

The story of two separated twins, from four of the doctors who made it happen

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Doctors have no map for how to separate conjoined twins.

The complex surgery is so rare and unique to each individual pair of



babies that medical teams often start from scratch when evaluating whether twins could even survive the operation. Add the months of planning required before entering the <u>operating room</u> and the surgery becomes even more arduous.

A group of 25 medical staff at Cook Children's Medical Center carried out such a surgery on Jan. 23. For one <u>plastic surgeon</u>, Dr. Ben Gbulie, the case represented his third time separating twins. For most of the other practitioners, it was the first time they'd ever performed the risky operation.

But by the time the team got to surgery day, they were all on the same page.

"A few days before, the one thing I said was 'ego goes all the way out of the room. Everybody knows their role and everybody helps out.' And you guys actually did amazing," Gbulie said.

The monumental surgery gave independence back to 16-week-old AmieLynn and JamieLynn Finley. Here's what four of the doctors had to say about how they made it happen and what lies ahead for the twins.

The team assembles

Amanda Arciniega, mother of AmieLynn and JamieLynn, saw specialists during her pregnancy that most <u>pregnant women</u> never have to visit. The long road to the separation of the twins—the first ever such surgery performed at Cook Children's—began months before their birth and was a highly unusual process.

Gbulie, who runs a private practice in Mansfield and is a member of the plastic surgery faculty at Cook Children's, joined the twins' medical team when Arciniega was three months pregnant, meeting with the mom



of five a handful of times before she delivered her fourth and fifth children via <u>cesarean section</u> at Texas Health Harris Methodist.

"It was always interesting having a <u>pregnant woman</u> come to a plastic surgeon's office," Gbulie said.

The doctors at Texas Health and Cook Children's took scans of the babies while still in their mother's uterus in an attempt to visualize where they were joined and what organs they shared. Luckily, the imaging showed they only shared a liver, making the separation easier.

Neonatologists Dr. Mary Frances Lynch and Dr. Chad Barber, who primarily care for newborns, also joined the team during Arciniega's pregnancy. They immediately hatched a game plan for before and after the surgery that would focus on the twins as individuals so that each could receive the special treatments they needed.

"With them being conjoined, it was still really important that we focus a lot on them being individuals. We know it was important just starting at delivery that we needed a full team for each baby," Barber said.

The medical staff divided in two: One side wore green scrub caps and focused on AmieLynn, while the other wore purple and focused on JamieLynn.

The decision to use the colors purple and green was partially influenced by the fact that other colors, like blue and red, have other meanings in an operating room. The other, much smaller part of the decision "was a Baylor-TCU thing, a little bit," Barber said.

Ahead of the surgery, the teams made a 3D model of the twins' conjoined chest and practiced the intricate movements of the surgery on plastic babies. They prepared for the moment they would have to move



one of the babies to a second operating table. They thought through every possible worst-case-scenario and stocked up on any technologies they could need.

No one would know exactly what surprises could have evaded their careful preparation until the first incisions were made.

"We were preparing for all kinds of potential surprises. We had detailed imaging, but we hadn't seen inside yet," Barber said. "Were there other blood vessels that were crossing over? Or were their intestines joined?"

Surgery day

The surgeons and <u>medical staff</u> walked into their operating room on Jan. 23 like athletes walking into a championship game: Completely focused and ready for a fight.

"I was thrilled and just really excited for the opportunity," Lynch said. "These are so rare and it's what we train for."

The operation itself spanned 11 hours, although no surgeon made an incision until hour five. Like a finely choreographed dance, each team member performed their job with precision and focused on their assigned twin.

Separation of the twins marked the one time the Cook Children's group allowed themselves to cheer. Then, just as quickly as they breathed a collective sigh of relief, they returned their focus to finishing the surgery.

Almost none of the potentially-bad surprises the team prepared for came to fruition.



"It's definitely hard to put a number of hours on the length of time we spent preparing, but we had multiple meetings leading up to it not only in preparation to make the plan for the surgery but also to plan for the actual day," said pediatric surgeon Dr. Marty Knott. "So, it's a lot of hours, but it was worth it when it all went so well."

Surgeons successfully closed JamieLynn's incision but had to leave AmieLynn's open. Still, Gbulie said he expects she'll heal well.

The road ahead

Recovering from any major <u>surgery</u> takes time, especially one this intense. Doctors wouldn't speculate when the girls will get to go home—right now they're only focused on moving through one day at a time.

Some of the biggest priorities are pain management and making sure their major organs, like their lungs and intestines, are working properly. The twins are still on ventilators and it might be a while until they can breathe on their own.

The team will have to constantly evaluate what types of support AmieLynn and JamieLynn need over the next weeks and months.

"Then, one of the biggest ones is all the developmental stuff," Barber said. "They can now try to be normal three-and-a-half month olds, not ones that are restricted in their movement and what they can do."

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