

**2019 OPTN Liver and Intestinal Organ Transplantation Committee
National Liver Review Board Subcommittee
Meeting Summary
November 14, 2019
Conference Call**

**James Trotter, MD, Committee Chair
James Pomposelli, MD, PhD, Committee Vice Chair
Julie Heimbach, MD, Subcommittee Chair**

Introduction

The National Liver Review Board (NLRB) Subcommittee (the Subcommittee) met via teleconference on 11/14/2019 to discuss the following agenda items:

1. PCLKD – SLK Clarification
2. Portopulmonary Hypertension Clarification
3. HCC Extension Policy Review
4. Exception Narrative Review – Data Request
5. Other Significant Items

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

1. PCLKD – SLK Clarification

The Subcommittee previously discussed adding language to the Adult Other Diagnosis guidance document for candidates with polycystic liver kidney disease (PCLKD) who also require a kidney transplant.

Summary of discussion:

The current Adult Other Diagnosis guidance document includes a section for polycystic liver disease (PLD). The Subcommittee has previously discussed adding a recommendation to this section for candidates also requiring a kidney transplant. In the previous discussions, the Subcommittee suggested that these candidates should be considered for an exception score equal to median model of end-stage live disease (MELD) at transplant (MMaT).

The Subcommittee discussed if recommending a score of MMaT for candidates with PLD who also require a kidney transplant is appropriate. The Subcommittee hypothesized that the number of candidates needing both a liver and a kidney is small but agreed that they needed more data on mortality and dropout risk for these patients to determine if they should be given a score equal to MMaT. The Subcommittee Chair pointed out that these candidates are different because they require two organs, which limits the available donors. A Subcommittee member noted that mortality risk might not be the ideal metric to determine priority for these patients because they may be on dialysis for an extended period of time. A Subcommittee member noted that this exception could also apply to children and that children on dialysis may not be at an increased risk for mortality but do suffer from other comorbidities. The Subcommittee agreed to submit a data request to get data on waitlist mortality and dropout rates for these candidates before including the recommendation.

The Subcommittee chair suggested adding language to include guidance for patients with PLD who have received a prior kidney transplant. The Subcommittee agreed with this recommendation.

The Subcommittee also discussed how specific the guidance should be when it states that a candidate “also requires a kidney transplant.” The Subcommittee agreed that these candidates should meet simultaneous liver-kidney (SLK) criteria.

Next steps:

The Subcommittee will submit a data request for mortality and waitlist dropout rates for candidates with PCLKD. They will consider the data before proposing any changes to the guidance for PLD.

2. Portopulmonary Hypertension Clarification

The Adult Other Diagnosis guidance document contains a section for portopulmonary hypertension (PH). The section includes outdated and potentially unnecessary language.

Summary of discussion:

The Subcommittee discussed the section in guidance for PH. PH is also included in OPTN Policy as a standard diagnosis that is awarded an automatic exception when specific clinical criteria are met. The Subcommittee agreed to remove the outdated and unnecessary language in the guidance document. They also agreed to consider modifying the clinical criteria in policy for PH in a subsequent round of public comment.

Next steps:

The Subcommittee will propose modifying the section in guidance for PH during the upcoming public comment cycle. They will continue to consider updating the clinical criteria in policy.

3. HCC Extension Policy Review

The Subcommittee previously discussed changing policy to allow any HCC candidate meeting standard extension criteria to be automatically approved, even if they were previously reviewed by the NLRB.

Summary of discussion:

The Subcommittee reviewed the proposed changes to policy that would allow any HCC exception candidate to have their exception extension approved as long as they meet the standard extension criteria. The Subcommittee approved all of the proposed language.

They then discussed creating a template to help guide transplant programs in writing HCC exception narratives.

The Subcommittee also approved the proposed changes to policy language for the update schedule for recalculation of median MMaT and median PELD at transplant (MPaT).

Next steps:

The full Liver Committee will review and vote on the proposed changes prior to public comment.

4. Exception Narrative Review – Data Request

The Subcommittee has previously discussed ways to review NLRB reviewers.

Summary of discussion:

The Subcommittee heard a presentation about a proposed data request to complete a qualitative review of exception narratives and reviewer comments. The Subcommittee Chair stated that individuals

with subject matter expertise may be needed in the review. The Subcommittee Chair noted that a data request may not enable the Subcommittee to see if reviewers are actually following guidance. A Subcommittee member suggested sending a test to reviewers to see how they respond. The test would ask reviewers to submit responses to fake cases outside of the NLRB system. Subcommittee members supported this idea as a way to educate and inform reviewers. The Subcommittee Chair clarified that the ultimate goal is to ensure that NLRB reviewers are consistent in their review of exception cases. The Subcommittee agreed that the results of the test could be used to create improved education for reviewers.

Next steps:

The Subcommittee and staff will continue to discuss the feasibility of the proposed test.

5. Other Significant Items

The Subcommittee Chair presented additional, potential changes to the NLRB system.

Summary of discussion:

The Subcommittee Chair suggested creating a template for transplant centers submitting HCC exception requests through the Adult Other Diagnosis and Adult HCC specialty boards. The Subcommittee proposed making it mandatory to submit a reason when a reviewer declines an exception request. The Subcommittee previously discussed having an Appeals Review Team (ART) leader for each ART. The Committee Chair stated that it would be important to have someone with subject matter expertise lead each ART call.

Next steps:

The Subcommittee will continue to discuss ways to improve the NLRB.

Upcoming Meeting

- December 12, 2019
- January 9, 2020

Attendance

- **Subcommittee Members**
 - Scott Biggins
 - Julie Heimbach
 - James Trotter
 - Patricia Sheiner
 - Sarah Jane Schwarzenberg
 - Terry Box
 - Eddie Island
 - Jennifer Kerney
 - Kimberly Brown
- **HRSA Representatives**
 - Jim Bowman
- **UNOS Staff**
 - Matt Cafarella
 - Samantha Noreen
 - Karen Williams
 - Laura Cartwright
 - Kimberli Combs