

30 Days/30 Stories®

Max

Diagnosed with bilateral retinoblastoma at age 4 months

Maximillian (Max) was diagnosed with bilateral retinoblastoma when he was 4 months old. Not comprehending the magnitude of this cancer (which has a high survival rate), I imagined 6 months of chemotherapy, a few eye surgeries, and this episode of our lives would be in the books. I wouldn't even consider myself a cancer mom. However, I quickly learned what "scan-xiety" looked like during every MRI and EUA. I learned that my son, my only son, would not only carry on the family name, but possibly the Rb1 cancer gene. I learned that we are now in the world of blindness, even though he was only half blind. Or as I like to say, half visual.

Later in our journey, I learned the fear of what a potential relapse felt like. I learned what it felt like to be precautionary and enucleate because the tumor wasn't visible. I felt what it was like to lose a battle (his eye), but win the war (cancer) 4 years after diagnosis. His right eye was removed in 2016. I learned that he would fall into the statistics of hearing issues when one of the chemo drugs that is audio-toxic would cause high frequency deafness in my son. He wears hearing aids in school. We are the .05% that has this result. And lastly, I learned of the aftershock that rips through the family years after the cancer is defeated and is in the past, and leaves everyone reeling and falling in a tailspin. This tailspin threw our family into a serious darkness which took years to rebound from.

Pediatric cancer isn't just the diagnosis, treatment, avenue of difficult decisions, and intense worry. The roller coaster doesn't end when tumors are removed, inactive, or in remission. It is just the beginning of learning what a family is truly made of and how many more battles can be fought. I am proud to say Maximillian, our amazing second grader, is healthy and thriving. Our entire family is so blessed and continues to grow stronger each day, because we, together, have WON this war!

Written by Max's mom, Tina

If you would like to donate in Max's honor Click Here

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