

**Interim Report of the OPTN/UNOS Minority Affairs Committee Meeting
Chicago O'Hare Hilton
March 27, 2009**

**Pang-Yen Fan, MD, Chairman
Henry Randall, MD, Vice-Chairman**

1. Executive Summary of the Meeting of the Board of Directors.

The committee was provided with a brief update on relevant actions from the March 2-3, 2009 meeting of the OPTN/UNOS Board of Directors in Houston, TX.

2. MAC Dialysis Facility Public Comment Opinion/Outreach Survey

The MAC is completing its survey of dialysis patients to collect baseline information on public perception of organ allocation policy and public awareness of the ability to provide input into the development of these policies. The data will provide insight into public awareness of transplant policies and potentially identify demographic differences. It is also hoped that the data may facilitate refinement of the public comment process and support the development of public education and outreach initiatives.

During the March meeting, the Minority Affairs Committee viewed preliminary results from the dialysis survey that included dialysis facilities in both Massachusetts (MA) and Alabama (AL) (**Exhibit A**). Dr. Fan presented the information to the Committee.

The survey methods consisted of a self-administered anonymous written survey of patients in seven dialysis facilities in Alabama (AL) and Massachusetts (MA). The questionnaires were developed in both English and Spanish versions. Survey administration and data entry was provided by UNOS staff or designee with data analysis conducted by a consultant. Of the approximately 700 patients approached, 147 completed surveys were returned (96 MA, 51 AL). Because the presentation was based on preliminary data, the data was manually separated for comparison purposes.

Demographic information was summarized for the group. In both sites combined, 59% of patients were male and 41% were female. The largest age category was 45-55. In general, patients in MA were older (39% were 65+) and primarily Caucasian ethnicity (67%) while patients in AL were younger (10% were 65+) and predominantly African American (90%). Overall, patients in AL had been on dialysis longer than the patients in MA (24% had been on dialysis for 7+ years versus 16% in MA). Most patients were unemployed (19% in MA vs. 49% in AL), however, more patients in MA reported that they were retired (55% vs. 28%). Medicare was reported as the primary source of insurance (30% in AL vs. 80% in MA). There were slightly more individuals who were college educated in AL than in MA (25% vs. 42%) with slightly higher income in the MA group (50% vs. 69%). Seventy nine percent of patients in the combined group were interested in receiving a transplant and 57% had been evaluated. Forty-nine percent were currently on the waiting list and 16% had received a prior transplant.

Patient responses to the question concerning knowledge of organ allocation policy were fairly similar in both states. Overall responses from the combined patient group showed that the vast majority of patients (99%) were aware of transplantation and most (74%) had discussed this option with a medical professional. Forty-six percent of patients reported having a good understanding of

organ allocation policy, while 28% reported having a poor or no understanding of organ allocation policy. When asked about how often they believed kidneys were allocated fairly (i.e., if policies were implemented as outlined) the majority believed that organs were always or usually allocated fairly (61%) while 36% were unsure if they were allocated fairly. Only 3% responded that they believed that organs were never or usually not allocated fairly. When asked if they believed that organ allocation policies were fair (measure of equity), 34% believed that organ allocation policies were very fair, 26% believed that organ allocation policies were somewhat fair, 5% believed that organ allocation policies were somewhat unfair, while 32% were unsure if organ allocation policies were fair.

Patients were then queried as to their awareness of the public comment period for expressing their feedback on organ allocation policies. Eighty-four percent of patients were aware of public comment, though only 2% had ever participated in the process. Twenty-five percent did not know how to obtain a copy of the policies, 15% did not know how to express their opinion, 9% did not believe their opinion would be taken seriously and 7% could not understand the policies.

When asked about the reasons for not using public comment, patients indicated the following:

- Doctors are more qualified to make policy decisions 23% (MA 30%, AL 11%)
- Do not know how to get a copy of proposed policy 25%
- Do not know how to express my opinion 13%
- Do not believe my opinion would be taken seriously 9%
- Could not understand proposed policy 7%

When queried as to the reasons why they were uninterested in expressing their feedback, patients indicated the following:

- Doctors are more qualified to make decision 74% (MA 80%, AL 64%)
- 22% Do not believe opinion would be taken seriously (MA 19%, AL 36%)
- 11% Other Reason (MA 6%, AL 18%)

In summary, Dr. Fan reported that the responses appear to document limited understanding of organ allocation policies and very limited participation in public comment among dialysis patients. The responses can be used to suggest revision and refinement of the public comment process and better educate patients with ESRD about organ allocation policy development.

