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Maintaining the Integrity of the National Organ Transplant Act**

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Advancing Organ Donation Without Commercialization: Maintaining the Integrity of the National Organ Transplant Act

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I would never want another person to resort to this. The payment could not be enough to live the rest of your life without your kidney, especially when it is for someone you do not know. I would not have done this if I knew the price I would pay.¹

Yuri, a 29 year-old Egyptian man residing in the outskirts of Cairo, worked an average of 12 hours a day on a bus calling out destinations at bus stops and collecting passengers' fees. When his dire living conditions worsened, it led him to desperation. "Many circumstances led me to this—my mother needed an intestinal surgery and my two sisters needed to marry. I no longer had a place to live and began to sleep on the streets." Yuri met a man at a bus stop who had sold his own kidney and found out how he could do this himself to help solve his family's problems.

The laboratory made a match and Yuri met Sherif, a 60 year-old auto service center owner who needed a kidney and would pay 2,200 USD to Yuri for his "donation." Yuri experienced pain, nausea and loss of appetite for weeks after his surgery. Several months passed before he could return to work, but even then he felt easily fatigued while standing long hours and had to take time off from work intermittently.

Eighty-one percent of commercial living donors (CLDs) in Egypt spend their "kidney money" within five months after their kidney sale.² This was also the case for Yuri. While the money helped finance his mother's surgery and living expenses for his siblings, Yuri's circumstances did not improve and he continued to reside on Cairo's streets.³

I. Introduction

In recent months, Senator Arlen Specter (D-Pennsylvania) has circulated at least five drafts of a proposed bill which would enable government entities to provide material compensation for organ donation. With the Organ Trafficking Prohibition Act of 2009

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¹ Interview by Amr Moustafa, Field Researcher and Donor Advocate, COFS Egypt office, with "Yuri" in Cairo, Egypt (Amr Moustafa trans., Sept. 24, 2006) (hereinafter Yuri Interview). All names have been changed to protect the identity of the participants.

² See Debra Budiani-Saberi, Consequences of Living Kidney Donors in Egypt, Presentation Before Middle East Society on Organ Transplants (November 2006).

³ See Yuri Interview, *supra* note 1.

(“OTPA”), Senator Specter and his co-sponsors⁴ would permit the material compensation for an organ donation for the first time in the United States. The OTPA would amend the National Organ Transplant Act (“NOTA”) to allow governmental entities (at the federal, state, and local levels) to compensate organ donation with a reward, thus providing material incentive for organ donation. The current draft of this bill commendably also includes clauses to combat organ trafficking in an effort to distinguish regulated from unregulated organ markets. However, a provision of material compensation to organ “donors” would dissolve NOTA’s central feature of prohibiting the buying and selling of human organs for transplantation.

Organ transplantation is the preferred therapy for medically suitable patients suffering from organ failure. Transplant procedures began in specialized medical settings and between genetically very similar individuals. The first successful live donor kidney transplant occurred between identical twins in 1954.⁵ Transplants have since become a life-saving therapy for thousands of patients through invaluable acts of generosity from altruistic and deceased donation. As such, deceased and altruistic organ donation is encouraged and should be advanced to its fullest potential.⁶ Transplants are conducted throughout developed and many developing countries in diverse clinical institutions and between recipients and donors (living and deceased) who are often strangers.⁷

Since its onset, a primary concern with transplant science has been that it would become a victim of its own success and create a desperate demand for organs that would far exceed supply.⁸ Indeed, over the years, the demand from patients with organ failure for organs has greatly exceeded supply and has created a global search for available organs for transplant. Because of the great demand for organs, reliance upon CLDs has developed in many countries outside of the United States. The World Health Organization estimates that approximately 10% of annual transplants worldwide involve CLDs. A recent article suggests that one fifth of the approximately 70,000 kidneys transplanted worldwide every year come from the black market.⁹

Material incentives for organ donation have been tested in many countries, both in regulated and unregulated, or “black,” organ markets. These organ markets consistently lead to violations of human rights, and present ethical, social, strategic and economic problems. Material incentives inevitably take unfair advantage of the poor and vulnerable who would otherwise not consider resorting to a commercial living organ donation. Employing material inducement to procure organs from a certain segment of a population may also damage society’s trust in medicine and transplantation and simultaneously undermine efforts to secure and enhance altruistic donation.

⁴ At the time of this writing, Senator Robert Casey and Senator Tom Harkin had joined Senator Specter in co-sponsoring the OTPA.

⁵ See United Network for Organ Sharing, *Transplant Living: Living Donation*, (2005), <http://www.transplantliving.org/livingdonation/default.aspx>.

⁶ For information on organ donor registry, go to <http://www.organdonor.gov/donor/registry.shtm> or [DonateLife.net](http://www.donatelife.net).

⁷ See *id.*

⁸ See RENÉE C. FOX & JUDITH P. SWAZEY, *SPARE PARTS: ORGAN REPLACEMENT IN AMERICAN SOCIETY* 74 (1992).

⁹ See Press Release, World Health Organization [WHO], WHO Proposes Global Agenda On Transplantation (Mar. 30, 2007), <http://www.who.int/mediacentre/news/releases/2007/pr12/en/index.html> (estimating that approximately ten percent of transplants world-wide involve commercial living donors). See also Jeneen Interlandi, *Not Just Urban Legend*, NEWSWEEK, Jan. 19 2009, available at <http://www.newsweek.com/id/178873/page/1>.

International opposition to commercial donation has emerged as a response to the negative experiences of many organ donors who have sold their organs. The proposal to lift the ban on the sale of organs in the United States and permit Americans to sell their organs would undermine international efforts to end such practices. Moreover, any deviation from this commitment in the United States also would have disastrous effects abroad, likely inducing more countries to open legal and possibly unregulated markets of their own. NOTA and its prohibition on commercial organ donation should be preserved and proposals to open an American market should not be pursued. There is significant potential in alternative methods to enhance altruistic and deceased donation that should be advanced without allowing the sale of organs in the United States.

