

**OPTN/UNOS Minority Affairs Committee
Report to the Board of Directors
November 14-15, 2011
Atlanta, GA**

Summary

I. Action Items for Board Consideration

- None

II. Other Significant Items

- Development of Educational Guidelines for Patient Referral to Kidney Transplantation. (Item 6, Page 7)
- Requested Development of a Survey on Referral to Thoracic Transplantation. (Item 12, Page 12)
- Review of Donor Conversion Rates by Ethnicity. (Item 12, Page 13)

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

This report includes items addressed by the Minority Affairs Committee (MAC) during its committee meeting held on July 12, 2010, and subcommittee conference calls.

1. Minority Affairs Committee Service Overview

The Minority Affairs Committee (MAC) was provided with an overview of OPTN Committee service for the benefit of its new members. The presentations included an overview of member and staff roles, provided by Deanna Parker, MPA, liaison to the Committee, the function of the OPTN Research Department and the process for Committee data requests, provided by Wida Cherikh, Ph.D, of the OPTN Research Dept., followed by a brief overview of the SRTR and the Minnesota Medical Research Foundation (MMRF) provided by Monica Colvin Adams, MD.

2. OPTN Strategic Planning

Silas Norman, MD, Chairman of the MAC, provided the Committee 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 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. Deanna Parker, MPA, liaison to the Committee, provided a brief update on the dialysis survey project, including background on the history and rationale for development of the survey project for the benefit of the new members. The results show that 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.

NAACP Collaboration Update

The Committee was updated on MAC input with regard to an advertisement promoting transplantation that appeared in the NAACP *Crisis* magazine. During the update, a member of the

Committee inquired about the possibility of partnering financially with pharmaceutical companies to produce educational materials. It was responded that this would depend on the nature of the project being proposed and its funding source. The MAC, operating under the auspices of the OPTN contract, would be unable to participate in a project comingling project funds with private funds. However, under certain circumstances UNOS, as an organization could potentially be the steward of such funding for a specific designated project. Committee members expressed caution with regard to participation in this type of activity as it could be perceived to be a conflict of interest and could introduce bias into the Committee system.

4. 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 transplant waiting list. Dr. Wida Cherikh, PhD, of the UNOS Research Department, provided the Committee with a summary of the background on the project, including the results of previous data requests (**Exhibit A**). 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.

The 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 to address the problem.

Following the presentation, the Committee discussed the inherent conflict of interest present among providers which may be preventing patients from being referred. The Committee discussed the fact that there is a significant financial disincentive for providers to refer patients to transplantation as treatment for ESRD versus dialysis. Though a nephrologist may provide care for both long term dialysis patients and transplant candidates, the nephrologist earns more money treating the patient receiving dialysis since dialysis treatment is covered by Medicare. It was further acknowledged that the dialysis companies are huge profit making corporations which do not directly benefit from transplantation. In addition, research reviewed by the Committee has demonstrated that though dialysis companies are now mandated to inform patients about their transplant options, many of the staff caring for the dialysis patients are not well-informed enough about transplantation to adequately

educate patients. To further compound the problem, there are no requirements accompanying the mandate which specify how transplant options should be presented to patients. Since minorities traditionally have reduced access to healthcare and are less well-educated, the Committee believes that this may explain lower referral rates for this population of patients and those located in more densely populated urban areas.

The Committee debated the financial disincentive as the primary cause of reduced referral. It was commented that there is no dearth of chronic kidney disease (CKD) patients nationally and the number is expected to rise. However, for the individual provider, though there may be a plethora of patients with CKD needing dialysis treatment nationally, once someone is referred to dialysis an empty chair exists in their unit that will need to be filled, and so theoretically the provider is losing money. A member remarked that the focus should be on the patient because the field is not able to adequately police itself. As an example, the member cited the revision to the 2728 Medical Evidence Form requiring providers to note that patients have been “informed” about their transplant options. The effort has proven ineffective in ensuring that patients are educated about transplantation prior to receiving dialysis treatment. It was further commented that the issue is not necessarily that providers are unwilling to do the right thing but that they do not have a particular financial incentive to do so. If there was funding to accompany any activity ensuring appropriate patient referral to transplantation, providers would subsequently modify their behavior. Thus, the Committee should not point fingers at providers but work toward finding a way to make timely referral a performance measure. It was noted that as healthcare advances more toward pay for performance, it will be important to look for ways to lump transplantation into a pay for performance model. This will present the best case for instituting standards for referral with accompanying penalties for noncompliance and will serve to reinforce the message that transplantation is the optimal treatment for ESRD.