The committee discussed the findings. Members noted that most patients appeared to have been approached about receiving a transplant; however, there were differences in the level of patient education and understanding about transplantation and awareness of public comment. The committee discussed whether or not this was a result of inadequate information and education provided to patients. It was commented that lack of patient referral is only one barrier to transplantation. How information on transplantation is presented to the patient is equally important. The member remarked that culturally competent patient education about transplantation could increase the likelihood that the patients who are referred show up for their meetings, evaluations, etc. The survey results could present an opportunity for additional education in this area.

Members also briefly discussed who should ultimately be responsible for appropriate patient education. Members debated whether this should be the responsibility of the dialysis unit or the responsibility of the transplant nephrologist. One committee member remarked that in her unit patients may be delayed while waiting on the sign off from the nephrologist before being listed. It was suggested that the committee could engage the American Society of Nephrology (ASN) and the National Kidney Foundation (NKF) for assistance in addressing patient education and referral. There could be a study of practice patterns, an educational forum or session at upcoming meetings, etc. It was further suggested that the community should refocus its thought processes on transplantation as the standard of care therapy with dialysis serving primarily as the bridge therapy.

The committee also discussed the possibility of additional government controls. One member suggested that the government could decrease the amount of dialysis funding once the patient has been evaluated and has been on dialysis for a year, as incentive for Centers to broach transplantation as an option for patients. This way, everyone would be referred and it would be up to the transplant center to decide who is an appropriate candidate. It was responded that there is no End State Renal Disease (ESRD) mandate or definition as to how transplant options should be presented to the patient. Further, this area is not within the purview of the OPTN and so ultimately, additional government regulation may be required. It was further commented that HRSA does not have jurisdiction in this area and that the Centers for Medicare Services (CMS) has authority over reimbursement issues. It was suggested that this issue could be added to the list of ongoing issues that the OPTN can add to its conversations with Health Resources Services Agency (HRSA) regarding CMS.

The committee discussed the appropriate role of public comment, given this knowledge about patient involvement. It was suggested that the public comment process should be used only as a forum for the dissemination of ideas and as a way to distribute points useful in a policy debate. The system should not be viewed as an election or a poll and responses should not be considered to be representative of the transplant community or patient population as a whole.

3. Update on Development of a Kidney Allocation System (KAS)

Silas Norman, MD, Minority Affairs Committee (MAC) liaison to the Kidney Committee, provided the MAC with an update on developments following the KAS public forum held January 26, 2009 in St. Louis, MO (**Exhibit B**). The committee was informed that 93 responses to the RFI were received and 9 organizations representing transplant professionals, patients, and histocompatibility experts weighed in at the forum.

Although support for various elements of the proposal were expressed, particularly the use of the Donor Profile Index (DPI) in place of standard criteria donor/expanded criteria donor (SCD/ECD) designations, as well as the use of dialysis time in place of waiting time; the public expressed very limited support for Life Years from Transplant (LYFT) overall. At this time, the Kidney Committee plans to investigate data elements to determine what data need to be collected to estimate survival and convene an expert panel to discuss cardio vascular disease risk assessment. The committee plans to convene a focus group to discuss allocation and revamp existing communication materials. There are also plans to discuss modeling proposed alternatives, including donor/recipient age matching as well as an examination of different combinations of DPI/donor age/LYFT/candidate age.

The committee briefly reviewed data showing the index of concordance model or c-statistic. The c-statistic is a measure of how well a clinical prediction rule can correctly rank order patients by risk. The purpose of the presentation was to demonstrate that despite the perceptions, the criticisms of the model made by the public are not data based.

The Committee discussed the need to refocus the patient education and communication message. It was expressed that the primary barrier to acceptance of the concepts presented is that the overall patient population has not been convinced that the change is worthwhile and that they should make a personal sacrifice for the benefit of the majority. It was commented that until the conversations begin to address this area, the proposal and its related concepts will not be supported. The Committee discussed the possibility of losing the modest gains in minority transplantation that may have been realized under the proposed concepts should the proposal be significantly delayed. The committee also noted and discussed the public support for specific parts of the proposal. Following the discussion, the Committee voted unanimously to approve the following resolution:

Resolved, the Minority Affairs Committee supports implementation of the various elements of the KAS concepts, specifically dialysis time and the donor profile index, if the current proposal for KAS will be significantly delayed. The MAC recognizes that the use of LYFT is in question and would like the minority patient population to be able to receive the benefits of implementation of elements such as dialysis time and/or DPI, while the community continues to debate the merit of the concept of LYFT in a revised kidney allocation system.

