A NEW HEART AND HOPE FOR HOSPITALIZED BABY

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OVERCOMING ADVERSITY: Lucas Pacheco smiles at his mother Alexia Orphanides and father Brett Pacheco, above, after receiving a heart transplant, far right. At right, Brett sets up Lucas' feeding pump at their New Bedford home on Saturday.

Transplant helps 7-month-old fight genetic disease

By ALEXI COHAN

Brett Pacheco of New Bedford will always remember Father's Day of this year — it's when he found out his infant son would get a life-saving heart transplant that would finally bring an end to a monthslong hospital stay as 7-month-old Lucas Pacheco battled a rare heart condition.

Now at home with Lucas' new heart beating strong, Pacheco said happy family moments still get him choked up.

"I don't think I got terribly emotional throughout the whole process but I have these pretty emotional moments that just slap me in the face," the little boy's father said.

It all started just three months after Lucas was born — the 2019 New Year's baby at Tobey Hospital in Wareham. He caught a cold and before long, Pacheco and his wife, Alexia Orphanides, noticed his breathing was quick and raspy.

What they thought to be a common virus quickly spiraled into a monthslong stay at Boston Children's Hospital. They watched as their son became nearly unrecognizable with each IV and tube that was hooked up to the tiny, infirm baby.

Lucas was diagnosed with dilated pediatric cardiomyopathy, a rare disease in which the left ventricle of the heart is enlarged and unable to function properly, reducing the amount of blood that is spread to the body.

The genetic disease was all too familiar, as Pacheco's sister, Tara Pacheco, 43, had been diagnosed two years prior. Hers was a less-severe case that was addressed with a defibrillator implanted in her chest. Lucas, with a more-extreme case, would require a heart transplant.

"I knew we were going that route but I didn't want to admit it to myself," Orphanides said of the transplant. "I knew we were not coming out of there without it, he just seemed so bad off.

"For the month of April into May, I pretty much cried every day," she said.

Doctors tried to stabilize, medicate, intubate and extubate Lucas, but nothing seemed to work, leaving his family with excruciating days in the hospital.

"I left prior to them reintubating him and, pretty much, I curled up in a corner in the bathroom for a few minutes ... it's hard to see," said Pacheco.

Lucas soon had open heart surgery to accommodate a Berlin Heart, a type of artificial heart pump that pulls blood from the left ventricle and then sends it to the aorta, giving Lucas precious time while he continued to wait at the top of the heart transplant list.

"He was on morphine and then he had to come off the morphine, he was on ketamine, fentanyl. You hear of these drugs that are killing people on the street and we're giving it to a 3-month-old," said Orphanides, who had to adjust to a constant shuffle between the hospital and taking care of her 2-year-old daughter, Callista Pacheco.

When the life-changing call finally came from the doctor on June 16, Orphanides said, it was a mix of emotions thinking about her own child but also the infant donor. Pacheco said the news took a few moments to sink it, "I couldn't believe it," he said.

Little Lucas underwent a nine-hour heart transplant operation in June, and remained hospitalized for another month after that.

His parents were finally able to bring their baby boy home to New Bedford on July 18. The family's living room is decorated with posters from the hospital, welcome home banners, balloons and family photos.

Lucas smiles bright, wiggling around in his bouncer unaware of the telltale scar that runs down the length of his entire body and the feeding tube that protrudes from his stomach.

Orphanides' and Pacheco's new normal involves a delicate balance of feedings and measuring out Lucas' medications, some of which he will stay on for life.

The parents still feel worried each time Lucas fusses and they're scared for the future too — Lucas could need a new heart every 10 to 20 years of his life. Soon, Callista will be screened for cardiomyopathy, as she has a 50% chance of carrying the gene for the disease, like her dad.

But Lucas, surrounded by his parents, sister, aunt Tara Pacheco and grandmother Carol Orphanides is loved and supported in ways he doesn't even understand yet.

So much loved that Tara, who works at the local YMCA, received so many calls offering to help Lucas, that she set up a GoFundMe page.

"People needed and wanted to do something and this was the only avenue I can think of for those folks," said Tara. "I was having people reach out all the time."

While many turn to the crowdfunding website in times of financial desperation, the family instead saw the page as an outlet for those looking to lend a hand and grow the supportive community that was built around Lucas.

"We're so lucky in so many ways, even through his process, we've been so lucky," said Brett Pacheco.

COURTESY OF ALEXIA ORPHANIDES

Pediatric cardiomyopathy: A rare medical condition

By ALEXI COHAN

A diagnosis of pediatric cardiomyopathy can be devastating for children and their families.

"There is this sense of doom that some of the kids have," said Dr. Steven Colan, a cardiologist at Boston Children's Hospital.

Cardiomyopathy is a genetic or acquired disease that affects the heart muscle and may result in an impaired ability to pump blood and, in some cases, progressive heart failure and sudden cardiac death.

The disease has three common types that each vary with symptoms and treatment and include dilated, hypertrophy and restrictive cardiomyopathy. About 1 in 100,000 children get the condition.

Colan said about a third of infants recover, a third get a chronic form of the disease and have decreased heart function and another third require a heart transplant.

"Outcomes for transplantation are actually very good in children and those patients basically return to a fairly normal life," said Colan, though many will require a second transplant as they age.

Finding a donor heart can take months or years, said Colan. "You can really only use the heart from an infant, so it's bad news for two families, that's the real dilemma of this whole situation."

If the disease is not inherited, it can be acquired through the inflammation of the heart muscle, or exposure to certain toxins, bacteria or viruses. Patients with cardiomyopathy can experience decreased exercise toleration, shortness of breath, fluid retention, arrhythmia or a heart murmur.

Lisa Yue founded Children's Cardiomyopathy, an advocacy group, after losing two of her children to the devastating condition.

"My first child died undiagnosed from cardiac arrest and my second child died — he was on the heart transplant list," Yue said. Many children don't present symptoms until it's too late.

"There isn't formal screening right now so what we can do is try to increase awareness and educate families and pediatricians," Yue said.