

**OPTN/UNOS Transplant Coordinators Committee
Report to the Board of Directors
June 23-24, 2014
Richmond, VA**

**Laurel Williams-Salonen RN, BSN, MSN, Chair
Jamie Bucio, EMT-P, CPTC, Vice-Chair**

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This report reflects the work of the OPTN/UNOS Transplant Coordinators Committee during October 2013 through April 2014 period.

Action Items

None

Committee Projects

1. Proposal to Notify Patients Having an Extended Inactive Status

Public Comment: [March 14 – June 13, 2014](#)
Board Consideration: *November, 2014 (estimated)*

The goal of the proposal is to promote effective and safe patient care, increased patient access to transplantation and assure patients are aware, on a regular basis, that they cannot receive an organ transplant while on an inactive list and allow them to be proactive in their plan of care.

The original proposal involved sending letters to patients who had been inactive continuously for one year notifying them of their inactive status, that they would not receive organ offers while inactive and the telephone number of the transplant center. After review by the Executive Committee and Policy Oversight Committee it was suggested that patients should be notified prior to one year. Thus the proposal was changed to notification of patients continuously inactive at 3 months and one year.

The new proposed policy will require transplant hospitals to provide written notification to candidates with an inactive waiting list status when the candidate has been inactive for:

- 90 consecutive days
- 365 consecutive days
- Annually, thereafter, for as long as the candidate remains inactive

The notification must include *all* of the following:

- The most recent date they became inactive,
- That the candidate cannot receive organ offers for transplant while inactive, and
- A telephone number at the candidate's transplant center to contact for more information

The Transplant Administrators Committee (TAC) provided pre-public comment feedback on the proposal. The TAC understood the purpose of this proposal but continued to have concerns regarding the resource burden it will place on transplant hospitals as well as maintaining compliance. Data on the possible resource burden and how to maintain compliance was reviewed and members commented that the resource burden was underestimated as compliance efforts were not included in the resource burden data. They also questioned if a letter is the most effective way to notify candidates of their inactive

status and if other alternatives were explored. A member suggested contacting candidates via telephone and documenting the contact in the medical record might be less burdensome for the transplant hospital. Due to their continued concerns, the Committee agreed this proposal should go out for public comment to obtain further feedback from the transplant community.

Comments received during the public comment period thus far mirror the TAC's above stated concerns. Other comments include:

- Concern that an additional patient notification letter at 90 consecutive days will be an additional resource burden for centers
- Only require notification at one consecutive year to lessen the burden
- Concern about ability to track deadlines for sending notification letters
- Maintaining compliance

The Committee will review all of the public comments this summer before deciding what post-public changes will be necessary to address these concerns.

For more information, see Committee meeting summaries from October 22, 2013 through March 19, 2014.

2. Tiedi® Help Documentation

Public Comment: n/a
Board Approval: n/a

The role of this Tiedi Subcommittee is to make recommendations that will improve the accuracy and the completeness of OPTN data by reviewing the documentation that exists in the help documentation. The group is also working to clarify what data needs to be entered into the forms for accurate/complete data to be collected and provide recommendations on how to educate users.

The Subcommittee met on January 15, 2014 to continue its review of the DonorNetsm Deceased Donor Registration (DDR) clinical fields. If needed, recommendations made by this group will be referred back to the organ-specific committees and/or the OPO and DTAC Committees. Recommendations for non-substantial deletions will be made without referring back to committees. Once the review has been completed, the Subcommittee will consider possible educational/training/communication efforts for the transplant community. The anticipated completion date for this project is November 2014.

3. Clarify Requirements for Blood Type Verification

The TCC contributed to the ABO Verification Policy Modifications and Standardization of Documentation project. The TCC representative for this subcommittee provided feedback regarding the potential impact of proposed policy on the entire transplant coordination process. For more information, see the **Operations and Safety Committee's Report to the Board**.

4. Involuntary Waitlist Transfer

The TCC contributed to the Involuntary Waitlist Transfer project. Current policy, 3.6.C Waiting Time Transfers, was not developed to address situations where a transplant center needs to transfer substantially all of their patients to another center(s). The OSC believes that a policy solution is needed to address these situations instead of applying a policy that

was never intended to be used for such circumstances. The TCC representative for this project provided the transplant coordinators' perspective on issues, including patient safety issues, related to large volume patient transfers. For more information, see the **Operations and Safety Committee's Report to the Board**.

