

WHAT DOES IT MEAN TO DIE?

When Jahi McMath was declared brain-dead by the hospital, her family disagreed. Her case challenges the very nature of existence.

By Rachel Aviv



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Before having her tonsils removed, Jahi McMath, a thirteen-year-old African-American girl from Oakland, California, asked her doctor, Frederick Rosen, about his credentials. “How many times have you done this surgery?” Hundreds of times, Rosen said. “Did you get enough sleep last night?” He’d slept fine, he responded. Jahi’s mother, Nailah Winkfield, encouraged Jahi to keep asking questions. “It’s your body,” she said. “Feel free to ask that man whatever you want.”

Jahi had begged not to get the surgery, but her mother promised that it would give her a better life. Jahi had sleep apnea, which left her increasingly fatigued and unable to focus at school. She snored so loudly that she was too embarrassed to go to slumber parties. Nailah had brought up four children on her own, and Jahi, her second, was her most cautious. When she saw news on television about wars in other countries, she would quietly ask, “Is it going to come here?” Her classmates made fun of her for being “chunky,” and she absorbed the insults without protest. A few times, Nailah went to the school and asked the teachers to control the other students.

The operation, at Oakland’s Children’s Hospital, took four hours. When Jahi awoke, at around 7 P.M. on December 9, 2013, the nurses gave her a grape Popsicle to soothe her throat. About an hour later, Jahi began spitting up blood. The nurses told her not to worry and gave her a plastic basin to catch it in. A nurse wrote in her medical records that she encouraged Jahi to “relax and not cough if possible.” By nine that night, the bandages packing Jahi’s nose had become bloody, too. Nailah’s husband, Marvin, a

truck driver, repeatedly demanded that a doctor help them. A nurse told him that only one family member was allowed in the room at a time. He agreed to leave.

Nailah, who worked in contractor sales at Home Depot, said, “No one was listening to us, and I can’t prove it, but I really feel in my heart: if Jahi was a little white girl, I feel we would have gotten a little more help and attention.” Crying, she called her mother, Sandra Chatman, who had been a nurse for thirty years and who worked in a surgery clinic at Kaiser Permanente, in Oakland.

Sandra, who is warm and calm and often wears a flower tucked into her hair, arrived at the hospital at ten o’clock. When she saw that Jahi had already filled a two-hundred-millilitre basin with blood, she told a nurse, “I don’t find this to be normal. Do you find this to be normal?” A nurse wrote in her notes that the physicians on duty were “notified several times over course of shift” that Jahi was bleeding. Another nurse wrote that the doctors were “aware of this post op bleeding” but said “there would be no immediate intervention from ENT or Surgery.” Rosen had left the hospital for the day. In his medical records, he had written that Jahi’s right carotid artery appeared abnormally close to the pharynx, a congenital condition that can potentially raise the risk of hemorrhaging. But the nurses responsible for her recovery seemed unaware of the condition and didn’t mention it in their notes. (Rosen’s attorney said that Rosen could not speak about Jahi; the hospital couldn’t comment, either, because of medical-privacy laws, but a lawyer said that the hospital is satisfied that Jahi’s nursing care was appropriate.)

There were twenty-three beds in the intensive-care unit, spread over three rooms. A doctor was standing on the other side of Jahi’s room, and Sandra asked him, “Why aren’t you guys seeing about my granddaughter?” The doctor instructed the nurse on duty not to change Jahi’s hospital gown, so that he could assess how much blood she was losing, and to spray Afrin in her nose. Sandra, who teaches a workshop at Kaiser Permanente on the “four-habits model,” a method for improving empathy with patients, told me she was surprised that the doctor never introduced himself. “He was all frowned up with his arms crossed,” she said. “It was like he thought we were dirt.”

At twelve-thirty in the morning, Sandra saw on Jahi’s monitor that her oxygen-saturation levels had fallen to seventy-nine per cent. She yelled to the medical staff, and several nurses and doctors ran toward Jahi and began working to intubate her. Sandra

said that she heard one doctor say, “Oh, shit, her heart stopped.” It took two and a half hours to restore Jahi’s heartbeat and to stabilize her breathing. Sandra said that when she saw Rosen early the next morning he looked as if he’d been crying.

Two days later, Jahi was declared brain-dead. With the help of a ventilator, she was breathing, but her pupils did not react to light, she did not have a gag reflex, and her eyes remained still when ice water was dripped in each ear. She was briefly disconnected from the ventilator, as a test, but her lungs filled with carbon dioxide. On an EEG test, no brain-wave activity could be seen.

Like all states, California follows a version of the 1981 Uniform Determination of Death Act, which says that someone who has sustained the “irreversible cessation of all functions of the entire brain, including the brain stem, is dead.” California law requires that hospitals permit “a reasonably brief period of accommodation” before disconnecting a ventilator—long enough to allow family to gather, but not so long that hospitals neglect the “needs of other patients and prospective patients in urgent need of care.”

Jahi at home with her family in January. “I knew that Jahi was in there,” her mother, Nailah, said.

Photograph by Doug DuBois for The New Yorker

At a meeting with Rosen and other medical staff, the family asked for an apology. According to a social worker’s record of the meeting, Rosen “expressed sympathy.” The family wasn’t satisfied. “Step outside your job,” Marvin told him. “This was totally wrong!” Sandra said that Jahi had not “got the treatment she deserved.”

Over the next few days, a social worker repeatedly urged Jahi’s family to make a plan for taking her off the ventilator. She also recommended that they consider donating her organs. “We were, like, ‘Nah,’ ” Marvin said. “ ‘First, tell us what happened to her.’ ” The family asked for Jahi’s medical records, but they weren’t allowed to see them while she was still in the hospital. Nailah didn’t understand how Jahi could be dead when her skin was still warm and soft and she occasionally moved her arms, ankles, and hips. The doctors said that the movement was only a spinal reflex, described in the medical literature as “a Lazarus sign.”

