Secret deaths: CNN finds high surgical death rate for children at a Florida hospital

By Elizabeth Cohen and John Bonifield, CNN Medical
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Update: In the week since this story first published, St. Mary's Medical Center and the State of Florida have responded to CNN's reporting. You can read the responses and other information about children's heart surgery mortality rates here.

West Palm Beach, Florida (CNN) She was only 7 weeks old, weighed a mere 10 pounds, and had just had delicate surgery to widen a narrowing in her aorta, the vessel that carries blood from the heart to the rest of the body. If that wasn't enough, after the surgery, Layla McCarthy stopped moving her legs. The doctors couldn't explain why.

Terrified she might never walk, Layla's mother, Christine McCarthy, sought solace from family and friends. A stranger overhead them talking in an elevator at St. Mary's Medical Center in West Palm Beach, Florida.

"Do you know a child with a heart problem here?" asked the stranger.

"Yes. My daughter," McCarthy answered, and explained what had happened to Layla.

"You need to get her out of here," the stranger warned.

The woman, who was visiting a family member in the hospital, told them staff had whispered to her about problems at the hospital's pediatric heart surgery program, which at the time was not even a year old. There was talk that an unusually large number of babies were having complications and many weren't surviving.

Shaken, McCarthy called her husband, Matt. Together they decided to call Layla's cardiologist, Dr. Emmanouil Tsounias, and ask to have Layla transferred to another hospital.

"That's a really good idea," they remember the doctor saying. "I'll be right over."

He arrived in Layla's room with the transfer papers and closed the door.

"Make sure you're adamant about this," McCarthy remembers him saying. "Don't let anyone here talk you out of it."

The McCarthys were shocked. Why hadn't he said something earlier? Had he known all this time that St. Mary's was not the best place for their baby?

Grateful for the stranger's warning in the elevator, the McCarthys arranged to have Layla transferred out the next day to Miami Children's Hospital, 80 miles away. Two and a half years later, she's a paraplegic, but alive.

The McCarthys had no idea the hospital their baby was at was extremely inexperienced at doing such complicated heart surgeries on newborns. By the end of 2013, the mortality rate for babies having heart surgery there was three times the national average.

At least eight babies have died since the pediatric open heart surgery program at St. Mary's Medical Center began in December 2011, including Keyari Sanders, Alexander Gutierrez-Mercado, Amelia Campbell, Pa'rish Wright, Landen Summerford, Weston Thermitus, Milagros Flores, and another baby.
whose family wishes to remain anonymous. Many of their parents want to know why no one warned them that St. Mary's was relatively inexperienced at such tremendously difficult and risky operations.

Surgical death rates for babies kept secret from parents

'Babies as sacrificial lambs'

Nneka Campbell didn't start out hurting and angry - in fact, quite the opposite.

In the beginning, Campbell thanked God that her baby's surgery would be performed at St. Mary's by Dr. Michael Black, the newly arrived "superstar" surgeon from Stanford University Medical Center.

Black impressed Campbell from their very first meeting. He'd been the chief of cardiac surgery at Stanford's Lucile Packard Children's Hospital. He said he had invented techniques for operating on tiny hearts. She says he told her he'd never lost a single patient during his time at St. Mary's.

"I felt like, wow, we've got this superstar that's come here," Campbell remembers. "He gave you the impression that he was working smarter and better than other doctors in the area, almost like the others were doing something that was a little antiquated."

So Campbell was shocked when her 8-month-old daughter, Amelia, came out of the operating room blue and needing to be intubated. Then she says Amelia's head swelled, her kidneys stopped working properly, and an infection developed in her leg.

Her parents asked for her to be transferred to Miami Children's Hospital. By then Amelia was so sick, her mother says, there was very little hope, and she died at Miami Children's.

Death certificates and interviews with parents show Amelia was the fourth baby to die after having heart surgery at St. Mary's with Black. She was not, as her mother says she was told, the first.

"There is no room for institutions that are lying to families to get them to offer up their babies as sacrificial lambs," Campbell says.

The shocking numbers

The hospital keeps its death rate secret. Calculating that rate required CNN to file a Freedom of Information request with the state of Florida's Agency for Health Care Administration.

According to the documents CNN obtained from the state, from 2011 to 2013, St. Mary's Medical Center performed 48 open heart surgeries on children and babies. Independently, CNN determined that six infants died, and confirmed the deaths with parents of all six children. From those numbers, CNN was able to calculate the death rate for open heart surgeries as 12.5%, more than three times the national average of 3.3% cited by the Society for Thoracic Surgeons.