Review of Public Comment Proposals

The Committee reviewed seven of the 17 policy proposals released for public comment from March – June 2014.

5. Proposal to Allow a MPSC Recommendation to the Board of Directors for Approval Consideration of a Non Qualifying Transplant Program Applicant Located in a Prescribed Geographically Isolated Area (Membership and Professional Standards Committee (MPSC))

The Committee opposed this proposal as it is a patient safety issue and exceptions should not be allowed. Members agreed that if a center is not routinely doing transplants, patient care is compromised for donors and recipients. The Committee also agreed that annual competencies need to be maintained by all transplant staff including surgeons and nurses. (0 in favor, 13 opposed, 0 abstentions)

6. Proposal to Clarify Data Submission and Documentation Requirements (Membership and Professional Standards Committee (MPSC))

This proposal was presented to the Committee and after some discussion, the Committee opposed the proposal due to the added burden it will have on centers and suggested the policy specifically state what source documentation is required and for which fields. (0 in favor, 9 opposed, 4 abstentions)

7. Proposed ABO Blood Type Determination, Reporting, and Verification Policy Modifications (Operations and Safety Committee (OSC))

The Committee did not vote on this proposal. They would like to request that the OSC clarify some terminology in the proposal and also provided comments for the OSC to review and consider.

- The proposal needs to better define the location for organ check-in. Currently, the proposal uses "OR suite" and this can have different meanings and can mean different locations for centers.
- If the proposal is intended to include both living and deceased donor recoveries from outside operating facilities, then that needs to be made clear in the policy language. Current language in the proposal for organ check-ins seems to be for living donors not deceased donors from another hospital. The Committee suggested using "hospital facility" or "OR room" instead of "OR suite or building" as the latter tends to mean the same hospital. The organ check-in requirements for living donors and deceased donor recoveries need to be universal.
- The Committee requested clarification of the definition of organ check-in, definition of who is required to check-in the organ when it arrives at the transplant hospital, when is it required, and the required timeline. Also, documentation of the chain of custody is important.
- A member also suggested that it be a requirement that all organs are checked in at the OR.
- Members thought the electronic labeling system will be helpful in documenting the chain of custody and will decrease organ discards.

- The Committee had concerns that the way the proposal currently reads, it could be assumed that the with the blood specimen label that accompanies the organ can be used as an ABO source document. Members of the Committee agreed that there needs to also be some form of paper/electronic document besides the label on the blood specimen inside the box as a lot of times these labels are handwritten and lends itself to human error. It was also noted that those labels sometimes fall apart or get damaged and should not be used as the sole source documentation. The policy proposal requirements were reviewed with the Committee and it was clarified that source documents can include: data transmitted directly into an electronic medical record, an original paper source document, original handwritten medical note, a copy of facsimile or original paper source document. A member noted that source documentation should be directly from a lab. Another member stated that blood tube labels should never be allowed to be used as an option for source documentation as labeling is the single most common area of error for OPOs.
- Current policy states that you cannot label the red top tubes with ABO and proposed policy is to remove that you cannot label the red top tubes. Labeling of red top tubes has been occurring for quite a while now.

8. Proposed ABO Subtyping Consistency Policy Modifications (Operations and Safety Committee (OSC))

This proposal was presented to the Committee and after a brief discussion, they voted to support the proposal as written (10 in favor, 0 opposed, 3 abstentions).

9. Proposal to Modify Existing or Establish New Requirements for the Informed Consent of all Living Donors (Living Donor Committee (LDC))

The Committee voted to support the proposal with no additional comments (12 in favor, 0 opposed, 1 abstention).

10. Proposal to Modify Existing or Establish New Requirements for the Psychosocial and Medical Evaluation of all Living Donors (Living Donor Committee (LDC))

The Committee voted to support the proposal with no additional comments (13 in favor, 0 opposed, 0 abstentions).

11. Proposal to Require the Reporting of Aborted Living Donor Organ Recovery Procedures (Living Donor Committee (LDC))

The Committee voted to support the proposal with no additional comments (10 in favor, 0 opposed, 3 abstentions).