Part II of this Issue Brief will review the history of the National Organ Transplant Act of 1984, which banned organ purchasing and sales. We will also discuss the movement to allow material incentives in exchange for donated organs from both deceased and live donors, which has culminated in draft bills by the co-sponsors of the OTPA. This section will review the OTPA as it has been circulated. Part III will outline the problems associated with material incentives for organ donation. This section will review lessons learned from countries that operate various kinds of markets for organ donation and present international responses to such markets. Finally, Part IV will present the many available alternatives to allowing material incentives for organ donation. Many of these options have the potential to increase organ donations beyond anticipated gains from the provision of material incentives.

II. NOTA and Proposed Legislation

A. The National Organ Transplant Act of 1984

The U.S. Congress passed NOTA in 1984 as the first attempt to regulate the growing practice of organ donation and transplantation in the country.¹⁰ Until the discovery of cyclosporine, an anti-rejection drug, and its FDA approval in the early 1980s, widespread organ transplants between individuals not closely related were not possible. The issue of material incentives rose to national prominence at the time because the first organ market was opening in the United States.¹¹ Dr. H. Barry Jacobs, a private doctor in Virginia, planned to pay donors their asking price for a kidney, add a few thousand dollars to the price for a profit, and sell the kidneys to recipients or to Medicaid and Medicare programs.¹² At that time, there were no legal prohibitions that would have prevented this doctor from implementing such a scheme.¹³

Reports of possible payment created a deluge of desperate offers from potential donors with no other hope of financial support.¹⁴ Robert Steinberg offered his kidney for \$25,000 to the University of Wisconsin-Madison Hospital and Clinics. He also offered to sell his left eye. He

¹⁰ See Pub. L. No. 98-507, 98 Stat. 2339. (current version at 42 U.S.C. §§ 201, 273-274(g)(2008)).

¹¹ See Margaret Engel, *VA Doctor Plans Company to Arrange Sale of Human Kidneys*, WASH. POST, Sept. 19, 1983, at A9.

¹² See *id.*; Linda Werfelman, *Washington News* UNITED PRESS INT'L WIRE, Nov. 9, 1983, at Wed. AM cycle.

¹³ See Engel, *supra* note 11.

¹⁴ See Margaret Scherf, *Experts Decry Buying and Selling Human Parts*, ASSOCIATED PRESS WIRE, Nov. 10, 1983, at Thurs. PM cycle (citing Dr. Oscar Salvatierra Jr., President, American Society of Transplant Surgeons).

said “Financially, I am in an awful mess... I don’t want to be on welfare.”¹⁵ Bob Reina placed a classified ad to sell his kidney for \$12,000.¹⁶ Steve Pollock had mortgaged his business and with no way to get a loan from a bank, took out an ad to sell a kidney for \$25,000.¹⁷ David Severn, faced with mounting debts and a house that would not sell in a down market, offered to sell a kidney, eye, or part of any other organ to raise \$5,000.¹⁸ Joseph Greco placed a similar ad after he had to sell his refrigerator for money and was keeping his food in an ice chest.¹⁹ He was willing to simply trade his kidney for a job.²⁰ These reports illuminated the economic desperation that drives people to an organ market. Then, as now, these stories evoked disgust and sadness at the idea that people were driven to such extremes in order to survive.

Public opinion quickly coalesced around the idea of banning such commodification. Dr. Ira Greifer, medical director of the National Kidney Foundation, derided the idea of the poor selling their organs as “supply-side cannibalism.”²¹ Lawmakers moved to pass NOTA in order to prohibit a market in body parts. Rep. Henry Waxman explained that “it is ethically offensive to look at organs and body parts the same way as we look at fenders from automobiles in the junkyard.”²² Ultimately, lawmakers passed NOTA, section 301 of which prohibits the acquisition, sale or transfer of any human organ for transplantation for “valuable consideration,” upon penalty of up to a fine of \$50,000 and five years imprisonment.²³

B. The Movement for Material Consideration for Organ Donation

Demand for organs remains high and unfulfilled. Various transplant professionals, academics, and attorneys in the United States²⁴ and abroad²⁵ argue that a regulated market in

¹⁵ *Unemployed Man Wants to Sell Body Organs*, ASSOCIATED PRESS WIRE, Oct. 14, 1983, at Fri. AM cycle.

¹⁶ *Domestic News*, ASSOCIATED PRESS WIRE, Oct. 4, 1983, at Tues. PM cycle.

¹⁷ *World News Tonight* (ABC television broadcast Sept. 22, 1983) (transcript available on LexisNexis).

¹⁸ *Man Offers to Sell Organs to Clear Debts*, ASSOCIATED PRESS WIRE, July 17, 1982, at Sat. AM cycle.

¹⁹ *Unemployed Man Will Sell Kidney for a Job*, UNITED PRESS INT’L WIRE, Sept. 30, 1983 at Fri. PM cycle.

²⁰ *Id.*

²¹ Margaret Scherf, *House Panel Told Human Organ Sales Are Unethical*, ASSOCIATED PRESS WIRE, Nov. 9, 1983, at Wed. AM cycle.

²² Catherine Gewertz, *Bill Prohibits Selling Organs for Transplant*, UNITED PRESS INT’L WIRE, Nov. 1, 1983, at Tues. PM cycle.

²³ 42 U.S.C. § 274e (2008). Much debate has ensued over the meaning of “valuable consideration,” which is not defined in the statute. Consideration is “[s]omething of value (such as an act, a forbearance, or a return promise) received by a promisor from a promisee” BLACK’S LAW DICTIONARY 300 (7th ed. 1999). Further, valuable consideration is “[c]onsideration that is valid under the law; consideration that either confers a pecuniarily measurable benefit on one party or imposes a pecuniarily measureable detriment on the other.” *Id.*, at 302. There appears to be no legal significance to the distinction between the terms, at least for the purposes of this discussion. It may shed light to note that a practice that came into question is that of paired donation. In a standard live donation, a donor donates an organ (e.g., kidney, partial liver) to a loved one. In a paired donation, a living incompatible donor-recipient pair is matched with another living incompatible donor-recipient pair in order to find a successful match. In 2007, the U.S. Department of Justice ruled that this practice would not be a violation of NOTA. See Memorandum to Daniel Meron, Gen. Counsel, Dep’t of Health and Human Servs. (March 28, 2007). Nonetheless, to avoid any confusion, Congress amended NOTA in 2008 to clearly exempt any paired donations from the definition of prohibited valuable consideration. See 42 U.S.C. § 274e (2008).

