

# INTRODUCTION OF AN ORGAN DONATION TAX CREDIT TO INCREASE ACCESS TO LIVING-DONOR KIDNEY TRANSPLANTS IN GEORGIA

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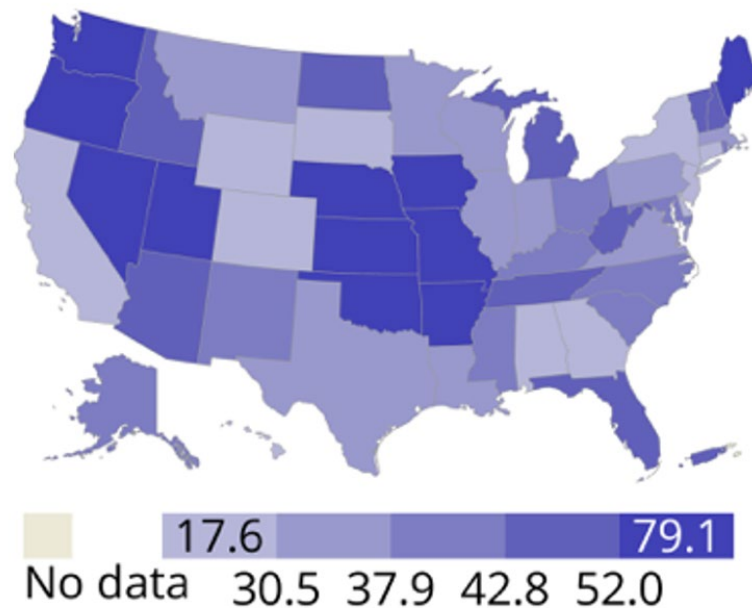
## EXECUTIVE SUMMARY

Living-donor kidney transplant is the best treatment option for patients suffering from End Stage Renal Disease (ESRD), but this option has become increasingly inaccessible for most patients. Over the past two decades, the rate of living-donor kidney donation has gradually declined in the United States, while ESRD prevalence has simultaneously increased by 67.4 percent (United States Renal Data System 2018). This decline in living-donor transplants is largely due to the financial barriers faced by prospective donors, as the average donor will incur \$5,000 in unreimbursed, out-of-pocket expenses associated with donation (Tushla et al. 2015). Such expenses, which include the cost of lost wages, childcare, and elder care, are generally not eligible for reimbursement by private insurers or Medicare, leaving prospective donors without financial recourse (HHS 2019). The resulting shortage of living-donor organs is especially critical in Georgia, the state with the lowest adjusted transplant rate in the nation and a high prevalence of ESRD patients (Patzner and Pastan 2015). Georgia currently offers living donors up to \$10,000 in tax deductions in order to incentivize transplant (Georgia Code 2010). However, such tax deductions disproportionately benefit those in higher tax brackets, leaving low-income donors with unmet financial needs. To remove the financial disincentive toward organ transplant, Georgia should replace its \$10,000 organ donor tax deduction with a \$5,000 tax credit to reflect the true out-of-pocket costs of donation. Similar tax incentives have been implemented in Louisiana and at least three other states, indicating the feasibility of this approach (Louisiana State Legislature, n.d.). The creation of an organ donation tax credit presents a proven and cost-effective solution for increasing access to kidney transplant in Georgia, which will translate to a more equitable system and fewer lives lost to ESRD.



## INTRODUCTION

Kidney transplant offers a potentially lifesaving treatment for patients suffering from End Stage Renal Disease (ESRD), but geography plays an outsized role in determining access to transplant (Patzer and Pastan 2015). In Georgia, a state with a large ESRD population, transplant centers currently fail to perform transplants at an acceptable rate. A recent study found that Georgia has a Standardized Transplant Ratio (STR) of 0.57, the lowest in the country. This indicator measures the number of transplants performed per transplants expected in a given time period. In other words, Georgia transplant centers perform only 57 percent as many transplants as would be expected, given their patient volume and organ supply. Georgia also has the longest transplant waiting list of any state, with a median wait time of 5.1 years (United States Renal Data System 2018). Meanwhile, the United States itself lags far behind its developed peers in terms of access to transplant. In 2016, only 29.6 percent of prevalent ESRD patients in the US had a functioning transplant, and only 2.8 percent of incident patients were able to receive a preventative transplant (Centers for Medicare and Medicaid Services n.d.). This places the US 39th out of the 61 countries that report to the United States Renal Data System (USRDS) (Centers for Medicare and Medicaid Services n.d.).



