

## Statement for the Record

### Subcommittee on Economic and Consumer Policy Remote Hearing on “The Urgent Need to Reform the Organ Transplantation System to Secure More Organs for Waiting, Ailing, and Dying Patients”

The National Kidney Foundation (NKF) has been a longtime proponent of reforming and modernizing our organ transplantation system. Our position is driven by our obligation to the almost 100,000 patients currently awaiting a lifesaving kidney transplant. Unfortunately, as only about 23,000 transplants take place each year, 12 kidney patients die each day on the transplant waitlist.

Stakeholders from all corners of the transplant community generally agree that there are numerous gaps in the transplant system. On the supply side, deceased donor organs go unreported by donor hospitals and unprocured by Organ Procurement Organizations (OPOs). Procured organs go missing in transport, possibly hundreds of organs every year.<sup>1</sup> Though the demand side of transplantation has received less scrutiny, it is no less important. Suitable candidates for transplantation are too often not referred to transplant centers. Those who are suitable and who are placed on the waitlist must run a 3-to-5-year gauntlet, and in some states wait up to 10 years, before they receive a transplant. Despite the lengthy wait, transplant centers turn down potentially clinically valuable organs on behalf of patients without their knowledge. Approximately 18 percent of procured deceased donor organs are discarded. Due to the interdependent nature of our system, however, no single stakeholder can be held responsible for wholesale improvements to the transplant system. NKF is committed to advocating for greater accountability that drives *all* stakeholders to be high performers on behalf of patients.

NKF applauds the Subcommittee for its interest in this important topic and for its hearing on deceased donor organ procurement. The NKF supported the revisions to the OPO Conditions for Coverage that were finalized in December 2020 and implemented on March 30, 2021. We believe it is unlikely that the regulation will result in significant, negative unintended consequences for patients. However, if additional concerns arise as the rule is implemented, NKF is committed to working with Congress and the Administration on sub-regulatory guidance, clarifications, and other policy changes, if necessary.

It is important to note, that changes to OPO regulation are only one part of a large and complex puzzle. The behavior of donor hospitals, OPOs, transplant centers, dialysis facilities, nephrologists, and patients are all closely interrelated. Policy changes that acknowledge the interdependence of the system can maximize their benefit to patients. For example, while the new OPO Conditions for Coverage will result in more organs being identified, procured, and transplanted, its implementation will be streamlined by ensuring transplant centers have concomitant accountability for accepting procured organs. Transplant centers frequently turn down organs that are “less than perfect” because they are procured from a donor who was older, had hypertension, or had other risk factors that potentially affect the perceived quality of their organs. In our comments to CMS about the rule, we recommended concurrent policy changes to create an organ offer-acceptance measure to create greater accountability for transplant centers.

In this instance, we are pleased that the United Network for Organ Sharing (UNOS) is considering a measure of organ offer acceptance for transplant centers. This will work in concert with the new

---

<sup>1</sup> <https://revealnews.org/article/lifesaving-organs-for-transplant-go-missing-in-transit/>

## Statement for the Record

### Subcommittee on Economic and Consumer Policy Remote Hearing on

#### “The Urgent Need to Reform the Organ Transplantation System to Secure More Organs for Waiting, Ailing, and Dying Patients”

incentives for OPOs to procure more organs from deceased donors to ensure that transplant centers are accepting *and* transplanting the organs procured, thus reducing turndowns and organ discards, and increasing the benefit to patients overall.

Looking ahead, NKF encourages the Subcommittee to expand the scope of its investigation to look at the whole of organ donation and transplantation, ensuring that every component of the system is operating at maximum efficacy for the patients we serve. Specifically, we encourage the Subcommittee to:

- **Examine the roles of dialysis facilities and transplant centers in the early steps to transplant.** Dialysis facilities have numerous responsibilities to patients regarding transplant education and referral. The extent to which dialysis facilities are meeting these obligations are not clear and at best, highly variable. Transplant centers are not obligated report data on patient referrals nor on the early steps to accessing the waitlist. It is hypothesized that the early steps to transplant particularly challenge low-income, diverse, and other structurally disadvantaged populations. Patients cannot benefit from the organ donation and transplant system if the barriers to entry are too steep to overcome.
- **Investigate whether the oversight the Organ Procurement and Transplant Network (OPTN) is creating the appropriate patient-centered accountabilities for its members.** Every transplant center, OPO, and histocompatibility lab in the country is a member of the OPTN. UNOS, which has been awarded the OPTN contract continuously since its inception, acts as its own supervisory body. In that capacity, UNOS must hold transplant centers accountable for the processes and outcomes that matter most to patients, including but not limited to increased education, transparency, shared decision-making, and communication.
- **Examine the tools available for patient decision-making on transplant.** The Scientific Registry of Transplant Recipients (SRTR) acts as a de facto Transplant Center Compare for patients seeking information about transplant centers. Patients report that the SRTR tools are difficult to use and thus impractical for decision-making. SRTR is engaged in developing more patient-centered tools. The Subcommittee should hold SRTR accountable for ensuring patients have access to patient-centered data presented in actionable formats.
- **Scrutinize the root causes of kidney discards.** As described above, approximately 18 percent of procured kidneys are discarded with no input from patients. UNOS’ proposed oversight over organ offer acceptance is an important, but preliminary, step forward. The OPO regulation will incentivize the procurement and utilization of more marginal deceased donor organs. These organs are often clinically valuable to patients and should be transplanted; however, they are more costly to transplant centers due to the increased complexity of the transplant and post-operative care. The insufficient Medicare payment for kidney transplant has been identified as a cause of kidney discards. We encourage the Subcommittee to review the adequacy of the Medicare reimbursement for kidney transplant in light of the implementation of the OPO rule, particularly in contrast to the extraordinary spending on beneficiaries with end stage kidney failure, exceeding 7% of traditional Medicare expenditures.<sup>2</sup>

---

<sup>2</sup> <https://adr.usrds.org/2020/end-stage-renal-disease/9-healthcare-expenditures-for-persons-with-esrd>

Statement for the Record

Subcommittee on Economic and Consumer Policy Remote Hearing on

“The Urgent Need to Reform the Organ Transplantation System to Secure More Organs for Waiting, Ailing, and Dying Patients”

- **Investigate mechanisms to provide greater protections for living donors.** Living donation is essential for increasing the number of transplants. Donation should result in no avoidable consequences for the donor, financial or otherwise. We encourage Congress to expeditiously enact the Living Donor Protection Act (H.R. 1255 / S. 377). The LDPA prohibits insurers from discriminating against living donors in the issuance, cost, or level of coverage of life, disability, or long-term care insurance. The Subcommittee should also examine policies to reduce the financial costs associated with donation, either through improving the Reimbursement of Travel and Subsistence Expenses Incurred toward Living Organ Donation program or through other means.
- **Address racial disparities in transplantation.** Kidney failure disproportionately affects communities of color and yet these communities are less likely to obtain and maintain a kidney transplant. Black or African Americans are almost four times more likely and Hispanics or Latinos are 1.3 times more likely to have kidney failure compared to White Americans. Although they make up only 13.5% of the population, Black or African Americans make up more than 35% of dialysis patients. Although a kidney transplant is the optimal treatment for kidney failure, Black patients face barriers to access at every step of the process and on average wait a year longer than white patients to receive a kidney transplant. Black patients are less likely to receive a transplant evaluation, have less access to the waitlist, spend longer on the transplant waitlist, are less likely to survive on the waitlist, and have lower rates of graft survival post-transplant. Additionally, socio-economic barriers can determine a patient’s eligibility for a transplant due to non-medical factors such as not having a cellphone, lacking access to reliable transportation, lacking access to dental care, or childcare difficulties. To begin to address these disparities in transplantation, the National Kidney Foundation proposes the creation of a discretionary grant program to support low-income transplant candidates by providing monetary assistance for transportation, technology, childcare, and other needs to improve their chance at a successful transplant. We also call on Congress to improve national data collection on the early steps of the transplant process, such as transplant referral and start of the transplant evaluation, and authorize programs that educate racially and ethnically diverse communities on organ donation, specifically living donation. Additionally, we ask Congress to mandate that all patients receive culturally competent, third party conflict-free transplant education provided by an unbiased provider that is unaffiliated with a dialysis or transplant program.

Working together to operationalize and build upon these recommendations, we can achieve our shared objective of collecting more organs, transplanting more organs, and saving more lives. In closing, thank you for your careful consideration of these important issues. Please contact Lauren Drew ([lauren.drew@kidney.org](mailto:lauren.drew@kidney.org)) with any questions.