²⁴ See, e.g., MICHELLE GOODWIN, BLACK MARKETS: THE SUPPLY AND DEMAND OF BODY PARTS (2006); Arthur Matas, *Ethics of Paid Living-Unrelated Donation: The Case for a Regulated System of Kidney Sales*, in LIVING DONOR TRANSPLANTATION (Henkie P. Tan, Amadeo Marcos & Ron Shapiro eds., 2007); Benjamin Hippen, *The Case for Kidney Markets*, 14 THE NEW ATLANTIS 47 (2006), available at

human organs would reduce the patient waiting list for organs and in turn work to ameliorate the global illicit market and conditions of poverty for organ vendors. In the United States, proponents of a regulated market have gained support from influential think tanks that favor market-based approaches such as the American Enterprise Institute for Public Policy Research²⁶ and the Cato Institute.²⁷

Proposals by market proponents have included financial payouts or non-monetary benefits in exchange, or as a “reward,” for an organ. The most commonly mentioned incentive is a tax deduction or a tax credit.²⁸ Either of these is in essence a government pay-out. Another proposed financial incentive is college tuition credits.²⁹ Incentives that are not inherently fungible yet still valuable include job benefits,³⁰ the shortening of prison sentences, or the commutation of a death sentence to one of life in prison.³¹

Senator Specter has circulated at least five drafts of a proposed bill, now entitled the Organ Trafficking Prohibition Act of 2009 (OTPA).³² The OTPA is an undertaking by proponents of material incentives to amend NOTA such that a government entity would be permitted to provide compensation for an organ donation. The most recent version available as of this writing states:

<http://www.thenewatlantis.com/docLib/TNA14-Hippen.pdf>; Robert M. Veatch, *Why Liberals Should Accept Financial Incentives for Organ Procurement*, 13 KENNEDY INST. OF ETHICS J. 1, 19 (2003), available at http://muse.jhu.edu/login?uri=/journals/kennedy_institute_of_ethics_journal/v013/13.1veatch.pdf

²⁵ See, e.g., Abdallah S. Daar, *The Case For a Regulated System of Living Kidney Sales*, 2 NAT’L CLINICAL PRAC. NEPHROLOGY 11, 600 (2006); J. Radcliffe-Richards, Commentary, *An Ethical Market in Human Organs*, 29 J. MED. ETHICS 3, 139 (2003), available at <http://jme.bmj.com/cgi/reprint/29/3/139>.

²⁶ See, e.g., WHEN ALTRUISM ISN’T ENOUGH (Sally Satel ed., AEI press forthcoming 2009). Dr. Satel is a resident scholar at the American Enterprise Institute.

²⁷ See, e.g., Charles T. Carlstrom & Christy D. Rollow, *The Rationing of Transplantable Organs: A Troubled Lineup*, 17 CATO J. 163, 171 (1997).

²⁸ See, e.g., Joseph B. Clamon, *Tax Policy as a Lifeline: Encouraging Blood and Organ Donation Through Tax Credits*, 17 ANNALS HEALTH L. 67 (2008). In arguing for a change to NOTA, proponents of market-based approaches to organ donation object that live donors must bear the costs associated with having an organ removed. However, NOTA clarifies that valuable consideration, whatever its definition, “does not include the reasonable payments associated with . . . the expenses of travel, housing, and lost wages incurred by the donor of a human organ in connection with the donation of the organ” 42 U.S.C. § 274e(c)(2) (2008). It is legal to compensate a living donor to cover costs he or she bears from the donation. Arguments to the contrary by market proponents are red herrings premised on a faulty reading of the law and a misrepresentation of the current debate. Critics of material incentives for organ donation largely support removal of disincentives for organ donation. Obstacles include political will and budget realities.

²⁹ See, e.g., Sally Satel, Op-Ed., *To Save More Lives, Move Beyond Idea of Organs as Gifts*, ST. PAUL PIONEER PRESS, April 30, 2007; John Pope, *Agencies Search for Ways to Increase Organ Donations*, TIMES-PICAYUNE, July 29 1999, at B3.

³⁰ See, e.g., *supra* note 24 and accompanying text; Associated Press of Pakistan, *Call to Recognize Living Donors for Altruism*, BUS. RECORDER, Aug. 5, 2007.

³¹ See, e.g., Jason Strain, *House Panel Nixes Plan for Inmate Organ Transplants*, ST. LOUIS POST-DISPATCH, Apr. 10, 1998, at C3 (describing Missouri bill which would have let death row inmates trade a kidney or bone marrow for a commutation of their sentences to life in prison); Chris Ayres, *Prisoners May Give up a Kidney to Spend Less Time Doing Porridge*, THE TIMES, (London), March 10, 2007, at 50 (describing South Carolina Senate attempt to reduce prison sentence by 180 days in exchange for a body part).

³² Draft Bill, Organ Trafficking Protection Act of 2009, 111th Cong. (2009) (on file with authors).

The Federal and State constitutions empower the governments to provide a benefit to individuals who donated the gift of life to fellow citizens. The sovereign's provision of a gratuitous benefit to organ donors is not commercial in nature and does not constitute a commercial sales transaction.

