

For my project, I explored the impact Cerebral Palsy has on the person who has it and the people surrounding them. Having two brothers with the disorder, I was able to use my family as a resource for my research. For my art pieces, I decided to paint portraits of my two brothers to represent Cerebral Palsy. I used different mediums for each painting. For one portrait, I used oil paint and for the other, I used acrylic paint. By using different types of paint, I wanted to represent the differences between them. They are twins, but they are fraternal. So when making their portraits, I wanted to add that as a small detail. This detail also contributes to bringing the art together to make a whole picture. The message of my work is to simply accept yourself for who you are. There is nothing better than feeling good about yourself and owning it.

Anastasia K.

Irvington, New York

Anastasia K.



Accommodating for someone's needs is hard enough for one healthy person. But accommodating for two people with cerebral palsy is even more difficult. My two older brothers, Jesse and Jake, are a huge part of my life and I am constantly figuring out ways to help and support them. Jesse sadly passed away on April 3, 2018, leaving behind his family and friends and, I pray, in a better place where his suffering has ended. Before Jesse passed away, I was always with him in the hospital, helping the nurses take care of him. Having grown up with my brothers, I learned at an early age how to feed them, give personal assistance and help them with the daily tasks most of us take for granted. This time spent with Jesse in the hospital, was a time in my life where I felt like I was truly myself. I felt like I had a purpose. I love to help people and care for them. My big heart is something I don't want taken for granted.

Not only does Cerebral Palsy (CP) affect the person who has it but it affects the people around them. When you grow up with something that is outside the norm, like disabled siblings, the personal effect is relatively unnoticed. It's all I know. I have always loved my brothers the same. Yet, reflecting back, I would always get nervous when introducing my friends to my brothers because I was scared we would be judged by the people who were scared of the unknown. My family has been greatly affected by my brothers because of the stress and fear that goes into caring for them. Whenever in the hospital, Jesse was on a multitude of medications. This affected his sleep schedule and made staying awake very hard for him. When we go out in public, Jake usually gets looks of confusion and worry from the people who are scared of what they don't understand. Throughout my life, I have come in contact with many bad experiences like going to the hospital to visit my brothers. The stress of living from crisis to crisis, the secrecy between my parents as they tried to protect me and my sister from the bad news of the moment, the days and nights of fear, the loneliness I felt when my mother has to spend countless nights with my brothers in the hospital, the wear and tear I saw on her face, yet, she never said a word. Even though these moments are sad to see, and difficult to cope with, they have taught me some incredible things. For example, Jesse has taught me to keep going and never give up. I have learned to accept people for who they are and to find their uniqueness interesting rather than frightening. I have learned empathy and advocacy. I believe my tolerance for people's differences is much greater as a result of life with my brothers. I have also developed a keen sense for people. I have learned that you really find out who your friends are in times of distress. While, if given the choice, I would choose for them to have enjoyed a healthy life, I believe their impact and legacy is even greater to those they have touched along the way. Preparing for my brother Jesse's funeral, I wrote the words I wished to speak about him. I believe my words reflected not only my love and devotion to my brother but also helped those in attendance have a better understanding. The following is an excerpt:

"His life was like a war. Battling all of these illnesses and disorders. Coming to the end of his final battle was unexpected but wanted by him. He got tired and

couldn't fight anymore. Jesse was my best friend. Going back just a couple of days ago, April 3, 2018, to a few years ago on April 3, 2003, that was my due date to be born. Like always, I was late. Pushing my birth to the next day, I somehow knew in my infant mind that April 3 is reserved for someone else, Jesse. I wouldn't be here today if it weren't for Jesse and Jake. So I want to take this opportunity to celebrate the life of Jesse."

The loss of a sibling with CP or any disability, is the loss of a human being like any other. It is the loss of a loved one, someone's child, grandchild, cousin, nephew, niece. A contributing member of society. Some would even argue that they are an elevated member of society as many people with disabilities are often the greatest teachers of endurance, perseverance, determination and courage. My brothers are all of those things. As I reflect back, I can honestly say, they have been my greatest teachers of all. They taught me empathy and to have an appreciation of life's little things that are often taken for granted. Most of all, they taught me unconditional love.

What is Cerebral Palsy?

