OPTN Patient Affairs Committee
Meeting Summary
October 19, 2021
Conference Call

Garrett Erdle, M.B.A, Chair
Molly McCarthy, Vice Chair

Introduction

The Patient Affairs Committee met via Citrix GoToMeeting teleconference on 10/19/2021 to discuss the following agenda items:

1. OPTN Ad Hoc Multi-Organ Transplantation Committee – *Establish Eligibility Criteria and Safety Net for Heart-Kidney and Lung-Kidney Transplantation* project
2. Introduction to Scientific Registry of Transplant Recipients (SRTR)

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

1. OPTN Ad Hoc Multi-Organ Transplantation Committee – Establish Eligibility Criteria and Safety Net for Heart-Kidney and Lung-Kidney Transplantation project

Charlie Alexander, the Chair of the OPTN Ad Hoc Multi-Organ Transplantation (MOT) Committee, provided an overview on the background of MOT and the developing eligibility criteria and safety net for Simultaneous Heart-Kidney (SHK) and Simultaneous Lung-Kidney (SLuK) transplant. This policy is in the development process and will be out for public comment in January 2022.

Summary of discussion:

A member inquired why the *Clarify Multi-Organ Allocation Policy* from the OPTN Organ Procurement Organization (OPO) Committee allows for discretion on who may receive a multi-organ offer. The MOT Chair responded that this discretionary system based on historical knowledge is the biggest issue with the existing policy, and by developing this new policy, it will remove some of that discretion to provide a consistent and replicable system. The member followed up, inquiring why there is an ongoing perception that higher quality kidneys end up in multi-organ patients as opposed to single organ patients. The presenter shared that, based on his experience, those who are able to donate their heart and lungs tend to have healthier kidneys, and those who are unable to donate their heart or lungs tend to experience kidney issues.

A member argued that the first organ, either the heart or lungs, is the lifesaving organ, while the second organ, the kidney, becomes a life-enhancing organ. There was a concern expressed over the utility of dual organs given to older patients as opposed to younger patients. The presenter assured the member that OPOs do not want to be in the position to be making decisions for a patient and this policy aims to reduce that. The member added that the dialysis requirement should be extended to 90 days, and the MOT patients should have a clear requirement to follow up with transplant nephrologists after starting dialysis. Despite this proposed policy reflecting that of the existing Simultaneous Liver-Kidney (SLK) policy, the member felt that the existing policy criteria was outdated and should be revised to reflect the prior comment.

A member inquired why the Committee is addressing multi-organ transplants in a sequential manner instead of developing a larger, more comprehensive policy that can be adjusted as needed. The presenter responded that the work is ordered sequentially through the charge given to the MOT Committee from the Policy Oversight Committee (POC). This allows for the MOT Committee to get policies out for public comment as they are ready, as opposed to waiting until there is a fully fleshed out, system-wide, multi-organ allocation scheme developed. The member further questioned that the sequential nature adds tension with developing a policy that will be consistent with continuous distribution. The presenter responded that the MOT policies are being developed in a way that allows them to be absorbed into the new continuous distribution frameworks, and the decision to address different multi-organ combinations was decided based on community need. UNOS staff clarified that, regardless of continuous distribution's allocation policies, medical eligibility for a multi-organ transplant will not be impacted.

A member asked that, if the allocation numbers for Simultaneous Kidney-Pancreas (KP) are so much higher than SHK and SLuK, why is the OPTN not addressing KP. UNOS staff responded that the first organ, whether that be liver, heart, lungs, or kidney, is what drives the allocation. For KP patients, they are kidney patients who also need a pancreas, as opposed to heart or lung patients who also need a kidney.

A member asked if allocating organs to sicker patients was a good utilization of organs if they could potentially have a shorter lifespan. The presenter responded that this philosophy is a utilitarian point of view, which the OPTN has transitioned to focusing on transplanting the sickest, most in-need patients, while considering their ability to sustain meaningful life after transplant.

A member noted that multi-organ transplants are increasing every year and asked if this policy will stabilize those numbers. Another member countered that the increase in MOT allocation has been consistent with the increase in organ transplants system wide, and the percentage of MOT has not increased in proportion to other transplants. The presenter responded that, by developing eligibility criteria, it is likely that the number of MOTs will decrease as consistency in allocation improves.

Members shared concern from the heart community that there is an increased risk to heart recipients enduring additional immunosuppression, and the benefit that patients receive when exposed to fewer antigens. UNOS staff shared that the OPTN Histocompatibility Committee reviewed the policy and commented that there are benefits to patients receiving organs from the same donor, but that this benefit should not drive allocation decisions.

Next steps:

Please send any additional comments or questions to UNOS staff.

2. Introduction to Scientific Registry of Transplant Recipients (SRTR)

Alyson Hart and Katie Audette introduced the Scientific Registry of Transplant Recipients (SRTR).

Summary of discussion:

Members discussed the role of the SRTR website. Members felt that the SRTR website can be improved to include context of what the data means for patients. Members offered assistance in recruiting patients and family members to participate in SRTR's consensus conference and focus groups.

The presenter identified two important gaps in data. The first being zip code and extensions to analyze socioeconomic information, and the second being prelisting data to evaluate access to transplant. The presenter clarified that the data the SRTR has access to is based on OPTN policy and data collection. The SRTR does not collection additional or supplemental data, they just analyze the existing OPTN data.

Upcoming Meetings

- November 16, 2021
- December 21, 2021
- January 18, 2021
- February 15, 2021
- March 15, 2021
- April 19, 2021
- May 17, 2021
- June 21, 2021

Attendance

- **Committee Members**
  - Anita Patel
  - Betsey Brada
  - Chris Yanakos
  - Darnell Wuan
  - David Skinner
  - Earl Lovell
  - Eric Tanis
  - Garrett Erdle
  - James Sharrock
  - Julie Ice
  - Julie Spear
  - Justin Wilkerson
  - Kenny Laferriere
  - Molly McCarthy
  - Sarah Koohmaraie
  - Sejal Patel
- **HRSA Representatives**
  - Jim Bowman
  - Raelene Skerda
- **SRTR Staff**
  - Allyson Hart
  - Katie Audette
- **UNOS Staff**
  - Eric Messick
  - Laura Schmitt
  - Lindsay Larkin
  - Matt Prentice
  - Ross Walton
  - Sara Rose Wells
  - Susan Tlusty
  - Tina Rhoades
- **Other Attendees**
  - Charlie Alexander
  - Colleen Reed
  - Paige Oberle
  - Precious McCowan