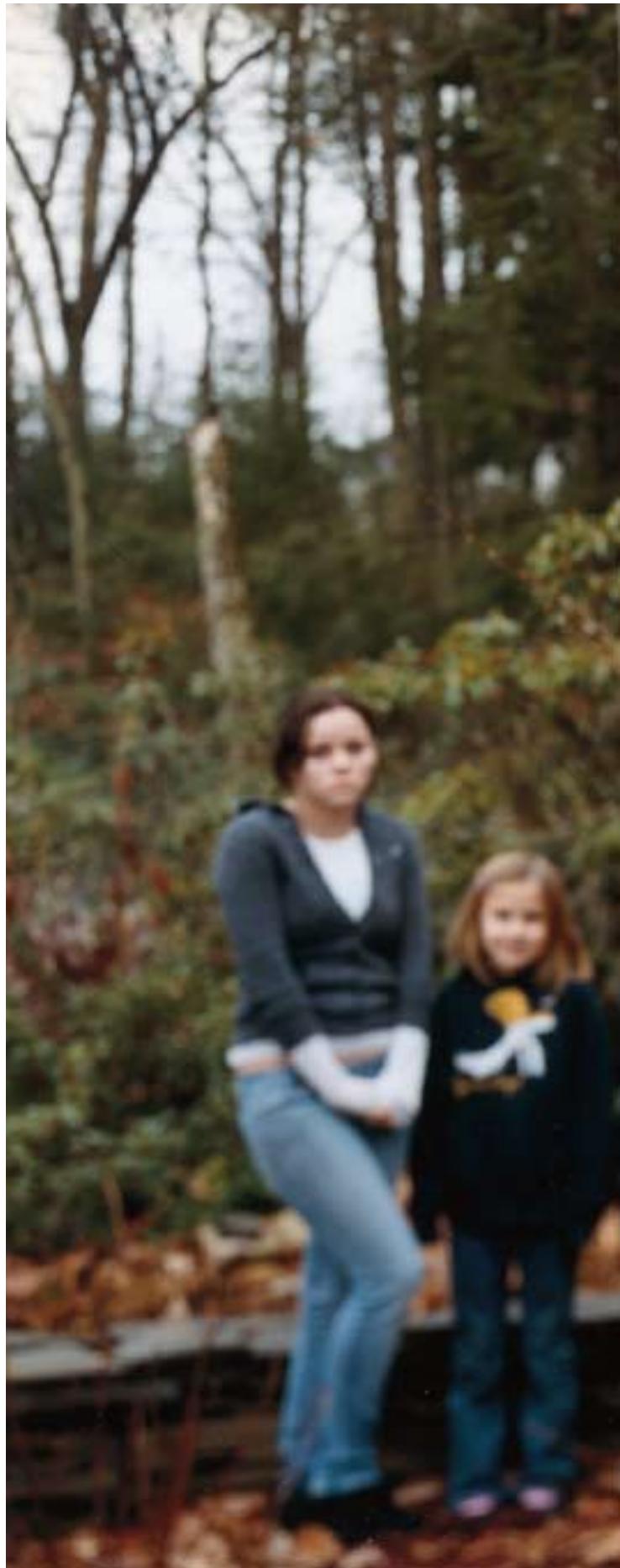


THE LAST DECISION

A new approach to organ donation doesn't require waiting until the donor's brain death. Instead, it poses a difficult question: When does death start?

BY DARSHAK SANGHAVI

Robin Beaulieu was telling me about her daughter's bike accident. It was an event that would force Beaulieu not only to confront the death of her child but also to embrace a new way of dying. We were sitting last spring in the kitchen of her small apartment in Manchester, N.H. Beaulieu took a drag on a Marlboro, poured a cup of coffee and told me that her daughter, Amanda Panzini, had been a rambunctious, bighearted teenager. She loved animals, even "flea-ridden, mangy dogs," Beaulieu said, and was a fiercely loyal friend. When confronted by the possibility of donating her brain-injured daughter's organs after the accident, Beaulieu never doubted that Amanda would have wanted them to go to someone who needed them. But Amanda first had to be declared dead, and in her case, the only way that could happen was if her parents chose a precisely choreographed



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Holleigh and Paul Tlapa with their children (Alexeigh, Aspen and Gage) at a shrine to their daughter Jaiden, who died at age 8.

death — one conducted by medical personnel in a hospital procedure meant to allow Amanda to die while preserving her organs. From this, the doctors and Beaulieu hoped, would come new life.

