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Tina Rhoades  
Transplant Community Administrator  
United Network for Organ Sharing  
700 N 4th St  
Richmond, Virginia  
23219

October 2, 2019

Dear Ms. Rhoades,

The National Kidney Foundation (NKF) is pleased to provide comments on the proposal to eliminate the use of Donation Service Areas (DSA) and regions in allocation of deceased kidneys to increase equity in access to kidney transplantation. We support the goals of the proposal to improve equity in access to transplant and to address geographic disparities caused by the DSA, however we do have concerns that the proposal may have unintended consequences that have not been captured by the modeling requests. We offer the following comments and alternative recommendations as follows.

The National Kidney Foundation is the largest, most comprehensive and longstanding patient centric organization dedicated to the awareness, prevention and treatment of kidney disease in the U.S. We have provided evidence-based clinical practice guidelines for all stages of chronic kidney disease (CKD), including transplantation, since 1997 through the National Kidney Foundation Kidney Disease Outcomes Quality Initiative (KDOQI).

NKF supports the development of more appropriate guidelines for the allocation of scarce organs. We agree that that DSA boundaries were designed for organ recovery purposes rather than for organ allocation and further recognize that DSAs and regions vary considerably in geographic size, population and transplant volume. Given that the DSA where the transplant candidate is located is the most significant factor resulting in disparities in access to transplant, we support the need for more equitable policies. We are concerned, however, that the modeling requests do not fully reflect the complex nuances of real-world implementation that will impact every stakeholder in the transplant system, most importantly, patients and their families. We recommend a more stepwise approach to implementation, beginning with a more manageable 250 NM circle while evaluating key patient-centered metrics such as equity, access, outcomes, as well as transplant center, OPO, and donor hospital activity under the new rules. After appropriate evaluation, expansion to 500 NM could be implemented if it is determined greater gains can be realized by increasing the distribution area.

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If implemented as proposed, we are concerned that some of the fixed-distance circles will result in territories that are seriously diminished by the presence of large bodies of water such as the Great Lakes and along the coasts. We encourage OPTN to consider how equity in access to transplant may be affected by this geographic issue. We also are concerned about increasing the amount of time organs may spend in cold storage as the median distance from donor hospital to transplant center increases from 72 NM to 199 NM. It may be wise to consider a change to the transplant center regulations to create allowances for worse outcomes as a result of longer cold ischemic times. While we understand the modeling that OPTN commissioned indicated that there would not be meaningful changes in waitlist mortality count or rate or graft failure, we note and are concerned that the projections are based on modeling data alone, which we believe has its limitations.

We believe our recommendation to more cautiously implement the proposal will better enable OPTN to monitor and mitigate any unintended consequences of the policy, especially as they pertain to access, outcomes, and the significant operational, logistical, and transportation hurdles that will result from a broader distribution of organs among many more transplant centers and thousands of patients.

In conclusion, though we support the goals of the proposal, we believe the potential for unintended consequences is high. OPTN must be sufficiently thoughtful about the unintended effects in the real world setting and how they can be reasonably mitigated with a less dramatic initial circle size or through other policy approaches. We are sympathetic to the reliance on modeling data but emphasize that modeling does not capture the nuances of how the proposal may function in the real world, especially for kidney patients who are the most important stakeholder in this discussion. We therefore note that extensive monitoring and data collection will be paramount.

Thank you for your consideration of our concerns. Please contact Miriam Godwin, Health Policy Analyst, at [Miriam.godwin@kidney.org](mailto:Miriam.godwin@kidney.org) if you require further information.

Sincerely,

*Kevin Longino*

Kevin Longino  
CEO and transplant patient

*Holly Mattix Kramer*

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President