

OPTN/UNOS Patient Affairs Committee

SUMMARY

I. Organ Availability Issues

Action Items for Board Consideration

- None

Other Significant Items

- The Committee offers an amendment to the proposed Policy language under 6.4.2 (Development Protocols in International Organ Exchange) for consideration by the Ad Hoc International Relations Committee. (Item 3, Page 7)

II. Patient Access Issues

Action Items for Board Consideration

- At its November 2003 meeting, the Board of Directors passed several broadly worded resolutions regarding patient education, multiple listing and transferal of waiting time. The Board is requested to approve and implement, pending programming, specific new policy language for Policies 3.2.2.2 (UNetSM Indication of Multiple Listing), 3.2.2.3 (UNetSM Notification of Transplantation or Death of Multiple Listed Patients), 3.2.2.4 (Non-acceptance of Multiple Listing and/or Transferal of Primary Waiting Time), and 3.2.3 (Waiting Time Transferal and Multiple Listing). (Item 7, Page 13)
- The Board is requested to approve and implement, pending programming, the creation of Policy 3.2.1.9 (Waiting Time Transferal) and modifications to Policy 3.2.2 (Multiple Listings Permitted). (Item 7, Page 13)

Other Significant Items

- The Committee received an update on a study regarding solid organ transplantation in HIV infected patients. (Item 6, Page 12)

III. Other Issues

Action Items for Board Consideration

- None

Other Significant Items

- The Committee fully endorses the creation of a Donor Affairs Committee. (Item 10, Page 16)

**Report of the
OPTN/UNOS Patient Affairs Committee
to the Board of Directors**

**Minneapolis, MN
June 24 & 25, 2004**

**Deborah Surlas, RN, Chair
David Burgio, MPA, LFACHE, Vice-Chair**

1. **Legislative Report.** William Lawrence, JD, UNOS Director of Patient Affairs addressed the Committee members on the role of the Director of Patient Affairs and informed the Committee that the position was created in order to have a constant presence and voice for patients and UNOS in Washington, D.C. The charge of the Patient Affairs Committee was discussed along with a brief summary of the OPTN Final Rule. A UNOS Update presentation was given. The presentation included 2004 deceased and living donor data, frequently asked questions, a policy compliance update and an update on the National Donor Memorial. The data presented show that since 1995 there has been an increase in patients waiting within each organ type, an increase in the number of deaths while waiting and a decrease in death rates while waiting. Data on issues such as causes of death for deceased donors, functional employment status pre- and post-transplant, and diagnoses of patients on the waiting list were also presented. The Committee was informed that UNOS is required to perform on-site audits of every transplant center and to verify allocation policy compliance. Although these policies are voluntary, every center has been complying with UNOS policy due to a general agreement amongst them in order to be able to do business and work together. According to the data presented, transplant centers are remarkably compliant.

The Committee discussed the Frist Donation Bill - S. 573 which passed the Senate on December 8, 2003. Highlights of the Bill include: creating an interagency task force on donation, grants to increase donation rates, donation public awareness programs, reimbursement of travel and subsistence expenses for needy living donors, a living donor registry authorized if the Health and Human Services (HHS) Secretary agrees and funding for Transplant Center and Organ Procurement Organization (OPO) cooperation. The Committee also discussed the Frist Minority Health Care Gap Bill - S. 2091, which was introduced on February 12, 2004. The major provisions of this politically controversial and expensive bill, which also includes non-transplantation provisions include: access and awareness grant programs; improved data collection and analysis; creation of HHS Office of Minority Health; promoting diversity in health care workforce through education, grants, etc.; promotes outreach efforts; and funds the Agency for Healthcare Research and Quality (AHRQ) and the National Institutes of Health (NIH) programs to identify sources of disparities and disseminate research results. The Committee was also informed that the National Institute of Allergy and Infectious Diseases (NIAID) Living Donor Registry concept has been approved and is requesting applications this year. This initiative will address survival and health outcomes of living donors, risk assessment for living donors, and medical care needs of living donors. The consortium will consist of centers with expertise in living donor transplantation that bring a substantial data set on living donors, and a data coordinating center. The objectives of this initiative are to establish a research consortium that will develop and implement a scientific agenda to address issues relevant to living organ (kidney, liver, lung) donors, including survival and health outcomes, risk assessment, and medical care needs and develop a database of existing registries and cohorts of living organ donors at transplant centers in the U.S. These data will be validated and include complete demographic, medical, and, where possible, immunologic data.

The Committee discussed immunosuppressive drug coverage under the current Medicare program, how the Medicare Drug Discount Card Program will impact coverage, and how coverage will be augmented by the full Medicare drug benefit in 2006. It was noted that benefits under the current and new law are dependent on Medicare eligibility. In order to be eligible for Medicare one must be at least 65 years old, disabled according to Medicare guidelines or have been diagnosed with ESRD. Starting in May 2004, people eligible for Medicare can sign up for a discount insurance card to help them with some drug costs. This temporary program will phase out when the second stage of assistance, a Medicare drug benefit, goes into effect in 2006. This optional discount card can save up to 10-15% on drug costs; you can only enroll in one Medicare-approved drug discount card each calendar year; and there is a fee for the card. Patients will need to research the benefits of each card in order to determine which one best suits their individual needs. Since each card does not necessarily cover each drug the patient may be taking, this can be extremely confusing to them. In addition, if a doctor changes to or prescribes a new drug that is not on the list for their particular discount drug card, the patient will need to pay the full cost for that drug. More information can be obtained by visiting www.medicare.gov.

2. Division of Transplantation. Richard Laeng, Program Analyst, Division of Transplantation (DoT), informed the Committee that the Final Rule established the Advisory Committee on Organ Transplantation (ACOT). The ACOT has done a great deal of work on living donor issues and the Secretary of the Department of Health and Human Services (HHS) has endorsed many of their recommendations. The ACOT meets twice a year. Summaries of the meetings can be reviewed at www.organdonor.gov. The Organ Donation Breakthrough Collaborative information is also available on the website.

There was a discussion of the Committee's resolution, approved by the Board of Directors in November 2003, to include prevention and health promotion issues in the ACOT's consensus recommendation #11. The Committee agreed that health promotion is extremely important in preventing some end stage organ failure and chronic diseases, which may in turn have a tremendous impact on the national wait list. The Committee noted that many deaths on the wait list can be prevented and money saved if prevention issues are addressed. Survival post-transplant is also related to better health. The Committee was informed that health prevention issues were also discussed at the Joint Commission on Accreditation of Hospitals Organizations (JCAHO) Organ Donation Roundtable.

