

“I may be changed by what happens to me, but I refuse to be reduced by it”

“You will die in 16 years.” This foretelling is not what most fourteen-year-old freshmen hear on their fourth day of biology class; but this is the statement that pounded through my head as I, a cystic fibrosis patient since birth, sat overwhelmed in my biology class seat holding back the tears that were just seconds away from rolling down my cheeks. Some might wonder how this statement was at all shocking to me. They ponder, “Is she really that naïve to not understand how unfortunate people with cystic fibrosis- people like herself, are?” The answer is no. I am not that naïve. Nor was I sheltered from the truths of cystic fibrosis while growing up. I was awed by this statement because I know a different truth, a different meaning to the disease cystic fibrosis, or as those who are familiar with it call “CF.”

Cystic fibrosis has always been just something that I know that I have: something in me that makes me have to take enzymes when I eat, that makes the word mucus a part of my regular vocabulary, that makes it necessary for me to put on a vibrating vest, that makes me receive extra fattening cheese on my nachos at lunch, and that makes me drive hours to visit doctors in hospitals. I am as used to living with CF as I am used to being an only child, used to having blonde hair, and used to moving up and down the east coast each time that my father receives a promotion. Having cystic fibrosis does not give me the sense of unease that I see creep up on others’ pitying faces when I tell them that I have the disease. Because I have never known my life to be any different; it is just something that I deal with day by day and something that has shaped every part of my being.

In all honesty, I am proud of my being. I am proud that I was stunned when I heard that there are high death statistics for people with CF. Because I was stunned, it made me realize that I have not submitted to my disease. Cystic fibrosis may have control over the weaknesses in my physicality, but it will certainly never engender any weaknesses in my spirit. Instead, my CF has characterized me as responsible and smart- I am indisputably the only person that I know who was handling her own medications at age six. I have also learned some of the most universal and seemingly overrated adages to be quite true because of my disease. I am certain that life is not fair but I also understand that everything happens for a reason. There are times when I cry, when I want to listen to my nebulizer break into one thousand pieces after I chuck it out of my window, and when I want to curl into a ball under my protective covers because of an imperfect doctor’s appointment. The next day however, I wake up, and move on because wasting time dwelling on something that I cannot change only takes away from the time that I have to prove that CF is tolerable to live with.

My definition of cystic fibrosis and the meaning that others should discern is this: to have CF means to live a life that values time, means to appreciate parents who provide a backbone of everlasting love and support, means to have compassion, means to overcome adversity, and means to have faith in a miracle that will bring a cure. Surely, cystic fibrosis will not hinder my resolve to succeed.