Other Committee Work

12. Transplant Coordinators Listserv

The objective of this listserv is to facilitate the sharing of information regarding the practice of transplant coordinators. Membership is open to transplant coordinators of UNOS approved (or pending approval) transplant providers within the United States. Membership is also open to employees of UNOS, HRSA, and other governmental or governmental contract agencies that participate in the management or oversight of organ transplantation. As of May 4, 2014, there are 350 listserv members with individuals requesting membership daily.

13. Scientific Registry of Transplant Recipients (SRTR)

SRTR requested the TCC's feedback on new ways to present information on their public website about transplant program performance. Since the SRTR will be moving towards Bayesian methodology for assessing program performance, they are looking to improve how program performance is summarized on the public website. A 5-level rating system is being considered ranging from 1 for poor (strong evidence of worse than expected outcomes) to 5 for excellent (strong evidence of better than expected outcomes). Each group in the 5-level rating system would be assigned a symbol for easy interpretation. Examples of the symbols and potential website presentation were reviewed. Members on the Committee were concerned that the rating system is subjective and patients may not understand the criteria used for the rating system.

14. Outreach Initiative

The Committee continued its outreach initiative to receive input from coordinators all over the country as it was noted that there is not a great deal of collaboration with their peers outside their individual programs.

The Chair wrote an article for NATCO's fall newsletter (**Exhibit A**). It provided information regarding the Committee's public comment proposal and made a request for community input.

TCC regional representatives contact information was also posted to Transplant Pro to encourage others to contact them to receive updates on TCC's initiatives.

15. Organ Offer Discussion

The Committee formed a subcommittee that will discuss the challenges of DonorNetsm regarding efficient organ placement and to develop effective practices from both transplant coordinators and OPO coordinators. This project will be discussed in further detail on a separate subcommittee conference call.

Meeting Summaries

The Committee held meetings on the following dates:

- October 22, 2013
- December 17, 2013
- January 28, 2014
- March 19, 2014
- April 22, 2014

Meetings summaries for this Committee are available on the OPTN website at:

<http://optn.transplant.hrsa.gov/members/committeesDetail.asp?ID=28>

UNOS Transplant Coordinators Committee (TCC) Report – We need your input!

The TCC represents **YOU**. When the TCC begins new committee projects, we want the input, suggestions, and support from as many coordinators as possible. Through regular reports in the NATCO newsletter, we hope to keep you better informed of upcoming projects and gather your valuable feedback.

We have been working on a proposal since 2011 that involves the notification of potential transplant recipients who are listed as “temporarily inactive” (Status 7) on the Waitlist. UNOS currently has no policies in place regarding the notification of patients having a “temporarily inactive” status. UNOS data indicate that as of July 19, 2013, 25,464 registrations were waiting in a “temporarily inactive” status for one or more consecutive years, of which 87% were kidney registrations.

In 2011 the TCC started gathering data on potential transplant recipients listed as “temporarily inactive”, and even before that in 2009, the TCC reviewed survey data about how transplant programs managed their waitlists. To summarize, we found that transplant programs generally feel they have a good handle on the number of inactive potential transplant recipients on their Waitlist, however data suggests that patients remain as “temporarily inactive” (Status 7) for up to 23 years and some of these patients die while waiting [Figure 1].

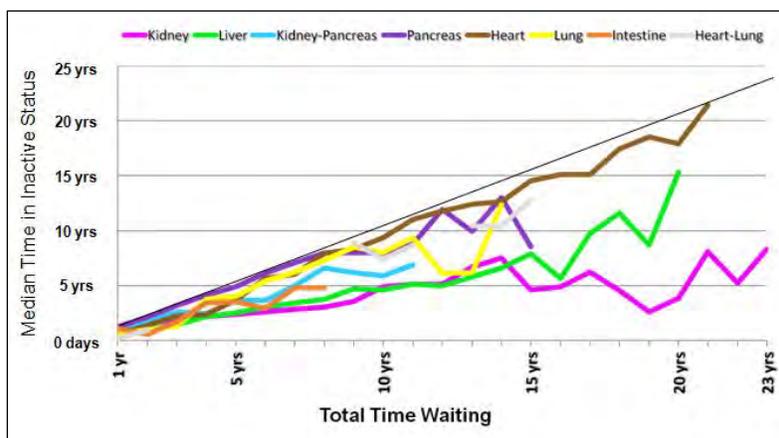


Figure 1. Median time spent waiting in most recent inactive status for “temporarily inactive” registrations on March 2, 2012 by organ and total time waiting.