The Committee viewed a 15-minute version of the HHS-funded Public Broadcast System documentary "No Greater Love," which was created to raise America's awareness of the critical need for organ and tissue donors. The film has won both a national Emmy from the Academy of Television Arts & Sciences and a Freddie Award from MediMedia USA in the category of community service.

3. Consideration of Policy Changes Proposed by Other Committees.

- (1) **Proposed Modifications to Local Voluntary Alternative System for Assigning Priority in Kidney Allocation to Original Intended Candidates for Living Donor Kidneys (Kidney and Pancreas Transplantation Committee)**

This proposal would clarify a previous proposal approved by the Board to create a generic alternative system that would provide priority in the kidney allocation system for original intended candidates (ICs) for living donor kidneys who are incompatible with their living donors due to crossmatch results or ABO blood type, when the living donors donate to candidates on the list of patients waiting for deceased donor kidneys. Under this proposal, when two ICs appear on a match run, the candidate with the earlier living donation date would be offered the organ first.

The Committee supports the proposed policy by a vote of 16-0-0.

(2) **Proposed Modifications to OPTN/UNOS Policies 3.5.3.3 (Mandatory Sharing) and 3.5.5 (Payback Requirements) (Exemption of Kidneys Recovered from Donation after Cardiac Death (DCD) Donors from Sharing Requirements for Zero Antigen Mismatched Kidneys or Payback) (Kidney and Pancreas Transplantation Committee)**

The Committee supports the exemption of Donation after Cardiac Death (DCD) donor kidneys from the requirements of the zero antigen mismatch kidney sharing policy, except at the local level of organ distribution, as well as, the kidney payback policy. OPOs would retain the option to offer DCD donor kidneys for payback, but would not be required to do so under the policy. The intent of the proposal is to place DCD donor kidneys as rapidly as possible to avoid adverse impacts from increased cold ischemia time, as well as, increase organ donation by providing an incentive for transplant centers to develop and enhance their DCD donor programs.

The Committee supports the proposed policy by a vote of 16-0-0.

(3) **Proposed Modifications to OPTN/UNOS Policy 3.5.5 (Payback Requirements) (“ECD Kidney Exemption from Payback Sharing Requirements”) (Kidney and Pancreas Transplantation Committee)**

The Committee supports the proposed modifications that would exempt expanded criteria donor (ECD) kidneys from the requirements of the kidney payback policy. OPOs would retain the option to offer expanded criteria donor kidneys for payback, but would not be required to do so under the policy.

The Committee supports the proposed policy by a vote of 15-0-0.

(4) **Proposed Modifications to OPTN/UNOS Policies 3.5.5.1 (Kidney/Non-Renal Organ Sharing) and 3.5.5.2 (Deferment of Voluntary Arrangements) (Kidney and Pancreas Transplantation Committee)**

The proposed modifications would increase the ABO blood group payback debt threshold from four to six in terms of an OPO’s ability to retain local kidneys or receive shared kidneys to be used in a simultaneous kidney-pancreas transplant. The intent of the proposal is to provide additional flexibility in the payback system and enhance opportunities to use both kidneys and the pancreas from donors.

The Committee is highly supportive of Policy changes that discourage any waste of organs and supports this policy change. There was discussion among the Committee as to why the debt limit is being increased to six instead of eight. One member suggested that increasing the debt limit to six would give the OPOs increased flexibility in managing their paybacks, yet maintain reasonable limits. It was noted that this new system will be monitored and adjustments made if adverse consequences are noted.

The Committee supports the proposed policy by a vote of 14-0-0.

(5) **Proposed Modifications to OPTN/UNOS Policies 3.5.5 (Payback Requirements) and 3.5.11.5.1 (Pediatric Kidney Transplant Candidates Not Transplanted within Time Goals) (Kidney and Pancreas Transplantation Committee)**

The proposed modifications, originally developed by the Joint Kidney and Pancreas, Pediatric Transplantation, Minority Affairs and Histocompatibility Subcommittee, would elevate the priority at the local level of organ distribution assigned to high scoring high panel reactive antibody (PRA) candidates and pediatric candidates who surpassed their transplant goals ahead of payback debts and credits. The Committee did, however, question the threshold for pediatric patients because they do not do as well on dialysis.

The Committee supports the proposed policy by a vote of 13-0-0.

(6) Proposed Modifications to OPTN/UNOS Policy 3.5.11.2 (Quality of Antigen Mismatch) (Kidney and Pancreas Transplantation Committee)

The Committee supports the proposed modifications, originally developed by the Joint Kidney and Pancreas, Pediatric Transplantation, Minority Affairs and Histocompatibility Subcommittee, that would increase from 2 to 6 the total allocation points awarded to pediatric candidates who have a zero DR mismatch with a standard criteria deceased kidney donor. The additional points would not apply in determining priorities among zero antigen mismatched patients, prior living organ donors, or patients listed with OPOs receiving kidney payback offers. The modifications also would not apply to expanded criteria donor (ECD) kidney allocation.

The Committee supports the proposed policy by a vote of 15-0-1

(7) Proposed Implementation Protocol for Modifications to OPTN/UNOS Policy 3.8.1.5 (Islet Allocation Protocol) (Kidney and Pancreas Transplantation Committee)

The proposal would determine how modifications to Policy 3.8.1.5 recently approved by the Board of Directors are to be implemented on the UNOS Computer. For pancreata identified for islet transplantation, waiting time would be used to designate the candidate for whom the first pancreatic islet offer would be made. The designated candidate's transplant center would then have the latitude in those situations where it is determined that the islet preparation is not medically suitable for that candidate, to determine the most medically suitable candidate from its waiting list. The islets would next be offered to the candidate with the longest waiting time at a transplant center(s) within the OPO (or other applicable local unit), if such candidate's transplant center shares an Investigational New Drug (IND) application with the center receiving the initial islet offer. If such a transplant center does not exist within the OPO (or other applicable local unit), the islets would be offered outside the local area to a transplant center(s) that shares in the IND. The intent of the policy is to better address the need for applying medical judgment in pancreatic islet transplantation decisions and avoid islet wastage.

There was discussion among the Committee as to how islet cells are spun down and pooled, that the islet cell yield cannot be determined prior to processing, and that individual candidates can require varying numbers of islet cells per injection. The Committee also discussed the fact that islet cell transplantation is still considered experimental, under FDA investigation and not covered by insurance. The Committee was very concerned about the possibility of abuse or even an innocent situation that could occur if a particular center has a candidate with a lengthy waiting time who needs a large islet yield. While that candidate might be constantly turned down due to unsuitable yields, the center would still pull all of the local blood type specific islet offers due to allocation based on waiting time alone.

