

**Maine Medical Center
Transplant Program
Policies and Procedures
Independent Donor Advocacy Program Policy**

Purpose

To describe the purpose and content of the Independent Donor Advocacy Program

Policy

It is the policy of the Maine Transplant Program that all potential living donors will have an assigned representative from the Independent Donor Advocacy Program (IDAP). IDAP exists to protect the rights and promote the best interests of living donor candidates and living donors of the Maine Kidney Transplant Program. Representatives of IDAP act as advocates on behalf of living donor candidates and living donors. Information about the MMC Independent Donor Advocacy Program (IDAP) is provided to every candidate prior to the donor workup and a representative of IDAP meets with every candidate. The IDAP program is administered by the Maine Medical Center Clinical Ethics Committee, which is independent in supervision and oversight from the Maine Kidney Transplant Program.

Qualifications and Training of IDAP Representative (Independent Living Donor Advocate: ILDA)

1. Good verbal and written communication skills; and ability to actively listen
2. Ability to directly communicate judgments and opinions, even when these differ from the views of others;
3. MMC staff or MMC volunteer who has successfully completed orientation training, including HIPPA, Fire, Safety and Infection Control
4. Successful completion of IDAP orientation, including knowledge of:
 - living organ donation process (evaluation, surgery and follow up)
 - Potential complications (medical and psychosocial) of living donation
 - Donors medical history and implications for suitability for donation
 - Emotional and psychological aspects of donation
 - Financial aspects of living donation, including need for insurance and financial supports
 - Potential donors ability to obtain insurance after donation
 - Transplantation and options available to recipients
 - Potential donor complications,
 - understanding of family or other support systems e potential coercive pressures on donor candidate,
 - medical ethics and informed consent.(including concepts of confidentiality of all communication, national and center outcomes, donor right to opt out at any time)
 - High risk social behaviors that could lead to increased risk to recipient
5. ILDAs will be expected to complete at least two documented training sessions annually relevant to the role of the ILDA. Topics may include ethics, living donor policies, transplantation, or living donor rights.
6. An annual review of competencies will be completed and maintained in the ILDA file. This competency review will include a review of living donor policies and procedures.

Procedures

1. Independent Donor Advocacy Program membership and organizational structure
 - IDAP representatives are not employed or supervised by the Maine Transplant Program. The program is administered by the MMC Clinical Ethics Committee, under the direction of the Director of Clinical Ethics.
 - The Clinical Ethics Committee at Maine Medical Center consists of representation from physicians, nurses, and other health care providers practicing at Maine Medical Center, as well as lawyers, clergy, professors, patient, families and other representatives from the community.
 - The IDAP representative assigned to a potential donor will have no prior relationship to the potential recipient. The Maine Kidney Transplant Program may from time to time pay expenses relating to education of IDAP representatives.
 - Prospective ILDA's will be presented to the Living Donor QAPI Committee for approval after successfully completing training and orientation.
 - ILDA education and training files will be maintained at the Maine Transplant Program
2. An IDAP representative will meet with every living organ donor candidate and in private offer the opportunity to withdraw from the donor evaluation and insure the candidate that his or her reasons for withdrawing will remain confidential if he or she wishes. Responsibilities of the IDAP Representative include:
 - An initial introductory contact prior to the initiation of the evaluation process to explain the role of the ILDA, and identify any initial concerns on the part of the potential donor.
 - Meet in-person with the potential donor as part of the living donor evaluation
 - Explain the voluntary nature of donor evaluation and kidney donation
 - Privately offer the potential donor the opportunity to withdraw without penalty and in confidence
 - Underscore key information about kidney donation
 - Contribute to the evaluation of the donor's understanding of information about kidney donation
 - Contribute to the evaluation of the voluntary nature of the potential donor's consent to evaluation and transplant
 - Make known any reservations about proceeding with donation
 - Submit documentation relating to the above
 - Remain available to the potential donor as the process moves forward
 - Meet with the living donor in the hospital following surgery to address any concerns or needs; remain available after discharge for ongoing needs that arise
 - Inform the potential living donor of Maine Medical Center's Patient Complaints and Grievances Policy
 - Documentation of all elements required by current regulatory standards including UNOS and CMS
3. IDAP representatives will work to resolve any concerns that candidates have, and offer themselves as a resource for the resolution of concerns and complaints that may arise as the process moves forward.
4. The IDAP representative is not responsible for obtaining the informed consent for the evaluation process or the procurement surgery. However, the IDAP representative is responsible for underscoring key information about kidney donation, and contributing to the Transplant Program's evaluation of the potential recipient's understanding of the consent and evaluation processes, the surgical procedure, and the benefit and need for follow up care post donation. The IDAP representative helps to assure the voluntary nature of potential recipient's consent.

5. IDAP representatives have the responsibility to make known to Transplant Program staff any reservations they have about a potential transplant and/or whether they believe that donation will adversely affect the interests of the donor to a significant extent.
6. The ILDA will participate in the living donor multidisciplinary selection process. As the Transplant Candidate Review Committee meeting may include a review of both living donor and recipient candidates, he/she will attend and participate in the Transplant Candidate Review Committee meetings **only** for the living donor portion of the meeting and present his/her evaluation and recommendations to the Committee. **The ILDA will not attend and participate in transplant candidate selection.** Meeting etiquette will include a clear break in presentation of living donor and recipient candidates.
7. If an IDAP representative concludes that a donor evaluation should not move forward and if after the usual discussion there remains a difference of opinion between the IDAP representative and Transplant Program staff, a joint meeting of the executive committee of the Clinical Ethics Committee and Transplant Program leadership will be arranged to adjudicate the issue. Documentation of this meeting will be included in the medical record.

Original Date: 9/21/09

Review Dates: 4/9/12, 1/13/14, 8/21/15; 5/19/17; 8/23/19; 7/1/22