

OPTN Transplant Coordinators Committee

Meeting Summary

December 15, 2021

Conference Call

Stacy McKean, RN, Chair

Natalie Santiago-Blackwell, RN, MSN, Vice Chair

Introduction

The Transplant Coordinators Committee (the Committee) met via Citrix GoToMeeting teleconference on 12/15/2021 to discuss the following agenda items:

1. Effective Practice: Boston Children’s Hospital Transplant Transition Clinic
2. OPTN Winter 2022 Public Comment Preview

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

1. Effective Practice: Boston Children’s Hospital Transplant Transition Clinic

The Committee heard an effective practice presentation from a member on operating a transition clinic for pediatrics as they approach adulthood.

Presentation Summary:

The presenter began by explaining the need for a transition clinic for pediatrics who are moving into adult care. Despite more pediatrics being transplanted and surviving long enough to move into adult care, that age group is the second highest for graft loss, after adults aged 65 and older. This is due to poor adherence and being lost to follow up. Both of these could be contributed to a lack of necessary communication between the candidate and the program, as the pediatric setting operates differently than the adult setting.

The purpose of the transition clinic was to create an intermediary step to facilitate the transfer from a pediatric treatment program to an adult program, and to provide education for the patient such that they will have fewer issues navigating adult healthcare. The first such clinic had lung and liver patients ages 14 to “college age”. During their visit, they would meet with a social worker, provider or coordinator, transplant pharmacist, adolescent medicine provider, and an organ specific attending. These were chosen to ensure the patient has a well-rounded grasp of how their treatment will change moving forward and the changes to expect over the next couple years. The patient’s grasp of the changes will be assessed with a transplant readiness assessment over the course of their term with the clinic.

The feedback for the clinic from the patients has largely been supportive, and the presenter excerpted quotes that showed support from providers, patients, and parents.

The final step is communicating with the adult clinics that the patients move on to, to see if there has been a successful transfer of care. This not only helps the program validate the transition clinic’s work, but also ensures the patient is not lost to follow up in the transfer. One area that the clinic has put significant work into is ensuring patients are aware their prescriptions may change, or the route in which they receive prescriptions may change. A downfall the program identified was patients not

understanding how to refill their medications as an adult or not being aware their medications have changed after leaving pediatric treatment.

The COVID pandemic has impacted the clinic practices, and in-person visits have been cancelled. Zoom group sessions have been started for patients and parents in place of in-person group sessions.

Summary of discussion:

The Chair inquired whether there was pushback from the pediatric providers about transitioning every patient on the same timeline, as, in their experience, providers appreciated the flexibility of determining when a patient was ready to move to adult care. The presenter replied there was definitely some resistance early on, as there had been little communication between their pediatric team and the surrounding adult teams. They did add that some patients still did not transition on the established timeline due to developmental disorders or comorbidities. A member added that, while their program had a similar clinic, they had two different practices: the first, that a social worker attended the first adult visit with the patient, and the second, that the patient returned to the pediatric clinic after their first visit to discuss it. They clarified that the patient was not officially transferred to the adult provider until after that first visit, so as to prevent confusion surrounding care for the patient.

2. OPTN Winter 2022 Public Comment Preview

UNOS Staff presented on the proposals going out for public comment during the winter 2022 cycle. The Committee was encouraged to think of which they would want to provide input on.

Presentation Summary:

The Committee heard very brief highlights on the following proposals:

- Pediatric Candidate Pre-Transplant HIV, HBV, and HCV Testing
- Establish Eligibility Criteria and Safety Net for Heart-Kidney and Lung-Kidney Allocation
- Update on OPTN Regional Review Project
- Project to Revise the OPTN Charter
- Change CPRA Calculation
- Update on Continuous Distribution of Kidneys and Pancreata
- Minimum Criteria Appropriate for Kidney Biopsy
- Standardized Kidney Biopsy Reporting and Data Collection
- Improving Liver Allocation: MELD, PELD, Status 1A and Status 1B
- Ongoing Review of NLRB Diagnoses
- Modify Living Donor Exclusion Criteria
- Reassessing the Inclusion of Race in eGFR Equation Proposal
- VCA Graft Failure Definition

The full proposals will be available [on OPTN](#) for public comment between January 27 and March 23.

Upcoming Meeting

- January 19, 2022

Attendance

- **Committee Members**
 - Stacy McKean
 - Natalie Santiago-Blackwell
 - Jill Campbell
 - Maria Casarella
 - Brenda Durand
 - Lisa Gallagher
 - Rosa Guajardo
 - Sharon Klarman
 - Angele Lacks
 - Heather Miller-Webb
 - JoAnn Morey
 - Jaime Myers
 - Melissa Walker
 - Rachel White
- **HRSA Representatives**
 - Raelene Skerda
- **UNOS Staff**
 - Brooke Chenault
 - Isaac Hager
 - Elizabeth Miller
 - Susan Tlusty
 - Ross Walton