Girl Who Took On Transplant Rules Gets New Lungs

Malcolm Ritter

A 10-year-old girl with cystic fibrosis was recovering from a transplant of adult lungs after a judge's ruling expanded her options for lifesaving surgery.

Sarah Murnaghan underwent a six-hour surgery Wednesday at the Children's Hospital of Philadelphia, a procedure her aunt said resulted because of the larger list of available organs.

"It was a direct result of the ruling that allowed her to be put on the adult list," Sharon Ruddock said after her niece's surgery was completed successfully. "It was not pediatric lungs. She would have never gotten these lungs otherwise."

She said the donor lungs came through "normal channels" and not through the public appeals the family made in its bid to find a compatible donor. No other details about the donor lungs are known.

The Murnaghan family's quest to qualify their daughter for an organ transplant spurred public debate over how donor organs are allocated.

Her family and the family of another cystic fibrosis patient at the same hospital challenged a lung transplant policy that creates a separate waiting list for children under 12. The national transplant network says the under-12 policy was intended to increase access by giving children priority to donors of similar age and size but that children could also be offered donor adult lungs after teens and adults on the waiting list had been considered.

The families argued that pediatric lungs are rarely donated and asked for their children to be put on the adult waiting list, too.

Sarah's health was fading when U.S. District Judge Michael Baylson in Philadelphia ruled June 5 that Sarah and 11-year-old Javier Acosta of New York City should be eligible for adult lungs.

Critics warned there could be a downside to having judges intervene in the organ transplant system's allocation policy. Lung transplants are difficult procedures and some say child patients tend to have more trouble with them than adults. Complications from transplants can include rejection of the new lung and infection.

Ruddock said the family was optimistic about Sarah's recovery.

"If everything goes perfectly, she could be out in a couple of weeks, running down the hall," Ruddock said. "It could take a couple of months, it could take three

weeks."

The Murnaghan family noted that Sarah's successful surgery was the result of another family's loss:

"We are elated this day has come, but we also know our good news is another family's tragedy. That family made the decision to give Sarah the gift of life — and they are the true heroes today."

On Wednesday, in a posting on her Facebook page, Janet Murnaghan said she and the family were "overwhelmed with emotions" and thanked all her supporters. She said the donor's family "has experienced a tremendous loss, may God grant them a peace that surpasses understanding."

Ruddock said Sarah doesn't yet know the full extent of the impact her case has had.

"She really wanted to Google herself the other day and we were like, no."

The Organ Procurement and Transplantation Network — the national organization that manages organ transplants — added Sarah to the adult waiting list after Baylson's ruling. Her transplant came just two days before a hearing was scheduled on the family's request for a broader injunction.

The network has said 31 children under age 11 are on the waiting list for a lung transplant. Its executive committee held an emergency meeting this week but resisted making emergency rule changes for children under 12 who are waiting for lungs, instead creating a special appeal and review system to hear such cases.

Murnaghan's family "did have a legitimate complaint" about the rule that limited her access to adult lungs, said medical ethicist Arthur Caplan of the NYU Langone Medical Center in New York.

"When the transplant community met, they didn't want to change that rule without really thinking carefully about it," he said. The appeals process that was established this week was "built on evidence, not on influence."

He added: "In general, the road to a transplant is still to let the system decide who will do best with scarce, lifesaving organs. And it's important that people understand that money, visibility, being photogenic ... are factors that have to be kept to a minimum if we're going to get the best use out of the scarce supply of donated cadaver organs."

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