

## **Company in the Trenches Fighting a Chronic Disease**

My life has been far from average: a constant struggle from birth, a constant struggle today. When I exited the womb, I had a host of problems. I had a cleft palate. I couldn't eat. I couldn't breathe. The doctors fitted me with eating and breathing tubes, and later repaired my cleft---all meticulous operations, successful jobs with an impressive outcome. My speech and appetite never betray my original deformity.

Then the news came. The diagnosis was a rare disease called Diamond Blackfan Anemia. DBA became three dreaded letters. It is a dire medical condition. My bone marrow cannot naturally produce a sufficient supply of red blood cells. The condition is also responsible for my earlier medical troubles. My parents knew then that my life going forward would be far from normal.

Because of my disease, I would never be able to achieve "academic excellence."

Because of my disease, I was discouraged from picking up contact sports, the kind that could break my already fragile bones.

Because of my disease, I would never be truly healthy.

Nevertheless, I had as many privileges as disadvantages. Sitting in the spacious bedroom in my suburban mansion, I can't help but think about how lucky I am to not worry about fighting the insurance companies for medical expenses. Most DBA patients could only dream of living in a town so close to one of the top medical research institutions for this disease. My family is well off. Myriad of toys line the bookshelves in my room. Many more are packed away inside boxes. I traveled to countries in five of the seven continents and plan on taking many more adventures.

Additionally, school never seemed like a nightmare. My parents never had to fight for special services in elementary school. My classmates never teased me for my shortcomings. I have many friends who are great role models. They are willing to push themselves. They have some of the highest scores on standardized testing. They win competition after competition. The academic curriculum is more advanced than typical American schools. Despite my circumstances, my life is charmed. I did not come to this realization until I started meeting others with the same disease.

There is this seemingly typical but actually unique camp called Camp Sunshine. This is a camp for families whose kids have various medical conditions. DBA families meet biannually there. This was where I met one of my best friends, which marked the beginning of my DBA network. From then on, I knew I was not alone in the fight.

I was sitting on my own in the computer room of Camp Sunshine. Rows of computer screens lined the table. On one wall of the room was a mural with a cartoon of moose and bear. This is no different outwardly than any other camp. I was scrolling through the top hamster videos on Youtube, trying to find that one video that would spark laughter in even the most solemn of people. Humor has always been a distraction for the ill effects of my disease. Then I found it. The perfect video. Thirty seconds of a hamster running on a wheel with a high pitched voiceover.

I suddenly felt someone approaching from behind.

“Hey, could I sit next to you?”

I turned my head to find that it was a girl with pale skin, a dead giveaway that she had DBA just like me. I recall seeing some bruises on her arms; now I know that those were telltale signs of the numerous blood transfusions she had already received. I smiled at her and patted the

chair next to mine. I then offered to show her the video, which she happily obliged. After thirty seconds, we were hooked. For the first time in my life, I felt truly connected to someone. I'm sure she felt the same way. For what seemed like an eternity, we clicked the replay button over and over, hooting in laughter, rolling over in the chairs like two regular kids. At that moment, nothing else existed. Not even DBA. Only the two of us, that computer, and that video.

I later found out that her name was Grace and she came from Newfoundland.

It was not until then that I realized there were people that could relate to me. Someone who understands the enervation from a low blood count. Someone who can commiserate about the ill effects of the treatments. From that moment forth, Grace and I were inseparable, if only in spirit sometimes.

That was over ten years ago.

As quickly as I grew, so did the DBA community, and with it my network. Late last year, I met teens and adults like myself through a DBA adult meeting. For most of them, it was their first time meeting someone else with DBA. This is not the case for me but I gained something else. I realized that there are others like me who have managed to lead long productive lives. Most of the attendees have held down decent jobs, with some of them even working for the very medical establishments that helped them in the first place. What I was most astonished by was the kind gentleman who managed to live to 70. He was born when the discovery of DBA was still recent, yet he survived even without an official diagnosis. In him, I see the opportunity of longevity in myself.

