

A World Of My Own

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You think that after living in Cajun Country for twenty-five years, I would be used to this cursed heat. But then again, that's the beauty of Louisiana- she's only hospitable to those who are willing to sweat it out. I squint and try to make out the location of Rob, who thought the hottest day of the year would be the perfect occasion for a concert. It's just a local band called The Cajun Chaps, but they're mighty fun to watch with their bedazzled vests and shaky dance moves. When I'm sixty, I'd love to join them on stage. But then again, I picked up a guitar once and my hearing friend said I shouldn't quit my day job.

After five minutes, my interpreter Judy points me in the direction of Rob and he excitedly pulls me in for a bear hug. Every time I see him, he reminds me why I hired him at the restaurant in the first place. I mean for God's sake, the man is just as excited about a new shipment of sauerkraut as he is for a meteor shower. He signs to me that I came just in time because The Chaps are about to go on stage. I laugh to myself at his restrained and unnatural looking signs. I told him last week that my tunnel vision was getting worse so I couldn't make out all of his bold gestures. I'm glad that he remembered because piecing together his sentences from a bunch of flourished hand movements was getting a tad bit difficult.

I wipe off the sweat that keeps forming on my brow as I watch the wrinkled men dance around with their Fender Stratocasters. Suddenly, I feel a tiny tap on my shoulder and I turn around to see its source. Standing behind me is a young girl with an oversized ice cream cone. She extends a sticky hand in my direction and I make out the words, "Hello sir, my name is Heidi!" I smile and sign to Judy, "It's nice to meet you, Heidi. My name is Danny." For a moment, I am taken aback by her striking features. She has a slightly upturned nose, a wide mouth that is filled with haphazardly placed teeth, and blue eyes that seem to be accented with white lace.

She plops herself down beside me and stares at my face, as if waiting for me to say something profound.

"I'm deaf, but you can talk to my friend Judy and she will sign it back to me," I say. A smile spreads across her face and she hurriedly crawls over to where Judy is sitting in the grass.

"It's okay if you're deaf. I'm different, too! I have Williams syndrome. You've probably never heard of it, but it's when a piece of your seventh chromosome gets lost. I have heart problems sometimes but it's not all bad..." she exclaims. I can see Judy struggling to keep up with her rapid pace.

Even more striking than her features is her ability to express herself. I sure didn't know what a chromosome was when I was her age!

"Well you don't seem any different to me," I sign back.

She pauses for a moment, as if she is carefully crafting sentences within her mind before she forms them with her mouth. "If you don't mind me asking, Mr. Danny, how do you listen to music if you can't hear it?" she says with inquisitive eyes.

"Well, if we get closer to the band I can show you!"

"Hold on one second! I need to put in my earplugs. I have a very acute sense of hearing, you know," she informs me.

As we walk towards the stage, she grabs my hand and our pace quickens until we're jogging straight towards The Chaps. I lead Heidi to the speaker system and I motion for her to place her hand on the fabric of the battered amp.

"Do you feel the beat of the bass? All you need to do is count the beats and move!" I instruct her.

At first she struggled to count the irregular beats, but within no time she was fluttering through the crowd, pounding rhythms on her chest. She grabbed the hands of a woman in a flowing paisley dress and attempted to spin her in circles, but before she knew what was happening, Heidi was already twirling towards her next partner. Eventually she spotted someone who must have been her mother, as she quickly ran over to me and shook my hand.

"It was very nice meeting you, Mr. Danny. I wish you the best of luck in your endeavors!"

Before I had the chance to reply, she had already disappeared into the crowd. I shook my head and smiled to myself as I made my way back to Rob. Throughout the remainder of the concert, I couldn't get my encounter with Heidi out of my mind. How could such a young girl be so cognizant of her condition? She appeared to be absolutely carefree; she was so consumed by the joys and poetry of life that she didn't have time to feel disparaged. I envied her eloquence and her ability to treat everyone she interacted with as long lost friends. If only all of humanity acted as she did.

For the past year, I have been mulling over the prospect of losing my sight completely. The unfortunate reality of Usher syndrome is that I was born without one sense and I will eventually lose another that I value greatly. I am afflicted with this syndrome because I was arbitrarily born to parents who happened to live in an area with a history of incest. I have never known sound; I am perfectly content with a silent existence. But to live in darkness...it's difficult to conceive.

Meeting Heidi has changed me. If a girl with such a rare disorder can disregard her setbacks and wholeheartedly embrace her talents, why can't I do the same? Heidi, in her world of beautiful rhetoric, music, and genuine smiles, does not feel as though she has been slighted by nature. I live in my own world of tactile sensations, vibrations, and succulent smells and I am fortunate. I truly am fortunate.

Writing Process:

Before writing, I selected two characters from the series we watched in class and composed a list of the distinct characteristics of each individual. I then created an additional list that included key symptoms of Usher and Williams syndrome (from the movies and online sources). I selected Danny to narrate the monologue, as I found his perspective to be very uplifting and refreshing. I then created a scenario in my mind that would convey the aforementioned characteristics and symptoms well. In order to allow conversation between the two characters, I included Danny's interpreter and I attempted to convey Heidi's advanced linguistic skills through her formality and diction. The aim of my paper was to convey Heidi's contagious passion for life and Danny's spectacular ability to cope with a life largely deprived of sensory information. I wanted to convey that life does not stop because of a particular 'illness.' You must either perceive yourself as a victim or embrace what you uniquely possess.

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