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Wages, Travel and Lodging Reimbursement by the National Kidney Registry: An Important Step Towards Financial Neutrality for Living Kidney Donors in the United States

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Abbreviations:

DHHS Department of Health and Human Services

ESKD End-stage kidney disease

HRSA Human Resources and Service Administration

KDOC Kidney Donor Outcomes Cohort

KPD Kidney Paired Donation

NKR National Kidney Registry

NLDAC National Living Donor Assistance Center

NOTA National Organ Transplant Act (NOTA)

US United States

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Abstract

Background: Since 2007, the National Living Donor Assistance Center has provided the most financial support to US living donors meeting specific income criteria by reimbursing travel, meal and lodging expenses. In 2019, the National Kidney Registry (NKR) started providing lost wages, travel and lodging reimbursement via their Donor Shield program. Donor Shield is automatically provided to donors who participate in kidney paired donation through the NKR or who donate at a Donor Shield Direct center, without any income restrictions.

Methods: The support donors across the US received from the Donor Shield program between January 2019 and February 2020 was studied.

Results: During the study period, 326 (25.9%) of the 1,260 donors covered by Donor Shield, from 46 programs received reimbursements amounting to a total of \$647,384.45, with \$472,389.97 (73.0%) covering lost wages. Median reimbursement per donor was \$1,813.80 (range: \$44.0 - \$ 7,165.63). 81% of 108 reimbursed donors who were surveyed reported that the lack of these reimbursements would have posed a financial hardship, and 4% said they would have been unable to donate without this support.

Conclusions: Expansion of lost wages reimbursement programs to all donors in the US would be an important step towards achieving financial neutrality for this unique population, and could also help meet the growing demand for transplantable organs by increasing living donation rates.

INTRODUCTION

Living donor kidney transplantation is the best renal replacement therapy option for eligible patients with end-stage kidney disease (ESKD), offering superior outcomes compared to deceased donor transplantation.¹ This, along with the growing waitlist of kidney transplant candidates, and consequently the ever-increasing gap between the demand and the supply of organs, has significantly increased the demand for living donation in the United States (US). At the same time, fluctuations and decline in national living donation rates over time have been shown to be affected by rising unemployment rates and stagnation in wages brought on by economic instability during recessions.²⁻⁵ Indeed, Gill et al. showed that the effect on living donation was most pronounced in the lower household income groups.⁶

Living donors often incur direct, out-of-pocket costs including travel/lodging, meals, and uncovered medical expenses; they also incur indirect costs, including lost wages and effects on insurability or premium rates from donating their kidneys⁷. Previous studies in the US and Canada have shown that 92%-96% of living donors report increased direct, out-of-pocket costs and 36%-47% report loss of income from donating.^{2,8-12} The Kidney Donor Outcomes Cohort (KDOC) study of 182 living kidney donors found that one-third reported out-of-pocket costs exceeding \$2,500 and 20% reported costs greater than \$5,000.⁸ These losses were in addition to the average out-of-pocket costs of \$804 incurred during the evaluation.⁸ Concerns about donors having to pay out-of-pocket costs may deter some ESKD patients from asking others to donate at all and can prevent individuals from considering becoming a living donor.¹³ In summary, these findings suggest that financial concerns and actual direct and indirect costs associated with living donation are major driving forces affecting living donation decision-making and rates.

In contrast, the levels of donor expenses pale in light of the extremely high financial benefit each donor provides to both their recipient and to society. A recent cost-benefit analysis found that the lifetime value of a kidney transplant to society is about \$1.3 million per recipient, and the additional savings from stopping dialysis are about \$1.45 million per recipient.¹⁴ The enormous medical and financial benefit derived from living donor kidney transplantation makes it easy to justify further investment in programs aimed at achieving financial neutrality.¹⁵ In the US, until recently, the only organization providing financial support to donors at a national level has been the government-funded National Living Donor Assistance Center (NLDAC). The original NLDAC policy provided support in the form of reimbursement for travel, meals and lodging expenses,¹⁶ but did not cover lost-wages and used stringent income eligibility criteria based on the incomes of both the donor and recipient.^{7,17,18} In a study by Hayes et al., more than half (68%) of donors who might have benefited from the program were eliminated due to donors or recipients not meeting income eligibility requirements.¹⁸ The recent Human Resources and Service Administration (HSRA) funded NLDAC pilot program, referred to as the Lost Wages Demonstration Project, explored the effect of lost wages reimbursement on the decision of individuals to initiate the donation process.¹⁹ Partly as a result of this work, as of November 30th, 2020, NLDAC is accepting applications for reimbursement of lost wages.²⁰

