

OPTN/UNOS Patient Affairs Committee (PAC) Interim Report

October 22, 2012
Chicago, IL

The committee met for a face-to-face meeting on October 22, 2012 and discussed the following public comment proposals:

- Proposal to Change the OPTN/UNOS Bylaws to Better Define Notification Requirements for Periods of Functional Inactivity
- Proposal to Remove the OPTN Bylaw for the Combined Heart-Lung Transplant Program Designation
- Proposal to Substantially Revise the National Kidney Allocation System

HRSA Update

The Committee received an update from the Ex-Officio Representative from HRSA. The update highlighted new educational efforts that target both transplant patients and transplant professionals with HRSA at this time. Of significant interest are an *Animated Donation Process Film* scheduled for release in the Spring of 2013. The Committee requested clarification on *Vascularized Composite Allograft (VCA)* transplants and how this relates to current solid organ transplant. A brief explanation was provided. Efforts will be made to keep the Committee updated as the work with VCA progresses.

Legislative Update

The Committee received updates on three bills that may be of interest during the next congressional cycle:

- *Authorization to provide low income kidney donors with travel subsistence*
Identification of funding is identified as the largest roadblock to this legislation.
- *Authorization to transplant HIV+ livers into HIV positive liver candidates*
Transplant of any HIV+ organs, currently, violates federal law. The regulation dates back to the 1980's when HIV was first identified. Research and better understanding of the disease have prompted many researchers to encourage this process. In theory a change in the current Federal law would make a significant difference in the numbers of livers available for transplant.
- *Amendment to Medicare, providing lifetime coverage for immunosuppression*
There seems to be widespread support for this bill in Congress. The hindrance seems to be identifying funding. The Committee engaged in extensive discussion around ways to document the importance of lifetime immunosuppressant coverage as a means of promoting longer graft survival, minimizing costs involved with return to dialysis and decreasing numbers of deaths on the list. The Committee considered options for reviewing data to document the benefits of lifetime coverage of immunosuppressants. It

was determined that the benefit of such coverage is already well documented. Further action by the Committee is not warranted at this time.

The OPTN Policy Development Process

The Committee received a presentation on the policy development process within the OPTN. This presentation is included as a review of policy development for ongoing members and an introduction for persons new to the Committee. This presentation was very well received by the Committee

Social Media Subcommittee Report

During the May 21, 2012 Committee Meeting, the Committee received a presentation on The Use of Social Media in Transplantation. The Committee agreed that caution should be encouraged when using Social Media around health events. The Committee also emphasized the lack of consistent language, policy or general oversight for transplant centers striving to make decisions regarding recommending social media and evaluation of living donors identified via social media. The Committee asked that a subcommittee review this issue further and bring recommendations back for possible action from the Committee.

The Subcommittee recommended that the Committee work with TAC, TCC and Ethics to develop a Social Media Toolbox for Transplant Centers. There was a great deal of discussion around the benefits of social media for patients. There was also a great deal of concern that any resources developed not be perceived as discouraging use of social media.

The Committee voted to have the Subcommittee develop a second proposal. (14 in favor, 2 – Against, 0- Abstentions)

Inactive Registrations on the Waiting List (TCC)

Committee representatives have been involved with the Transplant Coordinators Committee (TCC) Waitlist Inactivity Workgroup. Based upon the amount of time registrants were found to have been held as inactive on the waiting list; TCC is considering recommendations to promote improved management of the waiting list at the center level. Today's presentation summarizes the data documenting the need for better waitlist management.

Registrants waiting for transplant as of March 2, 2012 were examined. The median time registrants spent waiting in each status was plotted against the total time waiting, by organ. There were a total of 1,111 inactive registrations removed from the waiting list during 2007-2011 for death or too sick that had been inactively waiting for 5 years or more prior to removal. Of those 1,111 registrations, 811 (73%) were removed for death and 300 (27%) were removed for too sick.

The numbers are small by comparison to the total number of registrants, but the impact on the entire system is significant. There is also a question of whether long term inactive registrants are aware of their inactive status.

The Committee raised concerns regarding centers that list patients in inactive status before all testing is completing as a concern. The Committee cited the cost involved with delisting and then relisting a patient. This practice necessitates paying a second registration fee. Maintaining a patient in inactive status long term eliminates this additional cost for centers.

The Transplant Coordinators Committee proposes requiring that centers notify registrants after 12 months in inactive status on the waiting list. Future plans include considering time limits on the amount of time a registrant can remain inactive on the waiting list as a further means of requiring management of the waiting list.

Incidence of Non Renal Solid Organ Transplant (NRSOT) Recipients Currently Awaiting Renal Transplant

The Committee received the data report on the numbers of non-renal solid organ transplant (NRSOT) recipients who are currently awaiting a kidney transplant. This report is in response to a request brought to the committee during the May 21, 2012 meeting by the Committee Representative from Region 8 to consider offering some type of priority to candidates who fit into this category. Per the report 1.3 % of current kidney alone candidates are recipients of prior NRSOT's. This translates into approximately 1,225 candidates.

During Committee discussion the emphasis was on the increased potential for death on the list for this population. The Committee felt strongly that the Kidney Committee should be approached with a request to consider providing priority for this reason. The Committee voted to form a subcommittee who would be tasked with developing wording for a formal request to the Kidney Committee.

Teen Adherence Project

The subcommittee is working on curriculum development for this project. After a brief review of the Teen Adherence Project, the Committee divided into small groups for a focused discussion around the following question *What Do Teens Need to Know* at the following stages of the transplant process:

- Transplant Evaluation Phase
- Waiting for Transplant
- Hospital stay following transplant
- At discharge following transplant
- Long Term Management of a Transplant

Results of the focus discussion will be compiled for review as the basis for the first step in the development of the curriculum for this project.

Resources for Patients and Professionals

Representatives of the UNOS Communications Department introduced new web-based resources for patients and transplant professionals:

- *Print-on-Demand*

This process provides transplant centers with the option to customize patient education resources with their center information. This fee based-service is being piloted. During the pilot period available resources include: *What Every Patient Needs to Know* (English and Spanish) and *What Every Kid Needs to Know*. All items continue to be available at no cost to patients through the UNOS Patient Services Line. The piloted items are also still available on the UNOS Online Store, but orders are limited to quantities of three. The new process imposes a cost, for all orders of quantities greater than 3 regardless to whether customization is used. Print-on-Demand also begins with a minimum quantity of 100 items. The Committee voiced concern that the Print-on-Demand items previously were available for the cost of shipping. There was concern that this would limit access to individuals or groups with limited funding or who need only a few items for a smaller event.

- *Transplant Pro*

This new website, designed exclusively for transplant professionals was unveiled for the Committee. Professionals on the Committee were very complimentary of the easy access and intuitive organization of the website. Patients and families voiced appreciation for having professional level resources available for their review.

- *OPTN/UNOS Patient Education Resources*

The Committee received a brief presentation about the print educational resources available through the OPTN/UNOS. Handouts outlining each educational resource with instructions for ordering were also provided.

Public Comment Proposals

- Proposal to Change the OPTN/UNOS Bylaws to Better Define Notification Requirements for Periods of Functional Inactivity

For – 16, Against – 0, Abstentions - 1

- Proposal to Remove the OPTN Bylaw for the Combined Heart-Lung Transplant Program Designation

For – 17; Against – 0, Abstentions – 0

- Proposal to Substantially Revise the National Kidney Allocation System

The Committee suggested that education around the proposal emphasize that series should receive more kidney offers over time.

For – 15, Against – 0, Abstentions - 2