After the meeting I discovered the social media groups for the DBA community. I am now able to connect to other families whom I would never have known otherwise. My

connections with the DBA community have expanded far beyond the friends I have made at Camp Sunshine.

In meeting other patients, I also came to discover that disabled people are not devoid of talent. Grace, for example, is an outstanding singer and Irish dancer.. Her anemia should have prevented her from reaching the highest of notes, to sustain even the simplest of melodies. But she attained a proficiency in singing that would arguably rival some of the most talented soloists at LHS. Her dancing abilities are no small feat either. Despite her supposed lack of stamina, she can twirl and jump for what seemed like hours. Like Grace, I too try to defy DBA in developing my talents. My piano playing is a good example. A lack of red blood cells has made me me short in stature and small in size. My palm may not be big enough to span the largest music intervals, but my fingers can still create a wide range of intricate sounds on the keys. I can accompany others. I can improvise. Despite my condition, I too have become a musician. Furthermore, I not only use my fingers and hands on the ivory keys but on punching bags as well. I initially picked up karate to maintain the health of my bones. At first, I did not nurture any ambition beyond the fitness aspect. However, with time, I overcame the difficulties of the art. Every martial artist's dream is the black belt. With my condition, the dream seemed out of reach. Nevertheless, every class I landed my punches a little harder, kicked with a little more precision. Now I walk into the dojo with the black belt proudly across my waist. In karate too, I have overcome what everyone thought was the impossible.

Networking is important. Through networking, I hope to become a role model to other DBA patients, particularly the younger ones. I hope they will see that they are not alone in this fight. I hope that they too will see their potential and develop their own unique talents. I want to

contribute more to the DBA community. I am already attempting to establish a group chat for teens with DBA and their siblings to communicate safely and privately. I plan to meet with many more people all over the world to let them know what I know and to let them know that they are not alone.

Diamond Blackfan Anemia has molded most aspects of my life. My current treatment of steroids gives me a slightly deformed appearance. My anemia gives me constant headaches. I tire much more easily than my friends at school. However, it has also spurred me to build the social network that I have today. I now have many a person to consult in times of possible hardships. I do not need to wonder from whom I can seek advice regarding treatment.

I plan to continue this fight ... with others. I am not alone.

<b>CREATIVE NON FICTION RUBRIC</b>	Is thoroughly compelling	Is apt and interesting	Is usually apt but may misstep	Is unclear or disjointed
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<b>Central message</b> Ideas are developed & analyzed with sophistication & creative risk-taking.				
<b>Structure</b> Development is logical and fluid. Shows significant thought regarding structure and division.				
<b>Conclusion</b> Conclusion connects memorably to the central idea and provides a strong reflective sense of closure.				
<b>Voice</b> Figurative language & literary conventions are used creatively Compelling tone and other strategies enriches the purpose				
<b>Syntax</b> Varied structure shapes the narration.				
<b>Features of the sub-genre <i>*See above*</i></b>  Choice of content: Vivid, compelling details enrich the narrative; balance of fact, anecdote, & personal stories  Use of persuasion and bias  Use of rhetorical styles				
Conventions	Nearly flawless	Mostly fine	Lack precision	
Score: _____ / 80				

Hello all,

Once again, I have a few announcements:

1. A couple of weeks ago, I wrote an essay on how the DBA family has affected my life. Here it is:

Let me know if you can't view it.

2. In the interest of our diverse community, I would like to announce that Chinese New Year is next week. Message me if you're interested in authentic Chinese recipes to get into the spirit 😊. (Some of the ingredients may require going to a Chinese/Asian supermarket. )

3. The Instagram account @beatdba is looking for some love. Again please message me if you're interested in having your or your kids' stories featured. Anyone with teens can even have them write their own captions!

4. If your son or daughter is interested in joining the DBA teens group chat, please message me for the WhatsApp link.

That's all for now,

Pascal