This current draft also curiously cites the example of Israeli policy and states:

Israel enacted a law that (A) makes it a crime to buy, sell, or broker the sale of an organ irrespective of whether the prohibited act is committed within the nation's territorial jurisdiction and (B) provides gratuitous government benefits (i.e., comprehensive health insurance for life, free admission to national parks, and burial benefits) to organ donors.³³

The OTPA proceeds to list potential government benefits that could be granted to organ donors in the U.S. including: medals, those benefits provided to veterans, tax credits and deductions, discounts or waivers of drivers' license fees, life insurance, disability and survivor benefits, a modest donation to a donor's chosen charity, preference on the transplant waiting list, and tax credits for employers who pay lost wages. To implement the proposed policy change, the bill would exempt all "actions taken by the Government of the United States or any state, territory, tribe, or local government to the United States to encourage organ donation" from NOTA's prohibition on organ trafficking, selling, and purchasing.³⁴

To be clear, this bill is not meant simply to allow small tokens of appreciation to be provided by the government. Rather, the OTPA aims to legalize government compensation of substantial financial benefits otherwise out of reach for most Americans, especially in financially perilous times. Under this proposed bill, any imaginable compensation provided by any level of government would be legal—there are no proposed limits. The government could conceivably compensate organ donors with anything ranging from citizenship, to commutation of penal sentences, to financial benefits.

The proposed financial benefits listed in a previous draft, such as funeral costs, college tuition waivers and health insurance, are not paltry sums. A funeral and burial can cost families \$10,000.³⁵ College tuition is another ever-rising cost. Currently, the average public university has a yearly tuition of \$6,585.³⁶ Approximately 17% of Americans, 45 million people, are

³³ It is noteworthy that Iran has had a similar policy and has stood as the only country to permit state compensation for an organ donation since 1996. This draft bill only mentions the Israeli model, still in its infancy, and disregards the experiences with the Iranian model that provides important evidence of the faults of such a system as discussed below in this paper. The draft bill also does not mention that Israel has a system of universal health coverage, funded through a progressive payment system. Health care in the United States is not comparable and not affordable to many Americans who would thus consider this a significant incentive.

³⁴ Draft Bill, *supra* note 32.

³⁵ AARP, Funeral Arrangements and Memorial Services, <http://www.aarp.org/life/griefandloss/Articles/a2004-11-15-arrangements.html> (estimating a no frills burial with 2001 data).

³⁶ College Board, 2008-09 College Prices, <http://www.collegeboard.com/student/pay/add-it-up/4494.html>.

without health insurance.³⁷ Without other government assistance to pay for healthcare or education, inducements of these levels may be irresistible for many people. Such incentive structures result in a variety of consequences—most of which are negative.

It is of particular concern that the bill's main intent of enabling the state to provide compensation or "rewards" for an organ donation has been increasingly deemphasized in each progressive draft. Each draft has instead worked to highlight the more agreeable terms of prohibiting organ trafficking while setting the aim to permit state provided material incentives and rewards to the background. For example, the initial draft of this bill was a three-page document that mainly discussed the concept of "valuable consideration" and government incentives and only mentioned a fine increase for violations of NOTA. The current draft, however, emphasizes that there has been a proliferation of organ trafficking and that there should be further prohibitions. It then proceeds to suggest that "ambiguous language in section 301" of NOTA had become "an unintended impediment" for financial incentives. The change of titles from "Organ Donation Clarification Act of 2008" to "Organ Donation Clarification and Antitrafficking Act of 2008" and finally to "Organ Trafficking Prohibition Act of 2009" demonstrates the effort to draw attention away from this central objective of the bill and towards the prohibition of organ trafficking, an already existing central element of NOTA.

III. Faults of Material Incentives for Organ Donation

A system based on financial or material incentives for donation is inherently flawed. This premise is supported by evidence that demonstrates that organ markets are universally problematic—both in the world's only regulated market in Iran as well as in the black and grey markets that exist in many other countries. Markets not only exploit donors, but also fail to meet the demand for organs, and may even harm organ recipients.

First, material incentives necessarily target the poor by providing inducements for their "donation." A material payment for an organ most appeals to those individuals with insufficient employment, health care, housing or education. It may even be coercive in a situation where a compensated organ donation is the only alternative for a destitute individual or family. This was the case in the United States before NOTA was enacted, with desperate people seeing organ-selling as their only alternative.

Second, material incentives would induce less-than-healthy donors to come forward and thus do not secure the best health outcomes for either recipients or donors. Payments for organ donations lure potential donors (and their profiting parties) to deny that they may have been exposed to HIV/AIDS, hepatitis, or tuberculosis. While appropriate donor assessment protocols should always be in place for a donor and recipient's well-being, screening diseases with incubation periods, such as HIV, cannot always produce results with certainty. Positive health outcomes must rely on structures of trust that will be hurt with the introduction of material

³⁷ KAISER COMMISSION ON MEDICAID AND THE UNINSURED, THE UNINSURED, A PRIMER: KEY FACTS ABOUT AMERICANS WITHOUT HEALTH INSURANCE 1 (2008), *available at* <http://www.kff.org/uninsured/upload/7451-04.pdf>.

incentives in exchange for organ donation.³⁸

Third, such incentives are likely to undermine altruistic living and deceased donation. Individuals will be less likely to request a donation from a family member if there is an alternative. Further, society's perceptions about transplantation may be adversely affected and individuals may be less willing to consent to an altruistic or deceased donation when a market value is given for a commercial donation. Compensation for organ donation also works to undermine the goal of gaining national self-sufficiency in organ supplies via altruistic and deceased donation, which is a necessary part of the prevention of organ trafficking.³⁹ This effect can be seen in countries such as Malaysia and Oman, where nationals seek organs commercially abroad with relative ease without facing legal or social approbation at home. As a result, Malaysians and Omanis typically do not rely on relatives or deceased donations domestically for organ donation.⁴⁰ Nationals of Malaysia and Oman therefore have no incentive to push their own governments or civil societies to increase altruistic donation. Thus, most transplants of patients from these countries are commercial in nature.

Finally, it would not be possible to completely regulate a market in organs domestically when, as with other commodities, global prices/rewards would vary. State compensation for organ donation is still unlikely to satisfy demand because patients who opt to shorten their wait-time and can afford to go abroad for an organ will continue to do so. Inasmuch as patients might bear a portion of the financial burden for a compensated donation, they would also have reason to go where prices were affordable. The proposals in OTPA would not ameliorate these dynamics that facilitate organ trafficking.