In reference to the Board of Director's concerns that islets cells be allocated based on severity of medical need, the Committee felt that some standards should be in place as to the severity of hypoglycemic unawareness and life-threatening hypoglycemic events in candidates wait-listed for this procedure. Since allocation will occur based on waiting time, it was felt that diabetics only wishing to achieve insulin-free euglycemia but without severe hypoglycemic unawareness should not be listed for islet cell transplantation at this time.

The Committee strongly urges careful monitoring of this policy change by the Kidney and Pancreas Transplantation Committee and the Membership and Professional Standards Committee once implemented.

The Committee supports the proposed policy by a vote of 14-0-0.

(8) Proposed Modifications to OPTN/UNOS Policy 3.8.1.6 (Mandatory Sharing of Zero Antigen Mismatch Pancreata) (Kidney and Pancreas Transplantation Committee)

The proposed modifications that would eliminate requirements for sharing isolated pancreata for zero antigen-mismatched patients except for highly sensitized candidates, defined as candidates with panel reactive antibody (PRA) levels of 80% or higher. The Committee discussed the fact that data now demonstrates the limited benefit for pancreas after kidney (PAK) and pancreas transplant alone (PTA), relative to the substantial survival benefit of simultaneous pancreas-kidney (SPK) transplantation.

The Committee supports the proposed policy by a vote of 12-0-1.

(9) Proposed Modifications to OPTN/UNOS Policy 3.6.2.1 (Allocation of Blood Type O Donors) (Liver and Intestinal Organ Transplantation Committee)

This proposal, which was approved by the Board of Directors for implementation concurrent with public comment, would increase the threshold for allocation of blood type O donor livers to blood type B candidates from the current MELD/PELD score of 20 to a higher MELD/PELD score of 30. The current MELD/PELD score of 20 was found to be disadvantageous to O candidates who have the longest waiting time. Increasing the score should equalize the donor pool for both O and B candidates, while still helping the sickest B candidates, without affecting the death rate of either blood group.

The Committee supports the proposed policy by a vote of 16-0-0.

(10) Proposed Modifications to OPTN/UNOS Policy 3.6.2.1 (Allocation of Blood Type O Donors). (Liver and Intestinal Organ Transplantation Committee)

The Committee supports the proposal to allow any remaining blood type compatible candidates to appear on the match run list for blood type O donor livers after the blood type O and B candidate lists have been exhausted at the local, regional and national level. The Committee also agrees that this proposal should help to decrease wastage of organs.

The Committee supports the proposed policy by a vote of 16-0-0.

(11) Proposed Modifications to OPTN/UNOS Policy 3.6.4.4.1 (Adult Patient Reassessment and Recertification Schedule) and 3.6.4.2.1 (Pediatric Patient Reassessment and Recertification Schedule). (Liver and Intestinal Organ Transplantation Committee)

The proposal specifies that patients whose MELD/PELD scores are not re-certified within the proper time intervals by submission of lab test values will be reassigned their previous lower MELD/PELD score. The patient may remain at that previous lower score for the period allowed for that score minus the time spent at the uncertified score. If the patient remains uncertified past the new re-certification schedule, he/she will be downgraded to a MELD/PELD score of 6. Pediatric patients whose uncertified score is less than 6 would remain at that lower, uncertified PELD score. Under the current policy, some patients have remained at uncertified score levels indefinitely.

The Committee stressed the point that candidates need to be aware that recertification needs to be done and that they need to take ownership of getting their labs done. The transplant center must let the candidate know that there is a specific schedule that must be followed and that personal responsibility is necessary for a successful transplant process. The Committee agreed that it is not too much for a candidate to be expected to follow the directions of the transplant center and their physicians. There was concern among some Committee members that there may be a lack of communication between the center and the candidate.

The Committee supports the proposed policy by a vote of 16-0-0.

The Committee recommends that the Liver Committee further discuss a standardized method of communication between the transplant center and the patient/parents regarding the recertification of MELD/PELD scores by a vote of 16-0-0.

(12) Proposed Modifications to OPTN/UNOS Policy 3.6 (Adult Donor Liver Allocation Algorithm). (Liver and Intestinal Organ Transplantation Committee)

The Committee supports this proposal that would modify the sequence of allocation for adult donor livers such that organs would be allocated to local and regional candidates with MELD/PELD scores of 15 or higher prior to candidates with MELD/PELD scores less than 15. Eighteen month outcome data shows that patients with a MELD score lower than 15 had a higher relative risk of mortality if transplanted compared to similar patients who stayed on the waiting list. Transplanting patients with a score less than 15 when others have higher scores is not the best use of a liver, yet 21% of all adult livers are allocated to candidates with scores less than 15.

The Committee supports the proposed policy by a vote of 14-0-0.

(13) Proposed Modifications to OPTN/UNOS Policy 3.6.4.1 (Liver Allocation, Adult Patient Status) (Liver and Intestinal Organ Transplantation Committee)

The Committee opposed this proposal which would institute minimum listing criteria of a MELD score of 10 for adult candidates, with the exception of candidates meeting the requirements of Policy 3.6.4.4 (Liver Transplant Candidates with Hepatocellular Carcinoma) and 3.6.4.5 (Liver Candidates with Exceptional Cases). Patients with Stage T1 HCC could be listed with their laboratory MELD scores upon prospective agreement by the Regional Review Board. Patients listed at the time the policy is implemented whose MELD score is less than 10, as well candidates whose MELD scores fall below the threshold of 10 after appropriate listing, would not be removed from the list. The Committee understands that analyses of OPTN data indicate that there is no demonstrable benefit of transplantation below a MELD score of 10 during the first year post-transplant.

The Committee was concerned about the fact that many patients do better under the care of a transplant hepatologist but many insurance companies will not cover this care unless the patient is on the wait list for a transplant. The Committee was also concerned that MELD scores can change drastically. A patient with a MELD score of 6 can approach a MELD score of 15 very quickly. Valuable data might also be lost by not listing patients with MELD scores of 6. It was noted that it is rare for someone with a MELD score under 10 to be transplanted. There was concern that this may have an impact on minority patients and smaller transplant centers and that some patients that need to be listed might be overlooked. From a safety perspective, the Committee decided that the listing criteria should remain the same. The Committee would rather see a patient listed at a MELD score of 6 or greater but placed in a Status 7 until their MELD score reaches 10 or greater. This would ensure that these patients receive the specialized care they need, yet deter transplanting them at MELD scores below 10.

The Committee opposed the proposed policy by a vote of 0-16-0.

