The Economic and Budgetary Impact of the Living Kidney Donor Support Act

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Executive Summary

The Living Kidney Donor Support Act would direct the government to take a number of steps designed to substantially increase the number of kidneys that come from living donors, a number that has been stagnant for the last two decades. The Act would introduce donor navigators to facilitate donations, promote a national education effort about living kidney donation, and provide for fully reimbursing donors for specific expenses incurred from donating a kidney.

Our analysis suggests that these efforts would cost just under $18,000 per donor, and that they would nearly triple the number of live donations from the current 6,000 to 17,000 a year, which would save the federal government approximately $16 billion in the next ten years by reducing Medicare expenditures on dialysis and other costs of treating end-stage kidney disease.

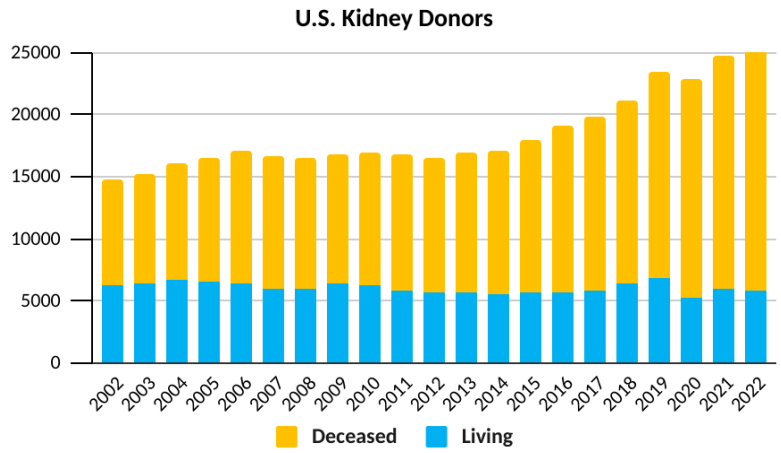
The broader economic benefits from moving more people off of dialysis would be much larger: people who receive a kidney transplant live years longer than those who remain on dialysis, and being free from dialysis greatly improves the quality of life and can allow people to return to work.

Introduction

The United States lacks enough kidneys to provide one to every person suffering from end-stage kidney disease who would benefit from a transplant. This shortage is costly to the people who end up waiting longer for a kidney transplant or who die waiting for one; to taxpayers, who pay most of the

healthcare costs of people with end-stage kidney disease; and to the broader economy, which loses the talents of people suffering from kidney failure.

Table 1: The Number and Source of Kidneys in the U.S.



Source: UNOS statistics available at https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/#

In 2022 hospitals performed 25,000 kidney transplants in the United States. About 6,000 of the transplanted kidneys came from living donors. Over 500,000 people are currently on dialysis and nearly 100,000 are on a transplant waiting list. An estimated 3% (4,000/132,000) of transplants are pre-emptive: but for the transplant, the recipient would go on dialysis.

Many good candidates for transplants are not placed on the transplant waiting list. Some are discouraged from going to the trouble and expense of being evaluated to receive a deceased donor kidney. Some physicians hesitate to refer patients for evaluation to spare them the risks of some diagnostic procedures (such as a coronary angiography) and the disappointment of not being approved for the list. Most transplant centers use stringent criteria for placing patients on the list to increase the likelihood of successful transplants.

Dialysis is costly: Medicare spends nearly $100,000 for each dialysis patient it covers. It spent over $130 billion treating kidney disease in 2022. Private insurers also paid billions of dollars to cover the costs of dialysis for their enrollees. Patients with End Stage Kidney Disease constitute less than 1% of the Medicare population but account for 7% of the Medicare budget.

What's more, the debilitating effects of kidney disease are not eliminated by dialysis, which is life-sustaining but imposes large costs. Most dialysis patients, regardless of age, find it makes them too fatigued to work. Dialysis patients also have a shorter life expectancy and greater health costs (beyond dialysis) during their remaining years than those who receive a kidney transplant.

In recent years there have been efforts to boost the number of kidneys available for transplantation. A promising effort is recent draft legislation called the Living Kidney Donor Support Act. It contains three major provisions to boost the number of kidneys from living donors. The first provision would fund a national campaign to make people aware of the need for more kidney donations, alert them that donating a kidney is generally safe, and publicize the benefits for the donor and recipient of saving a life through donation.

