

**OPTN/UNOS Patient Affairs Committee
Interim Report
Conference Call
December 6, 2012**

I. Non-Renal Solid Organ Transplant (NRSOT) Recipients waiting for Kidneys

The Committee received a report from the Non-renal Solid Organ Transplant (NRSOTO Subcommittee). The Subcommittee presented a statement requesting priority for kidney candidates who are prior recipients of Non-Renal Solid Organ Transplants. The goal of the subcommittee is to look at ways to prevent deaths on the waiting list. It is expected that this population would be:

- More highly sensitized
- Have longer wait times because of their higher CPRA's
- Greater potential for death on the waiting list

The Subcommittee recommended that the Committee adopt the statement below and present it to the Kidney Committee with a request for action in this area.

Recipients of lifesaving solid organ transplants like Heart, Lung, Liver and Intestine are at increased risk of Chronic Kidney Disease (CKD) due to multiple factors including diabetes, hypertension and calcineurin inhibitors used for immunosuppression. The presence of CKD in these patients is associated with increased morbidity and mortality. The number of these patients is only 1.3 % of all those awaiting a Kidney Transplant Or 1225 patients.

We propose that consideration (extra points) should to be given to these patients to shorten their wait times for a Kidney Transplant: in order to improve their survival following a life saving transplant in the past.

Discussion

The Committee raised the following questions during discussion:

- Why are prior kidney recipients excluded in the discussion
- How will the newly proposed Kidney Allocation System impact kidney candidates who have previously received non-renal solid organ transplants
- Wanted to see age breakdown of NRSOT's who die on the waiting list for kidneys

The Committee also engaged in an extensive discussion of their discomfort with what appears to be valuing one group of candidates over another.

The Subcommittee responded with the following points:

- Kidney candidates have already lost their graft. NRSOT recipients have a functioning graft, which they are in danger of losing while waiting for a kidney. Providing priority would save the functioning graft by providing speedier access to a kidney
- Recipients of NRSOT's die at twice the rate of other candidates on the waiting list
- Recipients of NRSOT's are more likely to die on dialysis while waiting

After considerable discussion, the Committee opted to develop a plan for work around this issue, which would include convening a workgroup of representatives from each of the solid organ committee's to discuss the issue in more detail.

This project will require approval from the Policy Oversight Committee (POC) to go forward. Proposals for new work will be reviewed by the POC in

II. Social Media Subcommittee

The Committee received a report from the Social Media Subcommittee. This report is in follow-up to a request from the Committee during the October 24, 2012 meeting in Chicago. The Subcommittee developed a more detailed presentation of the Social Media Toolbox. The Subcommittee outlined potential contents of a Social Media Toolbox. The presentation emphasized that the focus of the toolbox and the project is to:

- Educate Transplant professionals
- Provide resources related to social media and transplant in one place
- Develop written resources for transplant candidates and their families encouraging responsible use of social media
- Develop boiler plate language for print and online resources encouraging the responsible use of social media.

The Subcommittee presented a the Patient – Donor Information Sharing Toolbox, located on the Transplant Pro website www.transplantpro.org as an example of how a Social Media Toolbox might appear in design and be utilized.

Responses from the Committee were extremely positive. The Committee would like to move forward with this project. The Subcommittee related this project to the OPTN goal of increasing both patient and living donor safety. The Committee will have to propose this project as work for the 2013-14 Board years. Proposals for new work would go to the Policy Oversight Committee (POC) in February 2013.

III. Work Review

The Committee reviewed all current work as follows:

Patient Notification:

The Living Donor Proposal setting forth requirements for living donor medical and psychosocial evaluation was approved by the Board during the November 2012 Board Meeting. The Committee proposes to include a provision the dissemination of the UNOS Patient Information Letter as part of the Living Donor Consent Process. The Liaison will ascertain the status of the consent process proposal within the Living Donor Committee and report to the Committee during the next conference call.

Teen Adherence:

The Subcommittee continues work on curriculum development. The results of the Focus Activity at the October meeting are being compiled. Contacts have been made with transplant centers that are working on similar projects. The Subcommittee will request existing teen education materials from Pediatric Centers. These resources will be used as guides in curriculum development. The Teen Adherence Subcommittee will make a full report during the January 2013 Committee Conference Call.

What Every Patient Needs to Know – Organ Specific:

The UNOS Information Technology (IT) Department is addressing technical issues with locating the Phone line Database. Research and IT are collaborating to download information from the database into a format for review. Research will then determine whether the data is usable. The Liaison will update the Committee on progress during the next conference call.

IV. *Intra-Committee Work*

Members of the Committee are involved in the following workgroups, which are led by other Committees:

MAC subcommittee on education and awareness of patient options for kidney transplantation:

This is a joint workgroup with Minority Affairs Committee (MAC). The focus of this workgroup is to develop guidance resources to be used by dialysis staff and nephrologists in making transplant referrals.

Progress

The Workgroup has not met since the last conference call.

TCC Policy Group/ TCC Education Group:

This is also a multi-committee collaboration with the Transplant Coordinators Committee (TCC) to develop policy and /or criteria for patient notification and center justification for having an inactive status after a as yet, undetermined number of days. A group task will be to determine an acceptable number of days for which a center can keep a patient inactive before having to make a final disposition.

Progress

TCC is considering policy that would require that centers notify inactive patients of their status after a certain amount of time has lapsed. TCC will review these concepts with PAC as they are more fully developed.

Ops and Safety:

This is a newly formed workgroup. The workgroup is tasked with developing policy to address the process of candidate transfers from centers that have withdrawn their membership or inactivated a program indefinitely. The policy reference for this group is Policy 3.2.1.9 Waiting Time Transfer.

Progress:

This workgroup has not convened at this time.

V. Public Comment Proposal Review

Proposal to Modify the Imminent and Eligible (I & E) Neurological Death Data Reporting Definitions (Organ Procurement Organization (OPO) Committee)

The Committee received the presentation on this proposal. Committee comments were positive regarding the need to establish consistency with definitions in this situation. Eleven members of the Committee were present for this vote.

VOTE: For – 11; Against – 0; Abstentions – 0

Proposal to Require Reporting of Every Islet Infusion to the OPTN Contractor within 24 Hours of the Infusion (Pancreas Transplantation Committee)

The Committee received the presentation on this proposal. After considerable discussion, the Committee raised the following issues:

- Appears to create an unacceptable workload increase for coordinators
- Does not seem to address the real problem of tracking persons who have received islet infusion
- Question whether a suitable programming option could not be implemented through UNET
- Potential patient safety due to the use of multiple instances of listing and delisting of the same patient, resulting in an increased risk of input errors

The Committee was concerned about the adverse impact to patients in using this system.

The Committee voted as follows:

For 0 – 0, Against – 11, Abstentions - 3

VI. *Upcoming Meetings*

January 24, 2013 – Conference Call

March 25, 2013 – Chicago PAC Meeting