

## Original Investigation

## Views of US Voters on Compensating Living Kidney Donors

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 Invited Commentary

**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-digit 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.

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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.<sup>1</sup> During that time, 166 667 kidneys were transplanted, 105 214 from deceased and 61 453 from living donors.<sup>1</sup> 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 7604 such potentially preventable events compared with 5009 in 2004 (Figure 1A).

Currently, the US kidney transplantation waiting list exceeds 101 400 patients.<sup>1</sup> 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.<sup>2</sup> Although there are risks to living donation, negative incidences remain low.<sup>3,4</sup> Novel strategies, such as living donor kidney exchanges and other efforts promoting living kidney donation, have not met the ever-growing need.<sup>5,6</sup> Nearly all state-level policies have had a negligible effect on donation.<sup>7</sup> 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.<sup>8</sup> 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.<sup>9-11</sup> 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.<sup>12,13</sup> 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.<sup>14</sup> Additionally, it has been argued that payment would generate such a negative public response that living donation rates might actually decrease.<sup>15,16</sup>

The issue of financial incentives in organ donation has been deliberated for more than 2 decades.<sup>15-17</sup> 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-

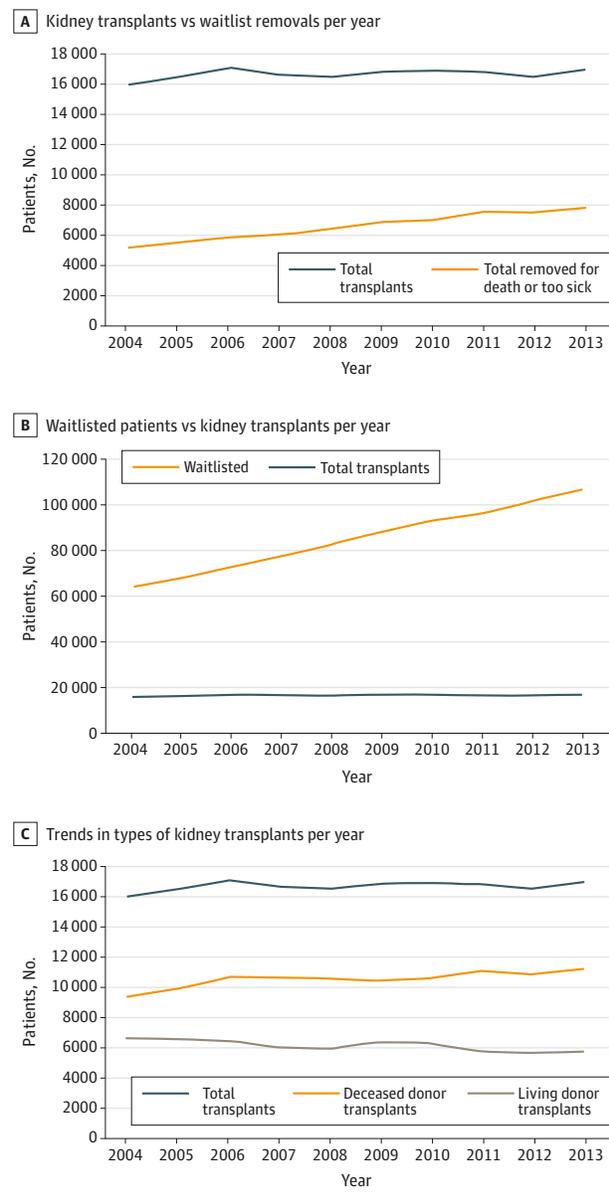
**Key Points**

**Question** How much do US voters support living kidney donation and financial compensation for living kidney donors?

**Findings** Of 1011 randomly selected US voters, 68% would donate a kidney to anyone, 23% would donate only to certain persons, and 9% would not donate. Most (59%) indicated payment of \$50 000 would make them even more likely to donate.

