

**Interim Report of the Minority Affairs Committee Meeting
July 12, 2011
Chicago, IL**

**Silas P. Norman, MD, Chairman
Meelie Debroy, MD, Vice-Chairman**

1. Minority Affairs Committee Service Overview

The MAC Committee was provided with an overview of OPTN Committee service for the benefit of new members including an overview of member and staff roles, function of the OPTN Research Department and the process for Committee data requests, followed by a brief overview of the SRTR by the Minnesota Medical Research Foundation (MMRF).

2. OPTN Strategic Planning

The Committee was provided with a brief slide presentation containing an overview of the new process for review and prioritization of Committee activities for alignment with recently developed OPTN key goals and performance indicators. The overview described the purpose for prioritizing the work of the Committees as well as the role of the POC and the Executive Committee in the process.

3. MAC Public Education and Outreach Initiatives

MAC Dialysis Facility Public Comment Opinion Survey

The Committee has conducted a survey of dialysis patients to help gauge the overall level of public understanding of organ allocation policy and awareness of the opportunity to provide comment on OPTN policy development activities. The goal of the project was to identify barriers to the process for all participants in transplantation. The Committee was provided with brief update on the dialysis survey project, including background on the history and rationale for development of the survey. Overall, survey responses appeared to document limited understanding of organ allocation policies and very limited participation in public comment among dialysis patients. Survey results did not show that African-Americans had less knowledge about public comment than Caucasians; though this was possibly due to the demographic and geographic limitations of the survey. Responses did suggest an overall desire among all dialysis patients to be involved in public comment; however, limitations in access to technology may be hampering their participation in discussions about policy changes. The Committee was also provided with a revised timeline for development of the manuscript summarizing survey results.

MAC Survey on Referral to Kidney Transplantation

The MAC has been exploring factors related to lower referral rates and delays for minority patients' access to the waitlist and eventual transplantation. As a result, the Committee conducted an online survey of kidney transplant centers to identify specific practices being used to ensure that dialysis patients eligible for transplant are referred to the kidney waiting list. The Committee was provided with a summary of the background on the project, including the results of previous data requests. The Committee was also provided with a presentation on the purpose and goals of the survey as well as final survey results for the benefit of new members.

The data show that:

- 92% of respondents monitor patient referrals.
- 44% of respondents monitor the percentage of eligible patients referred. Most utilize methods such as transplant center staff visits to dialysis units, transplant surgeon or physician review of medical records, or primary nephrologist determination of eligibility.
- 59% take some form of action if eligible patients are not referred, such as a letter to the dialysis unit, patient or primary nephrologist.
- On average, only 15% of the patients are referred before the initiation of dialysis.
- The most common reasons for delayed referral are medical co-morbidities, patient not being informed of transplant options, and financial constraints.
- 90% of responders use some methods to enhance referrals, such as letters/brochures/presentations to dialysis units and referring physicians.
- This survey demonstrates that even though kidney transplantation is the optimal treatment for ESRD, there is no system that monitors timely referral of all potential recipients.
- Transplant centers generally do not have the resources to determine if eligible patients are referred for evaluation or even informed of transplant options.
- Educational efforts to encourage and improve timely referral are needed.

Survey on Referral to Liver Transplantation

The Committee has reviewed data showing geographic differences and delays in minority access to the liver waiting list. To investigate further, the Committee conducted an online survey of transplant centers to examine the timing and rate of end stage liver disease (ESLD) patient referral for transplant evaluation. The Committee was provided with a summary of the background of the project and presentation of survey results. The data shows that:

- 100% of responders monitor patient referrals.
- More than half (61%) monitor the percentage of eligible patients referred.
- Almost half (42%) are unsure of what percentage of medically eligible patients are referred.
- Transplant physicians and surgeons review of medical records is the most common method for determining medical eligibility for referral.
- 80% take action when they find out a medically eligible patient is not referred.
- On average, 70% of referrals complete evaluation in less than 3 months.
- There appear to be no ethnic differences between patients on the waiting list and patients referred.
- The majority (98%) use some methods to enhance referrals, such as letters/brochures/presentations to referring physician and events/seminars.
- Distance does not appear to have an effect on patients completing the evaluation.

