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Mom: 'They are my babies'

Conjoined twins locked in battle for life

By Deborah L. Shelton, Tribune reporter

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Lying face to face, with one arm draped around the other, Kaydon and Kameron appear to be locked in a loving embrace.

But the boys, not yet 3 months old, have no choice but to hug each other every minute of every day. They are conjoined twins who share a liver and a single malformed heart.

Doctors discussed terminating the pregnancy with the mother, Brianna Manns, 21, after they determined the twins were not likely to survive. But Manns said abortion was never an option.

"I am a strong believer in not having abortions — very, very strong," said Manns, taking a break from the neonatal intensive care unit at University of Illinois Medical Center at Chicago, where her sons are hospitalized. "And they are my babies."

The boys, born March 31, have lived longer than doctors predicted, but they are critically ill. Medical experts say they cannot be separated and are not candidates for a heart transplant because of their complicated anatomy. They cannot breathe without a ventilator and are fed through tubes. Periodically, the babies go into distress and must be resuscitated to prevent them from dying.

Manns has declined to sign a do-not-resuscitate order, saying she wants to give her children every chance at survival. "There must be a reason why I have special babies like this," she said.

But the process has been agonizing for doctors and nurses at the medical center, some of whom worry that their interventions might be going too far. They don't want the babies to suffer.

"We empathize with her, but as health care providers, knowing what we know, we don't want to see the babies die in an agonizing way," said neonatologist Dr. Helen Kusi. "That's where we are not on the same page with her. We haven't given up, but we have to face reality."

Swirling around the two boys is a host of questions. How much intervention is too much —



medically, financially and ethically? Are the hospital's measures extending life — or prolonging death?

Twins are rarely born conjoined, but parents and health professionals frequently grapple with dilemmas about treating severely ill infants. Parents of these babies often find it difficult to turn off life-sustaining machines or stop treatment even when there is little or no hope of recovery, medical experts say.

In Manns' case, doctors have been wrong before about the twins' survival chances, first saying they would be stillborn, fueling her hopes that they could be wrong again.

On her visit, Manns caressed the babies' coal-black hair, stroked their silky smooth backs and cradled their delicate hands. The first-time mother hovered over their isolette in a darkened room of the NICU and turned on a Fisher-Price musical toy that serenaded the boys with a lullaby. Nearby hung a photo of Manns and the boys' father, Eric Hayes, wearing yellow hospital scrubs.

The twins' multiple medications, heart monitors, intravenous tubes, tracheotomy tubes and ventilator have not undermined Manns' faith that the babies will survive. She is supported in her decisions by members of both her family and the father's family.

"At the end of the day, it's God's say-so," she said. "I believe in God 100 percent. Yes, the machines are man-made. But God gave them those machines as well. Everything goes back to God."

Doctors say they recognize Manns' difficult situation, as well as their obligation to do what she decides is best for the boys. But they also feel an ethical obligation to spare the babies unnecessary suffering, a dilemma that a medical center ethicist said has caused some of the infants' caretakers "moral distress."

"Sometimes, goals conflict," said Lisa Anderson-Shaw, director of the medical center's clinical ethics consult service. "As much as we might want to fix all that ails these babies, it's just not possible."

At the same time, hospital staff understand Manns' position and want to support her during an emotionally wrenching experience, Anderson-Shaw said.

Thoracopagus twins, the most common type of conjoined infants, are united at the thorax, facing each other, and often share a fused or deformed heart.

The upper chambers of the Manns twins' single heart, known as the right and left atria, have a large hole between them, as do the lower pumping chambers, called the right and left ventricles. As a result, deoxygenated "blue" and oxygenated "red" blood are constantly mixing.

The twins also have other abnormalities of the heart and surrounding blood vessels. Most of the boys' shared liver is in Kameron's body. Both boys have undeveloped lungs, among other problems. Before Manns arrived for her visit, Kameron started having seizures for the first time, and his kidneys appeared to be failing.

Dr. Eric Strauch, associate professor of pediatric surgery at the University of Maryland Medical Center, said he has successfully separated two sets of twins connected at the atria but that no

twin connected at the ventricles has survived separation surgery. Manns' children share both types of chambers.

The hospital sought an outside opinion from a cardiologist and forwarded medical records to other medical centers after the boys' family members asked for additional evaluations.

Manns' mother, Yolanda Butler-Hamer, has scoured the Internet searching for medical centers that might consider the boys for possible separation surgery and a heart transplant. So far, none contacted by the family or the hospital think it is possible. Strauch said he sees at least one or two cases a year of thoracopagus twins, but most cannot be saved. The Manns twins "didn't have enough cardiac chambers, and there were too many cardiac abnormalities to successfully separate them," he said.

One of the twins' worst days was May 17, when their heart and breathing rates plummeted. Their parents rushed to the hospital, where they were told to say their goodbyes. The boys rebounded, but their conditions have become less stable.

"They would have died on the 17th if not for the aggressive intervention," Kusi said. "This is where the pain comes from. If we had left the children alone they would have died, but because we can push medications and fluids, we resuscitated them back."

Anderson-Shaw said the hospital's goal is quality of life that includes comfort care and pain management.

"We're not providing them curative therapy, we are just prolonging the dying process," she said. "They are growing, but their organs will fail."

The expense of treating critically ill children whose chance of survival is slim raises larger social issues. The hospital bill, which is being charged to Medicaid, was about \$792,000 as of June 1.

Manns says she will never stop trying to get the best for her boys. A homemaker for clients of a home care company, she spends up to two hours on public transportation getting to and from the hospital.

"It's tough, but I don't let it overshadow what I see every day," said Mann. "I will not give up. I will never give up. My boys have not stopped fighting, so why should I?"

Both sides of the family have bonded with the twins. The boys have regular visitors, including their paternal grandmother, Celinda Hayes. "They are my heart," she said.

Manns said she prays often for her little boys, hopeful that they will live as long as possible.

"I pray for strength, wisdom and guidance every night," she said.

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About conjoined twins

- There are nearly a dozen types of conjoined twins. Thoracopagus twins, who are joined at the thorax, make up about 40 percent of all cases.
- About 40 percent to 60 percent of conjoined twins are stillborn, and another 35 percent survive only one day. The overall survival rate of conjoined twins is somewhere between 5 percent and 25 percent.
- Because conjoined twins are genetically identical, they are always the same sex. They develop from the same fertilized egg and share the same amniotic cavity and placenta.
- More male twins conjoin in the womb than female twins, but conjoined girls are three times as likely as boys to be born alive. About 70 percent of all conjoined twins are girls.
- Fraternal twins occur when a woman releases two eggs instead of the usual one and they are fertilized by separate sperm. Identical or paternal twins occur when a single, fertilized egg divides and separates. With conjoined twins, the single fertilized egg does not fully separate and develops into conjoined fetuses.

SOURCE: University of Maryland Medical Center

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