

HEARTBROKEN



EVE EDELHEIT | Times

» CHILDREN continued from 13A

As Ellen continued to fold All Children's into Johns Hopkins, relationships with teams of private-practice cardiologists and critical care doctors who had played key roles in the unit began to fall away. Johns Hopkins preferred to use its own employees.

"Disrupting a chemistry in that program was what led to the problems that they have today," said Dr. Al Saltiel, who was the president of the critical care group. "You can't replace the entire team at the same time."

The changes troubled Quintessenza. After disagreements with Colombani, he was demoted, then pushed out of the program in June 2016. He had been at the hospital for almost three decades.

By the end of the year, Quintessenza was named chief of pediatric cardiothoracic surgery at Kentucky Children's Hospital. He declined to comment.

Colombani referred questions to an All Children's spokeswoman.

Midway through 2017, All Children's replaced Quintessenza with a young heart surgeon, Dr. Nhue Lap Do, straight out of fellowships at the Johns Hopkins Hospital and the Children's Hospital of Philadelphia.

Karl and Jacobs would handle all of the hardest cases.

'Take her home and love her'

Medical professionals noticed problems with surgeries performed by Karl and Jacobs as early as 2015.

Their patients were returning to the operating room to deal with unforeseen complications, six current and former employees told the *Times*.

Parents who had chosen the program for its strong reputation began having confounding experiences.

Madeline Hope Rebori was born with a complex heart condition in June 2015. Karl had already met her parents, who recall him saying the condition could be repaired with surgery. But after Madeline arrived, a different All Children's doctor told them nothing could save her, they said.

His instructions to the family: "Take her home and love her."

It is not clear who made the decision. But Brian Rebori was stunned. He asked to speak with Karl. The hospital would not make the surgeon available, he said.

The father found a surgeon at Stanford University Medical Center who agreed to review Madeline's records. In a letter, the surgeon acknowledged that her heart condition was an unusual variant of a defect called Tetralogy of Fallot. But his team had seen dozens like it and had repaired "a great majority" surgically, he said.



NEIL BEDI | Times

Jean Kariel Viera Maldonado's stitches broke, with life-changing results.

Jean Kariel Viera Maldonado first got sick in Puerto Rico, where his family lived. One hospital sent him to another. It was a cardiologist who realized his heart was enlarged and said he might be a candidate for a transplant. For that, however, he would need to leave Puerto Rico. The cardiologist recommended three hospitals: the Children's Hospital of Philadelphia, Boston Children's and Johns Hopkins All Children's. Jean Kariel's parents chose All Children's because they had family in Florida. Before the transplant in 2017, the family visited Walt Disney World. Jean Kariel sprinted through the parks and rode the junior rollercoaster. His parents hold on to that memory. Shortly after the March transplant, the stitching connecting Jean Kariel's new heart to his body broke, and he suffered a debilitating stroke. He can no longer walk. As he keeps growing, it's getting harder to maneuver him around the house and into the car. His parents worry about what's to come.



MONICA HERNDON | Times

Katelynn Whipple left the hospital with a needle in her chest.

Katelynn Whipple needed emergency heart surgery soon after her birth in July 2016. Her aorta, the body's main artery, needed to be lengthened. Her parents thought the surgery went well. But at a followup appointment days after she was discharged, they learned an All Children's surgeon had left a needle in their daughter's chest. Katelynn's parents took her back to the hospital and asked Dr. Tom Karl to remove the needle. Karl said the needle didn't exist, Katelynn's parents told the *Times* earlier this year. The needle was removed during a later surgery at St. Joseph's Children's Hospital in Tampa. All Children's ultimately settled with Katelynn's family. The hospital will give her \$5,000 annually for four years beginning on her 18th birthday, and \$25,384 on her 25th birthday, records show.

Cash Beni-King's parents begged doctors to fight for him.

