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Cerebral Palsy essay

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### **You Are More Than They Tell You**

When a child is born, the first thing a parent does is count fingers and toes. If they're all accounted for, the baby is considered "healthy." A while after my arrival home, the Antcliff (my mom's family's name) lore says my aunt Alice knew something was amiss. Why didn't I use my right hand to reach for things or use both legs to crawl? At the time, Alice was a support person for a woman who had left hemiplegia cerebral palsy, so I guess she had a point. My mom, however, was devastated by this implication.

My mom whisked me into her bedroom, and repeatedly tried to make me reach for a comb with my right hand. Not happening. Cue the tears and trip to my doctor's office. Low expectations were soon pronounced: never going to walk, talk, have a job, be a useful member of society, etcetera, etcetera. My knight in shining armor, my Grandpa Keith, balked at the doctor's words. He proceeded to teach me to walk up and down stairs, paid for endless amounts of physical, occupational, and speech therapy, continuously asked me questions, and proclaimed me "pretty smart" when I gave him the correct answers. An amateur pilot, he flew to the airplane hangar in the sky about a year ago. And I'm just now realizing how much he truly impacted my life, but that is a story for another day.

Growing up, I excelled at school, and took crap from no one. I stormed out of the resource room as they tried to make me trace around my hand; anyone who called me the R-word got a seat-full of dirt as I pushed them into the ground. There were occasional teachers

who doubted that I did my own work or that I was competent to understand the world around me. However, I eventually won over teachers and other adults with my unmistakable charisma and resilience. I even got a piggy-back ride from the playground into my grandma's waiting car when my knees swelled to the size of soccer balls, and I couldn't walk. I was diagnosed with rheumatoid arthritis when I was four years old. I would go on to spend a good deal of my childhood in the hospital, afflicted with attacks to my spinal cord, heart, spleen, joints, and blood platelets. As my friend eloquently put it, "right-hemiplegia cerebral palsy and rheumatoid arthritis are not remotely connected to each other, you just drew a sh\*tty hand." That may be true, but something in me continues to fight for a good life for myself and others.

I have learned that people who have cerebral palsy are a driven, unique group of people. We are determined to fight for what we need to thrive in our lives, and we're not afraid to talk about rights and equality. There seems to be a stigma out there that physical impairments signal mental impairments. I (and several) of my friends are here to say that is untrue. We have the same desires, feelings, interests, views, and vices as any typical person. For example, one of my friends met a woman at the bar (not me) who just happened to walk with a limp and have cerebral palsy. She made a pass at him, but he turned her down afraid that she didn't understand what she was doing, and she wasn't "all there." Later, he went online, and discovered that people with cerebral palsy are very intelligent, and that it was wrong of him to make presumptions about her without knowing her. I could have told him that, but sometimes people need to find out these things for themselves. My coworker and her husband have cerebral palsy, and her husband uses a wheelchair. They are avid advocates for disability rights and give many presentations to abled-body people about what it is like to have a disability, and how to be respectful to all people. I have another friend in Boise, Idaho who continuously talks about mindfulness and

making every moment count. Yes, people who have cerebral palsy have a harder road than most. We have learned to galvanize our struggles with courage, and strength, and humor. Likewise, my humor, intelligence, and education have made me a potent advocate for myself, and other people who are affected by cerebral palsy.

I never considered advocacy and disability rights as a passion or career. That changed in 2016 when I was hired at the Center on Disabilities and Human Development (CDHD), a branch of the University of Idaho. I work on the Idaho Living Well project, a grant funded about three years ago by the Administration for Community Living (ACL). My role is to do research on topics such as self-advocacy, disability rights, and preventing abuse and neglect. Recently, I was also given the task of providing content for a self-advocacy website for the CDHD. I'm forming a committee of self-advocates to inform my work. Also, through professional development at the CDHD, I have had the opportunity to engage with adult peers and people with disabilities in a myriad of other programs that promote and teach advocacy. I am using my own life experiences to teach others how to stand up for themselves and control their own destinies.

No one has the right to take someone's future. I could have easily given up and not fought for my rightful place in the world. But that is not who I am. I am adventurous and daring in my life, taking risks that others think are risky. I am me not despite my cerebral palsy, but because of it. CP is just one facet of my life. I am a crystal in the sun, always turning to find new and better perspectives. I hope I can teach one person that no matter what someone else says, they are more, and deserve to be in the world doing great things.

Thank you.

JEM

