The FAIR Foundation
Concept for Organ Donation Reform:

An Evidence Based
Healthcare Initiative to Save Lives

FAIR Foundation Policy Brief, February, 2017
www.fairfoundation.org
The Crisis...

Over 118,000 Patients waiting for an organ transplant
Less than 16,000 Average number of donations per year despite aggressive campaigns to increase organ donation

The Result...

On average, 22 people die each day while waiting for a transplant

The majority of Americans support a cost effective, compassionate solution...

*Financial Incentives for Organ Donation*
Crisis: Shortage of Organs for Transplant — Long waiting list for organ transplant

There is a world-wide organ donor shortage despite efforts to stimulate deceased and living organ donations. In this country alone, someone dies every hour waiting for a transplant or becomes too sick to survive transplant surgery. The global organ shortage has created a disturbing third world black market in human organ trafficking.

In America, everyone in the transplant process is paid except the donor: the procurement organizations, the hospitals, doctors, nurses and all of the peripheral support people. Donors are expected to not only donate an organ, but also provide personal funds for related expenses, such as medical travel and lodging, child care, and lost wages. Some reports indicate that donors may have difficulty obtaining life and affordable health insurance after giving an organ. Since altruism has failed in obtaining suitable numbers of transplantable organs, many believe that a legal and compassionate system of compensating living organ donors should be considered.

Lifting the ban on donor compensation, as imposed by the 1984 NOTA law, is now a key mission of the FAIR Foundation. Our Board, which includes patients, transplant professionals, and community advocates, has been working on this issue diligently for several years. The FAIR Foundation sponsored a nationwide survey of voting Americans regarding donor compensation, and results were published online March 23, 2016, in JAMA Surgery and in its August printed edition. The article reports sound data that shows a majority of American voters are in favor of financial compensation for live kidney donation.

There are over 120,000 Americans on the transplant waiting list with another half million patients on dialysis therapy for end-stage renal disease. All could go back to a productive, higher quality of life if there were not a severe shortfall in organs for transplantation. In addition, billions of dollars could be saved each year in the medical care costs now paid largely by government programs such as Medicare and Medicaid in keeping these hundreds of thousands alive while hoping for the transplant that never comes.

We understand that donor compensation is an emotional topic for patients who wait for a transplant and their doctors who do not have the resources at hand to save their lives. It is also a rich topic for medical ethicists and those with public policy interests, some of whom find the idea of donor compensation morally and ethically problematic at best, and repugnant at worst. At the FAIR Foundation, we support real-time studies of donor compensation to determine if lives now lost and imperiled could be saved and restored by programmatic, regulated, fair compensation to donors who render the only resource now so sadly lacking—the organ needed to save another’s life.

—Thomas G. Peters, MD

What the American People think...

In 2014, the FAIR Foundation contracted with Penn Schoen & Berland to find out what American voters think of the idea. The data was studied and peer reviewed in Journal of the American Medical Association Surgery. A copy of the article follows.
Views of US Voters on Compensating Living Kidney Donors

Thomas G. Peters, MD; Jonathan S. Fisher, MD; Robert G. Gish, MD; Richard J. Howard, MD, PhD

IMPORTANCE Patients in the United States waiting for kidney transplantation die in increasing numbers owing to the severe kidney shortage, which might be alleviated by compensating living kidney donors.

OBJECTIVE To determine the willingness of voting US citizens to become living kidney donors and to ascertain the potential influence of compensation for donation.

DESIGN, SETTING, AND PARTICIPANTS A professionally designed quantitative survey was administered by an international polling firm in June 2014. Information was collected on willingness to donate a kidney and the potential influence of compensation ($50,000); survey data included respondent age, income, education level, sex, US region, race/ethnicity, marital status, political affiliation, likelihood to vote, and employment status. The survey was performed via a random-dialing process that selected respondents via both landlines and mobile telephones to improve population representation. The survey included 1011 registered US voters likely to vote.

MAIN OUTCOMES AND MEASURES The degree to which the US voting public is willing to donate a kidney and the perceptions of current voters toward paying living kidney donors.

RESULTS Of the 1011 respondents, 427 were male and 584 were female, with 43% of participants between ages 45 and 64 years. With respondents grouped by willingness to donate, we found that 689 (68%) would donate a kidney to anyone and 235 (23%) only to certain persons; 87 (9%) would not donate. Most (59%) indicated that payment of $50,000 would make them even more likely to donate a kidney, 32% were unmoved by compensation, and 9% were negatively influenced by payment.

CONCLUSIONS AND RELEVANCE Most US voters view living kidney donation positively, and most would be motivated toward donor nephrectomy if offered a payment of $50,000. Because most registered voters favor such payments, and because thousands of lives might be saved should compensation increase the number of transplantable kidneys, laws and regulations prohibiting donor compensation should be modified to allow pilot studies of financial incentives for living kidney donors. Outcomes of such trials could then result in evidence-based policies, which would incorporate fair and just compensation to those persons willing to undergo donor nephrectomy.

Published online March 23, 2016.
Thousands of patients with end-stage renal disease in the United States have had preventable deaths owing to the shortage of transplantable kidneys. The Organ Procurement and Transplantation Network database confirms that from 2004 to 2013, 63,742 persons died or became too sick for transplantation while awaiting a kidney. During that time, 166,667 kidneys were transplanted, 105,214 from deceased and 61,453 from living donors. Thus, for every 1000 US patients who received a kidney, 382 eligible persons died of circumstances potentially correctable by kidney transplantation. In 2013, there were 76,044 such potentially preventable events compared with 5009 in 2004 (Figure 1A).

Currently, the US kidney transplantation waiting list exceeds 101,400 patients. The list grows each year, while the number of kidneys transplanted stagnates or diminishes (Figure 1B). There was an increase of 20% in deceased donor kidney transplants from 2004 to 2013 and a 14% decrease in living donor kidney transplants (Figure 1C). The graft survival rate from living donors is almost double that of deceased donors. Although there are risks to living donation, negative incidences remain low. Novel strategies, such as living donor kidney exchanges and other efforts promoting living kidney donation, have not met the ever-growing need. Nearly all state-level policies have had a negligible effect on donation. Increasing the number of living persons undergoing donor nephrectomy could expand the number of transplantable kidneys, but donation is dependent on altruism because it is illegal under the National Organ Transplant Act to pay any donor. Because altruism has failed, one way to increase kidney transplantation may be to provide financial compensation to living donors.

One type of donor compensation is to reimburse all costs, such as lost wages, travel expenses, and follow-up care. Such payments are legal and not contentious, but many donors do not qualify for assistance through existing programs. Thus, donor financial hardship remains a significant barrier. Another type of compensation, which is controversial but potentially more effective, is the provision of financial incentives beyond expenses. These may take the form of an in-kind reward (eg, a contribution to the donor’s retirement fund, an income tax credit, or a tuition voucher) or even a direct cash payment. Persons favoring payment believe that living kidney donations would increase and waitlist deaths would decrease and that remuneration could be ethical with respect to the donor. Those against financial incentives disagree and assert that even with a transparent and well-regulated compensation program, potential donors would be subject to coercion, undue influence, and body commodification. Additionally, it has been argued that payment would generate such a negative public response that living donation rates might actually decrease.

The issue of financial incentives in organ donation has been deliberated for more than 2 decades. Most relevant peer-reviewed reports and government policies are based on opinion, anecdotes, moral constructs, individual testimony, tradition, and personal beliefs. No evidence-based data generated from clinical trials of donor payment are available because such trials are illegal under the National Organ Transplant Act. There-
fore, the matter of payment in organ donation is a national political issue that should be addressed by US voters and legislators to develop evidence-based policies. A combined working group consisting of members of the American Society of Transplantation and the American Society of Transplant Surgeons recently argued that it was important to engage the public in discussions about increasing organ donation and that policies concerning financial incentives and the removal of disincentives may best be defined by the citizenry.18 While debate over the ethics, nature, and scope of donor compensation matures,12,19 we sought to understand the current attitudes of a statistically balanced sample representative of US voters regarding whether living kidney donors should receive cash payments.

