

September 12<sup>th</sup>: Kyle's Story, written by his mom, Jill

Few 17 year olds have had cancer; even fewer have had it twice. Meet Kyle, my two-time survivor. Yes two-time. Kyle was only 3 the first time he was diagnosed with Rhabdomyosarcoma. He doesn't remember much about this diagnosis, happening the week before his little brother was born and his older brother was starting kindergarten. But it would start his long road of battling cancer. Kyle doesn't know life before being a cancer survivor.

Kyle was diagnosed a second time shortly into 6th grade at the age of 11. He himself found the tumor growing back. Fortunately he showed it to his older brother and then to me, as catching things earlier is certainly better. He was diagnosed with the exact same cancer Rhabdomyosarcoma a second time. This relapse was 8 years after his original diagnosis, really unheard of so we were sent to the specialists at the Children's Hospital of Philadelphia to decide how to treat this rare reoccurrence of his cancer. Due to the odd nature of this relapse, he was treated with a protocol of chemotherapy and radiation that his oncologist would describe as "grueling, debilitating and life-altering."

And indeed it was. He spent most of his 6th and 7th grade years not at school but overnight in the hospital getting 5 different chemotherapy drugs and a month of daily radiation. He received countless blood and platelet transfusions due to constantly low blood counts from the effects of intense chemotherapy. These drugs were not only destroying cancer cells but also were toxic to his bladder and his heart. Kyle was literally beaten down to nothing so that we could rid his little body of the cancer cells.

While this was going on, Kyle did his best to attend school when he was able. He wanted only to be a normal student. He went to school when he felt good enough and would suffer from nose bleeds due to low platelets, his heart would race when he tried to walk upstairs due to low hemoglobin, and he would get nauseated and vomit at odd smells. He still wanted to return and go to class and kept up with practicing his music as much as he could.

PCFLV and their volunteers were lifelines for us during this time. Their visits to Kyle and me, as we were isolated from normal every day life trapped in a room in the hospital, were life saving. Not only the financial support of meal gift cards and gas cards when we were doing daily drives to Philadelphia, but PCFLV was so much more. When you are dealing with the unimaginable with your child, it helps to have other moms to talk to who know exactly what you are going through. These families are indeed the strongest I have ever met.

Kyle entered high school with a weakened body and years to make up in academics. He pushed through and fought physical pain, fatigue, and cognitive impairment brought on by very strong chemotherapy drugs. He has a lifetime of secondary effects from these two treatments to manage...constant monitoring of heart function, sterility, and scans every six months to monitor for reoccurrence just to name a few. I remember what it was like to wake up as a teenager and face normal daily struggles, I cannot imagine waking up knowing that I had already beaten cancer twice. Kyle is now a senior and planning his life and attending college next year. He and all of these other cancer survivor stories remind us of what it really means to be strong, to be a hero, and live life to its fullest despite any set back. Thank you to PCFLV for helping not only Kyle but also my family through a very hard time but for all these families during and after treatment.