Guidelines on Patient Referral to Kidney Transplantation

Based on its work on the above mentioned survey projects, the MAC created a *Subcommittee on Education and Awareness of Transplant Options* to develop an educational initiative to improve patient access to transplantation by helping to raise awareness among physicians, practitioners and their national societies about appropriate and timely patient referral to kidney transplantation. The goal of the initiative is to provide an opportunity for every medically eligible patient to be referred for transplant evaluation. The Committee was updated on the initiative for the benefit of new members and reviewed the latest draft of the *Guidelines* document. A request was made for additional members to serve on the subcommittee from among the new members on the Committee.

The Committee will convene an expanded subcommittee to include additional OPTN Committees and members representing the professional societies to review the draft document.

4. DaVita Collaboration Update

The Committee was updated on MAC input with regard to an advertisement promoting transplantation that appeared in the NAACP *Crisis* magazine.

5. Update Regarding Review of Policy 6.0 –Transplantation of Non-Resident Aliens

The Committee was updated on proposed revisions to Policy 6.0: Transplantation of Non-Resident Aliens, being initiated by the Ad Hoc International Relations Committee (AHIR). The AHIR has sought feedback from other Committees (including Living Donor, Patient Affairs, and Ethics) with regard to issues identified in the policy which need to be addressed. The Committee was informed that discussion and comment from the relevant Committees has been collected and is being considered for inclusion in a policy proposal that is planned for distribution in September. Several members expressed interest in the issue and the Committee looks forward to providing its comment on the proposal during the public comment period.

6. Ongoing Evaluation of CPRA

CPRA measures a candidate's overall immune sensitivity to potential donor antigens by calculating how many potential donors would be considered incompatible for a given candidate based on the patient's known HLA specific antibodies. The use of CPRA was adopted in 2009 and is intended to provide a more consistent and accurate definition of sensitization and improve the efficiency of organ allocation by reducing the risk of antibody rejection in a candidate. The MAC Committee continues to review CPRA to determine if it has increased transplants to sensitized patients, particularly minority candidates.

During the meeting, the Committee reviewed updated data showing CPRA results over a 12 month period. The data showed that:

- There was an increase in the reporting of unacceptable antigens on the waiting list and a substantial decrease in the number of kidney refusals due to positive crossmatch.
- The percentage of low sensitized registrations (1-20% PRA/ CPRA) decreased; while the percentage of non-sensitized (0/Not reported PRA/CPRA) and very broadly sensitized (PRA/CPRA > 95%) registrations went up.
- Transplant rates for broadly sensitized candidates significantly increased.

After brief discussion, the Committee requested to be able to continue to be updated with the ongoing evaluation of the CPRA policy and how it is being incorporated in the new kidney allocation concepts.

7. Living Donor Manuscript

The Committee was provided with a data presentation summarizing results in the recently published manuscript *Ethnic and Gender Related Differences in the Risk of End Stage Renal Disease After Living Kidney Donation* authored by UNOS staff and current and former chairs of the Minority Affairs Committee. The data show that while the relative risk of developing ESRD was very low among living kidney donors, the relative risk was higher for African-American donors compared with

Caucasians and males compared with females. In addition, of those living donors who developed ESRD, half did so within approximately 10 years of their donation.

The article recommends that transplant practitioners use these findings to counsel potential living donors. The researchers also emphasize the need for more comprehensive data collection to further assess the risk of ESRD or other long-term complications among living donors.

8. Update on Kidney Allocation Concepts

The Committee was provided with a brief presentation on the kidney allocation concepts proposed as part of a new national kidney allocation scheme for the benefit of its new members. The Committee was also informed that the kidney proposal is expected to be released for public comment during a special cycle as yet to be determined. The Committee requested to be updated on the timeline for release of the proposal.

9. Kidney Paired Donation Pilot Project

The Committee viewed a brief presentation on the background and history of the kidney paired donation pilot project for the benefit of new members.