Methods
A quantitative, nationwide telephone survey of 1011 registered US voters likely to vote was completed in June 2014. The survey was engaged by the FAIR Foundation, a 501(c)(3) volunteer organization interested in US health resources allocation, and designed and administered by Penn Schoen Berland, an international polling firm. Because this political survey was commissioned by a private 501(c)(3) corporation, and because the phone numbers are publically available and no identifying information was obtained, institutional review board approval was not necessary.

A random-digit dialing process selected respondents via both landlines and mobile telephones to optimize unbiased population representation. From 16 851 Americans willing to complete the survey, a final assemblage of 1011 persons was selected to produce a study population representative of the US voting public. Demographic information comprising age, income, education level, sex, US geographic region, race/ethnicity, marital status, political affiliation, likelihood to vote, and employment status was collected. Survey respondents were additionally queried about supporting or not supporting compensation in principle. This cohort of 635 was further analyzed with respect to age and income level to determine how these factors might clarify who would favor or disfavor paying living kidney donors.

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Answers to specific questions were graded on a 4-point scale (eg, “Do you strongly agree, somewhat agree, somewhat disagree, or strongly disagree with the following statement: I would be open to being a living kidney donor to anyone?”). Respondent choices were compiled so that answers of strongly agree and somewhat agree were reported in a single category: agree. Answers of somewhat disagree or strongly disagree were similarly aggregated. Some queries included an opinion statement and a question about how agreeable or disagreeable the respondent was to that statement; answer choices for these questions were graded on the same 4-point agreeable to disagreeable scale with an additional “don’t know” option.

The survey began by gathering demographic details. Next, with no mention yet about paying donors, respondents were asked how open they were to being a living kidney donor. As part of the analysis, respondents were sorted into 3 baseline groups corresponding to their willingness to donate without regard to donor incentives. Group 1 (anyone) included those positive to donating to anyone, including unknown persons; group 2 (family/friends) included those positive to donating with restrictions, eg, only to family or friends; and group 3 (no one) included those who would not donate to anyone.

All 1011 respondents were assigned to 1 of these groups. Next, to determine the effect of paying living kidney donors, all 1011 respondents were asked how a tax-free payment of $50 000 from the health care system would affect their willingness to donate a kidney to anyone, to family/friends, or to no one. This level of compensation was chosen because it is a substantial amount and is less than the annual Medicare center hemodialysis per-patient cost.20 To assess how voters might regard payment for other human biologic assets, the survey explored perceptions of payment for marrow, blood, ova, and sperm in relation to living kidney donation.

During the survey, it became apparent that, regardless of willingness to donate, some respondents perceived payment to themselves as different from the concept of paying living donors as a societal norm. To ascertain opinions about the social justification for paying donors, 635 of the 1011 respondents were additionally queried about supporting or not supporting compensation in principle. This cohort of 635 was further analyzed with respect to age and income level to determine how these factors might clarify who would favor or disfavor paying living kidney donors.

Statistical analysis used contingency tables built from survey questions, demographic information, and changes to respondent likelihood to donate under different conditions. Statistical significance was calculated (95% CI) for groups of respondents in related subgroups. Incomplete or missing answers prompted withdrawal from analysis only for that particular question; complete answers from that respondent were retained. Significance testing details across all groups are available at http://pic.dhe.ibm.com/infocenter/spssdc/v6r0m1/index.jsp?topic=%2Fcom.spss.dl%2Ftom_statisticalformulae_colprops.htm.

Results
Baseline Willingness to Donate Without Regard to Compensation
Of the 1011 respondents, 689 (68%) indicated that they were open to donating a kidney to anyone (group 1); 235 (23%) said that they were open to donating with restrictions, eg, only to family/friends; and 87 (9%) stated that they would not donate to anyone (group 3) (Table 1; Figure 2A). For all 1011 respondents, considering sex, age, and employment status, there was little variance about respondents’ self-designation regarding their own donor status. A range of 60% to 76% of respondents considered themselves donors to anyone, while 21% to 29% indicated that they would donate to family or friends. These replies confirm that voting Americans view living kidney donation positively, at least across sex, age, and employment groupings.
Payment for Living Donor Nephrectomy: Personal Decision Effects

All 1011 participants were evaluated to determine whether donor compensation would move them toward a positive or a negative decision to donate a kidney (Table 2; Figure 2B). For the 689 group 1 respondents, 428 (62%) indicated that payment of $50 000 would make them even more likely to donate. For the 235 group 2 respondents, 141 (60%) were more likely to consider undergoing nephrectomy. For the 87 group 3 respondents, 23 (26%) were more willing to donate if compensated. Conversely, movement away from donating when offered $50 000 occurred in 54 (8%), 22 (9%), and 16 (18%) respondents in groups 1, 2, and 3, respectively (all \(P<.05\)). A total of 323 respondents (32%) did not move toward or away from their original self-designation. Thus, payment motivated more US voters to positively consider donor nephrectomy rather than to reject the notion of donating a kidney.

US Citizens’ Support for Living Donor Compensation

For the 635 US voters asked about societal norms of paying living donors, 432 (68%) were in group 1, 149 (23%) were in group 2, and 54 (9%) were in group 3, reflecting the exact proportions of the entire 1011 respondents (Table 3). Of this cohort, 387 (61%) were open to supporting donor payments. When analyzed compared with baseline willingness to donate, 285 of 432 persons (66%) favored compensating donors, a two-thirds majority of already-willing donors. This degree of support was significantly greater (\(P<.05\)) than the 79 of 149 majority (53%) in group 2 and the 23 of 54 (43%) in group 3 favoring a societal policy of living donor compensation.

Results by respondent age revealed that 53 of 68 voters (78%) aged 18 to 29 years favored payment, a significantly higher percentage than all other age groups (\(P<.05\)). However, 68 of 108 respondents (63%) aged 30 to 44 years, as well as 266 of 459 respondents (58%) 45 years and older, favored paying living kidney donors. Thus, a majority (58% to 78%) across all ages of US voters favored the concept in principle that persons undergoing donor nephrectomy should be paid.

Data were available for 521 of 635 respondents (82%) willing to disclose their annual household income while stating their opinions about paying living donors. Of those who earned less than $50 000, 175 of 257 (68%) favored compensating donors, a proportion significantly higher than other income levels (\(P<.05\)). Of those earning between $50 000 and $100 000, 111 of 191 (58%) favored compensation, while 41 of 73 (56%) earning more than $100 000 favored payment. At no income level was a majority against compensation, and for all income levels, 327 of 521 respondents (63%) favored paying living kidney donors.
Compensation for Kidneys vs Other Living Donor Tissues

Regarding compensation for human kidneys, marrow, blood, ova, and sperm, more US voters favored payment for kidney and marrow donors than compensation for blood, ova, or sperm donors. Among all 1011 respondents, 56% and 58% agreed that compensation should be allowed for kidney and marrow, respectively. When asked about payment for blood, ova, and sperm, approval was significantly lower at 48%, 41%, and 35%, respectively (all \( P < .05 \)).