(14) Proposed Modifications to OPTN/UNOS Policies 3.6 (Pediatric Donor Liver Allocation Algorithm & Allocation Sequence for Patients with PELD or MELD Scores Less than or Equal to 6 (All Donor Livers)), 3.6.4.2 (Pediatric Patients Status), 3.6.4.2.1 (Pediatric Patient Reassessment and Recertification Schedule), and 3.6.4.3 (Pediatric Liver Transplant Candidates with Metabolic Diseases), 3.6.4.4.1 (Pediatric Liver Transplant Candidates with Hepatoblastoma). (Liver and Intestinal Organ Transplantation Committee)

Under the proposed modifications, adolescent liver candidates (age 12-17) would be assigned a MELD score rather than a PELD score. For the majority of adolescent liver candidates, a calculated MELD score offers an increase in allocation score and, thus, an increase in opportunity for transplantation. Based on the variables included in allocation score calculation in the MELD system, MELD scores may also offer a more accurate picture of mortality risk and disease severity for adolescent candidates.

Adolescents will, however, maintain pediatric status in the policy, including assigned priority for children in the allocation of pediatric donor livers.

The Committee supports the proposed policy by a vote of 14-0-0.

(15) Proposed Modifications to the Region 5 Status 1 Sharing Agreement (Liver and Intestinal Organ Transplantation Committee)

After discussion, the Committee supports the proposed changes to the Region 5 Status 1 sharing agreement that would eliminate the provision for payback for Status 1 liver shares, redefine criteria for Status 1 to better identify patients in urgent need, require retrospective review of all Status 1 listings, and evaluate the sharing agreement in 6 months and 1 year after implementation.

The Committee supports the proposed policy by a vote of 15-0-1.

(16) Proposed Modifications to OPTN/UNOS Bylaws Appendix B Attachment 1 (Standards for Histocompatibility Testing) Standard H3.100 and Proposed New Policies for Kidney Transplantation - 3.5.17 (Prospective Crossmatching), and for Pancreas Transplantation - 3.8.8 (Prospective Crossmatching), and Proposed Appendix D to Policy 3.

The proposed modifications to standard H3.100 of the Bylaws is intended to make the standard pertinent to laboratory practice. Concurrent with this modification, new policies 3.5.17 and 3.8.8 are proposed that are clinical practice policies and set out the conditions when a prospective crossmatch for kidney (3.5.17) and pancreas (3.8.8) organ transplantation is mandatory. The proposal also includes Guidelines for the Development of Joint Written Agreement between Histocompatibility Laboratories and Transplant Programs. The Committee is pleased to see more specific language on the circumstances when a crossmatch is required, especially for sensitized patients.

The Committee supports the proposed policy by a vote of 15-0-0.

(17) Proposed New OPTN/UNOS Policy 3.7.17 (Crossmatching for Thoracic Organs) (Histocompatibility Committee)

The Committee supports the proposed new policy 3.7.17 (Crossmatching for Thoracic Organs) that would require all thoracic organ transplant programs and their histocompatibility laboratory to have a joint written policy that sets out the circumstances when a crossmatch is necessary.

The Committee supports the proposed policy by a vote of 15-0-0.

(18) Proposed Modifications to OPTN/UNOS Policy 6.4 (Exportation and Importation of Organs – Developmental Status). (Ad Hoc International Relations Committee)

The Ad Hoc International Relations Committee proposes modifications to Policy 6.4 that would help to ensure the accuracy and fairness of organ allocation where organs are offered into the U.S. from foreign countries by requiring higher standards of verification from the foreign exporters. In addition, the proposed policy changes would ensure that imported organs would first be available to the OPO or transplant center that arranged to import them. The proposed changes to policy would require that:

1. Foreign donor organizations must provide verification of donor consent, brain death compliant with U.S. standards, and donor ABO.
2. Organ importers must obtain verification that foreign entities are medical centers authorized to export organs.
3. Imported organs will be first allocated locally to the OPO or transplant center that arranged the import, then according to UNOS policies applicable to that organ.

The Committee discussed the fact that more organs are exported than imported. Organs that are imported are currently coming from Canada, the Bahamas and Bermuda. Committee members strongly agreed that placement of these organs should be expedited and should first be allocated within the local area of the OPO or transplant center that made the arrangements for importation.

The Committee discussed informed consent on the part of potential candidates of organs imported from foreign countries and opined that any candidate being offered such an organ has the right to be informed of the origin of the organ and any safety or other concerns that might be involved and have the opportunity to accept or refuse the organ. Information that the candidate should receive could include concerns about increased ischemic time due to travel, potential unknown risks due to country-specific health conditions (such as viruses) for which testing might not be standard or available, the candidate's risk of dying if he/she did or did not accept the organ, etc. The issue of health conditions in other countries may not pose a significant problem at this time, but as more developing countries become involved in organ donation, the Committee would like to see this addressed, especially considering the fact that Chagas' Disease is endemic to Latin America and, in 2001, three transplant recipients were infected with this parasite after receiving organs from a Latin American immigrant donor who was presumably also infected with Chagas. One of the recipients died of Chagas myocarditis.

The Committee felt that that, in order to provide the safest and best quality organs for transplant candidates; imported organs should be held to the same standards as those procured in the United States. Therefore, the members felt that Policy 6.4.2 should state that proposed protocols must include a requirement that donor organs for importation must follow similar standards, wherever possible, to those addressed in Policies 5.2-5.5 (Standardized Packaging and Transporting of Organs and Tissue Typing Material), Policies 2.2 (Evaluation of Potential Donors), 2.3 (Donor Management) and 2.5 (Organ Procurement Quality). Since organs that are exported from the United States have initially been offered to candidates in the U.S., the Committee felt these standards would already be met and did not need to be re-addressed in Policy 6.4.

In addition, the Committee requested that, on a case-by-case basis, protocols be developed to incorporate country-specific testing on donors in situations where standard testing may not diagnose a health condition that may be prevalent in another country and could be transmitted through organ donation, such as a virus, bacterium or parasite (such as Chagas' Disease).

The Committee voted against the proposed policy as written by a vote of 13-1-1.

The Committee offers the following amendment (in double underline) to the proposed modifications to Policy 6.4.2 (Developmental Protocols in International Organ Exchange) for consideration by the Ad Hoc International Relations Committee:

6.4 EXPORTATION AND IMPORTATION OF ORGANS-DEVELOPMENTAL STATUS.

International exchange of organs for transplantation is technically feasible but remains an uncommon procedure. UNOS regards international sharing of organs to be in an early phase of development.