In 2019, the National Kidney Registry (NKR), a nonprofit, 501c organization and the largest kidney paired donation (KPD) program in the US, began reimbursement for lost wages, travel and lodging expenses via their Donor Shield program, which also provides donation life insurance, disability insurance, coverage for uncovered complications, legal support, and reimbursement of lost wages, travel and lodging expenses related to any post-donation

complications. In this paper, we provide an overview of the reimbursements donors across the US received from this program between January 2019 and February 2020.

MATERIALS AND METHODS

Overview of lost wages, travel and lodging reimbursements available through the Donor Shield

Donor Shield is a program offered by the NKR that is available to all donors who participate in KPD facilitated by the NKR or who donate directly to their recipient at a Donor Shield Direct center.²¹ NKR funds the Donor Shield program from fees charged to the member centers for Donor Shield. All donors involved in NKR swaps automatically receive the Donor Shield support and protections which are currently billed to the center at a rate of \$895 per donor. The support and protections for the Donor Shield Direct centers are also \$895, but there may be additional charges to centers based on how much reimbursement was previously paid to direct donors at the center. Additional details about the operation and various programs of the NKR are available on their website.²² Donor Shield provides lost wage reimbursement for up to 4 weeks with a maximum of \$1,500 per week. As a result, the maximum allowable lost wage reimbursement was \$6,000. Notably, this was available only to donors with annual salary of less than or equal to \$62,000 until November 21st 2019, when the income cap was removed. After this date, lost wage reimbursement for donors with higher incomes was processed as if their annual salary was \$78,000. Additionally, the NKR policy states that wages must actually be lost to qualify for reimbursement. If the donor opts to use paid vacation time, or their employer grants extra paid time off as per their company policy, the donor would not be eligible. Lost unemployment benefits are not covered under the reimbursement program. The program also includes travel and lodging reimbursement up to \$2,000 for donors, their support persons and/or

travel companions. For ground transportation, reimbursement is based on mileage so gas expenses are not separately covered. In addition, expenses related to childcare and meals are not covered.

No reimbursements occur until after donation is confirmed by the transplant center.

For lost wages reimbursement, employed donor applicants are required to submit their W2 form (that shows the amount of taxes withheld from the paycheck for the year, and is used to file federal and state taxes in the US) and a recent paystub dated no earlier than 31 days before the upload date, and reimbursement is based on the largest value qualifying document. In the case of multiple jobs, the paystubs are required to show the same or fully overlapping pay periods. The reimbursement for self-employed applicants is based on recent tax filings provided in the US through forms 1040, 941 or K1. Reimbursements are processed within 5 business days of the center confirming donation. For reimbursement for travel and lodging expenses, receipts are required to be submitted within 30 days of donation. Donors receive a 1099 Miscellaneous income form at the end of the tax year for the purposes of reporting this income on their tax return.

Of note, in addition to reimbursement for lost wages, travel and lodging expenses, additional protections provided by the Donor Shield program include 1) life insurance with a \$500,000 principal sum for a period of 365 days post-donation, 2) disability insurance with a maximum of \$1,500 per week for up to 52 weeks, 3) legal support in case of wrongful termination from employment, rise in insurance premiums or loss of healthcare coverage as a result of donation, 4) coverage for post-surgical complications that are not covered by the recipient's or donor's insurance and 5) reimbursement for travel, lodging and lost wages for uncovered complications.

Data collection and analysis

Through a data use agreement, de-identified information was obtained from the NKR on donations that occurred between 1/1/2019 and 2/29/2020. We limited the dataset until February 2020 due to the significant decline in transplant activity in the US as a result of the COVID-19 pandemic. To assess the financial losses recovered by donors through this program, the data set included total number of donors eligible for the Donor Shield program during the study period, and for donors who received reimbursements, date and center of donation, expenses reimbursed (lost wages vs. travel/lodging vs. both) and amounts reimbursed. Additionally, annual salaries for donors who were reimbursed for lost wages were also provided. The averages and ranges are reported for reimbursement in each category. To evaluate the trend in utilization of this program over time, we analyzed the number of reimbursements processed by month.