OTPA is not immune to these flaws. The bill would inevitably attract lower-income or vulnerable individuals into organ donation for compensation. It would also fundamentally change the structure of organ donation in America by abandoning our altruistic system and replacing it with a system based on calculated materialism. Inasmuch as patients may also bear a cost of obtaining the commodified organ in the OTPA's scheme, they are likely to go where prices and the wait time is most accommodating.

A. Lessons on the Consequences of Transplant Commercialism from the Global Stage

Experts on organ transplants and trafficking recently established the following definition of terms at international meetings on organ trafficking in Istanbul⁴¹ to capture the range of

³⁸ This same concern underlay the House version of NOTA, which was based on testimony submitted by Robert M. Veatch, a professor of medical ethics at Georgetown University. He was concerned that financial profiteers have motives to hide relevant medical history. See Scherf, *supra* note 14.

³⁹ World Health Organization [WHO], *WHO Guiding Principles on Human Cell, Tissue, and Organ Transplantation*, WHO Doc. EB123/5 (May 26, 2008), available at <http://www.who.int/transplantation/TxGP08-en.pdf>.

⁴⁰ Luc Noël, Coordinator for Clinical Procedures, World Health Org., *Developing Donation from Deceased Donors*, Presentation Before Middle East Society on Organ Transplants (November 2006).

⁴¹ Transplantation Society and International Society of Nephrology's International Summit on Transplant Tourism and Organ Trafficking, *The Declaration of Istanbul on Organ Trafficking and Transplant Tourism and Commercialism* (April 30-May 8, 2008), reprinted in 372 *THE LANCET* 9632, 5 (2008).

practices involved in the phenomenon. The definitions developed in Istanbul are useful to review here, as they describe the boundaries of markets around the world.

Transplant commercialism is a policy or practice in which an organ is treated as a commodity, including by being bought or sold or used for material gain.

Organ trafficking is the recruitment, transport, transfer, harboring or receipt of living or deceased persons or their organs by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability, or of the giving to, or the receiving by, a third party of payments or benefits to achieve the transfer of control over the potential donor, for the purpose of exploitation by the removal of organs for transplantation.⁴²

These definitions capture the variety of practices that are based on material incentives and compensation for organ donation that operate globally. These practices include regulated conditions, loosely structured trade, and flagrant abuses of the “donor.” Compensated organ donation in other nations also sheds light on the consideration of such a scheme in the United States and the consequences that would result from it.

Several countries, including Kuwait and Saudi Arabia, have compensated live donors and families of the deceased as a part of the consent process for procuring organs.⁴³ These countries have received criticism, however, as such donations have almost unanimously been from non-national laborers of the Indian sub-continent rather than national Kuwaitis and Saudis.⁴⁴ Only in Iran has commercial living organ donation been officially regulated by the government. In the Iranian system, government-affiliated groups match organ sellers and buyers, who set their own prices for the deal.⁴⁵ As discussed below, this framework has not prevented exploitative measures that take advantage of the poor as organ suppliers. It has also not closed the door on additional off-record payments to donors and fees to recipients.⁴⁶

Apart from these nations in which there are regulatory schemes for commercial living

⁴² *Id.* The Istanbul Declaration further defines “travel for transplantation” as the movement of organs, donors, recipients or transplant professionals across jurisdictional borders for transplantation purposes, which becomes “transplant tourism” when it involves organ trafficking and/or transplant commercialism or if the resources (organs, professionals and transplant centers) devoted to providing transplants to patients from outside a country undermine the country’s ability to provide transplant services for its own population. *Id.*

⁴³ See Abdaal W. Khan, Status of Deceased Donor Liver Donation in Saudi Arabia—A Single Center Experience: A Clinical and Ethical Perspective, Address at the Eighth Asian Bioethics Conference: Biotechnology, Culture, and Human Values in Asia and Beyond (March 19, 2007), www.stc.arts.chula.ac.th/ABC2007/abc2007pptfiles/190307-update/Session%202/ABDAAL%20KHAN.ppt.

⁴⁴ See Paul Garwood, *Dilemma Over Live-Donor Transplantation*, 85 BULL. WORLD HEALTH ORG. 1 (2007), available at http://www.scielosp.org/scielo.php?pid=S0042-96862007000100004&script=sci_arttext.

⁴⁵ See Debra A. Budiani-Saberi & Francis L. Delmonico, *Organ Trafficking and Transplant Tourism: A Commentary on the Global Realities*, 8 AM. J. TRANSPLANTATION 925 (2008).

⁴⁶ See *id.*

organ donation, unregulated practices have thrived in many parts of the world as a staple source of supplying organs for transplant.⁴⁷ Although such practices are technically illegal in Egypt, the institution that issues medical licenses (the Doctors' Syndicate), transplant centers and laboratories openly tolerate and accommodate commercial transplants.⁴⁸ Unlicensed transplants in Egypt reflect similar abuses of organ trafficking that operate in other global hot spots including Pakistan and the Philippines.⁴⁹

Poverty, vulnerability and destitution are social determinants for commercial living organ donation that remain consistent throughout the wide variety of contexts of the global trade in organs. Studies on CLDs who donated a kidney in Egypt,⁵⁰ India,⁵¹ Iran,⁵² Pakistan,⁵³ and the Philippines⁵⁴ indicate that CLDs are poorly educated, unemployed, and uninsured individuals living under the poverty line.⁵⁵ Most individual donors resort to a commercial living organ donation to solve a personal financial crisis.⁵⁶

Negative health consequences for CLDs have become evident in these studies. CLDs have consistently reported a general deterioration in their health status—78% in Egypt, 86% in India, 60% in Iran, 98% in Pakistan, and 48% in the Philippines. Further follow-up study is required to better understand these findings, but each of these studies indicates that most CLDs felt their health status worsened as a result of kidney donation. The Iranian study included specific inquiries about CLDs' health consequences and desires for health improvement. Half the CLDs would have preferred to lose more than 10 years of their lives and to lose 76–100% of their personal possessions in return for their preoperative condition.

