

**OPTN Liver and Intestinal Organ Transplantation Committee  
OPTN Pediatric End- Stage Liver Disease (PELD)/ Status 1B Work Group  
Meeting Summary  
June 17, 2021  
Conference Call**

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

## **Introduction**

The OPTN Pediatric End- Stage Liver Disease (PELD)/ Status 1B Work Group (the Work Group) met via Citrix GoToMeeting teleconference on 06/17/2021 to discuss the following agenda items:

1. Status 1B Data Request
2. Status 1B- Sorting and Scenarios

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

### **1. Status 1B Data Request**

The Work Group reviewed Status 1B data to inform the discussion on sorting candidates within Status 1B.

#### Summary of discussion:

A member noted that nearly 25% of pediatric candidates at Status 1B with chronic liver disease who were removed from the waiting list between 2018-2020 were removed due to death or being too sick to transplant, while 0% of pediatric patients at Status 1B with metabolic disease were removed for death or too sick to transplant. Another member clarified that the one patient who was removed for death or being too sick in the other diagnoses category had acute liver failure and was an infant. As the Work Group examined the distribution of waiting time across diagnoses, a member commented that the large number of candidates and recipients at Status 1B with metabolic disease could make it challenging for those candidates at Status 1B with chronic liver disease or needing a liver-intestine to be transplanted, as many candidates with metabolic disease will be ahead of them on the match run.

A member asked if there was any data that could examine the impact of extra waiting time on patient outcomes, such as comparing survival of patients transplanted at 1B with those who were transplanted, but not as 1B. This member continued with the idea that patients diagnosed with chronic liver disease should be categorized as 1B and that other diagnoses currently within 1B should be given more weight in the Model for End- Stage Liver Disease (MELD)/PELD. Another member noted that it may be challenging to obtain data showing the exact impact of extra waiting time, as there are other factors that could contribute to this correlation.

#### Next steps:

The Work Group will use the results of this data request when considering sorting within Status 1B.

## **2. Status 1B- Sorting and Scenarios**

The Work Group reviewed sample Status 1B scenarios and continued discussions on revising Status 1B policy.

### Summary of discussion:

A member asked how often waiting time points would be calculated. UNOS staff explained that waiting time points would be based off how many candidates are at 1B in that classification at the time of the match run. A member noted that there are a fair number of pediatric candidates with chronic liver disease open to all blood types. A member pointed out that if the Work Group wanted to change the priority for the identical blood group, they would have to consider the impact this would have on patients with type O blood as this group can only receive offers from blood type O donors. Excluding special considerations for blood type O, based on the presented data, members agreed that diagnosis is more important than blood type and waiting time. Members agreed that chronic liver disease and liver/intestine diagnoses be given the same amount of points. Members discussed that due to the wide variety of diagnoses, robustness, it would be difficult to give priority to the other category. The Work Group determined 15 points should be assigned to candidates at Status 1B with chronic liver disease and liver/intestine diagnoses to prioritize them before other diagnoses and give them greater weight than waiting time and blood type. Members suggested that tumor diagnoses should receive 5 points and metabolic diseases would receive 0 points. The Work Group determined they would not develop a classification based on age as the cutoff would be arbitrary.

### Next steps:

Members will continue to discuss which point values to assign to exception/other diagnoses.

### **Upcoming Meeting**

- July 15, 2021

## Attendance

- **Work Group Members**
  - Clark Andrew Bonham
  - Evelyn Hsu
  - Regino Gonzalez- Peralta
  - Patrick Kamath
  - Julie Heimbach
  - Steven Lobritto
  - George Mazariegos
  - Emily Perito
  - Jorge Reyes
  - Sara Rasmussen
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
- **SRTR Staff**
  - Michael Conboy
- **UNOS Staff**
  - Matt Cafarella
  - Julia Foutz
  - Kelley Poff
  - Niyati Upadhyay