

Newborn with heart defect saved after 13-hour operation

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Jackson Lane was just 5 days old when he underwent a 13-hour operation to overhaul his heart. Credit: Courtesy of the Lane family

The baby's condition, tetralogy of Fallot, was complicated by the fact that he was also missing his pulmonary valve and one of his pulmonary arteries was detached. But a doctor gave the distraught parents a glimmer of hope.



Five-month-old Jackson Lane has a large scar that looks like a giant zipper down the center of his chest.

His father, Andy Lane, a former coach for the Chicago Cubs, calls it a baseball scar. That's because it looks a lot like the seams of a hardball, and underneath the scar is a heart that some thought would never beat on its own.

Elyse Lane was 20 weeks pregnant in June 2014 when she went for a routine fetal exam at her doctor's office in Phoenix. She and Andy knew they were having a boy and, based on earlier appointments, they didn't expect any surprises at this one. But the ultrasound found there was something wrong with the baby's heart.

The first specialist they saw told them the baby was missing his pulmonary valve and that the <u>pulmonary artery</u> was massive. The artery was so large—10 times the size it should have been—that it was significantly and dangerously impeding the growth of his airway. Their doctor told them they should consider terminating the pregnancy. Even if the baby made it to term—and the doctor cautioned that it wasn't clear he would—he likely would need mechanical assistance to breathe.

Tetralogy of Fallot

"When we asked what the outlook was and what his life expectancy might be, we got vague answers," Elyse said. "It was heartbreaking."

Two days later, they took a red-eye flight to Boston in search of second opinion. There, a specialist told them their baby had a condition called tetralogy of Fallot, a rare heart defect affecting blood and oxygen flow. The baby's condition was complicated by the fact that he was also missing his pulmonary valve and one of his pulmonary arteries was detached. But the doctor also gave the distraught parents their first



glimmer of hope. The baby appeared strong and active in utero, and, if he made it to term, there was a surgeon who could fix the problem not too far from their Arizona home: Frank Hanley, MD, cardiothoracic surgeon at Lucile Packard Children's Hospital Stanford and Stanford Children's Health.

The couple came to Palo Alto to discuss an intricate and complex repair with Hanley. The baby's rare condition was extremely severe, but Hanley wouldn't know how quickly his team would need to operate until after the birth and determining how compromised the infant's breathing was. The most important thing the couple could do was to try to deliver the baby as close to term as possible. They went back to Arizona and waited.

"Once we met Dr. Hanley, I knew everything was going to be OK," Andy said. "We just fed off his confidence. He told us: 'I've done this before, and I can do this again.'"

Renewed hope

With renewed hope, the Lanes now had to find a way to make it all happen. Andy turned to his baseball roots, and contacted the Baseball Assistance Team to see if the league-affiliated organization could assist with their looming medical, lodging and travel expenses. Just before the delivery, they learned that BAT had approved a significant grant to help them out. Following their plight on social media, ballplayers who were <u>friends</u> of Andy, as well as their wives, also got involved, raising additional money for a Jackson fund that they created.

When Elyse was 36 weeks pregnant, she and Andy packed their bags and flew to California, expecting to spend the last four weeks of her pregnancy near Lucile Packard Children's Hospital, where she would deliver the baby and Hanley would perform the surgery. Two days later, however, with the baby's heart rate fluctuating wildly, doctors told the



Lanes they needed to induce labor.

Six-pound, 5-ounce Jackson Lane arrived at 10 p.m. Oct. 10—nearly four weeks early—in a room filled with a team of 13 care providers, including doctors and nurses. Jackson arrived "worst-case scenario," said Hanley—unable to breathe on his own. The enlarged pulmonary artery had severely compressed his bronchial tubes, and he was whisked away to the neonatal intensive care unit, where he was put on full life support.

"Jackson's presentation was about as dramatic as you can get," said Hanley, a professor of cardiothoracic surgery at the School of Medicine. "A case of this severity only comes around once every four or five years." Hanley decided he'd need to perform the surgery soon because the baby couldn't breathe on his own.

When he was just 5 days old, Jackson underwent a 13-hour operation that would save his life. Hanley and his team did a complex overhaul of Jackson's heart: They inserted a <u>pulmonary valve</u>, reduced the size of Jackson's right pulmonary artery, and enlarged his small, disconnected left pulmonary artery. Hanley also used an innovative and intricate procedure known as the LeCompte maneuver, which moved Jackson's right and left pulmonary arteries from the back of the heart to the front. This gave his severely compromised bronchial tubes – which had been compressed by the enlarged artery—room to grow and remodel after surgery was over.

Home in time for Christmas

"The benefit of moving it from behind to in front is that it takes the pressure off of the breathing tubes," said Hanley, who is also the Lawrence Crowley, MD, Endowed Professor in Child Health. "It's like driving a car; there are different routes you can take to get to the same destination. As long as the pulmonary arteries are re-routed in



unobstructed fashion, there is no downside to having it in front of the aorta."

Incredibly, Jackson and his parents left the hospital just after Thanksgiving when their newborn was just 7 weeks old—four months earlier than anyone expected. Because of the surgery, Jackson's airway tubes were wide open and he was breathing normally.

"Nobody in the hospital could believe how quickly he recovered," said Elyse. "We are just so lucky that we found Dr. Hanley and that our son fought for his life."

Jackson and his parents were thrilled to be home in time to celebrate his first Christmas. "We are so grateful. He's our Christmas miracle," said Andy.

Other than a few tune-ups—he'll need to have a heart valve replaced as he gets bigger—Jackson is now expected to have a long and normal life.

"He can now do anything he wants in life," said Elyse. "He's already made it through the biggest challenge."

Provided by Stanford University Medical Center

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