Studies in the developed world show that the health consequences posed by altruistically donating a kidney are negligible, especially when good standards of donor-selection criteria are employed. The outcomes from the studies mentioned here that included CLDs may be a result of poor donor selection criteria to include individuals who should not part with a kidney. Even in the best circumstances, these surgeries involve risks and longitudinal research on the long-term

⁴⁷ See *id.*; Yosuke Shimazono, *The State of the International Organ Trade: a Provisional Picture Based on Integration of Available Information*, 85 BULL. WORLD HEALTH ORG. 995 (2007), available at <http://www.who.int/bulletin/volumes/85/12/06-039370.pdf>.

⁴⁸ See Budiani-Saberi, *supra* note 2.

⁴⁹ See Syed Ali Anwar Naqvi, *A Socio-economic Survey of Kidney Vendors in Pakistan*, 20 TRANSPLANT INT'L 909 (2007); Yosuke Shimazono, *What is Left Behind?*, Presentation at an Informal Consultation on Transplantations at the World Health Organization (May 2006).

⁵⁰ See Budiani-Saberi, *supra* note 2.

⁵¹ See Madhav Goyal, Ravindra L. Mehta, Lawrence J. Schneiderman & Ashwini R. Sehgal, *Economic and Health Consequences of Selling a Kidney in India*, 288 J. AM. MED. ASS'N 1589 (2002).

⁵² See Javaad Zargoosh, *Iranian Kidney Donors: Motivations and Relations with Recipients*, 165 J. UROLOGY 386 (2001).

⁵³ See Naqvi, *supra* note 49.

⁵⁴ Shimazono, *supra* note 49.

⁵⁵ Demographic data indicate that they are also predominantly male (95% in Egypt, 71% in Iran, 78% in Pakistan, 93% in the Philippines, with an exception of 29% in India) and mostly middle aged (33 was the average median age). More research is required to explain the gender distinctions, but the study in India indicates that husbands of female CLDs in India pressured their spouses to sell a kidney.

⁵⁶ In a context such as Pakistan, many CLDs have been found to be bonded or debt laborers on a quest to end their bondage. These conditions have made them targets for exploitation by brokers and transplant professionals in search of donors for high paying patients in need of a matching organ.

effects of live organ donation in any country is scarce. Parting with a kidney is significantly more difficult when donors do not have clean water or sufficient nutrition, and rely on labor-intensive work to support themselves. Risks are especially high for a partial liver donation from a live donor, which often results in donor death.⁵⁷

Despite payment for a kidney, the economic situation of CLDs also tends to decline as a result of their commercial organ donation. The majority reported a compromised capacity to do labor-intensive work as a result of the donation. The organ sale did not enable them to escape debt and thus did not improve their economic status. In Egypt, 81% of kidney donors spent the money from their kidney sale within five months of their sale; in India CLDs reported that average family income declined by one third after the nephrectomy and 75% of CLDs remained in debt; in Iran CLDs reported that kidney vending caused somewhat (20%) to very (66%) negative financial effects; in Pakistan 88% reported that the sale made no economic improvement in their lives; and in the Philippines 93% of CLDs reported that the kidney sale did not help their economic hardship, while 21% reported that the donation negatively affected their capacity to work. Thus, with the supply of desperate people exceeding the demand of kidney patients, prices for a kidney sale could not provide a sufficient remedy for poor donors who continued to live in poverty after the donation.

Incentivized donation hurt CLDs socially and emotionally as well. The majority of CLDs reported feeling negative social consequences such as isolation and felt that there was stigma attached to the commercial organ donation. Egyptian religious and cultural beliefs that the body belongs to God explain why 68% of Egyptian CLDs did not tell anyone about their donation, 91% felt socially isolated about concerns related to their donation, and 85% were unwilling to be known as organ sellers. In Iran, 68% of CLDs' families strongly disagreed with vending, which increased marital conflicts for 73% of vendors, including 21% who divorced (as compared to a divorce rate of 1.39% in Iran in 2006).⁵⁸ Seventy percent of Iranian vendors felt isolated from society, and 71% had severe post-operative depression. Thirty seven percent concealed the truth of kidney sale from anyone, and 94% were unwilling to be known as CLDs for strangers.⁵⁹

Finally, CLDs expressed psychological distress and regret about the organ donation and discouraged others from making a commercial donation. In Egypt, 94% of CLDs felt regret about their donation and an inability to get further assistance from those involved with their donation, including from the recipient, broker, labs, or transplant center. In India, 79% percent would not recommend that others sell a kidney. In Iran, preoccupation with kidney loss was usually (30%) to always (57%) reported and 85% of CLDs would not vend if they had it to do over again. Seventy-six percent of CLDs in Iran strongly discouraged potential vendors from "repeating their error." In Pakistan, only 35% of CLDs encouraged future vending to pay off debts and to gain freedom from bondage. In the Philippines, 24% stated regret for selling a kidney and others reported feeling shame for being known as a kidney seller or getting bad

⁵⁷ See Karen Dente, *Donor Risk Remains a Challenge in Liver Transplantation*, MEDSCAPE NEWS, June 25, 2007, available at <http://www.medscape.com/viewarticle/558821>.

⁵⁸ 2006 U.N. Demographic Y.B. 37, U.N. Sales No. E/F.09.XIII.1, at Table 25 available at <http://unstats.un.org/unsd/demographic/products/dyb/dyb2006/Table25.pdf>.

⁵⁹ Data on social consequences were not reported in the studies in Pakistan or the Philippines. Social considerations of CLDs in the study in India concern marital matters around a commercial organ donation rather than consequences of the donation. Fifteen percent noted that their spouse had also sold a kidney.

‘karma’ or punishment, including a decline in their health and difficulty in finding a job.

