

Thank you to everyone who attended the Region 1 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: 5 strongly support, 1 support, 5 neutral/abstain, 0 oppose, 0 strongly oppose

Comments: This was not discussed during the meeting, but attendees were able to submit comments with their sentiment. An attendee inquired about the review process for this proposal once the device shortage ends.

2025 Histocompatibility HLA Table Update

Histocompatibility Committee

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

Comments: This was not discussed during the meeting, but attendees were able to submit comments with their sentiment. An attendee requested that the OPTN should ensure that policy requirements for OPO contract laboratories performing HLA typing of deceased donors clarify whether labs are required to resolve to the P group and null/low expressing allele level and added that NMDP has specific guidance on such alleles that labs are required to resolve in their typing.

Discussion Agenda

Require West Nile Virus Seasonal Testing for All Donors

Ad Hoc Disease Transmission Advisory Committee

Sentiment: 1 strongly support, 9 support, 1 neutral/abstain, 0 oppose, 0 strongly oppose

Comments: A member shared two concerns: the cost associated with testing and the uniform national recommendation, suggesting that adjusting testing periods based on regional seasonal risk would be more cost-effective. An attendee noted that the seven-day window allows time for NAT results from outside labs, with their center experiencing a four-day turnaround. A member emphasized the need to understand both the outcomes and financial impact of additional testing and asked for details on the regions where the 11 transmissions occurred, as well as consideration of other mosquito-borne



illnesses. An attendee expressed support but raised concerns about turnaround time, especially in expedited organ recovery cases, and suggested flexibility due to the low prevalence of the disease. A member questioned whether the policy could be adjusted to avoid forcing centers to choose between compliance and timely transplants, and raised concerns about unnecessary testing in non-endemic regions and the potential for false positives in rare diseases. An attendee noted that their OPO performs West Nile virus testing in-house with a 5–6 hour turnaround, but expressed concern for OPOs without that capability and suggested exceptions for urgent cases.

Update and Improve Efficiency in Living Donor Data Collection

Living Donor Committee

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

Comments: A member noted that this policy has been in development for two decades without materializing and sees a great opportunity to rely on the SRTR partnership proposed through the Living Donor Collective experience. An attendee asked how the policy will distinguish between healthy nondonors who chose not to proceed and those not accepted for medical or psychological reasons, and raised questions about donors who withdraw before their health status is known. A member opposed the policy as written, citing significant administrative burden and variability in defining the first inperson visit, which could lead to missing important data. An attendee recommended follow-up with the donor facility or current care provider if new medical concerns are identified. A member expressed conditional support, requesting clarity on the minimum dataset, SRTR protocols, and privacy protections. An attendee, both an HLA professional and family member to two living kidney donors, stated that donors deserve closer relationships and follow-up with transplant centers beyond two years, rather than only being contacted by a registry. A member voiced concern about administrative burden and confusion over what qualifies as an in-person evaluation. An attendee questioned the purpose of the policy, expressing concern that it may send the wrong message about donor care and raised doubts about how SRTR would collect data on complications such as creatinine levels, testicular pain, or hernias, noting that such a policy might worry donors rather than reassure them.

Require Patient Notification for Waitlist Status Changes

Transplant Coordinators Committee

Sentiment: 3 strongly support, 6 support, 1 neutral/abstain, 0 oppose, 1 strongly oppose

Comments: A member noted that this has been discussed for a long time and expressed concern about the burden, particularly the frequent movement between inactive and active status, fearing that programs may internally hold patients rather than make them inactive, and emphasized the need to consider differences across organs. An attendee emphasized the importance of continued patient engagement and asked whether a portal had been discussed, highlighting the value of real-time communication. A member stated that documentation of the conversation should be sufficient and that a letter should not be required. An attendee shared that their center already performs this communication, but patients often remain unaware of their inactive status, noting that mail is often ignored, and expressed support for the idea of a portal. A member agreed that a portal is a great idea and recommended keeping notification documentation general to accommodate different patient

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situations. An attendee stated that letters help reinforce communication with referring physicians and dialysis centers and shared that their program sends biannual letters with patient status. A member suggested that a longer duration of status change might be more appropriate for notification than a short time frame. An attendee asked whether OPTN data tools would be updated before implementation to help programs monitor. A member stated that most centers already practice this and patients appreciate it, recommending a patient portal as the logical next step. An attendee supported standardizing communication but emphasized that information should also be shared with referring physicians and that status changes are often misinterpreted as removal from the list, stressing the importance of maximizing patient understanding while minimizing administrative burden. A member noted that most centers have some process in place but highlighted the need for tools and time frame guidance as part of implementation. An attendee supported the policy with conditions, requesting multimodal communication options including phone calls if documented. A member stated that documentation in the EMR alone should be sufficient.

Establish Comprehensive Multi-Organ Allocation Policy

Ad Hoc Multi-Organ Transplantation Committee

Sentiment: 2 strongly support, 8 support, 1 neutral/abstain, 0 oppose, 0 strongly oppose

Comments: An attendee was impressed, noting that this is essentially continuous distribution for multiorgan and that the median appearance table helps clarify the structure. A member acknowledged the
significant effort behind the proposal and raised the issue of prioritizing first versus subsequent
transplants, questioning the ethics of bypassing a sick liver patient for someone with multiple prior
transplants. An attendee appreciated the committee's work and noted that the need for this policy was
identified in 2019. A member suggested that this would be better integrated with continuous
distribution and should be part of discussions on allocation out of sequence. An attendee expressed
concern that requiring a plan could hinder expedited recoveries of hearts, lungs, and livers due to delays
in receiving kidney HLAs, and noted that machine perfusion scenarios should not be considered
violations of multi-organ allocation policies. A member supported the proposal with conditions,
including transparent logic, exception tracking, and regional simulations before rollout. An attendee
acknowledged the complexity of the policy and encouraged continued effort.

Updates

Councillor Update

Comments: None

OPTN Patient Affairs Committee Update

Comments: A member expressed appreciate for hearing the presenter's personal story.

OPTN Executive Update

• Comments: An attendee asked in the meeting chat if the OPTN Board has plans to bring back the SRTR data tool which provided more specific information about allocation out of sequence (AOOS), for example, by organ type, than the new HRSA AOOS dashboard provides. Dr. Magee said he could not speak to SRTR's data tool but agreed that it is important to have information available by organ type. The attendee added that Region 1 through its OPO recently completed

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a four-week project examining AOOS for kidneys, where no "rescue placement" was used. The project's results indicate a significant decrease in utilization for kidneys in higher KDPI categories, which is an expanded part of the donor pool over the past several years. According to the attendee, this points to the urgent need for OPTN policy work to address allocation of these organs as the OPTN is focused on compliance related to AOOS.

HRSA OPTN Modernization Update

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