OPTN/UNOS Transplant Coordinators Committee
Report to the Board of Directors
November 12-13, 2012
St. Louis, MO

Summary

I. Action Items for Board Consideration

- None

II. Other Significant Items

- The Committee unanimously supports OPTN/UNOS leadership's decision to stop the work relating to the manuscript including the 2009 survey results on inactive waitlist management practices, and use the comments gleaned from the 2009 survey to provide background information in the development of an abstract for submission to NATCO on more recent data regarding the inactive waitlist. (Item 1, Page 2)

- The Committee unanimously supports the development of policies to require that transplant programs notify candidates having an inactive status, at the conclusion of twelve consecutive months of time in the inactive status. (Item 1, Page 4)

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Melissa A. Dunbar-Forrest RN, BSN, Chair
Laurel Williams-Salonen RN, BSN, MSN, Vice-Chair

The following report represents the OPTN/UNOS Transplant Coordinators Committee's deliberations and recommendations on matters considered during its meetings by conference call and Microsoft LiveMeeting on June 11, 2012, July 24, 2012 and August 28, 2012. The Tiedi® Documentation Project Subcommittee met by conference call and Microsoft LiveMeeting May 24, 2012, July 23, 2012 and September 19, 2012. The Education Subcommittee met by conference call and Microsoft LiveMeeting May 24, 2012 and August 21, 2012. The Policy Subcommittee met by conference call and Microsoft LiveMeeting July 30, 2012 and August 21, 2012. In addition, the Committee met in person in Chicago September 24, 2012.

1. Inactive Waitlist Management

During its May 24, 2012, meeting, the Education Subcommittee discussed the 1) development of a webinar on inactive waitlist management best practices; 2) a manuscript in development titled *Inactive Waitlist Management: Common Practices throughout the US*; and 3) the development of a resource for patients to define "active" and "inactive" status and what it means to have an "inactive" status. Discussion ensued with the following action plans:

- delay planning for a webinar until after a proposed policy is distributed for public comment and subsequently approved by the Board
- incorporate the most recent data in the presentation to the Committee on April 2, 2012 and June 11, 2012, in the manuscript for publication
- collaborate with the Patient Affairs Committee and organ-specific committees to define what it means to be "active" and "inactive" and how best to disseminate this information to potential and current patients waiting
- propose to the Policy Subcommittee that a policy for notifying patients after a determined amount of inactive days is developed to include transplant center justification of their patient's inactive status

During its June 11, 2012, meeting, research staff presented data on the most recent length of inactivity for inactive registrations removed from the waiting list during 2007-2011 for reasons of death or too sick. Highlights from this data included:

- of 20,543 registrations removed from the waiting list for death, 12,270 registrations were removed because the candidate was too sick
- 22.5% of inactive kidney registrations were removed for death after being inactive for between one and two years

- 1,111 inactive registrations were removed from the waiting list for death or too sick, that had been waiting in an inactive status for five years or more prior to removal

- 95 inactive registrations were removed from the waiting list for death or too sick that had been waiting in an inactive status for ten years or more prior to removal

After much discussion, members agreed that a patient notification policy for those patients with an inactive status for a prolonged amount of time is warranted and will plan to collaborate with other committees in the policy development process.

During its July 30, 2012, meeting, the Policy Subcommittee focused on previously reviewed data presented at its April 2, 2012, meeting on inactivity and plans to make a recommendation to the full Committee when patients should be notified of their inactive status, and how to calculate inactive time in UNet^{SM}.

During its August 21, 2012, meeting, the Education Subcommittee collaborated with Patient Affairs Committee members to develop a resource to define what "inactive" vs. "active" status means to patients. Members agreed that there is confusion not only with patients, but also with coordinators and physicians. It was noted that a new proposed Kidney Allocation System will be presented at its September 24, 2012, meeting to give members an opportunity to ask questions about how these statuses will be handled. In addition, members agree this is a patient issue and there needs to be a policy in place to hold centers accountable for informing their patients of their status.

