

**OPTN Liver and Intestinal Organ Transplantation Committee  
National Liver Review Board (NLRB) Workgroup  
Meeting Minutes  
July 11, 2019  
Conference Call**

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Julie Heimbach, MD, Chair, NLRB Workgroup  
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**Introduction**

The National Liver Review Board (NLRB) Workgroup (the Workgroup) met via teleconference on 07/11/2019 to discuss the following agenda items:

1. Update on Enhancements and Communications in Progress
2. Committee Appeal Process
3. Other Topics for Guidance Documents

The following is a summary of the Workgroup's discussions.

**1. Update on Enhancements and Communications in Progress**

UNOS staff provided an update on the system enhancements and communications that have been distributed since the last Workgroup meeting.

Summary of discussion:

UNOS staff stated that the NLRB one month report has been completed. They also stated that the case history will now be open by default in the system. Committee management for case reviews that are appealed to the Workgroup is also active. UNOS IT staff will also add a button to make it easier for a transplant program to appeal cases to the Workgroup. They also plan to convert manually submitted appeals, add a link to the NLRB guidance to the UNet<sup>SM</sup> screen, and incorporate a prompt to remind transplant programs to appeal a case if it is still within the appeal window.

The Workgroup Chair suggested comparing the data in the NLRB one month report to data from the Regional Review Boards (RRBs). UNOS staff said this would be included in the next report.

UNOS staff informed the Workgroup that a memo will be sent to liver program directors. Also, an e-mail will be sent to the reviewers who have been re-assigned several times asking about any barriers that are preventing them from voting.

Next Steps:

UNOS staff will continue their efforts to enhance the system.

**2. Committee Appeal Process**

The Workgroup discussed the process for when cases are appealed to the Workgroup.

Summary of Discussion:

The process for the Workgroup to handle cases is not as clear as it is for the specialty review boards and the Appeals Review Team (ART).

The Workgroup agreed that it should take a majority of the Workgroup to approve exception cases. They also agreed that the deadline for their review of the cases should be seven days. A Workgroup member asked how they would decide whether to have an online vote for each case or have a discussion on a phone call. The Workgroup agreed that they would have a phone call if one of the Workgroup members selected this option in the committee management system. UNOS staff asked what would happen if someone requested a phone call on the sixth day and they need to have a decision by the seventh day. The Workgroup chair felt that they should make every effort to complete the review of the case within seven days.

UNOS staff asked if there should be an automatic approval entered if there is no vote by the deadline. The Workgroup agreed that there should not be an automatic approval entered and the seven day deadline should just be a goal for the Workgroup.

The Workgroup then discussed if representatives from the program that submitted the appeal should be able to request and join a call for the Workgroup to discuss their case. Some Workgroup members felt that representatives should be able to request and join the call. Others stated that there should only be a call when the case is not clear. A Workgroup member stated that allowing a representative from the transplant program to join the call could introduce emotional bias to the Workgroup's considerations and may lead to inconsistent decisions. Other Workgroup members stated that there should be enough clinical information in the appeal and exceptions should not be granted based on who is the most persuasive. The Workgroup agreed that representatives from the transplant program should not be able to join the call.

#### Next steps:

UNOS staff will use the Workgroup's feedback to update the guidance document and operational guidelines.

### **3. Other Topics for Guidance Documents**

The Workgroup discussed other feedback on the NLRB and if it should be used to update the guidance documents.

#### Summary of Discussion:

The Workgroup Chair noted that there is no guidance for adults with metabolic disease. Another Workgroup member brought up cholangiocarcinoma (CCA) and suggested that they should receive a higher model for end-stage liver disease (MELD) or pediatric end-stage liver disease score (PELD). The Workgroup member suggested a score of median MELD at transplant (MMaT) for CCA candidates. The Workgroup Chair noted that the waitlist dropout rate for CCA candidates is relatively high. The Workgroup agreed to suggest changing the standard score for CCA candidates to MMaT to the full Liver Committee.

The Workgroup then discussed if the default should be to enter an approval or a denial when a reviewer is on the fence about a case. Some Workgroup members felt that the default should benefit the candidate so it should be an approval. Other Workgroup members argued that the candidate already has their lab MELD or PELD score and if the benefit is given to exception candidates, then non-exception candidates may be disadvantaged.

The Workgroup agreed that they should update the guidance document to provide more detail to reviewers on certain conditions so that reviews are more consistent.

The Workgroup discussed ways to review the performance of the reviewers. The Workgroup chair stated that they should emphasize that reviewers should vote in accordance with the guidance even if they do not agree with the reviewers.

The Workgroup Chair stated that they should update the guidance for autosomal dominant polycystic liver kidney disease (ADPCLKD). The Workgroup chair asked for volunteers to start writing updated guidance on ADPCLKD, adult metabolic disease, and cholangitis.

UNOS staff stated that they are still figuring out a way to have the Workgroup review the performance of the reviewers.

The Workgroup then agreed that programs submitting exception forms should address and clarify the information provided in the fields of the form in the narrative section to minimize confusion of the reviewers.

The Workgroup also agreed that reviewers should assume that tumors included in the exception forms are not resectable, even if it is not explicitly mentioned.

A Workgroup member asked which diagnoses are included in “Other, specify” in approved forms. UNOS staff stated that this could be any diagnosis that programs write in the open text field, but many of these forms are HCC-related.

Another Workgroup member suggested that Status 1A and 1B requests for pediatric candidates should go to the pediatric review board. The Workgroup chair stated that these cases need to be resolved too quickly for the pediatric review board.

#### Next Steps:

The Workgroup will continue to collect feedback on the NLRB and start drafting updates to the guidance.

#### **Upcoming Meeting**

- August 8, 2019 - Teleconference