ORGAN DONATION

NEW STRATEGIES FOR FINDING ORGANS

Joyce A. Griffin
At The Hastings Center, we believe moral problems can be clarified through reasoned debate and an honest attempt to find common ground. Our work is characterized by its openness to differing perspectives. We use a process of assertion, analysis, critique, and response. While we may never reach full consensus, we have successfully used this process, time and again, to narrow differences, eliminate misunderstandings, and develop tolerance and trust.

This publication is part of a series that will capture cross sections of the contemporary debates about topics of longstanding interest in medicine and the life sciences. Some of that debate takes place within The Hastings Center, but it also goes on in our homes, in hospitals and doctor’s offices, in academic institutions and journals, and in government.

The series is intended to provide clarity about medical and scientific facts, about matters of law, about ethical standards, and about the underlying values that inform those standards. We hope to point out where genuine controversy over facts or policies exists—and where it does not.

Founded in 1969 in Hastings-on-Hudson, New York, The Hastings Center was the first bioethics research institute in the world. Some of the enduring topics we will address in this series received their earliest consideration in research conducted at the Center during the 1970s and 1980s.

Today, The Hastings Center confronts ethical issues in genetics and biotechnology, health care and health policy, and medical research. Privacy and confidentiality, fair allocation of scarce health care resources, protection of human research subjects, medical error and forgiveness, and the ingredients of human flourishing are core themes of our work.

Please visit www.thehastingscenter.org for more information about the Center, our publications, and our research programs.
Learning to Wait

Grace Peterson has seen organ donation from both sides. In 1994, after her son Jerry’s accidental death, hospital staff asked her to donate his organs for transplant. She didn’t hesitate. With a cousin’s recent liver transplant still fresh in her mind, she personally understood the importance of donation. Even though a blood clot ended her cousin’s life a day after the operation, the hope the transplant had given her family had convinced her to offer her own organs after death. Deciding to donate her son’s organs was both an extension of that conviction and a way to ease her grief. Doctors gave Jerry’s kidneys, heart, liver, and corneas to six people in dire need of them—four to save their lives, and two to save their eyesight. The knowledge that Jerry’s death had done some good helped Grace. “I figure he’s still walking around somewhere,” she says.

But Grace’s experiences with organ donation weren’t over yet. While in counseling for depression after Jerry’s death, she complained of growing fatigue, prompting her doctor to do blood work to see if the cause was physical. Sure enough, tests showed she was suffering from hepatitis C, a blood-borne viral liver disease that can lead to cirrhosis, cancer, and ultimately liver failure and death. Doctors suspect she contracted it from transfusions she received after Jerry’s birth in 1975 and a hysterectomy in 1981. Having carried the virus for so long, her treatment options were limited. Her only chance to recover would come from a new liver. And so, just three years after her son’s organs had been transplanted to gravely ill recipients, Grace Peterson herself was placed on the national transplant waiting list in the hope that the same operation would eventually save her own life.

That was nine years ago. Now 60, she’s still waiting, and she fears her time is growing short. She must take numerous medications and suffers from unexplained bruises, bleeding in her mouth, and a painful gallstone that doctors can’t remove for fear of leaving scar tissue
that could jeopardize a transplant. Any bleeding is worrisome because liver disease dramatically reduces the number of platelets in her blood, making it less likely that her blood will clot enough for wounds to heal. Her doctor warns her that these complications—and others waiting in the wings—may make surgery too dangerous for her.

“The longer I wait, the more chance I have of getting cancer or something that will prevent me from getting the transplant,” she says. She feels caught in a bind: as her deteriorating health pushes her up the waiting list, making it more likely that she will be offered the liver she needs, it also makes her less likely to survive the operation, and in fact less likely even to be considered for it. So she lingers, and her hope dwindles.

She is not alone. At the moment this sentence is being written, over 94,000 people are in the same predicament, waiting for organs that may come too late or not at all. The odds are not in their favor. Last year, about 21,000 transplants were performed using organs from deceased donors, and nearly 7,000 additional transplants used organs from living donors. The depressing reality for the people on the waiting lists is that only about 30 percent of them will receive organs.

What could we do, and what should we do, to make more organs available? The waiting lists have grown steadily over the last couple of decades, and in the last few years, widespread concern about them has reached critical mass. A diverse assortment of policy options have emerged for promoting organ donation, leading to intense policy discussions about the merits and drawbacks of each. Some proposed strategies would use financial or other incentives to promote organ donation; some already in development take advantage of the Internet’s unique capacity to disseminate information and put strangers in touch with each other; and some of them preserve and refine the current approach. They will not be equally effective, however, and some strategies that might be effective might not be ethically appropriate.

Burgeoning Need, Limited Supply

The era of organ transplantation began in 1954, when doctors at Peter Bent Brigham Hospital in Boston performed the first successful kidney transplant. The donor was Ronald Herrick, a healthy twenty-three-year-old just discharged from the Army, and the recipient was his identical twin brother, Richard, who was dying of kidney disease.

The operation worked primarily because Ronald and Richard Herrick shared the same genetic makeup. Doctors had yet to figure out how to keep a patient’s immune system from rejecting a transplanted organ. The very first human kidney transplant, performed two years earlier, had failed for precisely this reason. That operation transferred a kidney from a mother to her sixteen-year-old son, but the boy lived for only twenty-two days before his immune system attacked and destroyed the kidney. But Richard Herrick’s immune system accepted his brother’s identical kidney, and he went on to marry his recovery-room nurse, father two children, and live for eight years before a heart attack killed him in March of 1963.

Of course, most people with kidney disease are not lucky enough to have an identical twin to provide a perfectly matching kidney, so organ transplants did not really become a viable treatment option until the first antirejection drug, Imuran, was developed in 1962.
The Gift That Is a Loss

Each of these scenes is distinctive unto itself. And yet each bears clear resemblance to every other of the thousands that have preceded it:

Separated from eternal stillness only by the automated impulsions of a respirator, the body of a young man vibrantly and optimistically alive only days or hours before now lies waiting for a final decision. Depending on its outcome, something of him will or will not live on in another. For those professional personnel who bear witness, watching is never easy. There, in all of its stark injustice, is the ultimate tragedy that can befall a parent. No matter how well prepared and no matter how committed to such decisions they believed themselves to have been before this night, a father and a mother, together and yet each alone with unshared thoughts, must now sign a piece of paper sealing the inevitable loss of their son. The doctors have been thoughtful and understanding, the nurses not only empathetic but tearful as though they themselves were losing a friend. Still, even these reminders of the goodness of others do not mitigate the pain or lessen the anguish.

