

**OPTN/UNOS Minority Affairs Committee  
Meeting Summary  
July 8, 2014  
Chicago, Illinois**

**Meelie Debroy, MD, Chair  
Jerry McCauley, MD, MPH**

*Discussions of the full committee on July 8, 2014 are summarized below and will be reflected in the committee's next report to the OPTN/UNOS Board of Directors. Meeting summaries and reports to the Board are available at <http://optn.transplant.hrsa.gov>.*

## **Committee Projects**

### **1. A Patients Guide to Kidney Transplantation**

Phase One of this project involved developing guidelines for general referrers, including primary care physicians, referring nephrologists and social workers, among others. The goals of this documents were:

- Education about transplant referral, especially early referral
- Dispel myths around transplant

The referral guide has been completed in document form, and is currently available to health care providers and the public on [www.transplantpro.com](http://www.transplantpro.com).

During the process of developing the referral guide, the committee determined that a significant portion of the information was more appropriately disseminated to patients directly. With that consideration, the Committee is collaborating with the Patient Affairs Committee (PAC) to develop a companion Patient Focused Referral Guide.

The joint subcommittee has held one meeting in March 2014. During that meeting the subcommittee focused on defining parameters for the project. The decision at that time was to focus on patients' currently on dialysis and on patients who are approaching dialysis. The subcommittee began to outline the messages that should be disseminated and the best platform for dissemination. Options might include print resources, online resources, video or audio tapes. The Committee will continue to work on this project.

### **2. Educational Guidance on Informed Consent for Living Donors Representing Vulnerable Populations**

The Committee received a presentation of data requests from this project and the accompanying review of the literature. The data request was an initial effort to quantify safety issues among living donors who later were placed on the waiting list as a result of ESRD. Data was primarily obtained using the OPTN Database. The study considered the characteristics of the donor and sought to determine differences in the post-living donation onset of ESRD among blacks versus non-blacks.

The study covered living donors who were later placed on the waiting list between 1/1996 and 2/2008. If data was lacking, additional data was obtained by contacting the transplant programs directly.

The Median age at donation was 31. The median age at listing was 50-64. The median amount of time that elapsed from donation to listing was 19 years. Among whites the median length of time was 21, and 18 among blacks. Sixty-one percent of living donors who were later listed for transplant were female. The most common diagnosis among living donors who were later listed for transplant was hypertensive nephrosclerosis.

The Committee voiced felt the incidence of hypertensive nephrosclerosis among black donors was much higher than what would be expected in the general population in the study, they did discover that there might be some familial linkage since 50% of the donors had the same primary diagnosis for ESRD as their recipient. It was determined that the data is very informative, but that it is difficult to draw conclusion due to the small sample size (70 subjects). However, the data did provide some areas for further study.

### **3. Review of KPD Program**

The Committee became interested in the KPD program after noticing what appeared to be a lack of participation by minority candidates. This was concerning since it would appear that the program would be of great benefit in the minority transplant community. A review of available data at that time, led the Committee to decide to review the data on a bi-annual basis looking for trends. Improvements were noted in some areas.

Committee consensus gelled around the needs for education on qualities that make a good living donor candidate and education to dispel common myths regarding living donation. This education is especially needed among referring doctors and their staff and in the public at large.

### **4. Educational Guidance on Referral to Kidney Transplantation**

This project has been completed and is available on the Committee SharePoint Site and on [www.transplantpro.com](http://www.transplantpro.com). A future goal is to have the document posted or made available through other professional sites, including NKDOKI.

### **5. Dialysis Manuscript**

The manuscript was submitted for publication and was turned down. Ten years ago, the project team did visits in dialysis units and discovered that dialysis staff and patients had many misconceptions regarding transplantation. The Committee agreed that this is an area for further exploration.

### **6. Kidney Referral Project**

This project is still in progress.

### **7. KPD Video Project**

This video is available on the Committee SharePoint Site.

## Committee Projects Pending Implementation

### 8. None

## Implemented Committee Projects

### 9. Historical Overview of the Work of the Minority Affairs Committee

The Committee received a brief history of the Committee and its' work over the years. This presentation is intended as an introduction for members who are new to the Committee at this meeting. In 1992 the Ad Hoc Minority Affairs Committee was established to study difference in waiting times and transplant rates among minority populations. In 1993, it was determined that the issues involved in the review of trends in access, matching and allocation in minority populations were significant enough to warrant establishing the Minority Affairs Committee as a permanent standing committee.

