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## Schiavo family honors parents of brain-dead girl

by [Michael Vitez, Inquirer Staff Writer](#), Posted: March 28, 2014

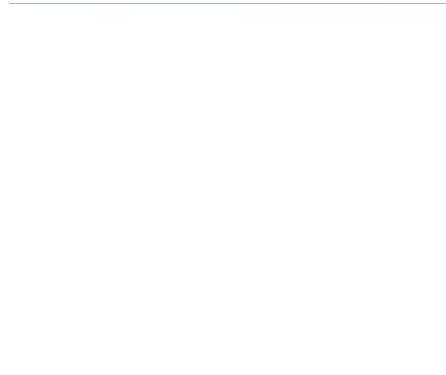


The family of Jahi McMath, the 13-year-old California girl whose parents refused to accept a finding of brain death, was honored for courage and perseverance Thursday night at the Union League by the family of Terri Schiavo.

The McMath family went to court in December to oppose the removal of a ventilator and feeding tube even after three physicians determined that there was no brain function and a coroner issued a death certificate.

A month later, the body of the girl - organs still working - was taken to an undisclosed medical facility, where the heart still beats. A manicure and pedicure are given every Friday.

Her mother, Nailah Winkfield, said Thursday that her daughter "is getting love, respect, and care. She is beautiful. Her skin is flawless. Physically she is healthy and stable. We are waiting for her to wake up."



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It has been a decade since the case of Schiavo, who was born in Huntingdon Valley and met her husband at Bucks County Community College, embroiled Congress, President George W. Bush, and much of the nation in a family dispute over the removal of a feeding tube 10 years after she collapsed into a coma in Florida.

Her brother, Bobby Schindler of Narberth, said that he felt the McMaths' decision to fight for their daughter was about medical rights and patient autonomy, which he sees as being eroded.

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Brain death diagnosis is not a settled matter, he said. "The McMath family saw signs of hope, and they should be given the opportunity to provide their daughter hope. That's the bigger picture here. Who ultimately is going to make decisions for our loved ones? Is it going to be strangers - hospitals and ethics committees? Or is it family members?"

Two medical ethicists, a neurologist and a lawyer specializing in end-of-life issues all expressed dismay at the award, saying that it ignores reality, will confuse the public, and attempts to turn back what has been accepted by every state and the Vatican - that brain death is death.

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"Patient autonomy is important and so is family decision-making, but they come to an end when death comes," said Arthur Caplan, a bioethicist at New York University.

"One bright line that I don't think we can cross without causing havoc in our society is the line between life and death," he added. "And the line is set by medicine - not by families, not by lawyers, not by theologians. It's doctors who say that person is dead. They are the experts."

Howard Hurtig, a Pennsylvania Hospital neurologist who has diagnosed brain death in many patients, called the presentation of an award under these circumstances "obviously surreal."

Hurtig said he understood the shock and pain of grieving parents, but said that doesn't alter the facts. "Every professional in this field accepts that when brain death is defined properly by the rules, it's death," he said.

Jahi McMath - "everyone's favorite," her mother said - had her tonsils removed to alleviate sleep apnea at Children's Hospital Oakland on Dec. 9.

"There were complications after surgery," she said, tears welling in her eyes. "She bled severely and went into cardiac arrest in front of me. It was traumatic, and I will never be the same."

Two doctors at the hospital and a pediatric neurologist from Stanford University concluded there was no brain activity and she was brain-dead. The Alameda County coroner's office issued a death certificate.

The parents sued to prevent removal of life support; a judge urged the parties to work out an agreement. The hospital allowed the family to remove the body with machines still working.

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"I don't feel that anybody with a heartbeat and blood flowing through their veins, being treated in a medical facility, deserves a death certificate," said Winkfield, 34, who has worked for Home Depot for 12 years. "As a mother, I have unconditional love for my daughter, and I'm going to fight for her until I have no more life left in me. My hope is that she will change how people view brain death, and ultimately that she wakes up."

She declined, as she has in the past, to say where Jahi was taken or who is paying the bills. Caplan, the bioethicist, said he was certain that no insurance company would continue to pay for medical care once a person had been declared legally dead.

The award to the McMath family was presented by the Terri Schiavo Life and Hope Network, started in 2005 by Schiavo's brother, parents and others.

Talk-show host Glenn Beck was Thursday evening's scheduled keynote speaker but canceled hours before; an event spokesman cited a family emergency.

The award recognizes families that overcome high resistance in fighting for loved ones.

The Schiavo and McMath cases are different in essential ways. Schiavo suffered a heart attack in 1990, and was left with a severe brain injury due to a lack of blood and oxygen, similar to what happened with Jahi McMath.

In Schiavo's case, however, the brain damage was not as severe, and some activity remained. Her body could breathe on its own and respond to stimuli. As Caplan put it in lay terms, "the thermostat's still on," and with nutrition and hydration, such a body can be maintained for years. Schiavo lived in such a persistent vegetative state for 15 years.

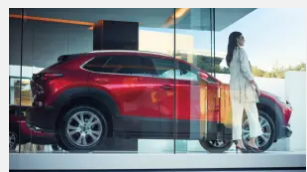
In cases of brain death, like McMath's, the brain has no function at all - no brain waves. Even with a ventilator and feeding tube, the body will break down after brain death. Neither Caplan nor Hurtig would predict how long a brain-dead body can continue to function. They said there is no precedent for it.

Thaddeus Pope, a lawyer and expert in medical futility at Hamline University in Minnesota, said brain death has been accepted by all states and medical societies for 30 to 40 years.

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There is no organized effort to remove such laws or to revisit the issue of whether brain death is death, Pope said, though he noted that a small minority of bioethicists and physicians question the rules by which brain death is determined and whether those rules should be changed.

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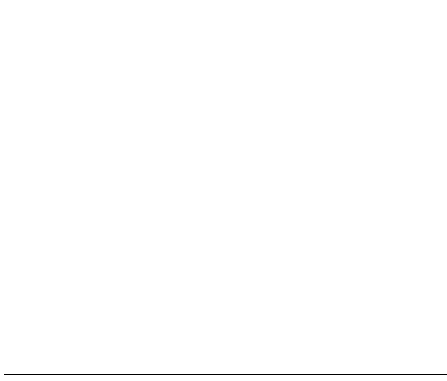
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