*Figure 1: Percentage of adults in 2013 on the deceased-donor kidney transplant waitlist who received a transplant within five years of listing, by state. Source: 2018 Annual Data Report. Scientific Registry of Transplant Recipients (Scientific Registry of Transplant Recipients 2018).*

The issue of insufficient kidney transplants takes a stark human toll. Every year, between 4,400 and 5,000 Americans die while waiting for a kidney transplant, and an additional 4,000 to 4,500 are removed from the waitlist because they are no longer healthy enough to be candidates for transplant (HHS 2019). While many patients can continue receiving dialysis indefinitely, transplant is associated with reduced medical expenditures, far greater five-year survival rates, and improved quality of life. Between 2010 and 2014, the five-year survival rates for recipients of living-donor and deceased-donor transplants were 93.1 percent and 86.1 percent, respectively (Wang, Skeans, and Israni 2016). This far outstrips the 42 percent five-year survival rate of patients on hemodialysis (United States Renal Data System 2018). Inadequate access to transplant also places the economic burden of providing costly dialysis services on the federal government, which oversees the Medicare ESRD Program that offers near-universal coverage to ESRD patients. Though ESRD beneficiaries comprise less than 1 percent of the total Medicare population, they account for an estimated 7.2 percent of total Medicare fee-for-service spending (United States Renal Data System 2016). This amounts to over \$35.4 billion dollars in federal spending, most of which funds maintenance hemodialysis (United States Renal Data System 2016).

Presently, ESRD patients have two main options for obtaining kidney transplants. The first is to join the United States Organ Sharing (UNOS) waitlist and hope to receive a compatible deceased-donor organ. However, there is a substantial backlog on the deceased donor waitlist, with 81,418 patients currently awaiting a kidney transplant in the US (United States Renal Data System 2016). The second option is to seek a living donor, usually a family member or friend. Living-donor transplant offers several advantages over deceased-donor transplant. First, it allows recipients to bypass the waitlist process by coordinating directly with their organ donors and transplant surgeons. Second, kidneys from living donors tend to survive much longer than those from deceased donors, with 84.6 percent of kidneys from living donors functioning after five years, compared to 72.4 percent among deceased-donor kidneys (Wang, Skeans, and Israni 2016). The deceased-donor transplant system is also fraught with structural inequalities and inefficiencies. Despite efforts by ESRD networks to decrease disparities over the past five years, there exists a pronounced racial divide in access to transplant, with Black ESRD patients being 24 percent less likely to receive a transplant compared to their white counterparts nationwide (Epstein et al. 2000). This disparity persists even after controlling for socioeconomic status, clinical factors, and demographic factors. In Georgia, this disparity is even more apparent. At Emory University Hospital,



the state's largest transplant center, Black patients have a 59 percent lower rate of transplant than white patients (Patzner et al. 2012). The causes of this disparity are complex, but seem to be partially rooted in a much longer average time between initiating dialysis and being referred for transplant evaluation among Black patients (283 days) versus white patients (84 days) (Patzner et al. 2012). Access to deceased-donor transplant is also hindered by lack of transplant education, especially at for-profit dialysis facilities (Balhara et al. 2012). These facilities have little incentive to educate their patients about transplant, as each patient who receives a transplant and no longer requires dialysis represents a financial loss.