Committee vote: 11, 0 ,0.

4. Kidney Paired Donation (KPD)

In November, the Committee viewed a detailed presentation outlining the background, history and concepts incorporated in the Board approved KPD pilot program. During the discussion, members of the Committee expressed concern with regard to the proposed inclusion of factors in the kidney paired donation program that are known to disadvantage minority candidates, specifically awarding points for HLA and zero mismatch. These factors were deemphasized in the proposed new kidney allocation system and members questioned why they were being included in the KPD program. As a result, the committee requested to view the results of KPD computer simulations showing the percentage of minorities matched in the system that were eventually transplanted through KPD.

During the March meeting, Dr. Cherikh presented the Committee with data from the KPD simulations which showed that the additional points awarded for zero mismatch in the KPD system did not affect the number of minorities matched through the KPD system (**Exhibit C**). Dorry Segev, MD and Sommer Gentry, Ph.D, were both available via teleconference to respond to questions about the simulations. Though the simulations do not show a negative impact on minorities matched through KPD, it was remarked that minorities do not have the same access to the system due to their difficulty in locating a suitable living donor. It was suggested that the program would need to be monitored for accessibility due to its potential to increase transplantation rates for candidates enrolled in the system.

5. Issues Regarding Geographic Variation in Organ Allocation

The “Share 29” liver policy was implemented in Region 8 on 5/9/07. Under this allocation sequence, livers from adult donors would be shared regionally for adult and pediatric candidates, except for candidates with exceptions. At the March 27 meeting the MAC was presented waiting list death rates, number of transplants and graft survival by status or MELD/PELD category and ethnicity in Region 8 before and after the implementation of the Share 29 policy (**Exhibit D**). The data showed that after the implementation of the “Share 29” policy in Region 8:

- Death rates went down (27 vs. 24) for the overall black population.
- Death rates for Status 1A/1B decreased for all ethnicities.
- Death rates increased for all ethnicities in the Meld/PELD 15-28 group.
- Death rates decreased for the Black and Hispanic populations in the Meld/Peld 29+ group but increased for White candidates.
- Median MELD/ PELD score at transplant seemed to increase slightly in the Hispanic population after the implementation of “Share 29” policy in Region 8.
- Seven day graft survival rate seemed to decrease in the Black and Hispanic populations but remained comparable in the White population after “Share 29” policy implementation.

A member of the Committee remarked that once regional sharing was instituted, it appeared that the sick African American patients began receiving livers as a result. However, another member commented that the geographic areas studied in Region 8 did not have large minority populations and so even small changes in the numbers would show a large impact graphically. Further, the policy illustrated that the Share 29 experiment was not based on data showing the significance of MELD score 29 as a cut point, except for the predicted mortality at those scores in those centers studied. It was noted that this observation might not translate nationally. The member commented that the center effect should be studied to determine what happened to the centers in those regions in terms of volume.

The Committee also discussed the case mix before and after the policy change. Waitlist characteristics both pre and post transplant may have changed with different patients listed. The Committee previously viewed MELD at waitlist by ethnicity to determine if African Americans are sicker upon entering the waitlist. Following the discussion, the Committee requested to continue to be updated on characteristics of candidates and recipients, waiting list death rates, number of transplants and post-transplant survival, stratified by MELD/PELD scores and ethnicity, before and after Share 29 implementation.

6. Waiting List Mortality Rates for Pediatric Candidates by Ethnicity

The Committee became aware of an analysis showing that minority pediatric heart candidates had a higher likelihood of dying on the waiting list. The Minority Affairs Committee and the Thoracic Committee were contacted to provide comment on the study. The Thoracic Committee ultimately responded to the queries. The committee was advised that the cohort used for the analysis was prior to the revised heart allocation system implemented on July 12, 2006. Outcomes following the implementation of the revised heart allocation system have been examined by status and era; however, there has not been a comparison of outcomes by candidate ethnicity. The MAC is

interested in examining the issue to ensure that there were not any unintended consequences of the policy change. The Committee was provided with waiting list mortality rates and probability of waiting list outcomes for pediatric candidates since the policy change, stratified by candidate ethnicity (**Exhibit E**). Dr. Wida Cherikh presented the information to the Committee.

