OPTN/UNOS Pancreas Transplantation Committee Meeting Minutes July 17, 2018 Conference Call

Jon Odorico, MD, Chair Silke Niederhaus, MD, Vice Chair

Introduction

The Pancreas Transplantation Committee (hereafter, the Committee) met via Citrix GoToTraining teleconference on 7/17/2018 to discuss the following agenda items:

- 1. Update on Geography
- 2. Improving Committee Structure Fall 2018 Proof of Concept

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

1. Update on Geography

The Committee received an update on the changes happening with geographic distribution.

Summary of discussion:

The Committee reviewed the principles of distribution approved by the Board in June and subsequent updates related to geography since the Board meeting. Specifically, the Health Resources and Services Administration (HRSA) received a critical comment on liver policy and Donation Service Area (DSA) and region being incompatible with the Final Rule. HRSA issued a request to the Organ Procurement and Transplantation Network (OPTN) to review DSA and region in current policy. The plan with liver is to revise geographic distribution to be more compatible with the Final Rule; the proposed geographic distribution changes will go out for public comment in October, and to the Board in December. Other organ allocation policies will be examined for compliance with the Final Rule and the opportunity to replace DSA and region with more compliant geographic units. These distribution changes will go out for public comment in January 2019.

A Committee member noted that the current changes happening with liver are very relevant for pancreas allocation, which may have to make similar changes to its allocation. The Chair noted that a previously active project, Broadened Allocation Across Compatible ABO Blood Types, will be put on hold due to the increased workload related to changing geographic distribution. Because the kidney and pancreas allocation systems are interconnected, a work group comprised of members of both committees will work on finding an alternative to DSA and region as geographic units in allocation.

The Committee reviewed the three frameworks for geographic distribution that the Geography Committee has identified as consistent with the principles of distribution and the Final Rule: fixed-distance circles, mathematically optimized areas, and borderless distribution. A Committee member expressed interest in the third framework's ability to incorporate disparate elements such as waiting time, severity of illness, and geography into an allocation system. The Liver Committee is working on a modeling request now, and other organ committees will submit modeling requests in early September. The Committee Chair expressed interest in looking at the liver modeling during the September meeting if it is available.

A Committee member expressed concern about the changes to geographic distribution implying broader sharing and having a negative impact on smaller programs. The Committee liaison

noted that there will still likely be a local distribution level even if it isn't DSA, so it could have an impact but doesn't mean the level of distribution itself is being eliminated.

Next Steps:

Some Pancreas Committee members will be asked to join the KP Work Group to identify alternatives to DSA and region in geographic distribution.

2. Improving Committee Structure – Fall 2018 Proof of Concept

The Committee heard about the proof of concept to improve constituent participation in the committee process.

Summary of discussion:

This proof of concept stemmed from the Expert Councils concept paper that went out for public comment in the Spring but received a number of concerns from the community about unintended consequences related to potentially decreasing the voice of constituent communities in the committee process. To respond to those concerns, a proof of concept was developed to test how to increase community engagement in the committee process. The Patient Affairs Constituent Council (PACC) and the Transplant Coordinators Committee (TCC) are both piloting the project. PACC has patient representatives from other committees in addition to the Patient Affairs Committee members, including a recipient who serves as the patient representative on the Pancreas Committee and is also the Vice-Chair.

The Vice-Chair expressed interest in seeing how the proof of concept will work out, and supported the effort to further engage patients. She indicated using Basecamp as a resource was initially overwhelming as a new tool, but found the desktop version easier than the app. PACC members are participating and utilizing the different functions on Basecamp. The Committee liaison gave the Committee a brief tour of the Pancreas Committee Basecamp site, and will provide more information on it during the next call.

Next steps:

The Committee liaison will invite Committee members to the Committee Basecamp site ahead of next month's call.

Upcoming Meetings

- August 15, 2018 (teleconference)
- September 19, 2018 (teleconference)