

**OPTN Liver and Intestinal Organ Transplantation Committee
National Liver Review Board (NLRB) Subcommittee**

February 10, 2022

Conference Call

James Trotter, MD, Chair

Introduction

The National Liver Review Board (NLRB) Subcommittee (the Subcommittee) met via Citrix GoToMeeting teleconference on 02/10/22 to discuss the following agenda items:

1. Ongoing Review of NLRB Diagnoses

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The Subcommittee discussed the next round of NLRB diagnoses.

Summary of discussion:

OPTN Policy 9.5.B: Requirements for Cystic Fibrosis (CF) MELD or PELD Score Exceptions

Members suspected that the current policy for CF is written in the context of needing a lung and a liver transplant, as there is no mention of liver disease in this section of policy. A member reported that about 250 candidates were diagnosed with this diagnosis code over the past 20 years. Another member added that they believe the majority of these candidates are pediatric. Should the Subcommittee decide to keep the CF diagnosis in policy, they suggested that language mentioning forced expiratory volume at one second (FEV) should be struck and replaced with requirements for evidence of liver disease. Members agreed that they will reach out to pediatric liver practitioners for subject matter expertise.

9.5. C: Requirements for Familial Amyloid Polyneuropathy (FAP) MELD or PELD Score Exceptions

A member suggested softening the language from “The patient is not a candidate for or has progressed on medical therapy” to “The patient is not a candidate for or has not responded to medical therapy”. UNOS staff discussed the recent resource constraints with the Subcommittee and advised that at this time the group should move forward with changes that do not involve IT programming. Members discussed changing the language so that no IT resources would be used when updating this diagnosis. The Subcommittee will continue discussing FAP during a future meeting.

9.5.E: Requirements for Hepatopulmonary Syndrome (HPS) MELD or PELD Score Exceptions

A member reported that there is not a substantial amount of new data that would suggest the need for changes to the standard criteria for HPS.

The Subcommittee made a data request to inform HPS which included the following:

- Count
- Age
- Count by MELD and PELD score
- Waitlist mortality rate by MELD and PELD score
- Waitlist mortality rate compared to other patients with a MELD exception (HCC and other)

Guidance for Candidates with Multiple Hepatic Adenomas:

A member suggested streamlining multiple hepatic adenomas into three “buckets”: 1) adenoma with glycogen storage disease 2) multiple adenomas, and 3) unresectable beta catenin adenomas. Members discussed removing “unresponsive to medical management” language to better define criteria for multiple hepatic adenomas. The Subcommittee determined the first paragraph in this section of the guidance document is unnecessary and advised removing it.

Guidance for Candidates with Budd Chiari-

Members agreed upon the removal of language indicating that a patient must have decompensated portal hypertension in the form of hepatic hydrothorax requiring thoracentesis more than 1 liter per week for at least 4 weeks.

Next steps:

The Subcommittee will continue these discussion at a future meeting.

Upcoming Meeting

- March 10, 2022 @ 2:30 PM ET

Attendance

- **Subcommittee Members**
 - Alan Gunderson
 - Allison Kwong
 - Greg McKenna
 - James Markmann
 - Kym Watt
 - Sophoclis Alexopoulos
 - James Trotter
 - Kim Brown
- **HRSA Representatives**
 - Jim Bowman
- **SRTR Staff**
 - Katie Audette
 - Nick Wood
- **UNOS Staff**
 - Matt Cafarella
 - Jenn Musick
 - Julia Foutz
 - Kelley Poff
 - Leah Slife
 - Niyati Upadhyay
 - Susan Tlusty