There is consolation and even reassurance in knowing that what is to be given is the ultimate benevolence to a fellow human being: the act called by many “the gift of life.” But this man and this woman—this father and this mother—can only wish that they themselves were on that respirator at this moment, instead of their son.

The long vigil is over, in which some small and ever diminishing flame of hope had still flickered. The imminence of death must now be faced, and the emptiness that will never lessen, left by a beloved boy whose promise has been extinguished. Frustration, impotent rage, remorse, self-blame—there can be no recovery from grief unless such damaging ruminations can be dispersed by the cleansing aura of clear thought, and unaccusing actuality. Perhaps the gift to be given to some unknown who cannot live without it may assuage the baseless feelings of guilt and anger and put them properly into the framework of the truth within which these parents must now live—a truth enabling them to persevere not only for themselves but for the son they have now lost.

The unknown recipient will cherish his or her healthy, vigorous organ, and so also cherish the young man, their beloved son, who provided it. And this too, is comforting; in such ways, the young man will live on. As a waiting heart transplant recipient once wrote to me:

For me to live, someone has to die. That’s a very complex thought; it deals in a way with a form of ethics. Is it right to want to live at the expense of others’ grief, to pray that I am found a strong young heart when I know full well that it was part of a person younger, stronger, and having more years to give than I will ever have? These thoughts are real and they have to be faced, and not superficially. Science has made me the potential recipient of a modern miracle. In a sense it’s a blessing and one that I will always treat accordingly. To do less is beyond my conception.

Finally, the piece of paper is signed, and the time for farewells has come. Though the wondrous magnitude of what they have just done leaves them with a certain hope they otherwise would not have found, these two bereft parents will nevertheless slowly and wordlessly leave the hospital and try to face the future without their son.

—Sherwin B. Nuland
Physician, author of How We Die, and Hastings Center board member
This advance encouraged doctors to try new kinds of transplantation surgery—using different organs, obtaining them from both living and deceased donors, and transplanting them into unrelated recipients. The discovery ten years later of the powerful immunosuppressant Cyclosporin and its approval by the Federal Drug Administration in 1983 made transplantation still more reliable, and improved methods of sustaining organs outside the body made transplantation possible even when the donor and recipient were not in the same hospital. Today, heart, liver, lung, kidney, pancreas, and intestinal transplants have become the preferred treatments for many previously untreatable diseases.

Hence the national waiting list: as organ transplantation has become more dependable, the number of people whose doctors recommend it has grown remarkably—and much more quickly than donation rates. Higher rates of organ-destroying diseases like diabetes and high blood pressure drive the need for organs higher still. Yet for decades, the number of organs donated has grown only very slowly.

Several factors are likely responsible for the slow rate of increase. The most significant is that the pool of eligible donors is very small. Most organs must come from deceased donors, and not everyone who dies can donate. To be medically suitable for transplantation, a person’s organs cannot be damaged by disease or injury, which means that the person must die in one of a small number of ways. Also, the death must occur in a setting in which it is possible to recover the organs and convey them to a potential recipient very quickly. Typically, a suitable donor is a healthy person who undergoes a health catastrophe (a motor vehicle accident is the paradigm) is taken immediately to a hospital, and is declared dead there while on mechanical ventilation, which keeps the circulatory system functioning and ensures that the organs are suffused with oxygen. Of the more than two million deaths in the United States each year, fewer than twenty thousand deaths fit this model.

Also, as this typical case already suggests, the overall process of obtaining the organs and getting them transplanted into recipients is complex and difficult. Potentially eligible donors have to be identified before they die and cared for appropriately during the end of life period. If possible, the prospective donor should have consented before death to having organs removed after death. The donor’s family must give their consent as well. The recipients must be identified, and the organs must be transported to them immediately once they have been recovered from the body, which must happen as quickly as possible after the donor’s death. Finally, the actual transplants must be performed. In the ideal case—as with Grace Peterson’s son—a donor can provide multiple organs, which means that to maximize the organ transplantation rate, multiple recipients must be identified, and multiple organs recovered, transported, and transplanted into them all more or less simultaneously.

All this means that recovering and allocating organs is a vast organizational effort. Many different things have to happen in just the right way. No one laments, of course, that so few healthy people die suddenly—although the limited pool of potential donors is one factor restricting the availability of organs. The distressing problems are those that prevent poten-
tial donors from becoming actual donors, many of which have to do with the consent process. For example, a general lack of trust in the medical system is sometimes an obstacle. James Warren, editor of an industry newsletter, *Transplant News*, said in a 2002 interview, “The bottom line is that people don’t trust the system, especially if they are [members of] a minority. It’s a manifestation of the health care they get in general. They think that in the health care system people are not going to treat them fairly.” These fears generate the myths and misperceptions targeted on the Web site of the Organ Procurement and Transplantation Network, the national system that matches donors and recipients. Two sample misperceptions: “If emergency room doctors know you’re an organ donor, they won’t work as hard to save you,” and “When you’re waiting for a transplant, your financial or celebrity status is as important as your medical status.”

Clearly, many people outside the medical establishment do not understand the process of organ procurement, and this confusion creates huge problems. For example, if the donor is deceased, that person must usually be declared dead by neurologic criteria—what is popularly called “brain dead.” However, because the donor must be on mechanical ventilation to keep the circulatory system functioning, the person may look alive but unconscious. Thus “brain death” is often confused with a coma or minimally conscious state—conditions in which brain function is impaired but exists—and people end up thinking, completely incorrectly, that recovery from brain death is possible. In the emergency rooms and intensive care units where decisions about organ donation are most often made, stunned and suffering family members struggle to grasp why their “brain dead” loved ones are kept on “life support” while teams wait to “harvest” their organs. It’s little wonder that organ procurement teams often fight an uphill battle when approaching a possible donor’s loved ones for permission.

Another fact few people know is that carrying an organ donation card or checking the organ donor box on the back of a driver’s license is meaningless unless next of kin back up the decision to donate. Though donor cards are legal documents, few doctors or hospitals are willing to take an organ when the deceased’s family opposes donation. And even if the family is not really opposed to donation, they may still decide against it for a variety of reasons. They may worry, for example, that they will be charged extra for the transplant operation (they won’t be); they may believe that their religious leaders would frown on donation (in fact, all major organized religions regard it as an act of charity and encourage it); and they may fear that organ recovery will disfigure the body (it can’t—removing an organ, even several organs, is no more detectable from the outside than an appendectomy).