The last time Beaulieu talked to her daughter was on the morning of June 21, 2008, a Saturday. Amanda attended an eighth-grade dance the night before; she told her mother that she had her first kiss there. After Beaulieu left for work at a nearby minimart, Amanda decided to ride her bike a few blocks to her friend Kate's house. She didn't take her helmet. At the crossing of Taylor and Young Streets, a Ford F-150 pickup truck slammed into Amanda and threw her into the street. When the paramedics arrived, Amanda wasn't breathing. They inserted a tube into her windpipe and rushed her to Elliot Hospital nearby. Beaulieu received an emergency call at the minimart; the paramedics had identified Amanda by the name engraved on her iPod.

The rest of the afternoon passed in a harrowing blur. Beaulieu remembers a concerned doctor trying to prepare her to see Amanda. She remembers seeing her child's swollen face in the emergency room and then being loaded with her onto a trauma helicopter for transport to Children's Hospital in Boston. Though the lighted monitors showed stable vital signs, Beaulieu sensed, as she hovered in the sky, that her child had died. Doctors in Boston performed emergency neurosurgery to decompress her skull, but it was not successful. Amanda was then admitted to an intensive-care unit and put on life support. Monica Kleinman, the clinical director of the unit, examined Amanda the next morning. The girl's cerebral cortex — the part of the brain where desires, fears and hopes are created — was irreversibly damaged. In her 20 years of practice (I worked with her as a pediatrics resident years ago), Kleinman has treated dozens of similar injuries. Few of these patients ever left the hospital; those who did were in vegetative or otherwise neurologically devastated states.

Beaulieu, Kleinman recalls, digested the news and "immediately got it." Amanda was never coming back. Beaulieu decided to take her off the ventilator and asked to donate her daughter's organs. But there was an obstacle. When Kleinman examined Amanda, she noticed that some primitive and reflexive neurons of the brainstem were still working. Amanda gagged a bit when the back of her throat was tickled, and one of her pupils budged slightly when a flashlight was shined on it. The significance of this information was immediately apparent to Kleinman: Amanda was not brain-dead.

Organ transplantation must abide by the so-called dead-donor rule: a person has to be declared dead before any vital organs can be removed. Yet organs have to be alive if there is any hope of successful transfer to a recipient. Medical professionals have handled this paradoxical situation — finding a dead body with live organs — by fashioning a category of people with beating hearts who are said to be brain-dead, usually after a traumatic head injury, and who are considered just as dead as if they had rigor mortis.

To diagnose brain death, doctors typically go through a checklist of about a dozen items, including assessing reflexes like blinking, coughing and breathing, which are all controlled by the brainstem. The criteria are extremely strict, and only a tiny fraction of severely brain-injured people meet them. Kleinman realized that Amanda, despite her severe brain damage, was not one of them. There was, Kleinman told Beaulieu, another option — one that was still controversial and had never been pursued successfully at Children's Hospital. The procedure was called donation after cardiac death, or D.C.D., and it would exploit the other way the law defines death: as the "irreversible cessation" of the heartbeat.

D.C.D. requires doctors to confront the shadowy question of exactly when somebody dies after the heart stops. To authorize D.C.D., doctors

must follow a strict procedure. Amanda would be taken, technically alive, to an operating room, where her breathing tube would be removed. If her breathing ceased naturally and her heart stopped quickly (within an hour), she would be moved to an adjacent operating room and Kleinman would count off precisely five minutes, during which time Amanda would be prepped for surgery with antiseptics and surgical drapes, while Kleinman carefully watched for signs of a returning heartbeat. If there were none, Amanda would be declared legally dead; the stoppage would then be considered "irreversible." Before her organs were seriously damaged by the lack of oxygen (every minute counts), the surgeons would rapidly open Amanda's torso and remove them for transplant.