The shortcomings of the overburdened deceased-donor system therefore underscore the importance of increasing living-donor organ donation rates. Accomplishing this goal requires a concerted effort among states and the federal government to remove financial barriers to living organ donation, which are often prohibitive for low-income individuals. This paper proposes the establishment of an organ donation tax credit in Georgia, a policy that has shown promise in increasing living-donor rates both domestically and internationally (Mathur et al. 2018). If implemented, this policy will work towards removing financial disincentives for prospective living donors in Georgia, ensuring that anyone who wishes to donate an organ is able to do so.

## **BARRIERS TO LIVING-DONOR TRANSPLANT**

Rates of living-donor transplant have decreased slightly over the past several decades, even as ESRD rates have climbed across the nation. Living-donor transplants currently account for under 30 percent of all donations, despite their improved health profile (United States Renal Data System 2018). One category of living-donor transplants that has experienced an especially significant decline over the past 20 years is donations from relatives. From 2004 to 2014, living-donor transplants from relatives fell from 4,340 to 2,693 transplants a year (Saran et al. 2015).



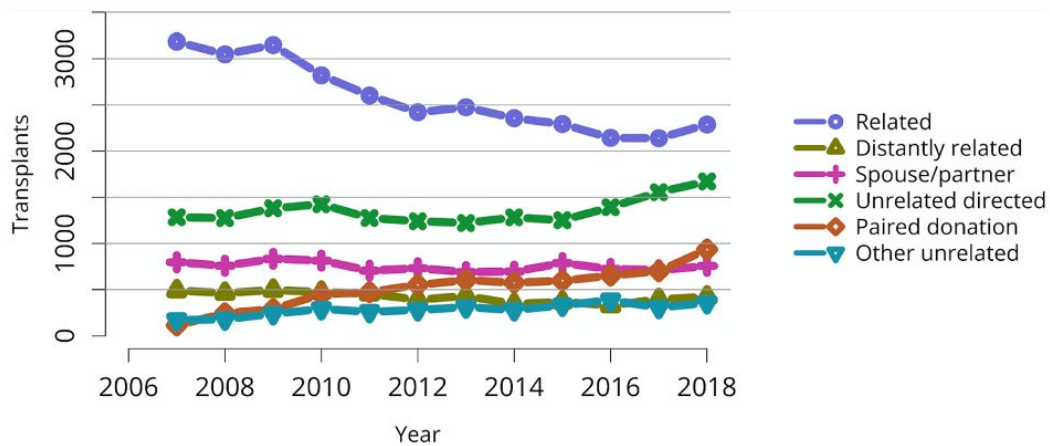


Figure 2: Trends in living organ donation by relationship to recipient, 2007-2018. Source: 2018 Annual Data Report. Scientific Registry of Transplant Recipients.

Meanwhile, ESRD rates have continued to climb across the nation, especially in the Southeast. In the US, the population-adjusted prevalence of ESRD increased by 67.4 percent from 1996 to 2016 (United States Renal Data System 2018). Georgia has experienced an even greater increase in ESRD prevalence over the same time period, at 77.5 percent (United States Renal Data System 2018). This increase is the result of a convergence of many factors, including an aging population and the rising prevalence of diabetes and hypertension, both of which are risk factors for ESRD (McCullough et al. 2019). Despite this growing need for kidneys, living donor rates have stayed flat or declined over the past several decades, indicating the growing inaccessibility of transplant for most ESRD patients.

This decline in living-donor kidney transplants is consistently attributed to the financial disincentives that many potential living donors face (Rodrigue, Schold, and Mandelbrot 2013). Though the recipient’s insurance generally covers the direct cost of pre-transplant testing and the transplant procedure itself, it does not offer any reimbursement for lost wages, travel, lodging, childcare, or other indirect expenses incurred by the donor. Living donors may also struggle to afford increased health insurance and life insurance premiums following organ donation (Rodrigue, Schold, and Mandelbrot 2013). Estimates of the total out-of-pocket cost of donating a kidney vary widely, but average around \$5,000 (Tushla et al. 2015). This cost may be prohibitive for potential donors, especially considering that ESRD is concentrated among low-income communities (Volkova et al. 2008). In fact, a study of all living-donor transplants in the US between 2000 and 2009



found that donation-related expenses totaled more than one month's income for 76 percent of donors (Gill et al. 2012). Another 2015 study that compared zip code level median income to living kidney donation rates found a strong positive relationship between income and likelihood of kidney donation, supporting the hypothesis that financial barriers often deter potential living donors (Gill, Dong, and Gill 2015).

