Life With Nation

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Originally written for a Creative Writing Class at DePauw University, Greencastle, IN
December 7, 2000

Driving home this past Thanksgiving break from DePauw meant seeing my family again, for the first time since September. While I enjoy my freedom from my parents, I knew it would be good to see them and my brother and relax for a week. As I pulled into the parking space, I saw the distinct outline of Nathan's form in his bedroom window, arm raised in his typical half-wave, half-salute. I got out of the car and started pulling my bags and suitcase out, my father appeared at the door to help, and mom greeted me warmly once inside. Nate, however, stayed in his room for a good ten minutes. Only after I had my coat off and was settling on the couch did the door of his room open three inches.

"Hey, sis," I finally heard. I got up from the couch and walked over to his door, which he opened wider so I could give him a hug.

"Hey Nate, how you doing?" I asked.

He flashed me a quick smile and looked back at the stereo claiming most of his attention. "Fine, fine," he muttered quickly. He pushed his smudgy glasses further up his nose with a damp finger and admitted, "Good to see you."

I smiled. "Thanks. You going to come out?"

"Nahhh. Listening to this CD."

"All right," I said, and closed the door as he readjusted the headphones lying askew across his head. Another typical exchange with my brother.

From a very early age, I knew my only sibling was not quite like the other kids. He is nearly three years my elder, but by the time I reached age three, I had passed him in terms of development. While I read voraciously and picked up on learning concepts very quickly, Nathan struggled to learn the alphabet. My parents told me he was learning disabled, and I accepted that explanation for years, using it to explain to my friends why my "strange" sibling liked to mimic commercials and make noises like glass breaking.

Through elementary school in eastern PA, he was often labeled "retarded." I, however, was told by my parents quite frequently not to use that word, they more sensitive than I to being not only PC but compassionate to the developmentally disabled and handicapped.

Indeed, Nathan had been labeled many things over the years by doctors – Mildly Mentally Handicapped (MiMH), possibly brain damaged, and the ever-popular catchphrase Persuasive Developmental Disorder (PDD). Later, he was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). I didn't really know or care about the full implications of any of those labels, that alphabet soup – I just knew my brother was, in my eyes, weird. He made noises and did things with his hands, made shapes and letters. He would repeat commercials endlessly. When he was frustrated, he bit his hand or sometimes threw his glasses. And he broke nearly every tape recorder he ever owned, because he pushed the buttons too hard playing the same tapes repeatedly.

As any sibling of a disabled child can probably attest to, there are stages you go through in the acceptance of your brother or sister. In my case, when I was in preschool

and early elementary school, Nate was my buddy and we played laughing, shrieking games together. By late elementary school, he had become more of an embarrassment, and I tried to avoid him. I probably called him a "retard" a few times myself.

When I was nine years old, Nathan 12, a breakthrough: finally, a diagnosis for my brother. Fragile X Syndrome, it turns out, is the most common inherited genetic cause of mental retardation. But since scientists only isolated the gene for it in the late '80s, nobody had any real idea. In the following year, we prepared to move to Indiana, as my parents dealt with the implications of the diagnosis.

You see, Fragile X is not only genetic, it is inherited. The simple explanation is that women have two X chromosomes; men have an X and a Y. With FXS, the X chromosome is mutated and looks as if it about to break; hence the "fragile." Men with a mutated X, then, are always affected; it can range from subtle learning disabilities to full-blown autism and severe mental retardation. Women can also be affected, although since they have two X chromosomes, it is nearly always milder. The real catch is this: Fragile X is almost always passed on from mother to son. Women can carry a pre-mutated gene or the full mutation. Even carrying the full mutation, however, does not mean a female will be affected; 50% of carriers with the full mutation do not display any symptoms or learning disabilities. Since a male cousin on my mother's side displayed similar traits as Nate – including physical traits such as a long face, flat feet, prominent ears and hyper-extendable fingers – it was a sure thing that my mother was a carrier. Which meant I was then faced with a quandary: what about me?