An African-American critical-care doctor named Sharon Williams asked the hospital's administration to give the family a little more time to grieve, expressing concern that taking Jahi off the ventilator right away "was not in the best interest of the family." But, after a week, when their position still hadn't changed, Williams asked to have a conversation with Sandra, "woman to woman." Sandra said Williams told her that, if she waited too long to take Jahi off the ventilator, she wouldn't look good for the funeral, adding, "You know how we are." (Williams disagrees with Sandra's description of the conversation.)

"Who's 'we'?" Sandra remembers thinking. "We African-Americans? I felt so belittled. Yes, a lot of black children die in Oakland and people do have funerals for their children—but that don't mean all of us are like that. Do you think we're supposed to be used to our children dying, that this is just what black people normally go through?" She said, "At that point, I just lost all my trust."

Nailah's younger brother, Omari Sealey, began sleeping in a chair next to Jahi's hospital bed, to make sure no one could "kill her off." He said, "I just felt her life wasn't worth that much in their eyes. It was like they were trying to shoo us away." A former baseball star at San Diego State University, he had a large following on social media, and on Instagram and Facebook he announced that the hospital was rushing them to unplug Jahi's ventilator. "They are trying to feed us legal bull shit," he wrote. "It's not over until God say so." In the comments section, one friend wrote, "This is universal chain of DISRESPECT!!!! FCK THIS HEALTHCARE SYSTEM!!!" Another wrote, "They either wana see us dead or in jail they don't wana see us alive."

A week after the surgery, Sealey called a personal-injury lawyer, Christopher Dolan, and told him, "They're going to kill my niece." Dolan agreed to take on the case pro bono, though he had no experience with legal issues involving the end of life. A self-described "cafeteria Catholic," he acted on a vague feeling that a child with a beating heart was not entirely dead. He wrote a cease-and-desist order: if doctors unplugged Jahi's ventilator, he said, they would violate her and her family's civil rights. Sealey taped the note to Jahi's bed and oxygen monitor.

In a petition to the Alameda County Superior Court, Dolan requested that a physician unaffiliated with the hospital examine Jahi. He wrote that the hospital had a conflict of interest, because if its doctors were found guilty of malpractice they could "drastically

reduce their liability by terminating Jahi's life." In cases of wrongful death, California places a cap of two hundred and fifty thousand dollars on damages for pain and suffering. But there is no limit on the amount that can be recovered when a patient is still alive. In a separate motion, Dolan argued that the hospital was infringing on Nailah's right to express her religion. He said that, as a Christian, she believed that her daughter's soul inhabited her body as long as her heart beat.

On December 19th, ten days after the surgery, David Durand, the hospital's senior vice-president and chief medical officer, held a meeting with the family. They asked Durand to allow Jahi to remain on the ventilator until Christmas, suggesting that the swelling in her brain might subside. Durand said no. They also asked that she be given a feeding tube. Durand dismissed this request, too. The idea that the procedure would help her recover was an "absurd notion," he later wrote, and would only add to the "illusion that she is not dead."

When they persisted, Durand asked, "What is it that you don't understand?" According to Jahi's mother, stepfather, grandmother, brother, and Dolan, who took notes, Durand pounded his fist on the table, saying, "She's dead, dead, dead." (Durand denies pounding his fist or repeating the word.)

Three days before Christmas, a group of church leaders in Oakland gathered in front of the hospital and asked the district attorney to investigate what had happened to Jahi. "Is not Jahi worthy of the highest amount of medical treatment?" Brian K. Woodson, Sr., the pastor of Bay Area Christian Connection, said at a press conference.

The next day, Evelio Grillo, a judge for the Alameda County Superior Court, appointed an independent expert, Paul Fisher, the chief of child neurology at Stanford University's children's hospital, to examine Jahi. During the hearing, two hundred people marched in front of the hospital, holding signs that said, "Justice for Jahi!" and "Doctors Can Be Wrong!" About a quarter of the protesters were Nailah's friends and neighbors. She lived a short walk from her mother, who lived a few blocks from her own mother, who had moved to East Oakland from Opelousas, Louisiana, during the height of the civil-rights movement.

Fisher repeated the standard brain-death exam and confirmed the hospital's conclusion. He also performed a radionuclide cerebral-blood-flow study. "You see a complete white void, a whiteout in the part of the head where the brain is," he told Judge Grillo the next day. "Normally it would be dark black." Grillo ruled that the hospital could unplug Jahi's ventilator in six days.

The family set up a GoFundMe page to pay for Jahi to be airlifted to another hospital ("We acknowledge that the odds are stacked against us," Nailah wrote), and strangers who learned about the case in the media contributed more than fifty thousand dollars. The Terri Schiavo Life & Hope Network—an organization founded by the parents and siblings of Terri Schiavo, who was in a persistent vegetative state for fifteen years and became a cause célèbre for the right-to-life movement—offered to use its contacts to find a facility. Nailah had never had an opinion on the right to life. On abortion, she was pro-choice. But, she said, "I just wanted to get her out of there." Sandra said she sometimes wonders, "If the hospital had been more compassionate, would we have fought so much?"

