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MY (INCREDIBLY UNIQUE) CYSTIC FIBROSIS STORY:

I know a story about a girl with cystic fibrosis isn't original. I know this is the part of the scholarship application that allows us to show what sets us apart, how we own cystic fibrosis, and how we carry a positive outlook. I am aware that an essay is on the boring side. It is less creative. It can be dull. However, I encourage you to read this through. I would not own my cystic fibrosis without the people in this story. This story is incredibly unique. It is a tale of two girls, who eventually become roommates, not knowing they both have cystic fibrosis. It is a story of deep friendship, and divine intervention. I hope you're able to look past what can be considered a "boring essay" and give this a chance, because I promise you, it is a beautiful tribute to the strength behind the people with this disease.

Before I get into too much detail, let me start by saying this entire tale is centered on cystic fibrosis. So, in case you are reading this and are unsure of what CF is, let me educate you a bit: CF is a genetic disease that causes lung infections and limits a persons' ability to breathe over time. A defective gene causes thick, sticky mucus, which blocks the airways of the lungs, the pancreas, sinuses, liver, and GI tract. This leads to many bacterial infections, pancreatic insufficiency, respiratory failure, sometimes lung transplants, and eventual premature death. The average life expectancy is 37. Most people are diagnosed at birth. I, however, was not.

This story has two main characters- Tori Tamborino and myself. We met at the University of North Carolina at Greensboro after joining the same sorority, Alpha Chi Omega. We barely knew each other when we were forced to live together. In August of 2014, I stepped foot into a room the size of a walk in closet. There sat Tori sitting cross-legged, unpacking, in a sports bra and shorts. Quickly I noticed two scars across her stomach. "Oh yeah, I guess I should tell you I have cystic fibrosis," she said as if it was a way to start small talk. I didn't know what that really meant, just as I didn't know what Tori would become to me. Throughout that year, I was introduced to nebulizers, vest treatments, coughing attacks in the middle of the night, high calorie diets, and the dozens of medicines taken everyday. I found out that the scars were from a bowel resection and a feeding tube that Tori had at some point in her childhood. That year I was also introduced me to a girl who was brilliant in her kindness, despite her dark, sad story, a girl who was utterly admirable in her strength, and who was unlike anything I can describe. It was during this year that I decided "best friends" is an overused label. Tori wasn't merely a "best friend". She became so much more. She was comfort. She was honesty. She was a voice of patience and understanding and reason. Her brain seemed entwined with mine- viewing the world with the same angry questioning, yet awestruck eyes that I did. No, she wasn't a best friend. I don't think there is a word strong enough to describe what we became to each other. Our stories before we met each other were heartbreaking. Sometimes I think the world knew I needed someone who's sad, hurt, and angry matched mine, but who still saw the beauty, kindness, and love in the world. I don't think I just got lucky in meeting Tori- I think there's more to it than that.

We lived together the following year in an apartment. I slept in her bed more than I did my own. I went with her family to New Orleans. I watched her sister get married in Bald Head Island. Tori shaved my head for St. Baldrick's while together we raised thousands of dollars. I went to Disneyworld with her family, proudly claiming the title "Megan Tamborino". It was during this year that Tori was hospitalized with a lung infection. I remember calling my dad sobbing while sitting the hospital lobby. I remember crying and saying something like, "she actually has it, dad. She has cystic fibrosis." It had never registered until that moment. Sure, I watched her do the medicines and knew she went to clinic appointments, but I had never seen her like that. It's amazing to me that when our loved ones get that sick, it somehow feels like *we're* the ones that are going to die. Isn't it remarkable that those illnesses are so powerful that they have the ability to hurt not only the one with the disease, but so many friends and family members as well?

Let me deviate for a minute and tell you about the Tamborino family. Tori's family consists of mom, Norine, dad, Frank, and 5 kids- Elizabeth (Lizzie,), Julie Ann, Victoria (Tori), Catherine, and Frankie. Of those five kids, four were diagnosed with CF as children (all except Lizzie). I have hinted at Tori's past, but I have yet to figure out just what to say about it. This is not a chapter of the Tamborino's lives that I lived with them. I have only witnessed the pieces after, and I feel as though it would be wrong to try to explain their feelings for them. So here is the story as factual as I know: Julie Ann Tamborino was diagnosed with cystic fibrosis at age 3. In December 2011, she was diagnosed with leukemia. On January 4, 2013, she passed away at age 21. I have heard many stories about Julie Ann. She attended the University of South Carolina while she was able to. She was president of Alpha Chi Omega. She was the typical big sister, a smart girl, and was sad to lose her hair. She was a soccer star. She was beautiful. She was a fighter. I never met Julie. But, my God, do I wish I could have. Again, I will not insert my thoughts on Julie's death. I will not pretend to know or understand what the Tamborino family felt and feels. I will simply say this: never in my life have I seen a family go through so much, yet still find so much love in the world and in each other.

