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## ‘There was no warning’: Rare disease that causes strokes in children shocked Bay Area teen

By [Catherine Ho](#), Health Care Reporter Updated July 18, 2024 9:51 p.m.

Gabby Lopes, 14, seen at home in San Leandro, had a stroke when she was 12. A UCSF pediatric neurologist is leading a first of its kind clinical trial that could change the lives of children with the rare disease that caused it.

Gabby Lopes doesn’t remember much about that day, two weeks before her 13th birthday, other than she’d just finished running a lap in her P.E. class at San Leandro’s John Muir Middle School and was about to do a pushup when she passed out.

She awoke to a crowd standing over her, including her P.E. teacher and a vice principal. She recalls someone told a “dad joke” and that she laughed — only to discover the right side of her face was numb. She tried to lift herself up but couldn’t move the right side of her body.

“I thought, ‘That was weird,’ ” said Gabby, now 14, of that day on Sept. 19, 2022. “It was really confusing. I felt like I was in a dream.”

She initially thought she was dehydrated, since it was a hot day and she hadn’t drunk much water. Her mother, Sara Lopes, who rushed to her daughter’s side and rode with her in the ambulance to UCSF Benioff Children’s Hospital Oakland, thought the same.

But medical scans soon revealed Gabby, then a [healthy](#) and active eighth-grader who’d played soccer since she was 6 and showed no signs of illness, had suffered a stroke — an occurrence so commonly associated with older adults that [many people don’t know it can happen in children](#).

Sara Lopes was shocked.

“There were no indicators, no symptoms,” she said. “There was no warning.”

Doctors later determined Gabby’s stroke was caused by a rare disease called focal cerebral arteriopathy of childhood, or FCA, in which one of the two internal carotid arteries in the brain suddenly becomes inflamed. The walls of the artery thicken and the blood vessel narrows, preventing blood from reaching the brain and causing an ischemic stroke.

FCA is rare, occurring in just two to five per 1 million children, based on estimates of pediatric stroke rates and FCA studies. It is rarely fatal but can result in permanent damage, including weakness or uncomfortable contractions on one side of the body, anxiety and depression.

“It’s a strange disease because it comes out of the blue,” said Dr. [Heather Fullerton](#), a pediatric neurologist at [UCSF](#) who helped treat Gabby at the hospital. “Most people are not aware children can have a stroke. You would not know about this unless you were very unlucky.”

What's more, FCA patients can get worse quickly in the few days after the stroke as their blood vessels get progressively narrower — a telltale feature of the disease. When this happens, their symptoms, such as weakness on one side of the body, can get even more severe, and they're at much higher risk for a second stroke.

For Gabby, this happened a week after her initial stroke, while she was still hospitalized, causing her right wrist to go limp and her hand to curl.

For years doctors treated patients with FCA mainly with supportive care such as fluids, raising their blood pressure so more blood can get past the narrowed part of the vessel, and giving aspirin to reduce clots. But they often felt helpless because there weren't approved treatments they could try to prevent this further narrowing from happening, Fullerton said.

That's why Fullerton is leading a first of its kind clinical trial for patients like Gabby. The trial is testing whether treating patients with high-dose steroids as soon as doctors suspect FCA — instead of waiting up to several days for a definitive diagnosis — can reduce inflammation and prevent further narrowing of the blood vessels from occurring.

It is one of the first pediatric stroke trials to receive funding by the National Institutes of Health, and the first to focus on stroke prevention in children, the agency said.

Photo: Gabby Lopes stands with her father Alex and mother Sara in their backyard in San Leandro. "There were no indicators, no symptoms," says Sara about Gabby's stroke at 12. Santiago Mejia/The Chronicle



Pediatric strokes in children with sickle cell — a disorder that causes the blood cells to take on a "sickle" shape, which makes it harder for blood to pass through vessels — have been studied more extensively because children with sickle cell are much more likely to have a stroke than healthy children. But strokes in previously healthy children like Gabby have not been as well researched.

Gabby is not part of the clinical trial because she had a stroke before the trial began enrolling patients. But Fullerton said the idea is to help patients like her in the future.

Treating FCA with steroids is relatively new, and there is limited data about its safety and efficacy. In 2017, researchers in Europe published the first papers examining the outcomes of a relatively small number of FCA patients who were treated with steroids. They found that children who got steroids had better neurological outcomes at six months, and may have experienced less severe narrowing of the blood vessels.

Even though the data was limited, it prompted many physicians to begin administering the steroid treatment for their FCA patients because they didn't want to stand by and do nothing while the children's condition worsened.

Gabby, for instance, did receive steroid treatments at the hospital, though not as part of the trial.

“As physicians, it’s really hard for us to sit and watch a child’s blood vessels get worse in front of our eyes,” Fullerton said.

Still, doctors need more data to better understand the risks and benefits of using steroids in FCA patients — data that Fullerton hopes this trial will help collect.

“Steroids have a lot of risk, they can suppress the immune system and can cause you to be unable to fight off an infection,” she said. “That’s why the trials are needed.”

It’s not clear why FCA happens, or why it afflicts children but not older adults. It doesn’t appear to be passed down from family members, and it doesn’t affect any particular ethnic group more than others. But one potential theory is that it’s the result of the body’s inflammatory response to a virus. Some viruses, including but not limited to the virus that causes COVID-19, can travel along nerve cells to blood vessels in the brain and cause inflammation in those vessels. This would be similar to the way the varicella virus that causes chickenpox can remain dormant, then travel along a nerve pathway to the skin and flare up, causing shingles.

Children with FCA are unlikely to have another stroke, and are not more likely than others to have a stroke as an adult, Fullerton said. But she and other doctors urge their patients with FCA to be extra careful about their vascular health — by exercising, maintaining a healthy diet and avoiding smoking — because they may have permanent damage in their blood vessels.

For Gabby and her family, the first year after she returned home from a monthlong hospital stay was hard, as they sought to find their new normal.

Photo: Gabby Lopes, at home in San Leandro, underwent months of physical therapy to regain the use of her right side and strengthen muscles needed to swallow food and water. “I didn’t expect to have to relearn a lot of things I could do before,” she says. Santiago Mejia/The Chronicle

She underwent months of physical therapy to regain the use of her right side and strengthen muscles needed to swallow food and water.

“I didn’t expect to have to relearn a lot of things I could do before,” she said. “I was frustrated because I was like, ‘I already know it. How come I can’t do it?’ ”



Typing on a computer with her right hand was especially hard, she said, and she’s still a little slower on that side. Sometimes her right hand can’t get a good grip if something is heavy or bulky. At times when she gets excited, she’ll stutter; when she’s tired, she’ll slur. She can no longer play soccer because she can’t risk getting a concussion, but is finding new joy in playing the piano and saxophone in her high school band.

The ordeal, Gabby said, made her want to become a pediatric nurse when she’s older.

“I loved how uplifting and encouraging everyone was,” she said. “I never thought a hospital could be a fun place. They made it that much better.”

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Health Care Reporter

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