Nailah asked Children's Hospital to perform a tracheotomy, a surgery that enables ventilator air to be pumped directly into the windpipe—a safer way for Jahi to breathe when transported to a new hospital. The hospital's medical-ethics committee unanimously concluded that the intervention was inappropriate. "No conceivable goal of medicine—preserving life, curing disease, restoring function, alleviating suffering—can be achieved by continuing to ventilate and artificially support a deceased patient," they wrote. They said that the doctors and nurses caring for Jahi were experiencing "tremendous moral distress," and that accommodating the family's requests would raise "significant concerns of justice and fairness."

Just before the court's protective order was set to expire, Judge Grillo extended it by eight days. Not long afterward, Dolan and the lawyers for the hospital reached an agreement: the hospital would release Jahi to the Alameda County coroner, who would declare her dead. Then the family would become "wholly and exclusively responsible" for her.

On January 3, 2014, the coroner issued Jahi's death certificate. For cause of death, he wrote, "Pending investigation."

Two days later, two nurses from an air-evacuation service slipped into Jahi's hospital room. A doctor from Children's Hospital detached her from the ventilator, and the two nurses connected her to a portable one and put her on a gurney. They took her to an unmarked ambulance at the hospital's back entrance. The San Francisco 49ers were playing the Green Bay Packers that day, and Dolan hoped the game would distract a crowd of journalists who had gathered in front. Dolan didn't tell anyone where Jahi was going—not even her family—because he was afraid that the hospital would find out and somehow thwart the plan.

Nailah and Marvin's wedding, with Jordyn and Jahi. Photograph by Ke'er Orr

Nailah was the only family member permitted on the plane, which was paid for with money received from GoFundMe. Nailah was terrified of the noise her daughter's portable respirator was making, which seemed as loud as the jet's engine. It wasn't until they landed that she learned they were in New Jersey, one of only two states—New York is the other—where families can reject the concept of brain death if it violates their religious beliefs. The laws in both states were written to accommodate Orthodox Jews, some of whom believe, citing the Talmud, that the presence of breath signifies life.

Jahi was admitted to St. Peter's University Hospital, in New Brunswick, New Jersey, which is run by the Roman Catholic Diocese of Metuchen. Nailah said, "I had no plan, no place to live, no nothing." She had packed one suitcase. "When it comes to my kid, I'm an animal," she told me. "It wasn't until later on that I was, like, What did I do?"

Children's Hospital hired Sam Singer, an expert in crisis communications and reputation management, to deal with the media that were covering the case. "The general perception inside the hospital was that they were under siege," Singer told me. "They were not used to engaging in a gutter fight." Two days after Jahi's departure, Singer (whom the San Francisco *Chronicle* calls the city's "top gun for hire") told a local paper, "I've never seen such reckless disregard for the truth." At a press conference in front of the hospital, he said that Dolan had "created a hoax. A very sad hoax. That Jahi McMath is in some way alive. She's not. She's deceased by every law in the state of California. And by every spiritual belief system imaginable."

Bioethicists also disparaged the family's decision. In an op-ed in *Newsday*, Arthur Caplan, the founding director of N.Y.U.'s Division of Medical Ethics and perhaps the best-known bioethicist in the country, wrote, "Keeping her on a ventilator amounts to desecration of a body." He told CNN, "There isn't any likelihood that she's gonna survive very long." In an interview with *USA Today*, he said, "You can't really feed a corpse" and "She is going to start to decompose." Laurence McCullough, a professor of medical ethics at Cornell, criticized any hospital that would admit Jahi. "What could they be thinking?" he said to *USA Today*. "There is a word for this: crazy."

Robert Truog, the director of the Center for Bioethics at Harvard Medical School, said that he was troubled by the tone of the media coverage. "I think that the bioethics community felt this need to support the traditional understanding of brain death, to the point that they were really treating the family with disdain, and I felt terrible about that," he told me. Truog thought that the social context of the family's decision had been ignored. African-Americans are twice as likely as whites to ask that their lives be prolonged as much as possible, even in cases of irreversible coma—a preference that likely stems from fears of neglect. A large body of research has shown that black patients are less likely to get appropriate medications and surgeries than white ones are, regardless of their insurance or education level, and more likely to receive undesirable medical interventions, like amputations. Truog said, "When a doctor is saying your loved one is dead, and your loved one doesn't look dead, I understand that it might feel that, once again, you are not getting the right care because of the color of your skin."

U ntil the nineteen-sixties, cardio-respiratory failure was the only way to die. The notion that death could be diagnosed in the brain didn't emerge until after the advent of the modern ventilator, allowing what was known at the time as "oxygen treatment": as long as blood carrying oxygen reached the heart, it could continue to beat. In 1967, Henry Beecher, a renowned bioethicist at Harvard Medical School, wrote to a colleague, "It would be most desirable for a group at Harvard University to come to some subtle conclusion as to a new definition of death." Permanently comatose patients, maintained by mechanical ventilators, were "increasing in numbers over the land and there are a number of problems which should be faced up to."

Beecher created a committee comprising men who already knew one another: ten doctors, one lawyer, one historian, and one theologian. In less than six months, they

completed a report, which they published in the *Journal of the American Medical Association*. The only citation in the article was from a speech by the Pope. They proposed that the irreversible destruction of the brain should be defined as death, giving two reasons: to relieve the burden on families and hospitals, which were providing futile care to patients who would never recover, and to address the fact that “obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation,” a field that had developed rapidly; in the previous five years, doctors had performed the world’s first transplant of a pancreas, a liver, a lung, and a heart. In an earlier draft, the second reason was stated more directly: “There is great need for the tissues and organs of the hopelessly comatose in order to restore to health those who are still salvageable.” (The sentence was revised after Harvard’s medical dean wrote that “the connotation of this statement is unfortunate.”)

