OPTN ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK

OPTN Pediatric Transplantation Committee
Meeting Minutes
March 20, 2019
Conference Call

George Mazariegos, MD, Chair
Evelyn Hsu, MD, Vice Chair

Introduction

The OPTN Pediatric Transplantation Committee (hereafter, "the Committee") met via teleconference on 03/20/2019 to discuss the following agenda items:

1. Ethics Committee White Paper on Candidates with Intellectual Disabilities Workgroup
2. Kidney-Pancreas Pediatric Prioritization
3. Heart Pulmonary Artery Pressures and SRTR Data

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

1. Ethics Committee White Paper on Candidates with Intellectual Disabilities Workgroup

The OPTN Ethics Committee is creating a workgroup to draft a white paper on candidates with intellectual disabilities. UNOS staff presented information on the workgroup and the issue they will address in the white paper to the Committee.

Summary of discussion:

Currently, there is no official guidance from the Health Resources and Services Administration (hereafter, "HRSA") or the OPTN on evaluating intellectually disabled individuals for transplant. As such, the listing criteria and standards for this population can vary from program to program. More so, several studies have indicated that individuals with intellectual disabilities, including pediatric patients, may face discrimination.

The purpose of the workgroup is to create a white paper that discusses the ethical arguments about evaluating intellectually disabled candidates. The workgroup will meet bi-monthly over the next two months to complete the white paper.

A Committee member noted that adults with disabilities often have no advocates in the transplant process, and suggested that this be addressed in the white paper. The Committee member also recommended that the white paper should be mindful of the terms used, and suggested that a parent of a transplant recipient with an intellectual disability be involved in the workgroup.

The Chair of the Committee was appreciative of being involved in the workgroup and committed to having a pediatric representative engaged in the project.

Next Steps

A representative from the Committee will participate in the workgroup.

2. Kidney-Pancreas Pediatric Prioritization

As part of the spring public comment cycle, the OPTN Kidney Transplantation and OPTN Pancreas Transplantation Committees sponsored a public comment proposal titled, "Eliminate the use of DSAs [Donation Service Areas] and regions from kidney and pancreas distribution." The two Committees are now incorporating the feedback received during public comment and are submitting requests for another round of modelling to the Scientific Registry of Transplant Recipients (hereafter, "SRTR"). The workgroup responsible for drafting the proposal is

considering including additional prioritization for pediatric candidates in the modelling request. The Committee was asked to provide input on the proposed pediatric prioritization.

Summary of Discussion

A Committee member that has participated in the workgroup informed the Committee that the workgroup has met recently by phone and is spending most of their time deciding what new modelling to ask for from the SRTR. Based on the public comment feedback, the workgroup is focusing on the hybrid model for allocation with circle sizes of 150 nautical miles (NM), 250 NM, and 500 NM. The workgroup will discuss proximity points during their next call. The Committee member felt that the problem with the proximity points in the inner circle is that each proximity point is equivalent to one year of waiting time, which defeats the purpose of removing geography from allocation.

The Committee member noted that the workgroup has not yet discussed the pediatric population during their calls. UNOS staff stated that pediatric prioritization is on the agenda for the workgroup's next meeting. The Chair asked if the workgroup already had a specific idea of how they would like to prioritize pediatric candidates. The plan is for UNOS staff to present options on pediatric prioritization to the workgroup, which they would then discuss and vote on. The Vice Chair asked if the options could be sent to the Committee prior to the next workgroup meeting so that Committee members could provide their input. Because the workgroup meetings thus far have been focused on public comment feedback and selecting the next round of modelling, the Committee member who is part of the workgroup has not had the opportunity to advocate for pediatric prioritization. However, when pediatric prioritization is discussed in the future, the Committee member needs to know what to suggest to the workgroup.

The Committee member stated that suggesting that pediatric candidates be prioritized ahead of multi-organ candidates will face significant opposition. The Vice Chair noted that it is difficult for the Committee to have any recommendations at this time because they do not know the options under consideration. The Vice Chair stated that it would be best for the Committee to see the options for pediatric prioritization and discuss them before making a recommendation.

A Committee member who previously participated in the workgroup noted that he or she circulated a paper regarding pediatric prioritization to the workgroup and the Chair of the workgroup seemed to be a proponent of putting the pediatric candidates in Sequence C higher than where they currently are. The workgroup was also planning on putting pediatric candidates ahead of some of the highly-sensitized candidates. Another option is to prioritize pediatric candidates ahead of kidney-pancreas candidates for pediatric kidneys.

A Committee member supported prioritizing pediatric candidates for pediatric donors. There is some precedent for this practice, as pediatric livers are allocated in this way. The main objective is to get the kidneys with the highest longevity allocated to pediatric candidates. One of the issues is that low kidney donor profile index (KDPI) organs are allocated to kidney-pancreas candidates prior to pediatric candidates. The Committee member was unsure how this would change with the new allocation system.

The Chair asked for clarification on the timeline for the Committee to submit feedback. The Chair also asked if the two Committee members who have participated in the workgroup could collaborate to draft a letter on behalf of the Committee. The comment will summarize what the Committee has discussed. A Committee member noted that the American Society of Transplant Surgeon's (ASTS) comment on the proposal also supported pediatric prioritization.

Next Steps:

Two Committee members agreed to draft a comment on the kidney-pancreas public comment proposal on behalf of the full Committee. The Chair and Vice Chair will review the comment prior to submission.

3. Heart Pulmonary Artery Pressures and SRTR Data

Summary of Discussion:

The SRTR liaison to the Committee noted that pulmonary artery pressure is often missing from data reporting documents. This has been an issue for the heart outcomes models. In the past, missing pressures were treated as the lowest risk value. However, there are many reasons why the pulmonary artery pressure value could be missing. The SRTR liaison already discussed this issue with Committee members that deal with heart transplants, but wanted to make the entire Committee aware of these conversations.

A Committee member noted that the pulmonary artery pressure measurements are also inconsistently collected. Because the values are often missing and they may be inconsistently collected, this predictor should not be used for risk adjustment. The Committee member suggested removing pulmonary artery pressure from risk adjustment models. Another Committee member agreed that how pulmonary artery pressure is measured varies between programs, some programs are not even reporting it, and it is often not useful information.

A Committee member asked if it will be replaced with a different value in risk adjustment models. A Committee member stated that there is no other data element to replace it. This will allow the effect of other predictors to be larger.

The Committee agreed that the pulmonary artery pressure variables should be removed from risk adjustment models for pediatric candidates.

Next Steps:

Pulmonary artery pressure will be removed from risk adjustment models for pediatric candidates.

With no further business to discuss, the call was adjourned.

Upcoming Meeting

- April 16, 2019 – Richmond, Virginia