

Thank you to everyone who attended the Region 6 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: 0 strongly support, 3 support, 4 neutral/abstain, 0 oppose, 0 strongly oppose

Comments: None

2025 Histocompatibility HLA Table Update

Histocompatibility Committee

Sentiment: 2 strongly support, 5 support, 2 neutral/abstain, 0 oppose, 0 strongly oppose

Comments: None

Discussion Agenda

Require West Nile Virus Seasonal Testing for All Donors

Ad Hoc Disease Transmission Advisory Committee

Sentiment: 1 strongly support, 5 support, 1 neutral/abstain, 2 oppose, 0 strongly oppose

Comments: One attendee commented that the policy language requiring living donor testing "within seven days of the planned organ recovery or as close to that date as possible" is difficult to monitor for compliance. They went on to comment that Region 6 covers a large geographic area, with patients often traveling from distant places such as Montana and Alaska. They expressed concern that requiring living donors to be present not only for the operation and recovery but also a week beforehand for testing would place a significant burden on these patients. They also asked if any Organ Procurement Organizations (OPOs) currently performing routine screening have identified any positive results. Another attendee also raised geographic concerns, stating that Region 6's large area can cause delays in testing. They cautioned that requiring test results prior to transplant could delay the process and impact OPOs' ability to proceed quickly with deceased donor recoveries, which often operate under strict time constraints. One attendee recommended changing the timeline for living donor testing to align with the timeline for serologies, which requires testing as close as possible but within 28 days prior to organ recovery. They noted that having consistent timelines would reduce confusion and help with planning.



Another attendee commented that adding this testing requirement could complicate the coordination of living donor surgeries without providing much benefit. They also noted that for deceased donors, the results would likely arrive post-transplant and the test has a high rate of false positives, reducing its usefulness. Another attendee raised concerns that requiring living donor testing within seven days prior to organ recovery and having results available before implantation could be problematic given the turnaround times for West Nile virus (WNV) NAT testing. They noted that this requirement could force living donors to travel and arrive earlier than necessary, adding hardship. They recommended that WNV testing for living donors be a recommendation rather than a requirement.

Update and Improve Efficiency in Living Donor Data Collection

Living Donor Committee

Sentiment: 1 strongly support, 4 support, 3 neutral/abstain, 1 oppose, 0 strongly oppose

Comments: Attendees discussed questions and concerns regarding living donor data collection and follow-up. Several attendees expressed concern that the 90-day non-donation form window would create additional burden for transplant programs and could discourage potential living donors, particularly those from at-risk groups, due to uncertainty about how their data might be used. One attendee recommended that SRTR follow up with the donors rather than transplant centers. Some attendees commented that requiring an in-person meeting as a threshold to submit data collection or follow-up could result in missing many living donor candidates who ultimately do not donate, especially since some centers conduct much of their evaluation process virtually. Another attendee commented that we need a true comparison group. They explained that people who consider living donation are typically healthier than the general population; tracking their long-term outcomes lets us compare them with actual donors in a meaningful way and interpret differences as donation-related versus baseline health. They added that it will help the community to understand where people encounter barriers, clinical, psychosocial, or practical, so they can target support and improve access and equity across the process. They emphasized that this comparator approach strengthens risk counseling and policy design by anchoring donor outcomes to a similar, healthy reference group while illuminating points in the pathway where candidates disengage.

