee brace. We did as they said but the

pain did not diminish and only worsened. We took her to her pediatrician and he thought it was Jr. Rheumatic arthritis and we were sent home.

As her mobility became greatly affected and she was sweating through her clothing at night, we took her 2 more times to see her pediatrician but both visits we left with no answers. About 3.5 weeks went by and Tiera became slightly anemic. She was unable to pull herself out of bed each day and had lost 20lbs since March. She was very pale in color so we immediately took her back to the emergency room and they did blood tests. Her Hgb levels were at 4.1 (13.5 is normal for females 15-19 years of age) so we were immediately sent to Medical City Children's Hospital in Dallas. More testing was done once we arrived and once the results came back, we were given the devastating news that our daughter had cancer. Our hearts were crushed and we were beyond scared of the unknown.

Chemotherapy began and it was extremely difficult watching our daughter go through treatments and not being able to take her pain away. From the moment of her diagnosis the cancer was metastatic throughout her entire body. However, after her first scans after beginning chemotherapy, the cancer was gone everywhere except for the primary tumor site which was her left femur. This still did not make her treatments less painful. The chemotherapy has made her extremely sick and sadly there are no other options for our children. We just continue to pray because ultimately that is all we have left.

Tiera had just finished week 35 of frontline treatment when we were told her cancer had spread to many other areas of her body again. She has now started a new trial relapse protocol and radiation. The long waits for receiving blood on the days when transfusions are needed are exhausting for Tiera. At this point we do not know how much time she even has left. The prognosis was never good from the beginning of her diagnosis and the odds have always been against her. You do everything you can not to lose hope but eventually even hope

is hard to hold on to. We know we will lose our daughter to cancer and we would give anything to change the outcome. How do you even process the fact that your child will not beat cancer? We are broken but doing our best to stay strong for our daughter.

Childhood cancer research is consistently underfunded. Each day, approximately 47 children are diagnosed with cancer in the United States, which means more than 17,000 children are diagnosed every year. Cancer is the leading cause of death by disease in children, resulting in the death of approximately 1,800 kids each year. Even those who are cured may still suffer long-term side effects as a result of the cancer treatments they received. Children who were treated for cancer are twice as likely to suffer chronic health conditions later in life versus children without any history of cancer. There are no guarantees that once a child is in remission that they will not relapse.

It has been extremely difficult not being able to see my other children as I am always with Tiera for her treatments. Ultimately, it has been by far the hardest on our daughter. When she was not in the hospital, she had to avoid crowds due to her poor immune system and was not able to do high risk activities that could spread viruses. Then to be told that anything else the doctors do is really only to buy us a little more time leaves us empty inside. All we can do now is sit with her and do our best to make her comfortable. Cancer has taken so much from us and I know our lives will never be the same. Although I call Tiera our "hypochondriac child" I truly believe that all the times we thought her issues were just growing pains in her joints, it was actually cancer cells. As hard as it is right now to speak about our daughter's journey, we are very passionate about raising awareness and will continue until we see the federal funding rise from 4% to 8%. This is crucial in order to help these children battling cancer.

The federal government is allocating a baffling 4% for federal funding for childhood cancer research. This is an insignificant amount to make much of a difference. 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 give researchers more funding to do more testing to ultimately find a cure for childhood cancer altogether. Even if a cure is not found it will potentially give researchers more abilities to find a childhood cancer vaccine to eliminate many of the other treatments that cause these children such horrific pain and side effects. Please stand with us and sign and share this petition so that these children can live a normal life.

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