CNN reached Dr. Michael Black on his cell phone to ask about the babies who died after his surgeries.

"I hear you've been asking questions about me," he said. "You should come down here and we can talk."

He said a hospital spokeswoman, Shelly Weiss Friedberg, would be in touch to set a date for the meeting.

A few days later, Friedberg emailed to say Black wouldn't be doing an interview, and neither would hospital executives.

After St. Mary's repeatedly denied requests for interviews, CNN approached Davide
Carbone, the CEO of St. Mary's, at his home. He shut the garage door without commenting.

Is your hospital keeping secrets? Check our chart

A very reassuring grin

Angie Loudon's son, Landen Summerford, had open heart surgery at St. Mary's less than a year after Amelia's death.

When the procedure did not go well, Loudon says, Black recommended another operation.

"He had a very reassuring grin on his face. A comforting grin -- like, 'I got this,' " she says.

Landen died shortly after that second surgery. He was 2 months old.

She says Black told her he loved her and her baby and seemed shocked he wasn't able to save Landen.

"Dr. Black told me he would write this up for a medical journal, because it was such an extraordinary situation," she remembers.

Loudon asks CNN a question. "Dr. Black said he'd lost only one other patient before Landen. Is that true?"

When she hears that her baby was the sixth to die after surgery with Black at St. Mary's, she breaks down, sobbing uncontrollably. She says she, too, was lied to.

"I put all my faith in him. How do you know not to put all your faith in someone?" she asks.

'A total mess with newborn babies'

Some of the parents now torture themselves. They trusted the cardiologists who referred them to St. Mary's for surgery. Should they have asked more questions, searched online for the hospital's mortality rate?

They wouldn't have found anything. St. Mary's website heralded the arrival of "nationally renowned pediatric heart surgeon Dr. Michael Black" with glowing claims such as "smaller incisions -- improved self-esteem."

But there's no actual data. Unlike most other pediatric heart programs in Florida, St. Mary's does not publicly report its mortality rate.

That's why CNN had to file a Freedom of Information inquiry to obtain the patient caseload data necessary to calculate the 12.5% death rate for open heart surgeries.

St. Mary's, owned by Tenet Healthcare, says CNN is wrong about the program's death rate, but refuses to say what it considers to be the right death rate.

In a statement to CNN, Carbone, the hospital CEO, wrote that providing raw mortality data "does not give proper context for the complexity and severity of each case, which could potentially lead to providing misleading information to consumers."

"Our goal is to provide the best possible quality care to every patient we treat," Carbone wrote.

But multiple studies show hospitals like St. Mary's tend to give the worst-quality care to children with heart defects, because they get so little practice. The studies show hospitals with fewer surgeries tend to have higher death rates, especially when the surgeries are complex.

While the specific numbers vary slightly according to how they are reported, the numbers at St. Mary's are very low.
According to an independent review of St. Mary's program, the hospital did 23 heart operations in 2013.

To put that in perspective, consider that in the United States, 40% of pediatric heart surgery centers in the United States perform more than 250 cases a year, according to data from the Society of Thoracic Surgeons. Eighty percent of centers do more than 100 cases a year. Anything less than 100 cases a year is considered "low volume" by the society.

The volume of open heart surgery cases at St. Mary's keeps getting lower: from 27 cases in 2012 to 18 in 2014, according to documents filed by the hospital with the Florida Agency for Health Care Administration.

"Like anything else, if you use a skill only occasionally, it's hard to develop," says Dr. Roger Mee, the former chief of pediatric heart surgery at the Cleveland Clinic. "With something as complex and dangerous as children's heart surgery, you have to develop a whole team, and it's hard to develop a team around 27 cases."

"With 27 cases a year," he adds, "it would be easy to make a total mess with newborn babies."

**A Christmas day effort too late**

Two months after Amelia passed away, Pa'rish Wright was born at St. Mary's Medical Center missing large parts of her heart.

The surgery to fix her condition, called hypoplastic left heart syndrome, is one of the most difficult a cardiac surgeon will ever perform, a level five out of five on the ranking of complexity devised by the Society for Thoracic Surgeons.

"After the surgery, she had internal bleeding, and Dr. Black said he couldn't stop it," remembers Pa'rish's mother, Marquita Campbell. "We could tell he didn't know what to do. But he told me he'd transfer her to another hospital and she'd be just fine."

She says Black called two closer hospitals that do heart surgery on babies, but neither would accept Pa'rish.

Finally, All Children's Hospital, nearly 200 miles away from West Palm Beach in St. Petersburg, agreed to take Pa'rish, not yet 2 weeks old. Doctors and nurses came in on Christmas Day to assess her. "They told me her heart wasn't working, and she was on a machine to stay alive," Campbell remembers.