The second provision would provide each potential living donor with a patient navigator to help them through the process of donation. The navigator could help simplify what can be a complicated and intimidating process and prevent fewer would-be donors from dropping out.

The third provision would permit the federal government to reimburse living kidney donors for certain costs, including travel, food, and lodging costs incurred throughout the donation process; foregone wages up to $2,500 per week for up to eight weeks; and childcare and elder care costs. Donors are typically unable to return to work for two to six weeks after a donation, depending on the physical demands of the job.

The Provisions of the Living Kidney Donor Support Act

The intent of the Living Kidney Donor Support Act is to reduce the non-medical costs--both tangible and intangible--of donation for live donors; increase awareness of living kidney donations; and allay concerns over the financial consequences and logistical difficulties of donating a kidney. The Act would remove certain barriers to donations coming from live donors.

A Living Donor Navigator Office

The Act would create a living donor navigator program. The program would train people to help potential donors, who often face time-consuming tests to determine their suitability for organ donation. Travel to testing sites can range from a few miles to hundreds of miles, depending on where the recipient is

awaiting transplant. Having a navigator who could request that tests be done in a place convenient for the donor and streamline testing to avoid repeat visits to the transplant hospital, could lessen the costs of donation.

Besides streamlining medical testing prior to surgery, a patient navigator could also provide other assistance to donors before and after surgery. Navigators would be employed by federally-contracted non-profit organizations.

Several nonprofits already facilitate more kidney donations and have navigator-type staff. They are largely financed by private donations and to some extent by hospitals that receive the organs to do the transplant. Unfortunately, this assistance is not widely available throughout the country. The Act would scale up these types of programs into a national system.

A National Education Campaign to Encourage Living Donations

The Act would fund a national education campaign to inform the public about the need for kidney donations and opportunities to make living donations. This campaign would be run by a contractor and entail a national educational outreach effort, paired with professional educational activities to train individuals and medical professionals in instructional outreach about the need for kidney donations.

One potential model for such a campaign is Be the Match, the federally-contracted organization that operates the national bone marrow program. In addition to providing extensive information on its website, Be the Match provides information and support for potential donors throughout the country. It organizes informational sessions in numerous communities where someone needs a bone marrow transplant. After these local informational sessions, the organization provides the opportunity for people to receive a swab test to determine if they are a match for a potential recipient. The potential donor is then asked if they would be willing to be added to the Be the Match national donor database.

If the potential donor is a match, they are asked if they wish to explore donating. If so, the organization arranges for the initial tests. It also provides someone akin to a patient navigator to help the donor through all steps from medical testing to marrow recovery (returning to normal levels of marrow after donation). Not-for-profit entities currently operate similar programs for kidneys on a local basis, but a national educational effort would be better.

Reimbursing Living Donors for Donation Costs

The Act also includes a provision to reimburse donors for non-medical expenses incurred during the donation process. (Medical costs typically are covered by the recipient's insurance.)

Such expenses fall into three broad categories: out-of-pocket expenses, such as food, lodging, and travel; lost wages during testing, the operation, and recovery; and childcare or elder care costs that a donor's family may need during the transplantation process. We discuss those expenses in more detail below.

The Budgetary Impact of the Living Kidney Donor Support Act

Each of the three provisions in the Living Kidney Donor Support Act calls for a government expenditure of some sort. However, since each provision should increase the number of kidney donors, each would save the government money. We estimate that the savings generated by moving people off dialysis-or keeping them off dialysis in the first place-outweighs these expenditures, ultimately saving taxpayer money.

The Cost (and Impact) of Creating a Living Kidney Donor Navigator Office

The Act's provision for a navigator office would entail having a trained professional--a nurse, counselor, or other health care professional--assist the donor throughout the donation process.

To estimate the hours this would entail, we interviewed the directors of two programs that currently provide such services to prospective donors.[1] Each described a similar process beginning with an initial meeting with a prospective donor, who has often attended an outreach event held by the group and been identified as a potential match for someone in their community who is in need of a kidney (about 300 living donors each year are non-directed out of a total of 6,000). The initial meeting lasts about two hours. About 7.5 percent of those who do an initial interview eventually donate a kidney.

