

Expecting the Unexpected

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It was the month leading to the end of Middle School. Nothing to worry about except enjoying my summer and getting ready for high school. I lived what I thought to be a normal life with a normal family. My mother was a kindergarten teacher at my school and my father was a contractor. My younger and only sibling was my brother, Beau, who was looking forward to celebrating his 11th birthday in the coming months. He was going into his 5th-grade year. As the school year narrowed down, Beau began feeling nauseous for no reason and weird bruises were showing up on his arms and back. Thinking it might have been nothing or at least nothing serious, we went to our family pediatrician for some blood work. A few days later we got a phone call saying we needed to come in and talk. We went in and were told that he couldn't give us any answers for sure, but he suspected something was wrong and that we should go to OHSU in Portland, Oregon to be certain. We rushed home and grabbed our things before hurrying to the hospital to get some answers. When we got there, the doctors had already been informed and got us right into a room. A nurse did a blood draw and they tested it, soon confirming that he had cancer.

None of us could believe it. As if that wasn't enough, we were informed that he had acute myeloid leukemia with a flit3 mutation, meaning he had the tougher of the two leukemia's, and he had a mutation that made it harder still. We never even left the hospital, we were just given a room to stay in. My father and I went home to get some overnight supplies for everyone. None of us knew it then, but that was the last day Beau was able to leave the hospital for months. The biggest problem in the coming months was not knowing. A flit3 mutation is rare and hard to cure, and try as they might the OHSU doctor didn't know enough about it to be effective. Our biggest wake-up call was when discussing treatment options further into his diagnosis, one of the lead doctors suggested putting him on hospice and making his death the least painful they possibly could. This is when my mother searched intensively for another way. After a round of chemotherapy at OHSU, we decided it was in our best interests to move Beau to Seattle to attempt to beat this at Seattle Children's Hospital. Fred Hutch organization and Seattle Cancer Care Alliance were both close and my mother had found specialists on the flit3 mutation in Seattle. It was a no-brainer, we needed to go.

Seattle is a 10 hour trip from our house, so not staying overnight was never an option, especially when we first moved him there. The doctors Seattle had already been updated to the fullest extent possible, and we started chemo as soon as we could. After what seemed like a lifetime, we got a phone call; Beau had reached remission. I'll never forget that day. We had been cleared to go out and about every once in a while, which was greatly needed considering he spent most of his time in the Cancer Ward. We were out for frozen yogurt one day when we got a

phone call with the good news. None of us knew what was going on because my mother had picked up her phone, listened for a moment, and began to cry uncontrollably. We thought it was bad news and my heart sunk. When she looked up and told us that he was in remission we all just sat there and hugged in silence for a few minutes.

If that had been the end of it, it still would have been the toughest experience of any of our lives. But we weren't even close to done. Beau now how to prepare for a bone marrow transplant. In the coming months, he had no immune system and was a boy in a bubble. He was on numerous medications, taking upwards of 40 pills a day. Each pill stopped or prevented something important, but each had side effects. Another pill with counteract the side effects, bringing more side effects of its own. We were staying in the Ronald McDonald House in Seattle, never knowing when we would find a donor and never knowing if we would be able to just go home. After about a month, we found a donor that was a match and had a successful bone marrow transplant. But he was still immune suppressed, and couldn't defend himself properly. During this period of being immune suppressed, he caught every disease even someone with an immune system wouldn't want. A cut on his foot turned into an Aspergillus fungal infection that threatened his life. He caught pneumonia, TMA (a red blood disease that he nearly lost his life to), mucositis, PRES (pressure on the brain causing amnesia and confusion), and some other various colds and cases of flu. Every single new disease or infection meant more stress and worry and pain for all of us, and less time together, as school was starting soon.

I began my freshman year living with a family friend in town as my parents tried to make ends meet and help Beau. I started feeling neglected and like I didn't exist anymore. I loved and worried about my brother and understood what needed to be done, but I felt forgotten. I began hanging out with the wrong people and making bad decisions because there were no rules anymore. As I look back it's apparent to me now that I was seeking attention or lashing out stupidly, but at the time that wasn't on my mind. Beau wasn't able to go back to school for about a year, and it was all he wanted. I took it for granted at the time but now I realize how lucky I was and am to have many normal things that so many don't have.

As I went into the summer before my sophomore year, Beau had miraculously come back from all of the life-threatening things he had been through. One by one, these impossible boundaries were overcome and his immune system was returning. The issue that came with his recovery was that the many new pills and side effects were too much for his underdeveloped kidneys to handle and they shut down. We had become so numb as a family to medical hardships that at this point it was just another thing to deal with. He began hemodialysis at the hospital as he began new medication and weaned off the things he didn't need. After a while, he was given a catheter and my mother was trained to do peritoneal dialysis on him.

Midway through my sophomore year, it happened. Beau was cleared to go home. He was cleared to be with his friends, be around dogs, and live the closest thing to a normal life as possible. The school threw a huge welcome back party where everyone cheered for him walking

into the building. My family and I wept. We never thought it would happen. The past years had created such an unfathomable hardship on my family, but the worst was over. I cleaned up my act and cut off some people in my life. I began participating in an alcohol and drug abuse awareness group and even became the vice president. I played football and basketball and track, and even was elected as school A.S.B president. Mom went back to teaching, dad went back to work, and Beau went back to just being a kid. We still deal with going to the doctors and the hospital a lot. He still deals with medication and dialysis, until he can get a new kidney. But none of it seems like anything, because we have seen our worst and overcame it, and it has given me a new perspective on life, health, privilege, and family.

Thank you