In light of this evidence, most experts agree that removing the financial barriers associated with living organ donation is the most efficient mechanism of mitigating the continued decline in living donations. In 2014, the American Society of Transplantation Live Donor Community of Practice convened a workgroup to explore this issue and concluded that the top priorities of policymakers should be to “allocate resources for standardized reimbursement of Living Kidney Donors’ (LKDs’) lost wages and incidental costs, and to pass legislation to offer employment and insurability protections to LKDs” (Tushla et al. 2015). Similarly, a longitudinal study of 71,882 living donors in the US concluded that “the financial implications of living donation have a greater impact on low-income populations and that policies to remove financial disincentives to living donation may be important in maximizing the potential for living donation” (Gill, Dong, and Gill 2015). From these recommendations, it is clear that policy change is needed to increase access to living-donor kidney transplant, thereby reducing mortality, morbidity, and unnecessary expenditure.

## EXISTING POLICIES TO ASSIST LIVING KIDNEY DONORS

In response to the steady decline in living kidney donation, several states and federal agencies have implemented policies aimed at removing financial barriers to organ donation. These policies typically take the form of tax credits, tax deductions, and/or sick leave guarantees.





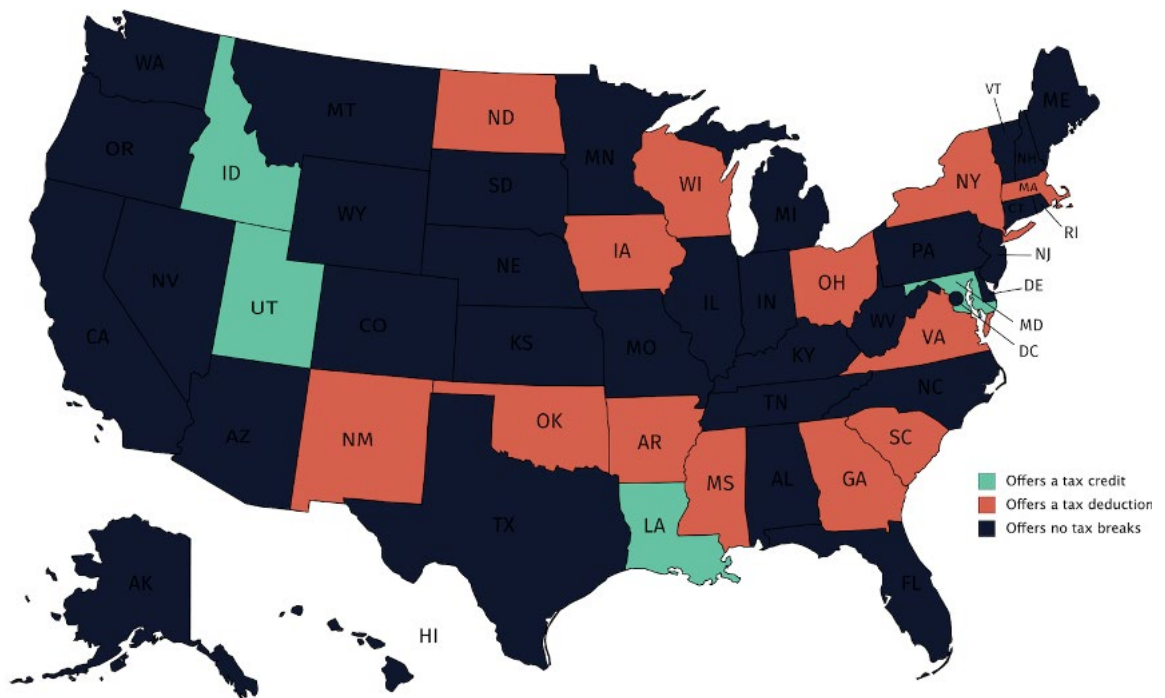


Figure 3: A map of the United States indicating the type of tax break offered to living organ donors. Idaho, Utah, Louisiana, and Maryland are currently the only states to offer tax credits.

