



PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

Jack went to school on January 27, 2021, just like he did every other day of the week. During one of his classes, he went to the office suddenly with a horrible headache. Things quickly escalated and before we knew it, Jack started seizing and became unresponsive. He was rushed to the hospital and admitted to the PICU. After several weeks, I received news that no parent ever wants to hear. Jack was diagnosed with Glioblastoma Multiforme.

This is a very rare and aggressive form of brain cancer more commonly found in adults. Very rarely is it found in children. Out of the 2,000 children diagnosed with brain cancer each year, only 6% of them are diagnosed with this kind. It grows and spreads rapidly and can often create pressure, causing headaches, nausea and vomiting. Jack underwent brain surgery, where they

performed a lobectomy on his right temporal lobe and were successfully able to remove the entire tumor. You would think that is where this story ends, but it was only the beginning.

Jack is a patient at St. Jude's, where he has been since the start of his fight. He had to undergo radiation which was an 8 week process and he is currently taking oral chemo, which we still do not know if it is effective. The mental and physical toll it takes on a single mother of two children, is overwhelming to say the least. I had to leave my older son home so he could go to school and look after the house. While Jack spent so much time traveling back and forth to appointments, his life has been greatly altered.

I am terrified to say the least. I cry all of the time for many reasons. One of them being that my son's life is at risk and there are so few options for Glioblastoma treatment, along with the lack of research toward brain cancer. While glaring statistics from the National Cancer Institute inform us that childhood cancer is the leading cause of death by disease past infancy among children in the United States. This year alone, it is estimated that over 15,000 children will be diagnosed with childhood cancer and over 1,700 of those children will die. A startling 20% of those diagnosed are brain cancer.

My son has not stopped fighting since receiving his diagnosis and we do not plan to stop fighting no matter what. I had to quit my job to make sure that Jack gets the care that he needs and deserves. Which means that things are tight financially. I have seen so many families facing the same struggle, not knowing what they are going to do because it is so hard for them to afford anything other than their child's care. I am passionate about finding a cure, so my son can go on to live a long and healthy life cancer free and so no other family has to endure this heartache.

On 1/4/2022, Jack's scans started showing a possible chance of recurrence. On 2/15/2022 it was confirmed that Jack's cancer was indeed returning. 2 spots are showing up, one in the scar tissue of his right temporal lobe and one in the corpus callosum. On our return to St. Jude's on 3/1/22, the MRI showed the spot in the right temporal lobe had grown by .2 cm and the corpus callosum had grown by .4 cm.

He began SJDAW stratum B treatment on 3/2/2022. The 2 oral medications are Trametinib and Ribociclib and will be given on a 21 day cycle. Jack is showing signs of extreme fatigue, he is weaker and has loss of appetite. He holds his emotions in, but I know that he is scared and home sick. He is currently 5'11.3" tall, weighs 157 pounds and is 13 years old. He will be 14 on September 3, 2022. Jack remains in good spirits and is full of fight. He just wants to live and live well...and fish everyday.

By signing this petition, you will be making a direct and lasting impact on future children and their families. These children are our future and they deserve to live long, healthy and happy lives. We need 12 million signatures to take this to Congress. We cannot do it alone, every signature is vital in this fight. Only allotting 4% for childhood cancer funding research, is a slap in the face to these thousands of families currently sitting in the hospitals watching their children suffer. We need to raise funding to 8% for proper research. Please stand with us.

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