



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

Just 2 weeks shy of her second birthday, Adley Gordon was diagnosed with B-cell Acute Lymphoblastic Leukemia. B-cell ALL is a cancer that effects your B lymphocytes (white blood cells) that grow in the soft center of your bones, called marrow. B lymphocytes are supposed to grow into cells that fight off infections. However, in this disease, they turn into leukemia cells that live longer than normal cells and reproduce quickly. They build up in your bone marrow and move into your bloodstream. From there they can advance to other organs in your body. Symptoms depend upon the number of leukemia cells you have. But the most common symptoms include loss of appetite, fever, fatigue and night sweats. The 5-year survival rate of this specific cancer is 89% for children under the age of 20 years old.

For roughly 3 days straight, Adley began showing signs that she was not feeling well. She was extremely lethargic and she did not want to walk. She was also very pale and her complexion was off. We immediately took her to see the doctor and on February 10<sup>th</sup>, 2022 she was diagnosed with cancer. We were shocked and never thought we would hear someone tell us that our child had cancer. Although the news was terrifying, we were determined that Adley was going to beat this ugly disease. It has been very difficult watching our sweet daughter suffer through her treatments knowing there is nothing we can do other than pray for her. She

has already had to undergo 3 bone marrow biopsies as well as 6 or 7 spinal taps. Soon she will be starting the delayed intensification treatments. She is on a 2.5-year treatment plan and we are on day 150.

Pediatric cancer is a worldwide problem. Every two minutes a family and their child are told of a cancer diagnosis. Cancer is the number one cause of disease related death in children under the age of 15 in the United States. According to the NCI, there has been a substantial increase in childhood cancers over the past few decades. In fact, the overall rate has increased 27% since 1975 in kids under the age of 19. Approximately 10,470 children in the United States under the age of 15 will be diagnosed with cancer in 2022. Each year, an estimated 400,000 children and adolescents worldwide are diagnosed with cancer. Every three minutes, a child with cancer dies.

Survival often comes at a price. Despite advances in childhood cancer research, over 75% of children who survive cancer live with permanent side effects, some of which may include deafness, blindness, motor impairments, growth issues, organ failure, cognitive difficulties, fertility issues, psychological, neurological and endocrine disorders. Although advances in research have somewhat improved the chances of survival, many children still die from the disease. High-risk cancers still continue to have relatively low survival rates, between 7 and 31%. This is why it is crucial that we see the 4% federal funding for childhood cancer research rise to 8%. Our children deserve a fighting chance and at such a low percentage of federal funding that cannot happen quickly enough.

Adley is such a strong-willed little girl. She amazes us daily at how well she is handling such a horrific disease. She is by far the bravest little warrior we know. She may get knocked down by treatments but she gets right back up to continue pushing herself forward. She gives my wife, her brother and myself the strength we often need. We know she will overcome this,

but the fear of the unknown still lingers in our minds as much as we try to push it away. There is always the terror of relapse or long-term affects due to her treatments. Cancer does not discriminate nor does it care who it tries to destroy. It can come back with a vengeance and that alone is terrifying to think about. There is also the stress of having to travel to her treatments twice a week. The travel alone is 80 miles each way. But just like in treatments, there is no other option.

The federal government is allocating a mere 4% for federal funding for childhood cancer research. This is not nearly enough to make 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. Essentially this will give researchers more funding to do more testing and potentially find a childhood cancer vaccine. This would help decrease the time these children would have to fight as well as less suffering due to treatments. We are in need of 12 million signatures to advance to the next step in this process. Please stand with us by signing and sharing this petition so these children and families can be heard.

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