OPTN

Thank you to everyone who attended the Region 5 Summer 2025 meeting. Your participation is critical to the OPTN policy development process.

Regional meeting presentations and materials

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: 5 strongly support, 13 support, 8 neutral/abstain, 0 oppose, 0 strongly oppose
Comments: None

2025 Histocompatibility HLA Table Update

Histocompatibility Committee

Sentiment: 4 strongly support, 14 support, 8 neutral/abstain, 0 oppose, 0 strongly oppose
Comments: This was not discussed during the meeting, but attendees were able to submit comments. One attendee recommended that additional HLA table updates be included.

Discussion Agenda

Require West Nile Virus Seasonal Testing for All Donors

Ad Hoc Disease Transmission Advisory Committee

Sentiment: 4 strongly support, 15 support, 6 neutral/abstain, 1 oppose, 0 strongly oppose
Comments: During the discussion, several attendees recommended changing the timing for the West Nile Virus (WNV) testing in living donors to 28 days to align with other living donor testing requirements. Another attendee commented that there should be consideration of geographic requirements given prevalence and incidence of disease. Several attendees had concerns about the turn-around time for the test results for both OPOs and transplant centers, noting that it is variable depending on where the test is sent. One attendee commented that there seem to be a lot of unanswered questions about the timeframe for this test-so it's hard to provide any sentiment. They support the concept but feel like timing and feasibility require additional consideration prior to finalizing. Another attendee noted that the incubation period for WNF can be as early as 2-6 days.

Update and Improve Efficiency in Living Donor Data Collection

Living Donor Committee

Sentiment: 5 strongly support, 12 support, 4 neutral/abstain, 5 oppose, 0 strongly oppose
Comments: An attendee commented that implementing this will be a burden on both transplant centers and living donors. While compiling data could be beneficial, they worried this would make potential donors feel more obligated rather than free-willing. Another attendee commented that more data should be collected, since most of the existing data focuses primarily on recipients. An attendee commented that they support adding a Living Donor Non-Donation Form but do not support removing the 2-year follow-up form. They emphasized that the volume of living donors is small compared to other required submissions, so the data burden is not high enough to justify removing another form. They added that follow-up should be increased rather than decreased and believed SRTR's response rate would be minimal compared to what transplant centers can collect. One attendee commented that it is important for us to learn why some potential donors may not want to proceed and questioned what the overall response would be from these candidates. Another attendee commented that the ever-growing data burden is already challenging for centers, and this proposal appears to add to that burden with limited utility. They support collecting data on living donors, but not individuals who did not donate. An attendee commented that they support the proposal for SRTR to be responsible for completing the long-term living donor follow-up forms, but they had significant concerns about the increased volume of forms required for people who do not become donors. They felt these two items should have been voted on separately. Another attendee commented that while they support efforts to collect better and more accurate data, they were concerned that cold calls from SRTR may not be answered by donors or potential donors. An attendee commented that they support the concept of both longer data collection on non-donors and longer-term follow-up of donors but found the proposal problematic. They felt it requires much more clarity on what is meant by "in person meetings" or "met with the transplant team," since not all donors meet in person during evaluation. Using themselves as an example, they said they only met the team in person three days before surgery. They suggested clarifying whether this refers to after evaluation and decision-making. They also questioned how donors will be motivated to provide follow-up data to SRTR, noting that most donors have no idea what SRTR, OPTN, or UNOS are their only interactions are with the transplant center. One attendee questioned how this data collection will help understand the long-term risk for donors.

Require Patient Notification for Waitlist Status Changes

Transplant Coordinators Committee

Sentiment: 10 strongly support, 14 support, 0 neutral/abstain, 2 oppose, 0 strongly oppose
Comments: One attendee thanked the committee for moving forward with this initiative. Another attendee commented that the volume of letters could be confusing for candidates who experience multiple status changes in a short period of time. Similarly, one attendee felt that very short periods of inactivity, such as less than 24 hours for a fever or a few days for an insurance change, would make written letters unnecessary and potentially confusing, since patients could receive multiple letters in the mail on the same day. Several attendees agreed that letters are not always practical, as patients do not always check their mail daily, and mailed notification is an outdated way to update patients on their care. They supported verbal or electronic communication documented in the medical record as sufficient and noted that this is already standard practice within many transplant programs.