6.4.1 Exportation. Exportation of organs from the United States or its territories is prohibited unless a well-documented and verifiable effort, coordinated through the UNOS Organ Center, has failed to find a suitable recipient for that organ on the UNOS Waiting List.

6.4.2 Developmental Protocols in International Organ Exchange. After prior approval by UNOS, UNOS members may enter into formal organ exchange arrangements, each not to exceed two years in duration, with a foreign transplant program or programs. Negotiations with foreign transplant programs or foreign agencies, which include importing organs, must be approved by the Ad Hoc Foreign Relations Committee. Importation of organs is defined in Policy 6.4.5 (Importation). Proposed protocols must be submitted to UNOS describing the basis for such arrangements, expected benefits to both foreign and domestic participants, credentials of the foreign source, number and type of organs anticipated to be

involved, and plans for allocation procedures and reporting of results. Proposed protocols must include a requirement for the donor organization to submit documentation certifying the informed consent of the donor of his or her legal representative. Proposed protocols must also include a requirement for the donor organization to submit documentation certifying that the donor has met the brain death protocols that are in compliance with recognized U.S. standards for domestic organ procurement. Proposed protocols must include a requirement for the donor organization to submit documentation of the donor's ABO. Proposed protocols for importation must incorporate similar standards, wherever possible, to those addressed in Policies 5.2-5.5 (Standardized Packaging and Transporting of Organs and Tissue Typing Material), 2.2 (Evaluation of Potential Donors), 2.3 (Donor Management), and 2.5 (Organ Procurement Quality). On a case-by-case basis, proposed protocols must incorporate country-specific testing on donors in situations where standard testing may not diagnose a health condition that can be transmitted through organ donation. Proposed protocols must include a requirement that potential recipients of imported organs must be informed of the origin of the organ offer and any potential risks and given the opportunity to accept or reject the organ in a timely manner pre-transplant. Proposed protocols will be reviewed by the UNOS Ad Hoc Foreign Relations Committee, which will then make recommendations to the Board of Directors.

6.4.2.1 All foreign organ exchanges must be reported within 72 hours to the UNOS Organ Center. All exchanges must satisfy UNOS policy that no organs can be exported from the United States without first a determination having been made by the UNOS Organ Center that there is no suitable recipient for that organ on the UNOS Waiting List. ~~All imported organs will be allocated according to UNOS policies.~~ All imported organs will be allocated first to the OPO or transplant center that arranged the importation of the organ. If the OPO or transplant center cannot use the organ then it must be allocated according to the UNOS policies that apply to that organ.

6.4.2.2 All approved international organ exchange protocols will be reviewed at least annually by the UNOS Ad Hoc Foreign Relations Committee. Any additional policies regarding international exchange agreements will be developed by the Committee based on experience acquired pursuant to approved developmental protocols. It is a goal of UNOS that international exchange of organs between UNOS members and foreign programs will foster the development of international organ sharing. It is hoped that such exchanges will occur through the regular national OPTN system, after feasibility has been established.

6.4.2.3 Importation of an organ for human transplantation in the United States is appropriate only if the foreign source is a UNOS recognized source. A UNOS recognized source is an organ transplant center or organ procurement program specifically authorized as a transplant center or organ procurement program by an appropriate agency of its national government. The OPO or transplant center responsible for importation of an organ must obtain official documentation from the exporting party that is a medical center authorized to export organs for transplantation.

[NO FURTHER CHANGES TO POLICY 6.4]

(19) Proposed Guidelines for Living Liver Donor Evaluation and Proposed Guidelines for Living Kidney Donor Evaluation. (Ad Hoc Living Donor Committee).

The Committee supports this proposal that would establish specific guidelines for potential living kidney and liver transplant recipient and donor evaluation, including provisions for an independent donor team, psychiatric and social screening, and appropriate medical, radiologic, and anesthesia evaluation. The Committee understands that while these are not being proposed as Policy, the Ad Hoc

Living Donor Committee believes that the guidelines could evolve into the standard of practice for living donor evaluation.

The Committee felt strongly about the fact that there needs to be a person that does not work with the transplant team who is looking out for the best interests of the donor. This person needs to be part of the medical staff but who does not work directly with the recipient. The Committee stressed the fact that the donor should never feel pressured to donate. It is important to remember that living donors are patients and have the right to proper medical care. The Committee suggested that the living donor may feel better about the donation if they are cared for on the transplant unit rather than moved to a different floor. Some committee members discussed the difference in psychological needs of living related and non-related donations.

The Committee discussed the section of the policy that states that a “dedicated medical social worker familiar with transplantation and living donation should evaluate the potential donor for...” The Committee agreed that there was no need to specify who the person is in this case. They felt it is more important to have an individual who knows the dynamics and ramifications of transplantation. Some members stated that a psychiatrist may pick up on emotional issues but may not understand social aspects of transplants. Other members thought a psychologist or psychiatrist or others with similar training and education could also do the job equally as well.

The Committee supports the proposed policy by a vote of 16-0-0.

(20) Proposed Guidelines for Living Kidney Donor Evaluation (Item 2 of 2) (Ad Hoc Living Donor Committee)

The Committee supports this proposal that would establish guidelines for evaluation of potential living kidney transplant recipients and donors, and includes recommendations for an independent donor team, psychiatric and social screening, and appropriate medical, radiologic, and anesthesia evaluation. The Committee understands that while these are not being proposed as Policy, the Ad Hoc Living Donor Committee believes that the guidelines could evolve into the standard of practice for living donor evaluation.

The Committee supports the proposed policy by a vote of 16-0-0.

(21) Proposed Modifications to OPTN/UNOS Policy 3.1.4 (Patient Waiting List) (Ad Hoc Operations Committee)

The Committee supports the Ad Hoc Operations Committee in seeking public comment on new and modified policies for listing transplant candidates on the national waiting list. The proposed policies address: processes for ensuring the accuracy of a transplant candidate's ABO type on the waiting list; requiring transplant centers to enter and maintain transplant candidate data electronically using UNetsm; requiring transplant candidate ABO typing on two separate occasions prior to listing; and listing transplant candidates with their actual ABO type.

The Committee supports the proposed policy by a vote of 15-0-0.

(22) Proposed Modifications to OPTN/UNOS Policy 3.2.3 (Match System Access) (Ad Hoc Operations Committee)

The Committee supports the Ad Hoc Operations Committee in seeking public comment on modifications to Policy 3.2.3, (Match System Access). The proposed modifications would require two separate determinations of the donor's ABO type prior to initiating the organ recovery incision, and more specific policy language for the process of distributing organs using the match.

The Committee supports the proposed policy by a vote of 15-0-0.

