

PERSONAL PROFILE

Amber Hall

Eighteen-year-old Amber Hall is a high school senior in Florida. She was born extremely premature, weighing just 1 lb, 12 ounces, which resulted in cerebral palsy (CP), dystonia, and hearing impairment.

What is a typical day for you? How have you been coping during the pandemic?

I've been doing virtual online classes. At first it was a bit of a struggle because I was used to actual school, my regular classes. I have a job at a small farm. I have a stand where I sell my fruits and vegetables on Saturday mornings, now that the markets are open again. I'm graduating this year and then off to college and probably I'll get a second job.

I've also been doing this other thing, which is amazing, and it's called Taekwondo. I started doing Taekwondo in July. It has done so many things for me. Physically, I've been doing very well. It helps me to be more mindful about my body. Master Lee helped me align my spine, I learned the pressure points of my body, and he helped me walk better. I take stretching very seriously. I never had heel-toe movement in my ankles before Taekwondo. I never had sensation in the back of my calves. I am building muscle. I never really had muscle control in my legs, but now I do, which was a great achievement and it's really awesome.

How I got going with Taekwondo in the pandemic is: we went to four specialists to see about a tendon repositioning procedure in my legs, but they said no because of the dystonia. We decided to go to Taekwondo and see if it could help. We found out that Master Lee's brother has CP, and he helped his brother with rehab when he was young. Every week his understanding about my body gets better. He's amazing in his knowledge, and I work very hard. I have been going three days a week. Jumping was another thing that I started doing. I learned how to jump during the pandemic.

I practice real Taekwondo moves, like kicking, blocking, and punching, about one day a week, and the other days are focused on learning how to place my body in space and keep my balance. Trying to rehabilitate my brain to

Cerebral palsy (CP) is a group of disorders that affect a person's ability to move and maintain balance and posture. CP is caused by changes in brain development or damage to the developing brain that affect a person's ability to control their muscles. CP is the leading cause of dystonia in children.

Complementary & Integrative Therapies

The DMRF encourages individuals with dystonia to consult their doctor about non-traditional therapies they may be interested in pursuing including dietary supplements, products, and mind-body practices. Information about the use of complementary therapies for dystonia is available at: dystonia-foundation.org/complementary-therapy/

take control of my muscles without falling, getting jerking movements, or being startled. It has also helped me emotionally and helps me speak better. I have confidence and motivation. I sleep better. Since I started Taekwondo I don't get these awful cramps in my legs and my toes. My toes used to fold underneath when I walked. Now they are flat and I can control them and wiggle them and paint my toenails. I can keep the polish on the nails because I don't walk on my toes anymore. At first I even struggled with taking off my uniform. I had to do it over and over again until I could get it off finally, but now I don't struggle with it.

What therapies or interventions have helped you?

I used to take medicines, baclofen and Artane® [trihexyphenidyl]. Artane® helped me get balance and stop my jerky movements, but there were side effects. Now the only thing I take is CBD oil [cannabidiol] and



Amber Hall studies Taekwondo with Grandmaster Chu Young Lee. Taekwondo is an ancient Korean martial art.

some teas, naturopathic things that maybe relax muscles. I used a walker until I was six years old. Then I started using the walker like a skateboard, and they took it away. I love skateboards. I wish I could ride one. My physical therapist was very hands-on and she would strap my legs to her legs and we'd ride the skateboard down the street together and go to the park. I wore AFOs with SMO inserts, and twister cables to keep my knees apart. And some nighttime bracing and casting and Botox® and so many things throughout the years. And then conductive education—summer camp for CP and other people who are struggling with mobility. I had an occupational therapist who helped me a lot with my feelings and thinking skills and executive functioning skills.

What impact has CP and dystonia had on your life?

I have had CP and dystonia for my whole life. It affected me more as I became more aware about myself. It also affected

me emotionally and mentally. When I was like nine or eight, I knew I had a disability but I felt I was still like every other kid. As I got older, like middle school and high school, I became more aware of how other people felt around me because I had CP. It's 50/50. Either they bully you or they take it seriously and try to be nice to you. I had very challenging problems with bullies in high school. That's when I started focusing on things that help me cope through these problems. I had arts, music, family, and my mom—she's the best. My mom took me to private school junior year. It's my second year there. Before the pandemic hit, I was independent for the first time. It was amazing. I met a lot of kids there. I have a troubled time trusting people. I made one or two friends. I'm fine with that. Private school was amazing. It made me feel like I'm an average high schooler.

I was mainstreamed with a para [classroom assistant] in sixth grade. Before that I was in the deaf and hard-of-hearing classes. My para was awesome in middle school. But at the same time I was struggling because I wanted to be free. I didn't want anybody helping me. Now I am independent, and I'm happy.

I want to become a digital artist and a comic book illustrator. I like doing portraits and cartoons. I love movie posters, especially old ones. One of my favorite all-time movies is *Halloween*, the classic 1978 one. I also like *Friday the 13th* from the 1980s. As a kid I loved *Looney Tunes* and *The Three Stooges*. I also take cartoon shows seriously. Especially from around the late 1990s and the 2000s. I get inspiration from them, like *Invader Zim* and *SpongeBob SquarePants*. I love my mom's art books. My art is a combination of things. It's either dark humor or comedy, like slapstick comedy. Sometimes it's venting my feelings. It helps me cope with anxiety. I also want to become an animator in movies.

What are you most proud of?

I'm proud of what I am doing with Taekwondo: balancing, walking, thinking, speaking, and having conversations with people, trying to be very aware. I'm proud I'm alive. I'm proud that I am independent and strong and determined. Focus is the number one thing. Number two is determination. The greatest challenge I overcame was bullying. Always speak up for yourself and be an advocate for yourself, and you can help others too. Be kind.