

I am writing to you on behalf of my 14 year old son, Matthew, to ask for your support on HB 2166.

Matthew was like any 11 year old boy. He loved fishing, swimming, riding bikes, hanging with his friends and playing football. He was a straight A student and had many hopes and dreams. All of this was taken from him December 14th, 2017 with one 6 letter word: CANCER.

Metastatic Ewings Sarcoma, a "rare" bone and soft tissue cancer, is a genetic mutation of the chromosomes 11 and 12 in utero. At diagnosis, Matthew had a tumor attached to his 9th and 10th ribs along with 3 nodules in his left lung. His survival rate was 33%. Immediate treatment was our best plan of action.

Matthew's treatment plan consisted of 14 cycles of 5 different chemotherapy drugs that are made for adults but approved for use in children. They are extremely strong and dangerous to any person, especially children. One chemo is so toxic that there is a lifetime maximum amount that can be administered. Matthew reached that limit early in treatment. He also had major surgery to remove the tumor, the 8th-11th ribs and anything else that had cancer cells in them.

After all of that, roughly 11 months, routine scans showed no evidence of disease, or NED, meaning he could stop treatment. He would continue having routine scans every 3 months to make sure his cancer didnt come back.

Sadly 8 months later, scans confirmed our worst nightmare. Matthew had relapsed, his cancer had returned. The new tumor was growing out of what was left of his 10th rib, growing into his spinal column and pressing on his cord. Surgery was not an option at that point. He started radiation approximately 1 1/2 weeks after we found out.

Matthew completed 33 radiation treatments 5 days a week. When he completed that he started a relapse treatment protocol that consists of 3 chemo drugs 5 days a week. Two of these chemos are for other cancers but show good response in trials. The other chemo he had in frontline treatment. All are adult chemos that are approved for use in children. There is no set protocol for relapse treatment, which is one reason your support on HB 2166 is necessary.

As of right now, Matthew's cancer is stable. There is no disease progression, but he still has mild activity. Therefore we cannot stop treatment at this time. He has been on this protocol for 1 1/2 years and completed 23 cycles. In the past 3 years, Matthew has spent more time on treatment than he has off. No child should have to spend that much time on treatment. This is another reason we need your support on HB 2166.

Did you know that, out of all monies given to cancer research, only 3.8% is dedicated to pediatric cancer research? That's barely 4 cents out of every dollar. And that is divided among the many subtypes of pediatric cancer. These children rely on outdated treatments that are extremely harsh on their growing bodies. But you will never see someone fight as hard to live as a cancer kid. They shouldn't have to fight just to live. They give up their childhood and trade it for a life of doctors, nurses, endless pokes, scans, and procedures. They take more medicine than they can count. And learn names of drugs they should never have to. The St. Jude commercials are very misleading. Pediatric cancer is not the cute, bald, smiling kids laughing and playing. It is watching your child throw up nothing from the harsh poison coursing through their tiny bodies. Its watching them see their friends going off to play while they get ready for another treatment. Its having to answer the questions of "Why me?" and "Am I going to die?" and not knowing the answer. That is the life and reality for my child. Now imagine if this was your child. I never thought twice about pediatric cancer, until it was my child.

Because there is so little funding, relapse treatment for Matthew's cancer has no set protocol. All we have is chemo drugs that have shown good response in working to kill his cancer. But there is no guarantee these protocols will work. If there was more funding dedicated to pediatric cancer research, they could find the answers as to why pediatric cancer exists. They could make more drugs specifically for children with cancer. A cure for pediatric cancer could even be found. The possibilities are endless.

These kids and future kids might get to grow up and achieve their dreams.

I am asking you today, tomorrow and always, what if this was your child? Wouldn't you want the best treatment, answers and a chance of a normal life for your child? I know I would. These children, including mine, are our future, our legacy. We owe it to them. They deserve our support. I am asking you for your support of HB 2166. Matthew is asking for your support of HB 2166.

Thank you
Melissa Carriker
Mother of a pediatric cancer child
Belle Plaine, Kansas