

## SPECIAL SECTION

# Ideas to Increase Transplant Organ Donation

## Introduction

BY IKE BRANNON

The United States has an endemic shortage of kidneys available for transplantation, and this shortage is costly in both money and lives needlessly lost. There are currently a half-million Americans receiving dialysis, and the federal government bears nearly all of this cost. Medicare spends over \$50 billion a year providing dialysis and other treatments for people with end-stage renal disease.

Over 100,000 people are on the waiting list to receive a kidney, but many of them will perish before receiving a transplant. Thousands more would benefit from a new kidney, but they never make it on the transplant list simply because there is no chance they would receive one in time to save their lives. Over 40,000 people die of end-stage renal disease each year, about the same as die from car accidents or gun violence. Many of those deaths would be prevented with an adequate supply of kidneys.

Kidney disease also disproportionately affects African Americans, who are five times more likely to have end-stage renal disease than people of European descent.

There are several efforts afoot to change government policy on organ transplantation. I asked some of the people involved in these efforts to write about their work on the issue. Josh Morrison and Sammy Beyda of the advocacy group Waitlist Zero write about kidney donation in Israel, which saw donations increase dramatically when it began paying all costs and forgone wages of kidney donors. American Enterprise Institute scholar Sally Satel has proposed that kidney donors receive a generous federal tax

credit, and she and AEI colleague Alan Viard discuss the mechanics of providing one as well as the degree to which it might boost supply. Former White House domestic policy adviser Abe Sutton writes about the poor performance of many organ procurement organizations (OPOs) and the organ procurement and transplantation network (OPTN), which are tasked with retrieving and allocating transplant organs in different parts of the country. Sutton recommends steps to improve their performance and boost supply by using competition to modernize their technology

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and governance. Finally, Johns Hopkins University economist Mario Macis writes about his research on public objections to the government directly compensating kidney donors and how their opposition softens if compensation substantially increases donations and lives saved.

Unlike our expensive and ineffective efforts to reduce deaths from auto accidents and drug abuse, these proposals, if enacted, would save the government tens of billions of dollars a year by removing people from dialysis. The fact that a sensible reform of this failed system would also save thousands of lives is why our authors — and many others — are passionate about these efforts.

# Emulate Israel's Program of Covering Donors' Expenses

BY JOSH MORRISON AND SAMMY BEYDA

In 2019, President Donald Trump issued Executive Order 13879, “Advancing American Kidney Health,” which instructed the U.S. Department of Health and Human Services to remove financial barriers to living organ donation. In 2020, the Health Resources and Services Administration (HRSA), the agency within HHS tasked with increasing support for living donors, issued a final ruling that fell pitifully short of the mandate in the executive order.

HRSA's action demonstrates the need for Congress to enact robust policies to ensure that kidney donors receive adequate compensation for their expenses and are not thwarted by bureaucratic maneuvering. We suggest that such legislation be modeled after a successful and time-tested Israeli policy.

While the Trump administration's primary intent in issuing EO 13879 was to increase kidney donations, HRSA's stated goal, according to the *Federal Register*, was to implement new guidelines that would reimburse only the bottom 70% of households in the U.S. income distribution for donation-related expenses such as travel, lodging, forgone wages, and child and elder care. To accomplish this, HRSA limited the eligibility for reimbursement to people who earn no more than 350% of the federal poverty level, which in the continental United States in 2022 is \$97,125 for a household of four. Not only does this income limitation reduce the efficacy of the order in boosting donations, but it also fails to reach HRSA's own stated goal, as only half of all U.S. households fall under the 350% threshold. A realistic estimate that would cover 70% of U.S. households would be 500% of the poverty level (\$138,750 for that household of four), as HRSA's Advisory Committee on Transplantation recommended.

The very notion that wealthier households should be excluded from being compensated for expenses related to organ donation makes no policy sense given that kidney donations save the government money by reducing dialysis costs. Because living donors disproportionately come from wealthier households, many potential donors would not benefit from this policy. That is the main reason the Trump executive order has not meaningfully changed the nation's kidney shortage. HRSA's preoccupation with not compensating well-off donors rendered the resulting rule largely ineffective.