**Meaning** Most US voters view living kidney donation positively and would be motivated to become a living donor by a payment of \$50 000, which implies public support to modify current restrictive laws to permit studies of financial incentives for living kidney donors.

**Figure 1. US Kidney Transplant Waiting List Trends, 2004 to 2013**



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.<sup>18</sup> While debate over the ethics, nature, and scope of donor compensation matures,<sup>12,19</sup> 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 self-described as US citizens registered to vote and likely to continue voting. All survey questions and response choices are available at <https://fileshare.ps-b.com/dl/3yF2PPoHc8>.

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 in-center hemodialysis per-patient cost.<sup>20</sup> 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.ddl%2Ftom\\_statisticalformulae\\_colprops.htm](http://pic.dhe.ibm.com/infocenter/spssdc/v6r0m1/index.jsp?topic=%2Fcom.spss.ddl%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 (family/friends; group 2); and 87 (9%) stated that they would not donate a kidney 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.

Table 1. Baseline Willingness to Donate Without Regard to Compensation

Characteristic	No. (%)			
	Total	Would Donate to Anyone	Would Donate to Family/Friends	Would Not Donate
All	1011 (100)	689 (68)	235 (23)	87 (9)
Sex				
Male	427 (42)	293 (69)	106 (25)	28 (7)
Female	584 (58)	396 (68)	129 (22)	59 (10)
Age, y				
18-29	121 (12)	92 (76)	25 (21)	4 (3)
30-44	169 (17)	113 (67)	46 (27)	10 (6)
45-64	437 (43)	302 (69)	103 (24)	32 (7)
≥65	284 (28)	182 (64)	61 (21)	41 (14)
Employment status				
Employed	496 (49)	357 (72)	113 (23)	26 (5)
Student	42 (4)	26 (62)	12 (29)	4 (10)
Unemployed	65 (6)	39 (60)	19 (29)	7 (11)
Retired	322 (32)	206 (64)	73 (23)	43 (13)
Other	70 (7)	50 (71)	14 (20)	6 (9)

**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%) in group 1 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

Figure 2. Willingness to Donate a Kidney

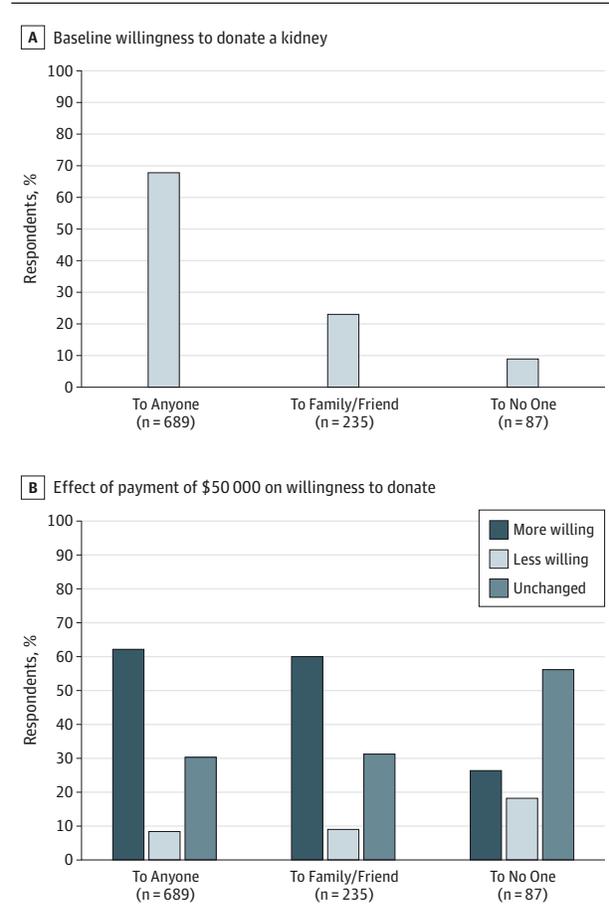


Table 2. Effect of Compensation for Living Donor Nephrectomy on Willingness to Donate

Baseline Willingness	Total No.	No. (%)		
		More Willing	Less Willing	No Change
Donate to anyone	689	428 (62)	54 (8)	207 (30)
Donate to family/friends	235	141 (60)	22 (9)	72 (31)
Would not donate	87	23 (26)	16 (18)	48 (55)
Total	1011	592 (59)	92 (9)	327 (32)

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.

