

**OPTN Liver and Intestinal Organ Transplantation Committee
National Liver Review Board Subcommittee
Meeting Summary
August 13, 2020
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 08/13/2020 to discuss the following agenda items:

1. Pediatric NLRB Data Request
2. Changes to Pediatric Guidance
3. PSC Guidance and Public Comment Update

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

1. Pediatric NLRB Data Request

The Subcommittee reviewed a data request and report to evaluate Pediatric NLRB data on what happens to Waitlist registrations with denied exception forms.

The report concluded:

- Of the 128 waitlist registrations that submitted exceptions to the Pediatric NLRB that were denied for requesting too many points and/or denied for submitting insufficient information, 50 percent submitted an appeal, 30 percent submitted a new case without first submitting an appeal, and 20 percent took no further action after the form was denied.
- It was more common for waitlist registrations to request fewer MELD or PELD exception points post NLRB denial than to request the same amount or additional MELD or PELD exception points.
- Nearly all exception narrative submissions post NLRB denial included additional information. Common themes found in the additional narrative information included new clinical information, justification of MELD or PELD exception points, and quality of life factors.
- Despite having at least one form denied, over two thirds of these waitlist registrations received a transplant. However, one in five waitlist registrations are still waiting and three registrations were removed for death or too sick to transplant.

Summary of Discussion

The Subcommittee expressed interest in further evaluating data on different comparison groups and their outcomes, specifically candidates who were denied and then requested less points on appeal and were approved, and those who have not had an exception.

A member commented the ultimate goal of any changes should be to decrease waitlist mortality. The Subcommittee briefly discussed the possibility of establishing a cap on PELD scores. Another member

recommended increasing the allocation of adult livers to pediatric candidates with the intention of splitting the liver.

2. Changes to Pediatric Guidance

The Subcommittee reviewed proposed additions to pediatric NLRB guidance including language on metabolic liver disease and an overall conclusion clause for the guidance. Additionally the Subcommittee reviewed proposed changes to the existing language on complications of portal hypertension.

Summary of Discussion

The Chair commented the metabolic liver disease language is being added at the request of the Pediatric Transplantation Committee to acknowledge rare metabolic disorders treated with transplantation.

For the language on portal hypertension, the Subcommittee recommended adding language that specifies documentation for case review should include detail on contraindications to standard of care. A member recommended education should be provided on what are the expectations for exception narratives.

3. PSC Guidance and Public Comment Update

The Subcommittee received a brief Public Comment update on the *Further Enhancements to the National Liver Review Board* proposal. The Subcommittee was informed of a patient-led campaign to update guidance for primary sclerosing cholangitis (PSC) and give additional priority for PSC candidates.

Next Steps

The Subcommittee will submit a data request to review the following information:

Data request on waitlist mortality:

- 5-year historical waitlist mortality for candidates with PSC
- Stratified by exception vs. non-exception
- Compare waitlist mortality to other cohort

Upcoming Meetings

- September 10

Attendance

- **Subcommittee Members**
 - Alan Gunderson
 - Julie Heimbach
 - Jennifer Kerney
 - Jorge Reyes
 - James Trotter
 - Greg McKenna
 - James Pomposelli
 - James Eason
- **HRSA Representatives**
 - Jim Bowman
 - Marilyn Levi
 - Bob Walsh
- **SRTR Representative**
 - John Lake
 - Michael Conboy
- **UNOS Staff**
 - Roger Brown
 - Matt Cafarella
 - Julia Foutz
 - Jennifer Musick
 - Leah Slife
 - Lindsay Larkin
 - Samantha Noreen
 - Carolos Martinez
 - Victor Melendez
 - Karen Williams
- **Other Attendees**
 - George Mazariegos