

PETITION TO INCREASE FEDERAL FUNDING FOR CHILDHOOD CANCER RESEARCH

Cheviona Meyer was diagnosed with Stage 4 Group 4 Rhabdomyosarcoma at the age of 5 years old. This is a rare type of cancer that forms in soft tissues, specifically skeletal muscle tissue or sometimes hollow organs such as the bladder or uterus. RMS can occur at any age, but it most often affects children. Stage 4 means distant metastases are present at diagnosis. The primary tumor can be of any size or location. Symptoms that often occur include persistent lump or swelling in the body that may be painful, bulging of the eyes or drooping eyelids, headache, nausea, trouble urinating or having bowel movements and blood in the urine. Cells from this cancer are often fast growing and can spread to other parts of the body. Children can develop this type of cancer at any age, but most cases are in children between 2 and 6 years old. The 5-year survival rate of Stage 4 RMS is at a devastating 20% to 30%.

Early one morning I noticed a lump on her cheek that had shown up overnight. I took her to see her pediatrician and x-rays were done. Later that day I received a call asking us to come back into to the office. We were told that the doctors suspected that her mass was cancerous and they needed to refer us to another hospital for further testing. Within a few days

we took her to the hospital and a biopsy was scheduled. I then received a call from the scheduling department of that same hospital wanting to schedule a scan with radioactive isotopes to see if the cancer was anywhere else in her body. I was completely shocked and could not speak for several minutes. Once I gained my composure, I asked what they meant as we had not yet received the results from her biopsy. They quickly apologized as they had thought the doctor had already called to give us the results. I quickly hung up the phone and immediately called her doctor, who confirmed that the results of the biopsy came back. The mass was in fact cancerous and we were told it was Stage 4 rhabdomyosarcoma. I was in disbelief and felt my heart drop. I then had to call her father to give him the news. That day was the first of a very long line of many hard days ahead of us.

Treatments have been very hard on Cheviona's body and as a parent it was incredibly difficult to watch her struggle knowing there was nothing, we could do for her. She has chemotherapy which includes 3 medications every 3 weeks and requires an overnight stay at Children's Mercy Hospital. She also is given the drug vincristine every week as well. She had to have bone marrow taken along with surgery to remove and preserve her ovary. She also had to undergo surgery to remove her lymph nodes as well as dental surgery. As if that was not enough, Chevi had to also have surgery to remove part of the tumor in her right cheek. The chemo treatments caused nerve damage and now she has to have physical therapy every week. However, her personality remains bubbly and she often likes to dance to bring herself joy. She has been such a brave little warrior through everything and continues to fight hard.

Each year, the parents of approximately 15,700 kids will hear the words "your child has cancer." About 10,470 children in the United States under the age of 15 will be diagnosed with cancer in 2022 and approximately 1,050 children are expected to die from cancer this same year. Cancer is the leading cause of death by disease past infancy for children in the United States. Childhood cancer is said to be rare, and the rate at which new cases develop among children is 15.3 per 100,000 per year. That is roughly 1 in 6,500 children and adolescents under

the age of 20 years old. This amount is devastating and something needs to be done. This is one of the many reasons it is so crucial that we see the federal funding rise from 4% to 8%.

Cheviona now has an appointment scheduled to do scans to schedule her radiation treatments. Once we have the schedule in place, she will have radiation every single day for 6 straight weeks. We live 2 hours from the hospital so we will be staying at the Ronald McDonald House for the duration of her radiation treatments. Without the Ronald McDonald House I am not sure what we would do. This has caused extreme financial hardship on us as well as stress. All we can do is pray and hope that these treatments will help our sweet daughter. Sadly, Chevi does not completely understand what is happening to her or why she is continually being poked and prodded and feels everyone is being cruel to her for no reason. As much as we try to explain to her why this is happening, it is very hard for her to grasp and that alone is heart breaking. This is why I am so passionate about doing all I can to raise awareness on childhood cancer.

The federal government is allocating a mere 4% for federal funding for childhood cancer research. This is not enough to make the difference we need to see. 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 testing to potentially find a vaccine for childhood cancer. Which in turn would eliminate much of the pain of treatments and possibly shorten their time of having to fight this ugly disease. There is even the chance that a cure could be found. Please stand with us by signing and sharing this petition so these children can have a fighting chance.

CLICK HERE TO SIGN PETITION