Since its' inception, the Committee has been involved in four significant policy initiatives to improve access to transplantation for minority populations. These include the following:

- *1995-Proposal to Increase Points Assigned for Renal Waiting Time*  
The Committee proposed that the number of points assigned for renal waiting time be increased from .5 points to 1 point for each full year of waiting time. This additional ½ point assisted in moving hard-to-place minority candidates up on the waiting list, thus, decreasing the number of actual years spent waiting for organs in a vulnerable minority populations.
- *2001 – Proposal to Eliminate Preferences for Phenotypical Identity*  
The Committee proposed eliminating the preference for phenotypical identify in allocation of 0 mismatch kidneys when there were multiple eligible candidates with fewer than 2 antigens at 1 or more loci, AB & DR. The Committee believed that the existing policy resulted in decreased access to 0 antigen mismatch kidneys for minority candidates. The Kidney Transplantation Committee supported this proposal. The proposal was approved in 2001 and implemented in 2002.
- *2003 – National Variance to A2A2B Kidneys*  
A joint subcommittee of the Minority Affairs Committee, the Kidney Transplantation Committee and the Histocompatibility Committee proposed eliminating matching at the HLA B locus. The proposal was developed from the work done in an immunosuppression protocol, and was further supported at a National Waitlist Conference. Matching at the HLA A Locus had been approved in earlier policy. This proposal would minimize disadvantages for HLA B candidates without providing harm to other candidates. The proposal was approved in 2003, implemented in 2004 and is now a part of the new Kidney Allocation System.
- *Proposal to Have Waiting Time Begin to Accrue at the Start of Dialysis*  
The Committee, with support from the joint Minority Affairs, Kidney Transplantation and Histocompatibility Subcommittee's, proposed that waiting time begin to accrue from the start of dialysis. This proposal did not do well in public comment. Instead it was implemented as a pilot project in several areas,

with positive outcomes on access for minority and other hard-to-match candidates. This project has now been implemented as a part of the new Kidney Allocation System.

- *New Kidney Allocation System (KAS)*  
The Committee was involved in discussion regarding the development of the newly implemented Kidney Allocation System in 2013.

## **Review of Public Comment Proposals**

### **10. None**

## **Other Significant Items**

### **11. Liver Committee Update**

The Committee received its bi-annual update from the Liver Committee. The Liver Committee has been involved in the following policy proposals since the last presentation:

- HCC Modifications
- Sodium adjustments to make MELD more accurate
- National Review Board proposal to standardize MELD scores across the country.

The Final Rule sets forth the following requirements:

Transplants should:

- Go to the sickest patients first (accomplished by the MELD score)
- Not be based on where a candidate lives
- Provide equal access to all candidates

The Liver Committee has been tasked with addressing geographic redistricting for livers. The Committee raised issues that are being heard in various regions across the country.

- Concerns that some regions will lose livers
- Concerns that programs will lose money or even have to close
- Concerns that programs are currently manipulating the system

The Liver Committee hopes that national standardization in the form of a national review board and encouraging the use of evidence based practices for assigning HCC Exception points will also alleviate concerns.

### **12. Kidney Committee Update**

The Committee received an update on the status of the new Kidney Allocation System (KAS). This presentation outlined the changes that will occur as a result of KAS. The presentation also outlined the comprehensive education plan that the Kidney Committee has embarked on as part of the KAS Implementation Plan:

- Phased Technology Implementation
- Web-based presence for education of patient and transplant professionals
- System training for transplant programs
- Education for patients scheduled for release in September 2014
- Education at professional meetings

### **13. Histocompatibility Committee Update**

The Policy Oversight Committee released the OPTN ‘plain language’ rewrite. As part of this process, UNOS staff flagged Histocompatibility policies that needed to be resolved. As a result, the Histo Committee put out a substantial Histo policy rewrite in 2013.

The Histocompatibility Committee has two major projects at this time:

- Histocompatibility Bylaws Rewrite Phase II
- Deceased Donor HLA Typing Requirements

The Committee believes that the proposed changes will increase transplant safety by relaying critical information on deceased donors in a timely manner. These proposals should also expedite transplant by improving virtual cross matching.

HLA matching is an interest among minority candidates.

### **14. Pediatric Committee Update**

The Committee received updates on 3 current Pediatric Committee projects. The Pediatric Committee has discussed potential policy changes so that every candidate who remains on the waiting list after their 18th birthday would continue to be classified as a pediatric liver candidate. Additionally, the option to request pediatric classification for pediatric liver candidates who have returned to the waiting list after their 18th birthday would be eliminated. The Committee (and thus, likely most of the community) was under the impression that this is how pediatric liver classification already worked.

The Committee is interested in continuing to see results from future modeling.

### **15. Thoracic Committee Update**

The Committee received updates on current projects from the Thoracic Committee Projects. The Thoracic Committee is currently involved in 5 projects. The Committee received the updates without discussion. The Committee will be updated on progress at future meetings.