Starting May 6th, 2019, donors applying for the Donor Shield reimbursement program were asked to report their level of financial hardship prior to donation using a three-point scale: 1: “I plan to donate my kidney regardless, and my lost wages and/or travel/lodging costs will not be a financial hardship,” 2: “I plan to donate my kidney regardless, but my lost wages and/ or travel/lodging costs will be a financial hardship,” and 3: “I will not be able to donate my kidney without reimbursement for my lost wages and/or travel/lodging costs.” We provide a summary of responses received between 5/6/2019 and 2/29/2020.

The clinical and research activities of this study are consistent with the Declaration of Helsinki and Declaration of Istanbul. The Institutional Review Board at the primary institution, the University of Wisconsin-Madison determined this project to be exempt from federal regulations pertaining to human subjects research.

RESULTS

Donor applicants and reimbursements

Between 1/1/2019 and 2/29/2020, 326 donors at 46 transplant programs in the US received some level of reimbursement from the NKR's Donor Shield program. This represents 25.9% of the 1,260 donors covered by Donor Shield during the time period. The median of donors reimbursed per transplant program was 4 (range: 1 - 53).

The total reimbursements processed over the 14-month time period were \$647,384.45, with \$472,389.97 (73.0%) covering lost wages and \$174,994.48 (27.0%) covering travel and lodging. On average, each donor received a median of \$1,813.80 (range: \$44.00 - \$ 7,165.63). Of the total of 326 donors reimbursed, 121 (37.1%) received reimbursement for lost wages only with a median amount of \$2,192.88 (range: \$213.62 - \$6000.00; Table 1) and 131 (40.2%) received reimbursement for travel and lodging expenses only with median amount of \$788.40 (range: \$44.00 to \$2000.00). The remaining 70 (22.7%) donor applicants received reimbursement for both lost wages, and travel and lodging expenses with a median amount of \$2990.72 (range: \$1,127.20 to \$7,165.63).

The median estimated yearly salary of the 195 (59.8%) donors who received wage reimbursement was \$44,356.00 (range: \$5,538.00 to \$109,451.7). 22.0% (43/195) had an estimated salary above \$62,000.00; all of these donations occurred after November 21st, 2019.

Reimbursement Trends

Monthly reimbursements over time showed a statistically significant increase in all reimbursements processed per month ($p < 0.001$; Figure 1) as well as lost wages reimbursements (alone or in combination with travel and lodging reimbursements) processed every month ($p < 0.001$; Figure 2). Since some of the increase in the lost wages reimbursements processed may

have been related to the removal of annual salary cap in November 2019, we additionally analyzed the lost wages reimbursements for donors with estimated yearly salary of less than or equal to \$62,000.00 and found that the trend remained significant with a p-value of 0.002.

Impact of reimbursement on ability to donate

Between 5/6/2019 and 2/29/2020, 108 applicants responded prior to donation to the question regarding the level of financial hardship incurred from the donation process. 4% reported that they would not have been able to donate without the reimbursement for lost wages and/or travel and lodging costs, and 81% reported that they had planned to proceed with donation regardless, but the lost wages and/or travel and lodging expenses would have been a financial hardship.

Only 16% of the donors who received reimbursement noted they had planned to proceed with the donation regardless, and that the expenses incurred would not have posed a financial hardship.

DISCUSSION

Published research on barriers to living donation consistently name financial concerns about out-of-pocket and indirect costs as a critical deterrent to living donation for both recipients and donors considering living donation.^{2,6-8} As defined in the 2018 edition of the Declaration of Istanbul on Organ Trafficking and Transplant Tourism, “financial neutrality” means that the donors and their families neither lose nor profit financially as a result of donation.¹⁵ Compared to several other countries such as Australia, Canada and the Netherlands, the US has less comprehensive living donor financial reimbursement programs, resulting in donors frequently incurring unreimbursed predonation and postdonation expenses.^{13,23-26} It is critical to achieve financial neutrality to promote living donation, but more importantly, because it is the right to do. Living donor do not receive health or economic benefits from donation, but transplant recipients, centers and society as a whole does benefit from the donation. As such, from an

equity standpoint, it is reasonable that the costs of donation not be imposed on the donors themselves.