[1] The organizations we interviewed were from specific local communities, and the data we gathered from these interviews may be specific to these organizations. However, we believe that there is nothing unique about the time, cost and effort incurred by these organizations that would differ if the program were scaled nationally. For this reason, and in the absence of other published data, we believe the information we collected is accurate. We do not include in our estimates those studies that indicate the addition of patient navigators actually reduces care costs.

If the potential donor decides to continue with the evaluation process, navigators make themselves available when the donor has to go to the hospital for initial tests, which typically take between one and three days, depending on the requirements of the transplant center.

Navigators help coordinate subsequent hospital visits as well and are in the hospital during and after the surgery. They are in regular contact with the donor during the entire process, and they meet briefly with the donor each day after the surgery while in the hospital, if requested.

Each organization remarked that the time they put forth for each donor depends somewhat on the hospital: transplant hospitals, which by regulation (42 C.F.R. 482.94(a)) must provide living donor services themselves, strive to provide useful services and advice to prospective donors, which reduces the time navigators felt they needed to spend with donors. Based on our interviews, we estimate that a navigator would spend 14-16 hours with each prospective donor.

We determined that the appropriate analogue for such a job in the U.S. Bureau of Labor Statistics nomenclature of jobs would be clinical and counseling psychologists who work in medical and surgical hospitals. The reported average annual salary for such a position, converted to current dollars, is $110,700, or $2,130 per week. Given our estimate that the task requires approximately two full days, this would translate to a cost of $850 per donor.

However, more than thirty percent of potential donors are ultimately unable to donate for medical reasons, and this determination often is not made until they are well into the process. To account for the cost of time spent with people who ultimately do not become living donors, we have increased the cost per living donor by 50 percent, which is a reasonable estimate of the additional time that would be spent with that cohort.

That gives us a **total cost per donor of $1275** for the proposed navigation process.

The Cost (and Impact) of an Educational Campaign to Encourage Living Donations

The amount of money to be spent on an educational campaign would be specified by the legislation and the appropriations process. Its efficacy might be

difficult to ascertain, but other health-related informational efforts--such as Be the Match--have been successful.

The Cost (and Impact) of Reimbursing Living Donors for Their Expenses

The Act would reimburse living kidney donors for non-medical expenses they incur throughout the donation process. These expenses fall under the following major headings.

The Cost of Travel and Lodging

Frank McCormick, Philip Held, Glenn Chertow, Thomas Peters and John Roberts estimated the aggregate costs of travel and lodging, lost wages, and dependent care to be $13,800 per person in their 2019 paper, or the equivalent of $17,000 in current dollars. Their estimate for travel costs of $3,100 comes from a report published in 2014 by the National Living Donor Assistance Center (the "NLDAC"), which equals nearly $4,000 in today's dollars.

The NLDAC provides funds to certain living kidney donors to cover a portion of the expenses for donors in cases where the recipient's income is below 350 percent of the HHS poverty guidelines, and the donor meets a similar means test. The NLDAC reports that most donors must travel to the donation center at least three times before the operation, and they typically must remain near the center for one to two weeks afterwards for monitoring.

The NLDAC caps reimbursement for travel and subsistence expenses at $6,000, so the data reported to them is truncated and may not be representative of the true distribution of such costs.

Other studies exist on the subject, though. Robert Gaston and his coauthors produced a higher estimate of $4,300 for necessary travel and lodging costs in their 2006 publication in the *American Journal of Transplantation* ($5,300 in 2023 dollars). James Rodrigue and his colleagues estimated a cost of just under $2,000 ($2,500 in 2023 dollars) for travel and lodging costs in their *American Journal of Transplantation* article.

The NLDAC estimate is based on the largest sample size, 960 donors, and provides the most detailed accounting of donors' expenses. Rodrigue et al. have a sample size of 181 donors, and Gaston et al. reports on 622 donors, for whom the authors do not have information as granular as in the NLDAC analysis.

We believe the McCormick et al. estimate, updated for 2023 prices, of **$4,000** to be the most appropriate estimate of transportation and lodging costs for a kidney donor. It also happens to be a midpoint of the papers we consider to be most relevant.