Another attendee commented that they supported the proposal overall and believe that some type of written or electronic mechanism is necessary to trace that the patient has been updated. They added that, ultimately, they would like to see a centralized portal through HRSA where patients could log in and view their status. Several attendees also recommended aligning OPTN policy with CMS practice requirements, noting that as written, the proposal may seem redundant. One attendee stressed that providing more information to patients beyond the fact that their status has changed is essential, since patients need clear guidance and tools to understand the reasons for the change and what actions they can take. Multiple attendees supported the requirement for notification of status changes but felt strongly that centers should have flexibility in how this is done. Some suggested letters could be reserved for patients who remain inactive for longer periods, such as six months or more, when conversations may be forgotten. Another attendee suggested simplifying the process by allowing patients to choose their preferred method of notification, electronic or paper, and excluding in-house patients from the requirement. Several attendees commented that waitlist changes expected to be short-term, such as less than a month, should not require notification because this could increase patient confusion while providing little benefit. Another attendee added that communication should be required when a patient is made inactive, but not for changes within heart status levels.

Establish Comprehensive Multi-Organ Allocation Policy

Ad Hoc Multi-Organ Transplantation Committee

Sentiment: 8 strongly support, 18 support, 0 neutral/abstain, 0 oppose, 0 strongly oppose
Comments: One attendee commented that the examples provided were incredibly helpful, noting that policy does not truly come to life until it is seen in practice. They emphasized that post-implementation monitoring will be essential and pointed out that the OPTN and MPSC do not currently have the same monitoring for post-transplant outcomes in multi-organ transplant (MOT) as they do for single-organ transplant (SOT). They questioned whether the committee was comfortable moving forward without equivalent regulatory monitoring. Another attendee thanked the committee for its hard work and said the only way to understand what is happening is to have a system that allows it to be studied. They added that it would be helpful to have guidance for situations where plans change, since MOT cases are most likely to change at the last minute due to many factors. They added that perfect should not be the enemy of good and raised a question about differences in point assignments, noting that the Kidney Allocation Score (KAS) gives blood group O candidates five additional points, while the difference here is four, and wondered if that was intentional. One attendee commented that it will be important to follow the impact of this policy on all groups, emphasizing concern about further barriers to pancreas transplantation given the already declining numbers of pancreas and kidney/pancreas transplants. Another attendee said they supported the concept but found it difficult to evaluate based on the presentation. They expressed concern that the proposal might slow allocation, putting kidneys already allocated too late at higher risk of non-utilization, and worried that kidney-only candidates could face additional delays. Another attendee stated that they only support multi-organ allocation if it does not disadvantage patients with high cardiac status (statuses 1 and 2) or lung candidates with a Composite Allocation Score (CAS) greater than 40. One attendee questioned why living kidney donors had moved so far down on the kidney allocation list. An attendee proposed that the highest organ severity index should lead the allocation order. Using the example of a heart-lung transplant, they explained that a candidate with a high CAS and a status 3 heart must currently wait for the heart allocation to be completed before receiving the combined organ. They expressed agreement with the proposed changes, particularly with a lung CAS threshold of 3 depending on donor blood type O. They stressed

that careful attention must be paid to avoid disadvantaging patients listed for a single organ but at a very high status, such as a status 1 liver or a high MELD score for liver, compared to multi-organ candidates.

Updates

Councillor Update

- **Comments:** None

OPTN Patient Affairs Committee Update

- **Comments:** Several attendees thanked the presenter for giving voice to how difficult and frustrating living donation can be from the donor's perspective.

OPTN Executive Update

- **Comments:** One attendee commented that recent lay media coverage has focused heavily on a few problematic cases of organ donation involving DCD donors, even though these cases are exceptions rather than the norm. They noted that public attention has remained fixed on these issues and expressed appreciation for the task force's efforts to streamline work on NRP from a scientific standpoint. Another attendee was interested in opportunities for the community to get involved with DCD and NRP stakeholder engagement.

HRSA OPTN Modernization Update

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