

Chair McMorris Rogers, Chair Griffith, Ranking Member Pallone, Ranking Member Castor, and distinguished members of the committee, thank you for the opportunity to testify today on behalf of the National Kidney Foundation regarding the implementation of the Securing the U.S. Organ Procurement and Transplantation Network Act.

I am Dr. Jesse Roach, and in addition to leading the government relations department at the National Kidney Foundation, I am also a nephrologist who has worked with many patients in kidney failure and throughout their transplant process.

I am grateful to be here today to speak on behalf of the over 800,000 people living with kidney failure and the nearly 90,000 people on the kidney transplant waitlist. These patients, who wake up every day hoping for a life-saving transplant, are the reason we are all here today.

The passage of this Act brought hope to these patients and their families. It promised a more equitable, transparent, and patient-centric organ donation and transplantation system. Today, we are beginning to see that promise materialize, but there is still much work to be done to truly meet the needs of those waiting for another chance at life.

HRSA's OPTN Modernization Initiative is a comprehensive effort to address longstanding challenges in our organ donation and transplantation system. For patients, this initiative represents the potential for shorter wait times, better-matched organs, and ultimately, more lives saved. We commend Congress and HRSA for taking on this ambitious project and for the progress made thus far.

While progress has been made, we remain concerned about the lack of transparency, patient-focus, and equity in the organ transplant system, and are deeply troubled by the increasing number of kidneys that are thrown away each year. 1 in 4 recovered kidneys are not transplanted, and in 2023, there were 8,574 kidneys recovered with the intent to transplant, but that were later discarded. That comes out to about 23 kidneys wasted per day. At the same time, an average of 12 people die each day waiting for a kidney transplant. This is a system failure and is completely unacceptable.

To further strengthen the implementation of the Act and directly benefit patients, we recommend that HRSA's Request for Proposals and the final OPTN contract include provisions that:

1. Explicitly state how vendors and HRSA itself will be held accountable for maximizing every organ donation and transplantation opportunity. Every unused organ represents a lost chance at life for a waiting patient.
2. Mandate regular, easy-to-understand reporting to patients on organ offers and declines made on their behalf. This transparency will empower patients to make informed decisions about their care and give them a clearer understanding of their status on the waitlist.
3. Require the collection and public reporting of data on the pre-waitlisting experience. For many patients, the journey to the waitlist is fraught with obstacles. Understanding referral rates, evaluation timelines, and living donor processes can help identify and address disparities in access to transplantation. This data can also be used to ensure that all patients are treated fairly and equitably.

Further, we would like to highlight a few areas where continued focus is needed to better serve patients:

1. We need a diverse and independent OPTN board that includes strong patient representation, bringing the lived experiences of those on the waitlist to the decision-making table. While institutional continuity is a valuable asset, this system has

been run by a small group of the same people for many years, and it is time that a broader set of stakeholders have space at the table.

2. Enhanced oversight of OPTN committees is essential. Many policy decisions are made at the committee level but it has traditionally been an opaque process. HRSA needs to have and use its oversight powers to ensure that decisions are made in a timely, transparent, and patient-centric manner. We must ensure that patient voices are heard, and their needs prioritized in all policy decisions.

3. While we understand the need for a smooth transition, we urge HRSA to act with urgency in implementing reforms. Every day of delay means a lost opportunity for a patient waiting for a transplant. Time is of the essence.

4. And finally, in keeping with the need for transparency and accountability, a robust system for addressing whistleblower complaints, at both the OPTN and HRSA level, is crucial to promote patient-centricity and maintain trust in the system.

Furthermore, we believe regular, transparent updates to Congress, stakeholders, and most importantly patients on the progress of enhancing organ donation and transplantation would give hope to waiting patients and their families, showing them

that real change is happening. This communication should be made available to the widest possible audience.

In conclusion, while we are encouraged by the steps taken thus far in implementing the Securing the U.S. OPTN Act, we must keep the focus squarely on the patients. For too long this system has prioritized the stakeholders and institutions at the top. Every policy decision, every system upgrade, and every new procedure must be evaluated based on its impact on those waiting for a transplant.

HRSA's efforts to modernize our organ donation and transplantation system are commendable, and we are cautiously optimistic about the positive impact these changes will have on patients' lives. However, for those on the waitlist, optimism isn't enough. They need action, they need results, and they need them now.

Thank you for your time and attention to this critical issue. On behalf of the patients we serve, I welcome any questions you may have.