



PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

Sloane's fight began in April of 2021, when we brought her to the doctors for 2 ear infections that were not getting better. We decided the best option would be surgery to put tubes in, but that did not fix her issues. It took a month and the request of a CT scan, for the doctors to find out that she had a mass at the base of her skull. We were promptly admitted to Nationwide Children's Hospital and after her first surgery and some testing of the tumor, pathology reports determined the tumor to be Poorly Differentiated Clival Chordoma.

Poorly Differentiated Clival Chordoma, was just recently recognized as a subtype of Chordoma by the World Health Organization in 2019. Due to the fact that it is so extremely rare, there is no treatment plan and the protocol used to currently treat a Chordoma is to use the regime for Sarcoma and adult chemotherapy drugs. Chordoma is commonly a slow-growing tumor found in adults between the ages of 50-60. In children particularly, the poorly differentiated

type is fast growing. It pushes up against the brain stem, is hard to remove and causes many side effects that look like typical childhood illnesses.

It was hard enough trusting doctors to try to save our baby and having them be unsuccessful. What's worse is having your child develop a cancer that is so incredibly rare and underfunded, that some of the doctors did not even know what it was. I am ready to do whatever it takes to get Congress and the White House to see the devastation that childhood cancer causes. 4% for childhood cancer research funding is not nearly enough. Our children deserve 8% at minimum to have proper research done on their behalf.

Not only is research for childhood cancer extremely underfunded. The treatments for cancer are something on a whole other level. My daughter was receiving 5 different chemotherapy drugs every two weeks. The treatment regimen was extremely aggressive. They had to hyper-hydrate Sloane so that the drugs that were supposed to make her better, would not destroy her internal organs. One of the drugs she received was called Doxorubicin, also known as "The Red Devil". How is this an approved medication to put into a 14 month olds body?

Sloane was admitted into the hospital for just over 100 days during her fight and was only able to come home for a total of two weeks. In that time she had two brain surgeries, two external ventricular drains placed, three rounds of chemo, she was put on a ventilator twice and she passed away in an ambulance while coming back from radiation treatment.

Life without our precious daughter is unexplainable. Losing her has broken us in a way that I never thought possible. Sloane has two older sisters who miss her so much and they do not understand why she had to go, but other children

get to stay. My 6 year old loved being a big sister and now she has completely lost that part of her. As Sloane's mom, I am struggling to come to terms with her death. She completed our family and now we will forever have a piece missing. I am not the same person I was before Sloane's passing, nor will I ever be that person again. Cancer took away my belief, my ability to always see the good and my baby girl.

By signing this petition, you are sending an important message to Congress to pass federal laws that will increase funding for childhood cancer research from 4% to 8%. We need 12 million signatures behind this petition to begin lobbying for raising the current funds towards children's cancer research. No child deserves to suffer the way Sloane had to. Help us to be the voice of change.

[CLICK TO SIGN HERE](#)