- (23) **New OPTN/UNOS Policy 3.4.7 (Allocation of Organs During Regional/National Emergency Situations), 3.4.7.1 (Regional/National Transportation Disruption), and 3.4.7.2 (Regional/National Communications Disruption) (OPO Committee)**

The Health Resources Services Administration (HRSA) has requested the OPTN to develop policies for maintaining the organ matching and allocation process during times of regional or national emergencies that compromise telecommunication, transportation, or the function of or access to the wait list or matching system. UNOS staff drafted the proposed policies for consideration by the OPO Committee. The policy was approved by the Board of Directors and became effective December 22, 2003, concurrent with public comment.

The Committee supports the proposed policy by a vote of 16-0-0.

- (24) **Proposed Modification to the Criteria for Institutional Membership, OPTN/UNOS By-Laws, Appendix B, Section III (C) (Transplant Programs): Proposed Modifications to Item (15) (Social Support) (Transplant Administrators Committee)**

The Committee supports the Transplant Administrators Committee in proposing a modification that delineates a transplant program's specific responsibilities in providing psychiatric and social support services (psychosocial services) for transplant candidates, recipients, living donors, and family members. Individuals trained in psychiatry, psychology or social work may provide these services. These individuals should be designated members of the transplant team, and work with patients and families in a compassionate and tactful manner in order to facilitate access to and continuity of care.

The Committee supports the proposed policy by a vote of 16-0-0.

- (25) **Proposed Modification to the Criteria for Institutional Membership, OPTN/UNOS By-Laws, Appendix B, Section III (C) (Transplant Programs): Proposed New Item (20) (Clinical Transplant Pharmacist) (Transplant Administrators Committee)**

The Committee supports the Transplant Administrators Committee in proposing a change to the By laws that delineates the specific responsibilities of a clinical transplant pharmacist in an active transplant program. The goal of the proposal is to provide additional detailed information about the essential care provided by pharmacists and teams led by pharmacists, in an effort to assure that this care remains available to transplant recipients and the transplant team. The Committee understands that it is not the Transplant Administrators Committee's goal to create a membership requirement on par with the primary physician or surgeon.

The Committee understood this proposal to say that pharmacists should provide the education to the patients and thought this might be a burden on many transplant centers. Some centers have pharmacists that do only patient education rather than dispense drugs. Some centers have a pharmacist that doesn't have everyday interaction with patients but does educate nurses and physicians on medications, who in turn educate their patients. Understanding that this Bylaw addition is a suggestion and not a requirement, the Committee was pleased with the proposal as it defines the role of the clinical transplant pharmacist better and may help facilitate education within transplant centers.

The Committee supports the proposed By-Law by a vote of 16-0-0.

- (26) **Proposed Modifications to OPTN/UNOS Policy 3.7.6 (Status of Patients Awaiting Lung Transplantation), Policy 3.7.9 (Time Waiting for Thoracic Organ Candidates), Policy 3.7.9.2, (Waiting Time Accrual for Lung Candidates with Idiopathic Pulmonary Fibrosis (IPF), and Policy 3.7.11 (Allocation of Lungs). (Thoracic Organ Transportation Committee)**

This policy proposal, presented by the Thoracic Organ Transplantation Committee would replace the current lung distribution algorithm found in current Policy with a new system that would allocate lungs

to transplant candidates based on their risk of dying on the waitlist and their possibility for survival following the transplant. The goals of the new system are to reduce the number of deaths on the waitlist, increase the transplant benefit among lung transplant recipients, and ensure efficient and equitable use of the scarce resource of donor lungs. The Committee supports the revisions made to the earlier version of the lung allocation algorithm that was first proposed in August 2003 and is pleased to see a policy based not only on medical urgency, but also on post-transplant survival. The Committee further understands that this system will be monitored and refined as additional data becomes available, much as the MELD/PELD system has been.

Patient education on the MELD/PELD system was started long before the system was implemented and helped tremendously in alleviating anxiety and fear in the patient community of a sudden change in the system they knew. The Committee strongly encourages early education of patients regarding this proposed Lung allocation system.

The Committee supports the proposed policy by a vote of 16-0-0.

4. ALU and Variance Requests.

- Mid-America Transplant Services – Midwest Transplant Network Missouri Statewide Liver ALU

The Committee was given a brief history of the proposed ALU, wherein after Regional Status 1 allocation, livers recovered from donors in Missouri would be allocated first to centers in the procuring OPO's local area, then to centers in the remaining Missouri OPO's local area, then to the remainder of Region 8 and then Nationally. The Committee agreed that from a patient perspective this makes sense because it equalizes waiting time between the two OPO service areas (median wait time of 37.2 months in St. Louis versus 2.2 months in Kansas City) and would decrease wait list mortality due to geography and demographics.

It was noted that if this ALU does not pass, Missouri would pass a state law to keep all donated organs within the state.

The Committee supports the proposed ALU by a vote of 16-0-0.

5. National Donor Memorial Update.

Walter Graham, UNOS Executive Director, provided an update on the National Donor Memorial located at the UNOS headquarters in Richmond, VA. The Committee members were given a special edition of the UNOS Update magazine dedicated entirely to the National Donor Memorial. The UNOS Information Technology Department is creating a "virtual wall," which will be unveiled at the June 2004 APOPO meeting.

6. Solid Organ Transplantation in HIV: Multi-Site Study.

Deborah Surlas, RN, Chair, provided an update on the Solid Organ Transplantation in HIV: Multi-Site Study. As a result of highly active and antiretroviral therapy (HAART), people with HIV are living longer and dying less often from HIV/AIDS-related complications. Liver failure is an increasingly important cause of death among HIV-infected individuals. People with kidney failure are also living longer, and as a result are increasingly vulnerable to complications of chronic dialysis. Therefore, it is important to understand the unique risks associated with solid organ transplantation in HIV-infected individuals and to develop effective strategies to optimize transplant outcome.

This is a prospective, multicenter study of HIV-infected people who undergo solid organ transplantation. The study is sponsored by the Division of AIDS and of the National Institute of Allergy and Infectious Diseases. The study will evaluate the safety and efficacy of liver and kidney transplants in HIV-infected adults and children. Eligibility will be based on standard clinical criteria for transplantation and the specific criteria for this study. There are currently 17 activated sites participating in the study. Twenty-four patients (14 liver and 10 kidney) have been enrolled and 8 of them (5 liver and 3 kidney) have been transplanted. To date, there have

been no graft failures or deaths. The Committee agreed that a great deal of patient and physician education needs to be done. In order to prevent miseducation among the general population, the Committee agreed that the transplant centers involved in the study need to involve their OPOs, as they may also be a source of additional education. OPOs need to be prepared to discuss this issue from a media standpoint in order to clarify the issues because HIV is often misunderstood and stigmatized. The Committee suggested that media issues, press releases and articles be included on the study's website (spitfire.emmes.com/study/htr). The Committee understands the need to make the distinction that these are people with HIV and not full-blown AIDS. Most of these people are dying from end stage organ failure as opposed to HIV. The Committee stressed the importance of fully informing living donors that the recipient will be HIV positive. These patients are put on the national list and allocated organs the same as every other candidate.