The data showed the following:

- There appeared to be no significant differences in death rates per 100 patient-years at risk for any of the ethnicity groups compared to White candidates, within medical urgency status or across all statuses in the post-policy era.
- In the pre-policy era there were no differences within medical urgency statuses.
- There appeared to be a slightly higher death rate pre-policy in the Blacks and Hispanics compared to Whites when all statuses were combined.
- But since there weren't any differences within status, this may have partially been a reflection of differences in distribution of medical urgency across the ethnicity groupings.
- There did not appear to be any significant differences in the probability of removal for death or too sick; the probability of removal for transplant; or the probability of removal for other reasons within 182 days of listing between the ethnicity groups pre- or post-policy.
- The same trend holds whether examining rates over all statuses or when stratified by initial medical urgency status.

The committee briefly discussed the analysis. It was suggested that the cohorts selected for the study were probably used to provide a large enough sample for analysis; however, because previous policies were in place at that time, different results were shown. It was remarked that it appeared as if the issue was already beginning to correct itself with implementation of the new policies.

7. Living Donation Issues

The MAC has been examining data that pertain to safety of living donation, particularly with respect to individuals who have donated their organ and ended up on the waiting list due to end stage organ failure. The Committee has been interested in determining if the rate of being placed on the waiting list within 5-6 years is higher for previous living kidney donors who are Black as compared to non-Black. Data was previously viewed showing that the rate of being on the waiting list was substantially higher for Black donors than White donors.

At the November 21, 2008 meeting the Committee was presented with information showing that the median age at donation and age at start of dialysis was younger for Black than White donors and the number of years from donation to dialysis was similar between Black and White donors. The Committee was interested in learning if the rate at which these African American donors are experiencing renal failure is what would be expected given their specific diagnoses. At the March meeting, the Committee reviewed the tabulation of the diagnoses that were reported in the CMS Medical Evidence (Form 2728) database (**Exhibit F**). The data showed that:

- Overall, there seemed to be more prior living donors reported with hypertension diagnosis at the time of dialysis, whereas diabetes was the most common diagnosis for overall waitlisted patients.
- Hypertension seemed to be a more common diagnosis for Black prior living donors who were subsequently placed on dialysis, or among Black waitlisted patients.

The Committee determined that until additional donors are added to the dataset the analysis is considered to be completed. The focus at this time should be to get the literature out into the public domain as the information may have some bearing on living donation efforts in the future.

8. Access to Transplantation

At the July 2004 meeting, the Committee reviewed an analysis the SRTR had prepared for the ACOT meeting in September 2003, regarding access to the heart waitlist among all patients with heart diseases. The waitlist rate was estimated by examining the population that died of causes related to heart failure, using national mortality data from the National Center for Health Statistics (NCHS) for deaths in 1998 of heart disease. During the March meeting, the Committee reviewed an update to the heart analysis using additional information supplied by the Committee (**Exhibit G**). Valarie Ashby, SRTR presented the information to the Committee. The data show the following:

- In 2004, the overall relative heart failure waitlisting ratio was about 0.015.
- All analyses showed that younger patients had higher ratios (0.105 under age 60) than older patients (0.003 over age 60).
- These analyses also suggest a two-fold or greater difference among regions.
- Ratios by sex and ethnicity are very different for all patients but similar for those under age 60.
- Analyses of data in prior years (1999 and 2001) showed similar results generally, with the notable difference of a large reduction in deaths for age 0-19 in 2004 versus 1999 and 2001.

At the next meeting, the Committee will review and updated analysis regarding access to the liver waitlist among all patients with liver failure for (a) acute and (b) chronic liver failure including more recent data.

9. Review of CPRA vs. PRA

Calculated PRA (CPRA) is a measure of candidate's sensitization level that is based on unacceptable HLA antigens listed for candidates. The goal of CPRA is to provide a more accurate and consistent measure of patient sensitization, and to improve the efficiency of organ allocation by reducing the number of predictably positive crossmatches. Because CPRA is obtained by determining the actual frequency of potential deceased donors who have one of more unacceptable antigens for a given transplant candidate, CPRA may benefit ethnic minority candidates who are sensitized to HLA antigens that are relatively common in the deceased donor population.