**Other solutions?** Some have argued that reforms to promote living donation are, at present, unnecessary because other potential

solutions, such as increasing cadaveric organ donation by implementing presumed consent (where the state presumes a decedent has agreed to be an organ donor unless he has communicated otherwise) and developing the technology to transplant organs from animals, will soon be at hand. While those are both efforts worth pursuing, neither appears to hold promise to increase supply in the short run, so the need to increase living organ donation persists.

It is worth noting the United States has the second-highest rate of cadaveric donation in the world. Its difference with the

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leading country, Spain, results almost entirely from Spain's more common use of donors over age 75. This suggests that there are no easy reforms that could dramatically increase cadaveric donation. Moreover, while there may be merit in making the presumption of donation the default for the deceased, European countries that have adopted it have not seen substantial increases in donation, mainly because hospitals inevitably defer to the wishes of the decedent's family despite the laws explicitly prohibiting them from doing so.

Similarly, xenotransplantation — harvesting organs from pigs genetically modified to produce organs for human transplantation — has shown growing promise in recent years, but it is likely at least a decade away from wide availability. For example, the University of Alabama at Birmingham's Phase 1 clinical trial of 20 patients has an estimated primary completion date of 2027, and the U.S. Food and Drug Administration traditionally requires multiple trials with far more patients before it authorizes such a new procedure.

**Israel's success** A well-proven and uncontroversial way to increase kidney donations exists in the form of the Israeli donor support system. Since its implementation in 2008, living donation rates in the country have roughly quadrupled. The reforms provide living

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donors with the following benefits:

- a three-year exemption from the national health insurance tax (which typically constitutes 3–5% of personal income),
- five years of reimbursement for private health insurance expenses,
- five years of reimbursement for life insurance and disability insurance expenses,
- up to 40 paid days off work,
- five therapeutic psychiatric sessions within four years of donation,
- a seven-night recuperative vacation within one year of donation, and
- reimbursement of approximately \$750 in travel expenses.

Such a program in the United States would save approximately 18,000 lives per year if it induced an increase in donations commensurate to Israel's. Given that per-transplant cost savings to the federal government for no longer having to provide services like dialysis have been estimated at \$136,000 by Medicare and \$145,000 by outside economists, achieving such an increase would save the government billions of dollars a year, more than offsetting the cost of a program similar to Israel's.

The Israeli policy has been in effect for over a decade without controversy. That bodes well for the political feasibility of implementing a similar program in the United States. The nation could even offer somewhat more generous benefits. This cost-saving, life-saving measure is worth pursuing post haste. R

## Give Donors a Tax Credit

BY SALLY SATEL AND ALAN D. VIARD

Under Section 301(a) of the National Organ Transplant Act (NOTA) of 1984, it is a federal crime for “any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce.”

Congress adopted NOTA with noble intentions, seeking to prevent a situation in which only wealthier patients could afford to buy organs that would mainly come from low-income “suppliers.” Unfortunately, the ban on donor compensation has made it difficult to address the nation's transplant organ shortage.

For decades, the transplant community has mounted educational efforts, improved its procurement efforts at the time of death of potential donors, and tried a variety of other approaches to increase the supply of transplant organs. Yet, the number of living and deceased donors has not risen significantly. More potent enticement for donors is needed.

We believe the prohibition on financial compensation for organ donation is responsible for tens of thousands of needless deaths. Fiscal imperatives also compel reform. Dialysis costs Medicare about \$100,000 per patient per year. With nearly 600,000 dialysis patients in the country, the total expenditure represents approximately 7% of the entire Medicare budget.

**Tax credit/** It is time to try another approach. Then-congressman Al Gore (D-TN), who spearheaded the adoption of NOTA, spoke at the time of using “a voucher system or a tax credit to a donor's estate” if “efforts to improve voluntary donation are unsuccessful.” Unfortunately, this sensible idea has long been forgotten by lawmakers, at least at the federal level.

