The Quest of a Lifetime

Category: Stories
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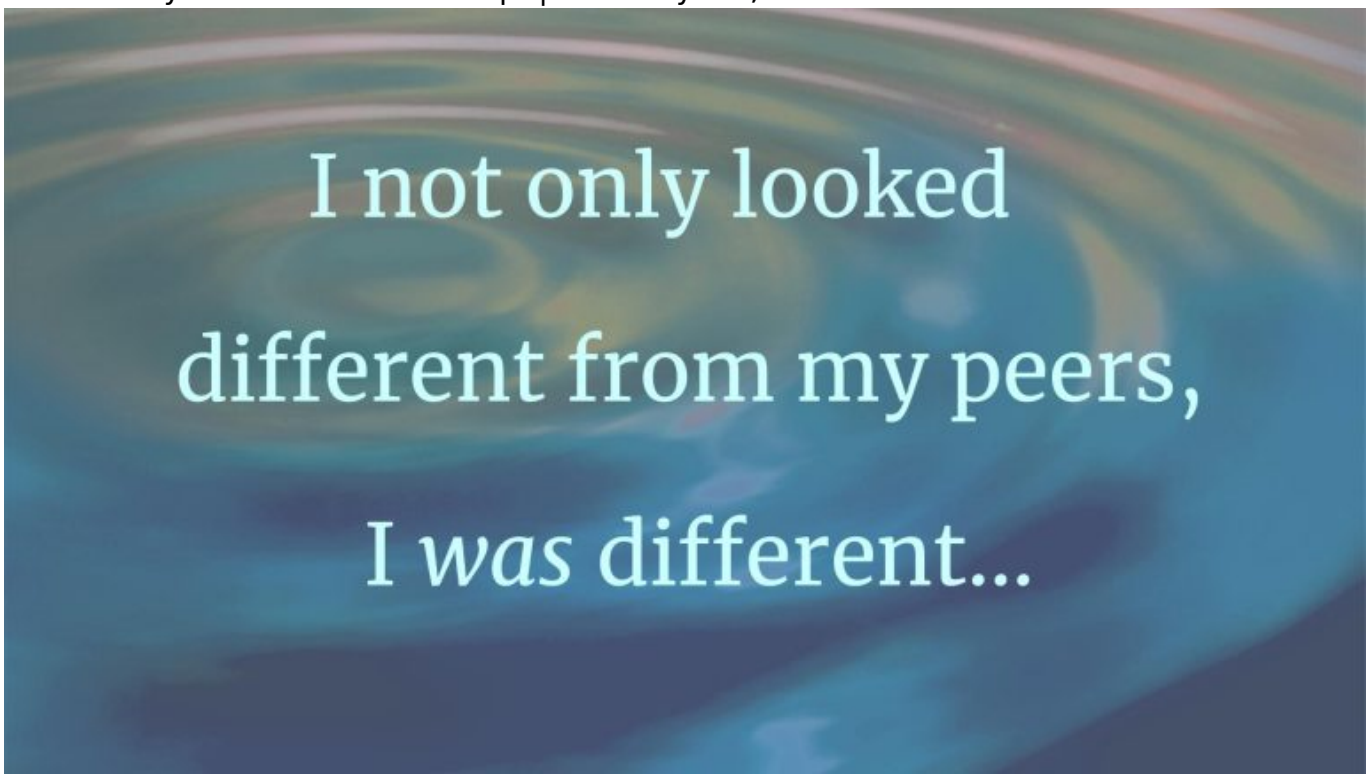

Editor's Note: This piece was awarded an honorable mention in the Pulse *writing contest, "On Being Different."*

From a young age, we're encouraged to stand out—to be who we truly are and to be proud of that person. We strive to understand both our strengths and our weaknesses. In doing so, we're driven to move forward, knowing we're doing our best. But sometimes we get stuck in a rut and can't find our way. That's where my story begins.

In the mid-Seventies, at age sixteen or seventeen, I was diagnosed with a genetic disorder called Klinefelter syndrome. There were no computers or internet, which meant no easy access to medical knowledge. Living in rural Northern Michigan complicated matters further. Our small town had no medical specialists, and medical journals at the library became my sole source of information.

Unfortunately, the books and articles presented worst-case scenarios—complete with photos and illustrations. The medical terminology alone made for confusion. This was the basic description: "Someone born male has an X and a Y chromosome. A female has two X chromosomes. However, 1/500 males are born with this classic, mosaic, Klinefelter combination of XXY."

That was me.

The literature described these patients as social misfits prone to erratic, delinquent behavior, criminal activities and a multitude of medical issues. I

wondered if someday I'd become that kind of person.