Phase I of the calculated PRA (CPRA) policy was implemented on 12/5/07 requiring centers to enter at least one unacceptable antigen in order for their highly sensitized patients (PRA \geq 80%) to receive the additional 4 points to receive deceased donor kidney transplant. The MAC has been reviewing the results of on-going Histocompatibility Committee analysis to monitor the policy by comparing CPRA and PRA by the old method and been presented with histocompatibility results by ethnicity (**Exhibit H**). During the March meeting, Dr. Cherikh presented an updated analysis to the Committee.

The data show that:

- 34% of the active registrations had CPRA values present, as compared to 27% of the inactive registrations.
- Black registrations were more likely to have CPRA present than all other ethnic groups, whether active or inactive.
- Concordance between Match PRA and CPRA seemed to increase as Match PRA values increased.
- Concordance rates seemed comparable for both White and Black registrations across all Match PRA groups.
- Across all ethnic groups, the median CPRA seemed to be higher than the median Match PRA for registrations with Match PRA of 0-20 and 21-79.
- Across all ethnic groups, the median CPRA seemed comparable with the median Match PRA for registrations with Match PRA of 80+.

The data did not appear to show major ethnic differences or patterns. The committee requested to continue to be updated on CPRA analysis by candidate ethnicity. Further, the determination of unacceptable antigens is an area that the committee will closely examine.

10. MAC Review Article

To support the MAC objective to build upon the body of evidence to improve minority access to transplantation, the Committee is preparing a comprehensive review of its work and the impact of OPTN/UNOS policy on minority transplantation. The Committee was informed that the initial subcommittee met and prepared a draft topic outline which has been submitted to the SRTR for review. The article has been revised to encompass one comprehensive article with three topic areas authored by present and past committee members focused on minority access to transplantation, minority organ donation trends and minority transplant outcomes. The Committee hopes to target the American Journal of Transplantation (AJT) for inclusion in the SRTR Annual State of Transplantation as a special interest article. A member of the committee expressed concern that the broad focus areas would present inadequate coverage of the topic areas and would not result in information that would be useful. He suggested that there could be several papers written on each of the three topic areas. It was responded that sometimes there is information that people believe is well-known in the community but which has not penetrated. The article could still provide important information to those outside of the transplant community.

Another committee member commented on the fact that changes in allocation policy will not address the underlying problem of the organ shortage, particularly for minorities who are overrepresented on the ESRD waiting list. It was responded that there is a need to continue to dispel the myths of organ donation and better inform the public about the strides that have been made in the minority community. It is not well known by the public that the actual rate of minority donation actually exceeds the ratio at which minorities are represented in the population. A message should be sent that the community's efforts are having an impact. Though the prevalence of ESRD in the minority community is much greater than in other populations, the burden should not be placed upon that population to match their representation on the waiting list. However, the message should be made clear that though we are experiencing some success, minority donation efforts should continue. The recognition of successes made in minority donation should complement efforts aimed at improving access to transplantation.

Another member remarked that HRSA continues to invest money in projects aimed at improving donation rates. It was also commented that there will be a forum at the National Medical Association (NMA) to address front line physicians regarding issues related to minority organ donation and transplantation to encourage them to become advocates. It was suggested that Ms. Parker forward the information about this meeting to the group when it is made available.

Discussion of Public Comment Proposals Distributed on October 10, 2008

The Committee briefly discussed the eight policy proposals being distributed for public comment. The Committee declined a formal vote noting that there did not appear to be an overt minority impact with regard to any of the proposals. The Committee did offer specific commentary on several of the proposals.

1. Proposed listing requirements for simultaneous liver-kidney transplant candidates (Policy proposed: 3.5.10 – Simultaneous Liver-Kidney Transplantation) (Kidney Transplantation Committee and Liver and Intestinal Organ Transplantation Committee)

The Committee observed that the proposal appeared to provide some safeguards for people experiencing liver failure where there had been no standards previously. The Committee also noted that the proposal could potentially improve minority access.

The Committee declined a formal vote citing that there was no overreaching minority impact from the proposal.

