

My name is Jen Edwards. I've lived in Maryland for almost 35 years. I have five beautiful, healthy children. Before 2017, I'd never met a child with cancer, in fact I thought it was only something that happened when children were exposed to a dangerous chemical. I didn't know that there were entire floors in major Children's Hospitals full of children battling cancer. I didn't know that the number one disease killer of children was cancer. And I never in a million years thought it could happen to our family.

I'd never heard of Ewing's Sarcoma prior to my daughter, Ella's, 9th birthday in 2017 when she was diagnosed. Up until then, she was rarely sick. We ate organic, we take vitamins, never even needed an antibiotic. We don't use chemicals on our lawn. I was careful in my pregnancies. How did this happen? I'm not sure I'll ever have an answer to this question - because we don't know what causes most pediatrics cancers. I was simply told by our oncologist that it wasn't caused by anything genetic nor was it caused by an environmental exposure. And the sad truth is, we won't know how to cure these cancers without causing major, sometimes irreparable harm to these children's bodies in the treatment process using harsh chemicals, invasive and often mutilating surgeries and radiation. And God forbid if they relapse, in most cases their chances of survival are dismal. Of the handful of friends Ella met during treatment, two died shortly after relapsing, and one is permanently injured and confined to a wheelchair and on a respirator for the rest of her life due to spinal cord injuries from radiation at the age of three. Childhood cancer is a tragic, unbelievably difficult thing for families to endure.

When my child first began chemo, she was in horrific pain from the side effects. She was blinded by migraines, and she could barely walk due to bone pain. Later came the mouth sores and

nosebleeds from the low blood counts. My once healthy child now needed to be carried from the parking lot to the clinic on my back because she was often too weak to walk. She was pale, she became so thin. She got infections. She nearly died from one. The radiation she endured literally burned her skin on her back so badly that she developed painful blisters. She couldn't go to school She couldn't go to church. Our lives as we knew it had shifted to a completely different, painful existence.

Ten months later she finished her treatment and was declared cancer free. Slowly, she returned to school. Now she is a straight A student and the goalie on her lacrosse team. In retrospect, I realize that we were the lucky ones. My child recovered from the treatments, and the cancer went away. There's not a day that goes by that we aren't on our knees giving thanks that she survived. It wasn't long into her treatment that we realized that the treatment for Ewing's Sarcoma hadn't changed in decades. Let me be clear - the same harsh, toxic chemotherapy drugs that my daughter was given have not changed in decades for her type of cancer. I then learned of the extremely small amount of federal funding that was allocated to pediatric cancer, around 4%. Our already overworked oncologists often had to do their own fundraising for their research.

After learning this, we decided to start raising money for pediatric cancer research, because if not us, then who? I didn't want another parent to sit in the hospital room forty years from now and have to experience the same misery we endured. Ella started to hold lemonade stands in between chemotherapy for her oncologist. We sold Ellastrong sweatshirts and hats to friends and donated the money to research. Over the course of just a few years, we have raised over \$45,000 donated to Ella's doctors for research. It's sad that the burden of fundraising for pediatric cancer research

often falls on the backs of families who are undergoing such tragedy and personal stress, many of whom are struggling themselves financially themselves.

It has been my goal since 2017 to help people understand that this is not rare. It can happen to any child. The treatments are often harsh and debilitating, and in the case of relapse, often ineffective. The halls of floor 11 at John's Hopkins Children's Hospital are filled with children, ranging in age from babies to teens. It would break your heart to walk through the halls on any given day. More research is needed to find safer, more effective treatments for them. If not us, then who? I am so grateful for this proposed bill establishing a pediatric cancer research fund. It is a critical first step, and I am grateful for everyone who has worked on it. Thank you for your consideration and for helping us come one step closer to finding a cure for these children.