

February 18, 2020

Mr. Frank Holloman, Director
Division of Transplantation
Health Resources and Services Administration
5600 Fishers Lane
Rockville, MD 20847

Ref. HHS Docket No. HRSA-2019-0001 - [Removing Financial Disincentives to Living Organ Donation](#)

Dear Mr. Holloman:

The Organ Procurement and Transplantation Network (OPTN) is pleased to submit a comment regarding the proposed rulemaking to remove financial disincentives to living organ donation posted in the *Federal Register* on December 20, 2019. The OPTN commends the Health Resources and Services Administration (HRSA) for further reducing barriers to living donation.

The OPTN strongly supports removing financial disincentives to living organ donation. We agree with the proposed rulemaking as we believe the act of living donation should have as little financial impact on the donor as possible. Living donors extend the lives of their recipients, enable another transplant to happen by removing a name from the wait list, and saves U.S. taxpayers money annually by avoiding more costly and medically inferior treatments. Living donors should be kept whole economically and the rulemaking is an important step in that direction. As cited in the Federal Register notice (p. 70143), studies have shown that reimbursement measures have increased organ donations and donor income plays a role in living organ donor transplant rates.

As authorized by the OPTN Final Rule to develop “Policies that reduce inequities resulting from socioeconomic status” including “recommendations to private and public payers and service providers on ways to improve coverage of organ transplantation and necessary follow-up care”, the OPTN’s work to improve the state of living organ donation has historically included discussions focused on eliminating financial barriers to living donors. Therefore, the OPTN supports the expansion of reimbursable expenses to include lost wages and child and elder care.

Lost Wages

The OPTN strongly supports reimbursing all living donors for lost wages as it is fundamental to financial neutrality. Reimbursing lost wages for living donors of certain income brackets is a critical first step to minimizing current socio-economic disparities in access to living donor transplant. Providing lost wages to living donors for the recovery period and for follow-up appointments appropriately aligns financial realities and medical needs.

Additionally, the underlying Executive Order directed HHS to propose a raise to the limit on the income of living donors eligible for reimbursement under the program. According to the Notice, HRSA plans to seek public comment on this revision to the Eligibility Guidelines separately. With the understanding that adjustment to income levels are to be addressed subsequently, we will note the costs associated with living donations strain families at all income levels. We look forward to weighing in on eligibility guidelines.

Child-Care Expenses and Elder-Care Expenses

The OPTN strongly supports the proposed rulemaking to allow reimbursement for child- and elder-care expenses for living donors. Living organ donation is an extended process of testing, surgery, recovery, and follow-up, requiring donors to make alternative arrangements to manage familial responsibilities. Including these core non-medical expenses as reimbursable is a positive step closer to minimizing the financial impact on living donors.

Per the Federal Register notice (p. 70144), by expanding the list of expenses eligible for reimbursement for living organ donors, the federal government expects to save money overall due to an increase in organ transplants performed with a decrease in dialysis and other treatments that the government covers financially. In fact, our preliminary review of the notice suggests that the cost savings may be even higher than estimated as the Medicare estimate of End-Stage Renal Disease (ESRD) expenditures may not account for all costs associated with ESRD patients (ex. long-term maintenance dialysis).

Payer of Last Resort

The Federal Register notice (p. 70143) describes the National Living Donor Assistance Center (NLDAC) as a “payer of last resort” which cannot reimburse qualifying expenses if the living organ donor can be reimbursed for these expenses through other means. Currently, the complexity of that requirement puts the burden on living donors to prove or disprove other sources of funding as a condition of NLDAC support. The OPTN believes this merits review as the complexity of this requirement could be a disincentive to living organ donation.

Other Financial Barriers to Organ Donation

The Federal Register notice requested feedback about other financial barriers to organ donation. The OPTN supports HRSA’s request for literature and evidence on such other financial barriers to enable consideration of further categories of reimbursable non-medical expenses. Consistent with the theory that the act of living organ donation should be financially neutral, we are providing below examples of literature that support consideration of direct and indirect costs that hinder donation. These studies agree that further reducing the financial impact on living donors would substantially increase the number of live donations.

In summary, the OPTN appreciates HRSA’s work to further reduce barriers to living donation and fully supports the proposed rulemaking. Please consider the OPTN a resource should HRSA need further information in support of its efforts.

Sincerely,



Maryl Johnson, MD, FACC, FAHA, FAST
President, OPTN Board of Directors

Recommended References

1. Wiseman J, Jacobs C, Larson D, Berglund D, Garvey C, Ibrahim H, and Matas A. *Financial Burden Borne by Laparoscopic Living Kidney Donors*, 2017 Sep;101(9):2253-2257
2. Hays R, Rodrigue JR, Cohen D, Danovitch G, Matas A, Schold J, and LaPointe Rudow D. *Financial Neutrality for Living Organ Donors: Reasoning, Rationale, Definitions, and Implementation Strategies*, Am J Transplant. 2016 Jul;16(7):1973-81LaPointe
3. Rudow, D. and Cohen, D. *Curr. Practical Approaches to Mitigating Economic Barriers to Living Kidney Donation for Patients and Programs*, Transpl Rep (2017) 4: 24