2. Proposal to create regional distribution of livers for Status 1 liver candidates (Policy affected: 3.6 - Allocation of Livers) (Liver and Intestinal Organ Transplantation Committee)

The Committee discussed the proposal in light of the Region 8 Share 29 presentation it viewed earlier in the meeting. Although the data showed that sick African Americans began receiving more transplants following implementation of Share 29, because Region 8 did not have a large African American population, the effect of slight changes in this small population may be inflated when shown graphically. Further, the significance of a MELD score of 29 has not been proven to be significant, except for the predicted mortality at that score in those centers studied. Members commented that the center effect had not yet been studied to determine if the observations shown in that region would translate nationally.

A member noted that there could be a minority impact if the larger centers were to receive the majority of organs, therefore forcing the smaller centers to close. Further, the increased travel could be an issue for some minority patients. The Committee noted that if the proposal were to pass, the Committee should monitor the policy for unintended negative effects on minority patients.

The Committee declined a formal vote citing that there was no overreaching minority impact from the proposal.

3. Proposal to create regional distribution of livers for MELD/PELD candidates (Policy affected: 3.6 – Allocation of Livers) (Liver and Intestinal Organ Transplantation Committee)

The Committee discussed the proposal in light of the Region 8 Share 29 presentation.

The Committee declined a formal vote citing that there was no overreaching minority impact from the proposal.

4. Proposal to standardize MELD/PELD exception criteria and scores (Policy affected: 3.6.4.5 – Liver Candidates with Exceptional Scores) (Liver and Intestinal Organ Transplantation Committee)

The Committee discussed the proposal briefly but declined a formal vote citing that there was no overreaching minority impact from the proposal.

5. Proposal to add the factors “current bilirubin” and “change in bilirubin” to the lung allocation score (LAS) (Policy affected: 3.7.6.1 (Candidates Age 12 and Older) (Thoracic Organ Transplantation Committee)

The Committee discussed the proposal briefly but declined a formal vote citing that there was no overreaching minority impact from the proposal.

6. Proposal to modify the high risk donor policy to protect the confidential health information of potential living donors (Policy affected: 4.1.1 - Communication of Donor History) (Living Donor Committee)

The Committee discussed the proposal briefly but declined a formal vote citing that there was no overreaching minority impact from the proposal.

7. Proposal to change the OPTN/UNOS Bylaws to clarify the process for reporting changes in key personnel (Bylaws affected: Appendix B, Section II,E (Key Personnel); Appendix B, Attachment 1, Section III (Changes in Key Personnel) (Membership and Professional Standards Committee)

The Committee discussed the proposal generally. A member of the Committee made specific mention of the requirement in Appendix A-III that centers report extended absences of the approved primary physician to the OPTN. It was noted that because UNOS does not allow more than one person to be certified as a primary physician at one time, smaller centers could be forced to deactivate their program if the primary physician was absent for more than two weeks. In light of the existing bylaw requirement, the additional paperwork being required could be a burden. It was also noted that this could be a minority issue depending on the demographics of the patient population at the center. It was suggested that UNOS should relax its qualifications in this regard.

The Committee declined a formal vote citing that there was no overreaching minority impact from the proposal.

8. Proposal to clarify, reorganize and update OPTN policies on OPO and transplant center packaging, labeling and shipping practices (Policy affected: 5.0 – Standardized Packaging, Labeling and Transporting of Organs, Vessels and Tissue Typing Materials) (Organ Procurement Organization (OPO) Committee)

The Committee discussed the proposal briefly but declined a formal vote citing that there was no overreaching minority impact from the proposal.

11. MAC Subcommittee on Referral to Transplantation

The MAC has been exploring ways to examine the factors related to referral rates and delays for patients getting onto the waitlist. Subsequently, the MAC formed a Subcommittee on Referral to Transplantation that is currently reviewing evidence and other activities being undertaken by centers geared toward increasing referral and wait listing rates.

During its March meeting, the Committee discussed a very preliminary draft list of questions to submit to transplant centers to inquire about any activities they may be performing to ensure that suitable patients are referred and evaluated for transplantation. The purpose of the questionnaire would be to identify best practices occurring in this area. After Committee discussion, several additional questions/issues were added to the list and will be refined when the subcommittee meets again.

Additional issues/questions that should be added included:

- Centers who are delaying referrals based on financial eligibility
- Centers where referrals are delayed based on ability to see the transplant surgeon

One committee member from North Carolina shared that her center is currently conducting a pilot program examining referral to listing time. The program emphasizes a specialized transplant education process. It was noted that the program has received positive feedback from patients and that referral rates in the center are rising. There was interest from the Committee in examining this program further, as well as programs operated in other localities.