She weeps as she talks about the day her baby underwent such a difficult procedure at St. Mary's.

"Why did they do the surgery there if they didn't know what they were doing?" she asks. "Why didn't they just send us right to All Children's?"

The doctors at All Children's tried to save Pa'rish, but it was too late. She died January 3, 2013.

**Operating solo on babies' hearts**

Dr. Gerold Schiebler is known as the Don Corleone of pediatric heart doctors in Florida: When you have a problem, you go to him.

As babies died -- Pa'rish was the fifth to pass away -- worried heart doctors in South Florida took notice and approached Schiebler for advice, according to multiple sources.

Schiebler, a pediatric cardiologist, once ran Children's Medical Services, a part of the Florida Department of Health. Then-Gov. Lawton Chiles honored him with the state's Heartland Award, and the University of Florida College of Medicine gave him its lifetime
achievement award. There's a Gerold L. Schiebler Children's Medical Services Center building at the University of Florida, where he's a distinguished professor emeritus.

On July 12, 2013, this elder statesman of Florida pediatrics, the state's own consultant on pediatric heart issues, walked into the office of Mary Beth Vickers, an executive with the Florida Department of Health, and handed her a seven-page letter detailing his concerns.

Among them: St. Mary's had told the state the program would be working under the training and expertise of the University of Miami, which ran its own pediatric heart surgery program. Such a partnership, the hospital told the state, "will ensure the development and implementation of a high quality pediatric program at St. Mary's."

The state told St. Mary's it could start operating on children's hearts under the condition that the hospital form that partnership with the university.

But the very same day the state issued its permission, lawyers for the hospital asked to have the condition removed, saying they never asked for such a condition and it shouldn't be required.

The state agreed to remove the condition. A spokeswoman for the Florida Agency for Health Care Administration declined to explain why.

Schiebler never received a response to his letter.

'The failure of the entire team'

Pa'rish Wright's death at the beginning of 2013 marked a sad milestone: She was the third baby in just a little over a year to have heart surgery at St. Mary's only to suffer major complications and be transferred out to another hospital and die.

But this time was different because the doctor at the receiving hospital was in a position to do something about it.

Dr. Jeffrey Jacobs, who took care of Pa'rish at All Children's Hospital, is also the chairman of the Cardiac Technical Advisory Panel for Florida's Children's Medical Services, a part of the state Department of Health. He wrote a letter to St. Mary's a month after Pa'rish died offering a visit from the panel of experts.

Winter passed, then spring, and then summer. At the end of August, Landen Summerford died, the sixth baby to pass away after surgery at St. Mary's. In December, Carbone, the St. Mary's CEO, sent a letter to the state agreeing to an evaluation of his hospital's pediatric heart program.

The team of five independent pediatric heart doctors arrived at St. Mary's on April 8, 2014.

Their reviews were scathing.

The doctors found that many vital tests and services for children's hearts were lacking.

"The echocardiogram reports are uniformly inadequate," wrote Dr. Ira Gessner, a pediatric cardiologist and professor at the University of Florida, referring to reports on ultrasounds of the heart.

"The institution does not currently have pediatric electrophysiology expertise nor a pediatric electrophysiological laboratory," wrote Dr. Jorge McCormack. Electrophysiology is the study of abnormal heart rhythms.

As for cardiac catheterizations, vital procedures that can open a child's blocked vessel or fix a leaky valve, McCormack, a clinical associate professor of pediatrics at the University of South Florida, says St. Mary's wasn't doing enough of them to become adept.
The most scathing review came from Jacobs.

"It is common knowledge that multiple pediatric cardiac surgeons ... have expressed serious concern about babies having complex pediatric cardiac surgery [at] St. Mary's Medical Center," he wrote.

The "extremely low volume" of cases at St. Mary's, he wrote, was evident the day the panel from Children's Medical Services visited.

"This is my fifth CMS site review performed as a reviewer. I have never before gone on a CMS site review where the hospital under review had ZERO pediatric cardiac patients in the [intensive care unit] and ZERO pediatric cardiac patients in the hospital. On our review of April 8, 2014, at St. Mary's Medical Center ... ZERO pediatric cardiac patients were in the ICU and ZERO pediatric cardiac patients were in the hospital," he wrote.

Jacobs, a professor of cardiac surgery at Johns Hopkins University, says St. Mary's was doing too few surgeries to get good at it.

"The number of cardiac surgical procedures performed [at St. Mary's] seems to be too low for the institution and its staff to acquire and maintain proficiency in these types of challenging procedures," he wrote.

