



News

20 years after surgery, a full life with half a brain



Five days before doctors removed half her brain, 8-year-old Christina Santhouse performed "It's the Hard-Knock Life" from the musical *Annie* at her elementary school talent show in Levittown.



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Today, Christina Santhouse is a speech therapist with the Bucks County Intermediate Unit. Santhouse, who has a master's in speech ... [Read more](#)
MICHAEL BRYANT / Staff Photographer

by By Kathy Boccella, Staff Writer
Published Feb 14, 2016

Five days before doctors removed half her brain, 8-year-old Christina Santhouse performed "It's the Hard-Knock Life" from the musical *Annie* at her elementary school talent show in Levittown.

Midway through, the third grader suffered yet another seizure - she was having as many as 150 a day - and

Popular; extroverted; obsessed with sports, especially soccer. And almost unnaturally upbeat - even after doctors said her seizures were the result of an extremely rare disease, Rasmussen's encephalitis, which would slowly paralyze, then kill her unless they removed the right side of her brain.

"Don't worry; I'll be fine," she told her parents as she was wheeled into the operating room at Johns Hopkins Children's Center in Baltimore on Feb. 13, 1996. "I'll dream I'm playing soccer" - the sport she'd never play again.

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For mother Lynne and future stepfather Albert Catarro, the little girl's optimism was contagious - to a point. They worried about what hard knocks might be ahead, especially when the operation dragged on for 14 hours, longer than expected.

At the end of that agonizing day, the prominent neurosurgeon who operated on Santhouse came out to speak to them. No one could have guessed Dr. Ben Carson would someday run for president, nor would it have mattered at that moment. They just wanted information.

Lynne realize the hugeness of what had happened - and what was to come. She looked at the scene and fainted.

On the 20th anniversary of the operation, Christina Santhouse has succeeded beyond anyone's expectations.

The petite 28-year-old lives in the three-bedroom ranch house in Yardley that she bought two years ago. On her family-room wall are pictures that reveal both who she was before the surgery - a tiny dancer in ballet shoes and a tutu - and how she found happiness and eventually the love of her life in the years since.

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Still, living with half a brain hasn't been easy.

Like the small number of others who undergo hemispherectomy, Santhouse lost motor skills on one side of her body - in her case, the left. She learned to walk with a brace, but had no use of her left hand and only half of her vision.

teacher at a technical high school said she doubted Santhouse would ever be able to do more than answer questions. Even the Johns Hopkins doctors said she'd never drive.

Yet, "I was full steam ahead," Santhouse said, recounting how she got her driver's license at 17, excelled on the high school bowling team, and pushed herself through college and on to a graduate degree. "I wasn't going to let [the brain surgery] stop me."

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Kristi Hall, cofounder of the Hemispherectomy Foundation, which tracks about 200 children worldwide who undergo the surgery annually, said that while many overcome the array of obstacles to graduate from high school, only a handful go on to college. Santhouse, who earned her master's degree in speech pathology in 2010 from Misericordia University, is one of just two to complete a graduate degree.

But Dr. George Jallo, pediatric neurosurgeon and director of the Johns Hopkins All Children's Institute for Brain Protection Sciences, said that patients - while losing motor skills on one side - typically can

Jallo, who was trained by Carson and replaced him at Johns Hopkins in 2013, said about 100 hemispherectomies are performed each year in the United States, mostly on children with severe seizure disorders.

"You have to disconnect the side of the brain that's bad," he said, "to give these children a good life."

A swimming pool at the Jersey Shore was where everything suddenly changed. In August 1995, the little girl who loved soccer, basketball, and Brownies was playing in the water at Cape May Courthouse, where her teacher parents have a house. She hopped out to retrieve a ball.

Albert Catarro first noticed that Santhouse's ankle was twitching. A nurse who happened to be at the pool saw it, too, and suggested the girl be taken to the hospital right away. Soon Santhouse was at St. Christopher's Hospital for Children in Philadelphia for tests.

recognized the symptoms.

Lynne Catarro - who had raised her vivacious only child as a single parent before she met Albert - said she was shocked when told the only cure was removal of the right half of the brain, where the inflammation had taken root.

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"I had never heard of surgery like that before. It was very barbaric," she recalled. "You can live with one kidney, but whoever thought you could live with half a brain?"

As the calendar flipped from 1995 to '96, the twitching spread to Santhouse's entire left side; soon, she was having up to 150 seizures a day. Her mother sent a beanbag chair to school, so Santhouse wouldn't fall when they occurred. She tried to keep playing soccer - even wearing a football helmet for a time - but finally had to stop.

