



**October 1, 2025**

Ms. Christine F Brenner  
Organ Procurement and Transplant Network  
Chair, Transplant Coordinators Committee  
Sharp Memorial Hospital  
7901 Frost St., San Diego, CA 92123

Ms. Heather Mooney J Bastardi  
Organ Procurement and Transplant Network  
Vice Chair, Transplant Coordinators Committee  
Boston Children's Hospital  
300 Longwood Ave, Boston, MA 02115

**RE: Public comment on OPTN Proposal: Require Patient Notification for Waitlist Status Changes**

**Dear Ms. Brenner and Ms. Bastardi;**

On behalf of the more than 37,000,000 Americans living with kidney diseases and the 21,000 nephrologists, scientists, and other kidney health care professionals who comprise the American Society of Nephrology (ASN), thank you for the opportunity to participate in the Organ Procurement and Transplantation Network (OPTN) Transplant Coordinators Committee (TCC) public comment proposal "Require Patient Notification for Waitlist Status Changes."

Broadly, ASN appreciates the Transplant Coordinators Committee (TCC) efforts to add transparency to the waitlist process and to empower patients to work with their transplant team to ensure their listing status is accurate. These goals are important, not only for the reasons stated, but also to provide patients and the care team opportunities for more seamless communication and provision of the information, tools and resources that may assist the transplant candidate in resolving issues that prompted the status change.

Direct communication is critical to both transparency and efficiency, including effective and timely communication between patients and transplant centers. Similarly, given that most patients being evaluated for and listed for kidney transplant receive dialysis and patients have very frequent contact with their dialysis centers, improved communication between dialysis facilities and transplant centers may improve care and increase transparency for patients. For example, both transplant centers and dialysis facilities may be aware of issues that impact care of these individuals. A dialysis facility may be aware of a recent diagnosis that may preclude transplant or medical issues that may increase the urgency for transplant; a transplant center may have results of medical tests or evaluations that impact dialysis care delivery. Currently, these important stakeholders are siloed, and the communications are not systematic. Fixing this shortcoming would create a tremendous improvement to current patient care, patient experience, and patient outcomes that have been challenging for decades.

ASN supports using waitlist status updates to improve communication among transplant centers, patients, and the broader kidney care team, helping correct inaccuracies and address

health changes that affect waitlisting. Furthermore, the society urges the TCC to ensure any policy changes are aligned with federal regulatory requirements:

Under the Centers for Medicare and Medicaid Services (CMS) Conditions of Participation (CoPs) for transplant programs (42 CFR §482.94)<sup>1</sup>, centers are required to notify patients promptly in writing when:

- They are added to the waiting list,
- There are changes in their waitlist status (active ↔ inactive), or
- They are removed from the list.

Specific to the stated questions and considerations for the community, ASN offers the following:

- Do community members think that written notification is necessary, or would documentation of notifications, including conversations, be sufficient?
  - ASN supports transparency and improved communication between transplant centers, patients, dialysis facilities and referring nephrologists throughout the waitlist period.
  - While written notification is already mandated for transplant centers under CMS's Conditions of Participation (CoPs) for transplant programs, the Society urges the TCC to consider aligning these requirements with CMS policy.
  - Additionally, ASN recommends exploring ways to tailor communication to meet individual patient needs, allowing notifications through conversations if they are documented in the medical record. The Society also urges clarification on what constitutes 'written notification' to ensure consistency and compliance with documentation requirements.
- Is there additional information that would be helpful to include in the patient notification, other than waiting list status?
  - ASN supports sharing waiting list status, the reason for the change in status, actions required (if needed) to resolve cause for status change, whom to contact to provide opportunities for patients to resolve inaccurate information and take action to regain health or specific issues that necessitated the change.
- This proposal lays the groundwork for future efforts to improve patient awareness and engagement in their transplant journey. Are there additional tools or efforts, such as a patient portal, that you feel would be helpful to better inform and engage patients in the future?
  - ASN supports patients having the option to elect how they would like to receive updates, whether mail, email, text or via phone call. When available and if already in use, tools like patient portal are very helpful to engage patients especially patients who are tech savvy and opt in to use these. This is in line with the Society's previous comment of individualizing this to patient needs.
- What education or guidance would be helpful for patients & patient families and caregivers?
  - ASN suggests the TCC collaborate with the OPTN Living Donor Committee, Patient Affairs Committee and any other that can provide guidance to address this question.

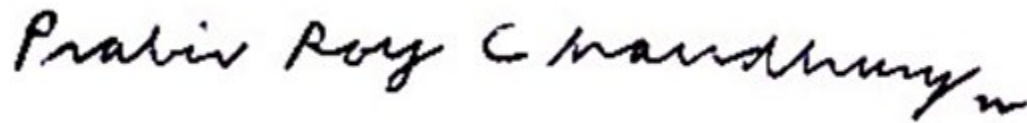
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<sup>1</sup> <https://www.cms.gov/medicare/health-safety-standards/conditions-coverage-participation/transplant-centers>

- What education or guidance would be helpful for programs to support the implementation of this proposal?
  - Clearly define what would satisfy the notification requirements in order to standardize across centers. OPTN may want to consider providing a templated letter (even better if it is available in different languages) of what is required in these notification letters to help standardize what is sent to the patient rather than each Center developing its own.

Again, ASN appreciates the opportunity to comment on this Proposal to Require Patient Notification for Waitlist Status Changes and hopes its recommendations are useful to the TCC. Please contact ASN Principal for Kidney Health Guidance, Sarah Sampsel, MPH at [ssampsel@asn-online.org](mailto:ssampsel@asn-online.org) with any questions or to discuss this letter in more detail.

Sincerely,

A handwritten signature in black ink that reads "Prabir Roy Chaudhury". The signature is written in a cursive, flowing style.

Prabir Roy-Chaudhury, MD, PhD, FASN  
President