For these and other reasons, many patients and families are inclined to say no to organ donation. Much of the policy discussion about the limited availability of transplantable organs has been directed at encouraging them to say yes.

**“Buy or Die”?**

In June of 2006, the right-leaning American Enterprise Institute for Public Policy Research held a conference entitled “Buy or Die: Market Mechanisms to Reduce the National

---

Recovering and allocating organs is a vast organizational effort. Many different things have to happen in just the right way. The most distressing problems are those that prevent potential donors from becoming actual donors.
Organ Shortage. The conference’s description asserted that “Although donor altruism is an inspiring virtue, generosity as public policy falls short.”

That statement echoes a growing movement in America urging policy makers to abandon one of the key features of the 1984 National Organ Transplant Act: the prohibition on organ sales. In the past year, everyone from Newt Gingrich to the authors of *Freakonomics* has suggested that a free market in organs would reduce the gap between supply and demand. Psychiatrist and kidney transplant recipient Sally Satel (also a resident scholar at AEI) wrote a *New York Times* op-ed in May 2006 pleading for donor incentives. She described her anguish when a possible donor fell through: “I wished for a Sears organ catalog so I could find a well-matched kidney and send in my check.” Advocating for her wish to become reality, she pointed out that “Charities rely on volunteers to help carry out their good works but they also need paid staff. If we really want to increase the supply of organs, we need to try incentives—financial and otherwise.”

There is no denying that in American medicine, money talks, and loudly. Those willing to pay a lot of it are rewarded with access to the finest hospitals, the best doctors, and the most comprehensive health insurance policies. They can buy human eggs or sperm and then compensate a woman to carry the child produced from them. But they can’t buy an organ. Why not? In an essay in the *New York Times Magazine*, the authors of *Freakonomics* described an impending transplant between an unnamed Donor and Recipient. “Consider the parties who stand to profit from this transaction: Recipient, certainly, as well as the transplant surgeons, the nurses, the hospital, the drug companies. Everyone will be paid in some form—except for Donor.”

Is the problem that a direct cash exchange sounds too crass when we’re talking about human bodies? Some evidence suggests this is the case. A survey conducted by the Institute of Medicine in 2005 discovered that 10 percent of respondents would be less likely to donate a family member’s organs if offered payment. It’s not hard to grasp why—no one wants to be accused of selling his relative’s body parts for profit.

More sophisticated versions of the financial incentives idea reflect a sensitivity to this fear. Across the spectrum of those who argue for financial incentives, not all are grounded in libertarian philosophy and free market rhetoric. Some feel that if financial incentives are to respect the feelings of all involved, they must be given in gratitude rather than barter. Return to Grace Peterson for a moment. What if when she was approached with the request to donate Jerry’s organs, she had been told not just that doing so would save four lives, but that in addition, she’d been given five thousand dollars as a token of appreciation? This is the scene envisioned by David L. Kaserman, an economist at Auburn University. He also proposes that the payment come from a third party, such as the federal government. He argues that for kidneys—the organ most in demand—the scheme would actually *save* the government money, compared to the amount Medicare could spend paying for years of dialysis for a person in kidney failure. And offering the money as a thank you from an overseeing body, rather than in a direct exchange from the person in need of the organ, might blunt the worry that body parts are being bought and sold.

Still, Kaserman’s debating style has a cash register ring to it. Despite the mitigating presence of a third party in the transaction, he still speaks in market terms. In summing up why
In recognition of having flourished in a new home far across the sea from their origins, the founding fathers of the Connecticut town of Saybrook in 1639 inscribed on their colony seal the words that would, in a later century, become the state’s motto: Qui transtulit sustinet, “He who transplants, sustains.” And so it is with the transplantation of organs from their place of birth to a state of thriving in their new home.

One or more transplant teams, sometimes from several states, converge on a hospital within the coordinating jurisdiction of their regional organ bank. Unless the distance is shorter than one hundred miles or so, each group comes in its own chartered jet plane and is then sped from the airport by waiting automobile or ambulance. The arriving team or teams gather in an operating room to which the donor has been brought, typically a young person whose brain has been irretrievably damaged as a result of an event involving no injury to his or her trunk. In the usual case, the brain has ceased to function and the person is technically dead. The body continues to function only with the help of a respirator.

In a surgical sequence meticulously organized and timed to the minute, the surgeons remove and carry away the healthy heart, lungs, liver, kidneys, pancreas, and intestine, which are to be implanted into the bodies of men and women, and sometimes children, who desperately need them. Recovered with delicate care and placed in nourishing fluids, the organs are gently placed into concentric plastic bags and then lowered into individual ice-filled containers, each of which will be cradled like the precious commodity it is, in the lap of one of the team, once again into a waiting vehicle and on to the airport. Constant communication is kept up with the home hospital, where a recipient—or perhaps more than one—awaits the surgery that will restore health and hope.

Before any of these events take place, the recipient is notified that a donor meeting the appropriate specifications has been located; immediate hospital admission is followed by final confirmatory blood and other studies, and then by the operation itself. When the last-minute preparations have been carried out and the elated but nevertheless apprehensive man or woman is being wheeled toward the surgical suite, a palpable energy takes hold of doctors, nurses, and everyone else involved in the previous care of the patient and in the coming transplant. It is as though some form of high-voltage electrical force is charging the atmosphere, bringing jubilation and optimism, tension and uncertainty.

Anesthesia is induced at a moment determined by the progress of the recovery team, so that the donor’s organ will arrive within the optimal time frame for transplantation. The plane lands at the home airport, and its precious cargo is rushed across the tarmac, securely enfolded in someone’s arms, and then transferred to an ambulance for a sprint across town to the hospital. Up the stairs or elevator and into the hands of a nurse goes the gift of life, to be carefully lifted from its nutritive bath and wrappings and, at precisely the right moment, handed to the senior surgeon to be stitched into its new home in the needful body of his patient. The team works with attentive swiftness, and before long the job is done. The clamps are removed, and the organ fills with the pulsating bright red arterial blood of a man or woman renewed. As the surgical team watches with an awe that never lessens no matter how often they have seen the phenomenon, the awakening structure begins to function as if it had been born to this place and this patient. A miracle of technology and science has occurred, as it will many times throughout the world on that same day.