During its August 21, 2012, meeting, the Policy subcommittee collaborated with Patient Affairs Committee members to discuss and provide input on the Committees' recommendations for notifying patients with an inactive status and having centers justify their status after a determined amount of time. Members suggest that patients waiting for an abdominal organ should be notified every twelve months if having an inactive status and those waiting for a thoracic organ is notified every six months. It was noted that patients shouldn't be on an inactive list for more than six months due to the fact that in one members' experience, patients become anxious after six months of waiting if they have not heard from their transplant team and it was further agreed that this is a patient safety issue.

During its September 24, 2012, meeting, 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 OPTN/UNOS leadership has since made the decision to not move forward with submitting the manuscript; however, recent data presented to the Committee on April 2, 2012 and June 11, 2012 will be used to develop an abstract to submit to NATCO in 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.

RESOLVED, that the TCC unanimously supports OPTN/UNOS leadership's decision to stop the work relating to the manuscript including the 2009 survey results on inactive waitlist management practices, and use the comments gleaned from the 2009 survey to provide background information in the development of an abstract for submission to NATCO on more recent data regarding the inactive waitlist.

Committee Vote: 15 For, 0 Against, 0 Abstentions

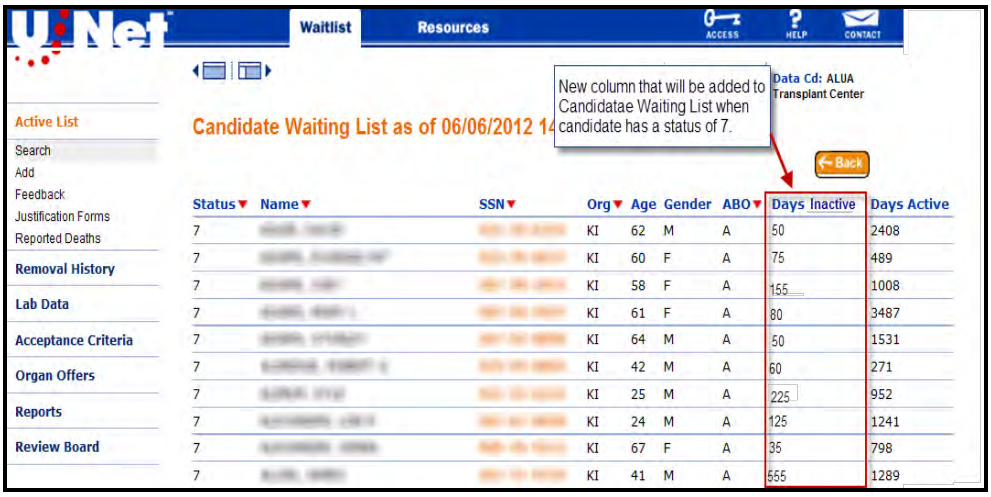
The Committee then began discussing a policy proposal for criteria for notifying patients with an inactive status. It was noted that the policy should mirror existing policies; have consecutive time not cumulative inactive time; and clarify that this is only patient driven inactive time and not due to 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.

RESOLVED, the TCC unanimously supports the development of policies to require that transplant programs notify candidates having an inactive status, at the conclusion of twelve consecutive months of time in the inactive status.

Committee Vote: 15 For, 0 Against, 0 Abstentions

Waitlist application in UNet^{SM} During its May 24, 2012, meeting, members reviewed a mock up screen shot (Table 1) to include inactive days that would be programmed in the UNet^{SM} Waitlist. The Committee agreed that a column should be added to indicate days inactive (greatest to least) for their patients. This would enable the coordinator to stay informed of how long their patient has been inactive. However, after several internal staff conversations with the Chrysallis Waitlist Team, it has been determined that this added column would not be feasible in the new Waitlist.

Table 1. mock up screen shot



During their September 24, 2012, meeting, UNOS staff on the Chrysallis 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.

2. Tiedi® Documentation Project

The goal of the project is to improve the accuracy and completeness of OPTN data by:

- Identifying problems with existing documentation (Items that lack sufficient detail, are confusing or have inappropriate descriptions)
- Providing recommendations for educating users to ensure that data coordinators are using the help documentation
- Identifying situations where input from other groups (e.g., clinical experts, organ-specific committees) is needed

A Subcommittee tasked to this project reviews fields, recommends changes that are then forwarded to either UNOS Professional Development to program the changes in the help documentation or to the organ-specific committees to address questions and concerns the coordinators have. To date, there have been over 200 data elements reviewed.

