Interim Report of the

OPTN/UNOS Transplant Coordinators Committee Meeting September 24, 2012

Chicago, IL

I. Old Business

<u>Inactive Waitlist Management</u> The staff liaison updated the Committee on the work of the manuscript for Progress in Transplantation. It was noted that the results from the survey on Inactive Waitlist Management Practices in 2009 had been presented at a previous Transplant Management Forum and annual NATCO meeting, and UNOS leadership has since made the decision to not move forward with submitting the manuscript; however, recent data presented to the Committee April 2, 2012 and June 11, 2012 will be used to develop an abstract to submit to NATCO early Spring 2013 for consideration at their annual meeting. Additionally, comments gleaned from the 2009 survey will be included in the background of the abstract.

The Committee also discussed a policy proposal for criteria for notifying patients with an inactive status. It was noted that the policy should mirror existing policies; have consecutive time not cumulative; and clarify that this is inactive time that is patient specific and not due to reasons that a program would become inactive. Discussion ensued and the following questions were addressed: how do you know if the patient receives the letter; is a phone call too much to ask; will a confirmation for certified mail get lost in the hospital; and is it better to use "notify" in a broad sense and not specify how? The Policy Working Group will begin to answer these questions; look at language used in other policies; and determine the implications for relisting.

UNOS staff on the Chrysalis Waitlist Team explained that there will not be a way to bring up a column of inactive days for patients at a center as the Committee would like because some patients are waiting for more than one organ; however, a report feature will be designed in waitlist to bring up all inactive candidates as a standard report including total days inactive and his report can be submitted as a member data request through the OPTN website. The Committee was then given a demonstration how the new Waitlist will function.

II. New Business

<u>Policy Proposals Issued for Public Comment</u> The Committee was presented with the proposals to Substantially Revise the National Kidney Allocation System and Modify the Imminent and Eligible Death Definitions for Data Collection distributed for public comment on September 21, 2012. The Committee agreed that more time was needed to formulate feedback on these proposals and plans to further discuss and vote on these proposals during an upcoming Live Meeting.

<u>Icebreaker exercise</u> The Committee formed small groups during the meeting to answer the following: how the OPTN can improve the coordinators role, and how the TCC can positively contribute to the OPTN. "Data" and relating issues were most often noted.

How can the OPTN improve the Coordinator's Role?

- Provide education or a tool to simplify the data that influences center and OPO SRTR results.
- Have resources available at the Helpdesk after hours.
- Establish a Task Force to address the impact of data submission along with the necessity of date and re-define what is important for CMS and the assessment of transplant outcomes.
- Provide UNOS Regional Meetings by webinar.
- Partner with NATCO, ITNS, and others to update and standardize core competencies for the coordinator.
- Simplify data collection and upload data in a timely manner. Ask the TCC what data is important to their practice.
- Clarify, simplify and have consistent definitions for data elements.
- Have CMS & OPTN on the same page for regulatory reporting.
- Quote data accurately to the public. (i.e. active vs. inactive list quotes)
- Improve communication at all levels.
- Improve data collection requirements.
- Clearly define survey expectations (i.e. combine surveys into 1)
- Develop a checklist to guide how to handle adverse events and culture reporting processes.

How can the TCC positively contribute to the OPTN?

- Continue to be the voice of coordinators on providing feedback to the OPTN on how policy will impact the day to day life of the coordinators and patients.
- Assist in streamlining the data collection process along with updating the data that needs to be collected so it is valid.
- Coordinators are in the front line and able to provide feedback on transplant issues that impact patients and families.
- Provide accurate data if requested in a concise manner.
- Provide a realistic view of daily operations.
- Become the voice of those healthcare professionals dealing with the groundwork in transplantation.
- Have a formal communication process for coordinators within their region.

III. Meetings

The next LiveMeeting is scheduled for October 23rd. Agenda items will include reviewing results from the icebreaker exercise from this meeting; begin crafting language for the proposed policy on patient notification for having an inactive status; and voting on the Kidney and OPO Committee policy proposals currently out for public comment.

Melissa Dunbar-Forrest, RN, BSN

Chair UCLA Medical Center 310-794-0839

Kim Johnson, MS Staff Liaison 804-782-4654