

Thank you to everyone who attended the Region 9 Summer 2025 meeting. Your participation is critical to the OPTN policy development process.

Regional meeting <u>presentations and materials</u>

Public comment closes October 1st! Submit your comments

The sentiment and comments will be shared with the sponsoring committees and posted to the OPTN website.

Non-Discussion Agenda

Modify Guidance for Pediatric Heart Exception Requests to Address Temporary Mechanical Circulatory Support Equipment Shortage

Heart Transplantation Committee

Sentiment: 3 strongly support, 2 support, 2 neutral/abstain, 0 oppose, 0 strongly oppose

Comments: No Comments

2025 Histocompatibility HLA Table Update

Histocompatibility Committee

Sentiment: 3 strongly support, 2 support, 2 neutral/abstain, 0 oppose, 0 strongly oppose

Comments: This was not discussed during the meeting, but attendees were able to submit comments. A

member stated that this is important because it will help HLA lab know how to put unacceptable

antigens in the OPTN Computer System.

Discussion Agenda

Require West Nile Virus Seasonal Testing for All Donors

Ad Hoc Disease Transmission Advisory Committee

Sentiment: 2 strongly support, 1 support, 1 neutral/abstain, 4 oppose, 0 strongly oppose

Comments: A member stated that bringing a living donor back for testing so close to donation is not ideal and proposed aligning it with existing serology testing guidelines. An attendee noted that many labs send out testing to reference labs, which delays results by 3–4 days, and expressed concern that requiring OPOs to have results prior to organ implantation could delay recovery, reduce authorizations, and hinder rapid cases involving donor instability. A member noted that while 7 days for living donors can seem burdensome, five days might be more appropriate since mosquito bites could happen at any time, while also acknowledging concerns about the emotional impact on recipients and the difficulty of ensuring test completion. An attendee encouraged all living donor programs to assess their turnaround time for West Nile virus NAT testing to ensure their ability to comply with the seven-day window. A member raised concern about false negatives from donor blood samples and asked DTAC to confirm the



clinical utility of requiring NAT on blood, noting WNV's stronger tropism toward the central nervous system, organs, and tissues. An attendee stated that seven days is too short, as most labs only run the test on certain days and results take 2–4 days. Two additional members agreed that 7 days is too short of a turnaround time. An attendee commented that the testing infrastructure is not robust enough to support efficient donor placement and that the 7 day timeframe is too short, suggesting that perhaps a middle ground could be 14 days. A member stated that the requirement for testing within 7 days of living donation is onerous for living donors, who are purely voluntary participants, and emphasized that the process should not be made more burdensome while maintaining safety. The member noted that infection via mosquito bite can occur at any time up to donation and recommended aligning any new proposal with the current policy, which requires serologies to be drawn within 28 days of donation.

Update and Improve Efficiency in Living Donor Data Collection

Living Donor Committee

Sentiment: 1 strongly support, 4 support, 0 neutral/abstain, 1 oppose, 0 strongly oppose

Comments: A member stated that collection of a potential living donor's social security number should be delayed until they are an approved donor. An attendee raised concern about donors opting out due to fear or pressure who would be uncomfortable with an individual they didn't know reaching out with questions and suggested adding an opt-out button to the form to allow upfront discussions with the patient. A member noted a unique issue in New York state where they are required to help donors craft a medical reason for not proceeding and asked whether responses should align with the donor's rights. An attendee requested revision of the proposal's details and opposed it in its current written form. A member emphasized that EMR programming for the new donor decision forms should occur prior to implementation to reduce burden on transplant centers. An attendee stressed the need for EMR infrastructure to support form submission and reduce administrative burden. A member supported collecting data to identify barriers to donation but opposed placing long-term data collection responsibilities on transplant centers for non-donors, stating that limited OPTN resources should not be used to track the general community's health.

Require Patient Notification for Waitlist Status Changes

Transplant Coordinators Committee

Sentiment: 2 strongly support, 6 support, 0 neutral/abstain, 0 oppose, 0 strongly oppose

Comments: A member suggested considering notifications based on the length of time a patient has been inactive, especially for renal organs, to prevent errors such as temporary inactivation lasting up to six months or longer-term inactivations lasting 1–2 years. An attendee emphasized the importance of notifying patients and recommended offering both verbal and written notification options, noting that verbal communication may be more effective for some patients. A member expressed surprise that this isn't already policy and supported the initiative, reiterating the need for verbal communication alongside written notification. An attendee shared that the original patient request was for an app or other digital access through the OPTN that allows patients to check their status 24/7. A member supported the proposal and strongly advocated for the rapid development of an OPTN-managed patient portal to provide timely access to listing status. An attendee stated that notifications should include the reason for the change to inactive status, allowing patients to work toward reactivation, and suggested that a phone call with chart documentation should suffice for status changes. A member recommended

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excluding inpatient changes and accepted verbal communications if properly documented. An attendee stressed the need for an OPTN-managed patient portal for verifying waitlist status. A member cautioned that overly complicated processes might confuse patients. An attendee emphasized, as a patient advocate and representative of an organization supporting individuals awaiting transplants, the critical importance of written notification regarding transplant listing status. While patient portals are useful, many patients face barriers such as age-related technology challenges, limited internet access, health conditions, and confusion stemming from informal conversations with providers. These issues can lead to misunderstandings about listing status, potentially delaying care. The commenter strongly advocated for multiple notification methods, including written letters for listing confirmation and status changes, phone calls for time-sensitive updates, and digital notifications as supplementary communication. Clear, written documentation was described as essential for patient safety and peace of mind.

Establish Comprehensive Multi-Organ Allocation Policy

Ad Hoc Multi-Organ Transplantation Committee

Sentiment: 2 strongly support, 6 support, 0 neutral/abstain, 0 oppose, 0 strongly oppose

Comments: A member expressed support for the proposal but noted that late declines of organs may still pose challenges. An attendee felt that the initial example presented at the beginning of the session represents an unmet need. A member asked whether stratifying highly sensitized patients above multiorgan candidates has been considered, given that all organs now have safety net access. An attendee highlighted a significant gap in patient education, noting that many patients feel overlooked due to misunderstandings about the allocation system and multi-organ listings, and emphasized the need for improved communication tools and standardized processes. A member requested data on how many highly sensitized candidates have had organs transplanted above them on match runs, suggesting that this revision could improve access for PRA 100% patients. An attendee expressed interest in a pediatric proposal that prioritizes multi-organ transplants, particularly heart-liver combinations. A member stated that regulation helps ensure the right decisions are made.

Updates

Councillor Update

- Comments:
 - o None

OPTN Patient Affairs Committee Update

- Comments:
 - o None

OPTN Executive Update

Comments: An attendee noted that the increase in allocation out of sequence (AOOS) seems to
have coincided with the introduction of the new CMS metrics for OPOs and wondered if there
would be potential proposals to redesign those. The presenter noted it has been raised and that
all options will be on the table to ensure AOOS is a rarity. A member thanked the presenter for
the update and expressed appreciation for the amount of work the new OPTN Board of
Directors has done in a short amount of time. An attendee inquired about the development of

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offer filters for non-renal organs. The presenter agreed that every organ needs individualized and applicable filters.

HRSA OPTN Modernization Update

• Comments: Attendees provided feedback to HRSA's Division of Transplantation during this session.