

**OPTN Liver and Intestinal Organ Transplantation Committee  
OPTN Pediatric End- Stage Liver Disease (PELD)/ Status 1B Work Group  
Meeting Summary  
May 20, 2021  
Conference Call**

**Evelyn Hsu, MD, Workgroup Chair  
James Trotter, MD, Committee Chair  
James Pomposelli, MD, PhD, Committee Vice Chair**

## **Introduction**

The OPTN PELD/Status 1B Work Group (the Work Group) met via Citrix GoToMeeting teleconference on 05/20/2021 to discuss the following agenda items:

1. PELD Characteristics- Summary
2. Status 1B and Status 1A: Progress to date and next steps

The following is a summary of the Work Group's discussions.

### **1. PELD Characteristics- Summary**

The Work Group discussed a summary of their review of PELD characteristics.

#### Summary of discussion:

A member asked if the Work Group would consider including a standard exception for candidates with a significant infection, which can impact receiving a transplant. Another member responded that gathering more data on infection occurrence could be considered in the future. A member added that the Work Group would have to define infection with specific criteria that predict mortality in order to develop a standardized exception.

#### Next steps:

The Work Group completed their review of PELD characteristics and will discuss Status 1B policy.

### **2. Status 1B and Status 1A: Progress to date and next steps**

The Work Group discussed sorting within Status 1B, Model for End- Stage Liver Disease (MELD)/PELD threshold, and began developing a data request.

#### Summary of discussion:

The Work Group discussed characteristics for consideration when sorting within status 1B. A member suggested the Work Group should review waitlist mortality data by diagnosis. He or she predicted that candidates with chronic liver disease would have the highest mortality, followed by candidates with tumors and metabolic disease, and then other diagnoses within 1B. Other members agreed that chronic liver disease patients are at the highest risk for mortality. A member noted that the metabolic disease candidates' morbidity should also be considered when stratifying 1B patients. A member confirmed that some metabolic disease candidates are able to wait on the list from home and suggested that these types of candidates should be sorted to receive offers after candidates within the 1B status that are hospitalized. A member noted that under those guidelines, patients at home may never be transplanted

because there will always be sicker patients before them. Another member agreed and suggested the Work Group develop a method for identifying the sickest patients within the metabolic disease diagnosis, such as those with Ornithine transcarbamylase (OTC). The Work Group came to a consensus that 1B patients with chronic liver disease are at the highest risk of mortality and should receive priority within the 1B status.

The Work Group determined they would need data in order to make a decision as to if chronic liver disease patients should always rank before metabolic and tumor candidates. Alternatively, they discussed use of a points- based system that would not only identify high- risk chronic liver disease candidates, but also recognize those high- risk metabolic and tumor candidates who have been designated 1B for a longer period of time. Members are also interested in the occurrence of metabolic and tumor candidates receiving an organ before those with chronic liver disease. A member suggested that points within 1B would be assigned based upon sickness to appropriately rank candidates.

Next steps:

The Work Group will look at Status 1B data to determine how they will proceed with stratifying 1B candidates.

**Upcoming Meeting**

- June 17, 2021

## Attendance

- **Work Group Members**
  - Walter Andrews
  - Julie Heimbach
  - Evelyn Hsu
  - Steven Lobritto
  - John Magee
  - Douglas Mogul
  - George Mazariegos
  - Emily Perito
  - Sara Rasmussen
  - Jorge Reyes
  - Sarah Jane Schwarzenberg
- **HRSA Representatives**
  - Marilyn Levi
- **SRTR Staff**
  - Michael Conboy
  - David Schladt
- **UNOS Staff**
  - Matt Cafarella
  - Julia Foutz
  - Kelley Poff
  - Niyati Upadhyay