Require Patient Notification for Waitlist Status Changes

Transplant Coordinators Committee

Sentiment: 0 strongly support, 2 support, 5 neutral/abstain, 0 oppose, 2 strongly oppose

Comments: Several attendees commented that they were in favor of patient notification but recommend that other forms of communication be acceptable for the notification. One added that a written letter is archaic, burdensome and inefficient. Another attendee added that mail is often delayed and many times status changes can be short term, so by the time a patient gets the written notification it would be outdated. Another attendee commented that you can also confirm that a patient has read the message in MyChart or a phone call, which you cannot do with mailed letters. One attendee commented that mail delivery in rural communities struggles sometimes, even going beyond 10+ days. They agreed that MyChart or a phone call would be the most feasible. Another attendee commented that not every patient has MyChart and would caution us not to require written notification. Phone calls would be more appropriate for those patients. Another attendee commented that the Portland VA serves veterans from Florida to Hawaii and Guam, so mailing is inefficient in terms of prompt

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notification. Another attendee recommended allowing for notification to be sent via any reliable method within 10-days of receiving status modification with appropriate documentation of notification attempts. Another attendee commented that for short inactivation's of less than a week, it seems like a lot of additional work and may be confusing to patients if they are required to send them something in writing. One attendee commented that their center is already notifying patients of status changes, and it has greatly improved communication amongst patients and care teams. Another attendee commented that requiring patient notification would place undue burden on centers with large waitlists and for patients that have frequent changes. They supported allowing for other methods of notification such as secure messaging and phone calls. They added that requiring written notification would place further burden on centers when there are frequent changes to a patient's active vs inactive status (within several days).

Establish Comprehensive Multi-Organ Allocation Policy

Ad Hoc Multi-Organ Transplantation Committee

Sentiment: 1 strongly support, 3 support, 3 neutral/abstain, 1 oppose, 0 strongly oppose

Comments: One attendee commented that the proposed multi-organ allocation plan could be a useful guide for Organ Procurement Organizations (OPO) coordinators when donor management, organ evaluation, and allocation proceed in a linear and timely fashion. However, they noted that this type of linear progression is typically the exception rather than the norm, due to changing donor clinical status and varying transplant center acceptance decisions. Several attendees commented that the change would not help transplant centers understand where their single-organ candidates stand when multiple organs are being allocated. They stated this is a major problem for transplant centers and recommended that the match run be modified so centers can see allocation priority. They emphasized that clear, easyto-follow instructions with color coding would be helpful, and that transplant centers need multi-organ transplant (MOT) sequencing incorporated into the match run so they can see where a patient falls in the MOT sequence. They went on to comment that doing this would be helpful in terms of planning and efficiency. One attendee recommended adding the ability for centers to see all the tables on the allocation plan. Another attendee commented that this could be a useful tool for OPOs, but it may extend case times; adding that one universal match run could be more efficient. Several attendees raised concerns about diverting too many high-quality kidneys to multi-organ transplants, potentially increasing pancreas non-use and disadvantaging CPRA 100% KP candidates. They suggested that the committee look more closely at the KP population. Another attendee also had concerns about the lack of prioritization for CPRA 100% pancreas candidates, diversion of high-quality low Kidney Donor Profile Index (KDPI) kidneys to simultaneous heart-kidney (sHK) and simultaneous liver-kidney/lung-kidney (SLiK/LuK) transplants, which have very high primary non-function (PNF) rates and the resulting decrease in access for kidney-alone candidates. One attendee commented that it is unclear exactly how this policy will be executed, adding that this policy should not further increase the non-use rate as other allocation changes have done. An effective policy also needs to be clearly understandable and support the allocation process without further lengthening the organ case times. Another attendee commented that this has been much needed as a clear as possible multi-organ plan would help with transparency for transplant hospitals and OPOs.



Updates

Councillor Update

• Comments: None

OPTN Patient Affairs Committee Update

• Comments: One attendee commented that the SRTR designed the subway map in the presentation and the graphics illustrate the journey of transplant with the central line representing the transplant candidate and patient and the phases of transplant and the various stakeholders that interact and cross paths during the journey. They also commented that we need to stress all our roles in correcting misinformation in the media.

OPTN Executive Update

• Comments: Attendees asked about what portion of the fee increase goes to the OPTN contractor. The OPTN budget is completely derived from listing fees and what HRSA pays the contractor. There was also a question about AOOS and what defines "an organ offer". There is a workgroup with a variety of stakeholders working on this.

HRSA OPTN Modernization Update

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