*It is the failure of the entire team and system.*

**Dr. Jeffery Jacobs**

The situation "is not the failure of any one individual. It is the failure of the entire team and system," he concluded.

When CNN filed a Freedom of Information inquiry to get the reviewers' reports, Carbone, the St. Mary's CEO, tried to intervene.

"We were under the impression this was a voluntary peer review consultative report and that the results would not be made public without our approval," Carbone wrote to Kelli Stannard, the director of Children's Medical Services, in an email obtained by CNN.

"I have been advised that we do not have the authority to 'hold' the records that have been requested," Stannard wrote back, and the documents were sent to CNN.

**Hospital performing complex surgeries against expert advice**

Jacobs' review wasn't all negative.

He commended St. Mary's for making the "important decision" to limit the complexity of the surgeries it would do on babies' hearts.

Another reviewer, Dr. William Blanchard, the associate statewide pediatric cardiology consultant for Florida's Children's Medical Services, echoed Jacobs' sentiments.

"A phased approach to performance of increasing case complexity is not just desirable, but recommended by safety and quality performance standards," Blanchard wrote, adding that only after making improvements should St. Mary's "advance to the next level of surgical case complexity in a graduated step-wise fashion."

But St. Mary's continued to do open heart surgery on tiny babies.

Nine days after Jacobs and Blanchard visited St. Mary's, the hospital performed open heart surgery on 2-week-old Weston Thermitus. He died about a week later.

Friedberg, the St. Mary's spokeswoman, acknowledged one patient died last year.
About a month later, the Department of Health sent St. Mary's a copy of the reviews from the expert panel.

Jacobs, who serves on task forces for the World Health Organization, the American Heart Association, and the Society of Thoracic Surgeons, recommended that St. Mary's not perform any heart surgeries on babies under 6 months of age. For older babies and children, he said the hospital should not perform complex procedures -- those that fall into categories four and five on the scale devised by the Society of Thoracic Surgeons.

Just 11 days after the state sent these recommendations to the hospital, Black operated on Jashnide Desamours, not yet 3 weeks old. The surgery to fix her broken aortic arch was complex, a category four out of five on the Society of Thoracic Surgeons' scale.

"The night of the surgery, she coded," Jashnide's mother, Judelande Damas remembers. Her baby was in cardiac arrest.

She came out and was bleeding through her nose and everywhere, laying in a pool of blood.

Judelande Damas

Black went back into the operating room and put bands on the baby's pulmonary arteries, another complex surgery, again a category four procedure.

"She came out and was bleeding through her nose and everywhere, laying in a pool of blood," remembers Damas, a certified nursing assistant at a rehabilitation center for the elderly.

Jashnide was put on life support, her mother says, and stayed in St. Mary's intensive care unit for more than two months.

Then she says Black wanted to do another operation.

"I said to myself, 'I'm a Christian, so let me pray.' I did, and I said I'm not going to do the surgery. I'm going to transfer her to Joe DiMaggio," she says.

After repair surgery at Joe DiMaggio Children's Hospital, which routinely averages more than 120 heart surgeries a year, Jashnide recovered and today is healthy.

On March 19 of this year, Black did another complex surgery on a baby just a few weeks old.

It also did not go well.

Davi Ricardo Brandao had truncus arteriosus, a rare defect where instead of having two vessels come out of the heart -- one to pump blood to the body and one to the lungs -- he had only one vessel. Like Jashnide, the surgery he needed was highly complex, a category four out of five.

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A few days after the March 19 surgery, Davi was placed on life support, according to his mother, Pautilia Gomes. He then underwent a second surgery, but that also did not go as expected. Doctors put him in an induced coma.

CNN contacted Dr. Amit Patange, the cardiologist who referred Gomes to St. Mary's for surgery to ask why he had chosen to refer Davi's mother to St. Mary's, given that heart doctors in the area had been concerned about the program for many months and there were two other nearby hospitals with success rates at or better than the national average.

Patange said to call St. Mary's and hung up the phone.

Then last month, Milagros Flores died after heart surgery with Dr. Black. She was 16 days old.
CNN asked Friedberg why the hospital chose to ignore the advice of the state's team of cardiac experts.

She pointed out it was just that -- advice.

"The recommendations received were not mandates by the state," she wrote.

Friedberg added that "the limitation on case selection was never intended to be permanent" and that the decision to do the complex surgery "was made following careful consideration of various factors, including specific characteristics of the patient and the cardiac defect, and the surgical team's familiarity with the procedure."