Table 3. Level of Agreement in Principle With Compensating Living Kidney Donors

Respondents	Total No.	No. (%)		
		Agree	Disagree	Don't Know
All	635	387	221	27
Willingness to donate				
Donate to anyone	432	285 (66) <sup>a,b</sup>	131 (30)	16 (4)
Donate to family/friends	149	79 (53)	61 (41) <sup>a,b</sup>	9 (6)
Would not donate	54	23 (43)	29 (54) <sup>a,b</sup>	2 (3)
Age, y				
18-29	68	53 (78) <sup>a,c</sup>	15 (22)	0 (0)
30-44	108	68 (63)	39 (36)	1 (1)
45-64	262	152 (58)	99 (38) <sup>a,c</sup>	11 (4)
≥65	197	114 (58)	68 (35)	15 (7)
Annual income level, \$				
<50 000	257	175 (68) <sup>a,d</sup>	75 (29)	7 (3)
50 000 to 100 000	191	111 (58)	73 (38) <sup>a,d</sup>	7 (4)
>100 000	73	41 (56)	31 (43) <sup>a,d</sup>	1 (1)

<sup>a</sup> Statistically significant at  $P < .05$ .

<sup>b</sup> Respondents willing to donate to anyone favor compensation more than restricted donors and nondonors, and restricted donors and nondonors disagree with living donor compensation more than respondents willing to donate to anyone.

<sup>c</sup> Respondents aged 18 to 29 years favor donor compensation in principle more than those of other ages; those aged 45 to 64 years disfavor compensation more than respondents of other ages.

<sup>d</sup> Respondents with incomes less than \$50 000 favor donor compensation more than those of higher income levels, who disfavor compensation more than the group with less than \$50 000.

### 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.<sup>21</sup> 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.<sup>13,18,22</sup>

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.<sup>23</sup>

Public and professional attitudes about paying donors have varied over time. Hoeyer et al<sup>24</sup> 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, preferential treatment should a living donor need transplantation, and deferment of any donation costs. In 2012, Canadian citizens, health care professionals, and those affected by kidney disease were surveyed about financial incentives to increase living kidney donation.<sup>25</sup> Although only 14% of professionals and 27% of kidney patients supported paying donors, nearly half (45%) of the general public favored compensation. The study concluded that the Canadian public saw payment as acceptable and that further research should determine what role financial incentives might play. In a Netherlands study, van Buren et al<sup>26</sup> surveyed 250 living kidney donors, arguably the population with the most investment in the issue. Respondents were asked in retrospect—ie, after donation was completed—whether they would have wanted a financial reward and whether they 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 payment system for future living kidney donors.

Concerns for undue inducement and coercion through financial incentives, particularly for payments beyond costs of the donor, remain<sup>19</sup> despite the work of Halpern et al<sup>27</sup> in 2010 that showed that (1) although higher payments increased the probabilities of donating, they did so evenly across different income strata and (2) poorer persons were more willing to donate independent of payment. Moreover, in agreement with our results, payment did not appear to adversely affect altruistic motivations to donate. Gordon et al<sup>28</sup> re-

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 found 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.

### ARTICLE INFORMATION

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**Study concept and design:** Peters, Gish, Howard.  
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**Drafting of the manuscript:** All authors.

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**Statistical analysis:** Peters, Gish.

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**Study supervision:** Peters.

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**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.

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