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When to have the surgery was left to her. By January 1996, Santhouse was ready.

The family has fond memories of Ben Carson as the operation approached. "The night before surgery, he came in the room and said, 'You say your prayers and I'll say mine,' " said Santhouse, who calls him her hero. He "has this presence, this aura."

(She keeps her thoughts about his presidential bid to herself. She last saw Carson a few years ago, when she introduced him at an event in Valley Forge where he awarded scholarships from his Reading Room program.)

The day after the surgery, Santhouse was alert, asking to see her "Gramcracker" - her grandma - and to watch *Annie* on video.

With intense therapy, she became accustomed to walking with a leg brace, and the awkward gait; to the reduced peripheral vision; to doing everything one-handed, since her left was now just a "helper"; to the sloshing sensation when she'd turn her head, as the empty space filled with fluid. But life presented other challenges, especially when she returned to school in April.

"After brain surgery, there's impulsivity, anxiousness, behaviors she didn't have [before]," Lynne Catarro said. Santhouse also "had to deal with a new way of learning."

She began with a half-day of classes and a half-day of therapy. She progressed from a three-pronged cane to a single cane to walking her own. She learned to turn her head so she could see and read better - and not walk into walls.

license at 17, using a modified car and prism glasses to compensate for her reduced vision.

She also discovered a novel way to still compete as an athlete: bowling.

"I didn't know how to bowl with one hand," she said. "I'd pick up the ball, and support it on my thigh. I'd walk up to the lane supporting it with my thigh, then plant my feet on whatever board I needed to stand for whatever pins I need to hit. . . . Then I'd bend down, do three swings with my arm to get speed on the ball to get some power behind it, and then on the third swing, I'd throw the ball."

She scored as high as 234 with that technique. She became team captain her senior year, and competed in England and Australia.

Santhouse seemed to have more faith in herself than many of her peers did. "We all know what goes on in high school," her mother said. "If you're not a typical person, high school is brutal."

Adults could be as bad.

With the help of an aptitude test, Santhouse decided she wanted to become a speech pathologist and attend college away from home. She picked Misericordia, near Wilkes-Barre, where her first professor said speech pathology would be too hard.

"She didn't do well on her first test, and they thought it reflected on how she was going to perform," her mother recalled. "It doesn't prove your resilience; it doesn't prove your drive. It doesn't prove anything."

She quickly got a job with the Bucks County Intermediate Unit, which provides educational services to county schools, and moved on to her next goal: buying a house. With that came a bonus. She joined a church group near her new home in Yardley, and met Vince Paravecchia, a teaching assistant and freelance sportswriter. It took a few months, but she eventually invited him to her house for a movie. They talked all night. As Paravecchia recalled, "Things just clicked."

At first, he said, he didn't even notice her disability. "One night, she mentioned 'my condition,' and I said, 'What are you talking about?' "

He added, "She's just so sweet, a great heart, she's infectiously lovable."

Along with the photos of the young ballerina on their walls, there is Santhouse at their 2014 wedding, stunning in a strapless gown, flanked by her bridesmaids in vivid blue. The wedding, like the house, the diploma, the driver's license - like everything else - was a triumph for the remarkable determination of the girl who popped back up during "It's the Hard-Knock Life" in February 1996.

Since The Inquirer first wrote about her 20 years ago, Santhouse has talked about her surgery to media worldwide. But that's only half the story.

"When they see the final product and how well she's doing, that's what's miraculous," her mother said, "and they're in awe."

in which half of the brain is removed, was first tried on humans in the mid-1920s. However, not until the 1950s was it performed successfully, mostly for cases of severe childhood epilepsy. Its use increased in the 1990s as surgeons, including Ben Carson, developed more sophisticated techniques that produced improved outcomes.

It is done almost entirely on children, whose brains have more neuroplasticity than adults', meaning that neurons in the remaining half can more easily assume the tasks of neurons in the missing half.

Christina Santhouse underwent an anatomic hemispherectomy, in which the entire cerebral hemisphere was removed. Increasingly, though, doctors perform what is called a functional hemispherectomy, in which some tissue in the damaged hemisphere is left in place but its connections to other brain centers are cut so that it no longer functions.

During both procedures, the patient's head is shaved and a portion of the skull removed. After all tissue has been cut and removed and all bleeding is stopped, the underlying tissues are sutured and the skull and scalp are replaced.