In the next twelve years, twenty-seven states rewrote their definitions of death to conform to the Harvard committee’s conclusions. Thousands of lives were prolonged or saved every year because patients declared brain-dead—a form of death eventually adopted by the United Kingdom, Canada, Australia, and most of Europe—were now eligible to donate their organs. The philosopher Peter Singer described it as “a concept so desirable in its consequences that it is unthinkable to give up, and so shaky on its foundations that it can scarcely be supported.” The new death was “an ethical choice masquerading as a medical fact,” he wrote.

Legal ambiguities remained—people considered alive in one region of the country could be declared dead in another—and, in 1981, the President’s Commission for the Study of Ethical Problems proposed a uniform definition and theory of death. Its report, which was endorsed by the American Medical Association, stated that death is the moment when the body stops operating as an “integrated whole.” Even if life continues in individual organs and cells, the person is no longer alive, because the functioning organs are merely a collection of artificially maintained subsystems that will inevitably disintegrate. “The heart usually stops beating within two to ten days,” the report said.

The commission’s staff philosopher, Daniel Wikler, a professor at Harvard and the first staff ethicist for the World Health Organization, told me that he didn’t think the commission’s theory of death was supported by the scientific facts it cited. “I thought it

was demonstrably untrue, but so what?” he said. “I didn’t see a downside at the time.” Wikler told the commission that it would be more logical to say that death occurred when the cerebrum—the center for consciousness, thoughts, and feelings, the properties essential to having a personal identity—was destroyed. His formulation would have rendered a much broader population of patients, including those who could breathe on their own, dead.

Despite Wikler’s reservations, he drafted the third chapter of the report, “Understanding the ‘Meaning’ of Death.” “I was put in a tight spot, and I fudged,” he told me. “I knew that there was an air of bad faith about it. I made it seem like there are a lot of profound unknowns and went in the direction of fuzziness, so that no one could say, ‘Hey, your philosopher says this is nonsense.’ That’s what I thought, but you’d never know from what I wrote.”

When Jahi arrived in New Jersey, she hadn’t been fed for more than three weeks, and her organs were failing. The chief of pediatric critical care at St. Peter’s wrote in her records that there was “no hope of brain recovery.” Nailah said, “I didn’t have a clue. I had really thought that I would get her a feeding tube and a tracheotomy, and she would just get up, and we would be good.” In the hospital cafeteria, she saw other families whispering about her.

A surgeon at St. Peter’s gave Jahi a tracheal tube and a feeding tube, which provided nutrition and vitamins. Nailah, who spent all her waking hours in the hospital, became friendly with some of the nurses, who told her that the surgeon who performed the tracheotomy had been ostracized by his colleagues. “They were, like, ‘You operated on that dead girl?’ ” she said. (The hospital did not return calls to speak about the case; in Jahi’s records, a physician wrote that the St. Peter’s administration had agreed to treat her “without medical personnel’s acceptance.”)

Nailah and Marvin slept at a house that the hospital owned, until, after three months, they were told they needed to move on, to make room for other families. They took a cab to a Motel 6. For the next three months, they stayed at whatever motel had the best weekly rate. Nailah’s youngest child, Jordyn, moved in with her aunt, and her son, Jose, moved in with his father, in Oakland. (Nailah’s oldest child was an adult, living on her own.) The human-resources department at Home Depot kept calling Nailah to ask

when she'd return. "I don't know," she told them. They finally stopped calling. Nailah, who owned her house in Oakland, told me, "I felt like I was exiled out of my state."

By March, Jahi's condition had begun to stabilize. Her skin became more elastic, her limbs and face became less swollen, and her blood pressure steadied. In their progress notes, her doctors simply wrote, "Status quo." No rehabilitation facilities would accept her as a patient, so she remained in the hospital's intensive-care unit, her treatment covered by Medicaid. Nailah said that the cost of care was roughly a hundred and fifty thousand dollars a week. According to New Jersey's 1991 statute on death, insurance providers can't deny coverage because of "personal religious beliefs regarding the application of neurological criteria for declaring death." Alan Weisbard, the executive director of the bioethics commission that drafted the law, told me, "I thought our position should be one of humility, rather than certainty."

Weisbard had previously served as the assistant legal director for the President's Commission on death and, like Wikler, he felt uneasy about the result. He said, "I think that the people who have done the deep and conceptual thinking about brain death are people with high I.Q.s, who tremendously value their cognitive abilities—people who believe that the ability to think, to plan, and to act in the world are what make for meaningful lives. But there is a different tradition that looks much more to the body." The notion of brain death has been rejected by some Native Americans, Muslims, and evangelical Protestants, in addition to Orthodox Jews. The concept is also treated with skepticism in Japan, owing in part to distrust of medical authority. Japan's first heart transplant, in 1968, became a national scandal—it was unclear that the donor was beyond recovery, or that the recipient (who died shortly after the transplant) needed a new heart—and, afterward, the country never adopted a comprehensive law equating brain death with the death of a human being. Weisbard, a religious Jew, said that he didn't think "minority communities should be forced into a definition of death that violates their belief structures and practices and their primary senses."

Nailah kept thinking about a conversation that she'd had with her children a year before. She'd been teasing them, saying, "I'm going to run your business for the rest of your lives." When her son bragged that he'd outlive her, she joked, "Well, I'm going to get put on a ventilator." Jahi had never heard the word and asked what it meant. "It's a

machine that keeps you alive,” Nailah explained. She told me, “I’ll never forget: the rest of the kids laughed, and Jahi said, ‘Well, if something ever happens to me, make sure you keep me on one of those.’ ”

At St. Peter’s Hospital, a music therapist visited the intensive-care unit every few days. She stood next to Jahi’s bed and played lullabies and soothing melodies on a harp. Nailah observed that Jahi’s heart rate, which tended to be high, would lower when the harpist played. She wondered if her daughter found the songs calming.