There was a chance none of this would work. If the comatose girl didn't stop breathing in the operating room, she would be returned to the intensive-care unit, though not put back on life support. Once taken off the ventilator Amanda would most likely die, but it might take hours or days, during which time her organs would deteriorate and would be unfit for transplantation.

Four days after Amanda's accident, Beaulieu and Amanda's father, Dan Panzini, sat in a darkened operating room and said their goodbyes as Amanda was disconnected from her ventilator. To Beaulieu's relief, she didn't breathe on her own, and her heart gradually slowed. "Amanda's heart has stopped," Kleinman soon said. Amanda's heart never started again, and the surgeons took her liver, kidneys and pancreas.

In procuring organs from patients like Amanda, doctors have created a new class of potential organ donors who are not dead but dying. By arbitrarily drawing a line between death and life — five minutes after the heart stops — they have raised difficult ethical questions. Are they merely acknowledging death or hastening it in their zeal to save others' lives?

With modern technology like respirators and tube feedings with synthetic formulas, Beaulieu might have kept her unconscious, brain-damaged child alive indefinitely. But as she sipped coffee in her apartment from a mug reading "#1 Mom," Beaulieu told me that if Amanda had lived, she could "never bike, rollerblade or go out with friends, and she'd never want that." If people with no hope for meaningful recovery can be kept alive artificially, shouldn't they also be permitted to die artificially?

Since the inception of organ transplantation a half-century ago, defining death has taken on both medical and ethical urgency. Before Joseph Murray performed the world's first successful kidney transplant in 1954 and showed that organs could be put to productive use outside their original host, doctors waited until the deceased was blue and stiff to declare death. Identifying a precise moment of death was a diversion for eccentric researchers like Duncan MacDougall, who, in the early 1900s, placed dying patients on a scale in order to determine when death occurred: the moment they lost three-quarters of an ounce, the presumed weight of the soul.

The paradox of needing a dead donor with a live body was first addressed in 1968. Henry Beecher, a Harvard anesthesiologist and medical ethicist, convened a 13-member committee to write a definition of "irreversible coma," or brain death, for The Journal of the American Medical Association. Not everyone accepted the four-page report's conclusions. After Norman Shumway, a Stanford University surgeon, performed the first American heart transplant from a brain-dead donor, he was threatened with prosecution by the Santa Clara County coroner. As a result of the widespread disagreement over the meaning of "brain death," President Jimmy Carter asked a blue-ribbon commission to examine the issue. The commission culminated in the Uniform Determination of Death Act in 1981, which defined death as "irreversible cessation of all functions of the entire brain, including the brainstem." The procedure to diagnose brain death, however, was never codified into law, and as a result, it varies from hospital to hospital. In 1987, the nation's pediatrics authorities tried to standardize the diagnosis, listing 14 different



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criteria to confirm brain death, like the absence of reflexes, and requiring, under certain conditions, additional X-rays and tests for brain-wave activity. Last year, in the journal *Pediatrics*, researchers from Loma Linda University reported that of 277 brain-dead children in California who were referred to the regional organ bank over many years, only a single child received the full set of diagnostic tests.

In 2008, a young Oklahoman named Zack Dunlap was declared brain-dead after an all-terrain-vehicle accident and was considered for organ donation. Then, suddenly, he recovered. He later appeared on NBC's "Today" show. The precise medical details of the case are not public, but it is possible that a diagnostic error was made because a checklist was not followed. Dr. Wiley Hall, the director of neurocritical care at the University of Massachusetts Medical School, where I am the chief of pediatric cardiology, told me about a similar case last year in Massachusetts; it turned out that a brain scan had been performed improperly.

Such sloppiness is potentially tragic, but it is also exceedingly rare. Whether or not a checklist is followed, by the time a neurologist is consulted to assess a critically ill patient for brain death, the odds of recovery are already minuscule. Doctors see that these patients have begun dying, and the uncertainty is not about whether it will happen but when. The families of dying patients often realize this, too, and ask to donate their relative's organs. Dr. Robert Truog, a professor of medical ethics at Harvard Medical School, says he believes this is a situation where "all the ethical vectors are lined up," since the patient's family, the doctors and the recipient's family all want to proceed with organ donation. The holdup is that the patient is not legally dead.

