OPTN Pediatric Transplantation Committee
Meeting Summary
January 19, 2022
Conference Call

Evelyn Hsu, MD, Chair
Emily Perito, MD, Vice Chair

Introduction

The OPTN Pediatric Transplantation Committee (the Committee) met via Citrix GoToMeeting teleconference on 1/19/2022 to discuss the following agenda items:

1. Review of Project Statuses & Next Steps
2. Review of Draft Pediatric Lung Data Request

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

1. Review of Project Statuses & Next Steps

The Committee reviewed the statuses of their current collaborative projects.

Evidence Gathering:

- Pediatric Heart ABO-incompatible (ABOi) Transplant Project (Heart Committee)

Winter 2022 Public Comment:

- Pediatric End-Stage Liver Disease (PELD)/Status 1B Workgroup (Liver Committee)
- Pediatric Candidate Pre-Transplant human immunodeficiency virus (HIV), hepatitis B virus (HBV) and hepatitis C virus (HCV) Testing (Ad hoc Disease Transmission Advisory Committee & Pediatric Committee)

Continued Collaborations:

- Continuous Distribution of Kidneys & Pancreata (Kidney & Pancreas Committees)
    - After public comment, the Kidney & Pancreas Continuous Distribution workgroup will review feedback from the Analytic Hierarchy Process (AHP) exercise and submit a modeling request
- Multi-Organ Transplantation (MOT) Committee
    - Next phase of the project: discussions regarding prioritization between kidney MOT and single organ transplant candidates

Upcoming Collaborations:

- Continuous Distribution of Liver (Liver Committee)
    - Beginning initial discussions to identify attributes currently in policy

Summary of discussion:

A member inquired if there are any updates on the Analytic Hierarchy Process (AHP) exercise for Continuous Distribution of Kidneys & Pancreata. Staff explained that there currently aren't any updates with the exercise, but there should be emails sent out within the next couple of weeks explaining how to

participate. A member also emphasized the importance of participation from all members, not just those with kidney and pancreas expertise.

There was no further discussion.

2. Review of Draft Pediatric Lung Data Request

The Committee discussed a potential data request, which was spurred by their Needs Assessment discussion in September 2021, to better understand the challenges faced by the pediatric lung population.

Data Request:

Evaluating pediatric candidates between the ages of 0-11 and 12-18, 4 years pre and post the removal of DSA from lung allocation and compare to the anticipated impacts of CD through the TSAM modeling report for the following metrics, when sample size allows.

- Distribution of Height and Weight of these listed patients
- Primary Diagnosis
- Waitlist Mortality Rates per 100 Patient years
- Transplant Rates per 100 Patient years
- Median Waiting Time (if possible)
- 1- and 2- year survival

The Committee will recommend changes to the data monitoring plan for Lung continuous distribution to ensure the impacts seen through the data request are evaluated and reviewed.

Summary of discussion:

The Chair inquired if there is any benefit in further stratifying age in the data request. A member stated that, as it is currently, this is a good starting point. The member further explained that, depending on the data the Committee gets back, there may be a need to focus on the 12-18 age range and it can then be further stratified into the 12-15 and 16-18 age ranges. A member mentioned that the younger kids are in a similar situation in terms of how they've been assigned lungs in the past, since the lung allocation score (LAS) really affects those over 12 years old.

The Chair stated that the data request really aims to answer the following questions: (1) did the transition to acuity circles in lung allocation change any outcomes for this high mortality group of patients and (2) what groups of patients were most affected?

The Chair inquired how the Committee can dovetail this data request with the work that is already being done by the Lung Committee. Staff explained that there wasn't much data broken out in terms of pediatric patients when lung moved to acuity circles, so there isn't much data to go off of prior to continuous distribution of lungs. Staff mentioned that the Committee can see what impacts the acuity circles had and then determine if those issues are still present in the continuous distribution of lungs allocation system.

Staff clarified that the continuous distribution of lungs proposal was passed by the Board of Directors in December 2021 and will be programmed within the next year – probably December 2022 or January 2023. Staff also mentioned that one of the attributes included in the proposal is height, so those candidates that are very short or very tall will also get some additional points.

The Chair stated that the justification for this data request is that mortality rates are by far the highest in pediatric patients awaiting thoracic organ transplantation and the Committee needs to be focused on how they can help that situation. The Chair also mentioned that this will hopefully give the Committee

some ideas about other reports and data that they should be looking at in order to assess pediatric mortality year to year.

The Chair inquired about next steps for the data request. Staff explained that, if the Committee is in general agreement to submit the data request, they can submit it and determine the timeline for receiving the results. The Chair also suggested presenting this data analysis at national meetings or writing a manuscript since a lot value in the work that the Committee does comes from disseminating the data analyses to the community.

A member inquired if there are any other markers of severity of morbidity or trajectory of disease in terms of accumulated damage while these patients wait for a lung transplant. A member stated that they look at how much oxygen the patient has, whether they're intubated, and whether or not they're receiving mechanical ventilation. The member also mentioned that they look at carbon dioxide levels but don't look at other comorbidities aside from diabetes.

A member suggested reviewing the forms that get filled out at listing and transplant to see if there's any other elements to include in the data request as indicators of waitlist mortality.

A member inquired if there's any value in including patients aged 19-24 for comparison if it's known that 12-18 year olds have particularly high mortality relative to other groups. A member mentioned that they would think about including that age group but would want to consult staff before. The member mentioned that patients in that age group may have similar illnesses, but might not have received a transplant until later. Staff explained that that would not be difficult to include the 19-24 age group, but there would need to be more discussion regarding data points for mortality indicators.

The Chair suggested that Staff should review the annual report on lung and compare what the report is analyzing to what the Committee is asking to be reported. Staff explained that the Committee can also make recommendations to adjust the monitoring report for continuous distribution of lung if they find something in the analysis of this data request.

The Committee agreed to submit this data request. There was no further discussion.

The meeting was adjourned.

Upcoming Meetings.

- February 9, 2021 (Virtual)

Attendance

- **Committee Members**
  - Evelyn Hsu
  - Emily Perito
  - Abigail Martin
  - Caitlin Peterson
  - Caitlin Shearer
  - Dan Carratturo
  - Geoffrey Kurland
  - Jennifer Lau
  - Johanna Mishra
  - Kara Ventura
  - Rachel Engen
  - Regino Gonzalez-Peralta
  - Shellie Mason
  - Walter Andrews
  - Warren Zuckerman
- **HRSA Representatives**
  - Jim Bowman
  - Marilyn Levi
  - Raelene Skerda
- **SRTR Staff**
  - Christian Folken
- **UNOS Staff**
  - Rebecca Brookman
  - Matt Cafarella
  - Betsy Gans
  - Jesse Howell
  - Katrina Gauntt
  - Leah Slife
  - Samantha Weiss
  - Susan Tlusty
- **Other Attendees**
  - Melissa McQueen