Now flash forward a bit. Tori and I both graduated college in December of 2016. I was planning on going to South Korea to teach English as a way to adventure and to save up some money before applying to physician assistant schools. Tori was staying in North Carolina, finding a job. I went back to St. Louis, my hometown, for the weeks before South Korea because I knew I needed sinus surgery. I was deaf in my left ear from many ear infections, I had polyps, underdeveloped sinuses, and to figured I should get things fixed before moving abroad. My ENT took a full history- from the day I was born until that very second sitting there talking to him. That history consisted of hospitalizations for pneumonia, many ear infections, sinus infections, bronchitis, being underweight as a child, passing out multiple times at track practice, going into pulmonary arrest after getting my gallbladder out at age 21, multiple GI problems, and many other issues I dealt with while growing up. He looked me dead in the face and said "I don't think anyone is this unlucky to have had so many random health issues in their life. I think there's a bigger issue. Give me some time to figure it out. Let's start with the biggest thing this could be and work our way down." Two days later I got a sweat test. One day after that, I was diagnosed

with cystic fibrosis. Tori cried and left work early the day I told her. I think she was sad that I would now enter her world a bit and have to feel some of the pain she feels on a daily basis.

I'm sure if you somehow were able to calculate the odds of two girls living together in a school in North Carolina, while they both (unknowingly at the time) have CF, you would find that it is something like a one in a million situation, maybe even less. Eighty percent of CF people are diagnosed before age 2. Now, CF screening is apart of newborn testing. But I was diagnosed at age 23. I was almost relieved to be diagnosed. Everything in my life made a little more sense. I passed out at track practice because I wasn't replenishing the salt I lost. I was underweight and small because my body couldn't absorb vitamins and nutrients like a normal person. My colds turned into pneumonia or bronchitis because my lungs couldn't rid themselves of the mucus trapped there. I was never afraid. I knew everything I needed to know. I immediately started on pulmozyme and hypertonic saline. I knew how to set up nebulizers. I knew how often to do vest treatments. I knew everything that CF was because of Tori. I wasn't afraid. I wasn't mad. I was okay. I was okay because of Tori. I often wonder how to thank her for that? How do you thank a person for preparing you so fully for the hardest thing life will hand you? I'm still unsure.

In the last year, I have been hospitalized 9 times for lung infections, surgeries, kidney infections, bowel obstructions, and kidney failure. Tori has had multiple PICC lines (a type of permanent IV) for IV antibiotics. I am currently on 31 medications. Tori is on "twenty something". In the cystic fibrosis community, they say were supposed to remain 6 feet away from each other at all times. They say we grow bacteria in our lungs and that by being so close to other people with CF, we are at risk of sharing our bacteria and getting each other sick. Tori and I say who cares? I would rather live in a world where Tori and I laugh too hard and talk too much and wonder about the crazy universe that merged our stories together, than live a dull life far from her.

I don't know if you've stuck around to read this all, but if you have, I hope you can maybe glimpse what this story is. It is a story centered on a kind of bond that has yet to be labeled, but is felt by so many. It's a story about two girls, who had no idea how that small dorm would change them. It is a story about the unknown and the unquestionable, the dark and the light, and the illness and the silver lining. I don't know what we want out of this story being told: awareness maybe, of CF and cancer? Or maybe we just want other's to wonder with us about whatever force or God or universe brought us together? Or perhaps, we just want our story out there- so anyone else who has a friend that's more than a "best friend" can smile and laugh, or people who have lost someone can remember for a second that there's still goodness out there? I don't know, I just know I was compelled to tell you a little about our magic. And I hope that whoever is reading this enjoyed getting to know my CF story and me. Maybe it isn't what was expected of this segment of the application, but it's how I own my CF and it's how I embrace my life.