Discussion

Every year, increasing numbers of US patients awaiting kidney transplantation die or become so ill that they are no longer considered transplantation candidates. The major reason for this failure of patient care is the shortage of kidneys for transplantation. An increase in living kidney donors could solve this problem, yet financial burdens often remain a barrier to living kidney donation.\(^5\) The idea that living donors should not be financially encumbered has been affirmed by the American Society of Transplantation and the American Society of Transplant Surgeons, professional societies that are now considering how donor remuneration might relieve the kidney shortage in America.\(^13,18,22\)

While many transplantation professionals still oppose direct payments in organ donation, others affirm that financial incentives should be debated in public. The attitudes of professionals opposing payment may lag behind those of the American populace, which often accepts policy changes before politicians, regulators, and judges address and modify laws and regulations. This “population-out-in-front” phenomenon has been evident in issues such as same-sex marriage, marijuana use, and end-of-life imperatives. A poignant example of the out-in-front phenomenon is that in 1947, fewer than 40% of Americans were likely to support physician-assisted euthanasia, while acceptance is as high as 70% today.\(^23\)

Public and professional attitudes about paying donors have varied over time. Hoeyer et al\(^24\) reviewed 23 articles published from 2002 to 2012 regarding public opinion of financial incentives in both living and deceased donation. They found broad differences for and against financial incentives, with a low overall acceptance for paying living donors. However, they noted a considerable preference for nonmonetary rewards, including paid lifetime donor health care, preference for the recipient, 60% favored payment to anonymous donors and 46% favored a regulated system of payment to stimulate kidney donation. While most (78%) did not desire a reward for themselves, noting that they donated out of love, they noted a considerable preference for nonmonetary rewards, including paid lifetime donor health care, preference for the recipient, 60% favored payment to anonymous donors and 46% favored a regulated system of payment to stimulate kidney donation. While most (78%) did not desire a reward for themselves, noting that they donated out of love for the recipient, 60% favored payment to anonymous donors and 46% favored a regulated system of payment to stimulate kidney donation.
ported that direct payment of money was the most preferred form of compensation in 61% of respondents and that compensation would increase the likelihood to donate in 29% of respondents but would not change the view of 70% of persons queried. Offering $5000 or $10 000 to give a kidney to family and friends or strangers, respectively, were amounts at which participants began to consider donation more positively. These authors further noted that undue inducement payment levels for nephrectomy were $50 000 and $100 000 for family and friends and strangers, respectively, thus concluding that lower amounts of payment may motivate the public in an acceptable fashion. In contrast, we have found that most US voters who would be willing to consider donor nephrectomy would be more willing to do so when offered a cash payment of $50 000, and even some initially not in favor of donation indicated that they would be swayed. Our findings refute the assertion that the US public, and particularly the American voter, holds payment for living kidney donation in disdain. Instead, our data suggest that a substantial proportion of US voters would consider living donation, would be more inclined to donate if paid a sufficient amount, and would favor compensating donors as a societal norm.

An overriding and virtually ubiquitous tenet of modern medicine is that decisions related to care must be based on evidence. The evidence regarding the circumstances in the United States related to sufficient organs for transplantation is clear: the current system to obtain organs, particularly kidneys, for transplantation is inadequate. Survey data suggest that many citizens would consider donating a kidney if there were no financial burden and adequate compensation. However, actual behaviors may not fully comport with survey responses. Therefore, the way to determine whether compensating living kidney donors would substantially increase the number of kidneys for transplantation and where exactly the line is between fairness and undue inducement or coercion is to design and carry out clinical trials, through which data could be obtained on the actual behaviors of potential donors and on the attitudes and opinions of actual donors who receive compensation.

Conclusions

Most US voters support living kidney donation, both in terms of donation and compensation. Persons self-described as potential donors appear even more inclined to donate if offered payment. Thus, the inclination toward donation appears strengthened, not weakened, by payment. More Americans believe that living kidney and marrow donors, who currently may not be paid by law, are more deserving of compensation than donors of ova, sperm, and blood, who currently can be paid. Because too many US patients are dying owing to the inadequate kidney supply, and because paying living kidney donors could increase the number of kidneys, we conclude that this option must be seriously considered. Amending existing federal law so that pilot studies concerning donor compensation can go forward is a reasonable start, and our findings show that it should be politically feasible. Results of such clinical trials should be the basis of regulatory policy. If pilot studies support paying living kidney donors, perhaps one day there might be a long waiting list of persons wanting to donate rather than a list of Americans waiting for kidneys that never come.

Funding/Support: All financial and material support for this work came from funds from the FAIR Foundation paid directly to PSB to undertake the survey on compensating living kidney donors.

Role of the Funder/Sponsor: While Drs Peters and Gish are current officers of the FAIR Foundation, its directors and staff had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; or preparation, review, or approval of the manuscript. The decision to submit the manuscript for publication was that of the authors.

Additional Contributions: Messrs Merrill Raman, BA (PSB), and Jordan Maitland, BA (PSB), were involved with the technical aspects of survey design, direction, analysis, data interpretation, and reporting. Each worked principally with Drs Peters and Fisher to assure that results reporting was accurate and fully understandable to readers. Messrs Raman and Maitland are employed by PSB, and neither reported conflicts of interest in matters of organ donation and transplantation. Ms Cathy Teal, BFA, is employed as executive director of the FAIR Foundation. She was fully aware of the financial and contract matters between FAIR and PSB. Financial support for the PSB work was entirely from FAIR Foundation funds; the 4 authors were not compensated for their work on this submission. Ms Teal was made fully aware of the details and progress of the manuscript.

REFERENCES


Press Coverage

A partial listing of press coverage about Views of US Voters on Compensating Living Kidney Donors, by Peters et al.

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Influential Supporters of Financial Incentives for Organ Donation

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Phil Berry, M.D., Advisory Committee for Organ Transplantation (ACOT) appointed by Secretary Tommie Thompson, Health & Human Services, 2001-2004; Past President, Texas Medical Association; President, Texas Medical Assoc. Foundation

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Diane Furchtgott-Roth, former chief economist, U.S. Department of Labor; senior fellow, Hudson Institute

Professionals of Note
Richard Darling, DDS; Past National Public Citizen of the Year (NASW); Author: Coma Life, an autobiographical memoir of three liver transplants

Dave Courtney, Vice President and Director of Public Relations; The Presumed Consent Foundation

Bill Remak, Chairman, California Hepatitis C Task Force; Secretary, National Association of Hepatitis Task Forces; Member, Board of Directors of the Pharmacy Council on Hepatitis and Liver Disease.

Ralph H. Treiman, Past-President, American Liver Foundation, Greater Los Angeles Chapter

Debbie Delgado Vega, Founder, President and CEO, Latino Organization for Liver Awareness (LOLA)

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Harold Kyriazi, Ph.D., Department of Neurobiology, University of Pittsburgh School of Medicine, Pittsburgh, PA; Founder: AHCSIOS (the Ad Hoc Committee for Solving the Intractable Organ Shortage; website www.ahcios.org)

Alex Tabarrok, Associate Professor of Economics, Department of Economics, George Mason University; Research Director, The Independent Institute; Research Fellow, Mercatus Center

Bob Aronson, blogger on organ-donation and the need for new OD policies, heart-transplant recipient at age 68

Darla S. Leibel-Burrow, Executive Director, Nevada Hepatitis C Task Force

Cathy Teal, Executive Director, FAIR Foundation.

Jerry Jackson and Dan Brumett, CEO/President of “Miracles Do Happen Productions” (MDH Productions, Inc.) Jerry and Dan, with the help of a young boy, Jimmy Younger, who needs a new liver to survive, produced one of the most powerful and professional videos we’ve ever seen to promote organ donation.

Private Citizens
Romara Black, Palm Desert, CA; Art & Angela Curley, Larkspur, CA; Kress Darling, Palm Desert, CA; John & Jennie Johnson, Banning, CA; John Juras, Palm Desert, CA; Larry E. Nazimek, Chicago, IL, liver-transplant recipient; Richard Reese, Sterrett, Alabama; Geoff & Stephanie Spencer, Manchester, NH; Carol Stafford, liver-transplant recipient, Apple Valley, CA; Robert & Nancy Zampieri, Charlotte, NC

The FAIR Foundation
H.R.5344 - Organ Donation Clarification Act of 2016

Committees: House - Energy and Commerce

114TH CONGRESS
2D Session

H. R. 5344

To clarify that pilot programs that honor and reward organ donation are not preempted by Federal criminal law and that offering and accepting such benefits in accordance with a pilot program are not criminal acts.