Loss of Income

Donating a kidney is safe, but becoming a kidney donor is time-consuming for most donors. The prospective donor must visit a hospital (usually the one where the surgery is to take place) either once for one to three days or multiple times for a variety of tests and interviews.

The donor also typically stays in a hotel near the hospital the evening before the procedure and remains near the hospital for several days after the surgery as well. Most donors take at least two weeks off of work for the procedure and recuperation. As donors must wait two weeks before driving, returning before then is a practical impossibility even for those in robust health post-donation. Rodrigue et al. found in their survey that the typical donor loses nearly an entire month of work from the donation process.

McCormick et al. examined the literature and determined the Rodrigue et al. paper to be the most comprehensive in compiling the value of lost income from a kidney transplant. Rodrigue's detailed questionnaire discerned that the average donor missed 180 hours of work, 40 percent of which was unpaid. McCormick et al. estimated the average cumulative cost of those lost wages to be $5,100 per person in 2017 dollars, or $6,300 in 2023 dollars.

Sebastian Przech and colleagues surveyed 912 Canadians who donated kidneys between 2009 and 2014 about the economic and other opportunity costs of donating a kidney. They estimated lost wages to be nearly $4,400 in 2017 wages, which would equal $5,400 today, broadly consistent with McCormick's estimate.

In its 2020 rulemaking, HRSA assumes the median hourly wage (then $28 an hour, $33.09 in 2023) and multiplies it by 40 hours a week times the 4-6 weeks people are out, which today equals $5,300-$8,000.

We believe that the midpoint of the HRSA estimate--**$6,650** per person--represents the best estimate of lost income.

The Cost of Dependent Care

Some prospective donors refrain because they are a primary caregiver for a young child or a parent, and the post-surgery recovery would keep them away from the house for several days and unable to take care of their loved ones for some period of time after that, not to mention the time they would be occupied prior to the surgery with medical appointments. The surgery constrains the physical tasks that a person can do for about a month after surgery. The Living Kidney Donor Support Act would provide funds to cover certain costs of childcare or elder care while the donor is unable to do those tasks.

The Przech study asked people whether they needed to obtain help to care for a dependent. Just over half reported that they did. The average number of days for which they obtained assistance was 15, they report.

The authors then assigned a daily wage to estimate the potential cost of providing such assistance. We use their estimate of the days a donor would need support and apply an updated estimate of the daily wage for elder care and childcare; The U.S. Bureau of Labor Statistics report those numbers to be $16.18 and $15.12 an hour.

We assume that donors would need such services 24 hours a day for 15 days, with demand split evenly between childcare and elder care. The cost of such help on an hourly basis, simply using the average hourly wage rates, would be $5,630.

A 2021 nationwide survey by Genworth, a long-term care insurance provider, estimated the monthly cost of a home health care aide for 44 hours a week to be $5,148, or $5,900 in 2023 dollars. Full-time care--which would presumably be necessary for someone who did not have another caregiver living with them--would require four shifts for 15 days, or about half a month, which would be approximately $12,000.

A U.S. News and World Report Survey of home health care providers found that average costs range from $12,000 to $16,000 a month, or half that--$6,000 to $8,000--for the half month that kidney donors require.

The HRSA rulemaking assumes childcare costs $420 a week, which it states comes from a National Center for Education Statistics 2016 survey. The survey reports an hourly out-of-pocket expense for primary nonparental care. For the entire transplant process of 4-6 weeks it calculates total costs to be $1,680--$2,520, or $2,130--$3,200 today. However, the survey merely provides an estimated hourly cost for daycare and does not include any possible coverage for children outside of working hours, which we believe would be necessary for a postoperative donor.

For that reason, we believe that **$6,000** per person is the appropriate estimate for the cost of lost dependent care.

An Aggregate Estimate of the Total Donor Costs Incurred from Donating a Kidney

Aggregating our estimates for transportation and lodging costs, foregone income, and dependent care costs during and after surgery gives us a total estimate of the opportunity cost of donating a kidney of $16,650**.** Adding the $1,275 per donor cost of a navigator program gives us a total of **$17,925 per person**.

