



## PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

Isabella Bauserman was diagnosed at the age of 4 years old with Anaplastic Ependymoma Grade 3 Brain Cancer on February 15th, 2020. Anaplastic Ependymoma is a fast growing cancer tumor often in the base of the brain and rarely in the spinal cord. It often tends to spread into nearby parts of the brain through the cerebrospinal fluid (CSF). Sadly these tumors tend to recur after treatment. In the United States, 200 new cases of ependymoma are found in children and adults each year. Ependymoma is the third most common type of brain tumors in children. An anaplastic ependymoma can grow quickly, which can make it hard to treat. In some cases, the tumor may be in an area that makes it difficult to remove completely. Of all individuals diagnosed with anaplastic ependymoma, approximately 55% are alive 5 years after the initial diagnosis. Children who do survive may experience side-effects from the treatment even after years of remission and that is extremely alarming.

Isabella began experiencing weight loss and vomiting before her diagnosis. We took her to the hospital over and over again which included seeing a heart

specialist as well as a gi specialist but nothing was found. She began to become unsteady and staggering often when walking which lead us back to taking her to see doctors again. We were then sent directly back to the ER and finally Isabella was given a CT scan. Results of that scan concluded that cancer was found. As a parent hearing the word cancer you automatically go into panic mode. You can not prepare yourself to even begin to fathom the idea of what all that entails. To say we were scared is an understatement. We were left feeling completely overwhelmed to the point of being completely numb. A hopeless feeling we will never forget. Something no parent should ever have to go through nor any child.

Isabella began treatments immediately which made her extremely sick. She was unable to keep food down and she was exceedingly weak. She also experienced hair loss due to treatments. Imagine your child having a beautiful head of hair then watching as it falls out due to treatments that these children have no choice but to go through. That is often the outcome with these type of treatments for our children. Watching Isabella struggle just to eat and seeing her hair falling out was horrific not only for us but for Isabella. The most difficult part is watching the life being drained out of our babies. Watching them struggle through every treatment was incomprehensible. No matter how hard you try to comfort your child you can not take away their fear or pain. All you can do is sit and watch as your child suffers, praying it will end. As hard as it is on us parents it is even harder on these children who are fighting just to stay alive.

Isabella underwent several surgeries throughout her battle with this awful disease. She had a spinal tap as well as a shunt, port and drain placed. She had a tumor resection as well which is common with this type of cancer. After her tumor resection Isabella was diagnosed with Posterior Fossa Syndrome. A condition that sometimes develops after surgery to remove a brain tumor in the posterior fossa region of the brain. Posterior Fossa Syndrome (PFS) is characterized by either a reduction or an absence of speech. There is no known cure for PFS, and the course of recovery varies widely. Children who have more

severe posterior fossa syndrome symptoms early in recovery are more likely to have symptoms that last longer.

Although as of May 12th, 2022 it will be 2 years that Isabella has remained cancer free, she still struggles daily. She is now scheduled to have eye surgery due to the tumor growth and pressure on her brain. Another battle she is now left fighting. Isabella struggles with even the simplest of daily tasks and sadly she will never be the same child as she was before cancer. She is struggling to learn to walk again and do normal daily activities that 7 year olds do. This is even almost 2 years after being cancer free. She also suffers from long term effects from the radiation treatments. The chances of that changing are very minimal. No amount of prayers can ever change that.

The non stop scans, fear and treatments that may or may not work are devastating to say the least. The worry you experience is never-ending. The heart ache is overwhelming and leaves you feeling completely at a loss. Watching other parents in our hospital family go through the loss of a child because treatments did not work knocks the wind out of you. It literally paralyzes you witnessing their loss and devastation all the while dealing with your own anguish. You want to be able to comfort them but know that no amount of comforting will ever come close to helping ease their pain. You then must go right back to watching your own child endure endless pain. It's crippling and terrifying and worst of all makes you feel helpless. No parent should ever have to lose their child to this disease. Cancer rips families apart and leaves them completely broken and forever changes the lives of the entire family.

We desperately need to find a cure for all childhood cancer due to it becoming a more common disease in children. This is why it is so imperative to sign this petition. The federal government right now is only allowing 4% funding for childhood cancer research and that is simply not enough funding to even pursue more research. By signing this petition to increase that 4% to 8% is

detrimental in helping to find a cure. These children deserve a fighting chance as well as their families. We must do everything we can to stand together and make sure these children are heard. There has got to be other avenues for treatment for these children because the treatments they undergo are treatments that are most commonly used on adults. However because of such a low amount of federal funding there isn't enough research to even begin to touch the spectrum of other alternatives for treating these children. Research helps us better understand diseases and can lead to advances in diagnosis and treatment. Children should be able to live their lives doing things they enjoy, but cancer strips these children of that. It takes away any elation that they once experienced. It turns their joy into absolute fear.

Approximately 10,470 children in the United States alone under the age of 15 will be diagnosed with cancer in 2022. Approximately 1 in 285 children will be diagnosed before the age of 20 years. The annual incidence rate of cancer in children and adolescents is 186.6 per 1 million children that are aged birth to 19 years. After accidents, cancer is the second leading cause of death in children ages 1 to 14. About 1,050 children under the age of 15 are expected to die from cancer in 2022. This is an alarming increase since the mid-1970s, when the 5 year survival rate was at 58%. This needs to change and together we can make that change possible. Sadly with all types of childhood cancer there is never a guarantee that once in remission the cancer won't return. Every day we now are left with the worry that her cancer may return.

It is my mission to do all I can, to help raise awareness of childhood cancer. I will not stop until something is done. I will do this for our Isabella and for every other child fighting childhood cancer. It is my hope that with enough signatures, we can get a new healthcare policy that will result in a higher percentage of national resources. Please help in this mission to raise the federal funding from 4% up to 8%. Signing this petition may just save the life of a child you know. Let's do all we can to make a difference for these children. It is time to stand up to

cancer and rally for every child fighting this disease. We need 12 million signatures to bring this to the next phase. Please stand with us by signing and sharing.

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