Transforming the Transplantation System for All Americans

The American Society of Nephrology (ASN) believes that every American should have equal access to transplantation: the gift of life. More than 800,000 Americans are living with kidney failure, and for many a kidney transplant is the optimal therapy, providing the highest quality of life at the lowest cost over the life of the transplanted kidney. Alarmingly, a kidney transplant remains out of reach of many. Every day, thirteen Americans die while waiting for a kidney transplant, and Black/African Americans, Hispanic Americans, Asian Americans, Indigenous/Native Americans, and Native Hawaiian and Pacific Islanders wait more than 2 years longer on average to receive a kidney than White Americans. Below are highlights of recommendations ASN has made to the Centers for Medicare & Medicaid Services (CMS) and the Health Resources and Services Administration (HRSA) in response to recent request for information on how to improve the organ transplantation system.

First and foremost, **ASN urges Congress to create an Office of Transplant Policy** in the Department of Health and Human Services (HHS) to oversee and coordinate the many transplant related pieces of the entire system housed within HHS. In addition, below is a list of ideas for Congress to direct HHS to address.

- **Equity**
  1. Prioritize achieving equity in transplantation across silos of care from organ failure diagnosis to postoperative care. Begin by developing and maintaining transparent guidelines, measurement and reporting tools, and data collection on all steps along the pathway to transplantation in real time all aimed at capturing and demonstrating efficacy of equity efforts throughout the transplant ecosystem.
- **Patient First**
  2. Provide web-based transplant information that is patient friendly and understandable, while also ensuring perspective transplant patient criteria and transplant center thresholds are transparent.
  3. Creation of shared decision support tools that would help patients and programs evaluate an organ offer with the perspective of what patients want and the probability of a better organ offer within a reasonable time frame which would justify declining or passing on an organ offer.
  4. Support increased reimbursement for care coordination across silos of care for all transplant patients and especially supporting the use of less-than-optimal organs. Increased use of less-than-optimal organs can lead to more complex patients post-transplant and increased instances where patients remain dialysis dependent for some duration post discharge.
- **System Reform**
  5. Incentivize maximum access to a transparent waitlist, increased deceased donor organ use, and transplant rates, while continuing to maintain post-transplant outcomes.
  6. Separate the IT infrastructure contract from the overall OPTN contract similar to the SRTR contract.
  7. Track data on organs that are declined on the behalf of patients and then are subsequently used for other patients.
  8. Elimination of a relative percentile score for quality of the kidney such as the Kidney Donor Profile Index (KDPI) and pursue metrics that reflect weighing transplantation options versus continued dialysis.
  9. Address the data gap resulting from increasing Medicare Advantage participation and coordinate patient outcome data sharing for CMS and HRSA.
  10. Ensure transparency for allocation system variations or violations to address “list diving” and out of sequence offers and conduct systemwide review of data in the national registry to achieve increased data quality.