Nailah said, “I knew that Jahi was in there.” She began requesting that she move different parts of her body. In one test, which Nailah recorded on her cell phone, she stands at the side of Jahi’s hospital bed without touching it. Jahi’s eyes are closed, and the upper half of her bed is raised at a forty-five-degree angle. Her hands are placed on rolled cloths, to keep them from contracting into fists. “Move your hand,” Nailah says. Two seconds later, Jahi cocks her right wrist. “Very good!” Nailah says. “Can you move your hand again? Move your hand so we can see it. Move it hard.” Nine seconds later, Jahi flexes her forearm, turns her wrist, drops the cloth, and lifts her fingers. Her face is expressionless and still.

In another video, Nailah says, “Kick your foot.” Jahi’s purple blanket has been folded back, revealing her bare feet and ankles. After fifteen seconds, she wiggles her toes. “Try your hardest,” Nailah says. “I see you moved your toes, but you have to kick your foot.” Twenty-two seconds later, Jahi flicks her right foot upward. “Oh, I’m so proud of you,” Nailah says, leaning over the bed and kissing her cheek.

Seven months after moving to New Jersey, Jahi began menstruating. Sandra was visiting, and she asked the doctor on call to give Jahi a heating pad and Motrin—all the women in her family had severe cramps—and to note in Jahi’s medical records that she had got her period for the first time. The doctor told Sandra and Nailah that he couldn’t say for sure what was causing the blood flow. Nailah told him, “Blood is coming out of a teen-age girl’s vagina, and nowhere else, for five days—what do you think it is? Is there another diagnosis?” Sandra said that they both became so agitated that the doctor finally told them, “Why don’t you two girls go for a walk in the park outside.”

In late August, 2014, Jahi was released from St. Peter's. Her discharge diagnosis was brain death. She moved into a two-bedroom apartment that Nailah and Marvin had rented in a colorless condominium complex near New Brunswick. They slept on an air mattress on the floor, and Jordyn, who had just moved to New Jersey, to begin first grade, slept on the couch. Jahi had the brightest room, with a large window overlooking the parking lot. Nurses, paid for by Medicaid, provided twenty-four-hour care, in eight-hour shifts. Every four hours, Nailah helped them turn her daughter's body. One of Jahi's most loyal nurses taped a note to the wall of her bedroom: "During your shift, interact with her," she had written. "She does hear you! Speak clearly, softly, slowly." She added, "No one knows if she understands, but just your comforting voice or touch should help."

Not long after the family moved in, two detectives and a patrol officer showed up at the apartment. The Franklin Township Police Detective Bureau had received an anonymous tip that there was a dead body in the house. Nailah led the detectives into Jahi's room and showed them her ventilator. The cops concluded that there was no criminal activity and left, but the nurse on duty was rattled, and she quit. Nailah had for months been flooded by e-mails and Facebook messages accusing her of child abuse or of exploiting her daughter for money. Strangers started a petition on Change.org to "stop NJ from paying for corpse care out of taxpayers money"; the petition said that Nailah had bought a Michael Kors purse and expensive wine, an accusation based on pictures on Instagram. Nailah's lawyer, Dolan, told me, "They think she's just some black lady sucking down social resources."

Nailah read the Bible more than she ever had, and she tried to entertain the idea that God had chosen her to suffer this way because she was resilient enough to endure it. On her Facebook page, she described herself as "just a strong black woman who is not in the mood for anyone's bullshit!" But she couldn't accept the idea that divine logic was at work. "I really don't feel like this was God's plan for my kid's life," she said.

A month after Jahi's discharge, the International Brain Research Foundation, a neuroscience think tank that supports novel research, helped pay for Jahi to have MRI scans at Rutgers New Jersey Medical School. Calixto Machado, the president of the Cuban Society of Clinical Neurophysiology, flew to New Jersey to analyze the scans. Machado has published more than two hundred papers on disorders of consciousness

and runs a symposium every four years that attracts the world's leading scholars of brain death. He said, "Everybody was talking about Jahi—Jahi this, Jahi that—but nobody knew the neurological picture." The fact that Jahi had begun menstruating—a process mediated by the hypothalamus, near the front of the brain—suggested to him that not all neurological functions had ceased.

Dolan sat beside Machado in the hospital as he looked at two computer screens showing images of Jahi's head and the top of her spine. In the rare cases in which brain-dead patients are sustained by a ventilator, neurologists have reported a phenomenon called "respirator brain": the brain liquefies. Machado said that if Jahi's original diagnosis was correct, and she'd had no cerebral blood flow for nine months, he expected that she'd have little tissue structure in her cranial cavity, just fluid and disorganized membranes.

On the scans, Machado observed that Jahi's brain stem was nearly destroyed. The nerve fibres that connect the brain's right and left hemispheres were barely recognizable. But large areas of her cerebrum, which mediates consciousness, language, and voluntary movements, were structurally intact. Dolan shouted, "She's got a brain!"

Machado also performed a test that measures the interplay between the sympathetic and parasympathetic nervous systems, a relationship that regulates states of arousal and rest. He used three experimental conditions, one of which he called "Mother talks to the patient." Nailah stood next to her daughter without touching her. "Hey, Jahi, I'm here," she told her. "I love you. Everyone is so proud of you." Machado noted that Jahi's heart rate changed in response to her mother's voice. "This CANNOT be found in a brain-dead patient," he wrote.