— Sherwin B. Nuland
more families don’t donate their relatives’ organs, he says, “If you set the price of anything on this earth at zero, you’ll have a shortage.” This statement may reflect a basic reality of the financial incentive position: that the idea of one’s being paid when donating—even if one is not necessarily being paid for the organ—is inseparable from the concept of buying and selling. Consider this: In 2002, an ethics panel of the American Society of Transplant Surgeons proposed that funeral expenses of deceased donors be partially covered “to express appreciation for the donation.” The panel was careful to warn that the sum was “not to provide payment for” the organ. Francis L. Delmonico, medical director of the Society, compares the idea to the Red Cross giving a coffee cup to someone who has just donated blood; even though the cup has monetary value, it’s unlikely that someone would donate blood just in order to receive one. But when a *Washington Post* headline trumpeted, “Surgeons Back Study of Payment for Organs,” the ASTS withdrew its support from the proposal. “If the public could not distinguish what was an objective to try and find some way of saying thank you,” he says, “the ASTS didn’t want to take us into the realm of endorsing payments for organs.”

The truth is that, in spite of the market model in American medicine, there is also a pervasive feeling in the United States that selling organs is just morally wrong. Economists may argue, as Kaserman does, that by not pricing organs, we’ve guaranteed a shortage; to use an economist’s favorite theoretical example, if “widgets” have no cash value, then few if any will be produced. However, donation rates are not at zero: Thomas Murray, now president of The Hastings Center, pointed out in a 1996 essay that even though roughly half of families approached to donate organs refuse, this means that roughly half donate, and without financial incentives. He suggests that voluntary donation is driven by other motives—that it may offer “consolation in our grief, or a sense that our relative in some way lives on in another . . . permit[ting] us to affirm our belief that our relative’s characteristic generosity . . . continues to enrich others’ lives even after his or her death.” Grace Peterson echoes these statements when she describes her feelings after donating Jerry’s organs, suggesting that families who donate find different rewards than money—a belief that leads Murray to conclude that organs and widgets cannot be equated.

Donald Joralemon, a medical anthropologist at Smith College, and Phil Cox, a philosopher at the University of Massachusetts, agree. In a 2003 article in the *Hastings Center Report*, they came out strongly against pilot studies proposed by the American Medical Association to gauge the effect of moderate financial incentives on possible donors. They reasoned that people do not view the bodies of their dead loved ones as property, but as seats of the self, no less worthy of respect now that the self has departed. “The claim that dead bodies ‘are no longer inextricably intertwined with a person’ and are therefore only protected as property,” they wrote, “is badly out of sync with the real world and the way families actually respond to the death of relatives.” How else to explain the extraordinary effort to recover even the smallest evidence of remains from disaster sites such as Ground Zero in New York City other than to affirm the idea of body as relic, not object? Even those who favor an open market for organs admit that repugnance at the idea will probably keep the United States from embracing one any time soon.

But those opposed to financial incentives point out that there are plenty of ethical and pragmatic arguments against the idea beyond repugnance. Foremost among these are the rampant possibilities for abuse that financial incentives may present. Sally Satel favors the idea of pilot studies to “resolve ethical and practical aspects,” envisioning variations of a reg-
ulated market, such as one resembling “a ‘futures’ market in cadaver organs” that would give a donor the choice of accepting payment in “installments before death or to his estate afterwards in exchange for permission to recover his organs at death.” But James Childress, chair of an Institute of Medicine committee convened to explore ways of increasing organ donation, believes a “futures” market in cadaver organs runs afoul of the fear that doctors might compromise a patient’s medical care in order to get the organs. “If I don’t want to sign a donor card for that reason,” he says, “You can be damn sure I don’t want to sell my organs now for delivery in the future if the only thing standing in the way of delivery is that I’m alive.”

Jerome Groopman, a professor of medicine at Harvard who supports financial incentives, nevertheless warns that they should not be offered to a dying person’s family. (He thought only the healthy potential donor should receive incentives.) In a May 1999 essay in the New York Times, Groopman criticized a plan conceived by the State of Pennsylvania to pay three hundred dollars toward a donor’s funeral expenses. He saw much potential for abuse. “End-of-life decisions are complex and influenced by many forces. Money should never be one. Would a family, overtly or subconsciously, decide to withdraw life support prematurely so as to have usable organs for donation? Might a doctor be asked by a family not to administer a treatment that had a small but finite chance of saving a life because it had a very significant chance of damaging the kidneys or lungs or heart, thereby making the patient ineligible as a donor?” He also envisioned states competing for viable organs, both with each other and against for-profit transplant centers that would likely have more resources than any government-funded center could hope to have. “Beyond prestige,” he wrote, “transplantation is a lucrative clinical program, and it has valuable spin-offs, like research grants, fund-raising and patents.”

Offering financial incentives for organs from live donors raises even stickier ethical concerns. Long-term data regarding the health of living donors are sketchy at best. We know that a person who donates a kidney sometimes experiences failure of the remaining one—an outcome that would essentially negate her good deed by placing her on the waiting list in place of the person who got her functioning kidney. If the donor comes from a developing country—and donors in the current black market in organs often do—the risk of illness is even greater.

“When you’re living in a slum in Bangladesh,” says Margaret Lock, a sociologist at McGill University and a critic of organ sales, “you’re at enormous risk for infection following the surgery and failure of the other kidney.” She adds that research indicates impoverished people usually realize no lasting economic benefit from selling an organ, and if they become ill, they will likely become worse off. “People will be exploited and are being exploited in horrendous ways.”

Atul Gawande, a doctor and columnist for Slate magazine, concurs. “When an organ seller is trying to decide whether the terrible dangers from kidney removal [are] worth a sudden cash infusion, his effort to identify his best interest will be confused by how the question is framed, by difficulties sorting out the statistical risks, by the vision of all that money, and many other factors,” he wrote in 1998. “These vulnerabilities are easily exploited. But even when not taken advantage of, plenty of people get serious decisions wrong.” He contends that
people are just not that good at making rational choices about risk assessment, even under the best circumstances. “Saying people are fine 98 percent of the time after surgery can lead patients one way,” he writes, “while saying people experience strokes 2 percent of the time can lead them in the other direction. . . . [T]here is no right way to frame the options.”