Cash Beni-King had multiple surgeries in the five months he was alive. After the first, his tiny heart was too weak to work on its own. After the second, a stroke left him paralyzed. Cash died on July 4, 2017. His younger brother is named Zven, pronounced "seven" and spelled with four letters in memory of the day Cash died. Cash's mother, Yiniisi Beni, recently created a remembrance wall in the living room, hanging photos of Cash around words like "family" and "love." Looking at it brings her to tears. His father, Gold King, said he blamed himself for a while. He believes things would be different if he had chosen another hospital for his son. "He would still be here with us," he said.

All Children's later conceded that a procedure could be done, medical records show. Madeline's parents took her to a hospital in Cincinnati, where she had life-saving surgery that August. She turned 3 this year.

"I went from planning a funeral to planning a life," Brian Rebori said.

Surgical intervention is almost always recommended for babies with Madeline's condition, even if the first step is to improve the baby's chance of survival, said Dr. Michael Monaco, a pediatric cardiologist at Morgan Stanley Children's Hospital in New York.

Back at the Heart Institute, things got worse after Quintessenza left in June 2016. With Karl and Jacobs as the only surgeons, the program experienced its highest six-month mortality rate in eight years, the *Times* analysis shows. At least four children died.

Karl and Jacobs each declined to comment when reached by *Times* reporters. They referred questions to the hospital and did not respond to emails outlining the *Times'* findings. The emails did not bounce back.

In one 2016 case, which the *Times* first reported in April, Karl left a surgical needle in the aorta of newborn Katelynn Whipple. Other physicians knew it was there. Nonetheless, Katelynn was discharged with the needle in her body. It was removed three weeks later during an unrelated surgery at St. Joseph's Children's Hospital in Tampa, records show.

Leaving a surgical needle inside a patient is virtually always a serious, preventable mistake. It happened two times that year in the Heart Institute, All Children's acknowledged in April.

In June 2016, Jacobs and Karl operated on 3-year-old Alexcia Escamilla.

Alexcia had been born with a heart condition requiring three surgeries. She had already undergone one of the most challenging procedures in pediatric open-heart surgery as a newborn, performed by Quintessenza. About one in five patients die.

She survived it, and a second surgery by Quintessenza.

Alexcia grew into a happy toddler who danced around the house and chased children at parties. She played with dino-

saurs and trains, never dolls. She preferred her hair in a side ponytail. She couldn't wait for the bus that took her to preschool. Some afternoons, when it took her home, she stood firmly on the top step, refusing to climb down.

The final surgery was supposed to be much less risky than the first. The chance of complications — bleeding, infection, stroke, major organ system injury, death — was in the 2 percent to 3 percent range, according to her medical records.

This time, Jacobs took the lead. Karl assisted.

After surgery, blood began pooling around Alexcia's lungs. A vein in her esophagus had burst. It isn't clear why. She had to return to the operating room.

The next day, nurses noticed Alexcia was less responsive. A brain scan showed she had suffered a stroke. Neurosurgeons removed a portion of her skull, so her brain had room to swell. She was put in a medically induced coma.

When Alexcia woke up, she could no longer control her movements or stabilize her neck. She looked "like Gumby," recalled her mother, Rosana Escamilla. Alexcia stared vacantly at her parents.

"She lost everything I loved about her," Escamilla said.

Strokes during or after pediatric heart surgery are rare. One peer-reviewed study found they happen in 5 percent of cases. Another pegged the rate as lower than 1 percent.

A variety of factors can cause a stroke, said Dr. Francisco Puga, professor emeritus of cardiovascular surgery at the Mayo Clinic. He said poor surgical technique is one of them.

Internal warnings

The errors and rising death rates weren't the first indications hospital leaders had that the program was in trouble.

Late in 2015, the four physician assistants who worked in the operating room called for a meeting with their supervisor and Colombani, the chief of surgery. They brought up specific operations that had gone badly and expressed doubt in Karl's and Jacobs' surgical abilities, according to several people with » See CHILDREN, 15A