

30 E. 33rd Street New York, NY 10016

> Tel 212.889.2210 Fax 212.689.9261 www.kidney.org

The Honorable Thomas J. Engels Administrator Health Resources and Services Administration Room 13N-192 5600 Fishers Lane Rockville, Maryland 20857

February 18, 2020

RE: Docket No. HRSA-2019-0001

Dear Administrator Engels,

The National Kidney Foundation applauds the Health Resources and Services Administration (HRSA) for its proposed rule that would reduce barriers to living donation by expanding the categories of reimbursable expenses under the Reimbursement of Travel and Subsistence Expenses Incurred toward Living Organ Donation program to include lost wages, child-care, and elder-care expenses. The National Kidney Foundation enthusiastically supports the proposed rule and urges HRSA to finalize it at the earliest possible opportunity. We also ask HRSA to expeditiously publish and then finalize the corresponding proposed rule that will revise the program's Eligibility Guidelines to raise the limit on the income eligibility threshold for reimbursement. Both proposed rules are meaningful steps to reducing barriers to living donation and achieving the Administration's goal of doubling the number of kidneys available for transplant within the next decade.

The National Kidney Foundation (NKF) is the largest, most comprehensive and longstanding, patient centric organization dedicated to the awareness, prevention, and treatment of kidney disease in the U.S. In addition, the National Kidney Foundation has provided evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD), including transplantation since 1997 through the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (KDOQI).

NKF is committed to eliminating barriers to living organ donation, thus giving more patients the opportunity to benefit from a transplant. We agree that there are many potential living organ donors who would like to donate, but cannot afford to due to loss of income, obligations to dependents, costs associated with travel to medical appointments, and other unreimbursed incidental expenses. NKF's position is that living donors should bear no financial loss from donation. The Reimbursement of Travel and Subsistence Expenses Incurred toward Living Organ Donation program was authorized in 2006 at the request of NKF to remove financial disincentives to living donation by providing reimbursement for categories of "incidental non-medical expenses" incurred by living organ donors.

National Kidney Foundation 30 E. 33rd Street New York, NY 10016

> Tel 212.889.2210 Fax 212.689.9261 www.kidney.org

NKF supports HRSA's proposal to amend the OPTN final rule to add lost wages, child-care, and elder-care expenses incurred by primary caregivers as reimbursable expenses by the program. We are pleased by the results of HRSA's analyses which demonstrate that the additional categories of reimbursement would result in four to six-times the number of applicants to the National Living Donor Assistance Center (NLDAC) and a commensurate increase in the number of living donor kidney transplants.

We share HRSA's concern that adding other categories of reimbursable expenses that increase the average reimbursement without a proportional increase in appropriations could result in fewer individuals being served by the program. NKF shares HRSA's desire to ensure the ongoing viability of the program, though we believe growing HRSA's annual appropriation is a much preferable solution as compared to capping reimbursement levels. Accordingly, NKF is seeking an additional \$10 million dollar appropriation to support NLDAC in FY2021.

As we have noted, NKF looks forward to both the rapid finalization of this proposed rule and the forthcoming rule that will revise the program's Eligibility Guidelines to raise the limit on the income eligibility threshold for reimbursement. NKF believes that eligibility should be based solely on the donor's financial status. Requiring the donor to request the recipient's financial information for the purposes of means testing is both burdensome and unproductive. Though we acknowledge that means testing the recipient is required by current statute, income level may not correlate with excess funds for those who are chronically ill. The recipient's income level is not necessarily a good indicator of whether s/he is in a position to pay the costs associated with living donation. In the absence of this change, we recommend increasing the upper threshold for both living organ donors and organ recipient household income in order to maximize the number of potential living donors who are able to benefit from the program.

NKF applauds HRSA for its continued stewardship of The Reimbursement of Travel and Subsistence Expenses Incurred toward Living Organ Donation program. The assistance provided by NLDAC makes a meaningful difference to the thousands of patients every year who benefit from a living kidney donor transplant. NKF is eager to partner with HRSA to ensure the success of the program into the future. We would welcome the opportunity to discuss the content of this letter further. Please contact Miriam Godwin, Health Policy Analyst, at Miriam.godwin@kidney.org.

Sincerely,

*Kevin Longino* Kevin Longino CEO and transplant patient Holly Mattix Kramer Holly Mattix Kramer, MD, MPH President