

## Testimony for SB69

Thank you for the opportunity to speak to you briefly.

I am Lisa Ward, the mother of 22 year old Jace Ward. We live in Wamego, KS. Jace is a senior at Kansas State University. He is also in the battle for his life against DIPG, the brain cancer that seeks to kill him. Jace is at Physical Therapy this afternoon, but I am honored to speak on behalf of my warrior.

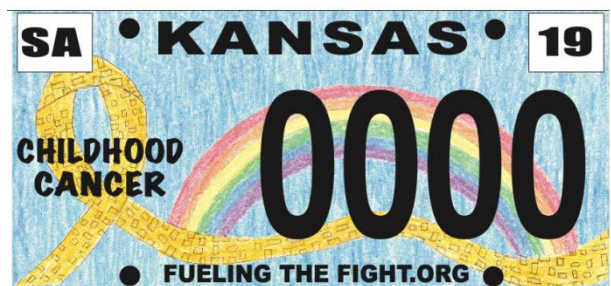


Jace was a typical college sophomore at Kansas State University in 2019. He had a little double vision in his left eye in May 2019. A CT scan, MRI and a conversation in the office of a neurosurgeon changed our lives forever. "There is no easy way to say this", the doctor started "You have an aggressive, inoperable, terminal tumor type in your brainstem. There is no cure and I cannot remove this tumor. It will kill you." My son looked the doctor squarely in the eyes as I trembled and said "How long do I have to live." The doctor hesitated as his eyes met mine. Jace said, "I'm not afraid to die, I'm afraid I won't have time to make an impact before I do." With that, the doctor replied "Nine months."

Nine months would end one day before Jace's 21<sup>st</sup> birthday. Before nine months had passed we traveled many, many miles. From Wamego to Kansas City, on to Texas to New York to San Francisco to Michigan, monthly to St. Louis and now monthly to Stanford University. Jace has been enrolled in two clinical trials. Currently, he is the first in the world receiving multiple Car T Cell treatments that are reducing his tumor.

During this time Jace also advocated at the NIH and keynoted the DIPG Briefing in Congress as well as on many zoom advocacy events. He now works in a paid internship on rare cancer policy with the Steve Jobs family. Jace's impact will be raising awareness so other parents do not hear DIPG for the first time looking at their child's MRI. DIPG is now the leading childhood cancer by disease and is considered 100% terminal at diagnosis. In Kansas last year, there were at least six children battling DIPG. All of childhood cancer receives less than 4% of NCI funding and far less from the American Cancer Society. Parents of children with childhood cancer bare nearly all costs for their child's treatment on their own.

We know first-hand the financial destruction caused by battling childhood cancer. Vehicle and air travel, Airbnb stays, missing work, food on the go, copays and deductibles have mounted to more than \$100,000 in 22 months. For that reason we support wholeheartedly this new Kansas tag to benefit in a very tangible way families like ours. You may wonder why we would not just treat Jace close to home. There is no option in Kansas City, Topeka or Wichita for treatment of DIPG other than the standard care. That is six weeks radiation. Then go make memories. The same first standard treatment offered in 1960. DIPG is the leading cause of death for children by disease. In Kansas last year there were at least 6 children battling this "rare" disease.



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Because we have chosen to travel to access brand new clinical trials and by God's mercy, Jace is almost 22 months past diagnosis. In DIPG terms he is lucky. Lucky is relative – Jace has double vision, lost hearing in one ear, has difficulty walking and using his right hand, but he still takes classes at KSU and works daily for rare cancer. Unless treatment is successful, Jace will lose his speech, his swallow and his voice, his breathing will become difficult and his heart rate will slow before it stops. All this, while knowing everything going on while locked in his body.

The adoption of this license plate does two very important things. First, it shows awareness of Childhood Cancer and solidarity with those in the battle. It highlights the beauty and innocence of these children. When seen on the road it will be a cheer for those in the fight. Our families need this. Childhood cancer is extremely lonely. It is a constant weight emotionally, financially and physically. After the diagnosis, no family is ever the same. Forever the child, his siblings and parents live very differently, they live with loss of the child or of childhood.

Second, it is an immediate way to financially support Kansas families faced with the inherent burden of travel to treatment to a children's hospital with specialized care for the cancer type.

Love, Chloe Foundation has a solid reputation for benefitting Kansas kids with cancer. For example, a gift of \$50 in travel funds means a tank of gas or airport parking. It is so appreciated by families who must absorb these costs out of pocket.

More than 1100 Kansans signed to support this license plate within a few weeks through a facebook post. The club of cancer families is tighter than alumni of a university or brotherhood of servicemen who proudly display their tags. If anyone needs a visual display of understanding, support and awareness, a reminder others are in their corner it is a childhood cancer family. To be able to ease the burden of such families through proceeds from this license plate would be a generous and needed show of support from our State government.

Thank you.