A kidney transplant recipient on the Committee commented on the disconnect he perceived between his nephrologist, the dialysis center and the transplant center while awaiting his transplant. The member noted being aware of the lack of oversight of the process and as a result, becoming a vocal self-advocate for his own transplant candidacy. He also commented on the social welfare culture of the patients receiving dialysis. Many patients seemed to be satisfied with dialysis due to their belief that this was the best treatment possible – only because they had not been told otherwise. There also did not seem to be an advocate to help patients think about and prepare for the next step in treating their disease, as morbidity and mortality increases the longer a patient is on dialysis. As an educated and articulate patient the member felt advantaged and even reported being physically separated from the other patients, because of their perception that he was somehow a “different” type of patient. Another member commented that his transplant center tracks patient self-referrals and they had seen the numbers decrease over the last several years.

The Committee also discussed the importance of identifying and understanding the patient and provider population being targeted, with a particular emphasis on the denominator, i.e. the eligible patient referral population. For kidney disease, dialysis is used as a proxy for identifying the ESRD population; however this number does not show the true denominator of patients with end stage kidney disease who may benefit from a transplant. This is even more difficult to determine with the liver disease population. After discussion, the Committee determined that education of referring providers as well as patients is key in helping to close the knowledge gap and improving access to transplantation.

The Committee will continue to refine the survey results for eventual publication.

5. 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. Dr. Wida Cherikh, Ph.D provided the committee with a summary of the background of the project and presentation of survey results (**Exhibit B**). 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 physician and surgeon 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.

Following the presentation, members of the Committee briefly discussed the survey results. A member of the committee commented that the ethnic representation of referrals for Hispanics shown in the survey results (17%) do not reflect the Hispanic population with liver disease in Texas. The member noted that approximately 40% of the population in Texas is Hispanic and that mortality from liver disease disproportionately affects Hispanics at an incidence rate that is twice that of Caucasians and African Americans. Therefore the number of Hispanic patients referred to transplantation should be at least twice as high as the number of people in the general population, if patients are being referred appropriately. The Committee was reminded that as with the kidney referral survey, results demonstrate the transplant center program director's best guesstimate as to the status of referral to liver transplantation in their individual transplant center. However, it was noted that the results do appear to support the perception of the Committee that as with kidney transplantation, there is little oversight of the liver referral process and little knowledge of the population of medically eligible patients who are not being referred.

Another member commented that the slide showing that 14% of patients are unaware of the option for liver transplantation seemed too low. He suggested that an equal if not greater call for education of those patients with liver disease is necessary, especially given its associated risks and mortality. The Committee also discussed the fact that substance abuse is a prevalent problem in liver disease patients. Further, the incidence of hepatoma is high in the Asian population but represents only 2% of Asians are on the liver waiting list. Another Committee member noted that there is an opportunity for education present among hepatologists, especially since there is not the same financial conflict that may be present in the nephrology community. This is also true with gastroenterologists. Another member commented that it would be interesting to see data on the percentage those two provider groups represent of total referrals, to help identify the correct target audiences for an educational initiative.

The Committee also discussed the average work up time shown in the survey. The transplant referral work up in some cases was less than six months; however, it was commented that the time frame for the decision to actually list a patient may take a similar length of time. Members commented that in

some cases that time is being used for deferral or patient rehabilitation. This may also occur with the existence of certain medical conditions or if further testing needs to be conducted. It was also noted that many referrals actually originate from nurse practitioners. These individuals serve as a social work surrogate for many patients and so they may also be an appropriate population which may benefit from an educational initiative.