Several states have adopted tax incentives for organ donors, but those incentives appear to be too small and too poorly publicized to significantly increase donations. It is likely that larger and better publicized incentives would have significant effects. A 2016 cost-benefit analysis published in the *American Journal of Transplantation* concluded that a payment of \$45,000 to donors would eliminate the waiting list for kidneys.

We propose a \$50,000 federal tax credit for living donors willing to save the life of a stranger by donating a kidney, and a \$5,000 federal tax credit for deceased donors of kidneys, intestines, pancreases, livers, and lungs. The credit would be refundable in cash for people who do not owe income tax, and it would not be phased out at high income levels. There would be no change in NOTA's restriction on payments by organ recipients and other private individuals and organizations; it would still be illegal for recipients to buy organs.

The credit would be available only for a qualified donation in which the donors' kidneys would be distributed to people on the waiting list. People who want to donate a kidney to a relative or other specific person would not receive the tax credit.

Prospective donors hoping to receive the tax credit would be carefully screened for physical and emotional health, as all donors are now, and a six-month waiting period before the procedure could be implemented to deter donations that might be impulsive or done under duress.

As an additional safeguard against ill-considered donations by financially desperate individuals, no credit would be provided in the year of donation. A living donor would receive a \$5,000 annual tax credit the first five years after his donation, with the remaining \$25,000 credited in the sixth year after the donation. If the donor dies before the full credit is received, the remainder would be claimed

on his or her final income tax return, benefiting the donor's estate.

This proposal would not only save lives, but it would also be fiscally responsible. Such a program would reduce tax revenue by several billion dollars a year, but it would save the government tens of billions of dollars a year by reducing the number of people on dialysis, thereby reducing Medicare expenditures.

**Commodification?** / Although some have objected that a tax credit for donors would “commodify the body,” those concerns are misplaced. Recipients would not be allowed to buy organs; instead, donors would receive compensation *from the government* for contributing to the public good. When a transplant is performed, the surgeons and hospitals are paid, as are the agencies that obtain and transport the organs in the case of cadaveric

organs. Currently, the only entity in the entire process that does not receive any compensation for its contribution is the donor, who bears a modicum of risk and myriad costs as well.

At the heart of the “commodification” claim is the concern that donors will not be treated with dignity. But our healthcare system provides dignity when it respects the capacity of individuals to make decisions in their own best interest while protecting their health and expressing gratitude for their sacrifice. The true indignity is to continue the status quo while thousands of people die each year for want of an organ. R

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# Expose OPOs to Competition

BY ABE SUTTON

Through the National Organ Transplantation Act (NOTA) of 1984, Congress set up a system of monopoly contractors to supply transplant organs and, roughly speaking, gave them blank checks from the taxpayer. The results have been disastrous. Thirty-three Americans die every day waiting for a lifesaving organ transplant — a stark indicator that the nation's organ donation system needs urgent reform.

Organ donation in the United States is managed by 57 organ procurement organizations (OPOs) that are responsible for coordinating local organ recovery efforts. An organ procurement and transplantation network (OPTN) is responsible for overseeing the national system.

Earlier this year, the Centers for Medicare and Medicaid Services identified the majority of OPOs as failing critical performance measures. The OPTN contractor, United Network for Organ Sharing (UNOS), is the subject of a bipartisan investigation by the Senate Finance Committee, which highlighted “serious concerns related to UNOS' role in overseeing our nation's OPOs.”

OPOs are failing those in need of a transplant by leaving an estimated 28,000 organs unrecovered each year. The House of Representatives Oversight Committee held a bipartisan hearing on the system in May 2021, noting that “OPOs have a history of poor performance and mismanagement, and they have passed costs for unnecessary luxury items onto taxpayers.” The Senate Finance Committee is investigating the OPOs for deadly patient safety issues, wasted taxpayer dollars, criminality, and the failure to recover organs. The House Appropriations Committee has highlighted the need for reform of the OPTN.

