

On April 22, 2010, at only 16 months old, my son Collin was diagnosed with Stage 4 Medulloblastoma, an aggressive brain tumor that had already spread to his spine by the time it was diagnosed. Between 2010 and 2013, he relapsed twice, and endured treatments that consisted of brain surgery, extremely high doses of chemotherapy, a stem cell rescue, gamma knife radiation, a phase 2 drug trial, and even though he was technically too young for it, radiation to his whole brain and spine. His treatment spanned three states.

The things that I had to watch my innocent little boy endure just to have a chance to grow up were horrible. I handed him over to the surgeon who would remove the plum sized tumor from his brain, and was given back a boy who could barely interact with us. The surgery affected the entire right side of Collin's body, leaving it very weak. I watched as the only way he could eat was through a feeding tube. I watched him go through intense rehabilitation to relearn how to swallow, sit, stand, walk, and talk. I watched as poison was pumped through his veins, and I watched as that poison made his hair fall out, gave him mouth sores, and made him sick. I watched him go through morphine withdrawal at less than a year and a half old. I watched him come close to dying more than once. I watched as he had radioactive material injected into his head with the hope it would find and destroy cancer cells we couldn't see. I watched as his head was covered with a mask and bolted to a table 28 times so the radiation beam could be lined up precisely. I watched him get radiation burns over his head and down his spine. And I've watched as these treatment side effects disappeared, only to be replaced with other side effects that he will deal with for the rest of his life.

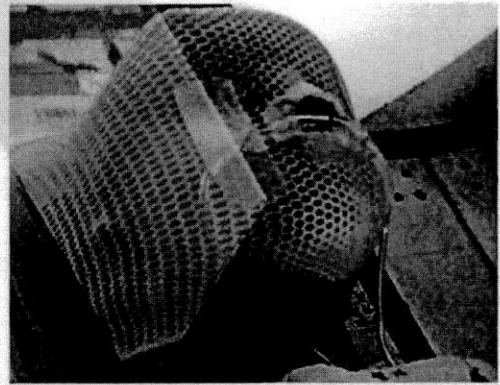
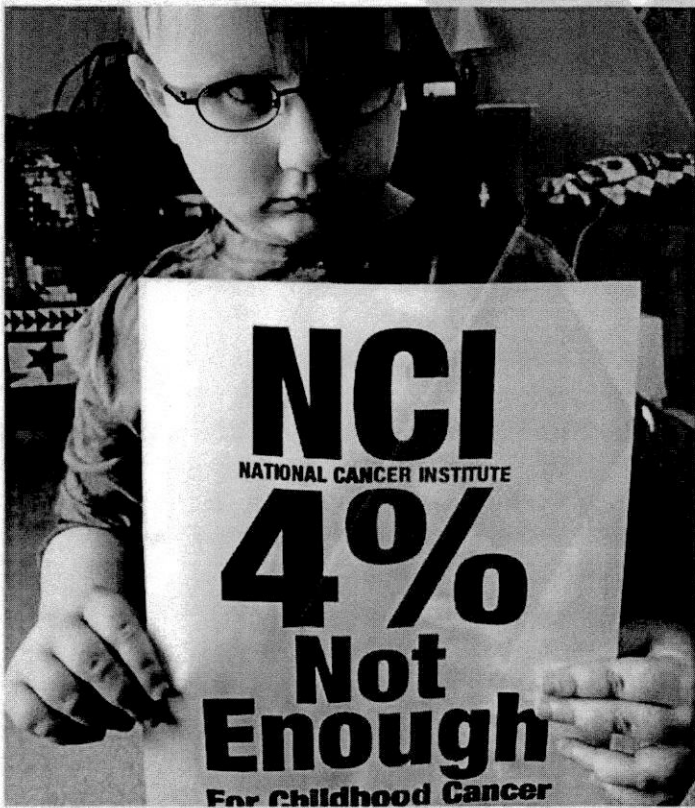
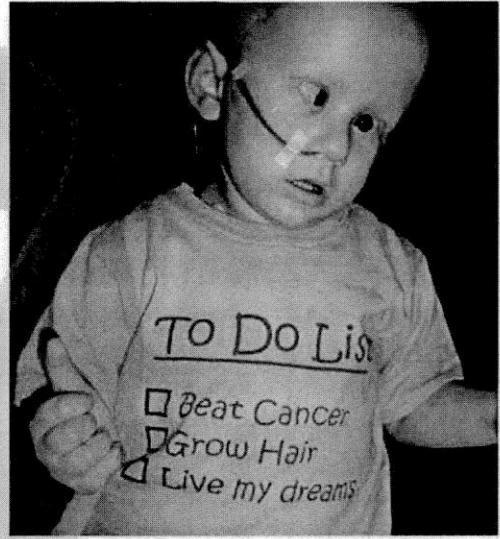
Collin has had years of speech and physical therapy, and continues to have occupational therapy to work on fine motor skills, strength, balance, and coordination. The right side of his face was paralyzed, as nerves were damaged by increased pressure in his head after his brain surgery. He has had surgeries to try to straighten his eyes and remove cataracts caused by radiation. He wears a hearing aid in school due to high frequency hearing loss. He has had acupuncture treatments to help his facial paralysis, and now attends a facial nerve clinic to hopefully help his facial nerves regenerate. Radiation has damaged his thyroid, adrenal, and pituitary glands, and he needs thyroid medication, stress hormone support, and costly daily growth hormone injections. He is treated by a gastroenterologist due to gastritis and an esophageal ulcer, which are side effects from treatment. He has a neuropsychology evaluation every year or so to monitor the toll radiation has taken on his brain, specifically in the areas of reasoning, concentration, problem solving, language skills, and memory. Due to the amount of chemotherapy Collin had, as well as the radiation to his brain and spine, he is at risk of developing a secondary cancer as a result of the very treatment that was meant to save his life.

