

Defying Inheritance, Gaining Power

Power flows from inheritance. Some inherit wealth; some high social position; some even desirable traits, such as blonde hair or the ability to run long distances. It is like being dealt a good starting hand in a game of cards. Most people only consider the positive, but just as in any game, hands can be bad as well as good. Take me for example. Most people inherit a fully functional body, but I inherited one gene that was damaged. The result is the condition called Diamond Blackfan Anemia, better known by its acronym, DBA. It is a congenital bone marrow disease, with the most prominent symptom being a low red blood cell count. I was dealt a bad starting hand. It seems I was destined to have diminished power, but I would not let fate have the final say.

Power comes from not surrendering to the inevitable. At birth, my flawed inheritance did not even provide me with the power to survive. The defective gene left me unable to breathe and eat properly. I was young and oblivious then, but, reflecting on the experience now, I understand this was my first lesson on power. My parents and doctors battled against nature for my life: they battled in the operating room, they battled in the rehabilitation center, they battled for my every breath and bite. I had a cleft palate, they repaired it; I had a compromised airway, they put in a tracheostomy tube; I couldn't eat enough to thrive, they put in a gastrostomy tube. They used every trick up their sleeves to defy what I inherited, to keep me alive. They succeeded. This is power.

Power comes from breaking free to explore the world, make friendships far and wide. People with diseases and disabilities often expect to be confined at home. They feel it is not within their power to go out and explore the world. However, this is not what my life is like. From a very young age, I was not confined to my home. At the risk of getting sick, I attended a daycare. I got to meet kids from many different backgrounds. On weekends and holidays, I

would visit zoos, farms, and aquariums. My horizons never felt limited. Camp Sunshine, a camp for sick people which I attend biannually, allowed me to meet people who inherited the same disease as mine. They come from different walks of life. They come from the United States and different parts of the world. At this camp, I realized that I am not alone in my struggle. Some endure even more severe symptoms than I do. Should my disease worsen, I know that there are others I can talk to. My horizons extended further when I was able to travel outside the country by myself. Two summers ago, I visited the Galapagos Islands. There I sealed a friendship with a kid living on the mainland of Ecuador. I saw rare animals found nowhere else in the world. Had I stayed in Lexington all my life, I would not have been able to meet these wonderful people. I would only be able to see wild animals in pictures or movies, but not in real life. My condition did not get in the way of my friendships and endeavors, and certainly won't get in the way of future journeys. I experienced life to the fullest. This is power.

Power comes from the ability to make choices. People with diseases feel that they have no choices as their treatment options are often limited. Sometimes the treatment itself limits their actions. However, I am more fortunate than most. To treat my disease, I could take prednisone every other day, a type of steroid to increase red blood cell production, or have blood transfusions every three weeks, which directly replenishes my blood, or undergo a bone marrow transplant. I chose the most convenient option, prednisone, even though it can lead to side-effects, such as stunted growth and brittle bones. I am also lucky that the anemia did not dictate what interests I pursue. One of my passions is music. My first instrument is the piano. My small hands, a result of stunted growth, and my crooked right thumb, a result of my disease, should have compelled me to give up the instrument. Playing the grandest pieces typically requires big hands with long fingers that can stretch far. However, I persevered. I adapted the pieces to accommodate my shortcoming. Now, I can play at parties. I can accompany my friends

when they sing. I have entertained friends and family. I was and still am often praised for my musicality. In fact, I became so invested in learning music that I tried to play other instruments. Despite having a compromised airway and a lack of stamina as a result of my inherited disease, I chose the flute, a wind instrument that takes a tremendous amount of breath and effort to play. It was a wonder that I managed to sustain even a single good-sounding note. Again I persevered. I played in the band. I played in the orchestra. Friends have come up to me after performances and complimented me on my playing. Through all this, my appreciation for and knowledge of music have grown. Against all odds, I ended up becoming a musician. Another interest of mine is karate. Brittle bones should have prevented me from pursuing karate, but, just as before, I did not let this get in the way. I literally found power as I punched and kicked bags. I never thought that I would attain the rank of black belt, but I did, two years ago. Karate also taught me confidence and respect. As a black belt, I now assist in teaching younger kids, imparting my knowledge, improving their skills. My disease seems to have destined me to never be proficient in my hobbies. Yet I have become a pianist, a flutist, and a martial artist. I have defied the constraints of my inheritance by my choices. I have learned and achieved. This is power.

Diamond Blackfan Anemia has shaped my physical abilities and appearance. But, just like James Richard Collins in Yaa Gyasi's *Homegoing* who defied his inheritance by leaving his old life in pursuit of one that would make him happy, I will not let my inheritance define my life. Power comes from stopping at nothing. Power comes from taking advantage of opportunities. In turn, these opportunities allow for friendships to be built. I have made my own choices and pursued my own interests. My friends and mentors from far and wide throughout the world have given me strength to soldier on. There are many hurdles that I have to jump over, but despite this, I have managed to persevere; DBA will not undermine my potential. A quote sits on the ledge of a small shelf in my house. It reads "Life is not about waiting for the storm to pass.

It's about learning to dance in the rain." I cannot control the storm, but I will not wait for it to pass. I choose to dance in the rain. That is power.

New Quote:

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