Among states that offer any financial assistance to living donors, the most common type is a tax deduction (Fishman n.d.). However, it is important to note that a \$10,000 tax deduction is not the same as a \$10,000 tax credit. Tax deductions are not subtracted from the taxes owed by an individual, but rather subtracted from an individual's taxable income. The true value of tax deduction therefore depends on an individual's tax bracket. For someone in a 10 percent tax bracket, a \$10,000 tax deduction would translate to \$1,000 in savings, compared to \$5,000 for someone in a 50 percent tax bracket. This example highlights the inherent regressiveness of tax deductions, which are more valuable to those with higher incomes and higher tax brackets than to those with fewer resources. The result is that those who most need this tax deduction in order to donate an organ would only receive approximately \$1,000, a mere fifth of the estimated out-of-pocket cost of donation (Tushla et al. 2015). State-level tax deductions therefore fail to meet the needs of those who are most likely to depend on them for financial assistance.

Several living-donor assistance programs also exist at the federal level, most notably the National Living Donor Assistance Center (NLDAC). Overseen by the Health Resources and Services Administration (HRSA), the NLDAC offers limited

compensation for living donors who fit strict criteria. Pursuant to the Public Health Service (PHS) Act, NLDAC can only reimburse expenses incurred by the donor as part of “(1) Donor evaluation, and/or (2) hospitalization for the living donor surgical procedure, and/or (3) medical or surgical follow-up, clinic visits, or hospitalization within two calendar years following the living donation procedure” (HHS 2019). Indirect expenses, such as lost wages or childcare, cannot be reimbursed. The NLDAC also has strict criteria for who is eligible to apply for assistance. First, the Organ Donation and Recovery Improvement Act requires that the NLDAC be the payer of last resort, meaning that it can only provide funds to donors who cannot be reimbursed by insurance companies, state programs, or the organ recipient (National Living Donor Assistance Center n.d.). Potential donors are also ineligible for NLDAC funding if the recipient’s household income exceeds 300 percent of the Federal Poverty Line (National Living Donor Assistance Center n.d.). Given these strict criteria, the NLDAC is not able to approve many applications for funding. In the 2018 fiscal year, the NLDAC only awarded funding to 1,055 donor applicants, at an average amount of \$1,934 per donor (HHS 2019). This represents only a fraction of the 6,849 living donors in 2018, and an even smaller fraction of those who likely could have donated if financial support were available (United Network for Organ Sharing 2019).

The shortcomings of the NLDAC have drawn significant public attention in recent years. In July of 2019, President Trump signed an Executive Order to launch the Advancing American Kidney Health Initiative, which outlines the administration’s priorities for reducing the burden of ESRD in the US (Whitehouse.gov 2019). One of the order’s stated goals is to double the number of kidneys available for transplant by 2030, largely by increasing compensation of costs associated with living donation (HHS 2019). Pursuant to Section 8 of this Executive Order, HRSA issued a notice of proposed rulemaking in December of 2019 detailing an amendment to the National Organ Transplant Act that would expand the scope of reimbursable expenses incurred by living organ donors (HHS 2019). Under this proposed rule, donors could submit applications to have the cost of childcare, lost wages, and elder care reimbursed by the NLDAC. At this point, it is unclear if this rule will be finalized in its current form—or at all—but it would certainly be a step towards removing financial disincentives for organ donation. However, the NLDAC would still be a payer of last resort, and its stringent income cap would continue to make it inaccessible to many prospective donors. Given the limitations of this federal reimbursement system, the need for policy reform at the state level to remove financial barriers to donation is clear. And the need for reform in Georgia, whose ESRD population has long suffered from lack of access to transplant, carries an even greater urgency.