The sad thing is, these long term effects are not unique to Collin. 74% of childhood cancer survivors have chronic illnesses, and some 40% of childhood cancer survivors have severe illnesses or die from such illnesses. Because of the treatments they had as kids, by the time they're 45, more than 95% of survivors will have a chronic health problem and 80% will have severe or life-threatening conditions. Physical and neuro-

cognitive disabilities resulting from treatment may prevent childhood cancer survivors from fully participating in school, social activities and eventually work, which can cause depression and feelings of isolation. Many childhood cancer survivors have difficulty getting married, getting jobs, and getting health and life insurance. Many of them are unable to have children due to infertility from their treatment. Many of them are unable to drive a car, or live independently.

A fellow brain cancer parent (Randy Hinton) once said, "If you force radiation, steroids, and chemo on a condemned prisoner without his permission, he can sue the state and win. If you do it to a child, it's called "best medicine available." This is the most accurate way I've come across to describe the current cancer treatments available to our children. Childhood cancers are different than the cancers that adults get, yet children are treated with the same chemotherapy as adults. We don't even give children cold medication until they are almost six, because we know that a smaller dose of an adult drug is not safe for kids. But when it comes to cancer, the only chemo we have to use are adult chemos that are over 25 years old. These chemos may kill cancer in some kids, but the side effects, both during treatment and after, are devastating. Many kids die as a result of the treatments available to them, not the cancer they are fighting. I know far too many parents who've lost children to cancer or it's treatment. I know of childhood cancer survivors whose quality of life has been so adversely affected by the long term effects of the treatments that saved their lives, they wish they had not survived. I know parents who've said, "My child survived... for this?!" I know children with cancer deserve better. "Isn't it a shame that the richest nation, with the highest standard of living, the greatest world power, the country that went to the moon, has to rely on kids selling lemonade while their parents get their heads shaved bald to try to stop the #1 killer disease for our children?"

Much of what is known about treating adult cancers has been learned from childhood cancer research. Much of this research is being done at hospitals like Penn State Hershey Children's Hospital and CHOP. With childhood cancer research receiving less than 4% of the National Cancer Institute's budget, it is crucial to find alternate sources of funding for this important research. There are many doctors and researchers who desperately want to find better, kinder treatments for kids fighting cancer, but they are unable to do so because research funding just isn't available. With your help, we have recently established the Children's Cancer Research Fund in Pennsylvania. Now we need to give researchers in Pennsylvania the money they need to perform the research. When medical students know there is a state that has funding for research, more of them will be attracted to the field. When they know they will have funding for the research they want to dedicate themselves to, more doctors and researchers will choose to live and work in our beautiful state, which will benefit our economy. Childhood cancer is the number one disease killer of children in the U.S. If Pennsylvania can become a leader in the fight against pediatric cancer, that will be a win for all of us, and most importantly a win for our children and grandchildren.



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