And the exploitation can go both ways, hurting buyer as well as seller. The price of a transplant is already sky-high. Medicare generally covers most of the costs of a kidney transplant for its beneficiaries, and Medicaid may cover some kidney transplants for the poor in some states. But people needing other organs often have to finance a transplant themselves. The United Network for Organ Sharing, a nonprofit private organization that manages the Organ Procurement and Transplantation Network, says most patients must rely on a variety of sources to pay for a transplant. Medical expenses for a liver transplant are more than $392,000, including follow-up care and immunosuppressive drugs. Nonmedical costs, such as lost wages and transportation to the site of the transplant, can drive this figure much higher. And the immunosuppressive drugs can run ten to fifteen thousand dollars a year for the rest of the recipient’s life—a cost that effectively bars some people from receiving transplants.

“I don’t know any center that will transplant anyone who doesn’t have the ability to pay for antirejection medicine,” says Laura Aguiar, president of the Transplant Financial Coordinators Association. Even if the person has health insurance, the immunosuppressive drugs may not be covered by it. Clearly, the poor are at a disadvantage already when in need of a transplant; how much more unaffordable would a transplant be if the donor also needed to be paid?

Financial incentives for organ donation are probably too controversial for consensus. Hence some reform proposals reflect Satel’s recommendation that we try incentives—“financial or otherwise.”
Directed donation is an increasingly popular strategy for connecting donors with recipients. In directed donation, a living donor (directed donation is prohibited for deceased donor organs) gives a kidney—or part of a liver, pancreas, lung, or intestine—to a specified individual. For the recipient, it’s a miracle: no years spent languishing on the waiting list; no split-second emergency surgery when the organ becomes available; no death required for a chance to be healthy. Instead, both donor and recipient can schedule surgery at their convenience. And both will come out of it alive.

It sounds perfect, and it can be. But one has to wonder, if financial gain doesn’t motivate the transaction (and by current law, it can’t), then what does? The screening process is long, the surgery complicated and disruptive, and the outcome uncertain. Data on the short-term effects to living donors are incomplete, and on long-term effects, data are nonexistent. There are certainly health risks involved, so why are an increasing number of people willing to take them on?

To find the answer, we must look at the complex web of relationships that binds the ill to their spouses, families, and communities. Sharing a history and an emotional background certainly affects the dynamics at play when one person asks another, explicitly or implicitly, for an organ, and many factors may shape the reply. These factors worry medical ethicists. They use the term “voluntariness” to describe a person’s right to make medical decisions free from undue influence. But a living donor’s voluntariness may be compromised. Spouses, siblings, family members, and friends may feel pressured into donating by the sick person or others close to him, but sometimes they simply rush forward on their own. As the IOM report states, “the close affective ties in most donations involving related donors may lead the prospective donor to make a decision to donate before he or she fully receives and understands all the pertinent information, particularly about the risks involved.” And once that decision is made, it’s hard to go back: “Potential donors sometimes feel trapped in a process that they do not know how to stop without jeopardizing their relationships with members of their family or other people,” the report notes.

Given the complexities of family relationships, protective oversight of living donation by the government or professional associations is nearly impossible. It’s not easy for a stranger to assess whether a donor understands the risks to her own health enough to competently weigh the benefits of donation against them. Still, the benefits to a donor who is emotionally close to a recipient are fairly easy to grasp—she will save her loved one further suffering, and she will have a chance to enjoy the continued presence of that person in her life, hopefully for years to come. These benefits may convincingly offset the risks.

But what if the donor is not emotionally close to the recipient? The majority of living donation takes place within families, but in the past decade, directed donation between unrelated donors and recipients has taken off. In 1995, roughly 5 percent of living donors were not related to the recipient of the organ. In 2004, that number had ballooned to 21 percent. Recipients include friends, acquaintances, and complete strangers.

Seeking altruistic donors from the general population is nothing new. In the past, families and friends of those searching for a transplant have taken advantage of local television, news-
papers, and radio to go public with their donor search. But with the Internet, they can take these searches to a whole new level. MatchingDonors.com, created in 2004 to foster directed donation between unrelated people, has more than a little in common with Match.com, the dating site: it lets total strangers make their pitches to invisible judges. People who need transplants tell their stories, trying to convince viewers in a few paragraphs that they have found The One, and potential donors browse through the listings to find just the right person, using any criteria they wish to decide whom to help.

This scenario is disturbing to its critics for a number of reasons, the first being that it features the ill competing against each other to catch the eye of visitors to the site. Soliciting an organ is potentially more inequitable than buying one. If a market in organs favors the rich over the poor, a site like MatchingDonors.com favors the attractive, the charismatic, those who understand the subtle art of manipulation, and those who just happen to have interesting stories over those who may be just as deserving of life but have less social savvy and no gripping personal details.

“I’m not waiting for an organ transplant,” wrote Timothy Murphy, a medical ethicist at the University of Illinois College of Medicine, in a 2006 Hastings Center Report commentary, “but what if I were? Would anyone find my story compelling?” He wondered how his story would “stack up against that of a sick Mom or Dad with children, someone bankrupted by medical debt, someone much younger, or someone friendlier to religion.”

This is another potentially troubling aspect of directed donation between strangers: the possible donor’s judgment may reflect personal biases, which some fear might unfairly skew organ allocation toward some groups over others. The United Network for Organ Sharing does not allow donors to designate the recipient’s demographic profile. The policy was prompted by a 1994 case in which the family of a murdered Ku Klux Klan member donated his organs after death with the stipulation that they go only to white people. But directed donation on the Internet need not follow UNOS policy. Indeed, as Murphy acknowledged, “Shopping the Internet for organ recipients . . . practically invites donation to groups.” It’s easy to imagine someone using the keyword feature on MatchingDonors.com to search for terms like “white” or “Christian.”

Murphy and other critics feel that the only fair standard by which to judge who gets an organ is medical need. This is the primary factor UNOS uses when allocating organs from deceased donors. Some transplant centers now accept undirected donations from living organ donors. The organs are given anonymously, like blood, and then allocated to recipients on the basis of medical need in the same way that cadaver organs are. The process has its own challenges. One is that, when donors and recipients have no relationship—even a tenuous one—donors are, not surprisingly, much less likely to follow through. This fact can make transplant centers leery of investing their limited resources in an effort so unlikely to succeed. And the practice of judging strictly by medical need has its critics as well. Sometimes the sickest person on the waiting list is just too sick to benefit from a transplant as much as a healthier person could. A good example of a scenario like this is the case of Yankee legend Mickey Mantle, who received a liver transplant in 1995. The transplant came too late: he was so sick and his body so weakened that he died a few months later, despite

The IOM report cautions that if we introduce a criterion not related to medical need, we start down a slippery slope to where we “award” organs on the basis of merit.
the new liver. And the new liver was buried with him—a questionable use of a resource so scarce.