These consequences occurred in countries with distinct contexts, including a regulated market in Iran, tolerated/facilitated commercialism in Egypt, and thriving illegal organ trafficking in India. Thus, commercial transplants, whether regulated or not, are socially arranged such that organs flow as commodities from poor and vulnerable individuals to those who are better off. OTPA would replicate such features in the United States and allow poor and vulnerable American residents to be induced into selling organs for whatever price or privilege a government entity could offer that would sufficiently appeal to potential living organ donors.

B. International Opposition to Material Incentives

Efforts to combat organ trafficking and transplant commercialism have gained momentum in recent years. International organizations such as the United Nations, the World Health Organization, the World Medical Association, the Transplantation Society and the United Network on Organ Sharing (UNOS) have made formal declarations and statements against these practices.⁶⁰

Two instruments of special importance were established in recent months to serve as guidelines to combat organ trafficking and transplant commercialism. First, the *Updated Guiding Principles on Human Cell, Tissue, and Organ Transplantation* were contained in the World Health Organization’s Executive Board’s report on human organ and tissue transplantation at its session on May 26, 2008.⁶¹ These Guiding Principles are a result of recommendations formulated by consultations of global experts and provide an ethical framework for transplantation in response to transplant commercialism, particularly from living donors. Second, the *Istanbul Declaration* is a result of an international summit by the Transplantation Society and the International Society of Nephrology to address organ trafficking, transplant tourism and commercialism in May 2008 that included more than 150 representatives of scientific and medical bodies, government officials, social scientists, and ethicists from around the world. This Declaration is a call to halt these unethical transplant activities and to foster safe and accountable practices that meet the needs of transplant recipients while protecting donors.⁶² Since its dissemination, many national transplant societies and ministries of health have endorsed it.

⁶⁰ See Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children, Supplementing the United Nations Convention Against Transnational Organized Crime, Dec. 25, 2005 (adopted by G.A. Res. 55/25, at 2, U.N. Doc. A/RES/55/25 (Jan. 8, 2001), http://www.uncjin.org/Documents/Conventions/dcatoc/final_documents_2/convention_%20traff_eng.pdf); World Med. Ass’n G. A., *Statement on Human Organ Donation and Transplantation*, Oct. 2006, <http://www.wma.net/e/policy/wma.htm>; Transplantation Society, Ethics Comm., *Membership Statement*, 2008, http://www.transplantation-soc.org/downloads/TTS_Ethics_Policy.pdf; Press Release, United Network for Organ Sharing, UNOS Board Further Addresses Transplant Tourism, (June 26, 2007), <http://www.unos.org/news/newsDetail.asp?id=891>; WHO, *Human Organ And Tissue Transplantation: Report by the Secretariat*, WHO Doc. EB124/15 (Nov. 20, 2008) available at http://www.who.int/gb/ebwha/pdf_files/EB124/B124_15-en.pdf

⁶¹ See WHO, *Human Organ And Tissue Transplantation: Report by the Secretariat*, WHO Doc. EB124/15 (Nov. 20, 2008) available at http://www.who.int/gb/ebwha/pdf_files/EB124/B124_15-en.pdf.

⁶² Transplantation Society, *supra* note 41.

In brief, both of these documents emphasize that organs, tissues and cells should only be donated freely and not under the coercion of material incentives. Engaging governments to establish a legal framework and oversight on transplants are essential components in the fight to combat organ trafficking and transplant tourism. A legal framework should include the establishment of a recovery system of deceased and living organ donations as well as a system to assure equitable allocation of donated organs without consideration of financial or material gain or regard to gender, ethnicity, religion, or social or financial status. Self-sufficiency in supply of therapies of human origin should also be an aim of every country or jurisdiction. Finally, transplantation practice should be transparent and all parties, including pharmaceutical companies and insurance companies, should be made accountable and perhaps penalized for their engagement in commercial transplants.

IV. Alternative Avenues to Enhance Organ Donation in the U.S.

Increasing the supply of available organs for transplants does not have to depend upon material incentives. There are alternative opportunities for the United States to foster increased altruistic donation. Proposals to permit material incentives distract from other important avenues for increasing organ donation that have yet to reach their maximum potential.

Furthering the Organ Donation Breakthrough Collaborative initiated by then-Secretary of Health and Human Services Tommy G. Thompson is of critical importance to fostering increased altruistic donations. This initiative was created to dramatically increase access to transplantable organs by spreading known best practices to the nation's largest hospitals in order to achieve organ donation rates of 75% or higher in these hospitals. The Collaborative has resulted in a major increase in deceased organ donations by developing best practices of organ procurement teams when approaching medical professionals and potential donor families.⁶³ The Health Resources and Services Administration (HRSA) estimates that more than 4,000 annual additional transplants have occurred as a result of these increases in organ donation.⁶⁴ This progress has much potential to make a significant impact on organ shortage in the U.S. if these best practices were to be adopted nationwide.

Advances can also be made to enhance altruistic living donation, particularly by improving living donor care and removing disincentives for organ donations.⁶⁵ Protocols to improve donor follow-up care have been refined in the Amsterdam⁶⁶ and Vancouver⁶⁷ Forums

⁶³ See Teresa J. Shafer et al., *Organ Donation Breakthrough Collaborative: Increasing Organ Donation Through System Redesign*, 26 CRITICAL CARE NURSE 2, 33 (2006), available at <http://ccn.aacnjournals.org/cgi/content/full/26/2/33>.

⁶⁴ See Teresa J. Shafer et al., *US Organ Donation Breakthrough Collaborative Increases Organ Donation*, 31 CRITICAL CARE NURSING Q. 3, 190 (2008).

