

## **OPTN Pediatric Transplantation Committee**

### **Meeting Summary**

**August 19, 2020**

**Conference Call**

**Evelyn Hsu, MD Chair**

**Emily Perito, MD, Vice Chair**

### **Introduction**

The Pediatric Transplantation Committee (the Committee) met via Citrix GoToTraining teleconference on 08/19/2020 to discuss the following agenda items:

1. Public Comment: Align OPTN Policy with Public Health Service (PHS) Guidelines
2. Public Comment: Continuous Distribution Update

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

#### **1. Public Comment: Align OPTN Policy and Public Health Service (PHS) Guidelines**

A representative from the OPTN Ad Hoc Disease Transmission Advisory Committee (DTAC) presented their Align OPTN Policy and PHS Guidelines proposal to the Committee. Members provided feedback and voted on their sentiment of the proposal.

#### Summary of discussion:

The Committee Chair asked how many discards are expected to be avoided and how much transplants may increase once these policies are implemented. The DTAC representative stated that this information was not currently available and that there are other mitigating factors that factor into organ discards.

The Committee Chair asked if the label of increased risk for donors would be going away. The presenter confirmed this would be the case and there would be efforts for increased education from the OPTN and Center for Disease Control (CDC) in how to have the conversation around risk behaviors for the general consent process.

The Committee Chair asked if the post-transplant testing information would be self-reported. The DTAC representative clarified that this will be policy and the reporting would be required to be done within the window outlined in policy. The representative also noted that the proposal's intention is to allow for some flexibility with the requirement window to acknowledge that there are often challenges with patient compliance to submit them on time. The Committee Chair asked why the testing requirements would be different for livers in comparison to other organs. The DTAC representative answered that this was in relation to the epidemiology around Hepatitis B and that this would be a universal testing requirement now.

A member of UNOS staff clarified that this requirement was based off of research information from the CDC that demonstrated that the liver was the only organ that showed detection of Hepatitis B at a later timeframe.

A member stated that Organ Procurement Organizations (OPOs) would appreciate this policy as it streamlines the information they are collecting and recording. The member shared that they believed in

addition to increasing transplants, this policy could increase the amount of pediatric transplants as there is currently stigma around transplanting an “increased risk” organ into a pediatric candidate. The member asked what the rationale was for the 96 hours for serologies from the donor. The DTAC representative shared that it is linked to NAT testing. There have been reports of patients who tested negative for Hepatitis C and were more than 96 hours post-transplant but later had a conversion to a positive result. The representative also confirmed that the 96 hours was based off of procurement.

A member stated that from their experience with educating families, it has been confusing to require additional consent for the former “increased risk” factor when so many other risk factors don’t require specific consent. The new guidelines have been a positive change in this process. This member and the Chair both expressed support that this change would take away the stigma from otherwise appealing organs and has the potential to increase transplants and therefore save lives. Several other members spoke in support for the same reasons.

The Committee Chair asked if the testing requirements would include living donors as well, which the DTAC representative confirmed.

One member of the public asked what educational efforts are planned. The DTAC representative shared that the educational rollout would include not only information for clinical teams, but also for patients and their families. The member stated that there are programs across the country that do not hesitate to take PHS increased risk kidneys and it is the hope that programs will be more willing to accept these offers as well.

Another member stated that it is important in making sure parents are aware. The better parents are educated, the better the process will be.

The Committee Chair stated that one overall message is that universal testing will be implemented and that the stigma of these organ will no longer be warranted. There is overwhelming support for this proposal with the caveat that there should be a strong emphasis on education once the policy is implemented.

The Committee Chair called for a vote on the Committee’s sentiment on the proposal.

**Vote:** 8 Strongly Support, 0 Support, 0 Neutral/Abstain, 0 Oppose, 0 Strongly Oppose

Next Steps:

The comments shared by the Committee will be synthesized into a formal statement that will be submitted for public comment.

**2. Public Comment: Continuous Distribution Update**

A member of UNOS support staff with the OPTN Lung Transplantation Committee (Lung Committee) presented their Continuous Distribution Update to the Committee.

Summary of discussion:

The Committee Chair asked if the Lung Committee was primarily seeking feedback through the prioritization exercise which the presenter confirmed. The Chair asked if this process was laying the groundwork for the other organ systems which the presenter confirmed.

A member asked if this process including the prioritization exercise, would be repeated for each organ. UNOS staff explained that there will be different attributes for different organs. For example, the Lung Committee did not use waiting time as one of their attributes, whereas Kidney and Pancreas would weigh waiting time differently.

The Committee Chair stated that it would be nice to maintain consistency across organs concerning the pediatric designation, as this gets adjudicated over and over with different policies.

A member asked if there is consensus about the approach to the project, considering the strong opinions that surrounded recent policies such as acuity circles. UNOS staff shared that the committee has taken a lot of time being very thoughtful and intentional as to the approach of the project. In particular, this project gives the community the opportunity to provide as much feedback through the beginning development stage.

A member asked for clarification on the feedback that this project is hoping to receive. UNOS staff stated that most organs have a sequence for adult donors and pediatric donors, however for lung, this has been eliminated and there will be one sequence that will include all donors.

There were no additional comments or questions. The meeting was adjourned.

Next Steps:

The comments shared by the Committee will be passed onto the Lung Committee as feedback on the proposal.

**Upcoming Meetings**

- September 16, 2020 (teleconference)

## Attendance

- **Committee Members**
  - Abigail Martin
  - Brian Feingold
  - Douglas Mogul
  - Emily Perito
  - Evelyn Hsu
  - Jennifer Lau
  - Joseph Hillenburg
  - Kara Ventura
  - Shellie Mason
  - Sam Endicott
  - William Dreyer
  - Johanna Mishra
- **HRSA Representatives**
  - Marilyn Levi
  - Jim Bowman
- **SRTR Staff**
  - Chris Folken
- **UNOS Staff**
  - Courtney Jett
  - Elizabeth Miller
  - James Alcorn
  - Joann White
  - Julia Foutz
  - Kaitlin Swanner
  - Kiana Stewart
  - Lloyd Board
  - Matt Cafarella
  - Matt Prentice
- **Other Attendees**
  - Sharon Bartosh
  - Lara Danziger-Isakov