



February 18, 2020

The Honorable Alex M. Azar, II  
Secretary  
Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

The Honorable Thomas J. Engels  
Administrator  
Health Resources and Services Administration  
5600 Fishers Lane, Room 13N82  
Rockville, MD 20857

**Re: HHS Docket No. HRSA-2019-0001: "Removing Financial Disincentives to Living Organ Donation"**

Dear Secretary Azar and Administrator Engels:

On behalf of Kidney Care Partners (KCP), I want to applaud the Administration for its efforts to try to eliminate barriers that could impact the ability of potential living donors from donating their organs, particularly a kidney. KCP supports the policies outlined in "Removing Financial Disincentives to Living Organ Donation" Proposed Rule (Proposed Rule). Specifically, we agree that it is important to add three new expense categories – (1) Lost wages; (2) Child-care expenses; and (3) Elder-care expenses – to the definition of incidental non-medical expenses incurred by donating individuals to the current program through the National Living Donor Assistance Center (NLDAC). We believe that this Proposed Rule, if finalized, would provide necessary assistance to qualified living donors and is another critical part of allowing the Administration to achieve the goals set forth in the Executive Order "Advancing American Kidney Health."

KCP is an alliance of members of the kidney care community that serves as a forum for patient advocates, dialysis care professionals, providers, and manufacturers to advance policies that support the provision of high quality care for individuals with chronic kidney disease (CKD), including End-Stage Renal Disease (ESRD).

With just over 21,000 kidney transplant performed in 2018<sup>1</sup> and nearly 95,000 patients on current waitlists,<sup>2</sup> nephrologists and facilities face substantial limits in what they can do to increase the number of kidney transplants. Everyone agrees that we need more coordinated effort that focuses on Organ Procurement Organizations, living donors, and transplant center criteria and policies is needed to improve access to transplant, especially for patients living with kidney failure. The Proposed Rule is an important step in the right direction to help increase the number of living donors.

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<sup>1</sup>UNOS Biweekly Update (January 10, 2020).

<sup>2</sup>National Kidney Foundation, "organ Donation and Transplantation Statistics" *available at* <https://www.kidney.org/news/newsroom/factsheets/Organ-Donation-and-Transplantation-Stats>.

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We are excited that the analysis of the Proposed Rule projects a four to six-fold increase in potential applications for NLDAC support, which would lead to a substantial increase in the number of organs available for transplant.<sup>3</sup> However, we believe that the increase could be even greater, if the current income levels for eligibility could be increased. Thus, we encourage to HRSA to increase the upper threshold for living organ donor and organ recipient household incomes. We look forward to providing additional comments on this recommendation once HRSA has published the notice referenced in the Proposed Rule.

We also encourage HRSA to make sure that the process is easy to navigate and the forms that must be submitted are clear and simple to complete. Such a system would help patients, caregivers, and other providers (such as dialysis facilities) to more readily leverage the resources of the NLDAC.

KCP also would like to offer support to HRSA and the Administration as it includes funding for the NLDAC through the President's annual budget, as well as the annual Congressional appropriations process. We encourage the Administration to increase funding in the President's Budget and work closely with the House and Senate appropriators to ensure adequate funding levels to leverage the expanded definition of non-medical expenses.

Thank you again for providing us with the opportunity to comment. Please do not hesitate to reach out to our counsel in Washington, Kathy Lester at 202-534-1773 or [klester@lesterhealthlaw.com](mailto:klester@lesterhealthlaw.com), if you have questions or would like to discuss our comments.

Sincerely,

A handwritten signature in black ink, appearing to read 'J. Butler', with a long horizontal flourish extending to the right.

John Butler  
Chairman

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<sup>3</sup>84 Fed. Reg. 70141.

**Appendix A: Kidney Care Partner Members**

Akebia Therapeutics  
American Kidney Fund  
American Nephrology Nurses' Association  
American Renal Associates, Inc.  
Ardelyx  
American Society of Nephrology  
American Society of Pediatric Nephrology  
Amgen  
AstraZeneca  
Atlantic Dialysis  
Baxter  
Board of Nephrology Examiners and Technology  
BBraun  
Cara Therapeutics  
Centers for Dialysis Care  
Corvidia Therapeutics  
DaVita  
DialyzeDirect  
Dialysis Patient Citizens  
Fresenius Medical Care North America  
Fresenius Medical Care Renal Therapies Group  
Greenfield Health Systems  
Kidney Care Council  
Medtronic  
National Kidney Foundation  
Nephrology Nursing Certification Commission  
National Renal Administrators Association  
Otsuka  
Renal Physicians Association  
Renal Support Network  
Rockwell Medical  
Rogosin Institute  
Satellite Healthcare  
U.S. Renal Care