

**OPTN Liver and Intestinal Organ Transplantation Committee
National Liver Review Board (NLRB) Subcommittee
Meeting Summary
December 9, 2021
Conference Call**

James Trotter, MD, Chair

Introduction

The National Liver Review Board Subcommittee (the Subcommittee) met via Citrix GoToMeeting teleconference on 12/09/21 to discuss the following agenda items:

1. NLRB 18 Month Report
2. Ongoing Review of NLRB Diagnoses

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

1. NLRB 18 Month Report

The Subcommittee reviewed the 18 month monitoring report for the NLRB.

Summary of discussion:

A Subcommittee member asked if OPTN members could be requesting fewer exceptions for diagnoses that fall into the "other" category because they are being approved less often. The presenter responded that the "other" category has likely become smaller due to the addition of an exception diagnoses drop down selection in the system.

A member asked how it is possible for candidates to have a Model for End-Stage Liver Disease (MELD) score over 37 if they also have a hepatocellular carcinoma (HCC) exception. The presenter explained that the figure shows candidates who had submitted an HCC exception form at any point, but may have also qualified for a higher MELD at a later date. A member suggested that in future reports the Subcommittee should have a closer look at candidates with MELD scores of 23-29 where most of the HCC exceptions exist.

A member asked if there was any information on the waiting list mortality rates for exception patients compared to non-exception patients. The presenter explained that these rates had some variability, but remained fairly equivalent at around 14-18 per 100 person- years waiting pre- and post- policy. This member commented that there is a 1 -1.5% HCC dropout rate each month for death or too sick to transplant and that this may not be reflected in the data.

Next steps:

Committee members and UNOS staff will continue discussions regarding data for HCC candidates who were removed for death or too sick to transplant.

2. Ongoing Review of NLRB Diagnoses

The Subcommittee discussed the next round of NLRB diagnoses for review.

Summary of discussion:

A member commented that most of the diagnoses in guidance that the Subcommittee has not yet reviewed represent a very small number exception submissions. In terms of policy diagnoses, a member commented that the Subcommittee should look into cystic fibrosis (CF) and familial amyloid polyneuropathy. The Subcommittee agreed to assess the remaining diagnoses for any updates to NLRB policy or guidance.

The Subcommittee also considered evaluating diagnoses to determine if candidates should receive a different policy assigned score.

Next steps:

Upcoming Meeting

- January 13, 2022 @ 2:30 PM ET

Attendance

- **Subcommittee Members**
 - James Trotter
 - Alan Gunderson
 - Allison Kwong
 - Kimberly Brown
 - Greg McKenna
 - Kym Watt
 - Sophoclis Alexopoulos
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
- **SRTR Staff**
 - Katie Audette
- **UNOS Staff**
 - Matt Cafarella
 - Betsy Gans
 - Julia Foutz
 - Jenn Musick
 - Kelley Poff
 - Hannah Brown
 - Niyati Upadhyay