## Maine Medical Center Maine Transplant Program Policies and Procedures

# Policy on Information Sharing between Living Donors and Recipients

### Purpose:

To outline guidelines and requirements regarding the sharing of Protected Health Information (PHI) between living kidney donors and recipients.

### Policy:

It is the Policy of the Maine Transplant Program to comply with all Federal and State laws regarding the disclosure of PHI for all living kidney donors and recipients. These requirements are referenced in the Maine Health "Privacy and Confidentiality Policy". The Maine Transplant Program gives high priority to the confidentiality of living donors and in accordance with United Network for Organ Sharing (UNOS) Informed Consent Requirements (Policy 14.3), the Transplant Program will take all reasonable precautions to provide confidentiality for the living donor and recipient.

#### Procedure:

- 1. As patients of the Maine Transplant Program and upon registration, all living donors and recipients will receive a Notice of Health Information Privacy Practices explaining privacy regulations, and how Protected Health Information can be shared with another person or entity.
- 2. Any information about the donor and recipient, including but not limited to Protected Health Information, will be considered confidential. This includes information on registration as a donor or recipient, status, and testing results.
- 3. Living donors are free to withdraw from consideration at any time for any reason; reasons for withdrawal will be considered confidential and not shared with the intended recipient by the Transplant Program at any time.
- 4. Living donors and recipients will be educated about the need for privacy and requirements for protection of confidential information. For both directed and non-directed donors, the sharing of information between donors and recipients will be discouraged, but cannot be monitored or controlled by the Transplant Program team.
- 5. Living donors and recipients who are in a close relationship, and/or desire to have their PHI shared by the Transplant Program/Maine Medical Center with their intended recipient or living donor will be required to provide specific written authorization for a release of information. Only when this authorization has been executed will information be shared and only information included in the consent will be communicated.
- 6. Living donation is planned in advance, and any need or request for disclosure should be discussed in advance of the donation. The potential need for disclosure to address insurance coverage and payment should be addressed prior to donation.
- 7. The Independent Living Donor Advocate may act as a resource to the living donor if communication issues arise that are of concern to the living donor.

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