A kind of directed donation that tries to even the playing field is utilized by the New England Program for Kidney Exchange. This program looks for couples rather than individuals. One spouse has kidney failure, but the other is not a biological match, so donation between them is impossible. The solution? Find another couple in the same predicament. The healthy spouse from Couple 1 donates a kidney to the sick spouse in Couple 2, and vice versa. The operations are performed at precisely the same time so neither couple can obtain an organ and then back out of donating. But because of the complex nature of the exchange, few have taken place.

**Giving and Receiving**

Another kind of nonfinancial incentive is employed to increase deceased donation. According to this strategy, the primary criterion for judging who will receive a donated organ is whether the recipient has also registered to donate organs after death. In other words, like the New York lottery, you have to be in it to win it. UNOS already uses a modified version of this idea. Those who have registered to donate organs get moved higher up the waiting list than they would otherwise be. But the primary deciding factor in the UNOS approach is still medical need.

The LifeSharers Network would like to see that change. LifeSharers—an active presence on the Web—advocates a preferential access program by which members direct that, at death, their organs be offered first to other LifeSharers members (unless no LifeSharers member is a suitable match, in which case the organs would go directly to whoever tops the general waiting list).

Grace Peterson is a member of LifeSharers. She’s frustrated by the fact that she’s not only agreed to donate her own organs at death, but has already donated her son’s organs, yet she still languishes on the waiting list while nondonors receive transplants. “I just think it’s unfair that I wait,” she says, “while others who haven’t even agreed to donate get a liver.”

Her views are understandable—after all, why *should* people who haven’t agreed to donate their own organs benefit from others’ generosity? But the IOM report cautions against preferential access. Once we introduce any criterion not related to medical need, we start down a slippery slope, it warns, where we begin to “award” transplants on the basis of merit. And if merit is the deciding factor, it says, “it is unclear why a willingness to contribute organs should be paramount.” People may make many different kinds of contributions to society, some of which might be more valuable than organs. And even when they understand all the arguments supporting donation, some people just flat-out do not want to donate their organs—for whatever reason, they are uncomfortable with the idea of being carved up and parcelled out after death. If they become ill, should we impose a death sentence on them for feeling this way?
Another criticism of preferential access programs is that they would penalize ignorance. Many people know little about organ procurement and transplant unless and until they need an organ, and they would likely not have signed on to an arrangement like LifeSharers. Conversely, preferential access programs might also reward ignorance, in a way, since those who sign on may become eligible to receive an organ even though, unbeknownst to themselves, they could not donate organs. Transplantation requires healthy, well-functioning organs that are free of infection. As a result, many who need an organ are actually unfit to donate their own, which makes their donation an empty gesture. And if that’s the case, then preferential access programs seem to promote and reward donations in which all parties—donors, doctors, and the organizing group—know the organs will never be transplanted.

Clearly, there are enough questions about preferential access to keep it from becoming a primary means of allocation in the near future. Even LifeSharers seems to acknowledge this. “Because we cannot guarantee the cooperation of next-of-kin or OPO personnel,” explains its Web site, “we cannot guarantee that deceased members’ wishes to donate their organs to other LifeSharers members will be honored.” Which may mean that joining a network like LifeSharers is an empty gesture as well.

Beyond Incentives

The hurdles to creating any kind of incentive-based program, financial or otherwise, may be insurmountable, at least for now. But several other ideas bandied about by public policy-makers might, if adopted, go a long way toward helping to make more organs available.

The first of these ideas is also the simplest. Its logic rests on the fact that not all organ procurement organizations have the same rate of success. And those with a higher rate of success are not just doing a little better than the norm, they’re besting it by as much as 20 percent. So what are they doing right?

The linchpin of the organ procurement system is the organ procurement organization, whose task it is to ask a dying person’s family whether they will agree to donate the person’s organs. OPOs serve local populations. Therefore, even though they are linked through the Organ Procurement and Transplantation Network, their priorities and standards vary, and not coincidentally, so do their results. In 2003, a Department of Health and Human Services study found that among one hundred and ninety transplant centers, the best had a success rate, when asking for consent to donate, of 70 percent. A 2004 study by the Scientific Registry of Transplant Recipients confirmed this trend. It showed that some OPOs had a donation rate (those who actually donate from among those eligible to donate) as high as 77.9 percent. At the other end of the spectrum, both studies found that OPOs doing the worst had consent and donation rates hovering around only 30 to 35 percent. The difference probably reflects different ways of making the request, as well as varying quality of health care around the country. Studies show again and again that a major factor in families’ decision to donate is their satisfaction with the quality of care their loved one has received during his or her final illness. Better care means more trust in the system; more trust in the system leads to open minds when a request to donate is made.
Despite its dramatic gap between the numbers of people on the waiting lists and the numbers of organs available for them, the United States actually has the second-highest rate of organ donation in the world. But U.S. donation rates are still far behind the country with the highest rates—Spain.

Spain’s donation rates best not just those of the United States, but all its European neighbors, and by a wide margin. Comparing data from different countries is difficult, given that some of the key terms do not have uniform international definitions. But with a donation rate 43 percent higher than the next highest country, it’s hard to argue with the premise that Spain is doing something right.

In fact, Spain has worked hard in recent years to boost donation, revamping the way its health care system collects organs and giving more support to the entire transplantation process. But the most controversial change Spain has made has been to implement a “presumed consent” law.

Under a presumed consent model, all deceased persons are presumed organ donors unless they formally object to being a donor during their lives. Many feel that this opt-out policy is responsible for raising the number of donors. “Spain has demonstrated that presumed consent works,” says Margaret Lock, professor at McGill University’s department of social studies in medicine. “There is a shared understanding that [organ donation] will happen, and most people are willing to cooperate.”

But the IOM questions this assumption. “If you look at their organization of transplantation,” James Childress, IOM committee chair and professor of ethics at the University of Virginia, points out, “there are several factors at work, and it’s awfully difficult to say exactly which ones are determinative.”

