

What's New with UNOS and MAC

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Ex-Officio

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Disclosures

Nothing to disclose

AMAT

- **Interim Report of the OPTN/UNOS Minority Affairs Committee Meeting**
- **November 16, 2010**
- **Henry Randall, MD, Chairman**
- **Silas P. Norman, MD, Vice Chairman**

MAC Public Education and Outreach Initiatives

- *MAC Dialysis Facility Public Comment Opinion Survey*
- *MAC Survey on Referral to Kidney Transplantation*

Data results

- 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

Data results

- 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

- 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

DaVita Collaboration Update

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

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.

Ongoing Evaluation of CPRA

- 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.

Living Donor 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.

Kidney Paired Donation Pilot Project

In progress across the country

MAC Comprehensive Review Article

- 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

- 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

- 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.