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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:

The American Kidney Fund appreciates the opportunity to provide comments on the above notice of proposed rulemaking (NPRM) that would amend regulations implementing the National Organ Transplant Act of 1984 and remove financial barriers to living organ donation.

The American Kidney Fund (AKF) fights kidney disease on all fronts as the nation's leading kidney nonprofit. AKF works on behalf of the 37 million Americans living with kidney disease, and the millions more at risk, with an unmatched scope of programs that support people wherever they are in their fight against kidney disease—from prevention through transplant. Through programs of prevention, early detection, financial support, disease management, clinical research, innovation and advocacy, no kidney organization impacts more lives than AKF. AKF is one of the nation's top-rated nonprofits, investing 97 cents of every donated dollar in programs, and holds the highest 4-Star rating from Charity Navigator and the Platinum Seal of Transparency from GuideStar.

AKF supports the proposed change to expand the scope of reimbursable expenses incurred by living organ donors to include lost wages and child-care and elder-care expenses incurred by a primary caregiver. We believe this is an important step in removing financial hurdles that can make it difficult for some individuals to be living organ donors. By making living organ donation financially feasible for more people, this proposed change has the potential to provide more opportunity for people in need of a lifesaving transplant to receive one.

As a nonprofit organization that helps thousands of kidney patients afford their medical expenses through our need-based programs, we understand the importance of financial assistance programs that allow all people with kidney disease to access needed treatments. Many patients with end-stage renal disease (ESRD) have low incomes, and their circle of family and friends who may be willing

to donate a kidney may also have limited financial means. The National Living Donor Assistance Center (NLDAC) is an important resource for lower-income living organ donors that helps defray the cost of indirect expenses that are not covered by insurance. The NLDAC currently provides reimbursements for lower-income donors who lack other forms of financial support to help offset the costs of travel, lodging, meals, and incidental expenditures related to donor evaluation or other donation related medical procedures. By expanding the scope of reimbursable expenses as proposed, the NLDAC will further help lower-income donors who also face financial burdens due to lost wages or child-care or elder-care expenses they incur during the organ donation process.

We are encouraged to see in the analysis of the NPRM that the Health Resources and Services Administration (HRSA) projects a four to six-fold increase in the number of applicants to the NLDAC if the proposal is finalized. We urge the Administration and Congress to work together to ensure adequate funding for the NLDAC so that the living organ donor reimbursement program will be able to meet this projected increase in demand.

AKF also recommends that HRSA ensures that applying for reimbursement through the NLDAC is a straightforward process for donors, recipients, and caregivers, and that the required forms are clear and easy to complete after incorporating the proposed changes in this NPRM. Minimizing complexity in the application process will help ensure potential living organ donors are not deterred from seeking available financial assistance through the NLDAC because of administrative burden.

Thank you for your consideration of AKF's comments.

Sincerely,



LaVarne A. Burton
President and CEO