The Committee also discussed additional barriers present for the liver patient population. It was noted that financial constraints are highlighted more in the minority population where insurance, access and the amount of insurance coverage a patient has plays heavily into whether a patient is transplanted. It was commented that kidney patients have a relatively level playing field because a patient has Medicare coverage once he or she is on dialysis. Additionally, three years of immunosuppression is covered for kidney transplantation through Medicare; however, this is not true of liver transplantation. Others responded that for minority patients, the playing field is still not level. For patients who do gain access to the waiting list for liver and heart transplantation, the rate of transplantation is similar to that of Caucasian patients; however, for kidney patients, the rate of access to referral, wait listing, and transplantation is significantly impaired.

A member noted a concern that many primary care physicians do not have a clear grasp on which liver failure patients are transplant candidates and so this may contribute to delayed referral. It was also commented that while the MELD score is essential for allocation, the indication for referral should be any form of hepatic decompensation, irrespective of the patient's MELD score. For example, if a patient has ascites, but a MELD score of 7, the patient should be referred because the mortality risk within two years is less than 50%. A primary care physician should not feel the need to use judgment with regard to non-compliance, substance abuse or any specific diagnoses that is believed to preclude transplant. In these cases, the provider should refer the patient.

The Committee will continue to refine the results of the survey for publication and development of a future educational initiative on referral to liver transplantation.

6. Guidelines for Appropriate Patient Referral to Kidney Transplantation

The Committee was provided with an update on development of its educational initiative *Guidelines for Appropriate Patient Referral to Kidney Transplantation* by Dr. Silas Norman and Pang-Yen Fan, MD. The Committee was informed that the impetus for the initiative was the results of the two survey projects initiated by the Committee which demonstrated that patient and provider education was critical in improving access to transplantation for specific patient populations.

The MAC subsequently created a *Subcommittee on Education and Awareness of Transplant Options* for the purpose of developing guidelines that would help improve patient access to transplantation by raising awareness among referring physicians, practitioners and their national societies about appropriate and timely referral to kidney transplantation. The guidelines would help providers better understand their patients' options for treating ESRD through early referral, preemptive transplantation and living donation, etc. The guidelines would address myths commonly associated with transplantation as well as identify medical co-morbidities which are no longer contraindications to transplantation. The ultimate goal of the educational initiative is to provide an opportunity for every medically eligible patient to be referred for transplantation to take advantage of its survival and quality of life benefit and help establish transplantation as the default pathway for treatment of ESRD.

The Committee intends to broadly disseminate the guidelines electronically and in written format. The guidelines would be paired with development of an implementation strategy, a national resource for locating information on transplant center criteria for patient acceptance, and a best practice

recommendation for institution of a functional staff role responsible for oversight of the entire referral process.

The guidelines would contain the following major elements:

- Focus on patients with Stage 4 and Stage 5 chronic kidney disease (CKD).
- Encouragement of referral prior to start of dialysis (preemptive transplantation)
- Recommendation for referral of all medically appropriate patients with a GFR of at least thirty so that the patients can begin to be educated about transplantation, have enough time to locate a living donor, to take advantage of the benefits provided by preemptive transplantation, and have an opportunity for early listing for maximum accrual of waiting time in geographic locations with long lists and waiting times.
- Focus on providing specific information to help providers counsel patients as they move across each stage of the spectrum of CKD toward discussions of their transplant options. The specific GFR used for recommending referral would be within a range (25 to 35) based on individual patient characteristics that would help identify the patients' anticipated progression to ESRD.
- Emphasis on referral as a continuous process with annual reassessment.

The committee plans to collaborate with other relevant OPTN committees and professional transplant partner organizations to finalize and disseminate the document as well as develop other opportunities for patient education. The subcommittee continues to refine the document to include relevant sections for providers, frequently asked questions with answers, and discussions about internal and external processes that would help support appropriate patient referral.

The subcommittee met on September 16, 2011, for the purpose of reviewing the most recent iteration of the draft guidelines document. Subcommittee members reviewed major revisions to the draft language, the addition of references with footnotes, and other resources for information. Following review of the document, subcommittee members were given assignments for editing specific sections of the guidelines or developing new sections to be added. Further, each subcommittee member was asked to provide questions to add to the FAQ section, posed from the perspective of a referring provider. Committee staff will continue to work on developing a high level graphic illustration of the existing kidney allocation algorithm as well as revising the graphic illustrating GFR ranges for referral.

