OPTN/UNOS Liver and Intestinal Organ Transplantation Committee Meeting Minutes August 28, 2018 Conference Call

Julie Heimbach, M.D., Chairman James Trotter, M.D., Vice Chairman

Introduction

The Liver and Intestinal Organ Transplantation Committee (Committee) met via teleconference on 08/28/2018 to discuss the following agenda items:

- 1. Review Geography Committee Public Comment Proposal
- 2. Patient Affairs Constituent Council Report
- 3. Region 8 Variance (Potential New Project)

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

1. Review Geography Committee Public Comment Proposal

The Committee reviewed and provided feedback on the Ad Hoc Geography Committee's proposal that includes three distribution frameworks identified as being in alignment with the adopted principles of geographic distribution and the OPTN Final Rule.

Summary of Discussion:

The Committee asked about spending time changing allocation according to one framework when a different framework may be the long-term goal. However, zeroing in on one framework is a long-term process and not the goal of the current efforts to change allocation to be compliant with the Final Rule by removing DSA and region. Eventually there will be a movement towards consolidating all policies under a single framework. It is important to note that the concentric circles framework could be transitioned into the continuous distribution model. Having organ committees work concurrently to address DSA/region in their respective distribution systems reflects the expedited timeline.

The Chair asked whether the Geography Committee could decide which framework to use so there will not be any conflict between allocation changes or additional work from modifying allocation in the future. There is a directive from the Board of Directors (BOD) to send the three frameworks out for public comment and get community feedback regarding which is the most supported option. Another Committee member expressed confusion over having multiple committees making separate recommendations to the BOD at the same time and felt it is likely causing confusion in other committees as well.

A Committee member commented that the borderless and circles frameworks are not necessarily conflicted. In terms of circles sized chosen, those can be thought of as pretty close in terms of patient illness. Model for End-Stage Liver Disease (MELD) score is medical acuity and distance is a discrete variable, but that does not need to be done. Those are different things that can be changed, so they should not be in conflict.

One question related to distance as a factor in the model and whether travel time factored into the equation of nautical miles. Distance is being used as a surrogate for proximity, but what really matters is the time it takes to get from point A to point B. Travel time may be a better measure than distance, but would require more work to determine due to variables such as availability of transportation, roadways, etc.

One Committee member asked about whether the Geography Committee is looking at high-risk organs to reduce discards. Organ-specific committees will be the most knowledgeable bodies about specific risks of discards for their specific organ, and therefore will guide the development of the policies as they relate to discards. This is why discussions with the Liver Committee include special consideration for donation after circulatory death (DCD) or patients over 70 years.

Liver does not have a kidney donor profile index (KDPI) equivalent, so the factors involved would probably be just MELD and distance, which could appear to favor urban centers with a lot of donors around recipients.

Another Committee member suggested considering giving patients located in rural areas a higher score. In addition, the proximity component of the total score could be the same value out to a certain distance, which would in effect be equal to creating a fixed radius circle of that distance. This is another point that demonstrates more similarity than difference mathematically between framework 1 and 3. The Chair expressed concern over the amount of work it would take to agree on point values for each of the variables. The Committee agreed that whatever point values are determined must be rationally justified.

One question was whether there was any consideration given to disparity or donor availability in terms of geography. For example, would a patient in a location that has fewer donors have equal access to an organ from a location with many donor organ? The first principle of distribution allows constraining geographic distribution for the reduction in differences in donor supply and demand, so therefore would be allowed for consideration. How to operationalize that, however, is still a subject of debate and discussion.

Next steps:

Committee members can individually provide feedback on the proposal through the link to RedCap they will receive by email.

2. Patient Affairs Constituent Council Report

Summary of Discussion:

The Patient Affairs Committee is working under a new structure called Constituent Council. The councils are designed to increase real-time communication between and within UNOS Committees. The patient rep on the Liver Committee will interact directly with the Patient Affairs Constituent Council (PACC) as an active member in all committee activities. The structure change has resulted in constituency feedback and projects and ideas earlier in the process.

A process has been mapped that will facilitate sharing project information between other committees and the PACC. A Committee Project Report is posted to Basecamp well in advance of Liver Committee's meetings, giving members the opportunity to review and post feedback via Basecamp. The patient rep also has the opportunity to learn more about the transplant world, and be more comfortable interacting with their home committee, as well as bringing discussion to the PACC for its input.

The Committee requested feedback from the PACC. There was strong support for a framework (in this case fixed distance) that does not prolong the allocation process, prioritizes the sickest candidate first, promotes utilization and mitigates discards, and considers recipient/graft outcomes. However, there was some confusion about the concentric circles. Additionally, many asked about time versus distance as a variable. Time would align better with ischemic times and outcomes, but can be influenced by factors such as method of travel. There were also concerns about patients in rural/isolated areas, as well as vulnerable populations such as veterans.

Feedback on communication was requested. There has been confusion as to how this is being presented in public comment and overlapping with the geography project. When information is shared is as important as how it is shared. To maintain public trust, it must be proactive, honest, and transparent. Communication strategy recommendations included collaborating with transplant centers, using social media, using plain language and layman's terms, and sharing context information, meaning the information around what is being discussed.

3. Region 8 Variance (Potential New Project)

Summary of Discussion:

The Region 8 Variance was previously discussed and supported by the Committee. Region 8 supports the opportunity to try their variance, which focuses on a center accepting a liver that they want to split to use the other lobe for another patient on the match run at their center or an affiliated center. However, since regions are no longer part of allocation, it would be difficult to go forward with this project. Under the December 2017 policy, the variance would apply if livers were recovered in Region 8 and transplanted in Region 8.

Committee members will decide if they support adding the Region 8 Variance to the list of existing variances during the special public comment. It still needs to be approved by the Policy Oversight Committee.

Next Steps:

This will be further discussed at the next meeting.

Upcoming Meetings

- September 4, 2018, Teleconference
- September 18, 2018, Teleconference
- September 25, 2018, Monthly Teleconference
- November 2, 2018, In-person Meeting in Chicago