

Dear Ladies and Gentlemen,

My name is Amanda Gray and I am the privileged mother to Chase Maddox Gray, an eleven-year-old cancer survivor. I am writing you with great hopes that you will strongly support HB 2166 after hearing our testimony.

My son, Chase, was diagnosed with rhabdomyosarcoma in 2009 at just four weeks old. Rhabdomyosarcoma is a childhood cancer of the soft tissue muscles. His tumor was along his spine. Part of Chase's treatment plan was eight, that's right EIGHT, different chemotherapy drugs. He received chemotherapy for the first eighteen months of his life. All eight drugs were developed over forty years ago and none of them provided Chase with a cure.

Chase's cure was the result of a sixteen-hour resection surgery that removed not only the cancer but also eight ribs and six vertebrae. Although this surgery ultimately saved his life, Chase has severe kyphosis, scoliosis, myelopathy, and restrictive lung disease because of the surgery. It is because of the severe lack of funding for childhood cancer research that this was our only option to save his life.

As I write this letter, I am sitting with Chase at Children's Mercy Hospital in Kansas City while he is in halo-gravity traction. My son being pulled by a metal halo that is attached to his skull and forty pounds of weight to straighten his spine. We have been here the last three weeks and still have at least two more weeks to go before he can have his final spinal surgery. This surgery will be number thirty-six for him. He has endured thirty-six spinal surgeries in eleven years! Chase deserved better. All children with childhood cancer deserve better. Chase's only treatment option shouldn't have been so barbaric. Kansans can do better.

We must find better, targeted treatments for our children. We must support more research funding to find these therapies. HB 2166 will give Kansans an opportunity to help our children and fund childhood cancer research. Thank you for your consideration and support.

Sincerely,

Amanda Gray

Manhattan, KS