

2018 CSCGP High School Teen Essay Contest

2nd Place Winner

Hailey Wiggins

Rare but There

Life was normal, average, and mundane. It was anything but rare. I had nothing but the typical teenage life. I went out with friends, attended school regularly, performed as a gymnast for almost 12 years, played soccer for my school team, went to work at Sesame Place, and so much more. Little did I know it was all about to change in the blink of an eye.

The night of August 5th, 2017 altered my life forever. I started out with a headache, but the headache worsened as the days went by. I wasn't able to take the pain anymore, so within days of one another, we traveled to two separate emergency rooms. I was diagnosed with a migraine first, but my mother pushed for an MRI at the second ER and my life took a turn for the worse. The doctor came in and told us there was a spot on my spine, and there were a few possibilities, but none of them offered a positive outcome. It was now 2:00 AM, and I soon found myself transported down to the Children's Hospital of Philadelphia. This was the start of my 26 days at CHOP. After waiting in this final ER for 16 hours, I was moved to my own room to await my fate.

On August 8th, I went in for a biopsy on what was now called a mass. The word *biopsy* was so scary for our family. While waiting for the results, I was scheduled for interior and posterior surgeries to remove the mass. From additional testing, they were able to tell us that the newly named tumor was growing out of my C2 vertebrae, attached from C1 to C5, and wrapped around my vertebral artery. The day of my posterior surgery, the doctors did confirm to my parents that I had Chordoma, a rare type of "sarcoma" occurring in the bones of the skull base and spine. Knowing that I

had two surgeries in the next few days, my mom and dad wanted me to be strong, so they waited to tell me when they felt the time was best.

Fortunately, I survived both major surgeries with only minor complications, but the worst was yet to come. On August 21st, my dad was the one to tell me exactly what I had a feeling was happening. He finally got out the word "cancer," but I put on my tough girl persona, shrugged it off, smirked and said, "I figured that." My parents and the medical team looked at one another in amazement. Unbeknownst to them, I was a mess inside.

When they left me alone in the room, I called my Nana, hysterically crying to her, "Why me?" So many questions crossed my mind, but still my diagnosis did not seem real. It is not fair to be told you have cancer. No one deserves to go through everything that comes along with that dreaded diagnosis. My mom has always used the phrase, "Everything happens for a reason," but I will never understand why, at this time in my life, God chose me to deal with a life-threatening illness.

Against the better wishes of my parents, I immediately posted my diagnosis on *Snapchat.* I felt like this was the only contact I still had with a world that was continuing without me, but social media was a double-edged sword. It allowed me to communicate with those close to me, and at the same time I was able to see how my friends were going on with life by getting senior pictures taken, going to the beach, and preparing for the first day of school. While they were being typical teenagers, I was the not-so-normal girl because of cancer. The distinction between them and me broke my heart and made me angry.

During my month stay at CHOP, I had CT Scans, MRIs, x-rays and EKGs. I survived a biopsy and two major surgeries, fought through 22 IVs, and had a feeding tube. After my hospital release, this journey wasn't over as I had to do physical and occupational therapies, while wearing a neck brace for what turned out to be almost four months. Still, coming home was the best feeling ever. I was able to sleep in my own bed, eat home-cooked food, and, mostly, be under the same roof as my family. I was safe, comfortable, and optimistic about my future. I felt strong. None of what I withstood was going to deter me from having a normal senior year of high school.

When I was allowed to go back to school, it was not what I expected it to be. With the neck brace on, teachers and students were constantly asking me what happened, and others were staring at me. I remember thinking that all those stares weren't the kind that a 17-year-old girl deserved, especially surviving all I had endured. Eventually, school became too painful and difficult for me as I couldn't even sit in the chair for the 47 minutes of each class. The pain of holding my head up, both literally and figuratively, was horrible. It forced me to go to the nurse constantly. I would hear, "Oh, she gets to get out of class whenever she wants," "She gets to leave class super early for no reason," and "She can leave school whenever she wants just because she has a neck

brace on." No one understood, and though I didn't wish this diagnosis on anyone, I do wish some could put their feet in my shoes to feel the way I did.

Due to the rare cancer I have, I needed forty-four high doses of radiation following the surgeries. This meant we had to travel to the University of Pennsylvania, five days a week, for the next two months, so I could get treatment. The thoughts going through my head were terrifying, but I kept telling myself I can do it because every day is a day closer to not having cancer. This radiation journey was another hurdle in my life that I never thought I would have to face, but it did not stop me because I knew I could keep my head up and beat this. Still, once my radiation journey started, the realization set in more strongly that I was in a position that other teens would never have to be in, and it depressed me. Walking into the room for my photon therapy, seeing the machines and equipment surrounding me, and then placing the five-point mask over my face and body was something no child should have to go through. I asked my parents how they felt seeing their daughter in this situation. They responded with, "Of course we cried, we tried to keep it together... though seeing you in that mask was indescribable." I now saw that cancer affects everyone, but everyone deals with the reality of it differently.

Another time I sat in the radiation room waiting to be called and I noticed this gorgeous girl, about my age, wearing a hat because she had lost all her hair. I found myself doing what my classmates were doing to me: staring at her. I could not imagine what she was going through, and it really made me aware that my situation could be much worse.

I survived the 14 photon treatments and moved on to the final 30 proton treatments. I was fortunate to have minimal side effects, but the traveling and late-night appointments were too much for me to handle. I had to be homeschooled, and I felt even more abnormal. My homeschool teachers were the closest people to friends that I had because my teenage friends disappeared. Although I had lots of other supporters, I really wanted my friends to invite me to hang out, or call to see how I was feeling.

On December 27, 2017, I rang the radiation bell to announce my cancer treatments were over. It was one of the greatest days of my life and another defining moment that motivated me to keep positive and not give up. Today, I know cancer will only be a chapter in my life, not the whole story. Yes, it impacts a family immensely, changing its form daily. From migraine to mass, tumor to cancer, Chordoma to radiation, my disease changed my life for the good but also the worst. It taught me life is short and not to take anything for granted, no matter how hard it gets. It taught me I am special, not only because I am one in a million to get a one-in-a-million disease like Chordoma, but because I will not let it stop me from achieving my dreams. I am stronger than cancer and will take on whatever comes my way because I am a warrior, not a worrier. Like the cancer that invaded my body, I am rare but there.