



PETITION TO INCREASE FUNDING FOR
CHILDHOOD CANCER RESEARCH

My daughter Bria Slingsby is two years old. She was diagnosed with Neuroblastoma at the age of one.

The emotional distress caused by cancer:

Here is a summary of Bria's last 365 days... Sedation with tumor biopsy. 1st MIBG scans (nuclear medicine). 1st Bone Marrow Biopsy Surgery to put her Port in.

Choosing a treatment plan: We describe this as having 3 doors to open and her life is on the other side of one. Multiple rounds of chemo for multiple days 21 days later. Multiple rounds of chemo for multiple days.

Trip to Houston for the Stem Cell Removal: sedation and a large catheter in her neck. This was a very hard and painful procedure. Removing the catheter was awful and she hemorrhaged on herself, me, the room. I passed out she was screaming bloody murder. I am still so traumatized by it all.

Multiple rounds of chemo for multiple days.

21 days later Multiple rounds of chemo for multiple days. 21 days later Multiple rounds of chemo for multiple days. 2nd MIBG scans with nuclear medicine; these scans happen for 3 days.

2nd Bone Marrow Biopsy. Audiology test, Ekg, Echo. News that Induction was not a success and she had a "minimal response" to chemo Unituxin, multiple chemos (the relapse miracle). 21 days later, Unituxin, multiple chemos. 3rd MIBG scans with nuclear medicine. 3rd Bone Marrow Biopsy. 2nd audiology exam, ekg, echocardiogram.

Clear Scans!!!! (Thank you God!!) Back to Houston for Stem Cell Transplant: Surgery to remove her port on the left side of her chest and put a double central line on the right. Multiple High dose chemos to deplete her blood counts for the first transplant. Rest/recover.

Multiple High dose chemos to deplete her blood counts for the second transplant. Scans/CT/MRI 13 days of sedated Radiation. 4th MIBG scans with nuclear medicine. 4th Bone Marrow Biopsy. Audiology exam, Ekg, Echocardiogram. Surgery to remove the central line and put her port back in on the left.

This doesn't include the countless appointments, all the horrible medications, port access and deaccess, dressing changes, blood transfusions, side effects like hearing loss/neuropathy that

causes her to walk on her tippy toes, arm IV's because she has too many IV medications they need additional lines, C-diff (3 times), nausea and vomiting, horrible abdominal pain and the cost of everything to the point that we have considered selling our home.

Cancer is very isolating. My other kids have been left without me for much of this last year and don't get to have the normal childhood of having friends over because Bria's immune system is weak. It has completely changed all of our lives.

We are finally to the "maintenance" phase of treatment and we chose to participate in a Clinical Research Trial through Beat Childhood Cancer. It consists of 5 rounds of Unituxin. "It is terrible enough to be diagnosed with cancer at any age but the actual "treatment" is gruesome, painful and terrifying. These children are all innocent and deserve better than 4% of Federal Funding. The hardest things are the diagnosis, feeling helpless when your baby is hurting, the unknown, treatments, costs, stress of insurance companies, obtaining prescriptions.

There are no updated treatment options for these children that don't result in harsh side effects and long-term life long issues.

Simple research from the National Cancer Institute on statistical data about childhood cancer paints a gruesome picture of how childhood cancer is the leading cause of death by disease past infancy among children in the United States.

Further, brain cancers are the second most common form of childhood cancer, accounting for over 20% of all cases.

By signing this petition, you will be sending a compelling message to Congress to pass federal laws that mandate relevant federal institutions and agencies to increase their spending on childhood cancer research from 4% to 8%.

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