Three days after the scans, Dolan submitted a report by Machado to the Alameda County Coroner's Bureau and asked it to rescind Jahi's death certificate, so that Nailah could return to California and have Jahi treated there. The coroner and the county's public-health department rejected the request. "Any opportunity to overturn the Court's holding that Jahi McMath is brain dead has long expired," their lawyers wrote.

D Alan Shewmon, who had just retired as the chief of the neurology department at Olive View-U.C.L.A. Medical Center, read Machado's report and wondered if Jahi had a condition, first proposed by the Brazilian neurologist C. G. Coimbra,

called ischemic penumbra. Coimbra hypothesized that this brain state could lead to a misdiagnosis of brain death in patients whose cerebral blood flow was diminished enough that it couldn't be detected by the standard tests. If blood was still flowing to parts of the brain, however slowly, then, in theory, some degree of recovery could be possible.

Shewmon has given a diagnosis of brain death to roughly two hundred people. He is measured, formal, and precise. When I asked him what he thought of the media coverage stating that Jahi would die imminently, he paused and said, "I sit back and let it play out." He laughed, harder than I would have expected, and said nothing more.

Two months after Machado's tests, Shewmon flew to New Jersey and visited Jahi at her apartment. He pulled a desk chair next to her bed and, with a notepad in his hand, watched her for six hours. Jahi did not respond to his instructions to move her limbs, a fact that Shewmon did not find particularly revealing. He had analyzed the videos that Nailah had recorded, and they suggested to him that Jahi was in a minimally conscious state, a condition in which patients are partly or intermittently aware of themselves and their environment. He wrote that her condition "creates a particular challenge to either disprove or verify, because the likelihood of Jahi being in a 'responsive' state during a random examination is small."

After Shewmon left, Nailah took more videos. She followed Shewmon's instructions not to touch her daughter during the filming and to begin the video outside Jahi's room. Shewmon eventually analyzed forty-nine videos containing a hundred and ninety-three commands and six hundred and sixty-eight movements. He wrote that the movements occur "sooner after command than would be expected on the basis of random occurrence," and that "there is a very strong correspondence between the body part requested and the next body part that moves. This cannot be reasonably explained by chance." He noted that the movements "bear no resemblance to any kind of reflex," and that, in one video, Jahi seemed to display a complex level of linguistic comprehension. "Which finger is the eff-you finger?" Nailah asked her. "When you get mad at somebody, which finger you supposed to move?" Two seconds later, Jahi flexed her left middle finger. Then she bent her pinkie. "Not that one," Nailah said. Four seconds later, Jahi moved her middle finger again.

James Bernat, a neurologist at Dartmouth who helped develop the theory of brain death that formed the basis of the 1981 President's Commission report, told me that Shewmon showed him some of the videos. "My thoughts about this are not fully formed," he said, adding, "I'm always skeptical of videotapes, because of the videos of Terri Schiavo." Her family had released video clips that they presented as proof of consciousness, but the videos had been edited, giving the illusion that she was tracking people with her eyes, even though she was blind. Bernat said, "I have a huge amount of respect for Alan, and if he says something, I am going to pay attention to it." He called Shewmon "the most intellectually honest person I have ever met."

When Shewmon was a college sophomore, at Harvard, he listened to Chopin's *Trois Nouvelles Études No. 2*, in his dorm room, and the music lifted him into such a state of ecstasy that he had an epiphany: he no longer thought it possible that all conscious experience, particularly one's perception of beauty, could be a "mere electrophysiological epiphenomenon," he said. The music seemed to transcend "the spatial limitations of matter." An atheist, he converted to Catholicism and studied Aristotelian-Thomistic philosophy. He went to medical school, in 1971, and then specialized in neurology, because he wanted to understand the relationship between the mind and the brain.

For the next fifteen years, he believed in and defended the notion of brain death, but in the early nineties he began to feel increasingly troubled by the concept. When he engaged in what he called "Socratic conversations" with colleagues, he saw that few doctors could confidently articulate why the destruction of one organ was synonymous with death. Usually, they'd end up saying that these patients were still living biological organisms but had lost the capacities that made them human. He thought the formulation seemed too similar to the idea of "mental death," which the Nazis embraced after the publication, in 1920, of a widely read medical and legal text called "Permission to Destroy Life Unworthy of Living."

In 1992, Shewmon was asked to consult on the case of a fourteen-year-old boy who, after falling off the hood of a moving car, had been declared brain-dead. The boy's family was religious and insisted that he remain on a ventilator. His physicians, certain that his heart would soon fail, acceded to his parents' request. He survived for sixty-three days and began puberty. "This case flew in the face of everything I had been

taught regarding the universality and imminence of somatic demise in brain death,” Shewmon later wrote. “It forced me to rethink the whole thing.”

Shewmon began researching similar cases, and found a hundred and seventy-five people, many of whom were children or teen-agers, who lived for months or years after they were legally dead. The longest survivor was a boy who had been declared dead after contracting meningitis, when he was four. His heart beat for twenty more years, during which time he grew proportionally and recovered from minor wounds and infections, even though he had no identifiable brain structure and the outside of his brain had calcified. In 1997, in a paper called “Recovery from ‘Brain Death’: A Neurologist’s Apologia,” Shewmon disavowed his earlier views. He acknowledged that “dissenters from the ‘brain death’ concept are typically dismissed condescendingly as simpletons, religious zealots or pro-life fanatics,” and announced that he was joining their ranks.

Shewmon’s research on what he calls “chronic survival” after brain death helped prompt a new President’s council on bioethics, in 2008, to revisit the definition of death. The council’s report referred to Shewmon’s research thirty-eight times. Although it ultimately reaffirmed the validity of brain death, it abandoned the biological and philosophical justification presented by the 1981 President’s Commission—that a functioning brain was necessary for the body to operate as an “integrated whole.” Instead, the report said that the destruction of the brain was equivalent to death because it meant that a human being was no longer able to “engage in commerce with the surrounding world,” which is “what an organism ‘does’ and what distinguishes every organism from nonliving things.”