The current shortage of organs gives urgency to any new avenue for donation. The United Network for Organ Sharing, a nonprofit, coordinates the nation's system of organ transplantation. Its Web site maintains a continuously updated count of people waiting for transplants. As of early this month, 105,172 men, women and children were in line. On an average day, the organization estimates, 18 people on the list die because they don't receive an organ in time. Despite widespread campaigns to encourage donation, availability has changed only modestly over the past decade — last year there were fewer than 8,000 deceased donors — while waiting lists have doubled in size.

The small number isn't because of refusal — to give one example, 85 percent of eligible brain-dead patients' families in central Massachusetts chose to donate last year — but because of the rarity of brain death. According to Kevin O'Connor, a senior vice president at the New England Organ Bank, improved public-safety laws — automobile safety belts, bicycle helmets — along with fewer violent crimes, have meant there simply aren't many people showing up in hospitals with severe head injuries and otherwise healthy bodies. At the University of Massachusetts, 238 people were on a transplant waiting list last year, yet our medical center, a leading source of donated organs in the state, recorded only 19 deceased donors.

A lack of organs because of better safety and lives saved is, unquestionably, a good thing. But it means that transplant doctors and patients are forced to think beyond brain-dead donors. The 1981 Uniform Determination of Death Act also defines death as the "irreversible cessation of circulatory and respiratory functions," which left an opening for another source of donors. In 1997, the federal government asked the Institute of Medicine, an independent advisory body, to gather experts to determine how a dying donor might be treated. The experts ended up endorsing the procedure for donation after cardiac death, in which death occurs through a process of withdrawing life support and allowing the heart to develop "irreversible cessation."

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There were two crucial conditions. First, families could not be pressured to stop life support; they had to come to the decision on their own, in consultation with their relative's doctor. No member of the organ-procurement team could participate in the family's decision or declare death. Second, "irreversible cessation" of cardiac function meant that at least five minutes had to pass without a heartbeat. That interval was arbitrary — the panel of experts made no reference to supporting research — and they admitted that "this recommendation is only an expert judgment."

The Institute of Medicine created a new class of potential organ donors: living patients with little hope of recovery who could be declared dead soon after life-support removal. Within a decade, the number of such donors increased tenfold; they now account for 8 percent of organ transplants nationwide, up to 20 percent in certain areas. Still, many hospitals were slow to adopt the practice.

The case of Children's Hospital in Boston is instructive. In 2005, Children's convened a 17-member task force of doctors, lawyers and health care professionals to explore the ethics of allowing D.C.D. After two years of regular meetings, the group was unable to reach a consensus. "The more we talked about it, the more polarized we became," recalls Dr. Peter Laussen, a committee co-chairman. Supporters of D.C.D. argued that the practice was legal and compatible with families' wishes. Those opposed worried that caregivers would see critically ill patients merely as organ donors, and their end-of-life care could be compromised.

At a certain point in the committee's debate, members were asked to mark where they stood on D.C.D. on a continuum, with one end signifying "totally disagree" and the other "totally agree." The participants almost uniformly chose one extreme or the other. There was no middle ground.

And then a few days before Christmas in 2007, an 8-year-old girl named Jaiden Tlapa ended up in the Children's Hospital intensive-care unit.

The snow was coming down quickly in Milford, N.H., and school had been canceled. Holleigh Tlapa baked cookies for her three children, and then they decided to play outside. There was a path to the yard, and Holleigh got out the snowblower to clear it.

I visited Tlapa last April. As she started telling me what happened that day, her voice cracked. She got a box of tissues and continued talking. She had started the snowblower and the powder began flying. Then — she doesn't know exactly what happened — Jaiden somehow lost her footing and fell into the path of the blower. Instantly, Jaiden was pulled into the powerful machine, and the strings from her hood tangled tightly around her neck. Tlapa couldn't free her daughter no matter how she struggled and pulled. Frantic, she called 911. It seemed like an eternity before the paramedics arrived. It took them several minutes to cut Jaiden free. Placed on a respirator, the comatose child was later taken by ambulance to Children's Hospital in Boston.