Summary of its Subcommittee Calls

During its May 24, 2012, meeting, the subcommittee completed their review of required data elements on the adult and pediatric heart, lung, and heart-lung Transplant Recipient Registration forms including: physician name, patient on life support, most recent hemodynamics, most recent serum creatinine, most recent total bilirubin, chronic steroid use, events occurring between listing and transplant, total organ ischemia time, graft status, date of graft failure, primary cause of graft failure, and events prior to discharge.

During its July 23, 2012, meeting, the subcommittee reviewed the following five miscellaneous fields that had inconsistent documentation throughout forms: patient status and status date; angina; acute rejection between transplant and discharge; acute rejection during follow up; and diabetes onset during follow up.

During its August 28, 2012, meeting, the Committee was presented with the frequency by which members submit fields as “unknown” on the Transplant Recipient Follow-up (TRF) Forms for Kidney, Pancreas, and Kidney-Pancreas between March 2009 and February 2012. The Committee wanted to know how often the “unknown” field was being utilized and consider a recommendation to remove that option on the forms if it was being used too often as a replacement for information pertinent to patient outcomes. After reviewing the data, it was determined, due to the low number of incidence, that there wasn’t sufficient evidence to remove the field from the forms. The Committee requested that the principles of data collection is reviewed at its September 24, 2012, in person meeting to better understand the rationale for having to fill out fields on the forms that are not clinically relevant as the coordinators feel that most of the data is requested for research purposes only.

During its September 19, 2012, meeting, the subcommittee reviewed required data elements that appear on all adult and pediatric Transplant Candidate Registration (TCR) forms including: citizenship, year of entry to the U.S., highest education level, diabetes, age of diabetes onset (KI, PA, KP), any previous malignancy, and type of malignancy. In addition, other TCR data elements were reviewed that appear on adult and pediatric Kidney, Kidney-Pancreas, Liver, and Liver- Intestine forms.

3. Transplant Coordinators Listserv

There are currently 302 members who subscribe to this listserv. Recent discussion threads have included: 1) announcements for upcoming webinars on Patient Safety, CMS regulations and OPTN requirements, and Brain Death Declaration; 2) nurse practitioners writing prescriptions for their out of state patients; 3) "lost to follow up" policies for post-transplant patients; 4) developing living-related kidney and liver donor coordinator positions; 4) examining a policy to require monthly panel reactive antibody testing; 5) tests during the donor work up; 6) age related tests for kidney donor; and 7) how to handle uninsured living donors.

4. Review of Policies and Bylaws Issues for Public Comment

During its June 11, 2012 meeting, a member of the OPTN/UNOS Liver and Intestine Transplantation Committee presented its proposal for Improved Imaging Criteria for HCC Exceptions. Members shared that if a patient is not completely ready for transplant they should not be listed. It was explained that this policy serves a very small group of patients that would benefit with treatment while on the waitlist. It was asked if there is a limit to how long the patient would remain on hold and the Liver Committee member answered that there is no limit. Although a quorum was not met, members voted in support [For 4: Against 1: Abstentions 0]

During its July 24, 2012, meeting, UNOS staff presented the Policy Rewrite proposal and members had an opportunity to asked questions.

During its September 24, 2012, meeting, 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.

5. Other Items

Member Orientation During its August 28, 2012, meeting, the Committee reviewed the Committee's charge: considers issues related to the coordination of efforts related to organ procurement, organ allocation, and the entire transplant process. It also considers the potential impact of proposed policy and bylaws revisions upon the process of procurement and transplant coordination, including the education and care of candidates, quality, efficiency and effectiveness of procurement and transplant coordination through OPTN initiatives and policy. The Committee's objectives are to:

- Develop policy regarding patient notification when placed on inactive status for a prolonged period of time
- Provide educational opportunities that focus on effective waitlist management practices
- Review help documentation for data collection forms and suggest modifications and/or recommend that the fields be reviewed by other committees for clarification

Additionally, details of the existing working groups were noted. The SharePoint site and Listserv were introduced for the new members on the Committee and the proposal for the policy rewrite was further discussed and was noted that members submitted comments individually through the online survey.