Granted, I didn't think about whether I was a carrier or not at the point of Nathan's diagnosis. My parents only slowly found out about the entire family of genetic implications, and I was sixteen when we visited a genetic counselor. There, I was to learn whether my genes had betrayed me; whether any theoretical sons of mine were likely to be like my brother, and whether my future daughters would befall the same fate as I.

I remember the counselor well. Her name was Nancy Cangany, and my mother joked constantly about how she must be a good person because they shared a first name. I had to go to the hospital and get two vials of blood drawn, and we watched Nancy and her charts explain the genetics of FXS. Then they shipped my blood to New York for DNA testing, and I was left with a slightly unsettled feeling in the pit of my stomach.

At that point, in high school, Nate was no longer an embarrassment to me, and most of my friends thought him either pretty cool or a little strange. I considered him, on the whole, a pretty cool guy. But I had seen all my parents had gone through, and even though at 15 I did not want to think about having kids, the implications for my future were indeed there. I did not know if I could handle raising a boy like my brother, who, although I wouldn't trade him for anything, comes with his own special set of issues to deal with, even now at 22.

When the call from Nancy came several weeks later, she talked to my dad. Why she didn't talk to me, I'm not sure – but it was he who told me that yes, I did have the permutation, at a higher rate than my mother, and any future sons of mine were entirely likely to be full mutation. My parents seemed amazed with the grace I accepted my genetic fate with; I myself saw no other way to deal with it. I couldn't change it, and I certainly didn't have to deal with its implications at that point, so I ignored it for a while and let it stew in the back of my brain.

During the summer of 1998, we traveled as a family in my cramped blue Chrysler LeBaron to Asheville, North Carolina for the International Fragile X Conference. Although I did not get much out of the seminars or speakers, it was rather nice to be in a setting where everyone completely understood, where Nathan was just another young man biting his hand or making noises and nobody thought twice about it. I also got to see my brother in action. He has always liked both music and television, and five days with MTV and VH1 on the television were heaven for him, since our TV at home was cable-free. We also did not have closed captioning at home, an invention Nathan delights in. So for two straight days, as my parents attended seminars and speakers and talked to professionals and other FXS parents, I hung out in a very nice hotel room with my brother, VH1 and closed-captioning. By the end of that time, I not only knew the videos for VH1's flavors of the week, "Torn" by Natalie Imbruglia and "One Week" by Barenaked Ladies, by heart, I knew all the words. Even the really fast rap-like parts of One Week. I probably sang them in my sleep, too.

People often wonder what it would be like if I had a "normal" brother. I have no idea, but I wouldn't trade Nate and my experiences growing up for anything – it has helped make me who I am, and given me an outlook on disabilities and abilities that I may never have found otherwise. During my Thanksgiving break stay at home, Mom and I made a trip to the local hair-cutting place to fix a chop job my usual hairdresser had done. While we waited for the lone woman working to finish the client she was working on, her son, who had been drawing on a pad of construction paper, approached us. He was a towhead, and his speech was slightly louder than it needed to be. Both characteristic of my brother. He wanted us to play "Wheel of Fortune" with him, a show Nathan has always loved, and explained to us meticulously the rules. He also sang along off-key with the radio playing, pronouncing how much he liked the song that was on. He played with us until his father came to pick him up, and when he left, Mom and I looked at each other. We have gotten to be unofficial diagnostics, seeing FXS tendencies in boys, where it often gets misdiagnosed.

Still, though he has been a challenge and frustration even to his younger sister, Nathan is still my older brother. This was illustrated perfectly to me earlier this week. I was asked out on a date for next week, the first "real" date I've had in quite awhile. I shared the news with my parents, and my Mom, being the mother that she is, sent a card saying she hoped my week went well and oh, *where* was I going to be going on this date exactly? And she enclosed a note from Nate. Scrawled on a sheet of paper torn from a notepad was:

Yes, Renita you CAN! go out on a Date.

Love Nate Leichty.

In both the style of an older brother and **my** brother, I had received permission to date. It amused me immensely, and warmed my heart. I do not want a "normal" brother – normal is boring. Mine will do just fine.