

Testimony on Childhood Cancer by Barb Sabulsky

Mother of a Cancer Warrior and Angel, Sean Sabulsky

Presented to the Senate Health Committee on HB96

Regarding Childhood Cancer Research Funding

May 13, 2025

Chairman Huffman, members of the Committee, my name is Barb Sabulsky. I am the mother of a brave, beautiful blonde hair, blue eyed boy with the best dimples the world has ever seen named Sean, who passed away from Ewing Sarcoma. Please forgive me if my emotions seem raw, yesterday marked one year since we said goodbye. One year since we watched a funeral home come and take our son from his bedroom, carry him down the stairs of our home, and place him on a stretcher. One year since the second hardest day of our life began. His diagnosis being the first.

Sean was just 13 years old when he was diagnosed. I remember taking him in to see his Dr. for rib pain. It was basketball season, and I was worried he had a rib fracture or had endured some sort of injury. I will be forever thankful to his pediatrician for sending us off for an x-ray. I will never forget that phone call. The words mass, Children's Hospital, cancer. Our world stopped. Numerous tests revealed Sean had a very rare form of bone cancer called Ewing Sarcoma.

The standard chemotherapy regimen for Ewing sarcoma, known as VDC/IE, comprises vincristine, doxorubicin, and cyclophosphamide (VDC), alternating with ifosfamide and etoposide (IE). These drugs were approved decades ago: cyclophosphamide in 1959, vincristine in 1963, doxorubicin in 1974, etoposide in 1983, and ifosfamide in 1987. Since then, no new chemotherapy agents have been specifically approved for Ewing sarcoma.

Sean successfully finished that standard regimen. During that year he also received 33 days of radiation and endured a very long surgery where they removed 3 ribs from his right side where the tumor originated from. He rang that bell with pride believing he was cancer free only to relapse months later.

For over 4 years Sean fought hard to live, but in the end no strength in the world could make up for the lack of options available to him. The truth is, the treatments available to Sean were outdated and brutal, because childhood cancer—especially rare forms like Ewing sarcoma—receive a devastatingly small portion of cancer research funding. Less than 4% of federal funding goes to pediatric cancers. Sean was fighting a monster with tools that were never made for him.

We researched and held out hope that even though he had exhausted all chemo options available for relapse, that a new drug would be developed that would work for him. We cried as new trials opened offering hope, only to watch the funding be withdrawn, forcing the trials to be terminated.

There is ongoing research into potential new treatments. For instance, elraglusib (9-ING-41), a novel GSK-3 β inhibitor, has received a rare pediatric disease designation from the FDA for the treatment of Ewing sarcoma. It's currently being evaluated in clinical trials for pediatric patients with relapsed or refractory Ewing sarcoma .

Additionally, regorafenib, a targeted therapy, is being studied as a first-line treatment option for Ewing sarcoma in clinical trials, marking a significant step forward in exploring new therapeutic avenues.

My son had dreams. He loved playing basketball, baseball, soccer and golf. We recently received his 5th grade letter from the school. It is a letter he wrote to himself predicting his future. He wanted to play basketball for Ohio State. He wrote, and I quote, "I will have a great family with 3 children and 11 grandchildren." But cancer stole that future. And worse—it did so not just because of biology, but because of policy. Because of funding priorities.

We can't change what happened to Sean. But we can change what happens next—for the children still fighting, and for those who haven't yet been diagnosed. We need more research. We need trials like the two I just mentioned to continue to receive the funding they need so more children can have a future full of life. Full of children and grandchildren.

Sean mattered. Every child with cancer matters. Please, I beg you. For Sean. For every child and family still holding on to hope. They need you. Please restore the \$5 million to the childhood cancer research fund and support the full \$10 million budget. Thank you for your time.

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