

Sarah Murnaghan Had Two Lung Transplants, One Failed

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The 10-year-old girl whose parents successfully fought a rule preventing her from qualifying for adult lungs didn't have just one lung transplant from an adult donor this month.

She had two.

Sarah Murnaghan's family today revealed her June 12 lung transplant failed almost immediately and left her on life support. Unlikely to survive for more than a week in that condition, Sarah went back on the transplant list. She had a second lung transplant – again from an adult donor – on June 15.

"After we announced the overwhelmingly joyful news on June 12 that Sarah's lung transplant was a success, things quickly spiraled out of control," Sarah's parents, Janet and Fran Murnaghan, said in a statement. "That evening, as we waited for Sarah to be transitioned back to her room, an emergency code blue was announced.... The news was grim."

Sarah was suffering from "primary graft failure" because the donor lungs were in poor condition, the Murnaghans wrote. Patients who experience this complication die half of the time, they added.

Sarah was put on life support and approved to be re-listed for an adult lung transplant the following night in accordance with the Organ Transplantation and Procurement Network's new policy that allows patients to be exempt from the so-called Under 12 Rule on a case-by-case basis.

Sarah's second donor lungs were high risk because they were infected with pneumonia, according to the statement. This was known before surgery. A healthier patient might have turned down the lungs and waited for a better pair, but Sarah was out of options, so they went ahead with the operation.

"They were Sarah's best and only hope," the Murnaghans wrote.

But the operation was "truly a success," and Sarah got better each day, the family wrote. A week later, on June 21, doctors closed Sarah's chest, and she was slowly brought out of her induced coma.

Sarah, who was dying of cystic fibrosis this time last month, had her chest tubes removed June 28, and she is expected to be able to breathe without the assistance of a ventilator soon.

Cystic fibrosis is a genetic condition that affects cells that produce mucus, sweat

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and digestive fluid. Patients typically suffer so much lung damage that they often go into respiratory failure, which is why Sarah needed a lung transplant to survive.

About a month ago, Janet Murnaghan started a viral Change.org petition, calling attention to what would become known as the Under 12 Rule, which said that even though Sarah would be given priority when pediatric lungs became available, adult lungs would have to be offered to adult matches in her region before they could be offered to her.

On June 5, a federal judge issued a temporary restraining order to prevent Health and Human Services Secretary Kathleen Sebelius from enforcing the rule for Sarah. By June 10, the Organ Transplantation and Procurement Network re-evaluated the Under 12 Rule and decided to keep it but created a mechanism for exceptions to be made depending on the case.

Doctors at Children's Hospital of Philadelphia first removed Sarah's chest tubes on June 26 but had to replace them because Sarah's body "could not handle the reduced support" at the time, Janet Murnaghan wrote on her Facebook page that day.

This, the Murnaghans revealed today, is because the surgeries caused Sarah to have a "partially paralyzed diaphragm." She will have diaphragm surgery to ease extubation on Monday.

"The important thing to us is that sweet little girl is back with us and is very much alive," the Murnaghans wrote. "She is communicating, she has sat on the side of her bed and started exercising her arms and legs. And she is determined than ever to walk out of the hospital and go home to her brothers and sister."

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