



Tel 212.889.2210 Fax 212.689.9261 www.kidney.org

David C. Mulligan, MD Yale Physicians Building 800 Howard Avenue, Ste 4th Floor New Haven, CT, 06519

Dear Dr. Mulligan,

The National Kidney Foundation (NKF) expresses our gratitude to the Executive Committee of the Organ Procurement and Transplant (OPTN) Network for the opportunity to comment on the 2021-2024 OPTN Strategic Plan. NKF strongly supports the four goals outlined in the draft plan; to increase the number of transplants, increase equity in access to transplants, promote living donor and recipient safety, and improve waitlisted patient, living donor, and transplant recipient outcomes.

Increase the Number of Transplants

NKF supports this goal and the described objectives. NKF stands for patient choice. Every patient who wishes to and who is medically eligible to receive a kidney transplant deserves the opportunity to receive one. Due to the dramatic gap between demand and supply, however, too many patients never have the chance to benefit from the advantages that a kidney transplant can provide. A key pillar of NKF's advocacy agenda is reducing the number of kidney discards by instituting policies that balance equity and utility. Clinically valuable organs continue to be discarded as a result of inaccurate characterization of organ quality, logistical challenges resulting in prolonged cold ischemic times, and fear of the repercussions of early graft failure on centers' publicly reported outcomes.

In 2017, NKF convened a Consensus Conference on Decreasing Kidney Discards. The experts convened for the conference put forth a set of policy and operational discard conference recommendations, including the creation of expedited placement pathways within allocation policy that directly offer organs at risk of discard to centers that have a demonstrated commitment to accepting and transplanting these organs. In short, allocation policies that expedite placement from the first offer for a subset of kidneys that are otherwise likely to be discarded. NKF hopes to work with the Executive Committee and the Kidney Committee on the development of a draft expedited placement policy for the consideration of the UNOS membership.

NKF believe that metrics and monitoring approaches have an important role in performance improvement, particularly as it pertains to increasing the number of transplants by improving the organ supply. NKF is a longstanding supporter of implementing an appropriately adjusted organ offer acceptance rate measure for transplant centers as a means to improve organ utilization and thus bring clinically valuable organs to patients who are waiting. Organ acceptance rate combined with post-transplant outcomes that are measured against dialysis mortality reflect what patients truly want.

¹ https://onlinelibrary.wiley.com/doi/full/10.1111/ctr.13419



We encourage the Membership Professional Standards Committee (MPSC) to incorporate transplant center organ offer acceptance into the evaluation of center performance. The measure should be carefully designed to ensure that centers are not penalized for matching the right organ to the right recipient. Better transparency into turndowns is also important to patients. We recommend that UNOS work with the Scientific Registry of Transplant Recipients (STtR) to provide these data to the community. Such an effort would complement an organ offer acceptance rate measure.

Finally, while NKF is a strong supporter of increasing geographic equality on behalf of patients waiting for kidney transplants across the country, we note that the elimination of the DSA and region policy has created unprecedented logistical and economic challenges. We recommend that UNOS closely monitor discard rates to ensure that the policy change does not increase the discard rate. We also note that broader allocation is likely to increase transplant center costs. Although we acknowledge that Medicare payment policy is not in scope for OPTN, it would be wise for policy development to consider the financial implications of policy revision on patients, providers, and payers. Doing so would enable organizations like NKF to advocate for the need for payment reform proactively as policy is debated and implemented, thus increasing the likelihood that policies that have financial impacts will successfully meet their objectives.

Provide Equity in Access to Transplants

NKF is pleased that UNOS continues to focus on improved equity. We strongly support this goal and its objectives. Structurally disadvantaged populations fall behind at every step of the transplant process. Payer status, social economic factors, and education are all correlated with lower waitlisting rates, yet none of these issues sufficiently limits success of transplant to justify exclusion of medically acceptable candidates. In addition, Black or African American patients are disadvantaged in access to the waitlist by race-based estimates of GFR that overestimate their kidney function. Improving equity in access to transplant for candidates of all races, ethnicity, and socioeconomic statuses is an obligation that every organization involved in transplantation shares. With regards to examining differences in access to transplant among ethnic, economic, and geographic grounds and developing strategies to address identified disparities, NKF is especially interested in better data collection and accountability to ensure timely transplant referrals and evaluations. It is hypothesized that referral and time to evaluation are bottlenecks for patients of racial and ethnic minorities, non-urban dwellers, and non-English speakers. Like many issues of importance to kidney patients, referral to transplant and time to evaluation involve numerous physician and provider stakeholders and must be addressed holistically. Although dialysis facilities are obligated by CMS regulations to evaluate patients for suitability for referral within the first 30 days of dialysis initiation and annually thereafter, it is well known that many patients are never referred for transplant, referred late, or are not regularly updated on their suitability for referral. Nephrologists are the gatekeepers for referral but have no formal accountability for transplant referral. NKF is working on these issues with CMS and the dialysis and nephrology communities. As it relates to the transplant community, we recommend that UNOS works with transplant centers and the ESRD Networks to develop metrics to assess and track timeliness of



referral, time to activation, and proportion of the waiting list that is inactive. NKF supports strategies to incentivize proactive implementation of approaches to reduce delays in evaluation and listing.

Promote Living Donor and Transplant Recipient Safety

NKF is a longtime support of removing financial disincentives to living donation. We encourage UNOS to work with HRSA to continue to reform the Reimbursement of Travel and Subsistence Expenses toward Living Organ Donation Program administered by the National Living Donor Assistance Center (NLDAC) to remove the means testing of the recipient and to increase the income eligibility threshold for both donor and recipient. We further recommend that UNOS is ensuring that living donors receive information on all possible economic assistance in order to prevent financial barriers from precluding donation. Finally, UNOS should work with centers to ensure that differences in candidacy for donation including race and ethnicity are based on assessments of donor renal function that do not use estimated equations or other methods that include race modifiers but instead use assessments that measure actual function (e.g., 24-hour urine creatinine clearance or nuclear medicine scan).

Improve Waitlisted Patient, Living Donor, and Transplant Recipient Outcomes

NKF supports this goal however we would encourage the MPSC to continue to lessen the focus on post-transplant outcomes, which is not the outcome that matters most to patients.² Getting on the waitlist and reducing time on the waitlist are highest priorities for patients. We recommend that UNOS work with the SRTR and organizations like NKF to develop outcome measures that reflect patient's priorities for the care. On this point, we would note again the importance of an organ offer acceptance rate measure that ensures patient access to transplant is not reduced by operational barriers, poor data, or unwarranted center concerns about citations for poor outcomes.³

NKF hopes to be a partner to UNOS in implementing the recommendations contained herein. Please contact Miriam Godwin (miriam.godwin@kidney.org) to discuss further.

Sincerely,

Kevin Longino

CEO and transplant patient

² https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6314030/

³ https://pubmed.ncbi.nlm.nih.gov/26954720/