IN THE HOUSE OF REPRESENTATIVES

MAY 26, 2016

Mr. CARTWRIGHT (for himself, Mr. GRIJALVA, Mr. HONDA, Ms. EDDIE BERNICE JOHNSON of Texas, Mr. POLIS, Mr. RANGEL, Mr. YOUNG of Alaska, Mr. MARINO, and Mr. POSEY) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To clarify that pilot programs that honor and reward organ donation are not preempted by Federal criminal law and that offering and accepting such benefits in accordance with a pilot program are not criminal acts.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Organ Donation Clarification Act of 2016”.

SEC. 2. FINDINGS.

Congress finds the following:
(1) As of January 2016, 121,000 people await an organ transplant, with 100,000 of those people waiting for a kidney, and average wait times are approaching five years for a kidney, with twice as many people being added to waiting lists as getting a transplant.

(2) Living donor kidney transplants peaked in 2006 and have declined since due to a scarcity of living donors.

(3) Of the roughly two million Americans who die annually, only 10,500 to 13,800, representing less than one percent of all deaths each year, possess major organs healthy enough for transplanting.

(4) On average, 22 people a day died while waiting for an organ, with the majority of those people waiting on a kidney.

(5) In 2013 nearly 3,000 people were permanently removed from kidney waiting lists and 2,000 from liver, heart, and lungs waiting lists because they became permanently too sick to receive a transplant.

(6) 90% of dialysis patients are not employed because dialysis requires multiple treatments per week which last several hours and leave patients drained, thus creating a huge financial burden on
the patients, their families, and the government which is not included in the cost estimates above.

(7) A patient receiving a kidney transplant on average has an additional 10–15 years of life at a much more enjoyable and productive level as compared with remaining on dialysis, while receiving a kidney from a living donor providing 4–8 years of additional life as compared to receiving a kidney from a deceased donor.

(8) As medical advances extend people’s lives as they wait for an organ transplant, waiting lists will get longer and the costs for individuals and the Federal Government will increase significantly.

(9) Roughly seven percent of the Medicare budget goes to the End Stage Renal Disease Program, with dialysis costing Medicare over $87,000 per patient per year, as Federal law dictates that Medicare will cover dialysis for everyone who has made minimal Social Security tax payments.

(10) A kidney transplant pays for itself in less than two years, with each transplant saving an average of over $745,000 in medical costs over a 10-year period, 75 percent of which is savings to the taxpayers.
(11) Experts project that if the supply of transplant kidneys could be increased to meet the demand, taxpayers would save more than $5,500,000,000 per year in medical costs.

(12) The World Health Organization estimates that 10 percent of all transplants take place on the international black market, the last choice for desperate patients facing an alternative of death, however recipients often face infected kidneys and have poor health outcomes and donors are often victimized.

(13) Present policy on domestic donation, which is not evidence based and has never been subject to studies or pilots to determine effectiveness in increasing the availability of donated organs and the effectiveness of safeguards that prevent coercion or exploitation, precludes all but altruistic donation, prohibiting any form of incentive or benefit for donors.

(14) Experts are arriving at a consensus that trials are necessary to find new methods of promoting additional organ donation which will save lives and reduce organ trafficking.
SEC. 3. CLARIFICATION OF CERTAIN PROVISIONS OF THE NATIONAL ORGAN TRANSPLANT ACT.

(a) RELATION TO OTHER LAWS.—

(1) GOVERNMENTS ENCOURAGING ORGAN DONATION.—Section 301 of the National Organ Transplant Act (42 U.S.C. 274e) shall not—

(A) apply to actions taken by the Government of the United States or any State, territory, tribe, or local government of the United States to carry out a covered pilot program; or

(B) prohibit acceptance of any noncash benefits provided by the pilot program under subparagraph (A).

(2) NO PROHIBITION ON OTHER BENEFITS PROGRAMS.—Nothing in this section shall be construed to prohibit actions, other than actions described in this section, taken by any State, territory, tribe, or unit of local government in the United States to provide benefits for organ donation, including pursuant to section 301 of the National Organ Transplant Act (42 U.S.C. 274e).

(3) CLARIFICATION OF MEANING OF BENEFIT.—For purposes of the National Organ Transplant Act, valuable consideration does not include the following:

•HR 5344 IH
(A) Reimbursement for travel, lodging, food during travel, and other expenses related to donation.

(B) Provision of or reimbursement for dependent care needs related to donation.

(C) Reimbursement for lost wages related to donation.

(D) Medical expenses related to donation and all related follow up care including preventative follow up care and medication.

(E) Paperwork or legal costs related to donation.

(F) Any insurance policy against the risk of death or disability as a result of donating an organ or the longer-term health effects of having donated an organ.

(b) DEFINITION.—In this section:

(1) The term “organ” means the human kidney, liver, heart, lung, pancreas, bone marrow obtained by aspirate, cornea, eye, bone and other musculoskeletal tissue, skin, and heart valves and other cardio and vascular tissue.

(2) The term “covered pilot program” means a pilot program approved by the Secretary of Health and Human Services, subject to an ethical review.
board process, with a term of not more than 5 fiscal years, for the purpose of measuring the effect of removing disincentives or providing a noneash benefit that may increase the organ pool. Distributions of organs from deceased donors under the pilot program shall be conducted only through the Organ Procurement and Transplantation Network at a transplant center approved by the United Network for Organ Sharing or any other entity designated by the Secretary of Health and Human Services.
Why GAO Did This Study

An estimated 17 percent of U.S. adults have chronic kidney disease—the most common form of kidney disease—a condition in which the kidneys are damaged and cannot filter blood sufficiently, causing waste from the blood to remain in the body. Kidney disease patients may progress to ESRD, a condition of kidney failure, which can cause death without dialysis or kidney transplant. In 2013, the Medicare program—which pays for ESRD treatment—spent $30.9 billion to treat approximately 530,000 patients. Given the high cost of kidney disease in terms of health consequences and federal spending, GAO was asked to examine how the federal government funds and prioritizes kidney disease research. This report describes (1) the level of NIH funding for biomedical research on kidney disease, and for other leading diseases and conditions; and (2) how NIDDK sets priorities for kidney disease research.

To describe NIH funding for research on kidney disease and other diseases and conditions, GAO selected leading diseases and conditions (based on mortality and prevalence) and analyzed their levels of research funding based on NIH data for fiscal year 2015. To describe how NIDDK sets priorities for kidney disease research, GAO reviewed documents—including those on research portfolios and strategic planning—from NIDDK, NIH, and other relevant federal agencies. Also, GAO interviewed agency officials and private kidney care groups representing a broad range of perspectives.

What GAO Found

The National Institutes of Health (NIH), within the Department of Health and Human Services, is the primary federal agency that conducts biomedical research on kidney disease, as well as various other diseases and conditions. NIH’s budget—$30 billion in fiscal year 2015—mostly funds extramural research that supports research personnel working at universities, medical schools, and other institutions. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)—one of NIH’s 27 institutes and centers (IC)—has primary responsibility for kidney disease research. NIH funding for biomedical research on kidney disease in fiscal year 2015 was approximately $564 million—an increase of 2.7 percent from fiscal year 2014. NIDDK provided the majority (60 percent) of this funding, supporting a broad range of projects, such as chronic kidney disease, end-stage renal disease (ESRD) treatment, and kidney donation. GAO also reviewed NIH research funding levels for other diseases and conditions in the United States—those that are associated with high mortality or are among the most prevalent chronic conditions. GAO found that funding for fiscal year 2015 varied widely among these diseases and conditions—for example, from $28 million for emphysema to nearly $5.4 billion for cancer. This variation in funding reflects a range of factors, including each IC’s mission, budget, and research priorities.