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By Kathy Boccella, Staff Writer

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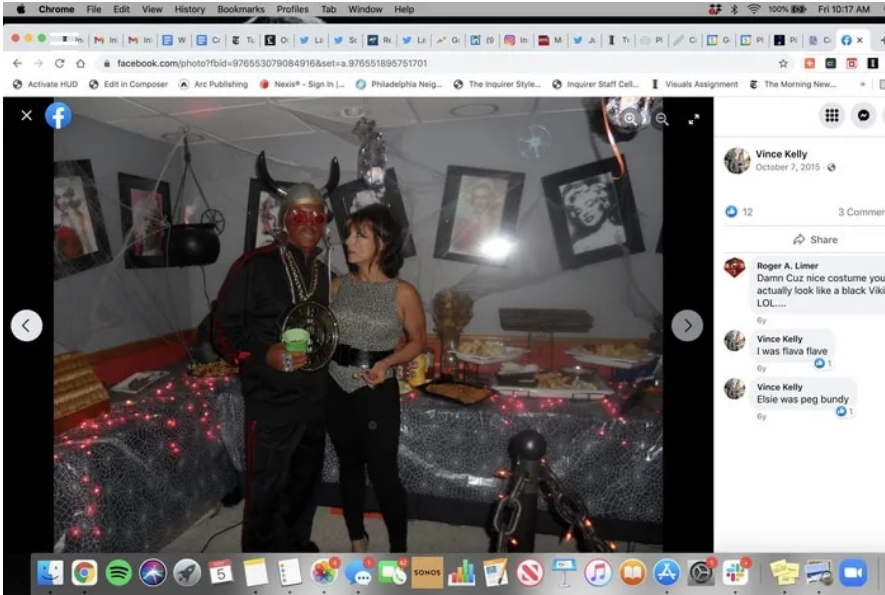
Jason Laughlin

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A boy with severe autism went to CHOP as a step on the way to intensive residential care. Four months later, he's still there. [inquirer.com/health/a/autis...](https://www.inquirer.com/health/a/autis...)

New Jersey Politics



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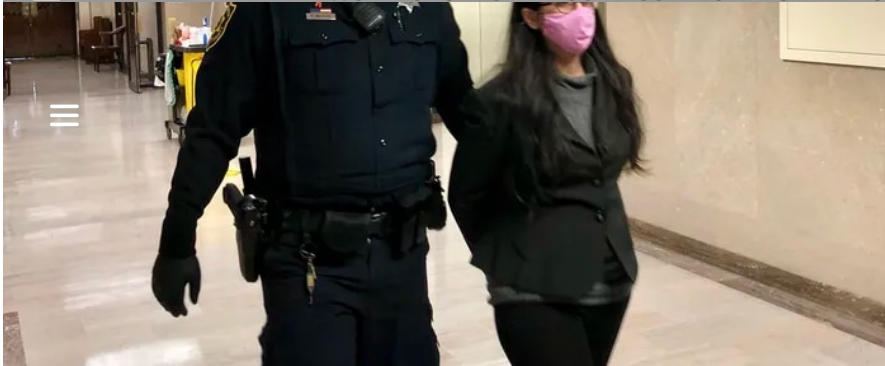


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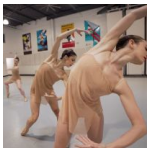
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Science



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The new, long-awaited Cramer Hill Waterfront Park, built on an old city landfill, opens to the public this weekend.



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Eight of the city's 13 sanitation districts averaged rates below 50% in late 2020 and early 2021, according to data released Thursday by the city controller.

Erin McCarthy 5 hours ago

News



federal climate action.

Justine McDaniel Nov 5, 2021

Clout



Clout asked Philly politicians these three questions on Election Day. Everyone dodged the third one.

Who will be the Democratic nominee for the U.S. Senate? Or the Republican nominee for governor? What happens with the trial of John "Johnny Doc" Dougherty and Councilmember Bobby Henon?

Chris Brennan, Julia Terruso, and Jo... Nov 5, 2021

News



It's freezing, but who cares? Homecoming dances take it outside for coronavirus precautions.

"We wanted to offer as normal a year as possible," said Collingswood Superintendent Fred McDowell. "The best place was outdoors."

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Health



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As It Happened · News



As it happened: Trial of Dougherty and Henon continues with focus on councilmember's fundraising

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Updated Nov 5, 2021

- [Recap: Bobby Henon's top aide tells jurors: 'I know with every fiber of my being that he did not do anything wrong'](#)
- [Trial ends for the day, resumes Monday](#)
- [Henon's chief of staff testifies about 'traumatic' FBI raids](#)

New Jersey Politics



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