While countries that employ presumed consent tend to have higher rates of donation than countries that employ express consent (with the United States forming a notable exception to this rule), Spain has altered its organ donation policies in many other ways besides adopting an opt-out system. The country also increased the number of transplant coordinators working at the hospital level to actively seek donors, funneled more money to hospitals for transplants, and mounted strategic educational efforts aimed at key professional audiences and at the public. And it expanded the pool of organ donors to include cardiac deaths as well as brain deaths—a policy change that could be responsible all by itself for a significant raise in the number of donors.

In any event, Spain’s use of presumed consent is termed “weak”: in practice, transplant teams check with the family of a deceased person before removing organs, and if the family says no, they respect that decision. Plainly, more affects Spain’s high rate of donation than meets the eye. Spain’s success could mean only that a broad-based reform agenda is more effective than any one policy change.
The Health Resources and Services Administration, a division of the DHHS, is examining why the request process can be more successful under certain circumstances. Through a series of “Organ Donation Breakthrough Collaboratives,” HRSA is attempting to increase organ donation rates by implementing continuous quality improvement practices, reflecting a larger trend in health care in general. Quality improvement means relying on empirical evidence of caregivers’ experiences to decide what works and what doesn’t.

In the case of organ donation, HRSA’s QI effort has sought to optimize outcomes in all phases of the process that leads to organ transplantation—from identifying donors and recipients and handling end of life care to managing the actual recovery, transport, and transplantation. One critical component of this process—and the counterpart to proposals for incentives that would egg people into donating organs—is the way OPOs approach a potential donor’s family. Hospitals where the OPO staff are present on site so that they can develop a relationship with a donor family seem to have much higher donation rates. Not relying on set practices also makes a difference. Hospitals whose staff know that every situation is unique can determine case by case which staff member has the best relationship with the family. This person will often make the most effective and well-timed request.

How the appeal is worded can also affect whether families respond positively to it. Again, QI studies show that those who conform their request to the particulars of the situation, rather than relying on a script, are likelier to convince a family to say yes. A method known as “expected donation” can also be effective: the person requesting the donation offers it as an opportunity to benefit the possible recipients, focusing on the positive good it can accomplish and framing it as the expected course. And if the family declines to donate, assuring them by word and deed that their care will continue to be of the highest quality regardless of their decision can bolster trust in the system, perhaps even encouraging the family to reconsider.

Another way to bolster trust in the system is to offer a mentor to guide families through it. Some OPOs are experimenting with programs in which the mothers of past organ donors provide support to families of those with no hope of recovery. They run simple errands—getting a cup of coffee, bringing toiletries or calling cards—and lend both a willing ear and the viewpoint of a person who’s been in this position before. There’s evidence that such a mentor program can raise donation rates to as high as 90 percent.

Just integrating donation requests more seamlessly into routine end of life care alone could strongly impact the number of families that say yes. Rather than viewing organ procurement personnel as vultures waiting in the wings to pick at the body, families could be encouraged to see them as members of a trusted care team offering a chance for hope in a dark time. Families who make the decision to donate tend to handle their grief better than those who don’t, and the overwhelming majority—94 percent—are satisfied with their decision afterwards. Which means that improving the request process for organs could benefit not just the recipients, but the donors as well.
The ethics of organ donation came to prominence in the very early days of The Hastings Center, and it has been an important topic here ever since. In 1967, state laws governing dead bodies varied considerably. Several incidents involving coroners who had removed body parts without consent had spurred national discussion of the ethical and legal implications of organ removal. Some argued that the state had the right to routinely salvage organs; others felt the deceased or next of kin must consent to removal.

Prominent anesthesiologist Henry K. Beecher formed a committee that year at Harvard University to explore organ donation and artificial life support. The group concluded that “responsible medical opinion is ready to adopt new criteria for pronouncing death to have occurred . . . as a result of permanent brain damage.” This revolutionary concept—“brain death”—allowed heart-beating cadavers to provide vital organs for transplant that were still awash in oxygen-carrying blood. Two years later, Beecher became a Hastings Center founding fellow.

Georgetown University professor of medical ethics Robert M. Veatch, a former Hastings associate and current Hastings fellow, headed a Hastings Center research group on death and dying in 1970. “The group had as its membership virtually all of the players in the donation versus salvaging debate,” he recalls. Two members of that group—Alfred M. Sadler, Jr., an internist, and Blair L. Sadler, a professor of law—served as consultants to the commissioners on Uniform State Laws in drafting the Uniform Anatomical Gift Act, which authorized adults to donate all or part of their bodies after death for medical purposes. If the deceased individual had left no contrary instructions, it also allowed next of kin to donate a body. By 1971, all fifty states had adopted a version of the model statute.

In a landmark article published in 1973 in Hastings Center Studies (a forerunner of the Hastings Center Report), the Sadlers argued for maintaining the voluntary nature of organ donation. “Voluntary donation and consent,” they wrote, “preserves individual freedom of choice, respects personal and aesthetic interests of the family, protects such important rights as freedom of religion and the right to privacy, and encourages public support and involvement in transplantation.” They recognized the possibility, however, that “the need for organs will far outstrip the supply and that the consent approach will prove to be seriously inhibiting.”

In 1984, University of Pennsylvania bioethicist Arthur L. Caplan, then a Hastings associate, predicted a severe shortage in cadaver organs. At the time, less than 15 percent of potential donors contributed organs. A Hastings project Caplan directed on improving the rate of organ recovery revealed that doctors simply did not ask families for organs. As a result, the project’s participants recommended that health care providers be required to ask families to consent to donation. In 1986, the federal government announced that hospitals eligible for Medicare and Medicaid must use specially trained representatives to approach families about organ donation. By 1992, nearly all fifty states had enacted some form of the “required request” law originally proposed by the Center’s project.

The widening gap between organ supply and demand was again the topic in 2005 when the Institute of Medicine of the National Academies of Science convened a committee on increasing rates of organ donation. Hastings Center fellow James F. Childress chaired the committee, and Hastings associate for ethics and health policy Mary Ann Baily served on it. The committee’s controversial report, Organ Donation: Opportunities for Action, explores ways to increase the supply of organs and recommends that the donor pool be expanded to include those determined dead by circulatory, as well as neurologic, criteria. The committee concluded that current evidence does not support using financial incentives to increase donation.
Opt In to Opt Out

On the other hand, what if we cut out the request process altogether? Instead of assuming that people don’t want to donate their organs—an assumption that puts the burden on individuals to prove that they do want to donate—the idea of the “presumed consent” approach is that everyone wants to donate, shifting the burden of decision-making to those who want to opt out, rather than opt in. Their silence on the matter can then be considered a form of tacit consent. Many European countries employ a policy of presumed consent, and the fact that Spain recently adopted this policy and greatly increased its donation rates has been good press for the idea (although the increase in Spain’s donation rate may have many factors—see sidebar). However, while countries with a presumed consent policy tend to have better donation rates than countries that require express consent, the United States may be the exception to the rule. In fact, Spain is the only country in the world with a better donation rate than the United States, suggesting that a policy of presumed consent might have little impact here.