In a personal note appended to the end of the report, the chairman of the council, Edmund Pellegrino, expressed regret regarding the lack of empirical precision. He wrote that attempts to articulate the boundaries of death “end in some form of circular reasoning—defining death in terms of life and life in terms of death without a true ‘definition’ of one or the other.”

In 2015, after Nailah filed her taxes, her accountant called to tell her that her submission had been rejected by the I.R.S. One of the “dependents” she’d listed was deceased. “I was, like, Oh, God, now I have to tell this guy what is going on—that she’s alive on a state level and dead on the federal level,” she said. She decided not to fight

the I.R.S.; she was sure that she'd lose. "It's not even about money," she told me. "It's the principle: I really have a human being that I get up and see about every day."

Nailah sold her house in Oakland to pay her rent in New Jersey. She almost never left the apartment. Consumed by guilt for having urged Jahi to have her tonsils removed, she was given a diagnosis of depression. "I used to watch the antidepressant commercials, where people would stare out the window and say they couldn't go outside, and I'd think, That is ridiculous," she told me. "Who can't go outside? Who can't get off the bed? Where I'm from, you have survival skills—you learn to adapt. If you're poor, if anything goes wrong, you can still make it. But this is one situation that I cannot adapt to."

In the spring of 2015, Nailah filed a malpractice lawsuit against Oakland Children's Hospital, seeking damages for Jahi's pain, suffering, and medical expenses. The hospital argued that deceased bodies do not have legal standing to sue. "Plaintiffs are preserving Jahi's body from its natural post-mortem course," the hospital's lawyers wrote. "It would be against public policy to hold health professionals liable for the costs of the futile medical interventions performed on a dead person."

Dolan submitted video recordings of Jahi and declarations from Machado, three New Jersey doctors who had examined her, and Shewmon, who concluded that Jahi had fulfilled the requirements of brain death at the time of her diagnosis but no longer did. He wrote, "With the passage of time, her brain has recovered the ability to generate electrical activity, in parallel with its recovery of ability to respond to commands." He described her as "an extremely disabled but very much alive teenage girl."

The hospital hired its own medical experts. Thomas Nakagawa, who wrote the 2011 guidelines for pediatric brain death, said that the only accepted criteria for brain death were those stipulated by the guidelines. MRI scans, the heart-rate analysis, the videos of movement, and the evidence of menstruation were not relevant to the criteria. Sanford Schneider, a professor of pediatrics at the University of California, Irvine, referred to Jahi as a "corpse," and told the court that she "cannot respond to verbal commands, because she has no cerebral mechanism to hear sound," a conclusion based on a test that measured Jahi's brain-wave activity in response to different noises. Schneider wrote, "There is absolutely no medical possibility that J McMath has recovered, or will someday recover, from death."

Last summer, a judge on the Alameda County Superior Court rejected the hospital's argument that the brain-death exam from 2013 "must be accorded finality for any and all other purposes." He ruled that "a triable issue of fact exists as to whether Jahi currently satisfies the statutory definition of 'dead.'" In a trial expected to last a month, a jury will decide if Jahi is alive.

Jahi's case has sparked what Thaddeus Pope, a bioethicist at Mitchell Hamline University School of Law, calls the "Jahi McMath shadow effect": a rise in the number of families, many of them ethnic or racial minorities, going to court to prevent hospitals from unplugging their loved ones from ventilators. In Toronto, the family of Taquisha McKitty, a young black mother declared dead after a drug overdose, argued that she couldn't have died, because she still had a menstrual cycle. At a court hearing this fall, her doctor said that he was aware of vaginal bleeding but "nobody knows if that was menstrual."

A similar debate unfolded in 2015, when an Ethiopian college student, Aden Hailu, was declared brain-dead at a hospital in Nevada after exploratory surgery for stomach pain. A district court rejected her father's request to keep her on a ventilator, but the Nevada Supreme Court reversed the lower court's decision, ruling that expert testimony was needed to determine whether the standard brain-death tests "adequately measure all functions of the entire brain." (The hearing never happened, because Hailu's heart stopped beating.)

Pope told me that "every extra hour of nursing time that goes into one of these dead patients is an hour of nursing time that didn't go to somebody else." He also worries that these disputes, which often get media attention, will cause fewer people to register as organ donors, a practice whose social acceptability depends on the idea that patients are dead before their vital organs are removed. When I expressed anxiety that my article could perpetuate the problem, he remarked that it could "do a small amount of harm." Then he reconsidered and said, "The cat's already out of the bag."

Nailah's lawyer, Dolan, a registered organ donor, told me that he struggles with the practical consequences of advocating for Jahi. "There's a part of me that's, like, Shit, we may screw up organ donation," he said. When families in similar situations call him, he tells Nailah's story to warn against following her path. "This is like Job," he said.

Truog, the director of the Center of Bioethics at Harvard, said that once, when he gave an academic talk on brain death, he described it as a catastrophic brain injury, rather than death. A transplant physician stood up and told him, “You should be ashamed of yourself. What you are doing is immoral: to put doubts in the minds of people about a practice that is saving countless lives.” Truog told me, “I’ve thought long and hard about that. In order to support public trust in the scientific enterprise, I guess I feel that the medical profession is always going to be better off, in the long run, if we speak honestly and truthfully about what we know.”

He continued, “I don’t think there’s anything morally wrong with the fact that we take organs from these people, even though there is no scientific reason for believing them to be dead. I believe it is a morally virtuous thing to do and we ought to facilitate it. We are doing the right thing for the wrong reasons.”

