OPTN/UNOS Patient Affairs Committee
Meeting Minutes
September 18, 2018
Conference Call

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Introduction

The Patient Affairs Committee (PAC) met via Citrix GoToTraining teleconference on 09/18/2018 to discuss the following agenda items:

1. Committee Report: Kidney, Pancreas, Thoracic, VCA Committee Reports

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

1. Committee Report: Kidney, Pancreas, Thoracic, VCA Committee Reports

Patient representatives from the Kidney, Pancreas, Thoracic and VCA Committees provided PAC with updates on eliminating the use of DSAs and regions from their distribution systems. distribution. All organ-specific committees, with the exception of VCA, have submitted modeling requests to the SRTR and plan to distribute public comment proposals in the spring of 2019. The OPTN Board of Directors will consider these proposals in June 2019.

Summary of Discussion

The PAC Chair noted that the average candidate and donor family member will not participate in the public comment process so it is important for this patient group to voice their opinions. The PAC asked for clarification on several more general questions. One member asked why all the organ-specific committees opted for the concentric circle geographic framework, when the group had recommended continuous distribution be the model the OPTN implement across all organs. UNOS staff responded that the Committees selected this particular framework for consistency with the Final Rule and ease of implementation, in light of the time constraints within which they were directed to make rapid changes. Distance instead of time.

Several members asked about ischemic time and travel limitations. If there is truly a limited time/distance that a specific organ can travel, is a "national circle" or "national share" feasible? In other words, if the profession understands a "national share" is practically an impossible occurrence, to include it is misleading to patients. Another member asked that if there are hard and fast ischemic timeouts for an organ, why is that not serving as the foundation of distribution? The patient representative to the Pancreas Committee explained that it was reasonable, and consistent with the Final Rule, to limit distribution to mitigate logistical impracticalities, such as organs crossing in the air if being shipped to candidates on opposite coasts. Another member agreed, surmising it would not be efficient or cost-effective for the procuring team from Seattle, WA, to fly to Miami, FL, to pick up an organ for an individual with high priority on the waiting list while the team from Jacksonville, FL, was flying to Portland, OR to pick up an organ for a patient with a clinically inconsequential difference in degree of illness and/or priority on the waiting list. One member voiced concerned with the focus on "miles" while its "time" that, as you note, determines success...ischemic time. Thus, she suggested using an application of known tools (MapQuest, just for example) that at any time will assist in the determination of the real time of transportation, based upon the mode and current conditions.

She stated that some geographic principles were more relevant to some organs than others. For example, limiting distribution due to ischemic time is critical for thoracic organs. In addition,

donor phenotypes matter, and donor characteristics are not readily captured in Final Rule, so the circles serve as a surrogate. Though donor organs are a national resource, a true the national allocation system without some modifications to take geography into account would also fail to meet Final Rule standards based on issues of efficiency and costs of organ distribution, as well as possible increased wastage of donor organs.

A general comment was made to prioritize patient education, but commented that educating patients about certain health-related things can be delicate and often needs planning and finesse; but it should always be done.

They also pointed out the concentric circle model still contained a hard boundary that could potentially disadvantage a patient just outside the circles.

Kidney/Pancreas Committees Report

The PAC did not have any recommendations, and look forward to reviewing the modelling.

One member asked what was meant when "slope" is being discussed in regards to the circles. The Pancreas Committee patient representative advised it illustrated how much value proximity over other medical conditions. Another member asked when will KP workgroup decide on points for the hybrid model, should they choose that model. The speaker advised that would not occur until the Kidney and Pancreas Workgroup vetted the modelling and determined a path forward.

Thoracic Committee Report

A heart recipient favored the 150 NM stated in the proposal with absolute leeway as appropriate based upon things like medical urgency. This member did not feel 500 NM, as a routine, was prudent based upon ischemic time and outcomes, and supported either the 150 or 250 NM distribution circles are better standards for hearts.

VCA Committee Report

One member found it interesting how the VCA Committee considered the impact on donation decisions by donor families based upon current and future allocation models. Another member asked whether there a cold ischemic time with VCA? The speaker advised the cold ischemic time is similar to heart (4 hours).

Upcoming Meeting

- October 16, 2018