



PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

Charley Rose was a happy baby girl reaching every milestone early in her first 5 months of life. On the day she turned 5 months old, I could tell she was not feeling very well. I did not think it was anything more than the common cold. The following day when she woke up she could not keep anything down, so I called her pediatrician. I was to take her to her pediatrician a bit later in the afternoon that same day. Immediately after hanging up with the pediatrician, Charley began to dry heave. I laid her down to change her clothes and left the room for no more than 2 minutes. When I returned to her, she was gray in color with her eyes rolled back to the back of her head and she was unresponsive. I immediately called for an ambulance and when they arrived, her vitals were all over the place. She was quickly taken to the hospital.

On December 24, 2020 the doctors found a softball sized tumor in her stomach that encased both her aorta and IVC. The following day, she was diagnosed with Stage 3 Neuroblastoma. Her doctors told us that the tumor had only been there for approximately a month before it was found. Neuroblastoma is a childhood cancer that starts in immature nerve cells (neuroblasts). The term "neuro" refers to nerves and "blastoma" refers to a tumor of immature or developing cells. Neuroblastoma tumors can occur anywhere in the body, however about 65% of them occur in the abdomen. Neuroblastoma tumors are unique. Some may go away on their own without any treatment while others may metastasize throughout the body. Neuroblastoma is the most common cancer in children under the age of 1. Every year there are about 800 new cases of neuroblastoma in the United States in children alone. At Stage 3 the tumor cannot be removed with surgery. The cancer has spread to regional lymph nodes

near the tumor, but not to any other parts of the body. The 5-year survival rate for neuroblastoma in children under age 15 is 82%. The 5-year survival rate for stage 3 neuroblastoma is around 50%. Nearly half of kids who reach remission relapse. There is no cure for relapsed neuroblastoma.

Charley spent most of her life at Cincinnati Children's Hospital, where she received treatment. Her hospital room was what she considered home. Both her father and I also spent all our time with her there. We were only able to leave the hospital very few times in the almost 9 months of Charley being diagnosed. She was able to spend roughly 8 weeks total outside of those 4 walls. The rest was spent fighting to beat this horrific disease. After her first initial discharge for the first time in 148 days, Charley was able to spend 2 weeks at Ronald McDonald House before being readmitted. This occurred a total of 4 times.

I cannot begin to express how devastating it was watching our sweet baby girl being pumped full of poison once a month. Poison that was supposed to save her life. Charley had been intubated more times than I can count. She was continuously sick and due to the chemotherapy, her teeth never grew in. Charley had to be placed on dialysis and ended up with heart and kidney failure due to chemotherapy. There was absolutely nothing that her father and I could do to take her pain away. That was the emptiest feeling either of us experienced. The helplessness I felt as her mother was torture. I was her mother and I was supposed to be able to protect my baby. I had to make decisions for my child that I would never make for myself. Because of the cancer, Charley had to relearn everything as if she were a newborn again. Cancer took everything from our sweet Charley Rose. It took everything from us as well. She was our first born and we were not ready to let her go. Sadly, cancer does not care about the children or their families.

During Charley's very last admission into the hospital, her father and I packed up everything from Ronald McDonald House to take back to Kentucky. Charley was finally supposed to be able to go home after being in the hospital and at RMH since February. It was late August and merely 1 day before our going home date. Charley started showing signs of infection. The week Charley passed; treatments wiped out her ANC (absolute neutrophil count) and she caught an infection before the doctors could recover. She was intubated and retained almost 20 pounds of fluid. She was leaking from every incision, from previous surgeries and from her eyes as well. Her tiny body was bruised from head to toe. Our baby girl was absolutely unrecognizable. She was placed on a ventilator setting so high; it would have blown adult sized lungs up. The dosages of blood pressure medicine they were giving her was enough to instantly kill someone. We watched our baby girl fight so hard but we also had to watch her suffer. A

parent should never have to watch their child pass away. That is not supposed to happen. Cancer did not kill my child, treatments did.

I now suffer from anxiety, depression, PTSD and I am traumatized from watching what treatment did to my baby's body. There is not 1 day that goes by, where we do not think about Charley. There are days I cannot even get out of bed. Every day is a constant reminder that she is no longer with us, as I pass her graveside on my way to work. I often fear Charley did not hear all the times I whispered in her ear that I was there. I am terrified that she felt alone and thought we had not been right by her side. This has been the most traumatic thing that her father and I have ever experienced. We will never be able to unsee the things our eyes have witnessed, while living on the pediatric cancer floor. Our child died before she even got the chance to live.

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. About 10,470 children in the United States under the age of 15 will be diagnosed with cancer in 2022. The federal government has allocated a mere 4% of government funding for cancer research in the United States. That is not nearly enough to make a difference. I am determined to do all I can to help raise that amount but I cannot do that alone. We need to get that 4% raised to 8% to ensure proper research needed for these children. By signing this petition, you will facilitate lobbying and passing of a healthcare policy that will allocate a higher percentage of resources for childhood cancer research. These children need to be heard as well as their families. Please help us come together by signing this petition. Let's do this, not only for all the children fighting cancer but for those who fought hard and lost their battle.

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