## PRECEDENT CASE STUDIES

### Louisiana

The state of Louisiana has successfully transitioned from a living-donor tax deduction to a living-donor tax credit, removing financial disincentives to organ donation. Specifically, Louisiana allows living donors to apply a tax credit of up to \$7,200 to cover 72 percent of all out-of-pocket costs associated with organ donation (Louisiana State Legislature n.d.). This includes the unreimbursed cost of travel, lodging, and lost wages during the donation and recovery process. A benefit of the Louisiana model is that it allows the tax credit to be carried forward to future years if the amount exceeds what is owed in that year. For example, if a person qualifies for a \$5,000 tax credit but owes only \$2,000 in taxes, they can carry \$3,000 forward to the next year. This system ensures that the individual receives the full amount of money to which they are entitled, regardless of their income bracket.

### Israel

The Israeli model provides further evidence of the power of financial incentives in increasing donation rates, despite being different from the model proposed here. In 2008, as part of a larger overhaul of its struggling organ donation system, Israel implemented the Organ Transplantation Law, which created a collection of reimbursement mechanisms for living donors (Lavee et al. 2013). The law provides lost wage reimbursement for 40 days, covers the cost of transportation and recuperation, and provides five years' reimbursement of medical, work capability, and life insurances. The impact of this legislation was almost immediate: between 2010 and 2011 alone, living donations increased by 65 percent (Lavee et al. 2013).

## CURRENT STATE OF LIVING-DONOR ASSISTANCE IN GEORGIA

Georgia currently offers a tax deduction of up to \$10,000 to cover the unreimbursed cost of travel, lodging, and lost wages for organ or bone marrow donation (Georgia Code 2010). Georgia also offers up to 30 days of paid leave for organ donation, but only for state employees (Georgia Code 2010). However, as



previously mentioned, a prospective donor in the lowest income bracket could only receive up to \$1,000 from this deduction, a sum that falls far short of the true cost of donation.

Prospective donors in Georgia may be especially sensitive to the high cost associated with kidney donation, as the state suffers from a poverty rate above the national average and is one of the few states that has not expanded Medicaid (United States Census Bureau 2019). This leaves many low-income Georgians struggling with the choice between donating an organ to their loved one and staying financially secure. The disproportionate financial burden of kidney donation on Georgians may therefore underlie Georgia's low transplant rate, pointing to the importance of removing financial disincentives at the state level.

## POLICY ALTERNATIVE

The state of Georgia should act to remove barriers to living donation by converting its \$10,000 living-donor tax deduction into a \$5,000 tax credit. This credit could be used to cover any unreimbursed costs associated with donation, as well as lost wages, childcare, and elder care. Any donor, regardless of income, would be eligible to apply this tax credit.

The switch from a living-donor tax deduction to a tax credit has precedent in other states. In Louisiana, as previously mentioned, living donors can apply a tax credit of up to \$7,200 to cover 72 percent of any out-of-pocket costs associated with organ donation, including lost wages, travel, and lodging (Louisiana State Legislature n.d.). Georgia should recreate this model, with a few alterations. First, it should expand the scope of reimbursable expenses to cover childcare and elder care. Second, Georgia should cover 100 percent of costs up to \$5,000, instead of covering 72 percent of costs up to \$7,200. It is worth noting that the full \$5,000 would not be given automatically to every donor. Rather, the donor would have to submit documentation of their expenses so that they can be matched dollar-for-dollar up to \$5,000. Such documentation is important to ensure the donor does not profit off of organ donation, which would be a violation of federal law.