⁶⁵ Protocols to improve donor follow-up care have been refined in the Amsterdam and Vancouver. See Transplantation Society Ethics Committee, *Report of the Amsterdam Forum on the Care of the Live Kidney Donor: Data and Medical Guidelines*, 79 TRANSPLANTATION S53 (2005), available at <http://www.livingdonorsonline.org/ConsensusStatementLong.pdf>; Mark L. Barr et al.; *Report of the Vancouver Forum on the Care of the Live Organ Donor: Lung, Liver, Pancreas, and Intestine Data and Medical Guidelines*, 81 TRANSPLANTATION 1373 (2006); Timothy L. Pruett et al., *The Ethics Statement of the Vancouver Forum on the Live Lung, Liver, Pancreas, and Intestine Donor*, 81 TRANSPLANTATION 1386 (2006).

⁶⁶ Transplantation Society Ethics Committee, *supra* note 65.

⁶⁷ See Barr, *supra* note 65; Pruett, *supra* note 65.

on care of the live kidney and liver, lung, pancreas and intestine donor respectively. These should be adopted by all transplant centers that engage live donors. Support should also be extended to live donors to provide job security, assured donor leave, and health and life insurance for donation-related events. Such provisions would serve to provide donor care and remove obstacles for those who wish to be organ donors. If this support were implemented, more individuals considering altruistic living donorship would confront fewer difficulties in the process and be more inclined to go through with the donation.

Recent strides made by the legalization of kidney paired donation (KPD) in 2007 have also paved a path to increase the supply of available organs for transplant. In a standard live donation, a donor donates an organ (e.g., kidney, partial liver) to a loved one. In a paired donation, a living incompatible donor-recipient pair is matched with another living incompatible donor-recipient pair in order to find a successful match. Transplant professionals suggest that KPD should be the preferred treatment for patients who have incompatibilities with their intended donors who wish to participate, as KPD is less expensive than desensitization therapy for a patient and requires less immunosuppression.⁶⁸ Optimized matching affords patients the flexibility of customizing their matching priorities and the security of knowing that the greatest number of high-quality matches will be found and distributed equitably.⁶⁹ The United Network on Organ Sharing has suggested that this measure would ensure that paired living donation may meet the needs of potentially thousands of kidney transplant candidates who have an intended living donor but are biologically incompatible with that potential donor.⁷⁰ Without having to turn to material incentives, these patients could receive an altruistically donated organ.

In addition to these strategies, a communitarian approach has been proposed to enhance deceased donation.⁷¹ This would consist of efforts to change the moral culture so that members of society will recognize that donating one's organs, once they are no longer of use to the donor, is the moral (right) thing to do. Developed by Amitai Etzioni, a communitarian approach requires much greater and deeper efforts than sharing information and making public service announcements. It entails a moral dialogue in which the public is engaged, leading to a change in what people expect from one another. Among the devices that he suggests could help to change the moral culture are a public statement, endorsed by community members and leaders, which expresses the community sense that donation "is what a good person does," and a community-specific web page that lists those who made the commitment. Such an approach works to build, rather than compromise, public trust in transplantation by advancing a structure of altruism rather than material incentives.

In addition to efforts to increase the organ supply, we must also work to decrease the demand for organs in the future with efforts to prevent organ-failure. In the example of kidney-

⁶⁸ See Dorry L. Segev, Sommer E. Gentry, Daniel S. Warren, Brigitte Reeb & Robert A. Montgomery, *Kidney Paired Donation and Optimizing the Use of Live Donor Organs*, 293 J. AM. MED. ASS'N 15, 1883 (2005), available at <http://jama.ama-assn.org/cgi/content/full/293/15/1883>.

⁶⁹ See *id.*

⁷⁰ See Press Release, United Network for Organ Sharing, UNOS Statement Regarding Bills to Clarify Paired Donation within the National Organ Transplant Act, (Feb. 8, 2007), <http://www.unos.org/news/newsDetail.asp?id=802>.

⁷¹ See AMITAI ETZIONI, INSTITUTE FOR COMMUNITARIAN POLICY STUDIES, ORGAN DONATION: A COMMUNITARIAN APPROACH, http://www.gwu.edu/~ccps/Organ_Donation.pdf.

failure prevention, legislation can support this with provisions for programs to perform blood pressure screenings and a urine analyses to detect hypertension and kidney dysfunction and treat patients before the necessity of dialysis or transplantation. Reducing the numbers of people who need transplantation will decrease the number of needed organs, and entails no questionable moral choices.

The OTPA's introduction of material incentives to organ donation would undermine these other important initiatives and the potential they have to enhance organ supplies. Material incentives, even as a final resort, should not be considered, particularly when there are significant strides to be accomplished in advancing deceased and altruistic donation. Slavish devotion to market-based solutions should not distract Congress's attention from these attainable solutions.

V. Conclusion

Transplants are said to be the most social of therapies. They rest on public trust in medicine. Transplant commercialism and organ trafficking worldwide have exploited social vulnerabilities to obtain organs for transplant. Although operating in various models, these practices inevitably target the impoverished and lead to inequity and social injustice.

OTPA's aim to permit compensated organ donation is contrary to the global movement to oppose commercial transplantation. The United States' transplant policies are important references for the rest of the world and are influential in shaping consideration of material incentives in countries that would not necessarily commit to regulation or best practices in donor care.

As illustrated at the beginning of this paper, Yuri resorted to selling a kidney when his poor living conditions became especially destitute and the reward particularly appealing. Those conditions drove him to the donation and he regretted the decision afterwards. Existing transplant commercialism operates in countries that are, by definition, different from the United States. Although proponents of compensated donation suggest that the experience would be different in the U.S., individuals are similarly likely to resort to a donation when compensation includes rewards such as comprehensive health care for life, health and life insurance, disability and survivor benefits or educational benefits. Like the cash payment to Yuri, these forms of compensation are considered to significantly enhance the life of an individual who cannot afford these basic needs.

The United States must join the international community to rebuild, not compromise, trust in transplants. This is especially important at this moment when markets have failed economic and social needs in global and historical dimensions and altruism has become especially priceless. Guided by the WHO resolution on organ transplants and the Istanbul Declaration, transplant practices can advance standards of greater social equality rather than exploit people in poverty. There are many opportunities to advance organ donation in the U.S. without subjecting individuals to experiences such as Yuri's.