A recent literature review indicates that:

1. “Temporary inactivation” is a risk factor for longer waiting time¹;
2. A significant number of hemodialysis patients mistakenly think they are listed when they are not²;
3. Inactive status is associated with higher waitlist deaths³; and,
4. Inactive status is associated with lower rates of transplantation³.

As patient advocates we need to make sure our patients know and understand what their current status on the waitlist is and what it means for them. Currently, UNOS only requires a patient to receive a letter when they are listed for transplant or removed from the transplant waitlist.

After multiple reviews of the data and literature, and input from other committees, the TCC submitted a proposal to the OPTN/UNOS Policy Oversight Committee (POC) and the OPTN/UNOS Executive Committee (EC) in the summer of 2013. The proposal is summarized below:

If a potential transplant recipient is listed with a “temporarily inactive” (Status 7) for one consecutive year, the listing transplant program will send them a letter stating the date they were made inactive, the reason they were made inactive, and who they need to contact regarding reactivation on the waitlist.

The program would be required to send this letter within 30 days of the patient’s one-year anniversary date of their most recent date of inactivity. The program would be required to send the same letter annually as long as that patient remained in this consecutive inactive status. The transplant program must also maintain documentation of this notification and copy of the letter sent to the potential transplant recipient in their medical record.

Data was analyzed to determine what the impact would have been for transplant programs in 2012 had this proposed policy been in place. It is important to note that many programs already notify their patients more often than on an annual basis, but there are a number of transplant programs that do not; therefore, the burden of this proposal lies on those outliers who delay notification or never notify their patients. Based on the data, a smaller program may need to generate an average of 6 extra letters yearly under this proposal and larger programs may need to generate an average of 100 letters yearly. The number of patient notification letters that would have been required to be sent in 2012 was based on how long registrations had been inactive. This data likely *overestimates* the actual impact this policy would have on transplant programs, as it assumes no policies or procedures were put into place for informing patients.

The POC feedback suggested the addition to our proposal that patients placed in an inactive status also be notified of the status change prior to one year. The TCC is assessing data to determine if there is a time interval that would best address earlier notification knowing that a patient’s inactive status may fluctuate due to infection, insurance issues, the need for additional testing, etc. The goal is not to capture short-term inactivity, but to capture long-term inactivity.

Concerns were brought forth by the OPTN/UNOS EC that UNOS does not have an easy process in place for listing transplant programs to be able to track their patients who have been “temporarily inactive” for one consecutive year. However current UNetSM programming has the ability to capture these patients using the “Create a Custom Report” tool through the UNetSM Waitlist Portal. All listing transplant programs have access to this tool. Education for the use of this tool could be achieved through UNetSM tutorials or educational programs. The screen shots attached demonstrate how this can be accomplished.

The TCC is aware that this policy could impact programs initially due to an increase in mailing expenses. It may also cause an increase in coordinator workload hours, based on staffing models; to ensure the notification letters are sent out in a timely manner. An intended benefit of this policy is that the inactive list should decrease over time as patients become more aware of their status and some patients are reactivated or removed from the list. The new KAS kidney proposal may also have an impact on the inactive waitlist; therefore, relieving some of the initial burden of the policy proposal.

The coordinators are going to be the primary constituency affected by this proposal and they are the ones that feel most passionate that moving forward with this proposal is the right thing to do for our patients.

The TCC would like to re-submit this proposal to the POC and EC for approval to be distributed for public comment in the spring of 2014. We would very much appreciate any thoughts or concerns as we move forward with this proposed policy.

Please feel free to send comments to the TCC Chair, Laurie Williams at: williamsl@unmc.edu or contact her directly at 1-800-401-4444.

1. Temporary Inactive Status on Renal Transplant Waiting List: Causes, Risk Factors, and Outcomes. Safi, S., Zimmerman, B. and Kalil, R. *Transplantation Proceedings* (2012), 44, 1236-1240
2. Lack of Listing Status Awareness: Results of a Single-Center Survey of Hemodialysis Patients. Gillespie, A., Hammer, H., Lee, J., Nnewiwe, C., Gordon, J., and Silva, P. *American Journal of Transplantation* (2011), 11: 1522-1526.
3. Delmonico FL, McBride MA. Analysis of the Wait List and Deaths Among Candidates Waiting for a Kidney Transplant. *Transplantation* 2008; 86 (12): 1678- 1683.