**Market power** / Critical ingredients of any productive reform would be for the U.S. Department of Health and Human Services to focus on the removal of barriers to entry for new organ procurers, an increase in transparency for all contractors, and hewing to basic principles of good governance and federal contracting. The logical first step would be for the Health Resource and Services Administration (HRSA) and HHS to insist upon competitive OPTN contracts consistent with standard government contracting policies.

The organ procurement policies have, in essence, prioritized OPOs' incumbency at the expense of patients' lives, and the monopolistic structure of the OPTN has undermined systemic pressures to improve, while patients are left to languish. While 90% of Americans support organ donation, an HHS-funded study showed that government contractors, protected by their government-enforced monopoly, recover as few as one in five organs potentially available for transplant.

UNOS performs three key functions: policymaking, technology delivery, and network member compliance. Its functions in all three have drawn criticism from congressional oversight, the media, and external stakeholders. A recent report from alumni of the U.S. Digital Service (USDS) and endorsed by all five past HHS chief technology officers remarked, “The OPTN contractor has devolved into a hostage-taking situation, where it has convinced the government that no one else can do what it does, but it doesn't perform its functions particularly well.”

Policymaking in this realm has been divisive in the last few years and has drawn criticism from both Republican and Democratic presidential administrations. The result has been the (rightful) erosion of public trust in OPOs. For example, in 2021

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a federal judge unsealed emails with incendiary statements from UNOS executives, prompting congressional concern about how policies are decided. In one instance, a UNOS board member told the CEO in an email, “The fact that some states do better than others in preventing preventable deaths and providing health care insurance coverage and access means [a person in need of a transplant is] a dumb [expletive] for living there.”

It’s also apparent that UNOS has failed to take advantage of the breathtaking gains in information technology to upgrade its systems and improve performance. The USDS alumni’s report decried the network’s “technology poverty.” For instance, UNOS data and tech are so outdated that 17% of kidney offers go to dead people, and a startling number of organs are lost or delayed on commercial flights because the network typically tracks organs with a primitive system of phone calls and paper manifests. The American Society of Nephrology observed that UNOS is 15 times more likely to lose an organ in transit than a passenger airline loses luggage.

**Recommendations** / To address the above failings and to best serve patients with a first-ever competitive OPTN contracting cycle, HRSA should:

- *Reform the governance of the OPTN.* The network’s board should be solely focused on the interests of patients. A high-functioning national organ donation and transplantation system must be separate from the interests of any OPTN-related contractor(s).
- *Subdivide the OPTN contract into policy and technology,* given the

fundamentally different core competencies of these two areas.

- *Make the technology component open to all bidders,* working with USDS procurement experts so that HHS can choose from the best vendors to serve patients. The need for this recommendation is evident in the USDS alumni’s report that amounted to a damning indictment of UNOS’s capabilities: “Our research indicates the vendor maintains an antiquated technology and limited technical acumen.”
- *Make all de-identified OPTN data publicly available* as a practical way to show evidence of equitable and effective treatment of donor families and patients. This is something noticeably absent from the status quo.
- *Streamline organ donation policymaking* through an elevated Office of Organ Policy that would address “conflicts of interest and gaps in oversight” from the OPTN.

The status quo is clearly not serving the best interest of those in need of an organ transplant, and the system has been effectively co-opted by those who profit from the status quo. HRSA and HHS should work with Congress to reform NOTA in a way that puts the interests of those in need of an organ transplant first and foremost. R

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# Help People Understand the Benefits of Donation

BY MARIO MACIS

In a 2020 *Proceedings of the National Academy of Sciences* article, Alvin Roth and Stephanie Wang observe that both markets and bans on markets require social support to be effective. For example, if a particular transaction is banned but a sufficient share of the population does not find it “repugnant,” a black market might develop or people might travel to other jurisdictions or countries where the exchange is legal.