NIDDK obtains input from the broader kidney care community to develop its research priorities. To develop funding announcements that target high-priority research areas, NIDDK considers the kidney care community’s input in the context of its ongoing work and its knowledge of the current state of kidney disease research. NIDDK’s process for obtaining input from the kidney care community is iterative by design to help ensure that the institute’s research priorities evolve to reflect the latest research developments and needs of the kidney care community.

NIDDK’s Methods for Obtaining Input from Stakeholders to Set Research Priorities

Representatives from six private kidney care groups GAO interviewed generally agreed with NIDDK’s kidney disease research priorities; however, some of the groups’ members identified kidney disease topic areas they believe warrant more attention from NIDDK, such as a lack of kidney disease awareness in the general public. NIDDK agreed with this and other topics raised by the groups, and pointed out a variety of ongoing NIDDK programs that address these topics.

The Department of Health and Human Services provided technical comments, which GAO incorporated as appropriate.
A Cost-Benefit Analysis of Government Compensation of Kidney Donors

Abstract
First published: 16 October 2015; P. J. Held, F. McCormick, A. Ojo, J. P. Roberts
Full article to follow abstract.

From 5000 to 10 000 kidney patients die prematurely in the United States each year, and about 100 000 more suffer the debilitating effects of dialysis, because of a shortage of transplant kidneys. To reduce this shortage, many advocate having the government compensate kidney donors. This paper presents a comprehensive cost-benefit analysis of such a change. It considers not only the substantial savings to society because kidney recipients would no longer need expensive dialysis treatments—$1.45 million per kidney recipient—but also estimates the monetary value of the longer and healthier lives that kidney recipients enjoy—about $1.3 million per recipient. These numbers dwarf the proposed $45 000-per-kidney compensation that might be needed to end the kidney shortage and eliminate the kidney transplant waiting list. From the viewpoint of society, the net benefit from saving thousands of lives each year and reducing the suffering of 100 000 more receiving dialysis would be about $46 billion per year, with the benefits exceeding the costs by a factor of 3. In addition, it would save taxpayers about $12 billion each year.
A Cost-Benefit Analysis of Government Compensation of Kidney Donors

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†Authors Held and McCormick are co-first authors on this work.

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Introduction

In June 2014, the American Society of Transplantation and the American Society of Transplant Surgeons held the joint Workshop on Increasing Organ Donation in the United States. They recently released a meeting report (1) on the workshop that concluded, “...we should be working together along the arc of change to remove remaining disincentives, explore opportunities to either change or modify NOTA (National Organ Transplant Act (2)), and lay the groundwork for the next steps with our professional colleagues, experts in economics, law and ethics, our partners in Congress and agencies responsible for US health policy and the American public.”

This paper is a response to that invitation. It provides a comprehensive cost-benefit analysis of a proposed change to NOTA, that is, moving from our current kidney procurement system in which compensation of donors is legally prohibited to one in which the government (not private individuals) compensates living kidney donors $45 000, and deceased donors $10 000. Such compensation would be considered an expression of appreciation by society for someone who has given the gift of life to another. It could include an insurance policy against any health problems that might develop in the future as a result of the donation, including disability and death. Compensation for living donors could be paid in a delayed form, such as tax credits or health insurance, so people who are desperate for cash would not be tempted to sell a kidney. Compensation for deceased donors would be paid to their estate. All other aspects of the kidney procurement and allocation process would continue exactly as they are under the current system. In particular, living donors would continue to be carefully screened and informed of possible hazards associated with kidney donation. Kidneys would be allocated as the organs from deceased donors are now—by the federally funded and managed Organ Procurement and Transplant Network (currently administered under contract by United Network for Organ Sharing). (Satel (3) and Beard et al. (4) have made similar proposals for government compensation of donors.)

A program of government compensation of kidney donors would provide the following benefits:

1. Transplant kidneys would be readily available to all patients who had a medical need for them, which would...
prevent 5000 to 10,000 premature deaths each year and significantly reduce the suffering of 100,000 more receiving dialysis.

2. This would be particularly beneficial to patients who are poor and African American because they are considerably overrepresented on the transplant waiting list. Indeed, it would be a boon to poor kidney recipients because it would enable them to reap the great benefits of transplantation at very little expense to themselves. Because transplant candidates would no longer have to spend almost 5 years receiving dialysis while waiting for a transplant kidney, they would be younger and healthier when they receive their transplant, increasing the chances of a successful transplantation.

3. With a large number of transplant kidneys available, it would be much easier to ensure the medical compatibility of donors and recipients, which would increase the success rate of transplantation.

4. When a first kidney graft fails, the patient would be readily able to obtain a second transplant kidney. (Other considerations might delay a second transplant but not a shortage of transplant kidneys.)

Table 1: Key estimates and calculations

<table>
<thead>
<tr>
<th>Monetary Value of a Year of Perfect Health</th>
<th>$200,000</th>
<th>Item 1 in S1: Sensitivity test in Item 2 of S8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Real Interest Rate (i.e., nominal interest rate minus inflation) Used to Discount Future Costs and Benefits</td>
<td>3%</td>
<td>Item 8 in S1</td>
</tr>
<tr>
<td>Quality of Life Compared to Perfect Health</td>
<td>While On Dialysis: 0.52</td>
<td>Item 2 in S1: Sensitivity test in Item 3 of S8</td>
</tr>
<tr>
<td></td>
<td>After Transplant: 0.75</td>
<td></td>
</tr>
<tr>
<td>Government Compensation Paid to Living Donors per Kidney</td>
<td>$45,000</td>
<td>Items 9 and 10 in S1: Sensitivity test in Item 1 of S8</td>
</tr>
<tr>
<td>Government Compensation Paid to Estate of Deceased Donors</td>
<td>$10,000</td>
<td>Item 10 in S1</td>
</tr>
<tr>
<td>Percent of All Costs Paid by Taxpayers (federal and state)</td>
<td>75%</td>
<td>S5</td>
</tr>
<tr>
<td>Patients Obligation (co-pays): Differ by Medicare A, B, D</td>
<td>Percent of Medicare Paid Claims: Dialysis: 21% Transplant: 16%</td>
<td>Average percent for all ESRD: 20% S5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Costs Below Include Patient Obligations (co-pays)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost of All Medical Care While on Dialysis per Year</td>
<td>$121,000</td>
</tr>
<tr>
<td>Cost of a Transplant Procedure (including OAC) per Event</td>
<td>$145,000</td>
</tr>
<tr>
<td>Cost of All Medical Care for a Functioning Graft (including drugs) per Year</td>
<td>$32,000</td>
</tr>
<tr>
<td>Cost of Kidney Graft Failure per Event</td>
<td>$88,000</td>
</tr>
</tbody>
</table>

Statistical Methods

- Trace treatment path of median dialysis and transplant patients, using half-lives for survival and means for costs
- Simple binary measures; Markov assumptions not needed S12
- Sample size for costs: 497,000; Half-lives were validated. S5 and S12

Model, Objectives, and Statistical Methodology

- Donor Compensation: No in Current Period Yes in Transition & Steady State S12
- Data: near census from national registries USRDS, SRTR, Medicare S5 and S12
6. Taxpayers would save about $12 billion each year. Dialysis is not only an inferior therapy for end-stage renal disease (ESRD), it is also almost 4 times as expensive per quality-adjusted life-year (QALY) gained as a transplant.
7. The incentive for Americans to participate in transplant tourism or the black market for kidneys would virtually cease.
8. The overall proficiency of kidney transplantation would increase as the number of transplants increases. Currently, the typical kidney transplant center performs only two transplantations a month.

Given the controversial nature of the subject matter of this paper, we have written 12 supplements to explain, justify, and document our key estimates and calculations (which are summarized in Table 1).

