



May 4, 2021

The Honorable Raja Krishnamoorthi
Chairman, Subcommittee on Economic and Consumer Policy
House Committee on Oversight and Reform
115 Cannon House Office Building
Washington, DC 20515-1308

The Honorable Michael Cloud
Ranking Member, Subcommittee on Economic and Consumer Policy
House Committee on Oversight and Reform
512 Cannon House Office Building
Washington, DC 20515-4327

Dear Representatives Krishnamoorthi and Cloud:

On behalf of the American Society of Nephrology (ASN) and its 22,000 members, thank you for the opportunity to provide comments for this important and timely hearing on “The Urgent Need to Reform the Organ Transplantation System to Secure More Organs for Waiting, Ailing, and Dying Patients.” This is a critically important issue for thousands of patients who may well die while waiting for an organ transplant as we nephrologists see far too often with patients awaiting a kidney transplant.

ASN commends Chairman Krishnamoorthi, Ranking Member Cloud, and the entire membership of the subcommittee for your ongoing commitment to increasing access to transplantation. The Trump Administration’s commitment to this issue and the 37,000,000 Americans with kidney diseases is why we are here today. Thanks to the leadership of the Trump administration, the “Organ Procurement Organizations Conditions for Coverage: Revisions to the Outcome Measure Requirements for Organ Procurement Organization” rule is now final and patients and taxpayers have transparency into the life-or-death performance of OPOs. We also commend the Biden Administration for allowing the finalized rule to take effect and striving to overcome disparities in health care that disproportionately plague individuals with kidney disease and those in need of a transplant.

The subcommittee rightly acknowledges that more than 107,000 patients in the United States are waiting for an organ transplant leading to an estimated 33 people in the United States dying everyday while waiting for their transplant. There are over 550,000 more Americans on kidney dialysis – many of whom could benefit from a kidney transplant but are either not on the waitlist or become too ill for a transplant while on the

waitlist and/or die before receiving the life-saving therapy. Simply put, the number of available organs for transplant does not meet this critical need nor has it for some time.

Therefore, ASN commends the subcommittee's focus and firmly believes the OPO final rule is a huge step to advance those efforts. Every American deserves access to an organ transplant, but the Trump Administration understood that minoritized populations bear the disproportionate burden of the organ shortage and the failures of the US transplant system, and that state of imbalance needed correction. In 2019, only 26% of Black Americans on the transplant waitlist received a kidney compared to nearly 50% of white Americans. Research has pointed to factors directly within the control of OPOs as responsible for part of this inequity, such as providing fewer opportunities for the families of potential organ donors to consider organ donation and not making OPO representatives available for consultation at the time of potential donation.

While transplantation is the best available therapy for kidney failure, Black Americans and other kidney patients of color face disparities in nearly every step of transplant care. Black Americans are less likely than white Americans to be identified as a transplant candidate, referred for evaluation, put on the kidney transplant waitlist, receive a kidney transplant, receive a higher-quality kidney from a living donor, while also being more likely to receive lower quality kidneys, and have poorer transplant graft survival.

Improving our organ transplant system will require improvement of many different, interconnected, and too often fragmented, systems, including OPO performance, streamlining government oversight of the US transplant system, cutting "red tape" surrounding the regulation of transplant centers, and above all else, ensuring that the US organ transplant system is built around and aligned with the needs of patients first. The Trump rule to measure OPO performance in an objective, standardizable, and transparent manner is an important first step in this process – one cannot fix what cannot be measured – however, Congress must make certain to follow this rule with further action to improve care for kidney patients.

ASN supports this rule for several reasons. First, the Centers for Medicare and Medicaid Services estimates this rule will increase transplants by 5,600 to 7,300 per year. That reason alone makes this the right step to make. In addition, the rule establishes both transparent, uniform metrics to help assess the performance of each of the 57 OPOs and clear procedures for evaluating those organizations including processes for improvement and re-certification. ASN believes that reforming the current system of OPO performance oversight is necessary to provide increased access to more kidneys available for transplant to end the unacceptably high levels of people dying daily waiting for an organ.

ASN supports holding OPOs accountable and supports intervening with any OPO that does not perform adequately and stands ready to work with Congress, the administration, and other stakeholders to achieve progress for Americans waiting for a transplant. For them, progress means life.

To discuss this letter further, please contact Zach Kribs, ASN Senior Government Affairs Specialist, at zkribs@asn-online.org or 202-618-6991.

Sincerely,

A handwritten signature in cursive script that reads "Susan Quaggin".

Susan E. Quaggin, MD, FASN
President

About the American Society of Nephrology

ASN leads the fight to prevent, treat, and cure kidney diseases throughout the world by educating health professionals and scientists, advancing research and innovation, communicating new knowledge, and advocating for the highest quality care for patients. ASN has more than 21,000 members representing 131 countries. For more information, please visit www.asn-online.org or contact the society at 202-640-4660.

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