



PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

On January, 19 2022, We brought Marleigh to the Children's Hospital of Alabama for what we thought were lingering effects of COVID. During a bedside neurological exam it was noted that she had developed a stutter over a couple of months and also had some left leg weakness. A CT scan followed and it was then we found out that our daughter had a 2 cm mass in the very middle of her brain. Continued testing would reveal that Marleigh was suffering from ATRT.

Atypical teratoid rhabdoid tumors (ATRT) are rare and aggressive tumors of the central nervous system. They occur primarily in the cerebellum (the part of the brain that controls movement and balance) and the brain stem (the part of the brain that controls basic body functions). 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. It has been formally estimated in 2022 that over 15,600 children will be diagnosed with childhood cancer, and 1,780 will die of the disease in the United States. Further, brain cancers are the

second most common form of childhood cancer, accounting for over 20% of all cases.

The next step was an MRI of her spine and head, followed by a biopsy and inserting an External Ventricular Drainage System. This is a temporary system that allows drainage of cerebrospinal fluid (CSF) from the ventricles to an external closed system. After what felt like a lifetime of waiting for the pathology report, we were told that her tumor was a high grade, rapidly growing tumor that would require immediate removal. She was brought back for a 6 hour surgery to remove the tumor. Marleigh also had a spinal tap and a central line implanted. The spinal checks to see if any cancer cells have migrated to the spinal fluid. She then has to have a total of 5 chemotherapy treatments and stem cell transplants over the course of 5 months, depending on how she heals each time. Followed by 6 weeks of direct proton radiation.

This entire ordeal has been a whirlwind of emotions and struggles for everyone involved, especially for our precious little girl. One of the worst things you can ever do is google your child's diagnosis. I mourned her while she was sitting right next to me, not knowing from day to day what could happen. Her cancer is so rare, there have not been enough cases to have proven treatment plans. We are following an ACNS 0333 clinical study for treatment and praying that she will win her fight. Knowing that the main reason for not having answers for Marleigh's particular case is due to the lack of research, really guts you. We need to do more for these children.

I have had to practically quit both of my jobs, which has taken our income to poverty level. Yet we still do not qualify for government assistance because we have savings. We also have 3 other children at home who are facing their own struggles with all that is currently happening. My parents have taken on the role of caregivers to ensure that my oldest daughter can get to school and so my husband can work 14 hours a day to make ends meet. We have no idea if or when our life will return to the way it once was. But we will not stop fighting until Marleigh wins.

The signing of this petition will facilitate the lobbying and passing of a healthcare policy or law that allocates a higher percentage of national resources to childhood cancer research. We need 12 million signatures to begin the next phase in raising the childhood cancer research funding from 4% to 8%. That sounds like a lot, but with your help we can reach that number a lot quicker. Please stand with us in the fight against childhood cancer.

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