Although Jahi has come to represent a different way of defining life, her family is not sure that they would keep her on a ventilator if she still fulfilled the expectations for brain death. Sandra said that, before Jahi was given the MRI scans at Rutgers, she told herself, “If her brain is jelly, we are going to have to accept that. I don’t think people should live on that way. If they’re gone, they’re gone.”

Jahi’s family believes that she is capable of a fuller range of thought than she is able to express, an idea that Shewmon has also considered. “Given the evidence of intermittent responsiveness,” he wrote in a declaration to the court, “we should be all the more willing to remain agnostic regarding her inner state of mind during periods of unresponsivity, rather than automatically equate it with unconsciousness.” Recent advances in neuroimaging have led some clinicians to consider the possibility that a significant portion of patients thought to be in a vegetative state—those who demonstrate no overt awareness of their environment and do not make purposeful movements—have been misdiagnosed; they may be periodically conscious and capable of some degree of communication.

Nailah said that nearly every day she asks Jahi, “Are you O.K. with what I’m doing? Do you want to live? Are you suffering?” She said, “I know that things change—people change. If Jahi has given up and doesn’t want to be here anymore, I’m just going to go with what she wants.” She said that Jahi answers her questions by either squeezing her hand or pressing her own index finger toward her thumb, a signal for “yes” that Nailah

taught her. “When I see that,” she said, “I think, Who am I to not want to live? Because many days I do want to die. But then I see her every day, trying her best.”

Last December, I visited Nailah at her apartment, and she said that she had begun to feel more hopeful. She felt more confident that the courts would allow her to bring Jahi home to Oakland, although the trial has not yet been scheduled. Recently, she had asked Jahi how long she thought it would take. Six months? she asked. A year? A year and a half? Jahi squeezed her hand after the third question. Nailah took it as her answer. “I am planning this big-ass welcome-home party in my head,” Nailah told me. “I know my city really, really loves us.”

“Hi, girl, are you sleeping or awake?” Nailah said to Jahi as we walked into her room. Jahi wore pink pajamas, and her face was clear and smooth but bloated, a side effect of a steroid she takes to raise her blood pressure. Her eyes were closed. “Are you sleeping? I want to know,” Nailah said. She picked up Jahi’s hand and held it with both of her palms. Jahi’s other hand was draped over the belly of a baby doll. Her hair was in thin braids that Nailah worried were getting thinner. Stacey, a nurse who had been caring for Jahi for the past year, stood by her feet. Stacey had spent the morning reading her a Sherlock Holmes story.

Nailah spoke about how much she had come to appreciate her own mother, who called Jahi three times a day, singing to her, reading prayers, relaying family gossip, and updating her on the Golden State Warriors. Stacey interrupted: “She’s moving her hand on the baby.”

Jahi’s index and middle finger had shifted about half an inch, moving from the doll’s belly to its chest. “Good job,” Stacey said. “Good job, Jahi!”

“Can you move your pointer finger on the baby?” Nailah asked.

Jahi’s fingernails, which Nailah had painted pink, remained still.

“That’s your baby,” Nailah said, referring to the doll. “That’s my grandbaby,” she said, laughing.

Jahi’s thumb trembled.

“Not your thumb, but your pointer finger,” Nailah said. “I know you can do it.”

After a few seconds, Jahi’s middle finger flickered. She raised it slightly and then dropped it.

“There you go,” Nailah said. “Thank you.”

Daniel Wikler, the Harvard philosopher, told me that he guessed Jahi’s family might be suffering from *folie à famille*, a rare condition in which a delusion is shared by all members of a family. It struck me as a coherent response to the death of a child: who wouldn’t find comfort in the fantasy that the child’s will had been preserved? It seemed so intuitive that I worried I could also be investing undue meaning in gestures nearly too subtle to discern. Given the weight of the evidence, though, it seemed unlikely. Jahi’s doctors and nurses were all converts, too. On Nailah’s cell-phone recordings, which document the past four years of her daughter’s life, several different nurses can be heard congratulating Jahi for gathering the strength and commitment to move a foot or a finger.

Jahi’s little sister, Jordyn, was similarly devoted. A wiry girl wearing faded skinny jeans and Day-Glo high-top sneakers, she walked into her sister’s room as soon as the school bus dropped her off. In Oakland, she and Jahi had shared a bedroom, and now she liked to lie in bed with her sister; sometimes she’d put lip gloss on her or rub lotion on her legs. Jordyn was unruly in school, and Sandra worried that her misbehavior was an expression of alienation at home. Once, when Jordyn seemed jealous of all the love directed toward her sister, Nailah said, “Do you think your sister would do this for you?” Jordyn said yes. “Well, that’s why we’re doing everything for her,” Nailah told her.

Jordyn has learned that if she wants to have a conversation in her sister’s room she needs to stand on the same side of the bed as her mother. “Jahi doesn’t like when two people talk over her,” Nailah said. “Her heart rate shoots up.” It makes Jahi nervous and upset, Nailah said, to be treated as if she didn’t exist. “She listens to everybody’s conversations—she has no choice,” she said. “I bet she has some secrets she can tell us.” She smoothed back Jahi’s hair. “You know how sometimes, when you’re just sitting still, thinking, you can take yourself somewhere else? I always say, ‘Jahi, one day, I want to know everything you know and everywhere that you’ve been.’ ” ♦

A previous version of this article incorrectly stated that Jahi's mother has a do-not-resuscitate order for her.

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Rachel Aviv joined The New Yorker as a staff writer in 2013. [Read more »](#)

Video

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