In 2018 the average NLDAC recipient received $2,300 (in 2023 dollars), and nine percent of living donors received money from NLDAC.

The Impact of The Living Kidney Donor Support Act on Kidney Donations

We have also projected how much living kidney donations would increase if we were to cover all expenses for kidney donors. Few studies have contemplated the elasticity of supply of kidneys from living donors, but some economists have tried to measure how much removing the barriers to donating a kidney would increase donations.

McCormick et al. analyzed three different studies that examined programs where a government reduced the opportunity costs of donating a kidney and observed the resultant increase in donations.

Kurt Schnier and his colleagues examined the impact of the creation of the NLDAC in 2007 and its impact on donations. At first it did not cover lost income or expenses. Its grants for travel and lodging were modest--averaging just over $3,000--and could only go to donors if their income as well as the income of the recipient were each under 300 percent of the poverty level. They estimate that the

program boosted kidney donations by 14 percent, and attribute 532 additional donations to the program's existence.
McCormick et al. extrapolate from their analysis to estimate that fully covering all costs for all potential donors would result in nearly 10,000 additional kidneys, which would effectively triple the number of live donations in a year.

McCormick et al. also looked at data from New Zealand's program for kidney donations, which covered $5,000 (US$) of expenses and was associated with a 22 percent increase in donations. They extrapolate from their data and estimate from it that removing all costs for potential donors would boost donations by about 9,500 per year.

Finally, McCormick looked at the data from Israel's generous program that more fully compensates living donors for their costs--explicit and implicit--from donating a kidney. They value the benefits provided at $37,745, which is what they ascertain to be the true opportunity cost of donating a kidney for the U.S. The implementation of the Israeli program boosted living kidney donations by 231 percent; applying a similar response to the U.S. market would result in 13,400 additional donations.

McCormick et al. take the average of those three results (along with a paper by Scott Halpern and several co-authors based on contingent valuation via surveys) and use the resultant number--11,500--as their estimate of the number of additional kidneys that would be donated if we fully compensated donors.

Excluding the Halpern study gives an average estimate of 10,900 additional donations from a program that increases reimbursement kidney donors for costs incurred in the transplant process. We use that number below.

The Budgetary Impact of Reimbursing Certain Costs of Living Kidney Donors

The increase in kidney donations from the Living Kidney Donor Support Act would be costly, but the accompanying savings for the federal government from moving people off dialysis or avoiding dialysis in the first place would be even larger.

The Additional Costs from Reimbursing Kidney Donors

We estimate that increasing reimbursement of living kidney donors for their out-of-pocket expenses and lost wages while also paying for a navigator program

would result in an average estimated cost of $17,925 per donor. Doing each of these things would increase donations from living donors from approximately 6,000 to 17,000 annually. The cost of these payments would amount to $305 million per annum. Currently, the NLDAC spends $12 million a year reimbursing kidney donors, so the incremental spending would be about $293 million per year.

These payments would also increase the number of kidney transplants performed, most of which would be paid for by the federal government, generating additional costs.

The average kidney transplant costs $133,000[2], and Medicare pays for 79 percent of all kidney transplants performed. The additional costs of the 11,000 additional transplants amount to $4.84 billion a year, and the federal government's additional cost would be $3.73 billion. The ten-year cost would be $37.3 billion.

More kidney donors mean more people with a transplanted kidney, and kidney transplant recipients must take immunosuppressants to prevent the body from rejecting the new kidney. These drugs cost $25,000 a year, and McCormick et al. estimate that the total annual health care costs associated with a kidney transplant is $34,000 per recipient.

In Year 1 the budgetary calculus is simple: transplants cost $133,000, dialysis costs $90,000 a year, and immunosuppressants cost $25,000, which means that in Year 1 the government pays $133,000 for the transplant and $25,000 for immunosuppressants and stops paying dialysis costs. For the next nine years it continues paying $25,000 a year for immunosuppressants instead of dialysis, achieving another $65,000 in savings each of those years of the budget window. In essence, we pay off the transplant in two years and are left with eight years of saving, or just over $500,000 apiece for 11,000 people, within the budget window. Tables 1 and 2 show the arithmetic for the cost savings.