For a moment on Christmas Eve, Jaiden opened her eyes, but her parents recall that they were "vacant." She never opened them again. The weeks rolled by. Repeated brain scans showed severe brain shrinkage. Despite her devastating cortical injury, however, Jaiden had a few primitive brainstem reflexes that kept her from being classified as brain-dead. "She looked normal, so you would assume consciousness, but that was misleading," Tlapa told me.

Over time Holleigh Tlapa and her husband, Paul, realized Jaiden wouldn't get better, and they asked about organ donation. Because she wasn't brain-dead, D.C.D. was the only option. Although the task force at Children's disagreed about D.C.D., the hospital drafted a protocol. The Tlapas were told

about the disagreement, but they chose to proceed. On Jan. 13, 2008, a dying but not dead organ donor was brought to the operating room and prepped for withdrawal of support for the first time in the hospital's history. Holleigh and Paul lay in their daughter's bed and played Jaiden's favorite Miley Cyrus song as the breathing tube was removed. They held their daughter and waited.

There's something remarkable about such families. I've known hundreds of parents whose children are stricken by terrible diseases. For many, the gravity of the situation is so overwhelming that they withdraw into themselves, letting no emotion escape, and then suddenly explode into a supernova of blame and anger. But there are others on whom this terrible pressure exerts a metamorphic power that turns some of their sadness into a compassion that is strong and diamond-brilliant.

Though her gasps were irregular, Jaiden didn't stop breathing entirely. After an hour her heart hadn't stopped, and, in this situation, the hospital protocol called for the patient to be returned to the intensive-care unit. The chance to donate her organs was over. Jaiden continued to take shallow breaths into the next morning, and then her heart finally stopped. She was legally dead. "It was so hurtful that she died so soon after," Tlapa said, disappointed that Jaiden's organs died with her. Still, she finds solace in knowing that Jaiden at least helped change some attitudes among skeptics and paved the way for the first successful D.C.D. procedure at Children's Hospital—the one involving Amanda Panzini. (Holleigh also founded a charity to help families facing similar decisions.)

Paul has some difficulty understanding why, if Jaiden was going to die anyway, she could not have been put under general anesthesia, undergone surgery to donate her organs, and then been declared dead. Removing the breathing tube to attempt D.C.D. had the same effect, only it took much longer and Jaiden breathed irregularly for many hours, which seemed to Paul more distressing. "If it was all up to me," he explained, "I would have said, 'Take her organs.'"

As Gary Greenberg wrote in *The New Yorker*, donating organs in such a manner, deliberately and with anesthesia, could simply be "a particular way to finish our dying, at the hands of a surgeon, after some uncertain border has been crossed." But Francis Delmonico, a professor of surgery at Harvard Medical School and a national leader in organ transplantation, fervently defends the need to establish death before removing organs. "I understand a family's anguish and inability to have consolation when a child doesn't die after removal of life support," he explains, "but I don't see this as a patients'-rights issue. It's a matter of public trust in the system."

Donation after cardiac death already arouses suspicion. Just as transplant surgeons like Norman Shumway were once harassed for procuring organs from brain-dead donors, a California-based surgeon, Hootan Roozrokh, was tried for dependent-adult abuse, a felony, after participating in an attempted D.C.D. A nurse who objected to the proceedings later registered a complaint about how painkillers were administered to the patient. Prosecutors charged him with trying to hasten the patient's death. Though none of this held up in court — Roozrokh was acquitted last year — the trial left many transplant surgeons shaken. Just think of the outcry, Delmonico cautions, if families and doctors also decided it was acceptable to euthanize patients to procure their organs. "You would destroy organ donation in this country," he said.

