OPTN Liver and Intestinal Organ Transplantation Committee OPTN National Liver Review Board (NLRB) Subcommittee Meeting Summary June 10, 2021 Conference Call

Julie Heimbach, MD, Chair

Introduction

The NLRB Subcommittee (the Subcommittee) met via Citrix GoToMeeting teleconference on 06/10/2021 to discuss the following agenda items:

- 1. Hepatocellular Carcinoma (HCC) Candidates
- 2. Candidates Listed at Multiple Programs
- 3. Next Round of Diagnoses

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

1. Hepatocellular Carcinoma (HCC) Candidates

The Subcommittee discussed updating policy/guidance to remove the six month waiting period for HCC candidates who have been treated and then recur.

Summary of discussion:

A member explained that HCC candidates who are removed from the list and recur two or more years after their last treatment can lose their exception. Another member suggested that treated HCC candidates should be allowed to be removed from the list and added back if they recur without the sixmonth delay. This member continued that these patients should be able to retain exception points, regardless of the time period between initial presentation, recurrence, and last treatment. A member asked why the two year threshold was originally established. This member also suggested looking into how long HCC candidates have been waiting since the implementation of Acuity Circles (AC) to help determine the frequency at which this issue occurs.

Next steps:

UNOS research staff will look into how long HCC candidates have been waiting since the implementation of AC.

2. Candidates Listed at Multiple Programs

The Subcommittee continued to discuss updating guidance to include candidates listed at multiple programs

Summary of discussion:

The Subcommittee discussed if they should continue to pursue this potential guidance. could vary between centers and that this should impact a candidate's ability to receive an exception. Members noted that because exceptions must be recertified every 90 days, the exception following the candidate would not lend itself to a more consistent system. The Subcommittee determined they would take no further action on candidates listed at multiple programs at this time.

3. Next Round of Diagnoses

The Subcommittee began prioritizing the next round of diagnoses for review.

Summary of discussion:

The Subcommittee determined for their next round of NLRB diagnoses they would review primary hyperoxaluria (PH), polycystic liver kidney disease (PCLKD), hepatic artery thrombosis (HAT), late vascular complications, small for size, and cholangiocarcinoma (CCA). Members agreed they would also review the policy assigned score for CCA.

Next steps:

The Subcommittee will finalize this list of diagnoses and seek project approval from the POC.

Upcoming Meeting

• July 8, 2021

Attendance

• Subcommittee Members

- o Alan Gunderson
- Jennifer Kerney
- Jorge D Reyes
- o James Trotter

• HRSA Representatives

- o Jim Bowman
- o Marilyn Levi
- o Adriana Martinez
- o Raelene Skerda
- SRTR Staff
 - o John Lake
- UNOS Staff
 - Matt Cafarella
 - o Betsy Gans
 - o Julia Foutz
 - o Savannah Holmes
 - o Jenn Musick
 - o Samantha Noreen
 - Kelley Poff
 - Niyati Upadhyay

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