



February 18, 2020

Thomas J. Engels
Administrator
Health Resources and Services Administration
U.S. Department of Health and Human Services
5600 Fishers Lane
Rockville MD, 20857

Re: Removing Financial Disincentives to Living Organ Donation (HRSA-2019-0001)

Dear Administrator Engels,

On behalf of the Nonprofit Kidney Care Alliance (NKCA), I write to offer our comments in support of the changes included in the Removing Financial Disincentives to Living Organ Donation proposed rule which will assist in efforts of the Administration, kidney care stakeholders including NKCA, and the patients we serve to encourage living donation by eliminating certain barriers for individuals who would like to donate.

NKCA represents six nonprofit dialysis providers: Centers for Dialysis Care; Dialysis Center of Lincoln; Dialysis Clinic, Inc.; Independent Dialysis Foundation, Inc.; Northwest Kidney Centers; and The Rogosin Institute. Collectively, we serve more than 21,000 patients at more than 300 facilities in 30 states. We also serve more than 5,700 patients with chronic kidney disease (CKD) with the goal of avoiding, or at least delaying, the onset of end-stage renal disease (ESRD) and maximizing the quality of life for our patients. We are committed to promoting kidney transplantation, eliminating barriers to access, and reducing organ discards. To that end, many of our member companies participate in value-based care arrangements such as the Comprehensive ESRD Care (CEC) model and will likely continue to expand their participation in such arrangements under new models as part of the Administration's Advancing American Kidney Health Initiative. Through the CEC model, many of our member companies are pursuing partnerships with various providers and suppliers, not only in nephrology, but across the care continuum, from primary care to hospice.

HRSA proposes to expand the National Living Donor Assistance Center's (NLDAC's) reimbursement criteria to include lost wages, child-care and elder-care expenses as "incidental non-medical expenses" reimbursable through the program. NKCA not only supports this change but encourages HRSA to continue to seek ways to bring awareness to living donation and the NLDAC as a resource for those who are interested in donation but may feel it is financially unattainable. From HRSA's data and what we have heard anecdotally as we assist patients in the process of seeking a living donor, financial burden can be a challenge in both asking for and committing to living donation. In addition to the existing medical expenses incurred in the donation process that are already covered by NLDAC, these indirect expenses of wages and child/elder care can be reasonable deterrent to many healthy donors.

This commitment of living donors to lost time at work was acknowledged last year when the Department of Labor released an opinion letter¹ clarifying that an organ donation can qualify as an impairment or physical condition that is a serious health condition under the Family and Medical Leave Act (FMLA). While the use of FMLA is a helpful resource for potential living donors to ensure they can retain their position, it is prudent that the government use the mechanisms and programs available, including NLDAC, to pair that policy with opportunity for reimbursement of lost wages as proposed.

We appreciate the agency's work to explore this issue over the past few years, testing the impact of this change in reimbursement through its demonstration as well as receiving stakeholder input through the Advisory Committee on Organ Transplant (ACOT). We are also pleased to see the data provided on the program from HRSA including the approval rate of applications, indicating that those pursuing these grants are truly in need and most would not have been able to donate without the NLDAC assistance.

HRSA states an expected "four to six-fold increase in the number of applicants" based on the proposed change. Understanding that not all applicants will receive funds, and not all recipients will be able to go on to donate an organ, we believe this change is a way to increase access to transplant without any detriment to the program. Any increase in access using this program is life saving and we believe that all of the policies proposed as part of the Advancing American Kidney Health Executive Order (EO) need to work in tandem to make the necessary changes being sought.

We are pleased to see HRSA note it will seek public comment on the Eligibility Guidelines of the NLDAC in a future notice and reiterate that any changes in this space that can assist in the successful increase in transplant rates is needed as soon as possible to ensure that all the other components of the EO can begin to be addressed.

Thank you for the opportunity to comment on the Removing Financial Disincentives to Living Organ Donation proposed rule. We would be pleased to discuss any of these comments in greater detail at any time. If you have any questions, please feel free to contact Martin Corry at 202-580-7707 or info@nonprofitkidneycare.org.

Sincerely,



Martin Corry
Executive Director

¹ https://www.dol.gov/sites/dolgov/files/WHD/legacy/files/2018_08_28_2A_FMLA.pdf