This type of reimbursement program has shown promising results in increasing transplant rates across the world. For example, a series of tax incentive laws in New York State led to a 52 percent increase in living kidney donations to non-family members, compared to a synthetic control (Bilgel and Galle 2015). Even the very



modest offerings of the NLDAC have been shown to increase living-donor kidney transplant by 14 percent (Schnier et al. 2018). Living-donor financial assistance is also extremely cost effective. A 2018 study of the return on investment (ROI) for living-donor financial assistance found a 5.1-fold ROI after one year and a 28.2-fold ROI after five years, compared to remaining on dialysis (Mathur et al. 2018). The cost-effectiveness of such policies is rooted in the much higher cost of providing dialysis versus financing transplants. Medicare spends approximately \$91,800 annually for a patient on hemodialysis, versus \$35,800 annually for a transplant patient (National Kidney Foundation n.d.).

The economic benefit of living-donor financial assistance is even greater when the cost of lost worker productivity due to ESRD is taken into consideration. Patients receiving hemodialysis must spend an average of 12 hours per week at the dialysis center, making it more difficult to hold down full-time jobs. Though there are very few estimates of the cost of lost productivity due to ESRD in the US, a comprehensive Canadian study from 2000 found that ESRD accounts for \$583 million per year in lost productivity (Zelmer 2007). This figure provides insight into what the total cost of lost productivity in Georgia today could be, since the number of ESRD patients in Canada in 2000 is similar to the number of ESRD patients in Georgia in 2017 (24,921 vs 27,843) (United States Renal Data System 2019). After adjusting for inflation, this results in an estimated \$874 million in lost productivity due to ESRD in the state of Georgia today.

Tax credits are also preferable to paid sick leave guarantees for two main reasons. First, paid leave guarantees run into the same issue as tax deductions of inherent regressiveness, since those who typically have lower wages will receive lower reimbursement. Second, a centralized tax credit is much easier to enforce than a law mandating paid leave for employees, which would likely invite pushback from corporations and other employers who resent being forced to offer paid leave.

## IMPLEMENTATION RECOMMENDATIONS

Within the current conservative culture of Georgia's State House of Representatives and Senate, it can be difficult to pass any legislation that increases state expenditure on health benefits. However, the cost projections showing a 28.2-fold return on investment over five years would likely draw the attention of even the staunchest fiscal conservatives (Mathur et al. 2018). Finally, with the Trump administration's public messaging indicating that ESRD reform is a top national priority, now may be the ideal time to implement this policy.



Raising awareness is just as important as passing this legislation. A tax credit will do nothing to allay financial concerns about organ donation if those who could benefit are left unaware. Legislators must therefore work with dialysis providers, patient advocacy groups, and publicity experts to devise best practices for reaching out to patients and prospective donors to inform them of this new avenue for reimbursement. A task force composed of policy researchers and dialysis providers should be established to monitor the efficacy of this legislation over the coming five to ten years. If effective in increasing transplant rates and decreasing spending on dialysis, this model should then serve as a template for other states struggling with low transplant rates and large ESRD patient populations.

## CONCLUSION

The creation of a \$5,000 organ donation tax credit in Georgia presents a feasible, cost-effective opportunity for increasing living-donor transplant rates. Georgia currently has the lowest standardized transplant rate and the longest waitlist in the nation, resulting in hundreds of preventable deaths. Georgia also suffers from a poverty rate above the national average, meaning that many prospective living donors simply cannot afford the estimated \$5,000 in out-of-pocket expenses incurred throughout the donation process. Though Georgia currently allows donors to claim up to \$10,000 in tax deductions, this model fails to adequately compensate donors, especially those in low tax brackets. The proposed tax credit would ensure that any Georgian who wishes to donate a kidney has the financial means to do so, thereby removing the financial barriers to donation. The cost-effectiveness of such a policy increases its chances of winning bipartisan support in the Georgia legislature. In sum, an organ donation tax credit offers a sustainable and tested means of creating a more equitable and accessible organ donation system, which will translate to fewer lives lost to End Stage Renal Disease.



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