9.0 RELEASE OF INFORMATION TO THE PUBLIC.

The following policies address information which the Executive Director and his or her staff are permitted to release to the public:

9.1 MAILING LISTS. Lists showing members' or Program Directors' names and addresses, and/or telephone numbers may be released, **ONLY** if (a) the Executive Director deems the request to be for a legitimate, non-commercial purpose furthering the objectives of the OPTN, and (b) the OPTN contractor receives an executed agreement restricting the use of the information for the permitted purpose.

9.2 DATA. Composite demographic national, regional or state data currently provided to HRSA through the OPTN Contract such as the following may be released:

9.2.1 The number of transplant recipients, according to organ type, race, ABO blood group, gender, and age.

9.2.2 The number of candidates on the Waiting List according to organ type, race, ABO blood group, gender, and age.

9.2.3 The number and disposition of organs retrieved.

9.3 ORGAN CENTER DATA. Composite Organ Center information such as the following may be released:

9.3.1 The number of organs allocated through the Organ Center.

9.3.2 Data reflecting Organ Center Activity (See Policy 9.6).

9.3.3 The number and final destination of kidneys placed internationally through the Organ Center.

9.4 SHARING ARRANGEMENTS. The names of institutions participating in interregional or intraregional sharing arrangements approved by the Board of Directors may be released.

9.5 MEMBERS. Listings of member institutions (including names of personnel) may be released.

9.6 PUBLIC RELEASE OF CENTER AND OPO ACTIVITY. Without obtaining permission from each member, the OPTN may release analysis results containing the following data:

9.6.1. Updated Center-specific waiting list activity, by organ type, including the number of candidates on the waiting list at the initiation of a period; the number of candidates added to the list; and the number of candidates removed from the list for death, transplant, and other reasons and, to the extent relevant to the organ type, the probability of survival on the waiting list within a specific period of time stratified by demographic and medical factors as determined appropriate by the Policy Oversight Committee (POC). These data may be presented on a calendar year basis and for such portions of a calendar year as determined by the POC. Updated Center-specific waiting list size, by organ type, stratified by demographic and medical factors as determined appropriate by the POC.

9.6.2 Updated Center-specific or OPO-specific waiting time information, by organ type, stratified by demographic and medical variables as determined appropriate by the POC, and the probability of receiving a transplant within a specific period of time stratified by demographic and medical factors as determined appropriate by the POC.

9.6.3 Updated Center-specific risk adjusted survival rate information, along with percentage of transplants with follow-up information, using data that may be

validated by the member through UNet[sm], by organ type, assessing transplants performed during a period that allows the OPTN contractor sufficient time to collect the data and compute the rates as determined by the POC. The adjusted, center-specific survival rate information may include, to the extent relevant to the organ type, the probability of survival pre-transplant, post-transplant and the probability of survival with or without a transplant. An appropriate period of analysis also will be determined by the POC.

9.6.4 Updated Center-validated transplant volumes as may be validated by the member through UNet[sm], by organ type, stratified by demographic and medical factors as determined appropriate by the POC. These data may be presented on a calendar year basis and for such portions of the calendar year as determined by the POC. At a minimum, the following center volume information will be releasable:

9.6.4.1 Center-specific transplant volume, by year, by organ type, using data that may be validated by the member through UNet[sm], for recipients of a particular age.

9.6.4.2 Center-specific transplant volume, by year, by organ type, using data that may be validated by the member through UNet[sm], for recipients with a particular diagnosis.

9.6.4.3 Center-specific transplant volume, by year, by organ type, using data that may be validated by the member through UNet[sm], by deceased and living donor transplant.

9.6.4.4 Center-specific multi-organ transplant volume, by year, by organ type, using data that may be validated by the member through UNet[sm].

9.6.4.5 Center-specific non-resident alien transplant volume, by year, by organ type, using data that may be validated by the member through UNet[sm], by deceased and living donor transplant.

9.6.4.6 Center-specific waiting list size on any given day, by organ type, according to the waiting list.

9.6.4.7 OPO-specific data on the number of non-U.S. citizen organ donors, by year and by organ type, using data that may be validated by the members through UNet[sm].