Members of the Committee acknowledged the contribution that the work would provide to the field of transplantation. If successful, the initiative would represent a dramatic shift in thinking for many providers. It was also acknowledged that some of the concepts might be a difficult sell due to longstanding beliefs and existing practice. For example, some providers may feel that a GFR of thirty is too early to refer patients. It was suggested that the initiative be linked as closely as possible to reimbursement for education of patients with Stage 4 and Stage 5 CKD to help make following the guidelines line up with existing educational programs. Finally, a request was made for additional members to serve on the subcommittee from among the new members on the Committee.

A subcommittee meeting will be convened in the weeks following the full committee meeting, with an expanded subcommittee meeting convened after the refinements to the guidelines have been completed.

7. 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 (AHIRC) by Meelie S. Debroy, MD, Vice Chairman of the MAC Committee.

The AHIRC requested 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 AHIRC has requested that these committees evaluate the content of Policy 6.0 and provide input on the relevance, and currency of the policies as well as suggestions for revising and eliminating language.

Some problems associated with the policy as currently written include:

- Transplantation of non-resident aliens and the audit performed by the AHIRC;
- Definitions of non-resident aliens;
- Exportation and importation of deceased donor organs;
- Valuable consideration and provisions the recovery and transplants of deceased and living organs
- Monitoring of the policy

The Committee was informed that during its meeting on June 28-29, 2011, the OPTN Board of Directors approved the changes to the information on forms collected by the OPTN. It was reported that the Board approved the modified list of items that will appear in the existing dropdown list of items to select in response to the “citizenship” data entry question in the Deceased Donor Registration Form (DDR), Living Donor Registration Form (LDR), and Transplant Recipient Registration Form (TCR). In addition, the data entry options will include the country of permanent residence and the year of entry to the United States for non-US citizens/non-US residents who traveled to the United States for transplant.

The AHIRC is also requesting the following modifications to Policy 6.0 for distribution during the Fall (September) public comment cycle:

1. Change in the proposal title;
2. Inclusion of a preamble that borrows language from the *Declaration of Istanbul on Organ Trafficking and Transplant Tourism*
3. Revisions to the citizenship definitions;
4. Deletion of policies that cannot be measured or are antiquated – 6.2.2, 6.2.3, 6.2.5, 6.2.6;
5. Allow the AHIRC to audit any transplant program that lists or transplants candidates who are in the “non-US citizen/non-US resident, traveled to US for transplant” category;
6. Delete Policy 6.5 (Violation), as all policy violations are subject to review by the OPTN/UNOS Membership and Professional Standards Committee;
7. Refocus the current organ exchange section to only organ imports;
8. Retain the ability to import organs ad hoc and through a formal arrangement;
9. Retain the ability to export organs as stated currently; and,
10. Delete the policy on ethical practices (decision made in 2010), because defining “ethical practices” could be problematic, and the import of an organ for valuable consideration is a criminal offense, which is not under the purview of the OPTN.

Following the update, the Committee discussed a hypothetical question concerning a patient seeking treatment for organ failure after receiving an organ transplant outside of the U.S. The Committee debated whether or not the patient should be denied medical care because of the way that the initial organ transplant was obtained; particularly if the person is experiencing complications as a result of the transplant. Some members of the Committee approached the hypothetical scenario from the perspective that the patient would be like any other patient in that after being turned down at one or more institutions for care or for relisting for a second transplant, the patient could still exercise his or her right to seek a second opinion. The MAC Committee, through its work on behalf of its constituents, encourages every patient evaluated for a transplant to seek additional medical judgment in the form of a second opinion. Another member responded that in this issue it is important to separate the medical issue from the ethical one. Caring for a patient is not a commitment to transplantation. It was also commented that there are differences in medical practice with regard to transplant candidates even within the United States. The issue can be framed from the perspective of organ utilization and should be left to the discretion of the local program. Currently, centers have no way to track where these patients are coming from and from which country they obtained their organ transplant, so the determination of medical treatment should be a clinical decision made by each center. National guidelines or even a national framework to guide practice in this area should be broadly defined and the handling of these cases should be left to the judgment of the individual transplant center.

