



CeCe Robért has resumed an active life after Children's Rehabilitation Team helped her recover from a surgery that disconnected half of her brain.

CECE'S CONNECTED

Swimming was second nature to eight-year-old CeCe Robért. The smell of the chlorine, the chill as she dove into the water, the exhilaration as she swam against the clock – she simply loved it. But CeCe suffered extreme, debilitating epileptic seizures each day that led her family to try a radical brain surgery that took her out of the pool and put her into intense rehabilitation.

CeCe had a stroke while still in her mother’s womb and was just two years old when she had her first seizure. She wasn’t responding to medication, and the seizures became more frequent and intense. The seizures weren’t just limiting CeCe’s life; as time progressed, they would affect her future. Soon, academic issues were starting to manifest.

“She would hold a pencil and start writing,” said her mother, Monique, “and it would just be totally random letters on the page.”

After six years, the condition was taking its toll on the young girl. She was already facing cognitive impairment. Without relief, the seizures could cause brain damage and even death. In January 2009, CeCe’s doctors made a sobering decision – they must disconnect half of her brain in order to stop the seizures.

When half is better than whole

The cerebrum, the largest part of the human brain situated above most other brain structures, is divided into two hemispheres, right and left. Each hemisphere controls the opposite side of the body. Amazingly, especially in children, if one hemisphere is removed or disconnected, the remaining side of the brain takes over the tasks that were controlled by the damaged section.

“Children’s brains are still growing and developing, so it’s easier for them to adapt to changes,” said Ann Tilton, CeCe’s neurologist at Children’s Hospital. “Even when one hemisphere is disconnected, the other compensates by forming new connections.”

Hemispherectomies are solely reserved for extreme cases in which seizures can’t be controlled with medication. Only a very small percentage of the 3 million people in the U.S. with epilepsy are hemispherectomy candidates; and CeCe was one of them.

Dr. Tilton told CeCe’s parents that the younger she was when she had the surgery, the better for her long-term health. Monique and her husband decided to proceed with the surgery,



optimistic about the pros yet unprepared for the cons. “CeCe had no chance at a normal life without surgery,” Monique said. “Surgery was no longer an option. It was a necessity.”

In January 2009, CeCe had the procedure at the University of California Los Angeles Health System. Now, they faced the arduous task of rehabilitation at the Gilda Trautman Newman Rehabilitation Center at Children’s Hospital. With the left hemisphere of her brain (the side that controls speech) completely gone, CeCe emerged from surgery as a different child. She was nearly paralyzed on her right side. She couldn’t walk. And worst of all, her sunny personality faded away. Monique had a sinking feeling that she made the wrong decision.

“The surgery was the easy part. I had no idea that rehab would be so difficult,” Monique said.

Becoming CeCe again

For patients with weakened limbs, like CeCe, constraint-induced movement therapy (CIMT) is a promising occupational therapy treatment that is still relatively uncommon in most hospitals. While the majority of children would have to travel to another state to receive pediatric CIMT, CeCe lived just minutes away from Children’s Hospital, where occupational therapists have used the technique for several years.

As part of her CIMT, CeCe’s strong left arm was put in a cast to encourage her to use and strengthen her weakened right arm. As CeCe engaged in repetitive exercises with her right arm, her brain grew new neural connections.

“Children with hemiparesis have motor weakness on one side of the body,” said Jenny Domiano, CeCe’s occupational therapist. “They struggle with developing the hand dexterity needed to perform basic self-care skills like eating, washing hands, dressing and brushing teeth. They tend to stop using their weakened limb because they are discouraged by the difficulty, making the physical disability worse.”





After going through weeks of therapy, CeCe's therapists saw her confidence soar. In less than a month her abilities drastically improved, and she was enthusiastic about continuing her therapy at home. For big brother Rene and big sister Maddie, helping CeCe with her home therapy for more than six hours each day was their summer job.

"Restraining that arm was intense for her, but she was so willing to succeed," Monique said. "She never complained."

In addition to occupational therapy, all of CeCe's rehabilitative needs were met at Children's Hospital. Physical therapists taught her how to walk again; speech pathologists taught her how to speak again; audiologists helped her with a post-surgery disorder in which background noise prevented her from thinking clearly; child life therapists helped CeCe to still be a kid, too, through music and art therapy.

"The rehab team here has been phenomenal," Monique said. "They've gotten her to do more now than before her surgery."

Though she still has some minor challenges to overcome, CeCe has maintained a remarkable attitude throughout this grueling ordeal and will have a fulfilling life. Her auditory disorder is under control, and now she doesn't need complete silence in order to process a conversation. Furthermore, her academic performance has drastically improved. She continues to restrain her strong arm in a sling on the weekends, and she goes to Children's twice a week for outpatient rehab.

Getting her freestyle back

It's been just a year and a half since CeCe had half of her brain disconnected, and she's already training to be on the swim team. Her fear of having a seizure while swimming has evaporated, and now, the water is CeCe's place to be free. "It's my sport," she says with childlike resolve.

"Hey mom, how far do you want me to swim?" CeCe shouts from the opposite end of the pool.

"Go all the way," Monique replied.
"All the way." —DC ■

