OPTN/UNOS Transplant Coordinators Committee

Report to the Board of Directors
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Richmond, VA

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This report reflects the work of the OPTN/UNOS Transplant Coordinators Committee from April through November 2015.

Action Items
1. None

Committee Projects

2. Proposal to Notify Patients Having an Extended Inactive Status

   Public Comment: March 14 – June 13, 2014

   Board Consideration: N/A

   The goals of the proposal were 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.

   In November 2014, the goal of this project changed from being a policy proposal to an educational project that would develop effective patient notification and waitlist practice articles and educational materials for professionals and patients. To do this, the Committee formed a Patient Notification Work Group. The goal of this Work Group was to develop effective patient notification and waitlist practice articles and educational materials for professionals and patients. The Work Group created a survey that would collect information on real-world practices, timing, and communication related to listing and managing candidates at an inactive status (Status 7) on the waitlist. The Committee planned to use the survey results for the development of effective patient notification and inactive waitlist management practices for the transplant community. The survey was distributed to transplant coordinators on February 20, 2015 and closed on March 13, 2015. The Work Group reviewed the survey results in May and planned to develop interview questions to use for effect practice articles. However, in June, the Policy Oversight Committee (POC) voted to send this project to the Executive Committee to decide if the project should continue or be placed on hold. The Executive Committee met at the end of June and decided to place the project on hold due to not yielding enough evidence that it would significantly improve access to transplant (strategic goal 2) and the OPTN had limited resources within that strategic goal. Therefore, the Committee has discontinued working on this project and will reevaluate the need to change its scope.

3. Operations and Safety Committee (OSC) Infectious Disease Verification

   The Transplant Coordinators Committee (TCC) has two representatives assigned to the OSC Infectious Disease Verification Work Group. The representatives for this Work Group provide feedback on the verification/confirmation of infectious disease results pre-transplant to help assure that recipients do not receive infected organs accidentally. For more information, see the OSC Report to the Board.
4. Liver and Intestinal Organ Transplantation Committee

The TCC received an update on redesigning liver distribution on September 23, 2015. Committee members questioned if redistricting would begin to eliminate smaller programs, if there was uniformity in recipient criteria for qualifying for liver transplants, and noted that since the implementation of the Kidney Allocation System, there has been an increase in transplanting patients that are thought will have a better long-term outcome. They wondered if the Liver Committee had considered ways to incorporate those concepts into the liver population. The TCC has two representatives assigned to work with the Liver and Intestine Committee on its Ad Hoc Subcommittee on Increasing Liver Donation and Utilization. The representatives for the Subcommittee will continue to provide the coordinator perspective on the Subcommittee’s initiatives. For more information, see the Liver and Intestinal Organ Transplantation Committee Report to the Board.

5. Kidney Allocation System (KAS)

The vice chair of the Kidney Transplantation Committee provided a brief background, overview, and update on the KAS six month data collection. Trends in the kidney waiting list, distribution of transplants since KAS implementation, longevity matching, geographic distribution of kidney transplants, and other findings were presented. In summary, for the first six months, KAS has been meeting key goals and increased transplant volume by 1%. However, there are several effects that deserve further attention and the Kidney Committee will continue to monitor. TCC members posed the following questions/comments after the presentation:

- There was thought that KAS would decrease the inactive wait list. It was noted that 40% of the kidney list is still inactive and has not changed.
- Has there been any effect on HCV kidneys or kidney discards?
- For SLK kidneys, when they are in the safety net, do they model where most patients fall in the system?

For more information, see the Kidney Transplantation Committee Report to the Board.

6. Ad-Hoc Disease Transmission Advisory Committee (DTAC) Modify How Results Received Post Procurement Are Communicated

The Committee received an update on the DTAC’s progress to improve communication regarding new information critical to recipient care, enhance recipient safety, and help to prevent or quickly react to potential donor-derived disease transmission. The DTAC is reviewing the current patient safety contact requirement as it is not functioning well in some institutions and has presented challenges in communicating important information in some cases. The DTAC requested a volunteer from the TCC to participate on a working group to identify, develop, and disseminate effective practices for transplant centers. For more information, see the DTAC Report to the Board.

Committee Projects Pending Implementation

7. None

Implemented Committee Projects

8. None

Review of Public Comment Proposals

The Committee reviewed three of the 12 policy proposals from August 14, 2015 – October 14, 2015.
9. **Reduce Documentation Shipped with Organs (Organ Procurement Organization Committee (OPO))**

The Transplant Coordinators Committee reviewed and supported this proposal. Some committee members had the following questions/comments:

- How will transplant centers receive last minute documentation from the OPO when organ offers have been accepted and recovered (i.e. anatomy, biopsy results)?
- Did the OPO Committee consider putting the PHS record in the box as a safety net?
- This change will require a lot of education for internal staff on how to access the information in DonorNet, particularly for OR staff.
- For the occasional case of pre-serology organ recovery, documentation that indicates pending infectious disease testing should be included.
- Serologies and infectious disease reports sent with the organ should include NAT, if results are available.

