

Layla's Story told by her mother Jennifer Beckstrand



Layla was diagnosed with stage 4 neuroblastoma at 18 months old. Her hair was straight and so blonde it looked white. She had a big toddler belly that jiggled when she ran. Layla's laugh was louder than a freight train and her smile was bigger than the world.

On October 29th, 2015, during a diaper change, her dad and I noticed her big toddler belly distended to one side instead of in the middle. Concerned was an understatement. Having the distention on the right side, we had fear of an enlarged liver. I took her into the nearest hospital to get an ultrasound, while her dad stayed home with her 3-year-old brother, and within 15 minutes we were on the phone with the chair of the hematology-oncology doctor at the children's hospital who told us the most heartbreaking words,

‘We think Layla has neuroblastoma, an abdominal cancer.
I need you and her to get to the hospital right now.’

Those words, that sentence, is etched into my soul. It became a part of who I am as a momma. Our entire four-person family was turned upside-down, inside-out and stretched beyond anyone's wildest dreams. For the next almost two years, we had to watch, while only being able to hold her hand, as we laid her life into the hands of the best pediatric oncologists there are.

Cancer is the number one cause of death by disease in children in the United States.

Layla went through the ringer. Six rounds of chemotherapy. The tumor was the size of a small football and had metastasized into all the major bones in her body and surgery to remove it. She had 12 days of radiation to her abdomen and spine, more body scans, and fevers than I can count, 38 blood and platelet transfusions, two stem cell transplants and six rounds of immunotherapy.

In children, ‘done with treatment’ does not mean done with side effects or worry.

In February 2017, Layla was declared done with treatment. The lifelong effects that Layla will have as a result of front-line treatment is nothing short of debilitating. Survivorship for kids with cancer are told secondary cancers, hearing loss, heart disease, organ troubles, fertility struggles, hormonal imbalances and mental health struggles, are what they have to plan for. Over 90% of children that ‘survive’ cancer will have one or more of these secondary issues later on in life. The longer these children live, the higher the risk of developing side effects.

Layla is now a healthy 8-year-old girl in 3rd grade. She only remembers the good parts of the hospital, how she was treated by the staff, the bond that she formed with her brother taking care of her. She loves the outdoors, reading fiction books, visiting historical places and her family. Because of her treatment, Layla has hearing loss. She also has over fifty percent chance of developing a secondary cancer along with heart or liver disease and thyroid issues. It's not a matter of if, it's when.

Childhood cancer is not rare.

I want people to know is childhood cancer may statistically rare, when you compare it to the adult population, but it is not rare. One in 285 kids will be diagnosed with cancer. There are more types of children's cancers than there are adult cancers. Research for childhood cancers needs to be at the forefront of what is funded at the state level and in the country. Seeing progress is the best way for us families to have peace of mind. And our kids deserve the best.