Committee members were encouraged to refer HIV patients to the EMMES website for contact information on centers involved in this study. Members will also be provided with materials to include in any web sites or patient groups they may be involved with to help disseminate information about this study.

7. Discussion of multiple listing/transferring waiting time Q&A draft.

Deborah Surlas, RN, Chair, informed the Committee that the Board of Directors accepted four multiple listing resolutions presented by the Committee during the November 2003 meeting. Two of these resolutions stressed the importance of more patient education. As a result, the UNOS Communications Department drafted a version of an educational brochure entitled "Multiple Listing, Transferring Care, Transferring Waiting Time Q&A." After reviewing the draft, Committee members suggested that there might need to be a brochure to educate transplant centers as well. The Committee stressed that the accountability to multiple list is on the patient and not the transplant center and this needs to be included in the brochure. The Committee also suggested that the brochure needs to let patients know that not all centers allow patients to multiple list and/or transfer their accrued waiting time.

During the discussion, the Committee was unclear as to why it may appear that policies are followed by transplant centers and others are not, such as a center denying a patient the ability to multiple list at that center. The Committee was concerned that there are many gray areas, which may be sending mixed messages to patients, some of whom may already distrust the system. Walter Graham explained to the Committee that there are policies that are "permissive" and other policies that are mandatory.

The following resolutions were passed by the Board of Directors in November 2003:

- **RESOLVED, that the OPTN/UNOS develop a system so that centers are aware that a patient is multiple listed, but not disclose the name of the other center/s at which the patient is also listed, effective November 21, 2003.
- **RESOLVED, that transplant centers should be notified when a multiple listed patient has been transplanted at another center so that they can be removed from all other center's waiting lists so as not to delay organ placement, effective November 21, 2003.
- **RESOLVED, that every transplant program that does not accept multiple listed patients and/or does not allow these patients to transfer their primary waiting time to that center if the patient so desires, must fully inform the patient during their evaluation or sooner, effective November 21, 2003.
- **RESOLVED, that every transplant program must inform every patient about the options of multiple listing, transferring primary waiting time, and the option to transfer their care to another transplant center without loss of accrued waiting time, during the evaluation process and maintain documentation that this was done and provide the patient written material on these options, effective November 21, 2003.

The Committee unanimously recommends the following resolution for consideration by the Board.

****RESOLVED**, that the new language of Policies 3.2.2.2 (UNetSM Indication of Multiple Listing), 3.2.2.3 (UNetSM Notification of Transplantation or Death of Multiple Listed Patients), 3.2.2.4 (Non-acceptance of Multiple Listing and/or Transferal of Primary Waiting Time) and 3.2.3 (Waiting Time Transferal and Multiple Listing) indicated by double underlined text, which were approved in concept by the Board at its November 2003 meeting, and shall be approved and implemented pending programming on the UNOS System.

3.2.2.2 UNetSM Indication of Multiple Listing. Transplant centers will be notified through UNetSM that patients are multiple listed, but will not be notified of the identities of other centers at which the patients are listed.

3.2.2.3 UNetSM Notification of Transplantation or Death of Multiple Listed Patients. Transplant centers will be notified through the UNET system when a multiple listed patient has been transplanted or reported as deceased by another center so that all other centers involved can investigate and request removal of the patient from the center's waiting list.

3.2.2.4 Non-acceptance of Multiple Listing and/or Transferal of Primary Waiting Time. Every transplant program that does not accept multiple listed patients and/or does not allow these patients to transfer their primary waiting time to that center if the patient so desires, must fully inform the patient during the transplant evaluation process or sooner.

3.2.3 Waiting Time Transferal and Multiple Listing. Every transplant program must inform every patient about the options of multiple listing, transferring primary waiting time, and the option to transfer their care to a different transplant center without loss of accrued waiting time, during the evaluation process, provide the patient with written material on these options, and maintain documentation that this requirement was fulfilled.

3.2.34 Match System Access. [NO CHANGES TO POLICY TEXT]

NOTE: The amendments to Policy 3.2.34 (Match System Access) shall be implemented following programming on the UNOS system.

3.2.34.1 Removal of Kidney Transplant Candidates from Kidney Waiting Lists When Transplanted or Deceased. [NO CHANGES TO POLICY TEXT].

3.2.34.2 Waiting Time Reinstatement for Kidney Recipients. [NO CHANGES TO POLICY TEXT]

3.2.45 Preliminary Stratification. [NO CHANGES TO POLICY TEXT]

3.2.56 Waiting Time for Patients in an Inactive Status. [NO CHANGES TO POLICY TEXT].

3.2.67 Pancreas Waiting List Criteria. [NO CHANGES TO POLICY TEXT]

3.2.78 Combined Kidney-Pancreas Waiting List Criteria. [NO CHANGES TO POLICY TEXT]

3.2.89 Waiting Time Adjustment for Patients Needing a Life-Saving Organ Transplant When the Need for a Second Organ Transplant Arises. [NO CHANGES TO POLICY TEXT]

The Committee also discussed patients who wish to change transplant centers and move their accrued waiting time to a new transplant center. Committee members were concerned that many patients are afraid that if they wish to move their care to a different transplant center that they will lose their accrued waiting time. Although this is common practice, there is no policy to address this issue other than what is noted under Policy 3.2.2 (Multiple Listings Permitted). Therefore, the Committee unanimously recommends the following resolution for consideration by the Board.

****RESOLVED, that new Policy 3.2.1.9 (Waiting Time Transferal) and modifications to Policy 3.2.2 (Multiple Listings Permitted), as set forth below in double underlined text, shall be approved and implemented pending programming on the UNOS System.**

3.2.1.9 Waiting Time Transferal. For the purpose of this policy, "primary waiting time" shall mean the longest time period a patient listed on the Patient Waiting List has been waiting for a specific organ transplant procedure, after having met qualifying criteria to accrue waiting time for that organ. A patient may transfer his/her primary waiting time from one transplant center (Initial Primary Center) to another center (New Primary Center) upon listing of the patient as a transplant candidate by the New Primary Center. After receipt of a UNOS Wait Time Transfer Form, the date the patient first met waiting time criteria (the date from which primary waiting time will be calculated) at the New Primary Center will be modified in the computer system by the UNOS Organ Center as the date the patient met waiting time criteria at the Initial Primary Center. Subsequent to the receipt of this request, the patient is to be deleted from the Patient Waiting List of the Initial Primary Center. A notice of the primary waiting time transfer will be sent from the UNOS Organ Center to each of the centers involved.

