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May 9, 2022

Carole Johnson
Administrator
Health Resources and Services Administration
U.S. Department of Health and Human Services
5600 Fishers Lane
Rockville, MD 20857

Re: Request for Information on ways to strengthen and improve the Organ Procurement and Transplantation Network

Dear Administrator Johnson:

The American Kidney Fund appreciates the opportunity to provide comments on the Request for Information (RFI) referenced above.

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 commends the Health Resources and Services Administration's (HRSA) efforts to improve the Organ Procurement and Transplantation Network's (OPTN) engagement with donors and patients and its focus on opportunities to strengthen equity, access, and transparency in the organ donation, allocation, procurement, and transplantation process. AKF's mission is to fight kidney disease and help people live healthier lives, including helping people access kidney transplants. AKF's financial assistance helped 1,889 low-income dialysis patients afford their health insurance and receive a kidney transplant in 2021—7% of all kidney transplants performed in the U.S. last year. Kidney failure has a disproportionate impact on people of color, and fighting health disparities has long been an integral part of AKF's mission. Many of the people we help each year with financial assistance that leads to a kidney transplant are from communities of color.

We focus our comments on the following question, with an emphasis on people with kidney failure:

Question E.4

Increasing Organ Donation and Improving Procurement

How can HRSA best incorporate the NASEM report's recommendations on increasing equitable access to transplants?

AKF agrees with recommendation 3, “Achieve equity in the U.S. organ transplantation system in the next 5 years,” in the National Academies of Science, Engineering, and Medicine (NASEM) report: *Realizing the Promise of Equity in the Organ Transplantation System*. Particularly, we strongly support the recommendations on expanding oversight and data collection, shared decision making with patients and public education, and elevating the voices of those facing disparities. In its report, NASEM recommends that:

- HHS should extend its regulatory oversight of the organ transplantation system beginning, at least, at the time a patient reaches end-stage organ failure and extending beyond 1 year posttransplant.
- HHS should update the OPTN contract to require the collection of disaggregated data by race and ethnicity, gender/sex, age, as well as language and the creation of new measures of inequity in the transplant system.
- HHS should develop, implement, and evaluate rigorous approaches for transplant teams to communicate routinely with (1) potential transplant recipients about their status and remaining steps in the process of transplant evaluation; (2) wait-listed candidates about organs offered to them, including information about the benefits, risks, and alternatives to accepting different types of organs to facilitate shared decision making about whether to accept the organ; and (3) wait-listed candidates about the number of organs offered and declined.
- HHS should develop, implement, and evaluate rigorous approaches for routinely educating the public about the benefits, risks, and alternatives to organ transplantation as a treatment option for end-stage organ disease or for those needing transplantation of tissue or a functional unit.
- HHS should conduct ongoing culturally targeted public education campaigns to convey the need for organ donation to save lives, to eliminate misconceptions about organ donation and transplantation, and to increase the trustworthiness of the transplantation system.

To incorporate these recommendations and increase equitable access to transplants, AKF suggests HRSA consider the following related issues and approaches to address them. We previously outlined these issues and suggestions in our comment letter to the Centers for Medicare and Medicaid Services' (CMS) RFI on transplant programs, organ procurement organizations (OPO), and end-stage renal disease (ESRD) facilities:

- As noted in the NASEM report, there are data gaps within the transplantation system that make it difficult to assess the socioeconomic status of transplant candidates, and the report noted the ongoing work of the OPTN Minority Affairs Committee to consider proposed

efforts to collect additional socioeconomic information related to disparities in access to kidney transplantation. AKF is supportive of efforts to improve data collection and data on the social determinants of health (SDOH). Transplant programs and OPOs should be aware of SDOH in their policies, but it needs to be very clear that the SDOH should not disqualify a kidney patient from being listed on the transplant waiting list or being asked to be a living organ donor. Transplant centers and OPOs should be cognizant that people have been denied treatment due to race, but also based on their income level, where they live and whether decision makers think that their living environment is going to be conducive for them to maintain their transplant. We should ensure that data around SDOH should not be used to discriminate against patients. Transplant centers and OPOs should focus on equity in-and-of itself. When transplant centers and OPOs focus solely on the outcome, all the SDOH creating the disparities that get patients to dialysis are reenacted in transplant patients.

- Patients commonly experience challenges in getting information to and from transplant coordinators, and many do not understand the various steps in the evaluation process. The volume of communications—especially at large transplant centers—can make it difficult for coordinators to be responsive to patients with their questions. The current transplant evaluation process should be easier for patients to navigate.
- HHS can work with patient and provider groups to lay out a framework or a start-to-finish set of expectations for patients. For example, it should include a list of needed tests to be done by their primary care provider and to whom they need to send the results. The framework will let patients know where they are in the process. It can be written, but also made into a video or podcast. Both written and oral education needs to be provided in easy-to-understand language and provided in the primary language of the patient. The educational materials should also include information on the organ procurement process and organ allocation system.
- Create outreach programs to contact dialysis patients who are in communities of color. For example, Northwestern University and George Washington University have outreach programs to specifically assist kidney patients from communities of color to educate them on kidney transplantation.
- HHS could require transplant programs or OPOs to conduct an organizational literacy audit and create documents for patients to show how to interact with the transplant program.
- Peer mentors and care navigators can be utilized to a greater degree to assist new patients with the process.
- Education should also be provided early in the process so more patients can be placed on the transplant list preemptively or soon after beginning dialysis. A focus on getting appropriate patients waitlisted or receiving living donor transplants earlier in their dialysis treatments is a strategy that both the community and HHS could adopt. It is regrettable when a patient has access to a living donor and could have been transplanted in the first or second year of dialysis, but could not get the transplant until the fourth or fifth year because of the transplant process.
- The cohort of people who get preemptive transplants have higher education levels and have a higher socioeconomic status. Those with lower socioeconomic status, inadequate

insurance, or who live in underserved areas can face barriers to kidney transplantation.¹ Education and assistance should be provided to people from communities of color, underserved communities and rural communities earlier in the process.

- Once individuals are on the waitlist, access to transplantation is generally equalized. However, there is potential in bias in the decisions to refer patients to the waiting list and in the timing of the physician assessment of appropriateness for transplant. Data shows that there are racial disparities in that process. There can also be a lack of knowledge at both the dialysis center and referring physician levels about the organ allocation system, which can lead to less timely referrals.
- Focusing on cultural competency can better ensure that transplant centers are aware of individual organ recipient's unique support systems post-transplant. They need to be aware of possible implicit bias when assumptions are made about a patient's ability to follow transplant instructions, a patient's unique support system, and the patient's financial challenges.

Thank you for the opportunity to provide comments on this RFI. If you have questions on our response or would like to further discuss these issues, please contact Holly Bode, Vice President of Government Affairs, at hbode@kidneyfund.org.

Sincerely,



Holly Bode
Vice President of Government Affairs

¹ David A. Axelrod, Mary K. Guidinger, Samuel Finlayson (2008). Rates of Solid-Organ Wait-listing, Transplantation, and Survival Among Residents of Rural and Urban Areas. *JAMA*, 299(2):202–207. <https://jamanetwork.com/journals/jama/fullarticle/1149365>
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