9.6.5 Center- and OPO-specific data submission compliance rates.

9.6.6 Updated OPO-specific donor procurement volumes, using data validated by the member through UNet[sm], including organ-specific authorization, procurement, and utilization volumes, by OPO; and numbers of donors by OPO, using data validated by the member through UNet[sm], stratified by demographic and medical factors for such period(s) as determined appropriate by the POC.

9.6.7 Updated OPO-specific organ transplant volume, using data validated by the member through UNet[sm], showing number of organs procured, number of organs imported into the OPO, and number of organs exported from the OPO. These data may be presented on a calendar year basis and for such portions of a calendar year as determined by the POC. OPO-specific organ transplant volume and size of waiting list, using data validated by the member through UNet[sm], by organ type, stratified by demographic and medical factors for such period(s) as determined appropriate by the POC.

9.6.8 Updated OPO-specific kidney payback debt and credit volumes, including number of short-term payback debts, long-term payback debts, and thresholds

for reducing long-term debt (please see Policy 3.5.4.2 (Kidney Payback Debt Limit) for definitions of "short-term debt" and "long-term debt"), for such period(s) as determined appropriate by the POC.

9.6.9 Center, OPO, or other organization-specific data as approved by the Executive Committee, which the OPTN anticipates will be otherwise duly released by the Department of Health and Human Services (HHS) to the public, together with such explanatory or other text or material as the Executive Committee shall deem appropriate to assist readers in understanding the data.

9.7 RELEASE OF CENTER SPECIFIC DATA. The OPTN may release to OPO members such center specific data as are required for the OPOs to prepare reports or other documents required by the OPTN for the purposes of assessing the impact of variances, alternative local units and sharing agreements on organ allocation.

9.8 REVIEW OF INSTITUTION SPECIFIC DATA. During the data validation process, the OPTN may release to institutional members for their review such primary data as may be needed for institution-specific reports for public release. For example, donor and histocompatibility data about transplants performed at a center may be sent to that center for review (but not for modification without instruction to the OPTN contractor by original institution submitters). Conversely, for these purposes, laboratories and OPOs may receive relevant data submitted to the OPTN by transplant centers. The institutions that receive the data will not publish or publicly disseminate outcomes of specific recipients, physicians or institutions.

9.9 ACCESS TO RECIPIENT OUTCOMES DATA. OPOs may receive recipient outcomes data, without permission from the transplant center, for each donor organ transplanted. This information would be used in determining the appropriateness of donor selection and management techniques as well as quality assurance of the procurement process. The data would be accessed and downloaded through the UNet^{sm} system. The institutions that receive the data will not publish or publicly disseminate outcomes of specific recipients, physicians or institutions. These data fields are located on the Transplant Recipient Registration Forms and include:

9.9.1 Recipient Status (all organs)

- Living – date of hospital report
- Dead – date and cause of death
- Re-transplanted prior to hospital discharge – date
- Cause of retransplant (thoracic only)

9.9.2 Clinical Information at Discharge (kidneys only)

- Most recent serum creatinine prior to discharge
- Did kidney produce >40 ml of urine in first 24 hours?
- Did recipient need dialysis within first week?
- Did creatinine decline by 25% or more in first 24 hours on two separate serum samples taken within first 24 hours?

9.9.3 Graft Status at Discharge (kidney, liver and pancreas only)

- Functioning or failed
- If failed, date and cause

9.9.4 Preservation Information (all organs)

9.10 OTHER INFORMATION. Information brought before the Board of Directors in public sessions may be released. Any requests for more detailed information or data will be processed according to the guidelines set forth in Policy 10.0.

9.11 RELEASE OF HLA TYPE OF A RECIPIENT'S PRIOR DONOR. The OPTN contractor may release a recipient's prior donor's HLA type to a transplant center if the recipient is

under that center's care, or to the laboratory that provides services to that transplant center, without obtaining permission from the transplant center that performed the original transplant or the laboratory that performed the donor's typing.

9.12 RELEASE OF HLA TYPE OF DONORS AND RECIPIENTS WITH LABORATORY NAME AND IDENTIFIER. The OPTN may release the HLA type of deceased donors and recipients with the name and identifier of the laboratory that performed the typing to member laboratories for the purpose of resolving discrepant donor and recipient HLA typing results as set out in Appendix C to Policy 3.0 without obtaining permission from each member laboratory.