This study documents the successful implementation of the Donor Shield program, a pioneering initiative from the NKR, whereby eligible donors can apply to receive reimbursements for lost wages as well as travel and lodging expenses. Several observations from the first 14 months of its operation are noteworthy. First, over a quarter of the donors covered under the NKR Donor Shield protections requested and received reimbursements for lost wages and/or travel and lodging. Second, 60% of these donors experienced a proven loss of wages due to donation, which qualified them for the wage reimbursement part of the program. Third, nearly three-quarters of the reimbursements processed were utilized to cover lost wages.

One limitation of the NLDAC program is that, as required by statute, applications must account for the financial resources of both the donor and their recipient in determining eligibility. The KDOC study found that only 6% of donors received any financial assistance from their recipients, and that it may be unrealistic to expect the transplant recipients to be able to cover any or all of the donor expenses, especially when their financial resources are comparable to that of the donor.^{5,8} The NKR's program also requires proof of lost wages and caps reimbursement, but does not weigh donor or recipient resources. It should be noted that currently, wage reimbursement through the Donor Shield program is available only to those whose donations are facilitated by the NKR's KPD program or those who donate at one of the NKR Donor Shield Direct centers, however, any US transplant center can contract with NKR to become a Donor Shield Direct center, based on the fee to service structure outlined earlier. To fully achieve financial neutrality for donors across the nation, further federal legislation and reimbursement programs are needed to expand this type of program to all centers, for donors and their

caregivers, and to cover different types of expenses incurred pre- and post-donation. To that end, on December 12th, 2019, the US Department of Health and Human Services (DHHS) proposed a rule titled ‘Removing Financial Disincentives to Living Organ Donation’ to amend the regulations implementing the National Organ Transplant Act (NOTA) of 1984. Section 301 of NOTA outlaws the sale and purchase of organs. Certain expenses are specifically excluded from the scope of valuable consideration, including expenses related to travel, housing and lost wages incurred by the donor in connection with the donation process. While child-care or elder-care expenses incurred by the donor are not specifically addressed. The DHHS has determined that reimbursement of these expenses is not valuable consideration under section 301 of NOTA. The intent is to remove financial barriers to organ donation in the US by expanding the scope of reimbursable expenses incurred by living organ donors.²⁷

Recent analyses have documented that removing financial disincentives would substantially increase living donation rates.²⁸ Consistent with this, our study found that 85% of the donors who received reimbursements reported that the lack of reimbursement would have either precluded donation or posed a financial hardship for them. In the US, the recent HRSA funded pilot program performed by NLDAC, the Lost Wages Demonstration Project, took this a step forward and further explored the effect of lost wages reimbursement on the decision of individuals to initiate the donation process.¹⁹ It was anticipated that by providing evidence of the need for and the value of lost wage reimbursement, this project would further justify coverage of these expenses, especially given the markedly lower cost of kidney transplant compared to maintenance dialysis. Indeed, significant changes have recently been made to the NLDAC policy, including inclusion of reimbursement for lost wages as of November 30th, 2020.

Additionally, reimbursement of child-care and elder-care expenses is expected to become available in February 2021.

A notable strength of this initiative from the NKR is that the coverage it provides extends beyond individuals who donated through their KPD program, and applies to all donors at their Donor Shield Direct centers. Longitudinal research is still needed to follow the increasing group of living donors over time and report on other Donor Shield protections, including disability insurance claims, life insurance claims, legal support provided and reimbursement for lost wages, travel and lodging from post-donation complications.

In conclusion, achieving financial neutrality, where donors and their caregivers neither profit nor suffer economic hardship as a result of donation, not only has an obviously strong ethical foundation but is also fundamental to promoting living kidney donation. Ability to reimburse incurred expenses for all living kidney donors, through programs such as the NKR's Donor Shield and the NLDAC would be a big step towards achieving financial neutrality for this unique population, and a major milestone in the history of transplantation in the US.

