



PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

Elijah Augustine was diagnosed with Rhabdomyosarcoma on November 2nd, 2018 at the age of 10 years old. This is a disease in which malignant cancer cells form in muscle tissue. Certain genetic conditions increase the risk of childhood rhabdomyosarcoma. It usually begins in muscles that are attached to bones and that help the body move, but it may begin in many places in the body. Rhabdomyosarcoma is the most common type of soft tissue sarcoma in children. There are many symptoms that can occur with this type of cancer but the most common are persistent lump or swelling in the body that may be painful, headache, nausea, constipation and blood in the urine. The 5-year survival rate for this cancer in children in the intermediate-risk group ranges from approximately 50% to 70%. When the cancer becomes high risk spreading widely in the body, the 5-year survival rate ranges from 20% to 30%.

We noticed one day that Elijah had a swollen inguinal lymph node. We took him to see a doctor and he was diagnosed at that time with a calcified lymph node. Approximately 6 weeks later his leg had swelled up on the same side as the swollen lymph node. We again took him to see the doctor and a biopsy was done. Shortly after, we were given the devastating news that our son had cancer. By this time, his cancer had already metastasized. The doctors never admitted just how poor his prognosis was. We had no idea the survival rate for high-risk rhabdomyosarcoma was at such a low percentage. Sadly, when you first hear the word cancer you do not think curable, you think death as much as you hate to.

You often hear of more children dying from cancer than surviving. If they do not pass away you then are forced to worry about the long term affects or worry that the cancer will return after remission.

Each year in the United States there are an estimated 15,780 children between the ages of birth and 19 years of age who are diagnosed with cancer. Approximately 1 in 285 children will be diagnosed with cancer before their 20th birthday. Globally there are more than 300,000 children diagnosed with cancer each year. In 2022 alone the estimated deaths of children with cancer are 609,360 which is completely alarming. This is why it is so crucial to see the 4% federal funding rise to 8%. Too many children are dying because of this vicious disease and something needs to be done so that this amount can decrease and our children can live a normal life.

We have 8 other children so we had to tell them the horrifying news and that was almost as difficult as hearing our son's diagnosis. It was such a shock to them and each had a rough time processing the news. Chemotherapy and radiation were tough to watch our son go through. Watching him become so sick from treatments was completely heart breaking. There was absolutely nothing we could do to ease his pain. Prayer was really all we had and we prayed constantly. Elijah was so brave and he was always the one telling us that it was going to be ok even when he knew it was not. Even with all the poison being pumped into our son's body and almost unbearable, he kept fighting.

In May of 2019 Eli had his 30-week scans done and there was no evidence of any cancer. Treatments continued until March of 2020. On May 4th his port was removed. Two months later our son developed a small mass that appeared on his bicep after slipping while climbing his bunk bed. Initially I wondered if the swelling was from banging his arm when he slipped. The swelling went down but the mass remained. We were told by an oncology that we had to have our son checked by his pediatrician first which we did right away. The oncologist then looked at the mass the day after Eli saw his pediatrician and an MRI confirmed relapse in multiple locations by the end of that same week. The doctors did not confirm that it was terminal until after the PET/CT scans were done the following week.

We decided to take the children to the ocean after the scans were done, knowing that whatever the results, it was not going to be good. The doctors then gave us the news via a virtual meeting while in

the hotel. We did not tell Eli or our other children until after we returned home. We were in complete disbelief; he did not appear to be sick. There were no specific signs that would have made us think the cancer had returned until it had spread to his foot, thigh and arm. That's the worst thing about this ugly disease. It comes back as quickly as it left and with a vengeance. When you think about what someone dying looks like, our precious boy did not fit that mold. He looked healthy and for at least 8 months appeared to be doing ok. Within 4 more months there was a rapid decline in his health. At this point he was in a lot of pain, limping and did not have much of an appetite.

Two weeks went by and we took our son in for his regular hospital visit and I insisted that Elijah have an MRI done as he had been having difficulty breathing. We received the news that he had a collapsed lung. At this point the doctors gave him 2 weeks to 2 months left to live. He had already surpassed the year mark so it was hard to believe he had very little time left on this earth. He was very weak and he was unable to do any chemo treatments in fear it would shorten his life rather than extending it. After 3 years of fighting his battle, we knew it was time to say goodbye to our son. None of us were ready but watching him in such pain and discomfort was too much for any of us to bare, including Elijah. Our son lost his battle on November 17th, 2021.

I promised my son that I would be okay, but it has not been easy at all. One of our daughters has struggled with her college classes and was going to drop a failing class, but agreed to let us study with her until she was caught up. 1 of our sons who had left to serve a mission for our church not long after his brothers funeral, struggled with grief and ended up coming home early to work through things until he is ready to return to his mission. The other children have each had their own struggles coping with their loss. My husband and I are doing our best to help them navigate through this process but it has not been an easy task. On top of our grief, we are still fighting insurance battles which have been ongoing since our son's diagnosis. We miss Elijah so much and none of us will ever be the same. We are very passionate about advocating for childhood cancer awareness and will do everything in my power to make sure my son's story is heard over and over, in hopes that more will be done for those children still fighting.

The federal government is allocating a minimal 4% for federal funding for childhood cancer research. This is not nearly enough to make a difference. By signing this petition, you will help facilitate lobbying and the advance of a healthcare policy that will delegate a higher percentage of resources for childhood cancer research. This will give researchers more funding to do more intense research to potentially find a childhood cancer vaccine which would help in eliminating such intense treatments for our children. Please stand with us and sign and share this petition so that these children can finally have a chance at living a normal life.

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