Delmonico certainly has a point about the importance of maintaining the public's trust, but it's hard to witness an actual D.C.D. procedure without conceding that the process of declaring death in any setting is inherently arbitrary. I saw this myself when I was permitted to observe a D.C.D. procedure at the University of Massachusetts hospital. The patient was a middle-aged woman with no close family ties who had been committed years before to a psychiatric hospital. Found unconscious after choking on French toast, she received CPR and came to the UMass intensive-care unit. She remained comatose with severe brain injury for days but was not brain-dead. Following hospital regulations, the doctors reported an "impending death" to the New

England Organ Bank, which agreed she would be a suitable donor. (These reports are mandatory, on the theory that they ensure no donation opportunities are missed.) Faced with the grave prognosis from the woman's doctors, her state-appointed guardian consented to donation after cardiac death.

The woman was wheeled to the step-down unit next to the operating rooms, prepped for surgery and covered with sterile sheets. With a medical student, a representative from the organ bank and me looking on, a nurse practitioner from the intensive-care unit supervised the removal of the breathing tube at 9:16 p.m. The patient didn't breathe. We gazed intently at the portable monitor at the foot of her bed, which showed her heart's electrical rhythm, oxygen level and blood pressure. By 9:18, her oxygen level fell from 95 percent to 60 percent. By 9:21, the oxygen level fell further to 22 percent, but her heart rate stayed normal at 74 beats per minute. At 9:25, her blood pressure dipped a little, her oxygen level was zero — which meant her blood was becoming acidic and possibly harming her organs — but her heart rate was still 62 beats per minute.

Watching someone die, observing her heart struggle and ultimately fail over the course of a half-hour, brought home how death occurs in its own way, at its own idiosyncratic pace. There is no escaping the tragedy of the moment. I thought about Jaiden and Amanda, and their stories together with this woman's seemed an endless loop of sorrow.

At 9:32, the woman's heart still beat 60 times per minute, though she was blue and unresponsive. At 9:38 her heart rate was 20, and then she flat-lined. Immediately, a stopwatch was started to count the five minutes before death could be declared.

The woman was wheeled to the operating room, where the surgeons were assembled. Three minutes passed without any heartbeat, and then four, then four and a half. There was silence. It was the nurse practitioner's sole responsibility to declare death without any interference from the transplant surgeon. Suddenly, there was a single blip on the heart monitor. The blip was almost certainly an artifact of some outside electrical interference and not a true heartbeat, but it was hard to tell for sure. Five minutes had passed, and every delay meant the organs were more starved for oxygen.

The nurse practitioner hesitated as she considered whether to call the death or restart the five-minute count, and then she made her decision. She looked at her watch and called out, "Time of death was 21:44." A flurry of activity began as the surgeons called for their instruments and the operating room sprang to life. There was no anesthesiologist at the head of the bed, so I stood there as the team prepared to make the incision. Suddenly, Dr. Adel Bozorgzadeh, the attending transplant surgeon, raised his hands. "Let us take a moment of silence and consider the gift that is being given on this day," he said. A few seconds passed. Then he brought the knife down.

Like Amanda Panzini, the teenager hit by the truck, the patient I observed bequeathed several abdominal organs, but not her heart. Although the liver and kidneys are relatively hardy and can withstand the five minutes of oxygen starvation before removal, the wait seriously damages the more delicate heart and renders it unusable. Heart transplants thus call only for brain-dead donors, whose hearts are still beating until just moments before they're removed.

This, it was thought, was the only way to get a viable heart. But a pediatric cardiologist named Mark Boucek at Denver Children's Hospital was growing tired of watching young children with incurable heart defects die. In 2004, financed by a federal grant, Boucek wrote a far more aggressive D.C.D. protocol that would save the heart, which was adopted after going through the hospital's review process. His version had two key innovations. First, large intravenous lines would be placed in the donor's groin before death, to enable the donor's entire blood volume to be replaced with a refrigerated salt preservative when it was time to remove the heart. Second, and most controversially, Boucek, who has since died from pancreatic cancer, rejected the five-minute rule imposed by the Institute of Medicine and ini-



Robin Beaulieu with a picture of her daughter Amanda, who was hit by a pickup truck when she was 15.