This paper updates and expands the path-breaking work of Matas and Schnitzler (6). The major differences are that this study (a) uses cost-benefit rather than cost-effectiveness analysis, (b) uses a consensus monetary value of the extra years of life gained from a transplant, (c) includes patient obligations (copays) in the costs, (d) uses consensus values of the quality of life before and after transplantation, (e) analyzes compensation of deceased donors as well as living donors, (f) uses more recent data on outcomes from dialysis and transplantation, and (g) is more transparent in methodology (Supplement 4 provides a detailed comparison of the two papers.)

Methods

Cost-benefit analysis is a tool for analyzing public policy issues. It helps clarify who wins and who loses from a given policy, by how much they win or lose, and whether the policy makes society as a whole better or worse off. The costs and benefits are conceived of in the broadest possible sense and include the value of the longer and higher-quality lives that kidney transplant recipients enjoy. These costs and benefits are calculated in greater detail in Supplement 2. As is standard in cost-benefit analysis, costs and benefits in the future are discounted back to the present. A consensus real (i.e. zero inflation) interest rate of 3% per annum is used.

Results

Costs and benefits at the current time when compensating donors is prohibited
(Note: The analysis of costs and benefits presented in this section is abbreviated; greater detail is provided in Supplement 2.) The left column of Table 2 shows

<table>
<thead>
<tr>
<th></th>
<th>No donor compensation (current situation) (2015)</th>
<th>If donors are compensated (steady state after first 5 years) (2020)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Expected remaining lifetime (half-life in years)</strong></td>
<td>If remain on dialysis on waiting list</td>
<td>12.3</td>
</tr>
<tr>
<td><strong>Increase in life years from receiving a transplant (vs remaining on dialysis on waiting list)</strong></td>
<td>If receive a transplant</td>
<td>19.3</td>
</tr>
<tr>
<td>Increase in life years from receiving a transplant</td>
<td>Increase in life years (unadjusted)</td>
<td>7.0</td>
</tr>
<tr>
<td></td>
<td>Increase in discounted QALYs</td>
<td>4.7</td>
</tr>
<tr>
<td><strong>Half-life of transplant kidney graft</strong></td>
<td>12.6*</td>
<td>15.7</td>
</tr>
</tbody>
</table>

In the current situation, when the graft fails in 12.6 years, 86% of the patients go back on dialysis. In the steady state case, when the first graft fails, most patients will be readily able to obtain a second transplant kidney.

Based on only 14% receiving a second transplant. In the steady state case, the percentage may approach 100%; hence the number (9.9) may approach 12 years.

The FAIR Foundation

statistics for the current situation when donors are not compensated. The top row indicates a typical patient receiving dialysis can expect to live 12.3 years, while the second row shows he or she can expect to live 19.3 years if the patient receives a kidney transplant. (The latter half-life is the weighted average of the half-lives of patients who have received kidneys from deceased and living donors, as explained in detail in Supplement 12, particularly Figure S12-5.) The third row shows the difference (i.e. the transplant recipient can expect to live an additional 7.0 years).

Since (as discussed above) the quality of life of a dialysis patient is 0.52 before a transplant and 0.75 afterward, the gain in QALYs for a typical kidney transplant recipient is 0.75 times the life expectancy after receiving a transplant minus 0.52 times the life expectancy if the recipient had remained on dialysis.

After discounting, this yields a gain of 4.7 discounted QALYs as a result of the transplant (row 4 of the left column of Table 2). And valuing each of these years at the consensus estimate of $200,000 produces a lifetime welfare gain of $937,000 per kidney recipient (top row of the left column of Table 3). It is well known that kidney recipients benefit greatly from receiving a transplant, and this puts a credible monetary value on it.

A second benefit of kidney transplants is the savings from kidney recipients no longer requiring dialysis and other medical treatments, which cost about $121,000 per patient-year and would have continued for the 12.3-year expected life of a dialysis patient on the waiting list. But the half-life of a kidney transplant is only 12.6 years (bottom row of left column of Table 2), after which a typical kidney transplant recipient has to return to dialysis for their remaining 6.7 years of life. Consequently, the lifetime net savings from temporarily stopping dialysis would be $735,000 (row 2 of the left column of Table 3).

Table 3: Present value of benefits and costs over a kidney recipient’s lifetime (per kidney recipient)

<table>
<thead>
<tr>
<th>Benefits</th>
<th>No donor compensation (current situation)</th>
<th>If donors are compensated (steady state after first 5 years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welfare gain for kidney recipient (over a lifetime)</td>
<td>$937,000</td>
<td>$1,335,000</td>
</tr>
<tr>
<td>Savings from stopping dialysis (over a lifetime)</td>
<td>$735,000</td>
<td>$1,454,000</td>
</tr>
<tr>
<td>Costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost of transplant (everything at time of transplant except compensation to donors)</td>
<td>$145,000</td>
<td>$236,000</td>
</tr>
<tr>
<td>Compensation to donors</td>
<td>$0</td>
<td>$73,000</td>
</tr>
<tr>
<td>Medical costs after transplant (including cost of kidney graft failure)</td>
<td>$395,000</td>
<td>$607,000</td>
</tr>
<tr>
<td>Net welfare gain for society per kidney recipient</td>
<td>$1,132,000</td>
<td>$1,873,000</td>
</tr>
<tr>
<td>Addendum</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taxpayer savings per kidney recipient</td>
<td>$146,000</td>
<td>$403,000</td>
</tr>
</tbody>
</table>


Turning to the other side of the ledger, the cost of the transplant itself (i.e. payments at the time of the transplant to all parties except the kidney donor) is about $145,000 (row 3 of the left column of Table 3). And compensation to kidney donors is zero because it is currently legally prohibited (row 4).

Medical costs following a transplant are about $32,000 per year for the 12.6-year expected life of the kidney graft, plus an additional $88,000 when the graft of the typical patient fails in 12.6 years. Thus, the lifetime total costs are $395,000, as shown in the fifth row of the left column of Table 3.

The net welfare gain for society over the lifetime of a kidney recipient (row 6 of the left column of Table 3) is just the net of the rows above it, or $1,132,000.

The bottom row of the left column of Table 3 shows taxpayer savings over the lifetime of the kidney recipient. Because taxpayers currently bear about 75% of the cost of both dialysis and kidney transplants (see Supplement 5), taxpayers would reap 75% of the benefits from patients stopping dialysis after receiving a transplant. Specifically, taxpayer savings are equal to 75% of the savings from stopping dialysis, minus: (a) the cost of the transplant, (b) compensation to donors (when allowed), and (c) medical costs after the transplant. This comes to $146,000 per kidney recipient.

Aggregating the per-recipient costs and benefits of the left column of Table 3 over all of the kidney recipients in a given year yields the left column of Table 4 (the top seven rows of which have the same arrangement as Table 3). For example, if the $146,000 taxpayer savings per kidney recipient (from the bottom row of the left column of Table 3) is multiplied by a conservatively high estimate of 17,500 kidney recipients each year, the result is the total taxpayer saving from all kidney recipients each year,
which is $2.6 billion per year (row 7 of the left column of Table 4).

**Life expectancies when donors are compensated**

Now consider two subperiods after the government begins compensating kidney donors: (a) the first 5 years, during which we estimate the 94 000-patient waiting list for kidneys will be gradually eliminated, and (b) the subsequent “steady state” situation that will obtain after the waiting list has been ended. We will first estimate life expectancies and then use them to estimate the costs and benefits of the government compensating kidney donors.

We assume compensation of $45 000 per kidney will be sufficient to elicit an adequate supply of kidneys from living donors, which, together with some additional kidneys from deceased donors, will end the kidney shortage and eliminate the waiting list in 5 years (see Item 9 of Supplement 1). Thus, during the 5-year transition period, the number of kidney recipients will increase to about 43 000 per year. This is the sum of the 31 000 patients currently being added to the waiting list each year, plus an additional 12 000 transplants per year needed to reduce the waiting list to zero in 5 years (see Supplement 11 for a discussion of the current capacity of the transplant community).