Roth and Wang study popular attitudes in Germany, Spain, the Philippines, and the United States toward three morally controversial markets: prostitution, surrogacy, and Global Kidney Exchange (GKE). In some cases, they find a disconnect between popular opinions and regulation: support for commercial surrogacy and GKE

is above 60% in all four countries, including those where the law prohibits the practices. In contrast, popular support for legalized prostitution is strong where the practice is legal (Germany) and weak in the countries studied without legal prostitution.

The examination of attitudes about a particular issue is helpful because it can give a sense of the type of pressure the public might exert on policymakers, and how that might shape future legislative or regulatory changes. Based on their survey results, Roth and Wang suggest that for surrogacy and kidney exchange, we are likely to see more (and more successful) efforts to remove restrictions where they are currently illegal.

**Americans and kidney donation compensation** / The National Organ Transplant Act (NOTA) of 1984 prohibits donors from

receiving “valuable consideration” for organs to be used for transplantation. But what do Americans think about paying organ donors? Julio Elias of Argentina’s Universidad del CEMA, Nicola Lacetera of the University of Toronto, and I investigated this question in a 2019 study published in the *American Economic Review*. In our research, we assessed the attitude of Americans toward different forms of compensation for living kidney donors under various institutional arrangements and hypotheses regarding their effects on the availability of kidneys for transplant (and thus on lives saved). We conducted an experimental survey with more than 2,500 participants whose main demographic characteristics matched, on average, those of the overall U.S. population.

We find that:

- Attitudes toward compensating kidney donors depend on both ethical considerations and the effect on reducing the nation’s kidney shortage.
- Support for compensated-donor systems increases with the hypothesized effect on the number of annual transplants performed.
- Respondents showed little support for systems where patients must pay for organs. Many people think that a “free market” in organs would be exploitative of the poor and violate principles of fairness because wealthy patients would be able to obtain life-saving organs whereas poor patients would not.
- Yet, more than 60% of respondents would support a system where a public agency provides compensation to kidney donors and allocates kidneys based on objective criteria such as medical urgency, blood and tissue match, and time on the waiting list.

These results suggest that a majority of Americans would support compensating organ donors if the system were governed by a public agency ensuring transparency and fairness. The system with the highest support was one with non-cash compensation (such as contributions to a retirement account) provided by a public agency. Support for such a system ranged from 64% to 77%, depending on its hypothesized effect on lives saved.

**Reform efforts** / In line with popular opinions about this issue, recent regulatory changes and proposed legislation go some distance toward expanding allowable compensation to organ donors. In September 2020, the Health Resources and Services Administration (HRSA) issued a new rule that amends regulations to remove financial barriers to organ donation by expanding the scope of reimbursable expenses incurred by living organ donors to include lost wages and child-care and elder-care expenses incurred by a caregiver. Previously, the federally funded National Living Donor Assistance Center could only reimburse eligible living organ donors for travel and subsistence expenses.

In June 2021, Congressmen Matt Cartwright (D-PA) and Joe Wilson (R-SC) introduced the Organ Donation Clarification Act. This bipartisan bill would clarify that certain payments are not “valuable consideration,” which NOTA forbids, but reimbursements for expenses a donor incurs. The legislation would also authorize government-run pilot programs to test the effectiveness of providing non-cash benefits to promote organ donation.

The latter provision would allow the United States to obtain

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important empirical evidence on the effectiveness of compensation. Our findings indicate that many Americans are not simply “in favor” or “against” paying living organ donors: the opinion of a significant share of the population depends on precisely what results would follow (in terms of additional lives saved) from compensating donors. That is, people’s opinions are affected by evidence.

However, in the absence of evidence, ideological considerations prevail. When that happens, the debate can become highly polarized, and reaching a compromise becomes difficult if not impossible. By authorizing government-run pilot studies, Cartwright and Wilson’s bill would inform the debate by allowing evidence to be collected on both the desired outcomes and possible unintended consequences.

It bears noting that efforts to induce more organ donation are not limited to the federal level. In New York, two bills currently being debated in the state legislature would fully remove financial disincentives to living organ donation. R

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