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Boy, 13, Dies After Dispute Over Life Support Is Settled

By Kareem Fahim

Teron Francis, the 13-year-old Bronx boy who slipped into a mysterious coma about nine days ago, died yesterday after his parents asked doctors at a Bronx hospital to turn off his respirator. His death ended a bitter feud between the family's lawyers and officials of the Montefiore Medical Center over his care there.

A spokesman for the medical center, Steven Osborne, said that the ventilator that had sustained Teron's organs was turned off at the request of his family, and that his heart stopped beating at 5:05 p.m.

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The arguments over Teron's treatment were marked by what both sides called miscommunications. Lawyers for the Francis family said that their clients felt mistreated by hospital officials, particularly when two doctors told family members that Teron would be taken off life support without their consent, an assertion the hospital denies.

"The family had difficulty reaching out and communicating after that," Mr. Genis said.

Montefiore's medical director, Gary Kalkut, said that Mr. Genis's involvement had disrupted the normal course of counseling between doctors, social workers and grieving family members.

Some of the dispute seemed to hinge on language, which was reminiscent of the case of Terri Schiavo, the Florida woman who was removed from life support last month after a prolonged and bitter legal fight between her parents and her husband and their respective allies.

Hospital officials said they used accurate medical terminology to describe Teron's state. They shied away from using the term "life support," for example, and maintained that the boy was dead—not "brain dead"—because he had no brain function. Mr. Genis said that language contributed to an atmosphere of mistrust on the part of the family.

"The Schiavo case is the backdrop, but it is important to understand the differences between the two cases," Dr. Kalkut said. "Teron Francis was dead and it wasn't a question of whether he was responding or not." He accused Mr. Genis of conflating Teron's case with Terri Schiavo's.

Teron was sent to Montefiore on April 19 at the request of Bronx-Lebanon Hospital, where he was first taken after he fell ill, Dr. Kalkut said. Doctors at Montefiore suspected then that he was brain-dead, Dr. Kalkut said, and when tests over the next two days confirmed that suspicion, he was declared dead on April 21. On Monday, Justice Douglas McKeon of State Supreme Court in the Bronx granted Mr. Genis's request for an injunction barring the hospital from taking Teron off his respirator.

Both sides say that in the days that followed, Justice McKeon's mediation eased the impasse between the family and the hospital. On Wednesday night, a doctor not connected to the hospital visited Teron, and confirmed the Montefiore diagnosis that he was brain-dead. Then yesterday, Mr. Genis returned to court at the request of the Francis family, and asked Justice McKeon to vacate the injunction, allowing for Teron's removal from the respirator.

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The Line Between Life and Death By Gary Kalkut and Nancy Neveloff Dubler.

Gary Kalkut is vice president and medical director of the Montefiore Medical Center. Nancy Neveloff Dubler is director of its division of bioethics.

LATE last month, New York's major newspapers reported that a 13-year-old boy had "died" after he was taken off "life support." That assertion reflected a fundamental misunderstanding of death as defined by the laws of all 50 states. In fact, the boy had died more than a week earlier—from a severe brain infection—after transfer to the hospital where we work. In the interim, advanced medical technology supported his organs, not his life.

Death shouldn't be this hard to understand, yet it often is. According to the 1987 New York State Public Health Regulation, death occurs when either the heart or the brain irreversibly ceases to function. Before medical technology provided breathing machines, there was no meaningful distinction between brain and cardiac death. Once the brain stopped sending signals to the lungs to breathe—on account of a stroke or head injury, for example—the heart would stop within minutes. Now that machines can deliver oxygen to the lungs, however, the heart can continue to beat for days without any signal from the brain.

For centuries we understood death, whatever its cause, as the cessation of heart and lung function. A person was dead when the pulse faded, the heartbeat became inaudible and the chest ceased to rise. Brain death is harder to discern. A brain dead person whose heart and lungs are sustained by machines looks as if he's in a coma. For a family who has lost a loved one, often from an acute illness or terrible accident, it is unspeakably difficult to accept that this warm body with a heartbeat is lifeless. And yet, to imply that a brain-dead person is still alive only prolongs the loved ones' anguish. Such misunderstanding gives false hope and preys on the survivors' feelings of guilt.

The way this subject has been addressed in recent news stories could leave a person bewildered, but the facts are actually straightforward. Brain death should not be confused with a persistent vegetative state or a coma. In brain death, the entire brain irreversibly ceases to function. Everything shuts down: the cerebral cortex, which controls higher functions, as well as the brainstem, which regulates automatic actions like heartbeat and breathing. In a persistent vegetative state, the cerebral cortex has been destroyed, leaving the person incapable of thought or memory, but the brainstem remains intact and functional. A person in a persistent vegetative state can live for years without a mechanical ventilator or other technological support. That was Terry Schiavo's situation. There was no question that she was alive. Her heart and lungs received signals from her brainstem -- they didn't need machines to sustain their activity.

Then there's coma, which is just a general term for lack of responsiveness. A person can fall into a coma for any number of reasons. The coma can be temporary, as it is during general anesthesia, or permanent, as sometimes happens following injury. Only detailed neurological testing can determine the extent of brain injury or its prognosis.

The 13-year-old boy who died this April was not in a coma or a persistent vegetative state. He died of a brain infection a week before he was taken off mechanical support. The obligation of a hospital after the death of a patient is to turn its expertise toward supporting the family. After this child passed away, his family's personal tragedy was laid bare in court and in the news media, as a result of a dispute between the family's lawyer and our hospital over the continued use of a respirator.

With a better understanding of death, this could have been avoided. The dead are not kept alive on life support, and they don't die again when machines are stopped. We need to make this clear if we wish to honor the dead, protect vulnerable families and use the astonishing medical technology at our disposal to heal those whom we can actually help.