To simplify comparisons of the current situation with the postcompensation period, we will focus on the steady-state case after the waiting list has been eliminated. Because the supply of transplant kidneys will now be sufficient to meet the demand, transplant candidates will no longer have to wait about 5 years for a kidney. This has two important implications. First, the average age of kidney recipients will fall from 50 to 45 years. Second, kidney recipients will now be far healthier because they will no longer have to suffer the debilitating effects of several years of dialysis. We estimate these considerations will increase the life expectancy of the typical kidney recipient to about 24.9 years in the steady-state case from 19.3 years in the current situation (shown in the second row of Table 2 and discussed in Supplement 12). In contrast, if the kidney patient had remained on dialysis, their life expectancy would have been only 15.0 years (top row of the right column of Table 2). This can also be seen in Figure 1, which shows the two treatment paths ESRD patients can take in steady state: dialysis or transplant. Note that the typical kidney recipient in steady state will receive a second transplant after the first graft fails in 15.7 years.

### Costs and benefits in the steady-state case

With these life expectancies, we can calculate the increase in discounted QALYs—and the benefits and costs of receiving a kidney transplant—in the steady-state case, using the same methodology we used in the current situation case.

A kidney recipient in this steady-state case gains an additional 9.9 years of life from receiving a kidney transplant (row 3 of the right column of Table 2), which translates into 6.7 discounted QALYs (row 4). When this is multiplied by the consensus estimate of the value of a year of life, the result is a lifetime welfare gain of $1 335 000 per recipient (top row of right column of Table 3).

The savings from stopping dialysis is again found by multiplying the expected life of a dialysis patient by the yearly medical cost of dialysis, which yields a lifetime gain of $1 454 000 (row 2 of Table 3). Note that this savings is almost twice that in the current situation case because the typical kidney recipient, instead of going back on dialysis after the first graft fails, will, because of the greater

### Table 4: Present value of benefits and costs for all kidney recipients in a given year (per year)

<table>
<thead>
<tr>
<th>Benefits</th>
<th>No donor compensation (current situation)</th>
<th>If donors are compensated (steady state after first 5 years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welfare gain for all kidney recipients in a given year</td>
<td>$16.4 billion/y</td>
<td>$46.7 billion/y</td>
</tr>
<tr>
<td>Savings from stopping dialysis for all kidney recipients in a given year</td>
<td>$12.9 billion/y</td>
<td>$50.9 billion/y</td>
</tr>
<tr>
<td>Costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Costs of transplants for all kidney recipients in a given year (everything at time of transplant except compensation to donors)</td>
<td>$2.5 billion/y</td>
<td>$8.3 billion/y</td>
</tr>
<tr>
<td>Compensation to donors for all kidney recipients in a given year</td>
<td>0</td>
<td>$2.6 billion/y</td>
</tr>
<tr>
<td>Medical costs after transplant for all kidney recipients in a given year (including cost of kidney graft failure)</td>
<td>$6.9 billion/y</td>
<td>$21.2 billion/y</td>
</tr>
<tr>
<td>Net welfare gain for society from all transplant recipients in a given year</td>
<td>$19.8 billion/y</td>
<td>$65.6 billion/y</td>
</tr>
<tr>
<td>Addendum</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taxpayer savings from all transplant recipients in a given year</td>
<td>$2.6 billion/y</td>
<td>$14.1 billion/y</td>
</tr>
<tr>
<td>Benefit-cost ratio for society</td>
<td>3.0</td>
<td></td>
</tr>
<tr>
<td>Benefit-cost ratio for taxpayers</td>
<td></td>
<td>1.7</td>
</tr>
</tbody>
</table>

availability of transplant kidneys, soon receive a second transplant.

The cost of the first transplant is, again, $145 000. The cost of the second transplant is the same, and after discounting for a delay of 15.7 years, this raises the total to $236 000 (row 3).

The fourth row of the right column of Table 3 includes the two $45 000 government payments to kidney donors. The first will occur at the time of the initial transplant, and the second occurs 15.7 years later for a typical patient, for a total cost of $73 000. Note that this number is much smaller than the other costs and benefits in Table 3, especially the huge welfare gain for kidney recipients and the savings from stopping dialysis. One of the most surprising and important results of this paper is how small the cost of compensating donors would be compared with the very large welfare gains for society that would result. Note also that it is conservatively assumed that all donors will be paid $45 000 per kidney, including those who previously were willing to donate their kidneys for free. If some of the latter are still willing to donate for free, that will just reduce the costs and increase the net benefits from compensating kidney donors. But if some now decline to donate at all, the cost of replacing their donations with kidneys from compensated donors is already included in the above calculation. This conservative $45 000 estimate also covers the small possibility that—after the government starts compensating kidney donors—all kidneys might come from living donors and none from deceased donors.

The fifth row of the right column of Table 3 shows the lifetime medical costs after a transplant. The 24.9-year life expectancy of a transplant recipient (from row 2 of the right column of Table 2) is multiplied by the yearly medical expenses. To this is added the $88 000 expense when the kidney graft fails in 15.7 years, bringing the total to $607 000. This is higher than in the current situation because the typical transplant recipient will receive a second transplant with its associated costs.

The net welfare gain for society over a kidney recipient’s lifetime will be $1 873 000 (row 6 of the right column of Table 3). This is much larger than in the current situation case because of the longer life expectancy of the kidney recipient and the greater savings from stopping dialysis (because the typical patient will not return to dialysis very long after the first graft fails). The value of these benefits would greatly exceed the additional costs of the second transplant.

The bottom row of the right column of Table 3 shows how much taxpayers would save over the kidney recipient’s lifetime, which is $403 000. This is more than twice as much as in the current situation because the additional savings from ending dialysis is much greater than the additional costs of the second transplant.

Aggregating these costs and benefits per kidney recipient in the right column of Table 3 over an estimated 35 000 transplant recipients per year during the steady state period, results in the right column of Table 4. Note in particular that with a successful donor compensation program—the net welfare gain for society (row 6 of Table 4) would more than triple to $65.6 billion per year from $19.8 billion per year currently. Note also that the savings
for taxpayers would increase to $14.1 billion per year from $2.6 billion per year (row 7 of Table 4). Finally, note in the bottom two rows of Table 4 that—moving from the current situation in which compensation of kidney donors is prohibited to one in which the government compensates donors—the benefit-cost ratio would be a large 3.0 for society as a whole and 1.7 for taxpayers considered alone.

Discussion

Would government compensation of kidney donors exploit the poor?

One of the major arguments of those who oppose compensating kidney donors is that poor people would be more likely to become living donors than would rich people, and, therefore, rich people would wind up buying kidneys from poor people, thereby “exploiting” them. So, it is argued, poor people would be worse off if kidney donors were compensated than they are under the present system.

Our cost-benefit framework reveals that this line of reasoning is exactly backward. As explained in detail in Supplement 3, the present system, in which compensation of kidney donors is legally prohibited, has resulted in a huge shortage of transplant kidneys that seriously harms all transplant candidates—especially the poor, and especially poor African Americans, because they are considerably overrepresented on the kidney waiting list due to the generally worse state of their health. In contrast, if the government compensated kidney donors, it would greatly increase the availability of transplant kidneys, making all transplant candidates, especially the poor, much better off. Indeed, the poor would enjoy the greatest net benefit because they would gain the $1.3 million value of a longer and healthier life, but almost all of the costs of transplantation for the poor person would be borne by the taxpayer through Medicare and Medicaid.

So the current prohibition on compensating kidney donors, which is supposedly intended to keep the poor from being exploited, is in fact seriously harming them. And having the government compensate kidney donors would be an enormous boon for the poor.

Key Innovations

One of the key innovations of this paper is using a consensus estimate of the monetary value of a QALY, which enables us to employ cost-benefit analysis to determine the net benefit to society from having the government compensate kidney donors. Our value of $200,000 per QALY is based on a careful review of the literature (see Item 1 in Supplement 1). Moreover, sensitivity tests of $100,000 and $300,000 per QALY were performed (see Item 2 in Supplement 8) and revealed that even for QALY values as low as $100,000, the net welfare gain for society per recipient in steady state would still be a large $1.2 million (vs $1.9 million using the consensus QALY of $200,000).