tially picked three minutes instead; after all, no law had codified a particular time period. But David Campbell, the pediatric cardiac surgeon at Denver who procured the first heart using the protocol, realized that even three minutes was too long. "When we opened the chest and pericardium, the heart was distended and blue," he told me. Upon transfer to the recipient, the heart failed to work well initially and required the child to remain on a dangerous heart-lung bypass machine for several days. "That's why I asked that we move the time down lower," Campbell said. In reviewing the medical literature, Boucek found the longest recorded time that a heart had ever stopped and then spontaneously restarted without medical intervention was 65 seconds. If the law required "irreversible" cessation of heart function, Boucek concluded, there was no reason to wait much longer than that.

Waiting just over a minute after cardiac arrest to declare death was unprecedented. Last year, when the Denver specialists published their provocative case reports in *The New England Journal of Medicine*, many observers assailed their work and called it a back-door method of performing euthanasia. Robert Veatch, a professor of medical ethics at Georgetown University, calls the Denver doctors "lone wolves," and he categorically rejects heart transplantation using D.C.D. because he maintains that a donor heart cannot have "irreversible" cessation. After all, it works fine after it's transplanted. Veatch is especially concerned about a potential public outcry against organ donation. "I spent all morning today dealing with conservative right-to-life scholars all worked up about stem cells," he told me recently, adding that he could only imagine their reaction to taking hearts from "helpless little babies."

The first baby whose heart was donated under the much-shortened wait period was a newborn girl named Addison Grooms in 2007. Her parents, David and Jill Grooms, have no tolerance for Veatch's viewpoint. Addison's brain was severely damaged in a complication from delivery. "There was no chance at all that our daughter was going to survive," says David, whose brother died of a malformed heart as a baby. "I can follow the ethicist's argument, but it seems totally ludicrous." Had the couple found out another child died because they weren't allowed to donate Addison's heart, it would be "like another slap in our faces." Further, both parents would have permitted simply taking out Addison's heart under complete general anesthesia—without the intermediate process of the choreographed death—which would have been a painless way to end their child's life, had it been legal.

Three months after Addison's death, a neuroscientist named Lori Driscoll gave birth to a son, Liam, with a catastrophic injury similar to Addison's, and he was also transferred to Denver Children's. Testing showed that almost every part of Liam's brain was destroyed, though some primitive reflexes remained. Lori and her husband consented to Boucek's novel protocol. They accompanied Liam to the operating room, where the breathing tube was removed. They held his hand for 10 minutes until his heart stopped.

Moving past a binary concept of life and death is, for most of us, an uncomfortable process. It's worth considering how various cultures think about the beginning of life. Tibetan monks believe a new life begins around the time of a mating couple's orgasm; many Catholics posit that it starts at the

union of an egg and sperm; Roe v. Wade effectively established a legal threshold of life at 24 weeks of fetal gestation; some consider meaningful life to begin at birth; the Navajo think a baby is fully human when it laughs for the first time. If the emergence of life occurs on a continuum, perhaps the same is true of life's recession.

Still, preserving the notion that the transition from life to death can be clearly defined may be a fundamentally necessary fiction. Though no religious organizations or right-to-life groups have yet mounted any opposition to D.C.D., including the Denver protocol, it is important to change practices in deliberate steps that give decision makers clear rules of action and establish gradual consensus.

Lori Driscoll, for one, is grateful for the changes Boucek made to the D.C.D. protocol. After her baby Liam died, she was told that a 3-month-old girl received his heart. That infant was prepped for surgery for her new heart in the room adjacent to the one where Liam died. The surgery went well. Months later, Driscoll learned that recipient was a girl with the uncommon first name Annika. She did some sleuthing and found Annika's mother's MySpace page. The women exchanged photos, arranging to meet last year. Driscoll fantasized about running up to Annika, holding her close and placing her ear over the toddler's chest to again hear her son's steady heartbeat and feel his presence. But something unexpected happened when she met the girl. "It was the most amazing thing to see her thriving," she said, and her initial emotional rush "had nothing to do with Liam." For a moment, the weight of the past was forgotten as Driscoll marveled at the healthy little person before her. ♦