Cerebral palsy is a group of disorders that affect a person's fine and gross motor skills, like walking, talking, holding items, etc. It can be mild or severe. It is caused by abnormal brain development or damage to the developing brain that affects a person's ability to control their muscles. Both Jake and Jesse have needed wheelchairs for mobility throughout their lives. They have also needed to be cared for constantly. Their needs have included a variety of tasks performed by our family and their caregivers who have become extended family. The boy's personal care makes up a great part of the day: feeding, changing diapers, positioning their bodies as they can not move independently, giving medications and washing. The day also includes physical and occupational therapy, speech (using technology for Jake and a simple tap of the wheelchair tray for Jesse), aqua therapy (in a pool), academics and vocational skills.

There are three main types of cerebral palsy. Spastic, dyskenetic, ataxic. These types of cerebral palsy all have different effects on the person who has the disorder. My brothers have/had spastic quadrapelgia, meaning it effect all parts of their body, including things like the tongue!

In addition to having the muscle spasms and tension, there are other complications to having cerebral palsy. For example some children might suffer from intense seizures, vision, hearing or speech problems, and bone abnormalities such as scoliosis.

As both a sister and one of the many caregivers to my brothers, daily life can be very challenging. Imagine being four years younger than your sibling and you're changing his diaper? Imagine having to wait until the last person leaves to get off the plane. Imagine having to dress them every single day. These are some of the troubles of caregiving but there are also positives.

Imagine being able to skip the lines at Disney World. Imagine being able to feel like you mean something to someone. Imagine being someone's person. Now imagine being that person.

Jake's life as a child, teenager and now adult, looks very different from that of a typical, healthy person. Throughout his life, he didn't have many friends because people were scared to be near him. He also wasn't invited to many social activities with peers. When there was a peer group gathering, all activities had to be facilitated by adults. For example, if it were a kid's birthday party playing backyard games, Jake and his friends would need to rely on the adults to do the game for them. While we tried to make it fun and "normal," it often felt strained and sad. As a family, we included Jake in all types of activities from going to the movies to tropical vacations in the Caribbean. I'll never forget Jake's first experience being in the ocean. My parents located a "floating wheelchair," strapped Jake in and off they all went with two nurses on stand by. Jake's expression says it all.

Jake has been in a special education school his whole life. But when our local public school wanted to highlight diversity, they asked Jake to represent the disabled population. For the first time, Jake entered our public high school, he took the stage and held up a sign (with the help of a local student) that said, "If you could hear my thoughts, they would be the same as yours!" He brought the house down. From that point on, Jake was finally known in the community. He was 12 years old.

At 14, Jake moved to a residential program called The Center for Discovery in Monticello, New York. At school, Jake works on traditional academics taught in ways he can understand. As he got older, The Center began training him for vocational work.

While we don't know what Jake's future holds, his favorite job is collecting payroll for the staff. He really enjoys all the attention from being "in charge" of the paychecks! Even though Jake can't do some things that I can do, one thing he did was fall in love with the sport of baseball. His favorite team is the New York Yankees. Not only did Jake go to many Yankee games, and play baseball on Miracle League, a program for children with disabilities, because of his disabilities he got to meet all of the Yankees. As you can see, while there are many downsides to living with a disability, there are also some perks. Though, I think we would all agree, not enough to make a trade.



Facts and Fiction

There are a lot of misunderstandings about CP here are just some of the fiction and the facts.

Facts	Fiction
<ul style="list-style-type: none">● CP is NOT contagious. This is because CP is a disorder and not a disease.● CP is NOT genetic, it is a deficiency of oxygen to the brain.● Not everyone with CP is retarded. It is a continuum disorder and can be mild to severe.● People with CP have emotions, they just can't express them the same way.● Some people with CP have a harder time learning, but can learn using modified teaching methods.	<ul style="list-style-type: none">● CP is contagious● CP is genetic● If you have CP, you're automatically retarded● People with CP have no emotions● People with CP can't learn

Life with my brothers offers a snapshot into life with and of a person with a disability. From the most challenging times to the lessons and the pleasures along the way. The stress of caring for my brothers has its moments. I still struggle with the looks of judgment from people who just don't understand. I have learned rather than get angry and want revenge for my brothers, to stop, think and invite them to say hello, to educate, hoping that one person at a time, my brothers and I can make a difference. My brothers are not people to fear or be disgusted by. They are people, first. To me, they are funny, loving, accepting of their situation and strong. Most importantly, if you look beyond the disability, you will find a person who is just like you.