Living Donor Webcast During its September 24, 2012, meeting, Ms. Allen announced the upcoming webcast that will subsequently be offered as a DVD for transplant centers and potential living donors and those healthcare professionals involved in their evaluation, informed consent, transplant and follow-up care to help centers comply with the large volume of requirements. Transplant centers can use this DVD to help to educate staff or potential living donors. The TCC will work in collaboration with the Living Donor Committee and Kidney Paired Donor Working Group. The webcast is planned for January 2013.

Feedback on improving the coordinator constituency During its September 24, 2012, meeting, the Committee took part in an exercise that identified ways 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.

1. *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, International Transplant Nurses Society, 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.

2. *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.

TRANSPLANT COORDINATORS COMMITTEE	MONTH	September
	DAY	24
	FORMAT	In Person Meeting
NAME	COMMITTEE POSITION	
Melissa Dunbar-Forrest, RN, BSN	Chair	X
Laurel Salonen, RN, BSN, MSN	Vice Chair	X
Cathy Pratt, RN	Regional Rep. 1	X
Kevin Carney, MSN, CRNP	Regional Rep. 2	X
Walt Nickels, RN, BSN, CCRN	Regional Rep. 3	X
Patricia Jones, RN	Regional Rep. 4	X
Michelle Sturges, RN	Regional Rep. 5	X
Marsha Larsen, RN	Regional Rep. 6	X
Nancy Carroll, RN	Regional Rep. 7	X
Monica Eaton	Regional Rep. 8	X
Charles Gonder, RN, MS	Regional Rep. 9	X
Michelle Crossley, RN, BSN	Regional Rep. 10	X
Marion Stewart, RN, BSN	Regional Rep. 11	X
John Belcher	At Large	
Jamie Bucio, EMT-P	At Large	
Ann Kalis, RN	At Large	X
Christine Radolovic, RN, BSN	At Large	X
Raelene Skerda, RPh, BPharm	HRSA, ex-officio	
Chinyere Amaefule	HRSA, ex-officio	
Bertram Kasiske, MD	SRTR	via conference call
Tabitha Leighton	SRTR	via conference call
Kim Johnson, MS	Committee Liaison	X
Marissa Clark	UNOS	X
Angela Allen, EdD	UNOS	X
Franki Chabalewski, RN, MS	UNOS	X
Kimberly Taylor, RN	UNOS	X

TRANSPLANT COORDINATORS COMMITTEE	MONTH	June	July	Aug
	DAY	11	24	28
	FORMAT	Monthly Full Committee Conference Calls/LiveMeetings		
NAME	COMMITTEE POSITION			
Melissa Dunbar-Forrest, RN, BSN	Chair	X		X
Laurel Salonen, RN, BSN, MSN	Vice Chair	X	X	X
Cathy Pratt, RN	Regional Rep. 1		X	X
Kevin Carney, MSN, CRNP	Regional Rep. 2		X	
Walt Nickels, RN, BSN, CCRN	Regional Rep. 3		X	X
Patricia Jones, RN	Regional Rep. 4	X	X	X
Michelle Sturges, RN	Regional Rep. 5		X	X
Marsha Larsen, RN	Regional Rep. 6	X		X
Nancy Carroll, RN	Regional Rep. 7			
Monica Eaton	Regional Rep. 8			X
Charles Gonder, RN, MS	Regional Rep. 9			
Michelle Crossley, RN, BSN	Regional Rep. 10	X	X	
Marion Stewart, RN, BSN	Regional Rep. 11		X	X
John Belcher	At Large		X	X
Jamie Bucio, EMT-P	At Large		X	
Ann Kalis, RN	At Large	X		X
Christine Radolovic, RN, BSN	At Large		X	
Raelene Skerda, RPh, BPharm	HRSA, ex-officio	X		
Chinyere Amaefule	HRSA, ex-officio		X	
Bertram Kasiske, MD	SRTR	X	X	X
Tabitha Leighton	SRTR	X	X	X
Kim Johnson, MS	Committee Liaison	X	X	X
Marissa Clark	UNOS	X	X	X
Angela Allen, EdD	UNOS		X	X
Franki Chabalewski, RN, MS	UNOS	X		X