

dealing *with a* disability

Sophomore reflects on the special relationship he shared with his brother.

an opinion of



»Matt Gannon

Since I was two-years-old it was just part of my life. The feeding tubes, the wheelchairs, the wailing through the nights. I always had the dream that one day it would be over. That he would rise up off the ground and talk.

But as I grew older, I knew it wouldn't happen. He would never walk or talk. My brother would always be trapped by cerebral palsy.

At first, I never thought that there was anything different between us. I still treated him like any older brother would. I laughed with him and yelled at him. I played catch with him by rolling the ball his way, and retrieving it when it was never pushed back. I rode in his wheelchair thinking it would be great to ride in it all day.

I was always thinking about how lucky he was that he never had to do anything.

Why did he get to watch episodes of "Barney," "Arthur," and "Mr. Rodgers" while I sat in class trying to grasp the idea of the alphabet?

Why did I have to get my own juice box and crackers, while my parents held him and fed him whenever he wanted?

Why was I always second and he was always first?

When I got older and began to rise up through the first years of elementary school, I realized that something was really wrong with him. For years I had thought of him as a baby brother, but he wasn't a baby anymore. He was going into kindergarten, but on the outside he still had only the abilities of a small infant.

I realized that it wasn't normal to make weekly trips to doctor. I realized that the hospital wasn't meant to be a second home. I realized that every child in our neighborhood ate with a spoon and a fork, while his milky food came through a tube inserted just above his belly button.

I realized that he was the one suffering, not me.

After kindergarten, my brother would never attend a public school again. He struggled to keep up with his friends, and his mind often wondered during class. My parents believed that he could receive a personal education somewhere else. He ended up going to a private school in Lenexa, called Hope Lutheran. It was a 20 mile drive from our house, while my school was only a few steps away from our front yard.

He enjoyed his time at Hope Lutheran. He made great friends there and the teachers were always willing to go the extra mile just to help him out. They understood that they couldn't give him the same homework as everyone else and expect him to do it on his own. They tutored him in our home, sang songs with him in our kitchen, and helped him keep up with his recess buddies on the playground.

My brother was always a happy guy. If I had a tough day at school, he would be sitting at home with a bright smile, and immediately he would cheer me up. When he laughed, it would make everyone in the room grin. He had this overwhelming feeling of joy, especially for someone whose life had been almost ruined on the day he was born.

Living with my brother brought cheerful moments, but also many that were scary and heartbreaking. He was often a victim to seizures, and I was often the one that would have to help him when they struck. I was only 7-years-old, sitting in the living room with him watching cartoons, all alone, when I witnessed one first-hand. I remember watching in fear, as he shook uncontrollably. I remember running to the kitchen screaming for my mom. After being unable to find her, I ran back to him, phone in hand. I looked at him one more time before I dialed. He was just lying there,

still, with a grin on his face.

It was a false alarm. He was okay.

Along with scares like these, there were also the awkward moments when people would just stare. It's one of the worst feelings in the world, just being watched. I don't know why, but I hated it. I understand why people would stare at us. He stood out in the crowd. But for someone to just stare at you, never blinking, never saying a word, it was one of those things that would stick with me for days.

He wasn't a fossil, or a Picasso, or an elephant. He was a human being, just like you and me. He knew what was going on around him. He had eyes and ears and a brain. He just couldn't walk away from you or say "what are you looking at" when he was stared down.

Traveling with my brother brought a new adventure. In the car, we would have to deal with the constant yelling and screeching, as he tried to communicate with us. But after an hour or so, a moment of peace would come. I would look to my right and see him, slanted awkwardly in his booster seat, sound asleep.

My family and I spent a lot of time traveling with my brother, always trying to find the newest wheelchair or computer that he could talk through. We would go from the snowy streets of Milwaukee to the warm sands of the Florida Keys. It was a trial and error system trying to find equipment that would fit him.

Eventually we would find a device that I called the "Walker". It was like a purple bike with two extra wheels and straps that would held in place. This odd looking device allowed him to move on his own, unlike any wheelchair. It was as close as he would ever get to walking.

One of the greatest moments I ever had with my brother was our first trip to Disney World. My brother squealed in excitement as we walked through the park. He could ride almost anything he wanted to. He could see anything he wanted to see. He smiled on the coasters and laughed on the log flume ride. He rolled his way to every costumed character he could. He tried to high-five every ride operator. He was just another kid living his dream.

But all great things must come to an end. Two days before the fireworks, hamburgers, and sparklers of the Fourth of July, I was sitting in a hotel room in Omaha, Nebraska watching the movie Elf with my brother. As I began to doze off to sleep, my parents put my brother in his bed of pillows we had assembled on the floor. My parents wanted to keep an eye on him through the night, like every other night.

When I woke up, I was living a nightmare. My brother was just where I had seen him the night before, but this time his face was white and there were medics all around him. I heard the word "pneumonia" over and over again. I saw my parents crying for the first time in my life. I knew it right then and there.

My best friend, my buddy, my 10-year old brother was dead.

Staring at his tombstone, I know I would not have traded him for anything in the world. No ordinary brother could have given me the moments that he and I shared. The laughing and the crying. The smiles and the tears.



Sophomore Matt Gannon rides on his brother Trevor's walker, a device that allowed him to move on his own after a push. »Photo courtesy of Gannon family

After minutes of complete silence, I begin to walk away from the tombstone. Back to the realities of school, friends, and sports. I am almost to the car when I glance back one last time and read his name "Trevor R. Gannon", and whisper to myself "the best brother in the world."

Lasting Memories

Gannon recalls fond memories with Trevor

- 1** One of my favorite memories was going to Key West and watching my brother swim with the dolphins. Although, all I got to do was watch, it was just fun seeing him do something he loved.
- 2** When we went to Milwaukee when I was about eight was a great memory too. We played miniature golf. Even though it was 30 degrees, it was still a lot of fun hanging out and playing a game with him.
- 3** I was the voice for his speaking computer. I spent hours saying basic phrases like colors and different types of food. It got rather annoying but I knew it was helping him.



For additional coverage about students who have siblings with disabilities read the next page.