Previous Committee discussion in this area focused on the determination of the patient's insurability and the existence of a support system following the transplant. The Committee felt that many of the other issues being addressed in the current policy were not based upon medical criteria. The Committee also cautioned that increased scrutiny of undocumented transplant candidates not only promotes centers engaging in areas in which they have no experience or authority (monitoring patient immigration status), but could adversely affect donation. Undocumented individuals contribute positively to the organ donor pool; whereby transplant tourists do not. It was remarked that it could become important to focus national attention on the issue if large numbers of these patients become relisted and then rise to the top of the list, thereby siphoning organs out of the system and away from other candidates.

The Committee looks forward to providing its comment on the proposal during the upcoming public comment period.

8. Ongoing Evaluation of CPRA

CPRA is the percentage of donors expected to have one or more of the unacceptable antigens indicated on the waiting list for the candidate. It 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 Committee continues to review CPRA to determine if it has increased transplants to sensitized patients, particularly minority candidates. For this meeting, the Committee requested a calculation of transplant rates per patient years during pre- and post-CPRA policy by sensitization level and ethnicity. The Committee reviewed updated data showing CPRA results over a 12 month period presented by Dr. Cherikh (**Exhibit C**).

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.

A member of the Committee inquired whether or not CPRA was operating as intended. It was commented that CPRA is still a moving target due to the fact that the sophistication of the test is a changing scenario as laboratories make improvements that better identify results that are clinically significant. However, the data does show that CPRA is working as intended. CPRA has increased transplants to highly or broadly sensitized patients and the number of refusals due to positive crossmatch has decreased dramatically. Further, identification of some of the lower and zero sensitized patients will change when HLA C is added to the calculation.

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.

9. Living Donor Manuscript

With the rapid growth of the kidney transplant waiting list, living kidney donors (LKDs) have become an important source of organs. The safety of living donation, particularly with respect to individuals who have donated their kidneys and ended up developing end stage renal disease (ESRD) remains to be of great interest and importance. However, currently there is limited data pertaining to the risk of ESRD after living kidney donation. 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. Dr. Cherikh, lead author of the study, presented the information to the Committee (**Exhibit D**).

To identify Living Kidney Donors (LKD's) who developed ESRD after the donation, the OPTN living donor, CMS Medical Evidence Form 2728 (certification of ESRD), OPTN kidney waiting list, and OPTN kidney transplant databases were linked using one or more of the following patient identifiers:

- SSN
- Last name and/or first name/middle name
- Date of birth (DOB)
- Gender

Living kidney donors who donated during 10/1/87-3/31/03 were included in the analysis (N=56,458) and followed through 3/31/09. Post-donation ESRD was defined using the following indicators:

- The initiation of maintenance dialysis; *or*
- Placement on the OPTN deceased donor (DD) kidney waiting list; *or*
- Receipt of a living or DD kidney transplant.

Dr. Cherikh reported 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. As such it should be recommended that transplant practitioners use these findings to counsel potential living donors. The study also emphasized the need for more comprehensive data collection to further assess the risk of ESRD or other long-term complications among living donors.

Committee members commented that the study should be considered a landmark paper; however, the Committee should assume a strong leadership role in determining how this information is presented to and interpreted by the community. It was noted that the results would be very easy to misinterpret or misconstrue.

10. Update on Kidney Allocation Concepts

The Committee was provided with a brief presentation by Dr. Cherikh on the kidney allocation concepts proposed as part of a new national kidney allocation scheme for the benefit of its new members (**Exhibit E**). 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.

11. Kidney Paired Donation Pilot Project

Dr. Cherikh also provided the Committee with a brief presentation on the background, history, and current status of kidney paired donation pilot project viewed by the Board of Directors during its July meeting, for the benefit of the new members (**Exhibit F**).

12. 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 has 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 which 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 similar to the kidney and liver referral surveys that would assess barriers to referral to thoracic transplantation. The member commented that many of the heart patients are being referred late which is the reason that the use of ventricular assist devices (VADs) have become more headlined. The Committee acknowledged 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.

It was commented that this new area of study would need to undergo the new Board review and approval process and added to the committee prioritization list. The Committee requested to be updated with regard to this process.

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 AMAT. The Committee requested to review data on donor conversion rates for different donor ethnic groups stratified by region for its November 2011 meeting.

It was noted that this data request could be provided for the Committee's review; however, any initiative resulting from the review would also need to undergo the BOD approval and prioritization.

**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 Amafule	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		