On the other hand, our proposed donor compensation of $45,000 per kidney is very conservative. It is three times the estimate made by Becker and Elías (5), which is the only serious attempt to estimate this parameter. Sensitivity tests of $25,000 and $65,000 per kidney were performed and had very little effect on our results because donor compensation is very small compared with the other magnitudes in this analysis (see Item 1 of Supplement 8). Indeed, donor compensation could be increased to $375,000 per kidney before taxpayers would no longer save money by paying for kidney transplantation instead of dialysis. And compensation could be increased all the way to $1,200,000 per kidney before society would no longer enjoy a net welfare gain from transplantation.

Cost-effectiveness

Although the central focus of this paper is a cost-benefit analysis of the government compensation of kidney donors, it also provides as a side benefit a comparison of the cost-effectiveness of dialysis and transplantation (see Supplement 10). In steady state, the cost of a QALY obtained through dialysis is $186,000, while the cost of a QALY obtained through transplantation is only $49,000, less than a third as much. Transplantation is clearly the more cost-effective treatment for ESRD, as has been shown by other studies (e.g. Matas and Schnitzler (6)).

Conclusions

The main conclusions of this analysis are that if the government successfully implements a kidney donor compensation program, the following would occur.

1. The lifetime value of a kidney transplant to a recipient would be very large—about $1.3 million per recipient. And the savings from stopping dialysis would be even larger—about $1.45 million per recipient.
2. In contrast, even a conservatively high $45,000-per-kidney cost of compensating kidney donors would be very small compared with the other costs and benefits. Indeed, the total cost of compensating all donors in a given year would be only about $2.6 billion per year. Yet this small cost is the key to unlocking the great welfare gains for transplant recipients and society, as well as the savings for the taxpayer.
3. The net welfare gain for society each year from kidney transplants would more than triple from $20 billion per year currently to $66 billion per year. This means the transplant community would be able to do three times as much good for society as it is currently doing. The
ratio of benefits to costs for society would be a very large 3.0.

4. Having the government compensate kidney donors would even be a good deal for taxpayers considered alone. Because they currently bear most of the cost of both dialysis and kidney transplants, they would reap most of the benefits from more patients stopping expensive dialysis treatments after receiving a transplant. Taxpayers would save $403,000 for every dialysis patient who receives a kidney transplant. The aggregate savings for taxpayers would increase from $2.6 billion per year currently to $14.1 billion per year, and the benefit-cost ratio for taxpayers would be a healthy 1.7.

5. It would also be an especially good deal for poor people considered alone because poor kidney recipients would gain the $1.3 million value of a longer and healthier life, but almost all of the costs of transplantation would be borne by the taxpayer through Medicare and Medicaid.

6. The bottom line of this analysis is that if the government compensated kidney donors, it would not only prevent 5000 to 10,000 premature deaths each year in the United States and substantially increase the quality of life for almost 100,000 patients on dialysis, but the benefits would greatly exceed the costs for both society in general and taxpayers and the poor in particular. One of the most surprising and important results of this paper is how large the welfare gain for society would be compared with the very small cost of compensating kidney donors.

7. We believe the estimates used in this paper are solidly based in the literature. But these are matters about which reasonable people can differ, so we invite others to offer their own numbers. Because the benefits of the government compensating kidney donors are so large and the cost of compensating donors is so small, we are confident that any reasonable estimates of these numbers will arrive at the same conclusion we did—that the benefits greatly exceed the costs.

8. Finally, we encourage those who oppose compensating kidney donors to place a monetary value on their concerns and to show how they outweigh the very large net benefits demonstrated by this analysis. If they do, they may discover—as we did in Supplement 6—that many of the arguments usually made against compensation of kidney donors turn out instead to be arguments in favor.

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Disclosure
The authors of this manuscript have no conflicts of interest to disclose as described by the American Journal of Transplantation.

References


Supporting Information

Additional Supporting Information may be found in the online version of this article.

Index of Supplements for: A Cost-Benefit Analysis of Government Compensation of Kidney Donors

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Studies and Demonstrations

The FAIR Foundation supports peer-reviewed demonstration projects conducted by public and/or non profit entities for the purpose of carrying out studies to increase organ donation and recovery rates, including financial incentives for living organ donation. The FAIR Foundation does not endorse the following draft of a sample project plan. The draft below is presented as an example of the kind of demonstration concept which may provide evidence which would allow healthcare policy makers to make informed decisions regarding financial incentives for living organ donations.

Sample Trial Study

Draft Outline of Projected Demonstration Project for Financial Incentives for Living Organ Donation

1) The program would be a three year project in a designated region. The designated region would be selected from those applying who fit the following criteria:
   a) The region would include an OPO.
   b) Program participation would be required of all hospital transplant centers in the region with active qualified kidney transplant programs with registered living donors.
   c) The regional Donate Life Affiliate would be an active program participant.

2) A local registry/database would be created of all listed recipients in that region taken from UNOS database and in coordination with Donate Life’s donor registry for that region and an additional category or flag application introduced in the functionality of the existing program would indicate those persons that are now enrolled in the demonstration project. Existing technology will be implemented to reduce cost and time to launch the project. Conservatively, an estimated two to four months will be required to launch the project.

3) Staffing would require 2 to 4 people to perform: program administration including reports to funding agency; tracking; healthcare/patient liaison; research design; analysis of data collected on economic outcome, return on investment, lives saved and increase in donor pool, etc.

4) Medically eligible, registered, living kidney donors in the project region would be offered a $50,000 tax credit which could be used in the following ways:
   a) The Living Donor may use the credit to pay current or future medicare deductibles, co-pays, premiums or medicines until exhausted. Should the Living Donor chose to use the credit towards future medical expenses, the credit would accrue interest at the going rate.

The payment arrangement would be reported to the Regional CMS Administrator, who in turn reports it to the appropriate national CMS office and the IRS. The Organ Donation Credit would not taxed as income. However, the medical credit would be reported by the donor in his tax filing for the year the donation occurs. The IRS also receives the same information independently from CMS and UNOS for confirmation.

b) The Living Organ Donor may request up to a 50% or $25,000 as a “cash tax refund” to cover lost wages and other expenses as long as the remaining balance remains as a credit towards future Medicare costs or the funds may be placed in a retirement account. The refund itself is not taxable income but any interest earned may be taxable. The money may also be used to pay unpaid debts to the IRS, but will not be subject to an IRS lien or government garnishment. No lean will be allowed to be placed against these funds that are held as a credit by CMS or IRS by creditors of the donor. However, that protection is dissolved for any refund amounts received directly in cash by the donor.
5) For those donors that wish to adhere to a complete altruistic donation premise as it exists at the present, they may still register and donate but may opt out of taking the tax credit through the demonstration program. The donor in the project region will note their decline of organ donation credit when they register as a donor through Donate Life and on their tax return. (How many Living Donors opt out of the tax credit may prove to be an enlightening statistic.)

6) The tax credit plan may mitigate some of the concerns about “cash for organs” and creates a control mechanism that eliminates “payment in full” for a cash payment for organ donation. It provides some cash for the donor’s current expenses and/or the option to pay forward for their own benefit or they may decline the organ donation benefit altogether. For the recipient, it is the gift of life, freedom from dialysis and a return to a productive life. The government benefits by reducing Medicare costs due to savings generated by reducing the number of people on dialysis, ensuring better outcomes from transplantation and returning patients to the tax paying work force. Most importantly, more lives are saved through a significant increase in the number of willing, living kidney donors. This is a win win for all stakeholders.

We estimate a working budget of $1.8 million to $3 million dollars for the demonstration project to accomplish measurable and evidentiary results over a three year period.
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