

**OPTN Liver and Intestinal Organ Transplantation Committee
National Liver Review Board Workgroup
Meeting Minutes
June 21, 2019
Conference Call**

**Julie Heimbach, MD, Chair
James Trotter, MD, Vice Chair**

Introduction

The National Liver Review Board Subcommittee (the Subcommittee) met via teleconference on 06/21/2019 to discuss the following agenda items:

1. National Liver Review Board Issues

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

1. National Liver Review Board Issues

The Chair presented a number of issues that have come up within the first month and a half since the National Liver Review Board (NLRB) was implemented.

Summary of discussion:

The Chair suggested posting a link to the NLRB guidance documents and policy language in UNetSM so that these resources are more accessible to all users. The Subcommittee agreed that this would be a good way to increase their visibility.

The Chair then asked the Subcommittee what score should be assigned to adult candidates with a metabolic disorder. One Subcommittee member stated that the default score for these candidates should be median model for end-stage liver disease (MELD) at transplant (MMaT). However, there should always be the ability to receive a higher score if the candidate is more urgent than MMaT. The Subcommittee agreed that MMaT should be the default for these candidates.

The Chair then suggested that cases that are appealed to the Subcommittee, should stay with the Subcommittee for any subsequent requests. The Subcommittee did not want to give feedback on cases only to have them go back to the regular NLRB. The Subcommittee agreed that they should stay with the Subcommittee, once they are appealed to that point. UNOS staff noted that they will need to check OPTN policy and the operational guidelines to see if this is an approved process.

The Subcommittee then discussed how to handle candidates who had hepatocellular carcinoma (HCC) but were fully treated prior to being listed for transplant. A Subcommittee member suggested changing the NLRB guidance so that these candidates are granted MMaT minus three. Another Subcommittee member commented that these candidates should be automatically approved for a policy-assigned score. The Chair noted that there would need to be some requirements for these candidates to get a policy-assigned score, such as the HCC diagnosis being within a certain timeframe of listing on the waitlist. The Subcommittee agreed to move forward with a policy or guidance change.

The Chair then asked if the Subcommittee felt like they could handle future case review through e-mail, and not have phone calls to review cases. The Subcommittee felt that they could handle the majority of cases through e-mail but may need a phone call for some of the more complex cases. One

Subcommittee member asked if the cases could be handled through UNetSM. UNOS staff stated that this may be possible, but they would need to check.

The Chair then stated that many reviewers on the “Adult, Other Diagnosis” board have noted that they are receiving HCC cases. The Chair commented that most of these candidates received their initial exception from the regional review boards (RRB) and the initial exception did not meet the current criteria for an HCC exception. The Chair stated that the only way to change this would be to submit a new request to the HCC review board. However, this would be burdensome for the programs so it is probably best to allow these candidates to cycle through the NLRB, as it will not be an issue for new exception requests.

UNOS staff noted that as long as HCC candidates meet the criteria in policy, they can move back and forth between automatic approval and NLRB review with each extension request. For example, if a candidate meets the criteria outlined in policy for auto-approval, the program can still request a different score, if they believe the policy-assigned score does not match the medial urgency of the candidate. However, if the HCC candidate does not meet the criteria in policy, they cannot be auto-approved, and must go to the HCC review board.

The Chair noted that it is important to have a way for candidates who fall off the automatic approval pathway due to missed deadlines to still be able to be automatically approved during subsequent extension requests. If a candidate who was on the automatic approval track did miss a deadline, the case would go to the HCC review board. The Chair stated that at this point, the HCC review board should be able to put the case back on the automatic approval track. UNOS staff stated that this would require a policy change. The Chair stated that this would make the workload easier for the review board so the policy change should be prioritized.

The Chair then discussed candidates with autosomal dominant polycystic liver kidney disease (ADPCLKD). The Chair noted that most exception candidates with ADPCLKD have been granted an exception score of MMaT minus three, but asked the Subcommittee if they should receive MMaT if they need both a liver and a kidney. A Subcommittee member noted that these patients need a liver transplant to improve their quality of life, not necessarily to save it. However, they do need a life-saving kidney transplant. One Subcommittee member suggested that these candidate receive a policy-assigned score that increases with each extension. Another Subcommittee member suggested that they receive MMaT minus one or MMaT minus two. A Subcommittee member felt that they should not be ranked higher than HCC patients, so they should get MMaT minus four. Another Subcommittee member stated that the Subcommittee’s disagreement on how to assign scores for these patients shows the need for a uniform way to treat these candidates. UNOS staff stated that they can pull data on this population to better understand their urgency and current situation.

The Chair stated that they will be sending out communications on some of the issues discussed to the NLRB reviewers and the entire liver transplant community.

The Chair also noted that they are trying to figure out a way to have blinded case reviews to examine reviewer performance.

The Chair then stated that some programs are resubmitting cases instead of following the usual appeal process. If their original case is denied, they are withdrawing the case and resubmitting as a new case, rather than going through the appeal process. A Subcommittee member noted that sometimes programs will need to withdraw and resubmit a case if the denial was caused by an error from the program. The Subcommittee agreed that they should find a way to monitor when this occurs. UNOS staff commented that they could add a prompt reminding individuals that the proper path after a denial

is to file an appeal, not to resubmit a new case. They could also remind reviewers that they have access to each candidate's entire case history, including previously denied cases. A Subcommittee member asked if it would be possible to notify reviewers if a candidate has a previously denied exception request. UNOS staff agreed to look into this possibility and suggested that they change the default view on the reviewers screen to have a visible case history.

Next steps:

UNOS staff will organize another Subcommittee meeting and provide an update on the items described above.

Upcoming Meeting

- July 11, 2019