### **16. Meeting Logistics**

There was a review of the logistics of the Committee. The Committee meets twice per year. Work on ongoing projects is managed in subcommittees. Leadership calls are currently held on the first Wednesday of each month. These calls are used for strategic planning.

The Committee uses various online resources for scheduling meetings. The primary committee worksite is a committee page on SharePoint™. Participation and attendance were stressed as critical factors in the success of all committee work.

The Committee received an overview of the role and function of both Research and SRTR Staff in relation to the Committee. The primary responsibilities of both Research Staff and SRTR Staff is to support the Committee in requests for data. Data requests should be generated from Committee discussions and cannot be based upon individual interests.

## **17. OPTN Project Development Process**

The Policy Development Process within the OPTN process is evolving, with the goal being improved communication and early involvement of all impacted and interested parties. Committees are encouraged to initiate the project development process immediately after identifying an area of interest. This process is then monitored by the Policy Oversight Committee (POC). A list of current and potential future projects are maintained by the POC for review. This encourages communication between committees early and often. This process also supports the establishment of thematic interests within committees; allowing committee's that are considering projects to consider and seek input from other stakeholders. This entire process is intended to promote early and effective use of all OPTN resources, and to channel resources toward certain key OPTN goals.

## **18. Policy Oversight Committee**

The Policy Oversight Committee (POC) is responsible for managing the resources of the OPTN, where resources are defined as committee's and committee work. The POC reviews all committee projects and makes recommendations to the OPTN/UNOS Board regarding the continuation of that project. Decisions on continuing projects are made based on several factors, including, but not limited to:

- Having a reasonable timeline or plan for completion
- Progress shown towards milestones as outlines within the timeline
- Impact of the project

Requests for data and any additional resources should be supported in the project timeline and fit into the initial milestones as established in the project form.

## **19. Introduction to the New OPTN Website**

The Committee received a presentation on the proposed updated OPTN website. The newly updated website is intended to serve multiple audiences with a range of usability needs. This might include patients, transplant professionals and researchers, among others. The goals for the new website are as follows:

- Help visitors find information and resources
- Engage public
- Mobile ready
- Update and expand content

A consideration for the website is to make public comment more accessible. On the new site, visitor comments on a policy proposal will be immediately visible after submission. Other visitors may 'like' a comment and offer other feedback. The goal of this future is to make public comment more transparent and more interactive.

The new website design will be mobile ready to accommodate the large number of users who access the internet from their smartphones. The new website will also obtain some new content.

The Committee raised the benefits of having the new website be social media ready.

## **20. Discussion on Reframing the Focus of the Committee**

The Committee has historically focused on access to transplant for minority candidates, where minority was defined as ethnic and racial minorities. This was essential work, since the literature clearly documents that limited access to transplant correlates with increased time on dialysis which often results to increased potential for death on the waiting list. The Committee believes that protecting the interest of minority populations also protects the interests of the OPTN. The Committee now notes a paradigm shift in transplantation, and in healthcare, such that the historical definition for minority may now be too narrow.

The Committee has begun to look at redefining its' focus to be that of access to transplant for vulnerable populations. The Committee heard a presentation on the definition of vulnerable populations in current literature. Available definitions included:

- Anyone who has a diminished ability to make a fully informed decision, or may be vulnerable to coercion, undue influence, physical control, and/or manipulation  
Source: Presentation from University of South Florida IRB Training

The CDC defines vulnerable populations in this way:

*Subgroup or subpopulation who, because of shared social characteristics, is at higher risk of risks*

Source: Presentation from Dean Schillinger, MD

There were additional definitions that sought to answer the question put forth for consideration by the Committee: "Who is vulnerable?"

In seeking to answer this question, the Committee considered populations that are currently underserved, such as persons living in prisons, and persons living with mental illness. The following issues were paramount in this discussion:

- Sensitivity to program level practice in seeking to intervene at the policy level
- Consideration of the limited available data for certain populations
- Consideration for factors that influence vulnerability that go beyond the OPTN purview:
  - i. Financial limitations
  - ii. State and Federal policy

The discussion moved to de-emphasizing the development of a definition of vulnerable populations for the Committee, and more to identifying current and future policy and projects that have the potential to impact access to transplant. The Committee will then have to consider the point at which Committee input would be most beneficial. This will require close collaboration with other Committee's and departments as they move forward in their work. The Committee also advocated strongly for an educational component to any new committee focus. The Committee agrees that this is an area that will require further consideration.

## **21. TMF Abstracts**

The Committee is interested in submitting abstracts on the following topics

- Defining Vulnerable Populations
- Approaching Loved Ones Regarding Living Donation

## **Upcoming Meeting(s)**

- To be Scheduled