3.2.2 Multiple Listings Permitted. Patients may be listed on multiple transplant centers local Waiting Lists. Each such multiple local listing may be added to the UNOS Patient Waiting List so that the same patient may be listed on the UNOS Patient Waiting List multiple times. However, transplant centers may not list the same patient on more than one organ procurement organization's patient waiting list.

3.2.2.1 Waiting Time Transferal for Multiple Listed Patients. For the purpose of this policy, "primary waiting time" shall mean the longest time period a patient listed on the UNOS Patient Waiting List has been waiting for a specific organ transplant procedure, after having met qualifying criteria to accrue waiting time for that organ. A patient may transfer his/her primary waiting time from one transplant center (Initial Primary Center) to another center (New Primary Center) upon listing of the patient as a transplant candidate by the New Primary Center. After receipt of a Wait Time Transfer Form ~~written request from the patient which states the patient's intention to transfer his/her waiting time,~~ the date the patient ~~s~~ met waiting time criteria listing date (the date from which primary waiting time will be calculated) at the New Primary Center will be ~~entered~~ modified into the computer system by the UNOS Organ Center as the date the patient ~~was listed~~ met waiting time criteria at the Initial Primary Center. ~~This request must be signed by the patient, a legal guardian, or other individual having the power of attorney to act on the patient's behalf. Subsequent to the receipt of this request, the patient is to be deleted from the Waiting List of the Initial Primary Center as well as from the UNOS Patient Waiting List for the Initial Primary Center unless the patient elects to be listed at both centers. If the patient elects to be listed at both the New Primary Center and the Initial Primary Center, the~~ The patient will be assigned a new listing primary waiting time date in the UNOS Patient Waiting List computer record for the Initial Primary Center which corresponds with either the date on which the waiting time adjustment form is received by UNOS or the date on which the patient is listed at the New

Primary Center, ~~whichever is earlier~~. A ~~written~~ notice of the primary waiting time transfer will be sent from the UNOS Organ Center to each of the centers involved.

8. Patient and Professional Education.

Amanda Pfeiffer, MSW, UNOS Staff, updated the Committee on the Ad Hoc Living Donor Quality of Life Subcommittee. Several Committee members are also members of the Subcommittee. The Committee was informed that a proposal and budget have been drafted for the creation of a living donor resource center as well as a Quality of Life Survey, which will be sent to living donors 6 months post-donation. Both of the proposals and budget will be sent to the Department of Transplantation for review for funding.

9. Discussion of JCAHO living donor pamphlet “Preparing to be a living organ donor.”

The Committee reviewed and discussed the Joint Committee on Accreditation of Hospital Organizations (JCAHO) living donor pamphlet “Preparing to be a living donor.” Overall, the Committee approved the pamphlet. Questions were raised, however, as to whether or not a potential living donor would understand what JCAHO’s Universal Protocol for Preventing Wrong Site, Wrong Procedure and Wrong Person Surgery is. The Committee agreed that there should be clarification on the “questions regarding medications.” There was concern that there was very little mentioned about work and other quality of life issues in the long term. The Committee suggested that the pamphlet make it very clear that a potential donor has the ability to “back out” or change their mind once they have already made the decision to donate.

10. Discussion on a Committee name change and potential creation of a Donor Affairs Committee.

Deborah Surlas, RN, Chair, provided background for discussion. At the November 2003 Board of Directors meeting, the Board rescinded its resolution changing the name of the Patient Affairs Committee to the Candidate Donor Recipient Committee and the title of the Vice President of Patient and Donor Affairs to the Vice President of Candidate Donor Recipient Affairs and reaffirmed that the name Patient Affairs Committee, and the title Vice President of Patient and Donor Affairs remain unchanged. There was also discussion at the board meeting about the creation of a Donor Affairs committee. Walter Graham, UNOS Executive Director, addressed the Committee and discussed his vision for the potential Donor Affairs Committee. It was stressed that the Donor Affairs Committee would not address the same issues as the Patient Affairs Committee, as many donor family members on the Board have expressed the desire to create a group to promote organ donation. The Committee agreed on the importance of maintaining the same make-up of the current Patient Affairs Committee. The Committee agreed that OPO’s already have a difficult time creating a common force and caution that a donor affairs committee should not go off on another tangent that OPO’s have also worked on. There would need to be communication between the new committee, OPOs and the Coalition on Donation. The Committee suggested that the Coalition and the DoT have a permanent seat on the committee. It was also suggested that recipients also be included on the committee.

The Patient Affairs Committee fully endorses the creation of a Donor Affairs Committee.

OPTN/UNOS Patient Affairs Committee Meeting
April 19 & 20, 2004
Chicago, IL

Committee Members Attending

Deborah Surlas, RN	Chair, Region 7 Representative
David Burgio, MPA, LFACHE	Vice-Chair, Region 11 Representative
Claude Young	Region 1 Representative
Rosalie Lopez	Region 2 Representative
Brenda Dyson	Region 3 Representative
J. Anne Whiting	Region 4 Representative
Richard Valli	Region 5 Representative
Judy W. Clark	Region 6 Representative
Kim Kottemann	Region 8 Representative
Jean Shumaker	Region 10 Representative
Jerry Butler	At-Large Member
Katherine Evers	At-Large Member
Bobby Howard	At-Large Member
Balaji B. Singh, PhD	At-Large Member
Howell (Tommy) Thompson	At-Large Member
Harlan I. Wright, MD	At-Large Member

Committee Members Unable to Attend

Barbara D. Musto	Region 9 Representative
James H. Clark, III, MD	At-Large Member

Ex-officio Members

Richard Laeng, MPH, Division of Transplantation

Guests Attending

Paul Oldam, Vice President of Patient and Donor Affairs, OPTN/UNOS Board of Directors
Rose Marie Gray-Finnell, OPTN/UNOS Board of Directors
Josh McGowan, SRTR/URREA Research Associate

UNOS Staff Attending

Walter Graham, UNOS Executive Director
William Lawrence, JD, Director of Patient Affairs
Alan Ting, PhD, Director, Research Department
Beverley Trinkle, UNOS Patient Services Coordinator
Amanda Pfeiffer, MSW, Staff Liaison