[2] Cost of a Transplant Procedure (including organ acquisition charge) per event - 2020 USRDS Annual Data Report: Epidemiology of kidney disease in the United States. Reference Table K11. Table 1: Row 7- The cost for a year in which the transplant occurred was $136,696 in 2018, and it increased $1,786 per year over the previous 10 years. Extrapolating to 2020 gives $140,268 [= $136,696 + (2 X $1,786)]. Subtracting a half year on dialysis therapy of $47,014 (= $94,029 X 0.5) and a half year with a functioning graft of $14,599 (= $29,197 X 0.5), and adding an organ acquisition charge of $36,000 raises the total to $114,655. Finally, including 16% for patient co-pays yields $133,000 (= $114,655 X 1.16).

Table 2a

Annual Costs per Patient over Ten Years ($) [3]				
	No Transplant	**With Transplant**		**Savings from**
			Immuno-	**Transplant**
	Dialysis	***Transplant***	***suppressants***	
2024	90,000	133,000	25,000	-68,000
2025	90,000	0	25,000	65,000
2026	90,000	0	25,000	65,000
2027	90,000	0	25,000	65,000
2028	90,000	0	25,000	65,000
2029	90,000	0	25,000	65,000
2030	90,000	0	25,000	65,000
2031	90,000	0	25,000	65,000
2032	90,000	0	25,000	65,000
2033	90,000	0	25,000	65,000
TOTAL	**900,000**	**133,000**	**250,000**	**517,000**

Table 2b

Annual Cohort Savings over Budget Window [1]			
	Savings	**Live**	**Budget**
	per	**Transplant**	**Window**
	Recipient ($)	**Recipients**	**Savings (bn $)**
2024	517,000	11,000	5.687
2025	452,000	11,000	4.972
2026	387,000	11,000	4.257
2027	322,000	11,000	3.542
2028	257,000	11,000	2.827
2029	192,000	11,000	2.112
2030	127,000	11,000	1.397
2031	62,000	11,000	0.682
2032	-3,000	11,000	-0.033
2033	-68,000	11,000	-0.748
TOTAL	**2,245,000**	**110,000**	**24.695**

[3] There are also savings in the out years beyond the 10 year budget window.

In Year 2 of the budget window there would be an additional 11,000 transplants, generating the equivalent of seven years of savings in the ten-year budget window for this cohort, so we are saving $512,000 - $65,000 (or $447,000) apiece for 11,000 people. In Year 3 we are saving $382,000 apiece for 11,000 additional live transplants; in Year 4 $317,000 times 11,000, and so on.

Table 1 sums the net savings over ten years from each of the cohorts. For the cohorts that receive transplants in Years 9 and 10 the budget savings within the ten-year budget window would be negative. The total savings from reduced need for dialysis is approximately $24.1 billion over the ten-year budget window.

Since the government pays 79 percent of all dialysis and transplant costs, the total savings to the government would be **$19.1 billion**.

The cost of the program would be the defrayment of costs for all of the 17,000 estimated living donors we would have upon the implementation of the Living Kidney Donor Support Act. This includes the 11,000 additional donors per annum and the estimated 6,000 annual donations that would have occurred regardless of any cost defrayments.

We estimate that the average cost reimbursement--along with a navigator program--would be $17,925 per person. Providing this amount for each of the 17,000 living kidney donors would total $293 million per year, or $281 million of incremental spending.

If we assume the cost of an informational campaign would be $25 million a year, the combined annual expense of cost reimbursement, the navigator program, and accompanying informational campaign would be a little over $300 million a year, or $3 billion over the ten-year budget window.

Subtracting this cost from the savings to the government from reduced dialysis gives us a ten-year budget savings of **$16 billion**.

Conclusion

Enacting the Living Kidney Donor Support Act would substantially increase the number of donations. We estimate that the law would substantially reduce government spending on dialysis, and that the budgetary savings would equal $16 billion over ten years once the program is fully operational.

Because the goal of this paper is only to quantify the costs of providing the services described above, our analysis does not quantify the savings impact of the legislation's establishment of a donor navigator program or a national educational program on increasing the number of donations. We believe that the actual number would be somewhat higher than the additional 11,000 donations we forecast, but quantifying it is not within the scope of this paper.