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An Open Letter to HHS Secretary Burwell on Ethically Increasing Organ Donation

Hon. Sylvia Mathews Burwell
Secretary of Health and Human Services
Washington, DC

Dear Madame Secretary:

In 1984, Congress passed the National Organ Transplant Act (NOTA). That statute not only established the Organ Procurement and Transplantation Network but also enshrined in law a principle that had guided the development of organ transplantation worldwide over the previous 30 years: organs from living and deceased donors are precious gifts, and should not be bought and sold as market commodities.

Remove the Obstacles to Donation

The growing demand for transplants currently exceeds the supply of donated organs. In the previous decade, a collaborative effort among the Department of Health and Human Services, organ procurement organizations, physicians, and community groups produced a 25% increase in the number of deceased donor organs. Yet, over the course of the past ten years in the United States, the number of kidney transplants (which account for more than two thirds of all transplants) made possible by living donors has declined by approximately by a thousand.

One major reason for this decline is that living donors in the United States incur on average more than U.S. $6000 in out-of-pocket costs. Potential donors may not be able to afford these expenses and may either be unaware of, or not meet the strict requirements for, programs that cover some but not all of donors' financial costs and losses.

If the United States wants to increase organ donation, we should begin by removing these financial disincentives. We are aware that some people have recently called on the President and Congress to repeal, or at least suspend, NOTA's prohibition on paying organ donors. However, when it looked at "Ways to Reduce the Kidney Shortage" (September 2, 2014), the *New York Times* rightly concluded that "there are lots of reforms that could be made without resorting to paying for kidneys."

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Appoint a New Task Force on Organ Donation and Transplantation

Thirty years ago, NOTA instructed your predecessor to establish a Task Force on Transplantation to address the then current issues and to recommend rules for the ethical procurement and distribution of organs. That body was charged to prepare "an assessment of public and private efforts to procure human organs for transplantation and an identification of factors that diminish the number of organs available for transplantation." That task now needs to be revisited for organ donation and transplantation.

We know that these disincentives include a range of financial burdens, such as the costs of travel and lodging for medical evaluation and surgery, lost wages, and the expense of hiring a replacement to provide services to one's own dependents during the period of organ removal and recuperation. Concerns over safety also arise and can be addressed by lifelong follow-up for all living donors, with guaranteed provision of any donation-related medical care not fully covered by donors' own health insurance. Likewise, donors' families should be protected by the provision of insurance to cover disability or death that results from having been a donor. Discrimination against donors seeking to purchase their own insurance has been reported and must be outlawed.

HHS could charge your Task Force to develop pilot programs to test out means of removing the financial and other obstacles to organ donation. The objective should be to ensure that being an organ donor is a financially neutral act—one that neither enriches living donors or the families of deceased donors nor burdens them with costs they would not otherwise face. The task force can also address inefficiencies in current living donor programs and promulgate best practices.

Covering these costs will actually save Medicare and private insurers' money because kidney transplantation is not only better for patients than long-term dialysis but costs much less. Increasing the number of kidneys donated each year means more transplants and less spending on end-stage renal disease. Another way to lower spending and reduce the number of patients needing transplants would be to correct an anomaly of current regulations under which the antirejection drugs that recipients need to keep their transplanted kidney working are only covered for 3 years. When that funding ends, those who are unable to afford the immunosuppressive medications may lose their transplant and end up back on dialysis, hoping for another transplant.

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Financial Incentives for Donation Would Violate Global Standards and Will Not Work

These are all matters that need urgent attention from a new Task Force. And they are all steps that would enjoy widespread support and would not contravene the law's prohibition on giving "valuable consideration" in exchange for an organ. In contrast, those who propose to begin pilot studies to provide financial benefits to incentivize organ donation are asking that you directly contravene principles against financially rewarding donors that were adopted, with strong American support, by the World Health Organization in 1991 and renewed in 2010.[1]

The World Health Organization drew on decades of global experience which shows that paying for organs inevitably exploits the poor. Configuring financial benefits for donors, such as funds for college education or retirement, would not change the laws of economics, which apply in the United States just as in any other country. The people who are activated by such benefits would simply be engaging in a financial transaction, trading the commodity they have (a kidney) for a commodity they need (such as education, retirement funds, or perhaps something more immediate, such as a mortgage payment).

Given this experience, United Nations bodies and the Council of Europe (by legally binding instruments aimed at stopping organ trafficking) and medical professionals (such as in the Declaration of Istanbul) have consistently opposed financial incentives for organ donation, while encouraging the removal of disincentives.[2,3] Global experience has also shown that paid donation replaces unpaid organ donation rather than supplementing it.

We urge HHS to convene a Task Force on organ donation and transplantation that will develop new ways to increase voluntary, unpaid organ donation, through means such as removing the financial burdens that deter donors rather than by adopting measures that will inevitably lead to human organs being treated as commodities, both in the United States and around the world.

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