Presumed consent may also simply not be ethically acceptable, at least in the United States. Some believe that countries with “presumed consent” policies are just putting a more positive spin on what is essentially a strong-arm tactic: your organs are removed without a chance to opt out really being offered to you. To be ethically acceptable, a policy of presumed consent must educate the public about the right to opt out and then give people a reasonable chance to do so. And in the United States, the legal system and social norms seem uniquely unsuited to a policy of presumed consent. Autonomy—freedom from external authority when making a decision—has arguably been the guiding concept of medical ethics for the past thirty years, and this reflects the philosophy of the country as a whole. The rule of autonomy, along with the cultural diversity of the United States and distrust some people have for the health care system—particularly in certain demographic groups—mean that it’s practically impossible to envision the state assuming the right to body parts without an individual’s express consent.

Expanding the Pool

Most organ transplants come from donors said to be brain dead—that is, declared dead on the basis of neurological criteria. Since death is very rarely determined this way, the IOM report recommends changing the standards for possible organ donation to include those determined dead by cardiopulmonary criteria—a group mostly made up of those who die by cardiac arrest. Although transplanting organs from these people can be much more complex than transplanting from donors who are brain dead (in part because cardiac death is much more common and therefore less likely to happen in a hospital), including those declared dead by cardiopulmonary criteria in the donor pool could dramatically boost donation rates—especially for kidneys, the most needed organ—which makes it a strategy worth pursuing.

In the past, doctors have shied away from donation after circulatory determination of death (DCDD) because organs are harmed by oxygen deprivation, and a body whose blood does not circulate cannot deliver oxygen to its organs. But as DCDD has become more com-
mon around the world, medical personnel have learned that taking immediate steps to preserve organs as soon as death is declared can vastly improve the chances that they’ll be viable for transplant.

The big worry concerning DCDD is just a heightened version of the familiar fear that confronts all organ donation—that agreeing to donate will lead to substandard health care at the end of life. Will caregivers do enough to ensure the patient’s comfort—such as administer morphine—if they are thinking about maximizing the odds of recovering transplantable organs? To allay these concerns and combat any possibility that they might be well-grounded, the IOM report advocates adopting a number of guidelines already widely employed in Europe, where DCDD is more common. These include requiring that those who decide to discontinue CPR or life support have clear knowledge of resuscitative medicine so that the patient has every opportunity to survive; that they not be affiliated with the organ recovery team; and that they base the decision to terminate resuscitation efforts on the best interests of the patient alone. In order for DCDD to work, hospital protocols that adopt these guidelines must be publicly created with the full cooperation of the community. That way, when someone who dies unexpectedly is considered for donation, everyone can know what to expect.

Deciding What’s Best Right Now

Technologies hovering just over the horizon could end the need for human organ donors altogether. Artificial organs, cloned organs, organs grown from stem cells, and organs from other species (so-called xenotransplants) all hold promise. But they are also all many years away from clinical use at best and may never reach the clinic at all. Xenotransplantation has been studied and debated for many years already. Some believe that concerns about viruses that might be harbored in animal organs—and transplanted along with the organs—may prove insurmountable.

So for the time being we are left trying to figure out how to do a better job at what we already know how to do—namely, recover organs from human donors. And the “best” approach will meet certain moral standards as well as practical ones. In fact, if we choose a strategy that most Americans find morally unacceptable, then we may also end up with one that is ineffective.

In the month it took to write this essay, Grace Peterson got lucky. On the afternoon of Thanksgiving Day 2006, she finally received the liver transplant that she’s been waiting so long for. Her doctors tell her she’s recovering well, and her prognosis is good. But approximately five hundred people died during that same month waiting for a transplant that never happened because no one donated a suitable organ. For each of these people, and for their families, hope was always just a hair’s breadth away.

For more information on how to be an organ and tissue donor, please visit www.organdonor.gov.
Further Reading

Then Hastings associate Caplan argues that hospital personnel should be required to request organs from families of the deceased—a principle eventually adopted into legislation by all fifty states.

A collection of essays by a variety of experts tackling such enduring ethical questions as whether people should be permitted to sell their organs and whether the government should simply take organs from the dead.

Cherry, associate professor of philosophy at St. Edward’s University in Austin, Texas, argues in favor of a market in human organs.

Journalist Cheney describes how body parts—particularly human tissue—are bought and sold in the United States.

A sociological study of organ transplants by two researchers who have become increasingly skeptical of the nation’s embrace of transplantation.

Institute of Medicine, Committee on Increasing Rates of Organ Donation, Organ Donation: Opportunities for Action, National Academies Press, 2006.
A blue-ribbon panel chaired by Hastings fellow James F. Childress and including Hastings associate Mary Ann Baily recommends expanding the pool of deceased donors to include those declared dead by cardiopulmonary criteria.

Joralemon, an anthropologist, and Cox, a philosopher, lay out the ethical arguments against paying for organs.

Hastings Center president Murray discusses why organ donations do not appear to follow market principles of supply and demand.

A doctor and a lawyer propose giving preferential access for organ transplants to those who have committed to donate their organs upon their death.

This special issue of the Report explores many topics in transplantation ethics, including the fallacy of the concept of the “Gift of Life,” organ swapping as a possible step toward for-profit organ transactions, and research on xenotransplantation.

In the first landmark article, the Sadlers—both members of the Hastings Center research group on death and dying convened in 1970—discuss three alternatives for procuring organs for transplantation from cadavers: voluntary donation, presumed donation, and compulsory donation. They ultimately conclude that voluntary donation best preserves the values traditionally protected in American society. The second article, written a decade later, urges that voluntarism and informed consent continue to be the basis of organ procurement laws in the United States.
ABOUT THE AUTHOR

Joyce A. Griffin is managing editor of the Hastings Center Report and IRB: Ethics & Human Research. She holds a BA from Sarah Lawrence College and an MFA in creative writing from Vermont College. She also publishes fiction.