She added that after receiving the reviews, the number of category four cases performed by the program decreased to 12.5% of overall volume, compared with 24.1% in the period before that. She declined to say to what extent the hospital followed Jacobs' suggestion to stop doing surgeries on young babies or to stop doing category five surgeries on any patient.

In his statement to CNN, Carbone, the St. Mary's CEO, noted, "We are working carefully to improve our volumes."

**Florida's response**

By the middle of 2014, the state of Florida had been warned several times by highly respected experts that there was trouble at the children's heart surgery program at St. Mary's Medical Center.

In 2012, the McCarrhys filed a complaint against St. Mary's with the Florida Agency for Health Care Administration. Shelisha Coleman, an agency spokeswoman, says the agency received a complaint in 2012 and "did not find any evidence to substantiate the allegations made."

Two years later, the agency looked into the concerns brought up by the panel of expert reviewers, but "did not identify noncompliance" with the agency's rules related to the issues that were raised.

In a statement, Tiffany Cowie, a spokeswoman for the Department of Health, said, "The death of any child is a tragedy," and noted, "We continue to monitor the treatment being provided at this hospital."

The parents of children who died say they're infuriated that Florida continues to allow St. Mary's to operate on children's hearts.

"I think it just needs to be shut down completely," says Ramona Strachan, who lost her 4-month-old daughter, Keyari Sanders, after heart surgery at St. Mary's.

'We're fortunate our daughter is paralyzed'

Christine McCarthy says she feels physically ill when she hears that St. Mary's is still doing heart surgeries on children, especially complex ones on newborns.

It brings her back to the day when 7-week-old Layla woke up from her heart surgery crying inconsolably, appearing to be in extreme pain.

She says Black came in and told her and her husband that Layla was just uncomfortable and didn't need narcotic painkillers.

Tsounias, Layla's cardiologist, came in and noted that Layla's blood pressure and pulse were very high. He wanted to give her morphine. The two physicians argued in front of the couple, and Tsounias won.

"Dr. Black just kind of stormed out," McCarthy remembers. When he returned, the McCarrhys say they found his behavior odd.
"He started bicycling her legs, just moving her legs around, and he kept repeating over and over, 'well, it can't be the surgery.' He just kept repeating it. It was almost like he was talking to himself, not to us," she says.

Tsounias says the McCarthys' memory of his involvement with Layla's case is accurate. In December he left Florida and now is practicing medicine in New York.

The McCarthys say that just as Tsounias predicted, the surgeon tried to talk them out of transferring Layla to Miami Children's.

"He said, 'If you just stay here, we'll figure this out. We'll get to the bottom of it,' " McCarthy says.

McCarthy remembered Tsounias' advice to stand firm in her decision. She repeated her request for the transfer and went to sleep in Layla's room.

At 5 o'clock the next morning, McCarthy says she was awoken to Black shaking her and whispering in her ear.

"I've been up all night, and I figured it out," McCarthy remembers him saying. "It's acute transverse myelitis. Miami will blame it on the surgery, but in a month she'll be fine and back to normal.' "

With acute transverse myelitis, brief but intense swelling of the spinal cord damages myelin, the protective covering around nerve fibers.

McCarthy says Black offered to drive her the hour and a half to Miami if she couldn't get on the helicopter with Layla. She says he offered her money and food.

She said no. She just wanted out of St. Mary's Medical Center.

When they arrived in Miami later that day, McCarthy told the doctors there about Black's theory that Layla had acute transverse myelitis.

The McCarthys say the doctors tested Layla for the disease, and she didn't have it.

Today Layla is 2 years old and gets around in a wheelchair. Her parents hope one day she'll be able to walk with crutches.

The McCarthys and Keyari Sanders' parents have filed lawsuits against St. Mary's. The McCarthys say that during the surgery, oxygen was cut off to Layla's lower extremities. Keyari's parents say an artery was kinked during their daughter's surgery. The hospital and Black have denied wrongdoing.

Matt McCarthy says after Layla stopped moving her legs, the doctors at St. Mary's started talking like politicians, not physicians.

"They were dodging my questions," he says. "They were very quick to get out of the room."

He and other parents wonder if St. Mary's persists in doing surgeries on children's heart defects just to make money. The surgeries are lucrative; a study of one type of defect shows one surgery on one baby can bring in more than half a million dollars.

The McCarthys say they'll always be grateful to that stranger in the elevator who warned them to get their daughter out of St. Mary's. Without her, they don't know if Layla would still be alive.

"We're fortunate that our daughter is paralyzed and still with us," Matt McCarthy concludes. "A lot of other parents can't say the same."