10. Minority Issues for Future Discussion

MAC Comprehensive Review Article

The Committee has expressed interest in publication of an article addressing access to transplantation from the historical perspective of the MAC Committee; however, the idea had been downgraded in priority due to Committee workload. The Committee was informed of plans to pursue a more general article in the *UNOS Update* which would document the accomplishments of the Committee in the area of supporting policies improving access to transplantation for minority candidates and would coincide with a donation event month. The Committee requested to be updated once the issue is discussed internally with UNOS staff.

Referral Survey to Assess Barriers to Thoracic Transplantation

During the meeting a Committee member inquired about the possibility of launching a survey to assess barriers to Thoracic transplantation. It was noted that this appeared to be a logical next step for the Committee in its work identifying barriers to referral to transplantation. The Committee requested to work with a subcommittee to develop the survey instrument for distribution to the Medical and Transplant Directors of transplant centers.

Minority Donor Conversion Rates

In previous years, the Committee reviewed data showing progress toward Health and Human Services (HHS) donor-related goals. The Committee had requested to be able to view results showing donor conversion rates by region and ethnicity; however, at the time OPOs were only required to provide monthly totals by donor hospital so this information was not available. The Committee orientation provided by the Research Department included a description of various data collection tools, one of which was the Donor Notification Registration (DNR). A DNR is required on all imminent neurological and eligible deaths in the OPO's donor service area (DSA). This more detailed

information is critical for analyzing donor conversion practices. The Committee was informed that data on the distribution of donor conversion rates has been presented to the OPO Committee and to the AMAT. The Committee requested to review data on donor conversion rates for different donor ethnic groups stratified by region for its November 2011 meeting.

**ATTENDANCE FOR THE JULY 12, 2011
OPTN/UNOS MINORITY AFFAIRS COMMITTEE MEETING**

| Committee Members | Position | In Attendance |
|----------------------------------|----------------------------------|----------------------|
| Silas P. Norman, MD | Chair | Yes |
| Meelie A. Debroy, MD | Vice-Chair | Yes |
| Isabel Zacharias, MD | Region 1 Representative | (Phone) |
| Stacey H. Brann, MD | Region 2 Representative | Yes |
| Yma Waugh, MBA | Region 3 Representative | Yes |
| Sherilyn A. Gordon Burroughs, MD | Region 4 Representative | Yes |
| Ricardo Elizondo, RN, CPTC | Region 5 Representative | No |
| Stephen A. Kula, Ph.D, NHA | Region 6 Representative | No |
| Bruce A. King, MSW | Region 7 Representative | Yes |
| Antonio Sanchez, MD | Region 8 Representative | Yes |
| Lani V. Jones, PhD, MSW | Region 9 Representative | (Phone) |
| Asif A. Sharfuddin, MD | Region 10 Representative | Yes |
| Kelly C. McCants, MD | Region 11 Representative | Yes |
| Remonia A. Chapman, MD | At-Large | (Phone) |
| Pang-Yen Fan, MD | At-Large | Yes |
| Mohamed A. Hassan, MD | At-Large | Yes |
| Eddie Island, MD | At-Large | Yes |
| Maria R. Lepe, MD | At-Large | No |
| Rosaline Rhoden, MPH | At-Large | Yes |
| M. Christina Smith, MD | At Large | No |
| Karen A. Sullivan, Ph.D | At-Large | (Phone) |
| Henry B. Randall, MD | At-Large | Yes |
| | | |
| Mesmin Germain, MBA, MPH | Ex-Officio, HRSA | (Phone) |
| Chinyere Amafulé | Ex-Officio, HRSA | No |
| UNOS Staff | | |
| Deanna L. Parker, MPA | Committee Liaison/Policy Analyst | Yes |
| Wida Cherikh, PhD | Sr. Research Biostatistician | Yes |
| MMRF Staff | | |
| Monica M. Colvin Adams, MD | SRTR | Yes |
| W. Ray Kim, MD | SRTR | No |
| Guests | | |
| None | | |