10. **Revise KPD Priority Points (OPTN Kidney Paired Donation Pilot Program)**

The Transplant Coordinators Committee reviewed and supported this proposal. Some committee members had the following questions/comments:

- What are some examples of informed consent of “remedies”?
- With the increase in points for the highly sensitized patient, will virtual crossmatches be done immediately after the match run to decrease the potential of broken chains or swaps before the center starts investing time in calling their surgeons and patients?
- Clarification was requested on how many points will be allocated to pediatric recipients, given there is more weight given to patients who are highly sensitized.

11. **Simultaneous Liver Kidney Allocation (SLK) (Kidney Transplantation Committee)**

The Transplant Coordinators Committee reviewed and supported this proposal. Some committee members had the following questions/comments:

- If a patient receives a SLK, and a kidney fails on day 95 and they are relisted for kidney, are they considered in the safety net?
- Please clarify why a center would provide a kidney transplant to a patient with only a moderate GFR and then for the safety net, the patient has to have a GFR of 20. Looking at the CRD breakdown for GFRs, it does not make sense that it would be modified.
- Most patients would not receive a kidney with a GFR of 30, why allow it with an SLK?
- Has the new KAS and Liver Share 35 changed some of this? Are sicker liver patients with worsening renal function showing up on these lists?
- Once a patient has a liver transplant, does the patient become more sensitized and have a harder chance at getting a kidney?
- This seems to greatly affect the kidney-only candidates. Are there models looking at kidney only candidates?
- When going down the liver match, it is required to offer the kidney if it was available, but the OPO would still have the choice which multi-visceral it chooses? It was one committee member’s understanding that if an OPO offers for an SLK locally, then the Share 35 must be offered regionally as well, but it was not said that they had to allocate an SLK at all. If chosen to allocate to a local SLK, then we must also allocate to a regional SLK.
- One concern is that the policy always references a “transplant nephrologist”. Not all transplant centers have a designated transplant nephrologist. The member suggested the Kidney Committee consider removing or changing that reference as it could
potentially cause problems for transplant centers as currently worded. Also, is it the designated nephrologist that has to follow the patient and document the results or can the transplant team manage the patient and get confirmation from the designated nephrologist of the results meeting criteria?

- A concern for some regions that have kidney only programs is that transplant centers are seeing a decline in local kidney transplants because a large number of kidneys are being exported out of the local area. One of the issues is the effect of hepatic-renal syndrome and where the line is. If a liver is transplanted, and there is some return of kidney function, should the liver center return the kidney? If function does not return then do they go into the safety net?

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 OPTN/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 October 29, 2015, there are 414 listserv members with individuals requesting membership daily.

13. Educational Work Group

The TCC Educational Work Group continues to provide structural and content feedback on OPTN/UNOS educational efforts regarding policy and their impact on practice upon request. It also discusses educational requests that are brought forth by other OPTN committees.

The Work Group plans to work with UNOS Instructional Innovations to develop an educational needs assessment survey that will identify topics and effective educational mediums for the transplant community.

The group has been looking at the issues surrounding organ allocation and acceptance and has discussed the challenges of DonorNet® regarding efficient organ placement. The most common concerns expressed were the misuse of the “provisional yes”, need for effective practices from both transplant coordinators and OPO coordinators, better communication between the OPO and transplant center, not being able to upload images to DonorNet, and not being able to access DonorNet on all mobile devices. In efforts to begin addressing these concerns, the Work Group requested that UNOS IT present its plan for DonorNet enhancements, review enhancements that have already been made, and any future enhancements to the full committee on a monthly basis. Committee members have also provided enhancement suggestions and received updates on the DonorNet Discussion Forum. Members agreed there needs to be a UNOS-driven, in-person, brainstorming effort to discuss these issues.

This Work Group will also write and submit articles for the NATCO Newsletter to provide an update on the Committee’s projects and the status of the Proposal to Notify Patients Having an Extended Inactive Status project.

14. Committee Project Brainstorming

The Committee dedicated time during its meeting on September 23rd to brainstorming project ideas that meet the OPTN strategic goals. While the goal to increase the number of transplants was the focus of the session, ideas for the other goals were also collected. The
top two ideas for increasing the number of transplants were DonorNet Enhancements and Best Practices, and Standardizing Reporting of DCD Data.

The DonorNet enhancement and best practices idea incorporates several specific topics that are related to making improvements to DonorNet and making resources available to assist members when using DonorNet. The main problem identified was the amount of time it takes to complete the organ allocation and acceptance process in DonorNet. The extended amount of time it takes to complete the process can lead to organ wastage. Identifying the barriers in place for organ allocation and placement can facilitate the process and increase the number of organs placed; therefore, ideally resulting in more organs transplanted.

The idea to develop a standardized form for DCD data was discussed as DCD data collection is different for each OPO. Time is wasted by the transplant center when staff has to search for information and missing data. There needs to be a standardized form with key data points that the transplant center can use to determine acceptance. A standard form can expedite placement of organs when pertinent information is consistently documented and available.

Meeting Summaries

The Committee held meetings on the following dates:

- May 20, 2015
- July 15, 2015
- August 19, 2015
- September 23, 2015

Meetings summaries for this Committee are available on the OPTN website at: http://optn.transplant.hrsa.gov/converge/members/committeesDetail.asp?ID=62.