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Figure legends:

Figure 1: Total donors reimbursed by month.

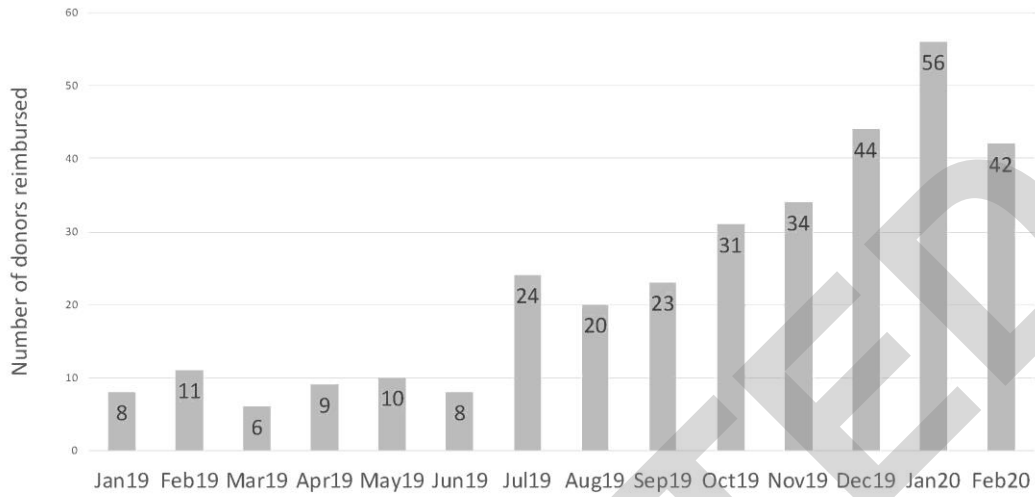
Figure 2: Donors who received lost wage reimbursement by month.

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Table 1:

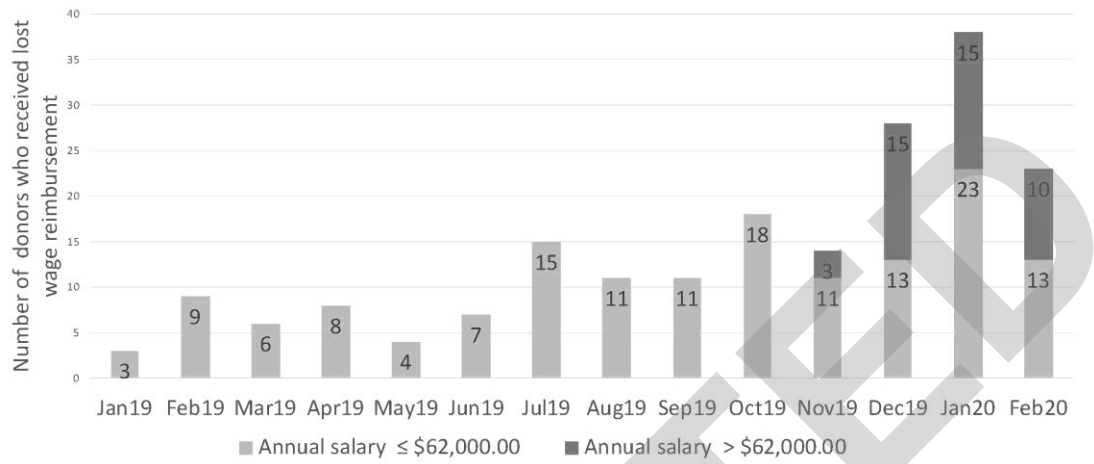
	Median	Mean	Range
Wages only (n=121)	\$2,192.88	\$2,397.84	\$213.62 - 6000.00
Travel/lodging only (n=131)	\$788.40	\$960.10	\$44.00 - 2000.00
Both (n=74)	Total: \$2,990.72 Wages: \$2,179.26 Travel/lodging: \$554.72	\$3,135.51 \$2,462.86 \$672.65	\$1127.20 - 7165.63 \$213.00 - 6000.00 \$20.57 - 2000.00

Figure 1: Total donors reimbursed by month



ACCEPTED

Figure 2: Donors who received lost wage reimbursement by month



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