

'Baby Jack' returns to Kansas City as one of the youngest heart-lung recipients in history

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With every beat of his new heart and every breath that flows into his new lungs, 8-month-old Jack Palmer is rewriting what's possible for babies with severe birth defects.

"Baby Jack" triumphantly returned home to Kansas City recently as a marvel of modern medicine and moxie, after becoming one of the youngest people to ever have a heart-lung transplant.

There is no medical textbook for this and no telling what his future will bring. But the boy who wasn't expected to live more than a few days after birth is already used to beating long odds.

"We just live each day as if it might be our last and we don't know what tomorrow brings," his mom, Tiffany Palmer, said. "We cherish every moment."

Jack was born exactly eight months ago, on Jan. 16, with an underdeveloped heart and severely damaged lungs. Many babies in his condition don't even make it to birth, much less live outside the womb.

But when The Star profiled Jack in March, he had somehow survived for two months. Surgeons at St. Louis Children's Hospital had agreed to try the double transplant—a Hail Mary pass of a procedure that only 19 other infants under age 1 have had.

His father, Chuck Palmer, is an air ambulance paramedic, and Tiffany is

a neonatal intensive care nurse, so they fully understood it was a long shot. But they also knew it was Jack's only shot.

They had a swirl of emotions when they got the call that compatible heart and lungs had become available. Jack went in for surgery May 23.

"Walking into that unit that day the entire staff was just ecstatic because Jack was up for a transplant and they had accepted organs," Chuck said. "Just the smiles, the tears. (But) I mean, it was scary. We didn't know if it was going to be our last day with him or if it was going to be a miracle that day."

Cardiothoracic surgeon Pirooz Eghtesady led the procedure, which ended up taking 11 hours.

He had done heart-lung transplants before, but never on someone Jack's age. Jack also needed a reconstruction of the arch where his aorta, a major artery, connected to his heart. Eghtesady had done that complex procedure before, but never in combination with a heart-lung transplant.

"I knew it was a high-risk operation, but at the same time the flip side of it was pretty obvious too," Eghtesady said. "Meaning that if we didn't operate on him, if we didn't do something, he wasn't going to live."

Jack had hypoplastic left heart syndrome, a congenital birth defect in which the side of the heart that pumps blood to the rest of the body doesn't develop properly. The syndrome is responsible for 23 percent of heart-related deaths in children under 1. And Jack also had an intact atrial septum, which means his heart was missing the hole that allows oxygenated blood to travel to the left side and be pumped to the rest of his body.

Only about 6 percent of babies are born with both conditions, according

to the Society for Cardiovascular Angiography and Interventions.

A paper published in the journal *Circulation* in 2004 called it a "highly lethal combination," and the authors said they were working to develop in-utero surgeries because attempts to fix it after birth had resulted only in "persistently poor outcomes."

As if that weren't enough, Jack also had damaged lungs. But no one knew how badly damaged they were until Eghtesady started the transplant operation and almost immediately ran into a serious complication.

Jack's left lung had completely collapsed and was stuck to the wall of his chest.

"It had become like one with his body, so taking that out was quite challenging," Eghtesady said.

Sitting in the waiting room, Tiffany and Chuck got hourly updates but were powerless to do anything. Jack had gone into surgery at 4 p.m. and wouldn't get out until 3 a.m., but neither of them could sleep.

Eventually an exhausted Eghtesady came out and told them the surgery was over. Aside from the complication with Jack's lung, everything had gone well. But Jack had been on a heart-lung bypass machine for an exceptionally long time for his age, and the next few hours would be critical.

"He more or less just said, 'It's up to Jack. We'll see how Jack does,' " Tiffany said.

Jack was the youngest person in 10 years to have a successful heart-lung transplant in the United States. No infant has survived for a full year

after the procedure, experts say.

But almost four months later, Jack is so far doing quite well.

He and his family stayed in St. Louis until late August as he recovered from surgery and got accustomed to the immunosuppressant drugs that he will have to take the rest of his life to keep his body from rejecting the new organs.

Back in their Northland home, Jack can now roll onto his side, hold his head up by himself and sit up with a little help. Minor milestones for most babies his age, but incredible gifts for Jack's family.

The Palmers have to wait a year after the transplant before they can send a thank-you letter to the donor's family. They feel for the donor's loved ones and want them to know what a tremendous gift they've given, but Tiffany said she and Chuck aren't sure yet how to put that into words.

"Every day I think of what that letter would look like and sound like," she said. "I have some time, but a simple 'thank you' isn't enough. (There are) just so many emotions, and we're just so thankful organ donation is even a possibility. Especially someone losing their child, who made that decision to give life to somebody else."

Chuck said he hopes that Jack's story spurs others to sign up for organ donation. And he hopes the experience advances medical knowledge so that other babies like Jack can live longer.

Eghtesady said he and his team are already writing up a case study of the little boy from Kansas City who beat the odds just by breathing.

"The main message that really Jack offers is a glimpse of hope for these babies," Eghtesady said. "What he has is not the cure, but I think it's at

least in the interim substantially better than what was historically the option for these babies.

"Hopefully there will be some degree of paradigm shift and more people will consider heart-lung transplants as a therapy for these babies who otherwise have dismal outcomes."

How to donate organs

You can sign up to be an organ donor in person at your local Division of Motor Vehicles office, or online at organdonor.gov. Tell your family about your [organ donation](#) wishes to ensure they're honored. To be a living donor of bone marrow or kidneys, contact [transplant](#) centers. More information is available on the United Network for Organ Sharing website, transplantliving.org.

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