I not only looked different from my peers, with a lack of body and facial hair; both emotionally and genetically, I *was* different. I *felt* different. In all honesty, I felt like I was a mistake.

It was very confusing, being born male yet with that extra X chromosome. I often wondered, *Can a person even* be *part male and part female?*

Going through puberty is difficult at best—but when something is genetically wrong with you, it's much worse. The path ahead seemed even more dismal. The urologist who'd diagnosed my condition had been matter-of-fact: I was told that I was sterile, and that my testes would never develop normally, meaning that I'd need testosterone replacement for the rest of my life.

In high school, I was always the odd one out—quiet and extremely shy. I never fit in. I had no sexual interest in either boys or girls. It's strange, thinking about this now, but I had no idea why I wasn't like anyone else I knew.

And I didn't have anyone, really, to confide in, as my "secret" was too scary to discuss. Of course, I talked about it with my parents, but without medical resources or knowledge, there were no answers in sight. With no support groups or ways to meet others like me, I felt utterly isolated and alone.

Initially I was prescribed an oral testosterone, with minimal result. From there, the only option was weekly intramuscular injections. I injected myself in the thigh, switching sides from week to week. The pain of the large-bore needle was brutal, and it left scar tissue: When I attempted to plunge it into my leg, it bounced right back at me and had to be replaced. Immediately after the shot, I felt a huge surge of energy, followed by extreme lows. My moods soared or dipped in sync with this; psychologically, I felt as if I were bipolar. Toward the week's end, I felt a deep depression and fatigue. This cycle repeated, week after week, for upwards of ten years.

Over time, some improvements took place. I met with endocrinology specialists and eventually found a few other Klinefelter patients in Facebook support groups and the like. I shared my diagnosis with very few others, and most of them—even the medical professionals—had never heard of Klinefelter.

As times changed, so did testosterone-replacement methods. The next one was a patch that literally burned my flesh to deposit the drug, leaving my arms and torso covered in welts. After that came a patch that, after being heated with a hairdryer, adhered to my shaved scrotum. Though less painful, and providing a more balanced dose of testosterone, it was still very uncomfortable. Thankfully, in the year 2000 the pharmaceutical firms developed a testosterone gel that stabilized my highs and lows and saved my sanity. At long last, a testosterone drug worked as intended.

But that improvement applied only to the medical side of my experience. The

mental and emotional roller-coaster raced onward. I now had sexual feelings—but for whom? I wasn't exactly sure. Dating brought a mix of bewilderment and alarm as I tried to figure out who or what I desired as a person.

Did I still feel different? Absolutely. I struggled with self-confidence and worried about my appearance. I felt ashamed. I felt cheated. I was afraid of what others thought of me. I felt like a freak of nature.

Amid all this inner turmoil, writing became my passion. I would write about anything and everything. I did a tremendous amount of journaling and soul-searching. I wrote down my thoughts and feelings of loneliness and discouragement. I tried to find humor in everyday circumstances, although that wasn't easy. I began writing poetry as an avenue of creative expression. Mostly I wrote about the darkness I had felt—and was still feeling. I felt trapped and confused. Relationships were difficult at best, and the right fit was elusive.

In the summer of 1989, I took an entry-level job as a unit secretary/unit aide in the medical critical-care unit at Butterworth Hospital. I planned to pursue a nursing degree; I'd graduated college eight years earlier with a bachelor's degree in communication, but hadn't found full-time work in that field. Going into nursing seemed the right thing to do.

The pay at my new job was decent, and the hospital reimbursed my college tuition. My grades were average, but I figured that things would change.

They didn't. Exams seemed impossible, as there was always a right answer and a *better* right answer. After a while, I decided nursing was not for me.

My job as a secretary, however, gave me the opportunity to continue with my writing, which I loved. Eventually I learned that my healthcare coworkers also enjoyed my writing. They would give me topics, ranging from humor to major life events, and I would write poems specifically for them.

Then, in 2019, at age sixty, I found true happiness. I met my future spouse online, and we pursued a long-distance relationship for three years. Six years after that, we were married. It was meant to be.

It took me a lifetime to learn the lesson that was right in front of me the entire time: Yes, I was born different. And yes, I may even look and feel different. But those differences do not define me. At long last, I'm able to celebrate my differentness with someone else.

My writing creativity at work gives my fellow healthcare professionals something to laugh about when days are bleak or sad. (Past favorites include the poems "Brown Visions" and "Poo… that's who.") Using humor in my writing, I've found a passion that not only gives me joy but can be shared with so many others.

It's a journey for each of us to find our way forward. If I can do it, anyone can.