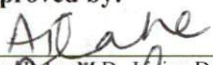

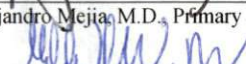
 The Transplant Institute METHODIST DALLAS Methodist Dallas Medical Center	Title: Independent Living Donor Advocate	Effective Date: 01/05/2012
	Section: Kidney – Living Donation	
Approved by:  Anna Dahe, M.D., Living Donor Medical Director		Revision Date(s): 01/05/2012; 02/01/2013; 05/26/2015; 01/08/2016; 07/30/2018; 10/04/2018; 04/28/2020; 06/2023; 05/2026
 Alejandro Mejia, M.D., Primary Living Donor Surgeon		
 Melody Holder, Director of Transplant Clinical Operations		Next review Date: 05/2029

Purpose:

To describe the role and responsibilities of the Independent Living Donor Advocate (ILDA)

Policy:

Qualifications

The ILDA will have at least 3-5 years of previous patient advocacy experience.

Training

Upon hire the ILDA receives on-site specific donor advocacy training from the previous ILDA or their designee. This training will include knowledge of living donation, transplantation, medical ethics, informed consent and the potential impact of family or other external pressure on the living donor’s decision about whether to donate.

These specific competencies are checked off once mastered on the ILDA New Hire Competency Checklist. On-going ILDA training includes ILDA specific on-line webinars, local, as well as national ILDA, specific conferences.

Role and Responsibilities

The Independent Living Donor Advocate (ILDA) may be a role combined with the Living Donor Social Worker. In the absence of the usual ILDA, a transplant Social Worker who is not involved with the transplant recipient may act as a back up to the primary ILDA.

The ILDA evaluates all potential living donors and provides advocacy and social work (if combined role) services. These services are provided throughout the evaluation, donation and post donation phase. The ILDA acts as an advocate for the living donor to ensure protection of the rights of living donors and prospective living donors. To protect the rights of the donor/potential donor and avoid conflicts of interest, the ILDA does not work with the potential organ transplant recipient and functions independently from the recipient’s transplant team. The ILDA is not involved in the decision to transplant the potential recipient. The responsibilities of the ILDA are:

- To represent and advise the living donor/potential living donor
- To promote the interests of the potential living donor
- To advocate the rights of the potential living donor
- To respect the potential donor’s decision and ensure that the donor’s decision is informed and free from coercion
- To assist the potential donor in obtaining and understanding information regarding the consent process, evaluation process, surgical procedure, and benefits of and need for follow-up

The ILDA shall be available to support the donor throughout the evaluation, donation, and post-donation process. Services provided include, but are not limited to:

- Reviewing the informed consent process and completing the Informed Consent paperwork
- Providing printed educational material that explains all phases of the donation process
- Providing sufficient time for the potential donor to reflect after consenting to donate
- Providing resources for supportive and/or crisis counseling
- Providing resources for community and/or hospital referrals
- Providing resources for follow-up services

The ILDA will identify candidates for donation as acceptable or unacceptable. The ILDA will report recommendations to the Living Donor Selection Committee

A potential living donor may stop the evaluation or donation process at any time. The potential donor shall be informed that if this occurs, the Selection Committee will state that the potential donor is not an acceptable candidate without providing specific reasons for this decision

ILDA Interview:

The initial interview will be conducted prior to initiation of the transplant evaluation and is typically done by phone

ILDA Assessment:

Assessment must be completed with all potential living donors

This may be completed in conjunction with the donor psychosocial assessment. The goals of the ILDA interview are:

- 1) To assess the potential donor's knowledge, understanding and preparation by exploring the prospective donor's awareness of the following:
 - Knowledge of living donation/application process
 - Access to educational material
 - Understanding of living donor rights (including the ability to "opt-out")
 - Availability of alternative treatments for the transplant candidate
 - Potential psychosocial, psychological and financial ramifications (including possible insurance risk)
- 2) To assess for vulnerabilities that could potentially increase risk to the prospective donor
- 3) To review the nature and degree of closeness (if any) to the recipient (i.e. how the relationship developed) and whether the transplant would impose expectations or perceived obligations on the part of either the donor or the recipient
- 4) To assess donor motives and the degree to which the donation decision is made free of guilt, undue pressure, enticements or impulsive responses. The ILDA will explore the rationale and reasoning for volunteering to donate, including whether donation would be consistent with past behaviors, apparent values, beliefs, moral obligations or lifestyle.
- 5) To assess the prospective donor's understanding, acceptance and respect for the specific donor protocol (e.g. willingness to accept potential lack of communication from the recipient and the donor's willingness to undergo future donor follow-up)

- 6) To assess the prospective donors' understanding of the potential medical, psychosocial and psychological risks associate with living donation and the potential donors' understanding of expected health outcomes and risks for the donor and the transplant candidate
- 7) To identify any factors that warrant educational or therapeutic intervention before donation can proceed

Living Donor "Time-out" period

If there are concerns by the Living Donor Selection Committee or the ILDA that require more consideration, the potential donor may be asked to take a "time-out" period to consider their decision to donate. During this time, the ILDA will follow up with the potential donor to discuss outstanding issues. Additional consultations may also be obtained with nephrologists, the living donor surgeon, social workers, psychologists, etc. At the conclusion of this "time-out" period, the potential living donor will again be presented to the Living Donor Selection Committee. After considering new information, voting will occur with candidacy determined by a simple majority of the voting members present

Independent Living Donor Advocate Follow-up

The ILDA will meet with all donors during the first 24 hours of his/her inpatient stay to reassess needs, address any concerns and provide post donation education and discharge planning. Additionally the ILDA will be available to assist donors for at least 2 years post-donation. The goals of follow-up services are:

- To assess for potential complications related to donation
- To encourage follow-up for living donors
- To assist with completion of UNOS TIEDI LDF forms post-donation as needed

Grievance Policy

In the event that the ILDA raises a grievance to protect the potential donor's rights and best interest, the transplant program will take the following steps to address and resolve the grievance:

1. Communicate the concern(s) to the manager of business operations
2. The business manager will convene an ad hoc committee consisting of 1) Vice President Transplant Services, 2) Director of Clinical Operations, 3) Transplant Program Clinical Manager and 4) Quality Manager, or any of their designees as deemed appropriate to adjudicate the issue
3. At the conclusion of this meeting, the potential living donor will be re-presented to the Living Donor Selection Committee

Reference: OPTN/UNOS Policy 14.0