



March 14, 2023

Re: OPTN Ethics Committee White Paper, *Ethical Evaluation of Multiple Listing*

The National Kidney Foundation (NKF) thanks the Organ Procurement and Transplant Network (OPTN) for the opportunity to offer commentary on the white paper, *Ethical Evaluation of Multiple Listing*, presented by the Ethics Committee.

NKF recognizes that this topic is complex and that sociodemographic, economic, and geographical disparities contribute to challenges in access to kidney transplantation. However, we believe in expanding, not reducing, transplant opportunities for patients. Equitable access to transplantation is a strong desire of our patient community, which we unequivocally support, yet we know this is fraught with varying intricacies. Still, NKF is not convinced that prohibiting multi-listing is a remedy for advancing equity in transplantation.

“For people who are doing this the first time, I totally understand why they go home and just give up and die because it is too hard! They need an advocate.”

M. Gilchrist, NKF Patient Advocate

Disadvantaged patient populations are often victims of social policies and actions that have led to structural racism and created obstacles to transplantation, such as insurance instability, low health literacy, financial and logistical barriers, and provider bias; ¹ We appreciate the Ethics Committee noting several resolutions to address these hurdles. We believe that navigators and accessible educational materials are valuable resources for patients with limited health literacy seeking a transplant to treat their kidney failure. NKF supports programs to cover housing and other expenses, waiving residency fees, and lobbying private payers to cover multiple transplant evaluations. These recommendations illustrate that we have the capability and forethought to progress toward equity, balancing distributive and procedural justice.

We also appreciate that the Ethics Committee noted that some of the problems patients face are structural and perhaps beyond the scope of the transplant community to fix. However, the committee raised a critical point: harmonizing efforts to achieve systemic improvements at the public health level. NKF has long been a proponent of breaking down siloes within the transplant community and coming together to create a fair, transparent, patient-centric, and accountable transplant system; patients deserve this. It is critical to remember that being a patient is only one identity of a person and that people contending with organ failure want to feel better and get back to living as healthy as possible. Therefore, we urge OPTN—as the entity responsible for linking all organ donation and

¹ Boulware LE, Purnell TS, Mohottige D. Systemic Kidney Transplant Inequities for Black Individuals: Examining the Contribution of Racialized Kidney Function Estimating Equations. *JAMA Netw Open*. 2021;4(1):e2034630. doi:10.1001/jamanetworkopen.2020.34630



transplantation professionals—to champion the alignment of policies, practices, and incentives to ensure the American transplant system represents and prioritizes equitable access for all people.

In further considering equitable access through the lens of multiple listing, we encourage the Ethics Committee to heighten the urgency for transplant programs to provide clear communication, education, and awareness to all potential transplant candidates on the ability to multi-list, and this should be a shared decision-making event that is not singular, but occurs frequently throughout the consultation and evaluation phases and via multiple pathways—verbally, digitally, and written.

As patients reach the stage of selecting a transplant program and navigate the challenging transplant evaluation process, which is exacerbated by variations in transplant center selection criteria and protocols, prioritizing transparency is valuable and beneficial to patients. Further, transplant centers should not create additional barriers to transplant access by restricting the acceptance of candidates who wish to list at another center or hamper approval for patients to list elsewhere in addition to their primary center. Programs should also utilize telehealth where applicable and appropriate to mitigate the burden of patient travel during the evaluation process.

“I had a very hard time on dialysis, including thoughts of suicide. I was able to continue dialysis until one day, my father got the call and told me the caller said it was time to get to the hospital.”

J. Brown, NKF Patient Advocate

The National Kidney Foundation thanks OPTN and the Ethics Committee for a thoughtful commentary on multiple listing, an issue that presents many ethical considerations. We are ready to provide our expertise and support to ensure equitable patient access to kidney transplantation. Please get in touch with Morgan Reid, Director of Transplant Policy and Strategy (morgan.reid@kidney.org), if there are opportunities for NKF to advocate for this initiative further.

Sincerely,

A handwritten signature in black ink, appearing to read "K. Longino".

Kevin Longino
CEO and Transplant Patient

A handwritten signature in black ink, appearing to read "S. Rosas".

Sylvia Rosas, MD, MSCE, KNKF, FASN
President