The Independent Living Donor Advocate Interview

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Essential Donor Team Concepts
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Conflicts of interest

• Chair, American Society of Transplantation Live Donor Community of Practice
• National Kidney Foundation Live Donor Council
• Honoraria last year from several transplant centers and from Connect to Transplant
Learning objectives

• Review required aspects of the ILDA role
• Offer tips, tools, and strategies for best practice with prospective living donors and with transplant teams
• Describe alternative role constructs, and define ways to maximize the benefits (and minimize the limits) to your team’s chosen approach
What is unique about informed consent in live donation?

• No medical benefits to describe
• The evaluation itself has some risks
• Potential for pressure affecting decision-making
• Risk of exploitation
• The procedure is a shared transaction—transplant candidate options & outcomes affect donor decision-making & outcomes
Who tackles donor preparedness?

• To some degree, whole team
  – Particularly for centers using the IDAT model

• Some aspects are in a designated role:
  – Independent Living Donor Advocate (ILDA)
  – Coordinator
  – Surgeon/ nephrologist
Were there many coerced, unhappy, ill-prepared living donors?

Outcomes overall great:

- Donor well-being => than controls¹-³
- Very low rate of donor regret
- Often affirming, even transformative
- No one on the transplant team wants a donor to be coerced/unprepared
- Yet processes could be improved

Informed consent process gaps

1. Pressure
2. Ambivalence
3. Poor understanding of risks
4. Inadequate assessment of risk of NOTA violations

All linked to poor outcome and increased risk

Gordon, EJ. AJT 2012; 12: 2273-2280
Thiessen C, et al. AJT. 2013. 2713-21
Dew MA et al. AJT 7 Aug 2013: 2672-2684
Informed consent standards

• Processes vary
• Controversies remain
  – Benefits/ limits to donor knowledge-testing
  – Challenges of assessing presence of exploitation
  – Complexities of consent in paired exchange

2. Thiessen C, et al. AJT. 2013. 2713-21
The concept of an ‘independent donor advocate’

**Transparency**
Open about purpose of evaluation, donor process
Asserts rights-- debunks process, including right to withdraw at any time

**Independence**
Separate from recipient interests and care. Separate from transplant center pressures around transplantation rate
Assesses voluntary status, understanding, & wish to proceed. Reduces risk of conflict of interest & influence of any pressure to transplant.

**Partnership**
Ascertains wishes & understanding; facilitates communication with donor team members.

**Advocacy**
Promotes donor candidate’s rights. Voices the prospective donor’s wishes and his/ her readiness to provide informed, uncoerced informed consent.

**Confidentiality**
Required ILDA components

1. Function independently from the transplant candidate’s team.
2. Advocate for the rights of the living donor.
3. Fulfill the qualification and training requirements specified in the recovery hospital’s protocols regarding knowledge of living organ 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...
4. Review whether the living donor has received information on each of the following areas and assist the donor in obtaining additional information from other professionals as needed....

OPTN, Policy 14.2,
Factors affecting informed consent in live donation

- Cognitively /mentally incapable of making an informed decision
- High suspicion of donor coercion or exploitation
- Inadequate understanding of live donation surgical, medical, or psychosocial risks
Advocate assessment is narrowly defined. Viewed simply:

- Does the prospective donor wish to proceed?
- Is the prospective donor’s decision-making affected by coercive or exploitative pressure?
- Does he/she understand the risks and benefits of proceeding?

Hays, RE Current Transplantation Reports 2015 Mar
https://optn.transplant.hrsa.gov/media/120optn_policies.pdf#nameddest=Policy_14.2
Donor advocate practice varies in the US

2012 survey of 120 ILDAs found range in:
• Background
• Training
• Scope of clinical practice

What ISN’T specified in the United States?

- **WHO** (disciplinary background)
- **WHERE** (affiliated with transplant center?)
- **WHEN** advocate sees donor
- **HOW** (does advocate participate in donor candidacy determinations?)

Key ILDA implementation recommendations:

- Needs a skill set rather than a specific profession
- Must be educated and demonstrate competence in core knowledge components
- Primary role is to assess components of informed consent
- There must be a transparent system to define ILDA independence
- There should be a reporting structure outside the transplant center
- The role should be integrated throughout the donor care continuum
- The role should generally include a narrow, defined ‘veto power’
Essential training components

Orientation to hospital, transplant, and ILDA role
  1. internal structure
  2. external policies

Fundamentals of medical ethics
  (informed consent components)

Donation and transplantation
  1. Know what a donor should know
  2. Shadow or be mentored by an ILDA
  3. Shadow a donor (or 2 or 10) throughout the process

Method of staying updated
Benefits of a semi-structured interview

• A formal opportunity for reflection
• Formal review of rights
• Pulls description of medical, surgical, and psychosocial risks together
• Many detailed OPTN elements—ensures these are all covered
Support for donor decision-making

Social work
- Examines ambivalence and expectations
- Intervenes:
  - Teaching
  - Cooling off period

ILDA
- Stages readiness
- Advocates with patient voice

In PKE
- Assess for readiness changes
- Higher standard for donor sureness?
Ambivalence

- Not uncommon
- Yet living donation must be an affirmative decision

Approaches:
1. Cooling off period,
2. ‘Scaling system’ of readiness
3. Motivational interviewing approaches

Valapour M et al Clin Transplant 2011 Mar-Apr
Dew MA et al Prog Transplant 2012 Sept
Donor Understanding

Social work:
- Cognitive & learning barriers?
- Teaching accommodations?
- Additional work-up?

ILDA:
- Understands risks?
- Expected outcomes and ESRD tx options?
- Structured interview

KPE:
- Unknowns
- Process
- Additional risks
  - Broken chain

Create climate conducive to informed, autonomous decision-making—
Informed consent as a process

- Donor decision making, readiness, and understanding changes over time
- As options and plans change, so may the patient’s wishes
- Affirm confidential ways to discontinue the donation process
- Factors are affected by complex medical evaluations, or in paired exchange

Dew MA et al. AJT 7 Aug 2013: 2672-2684
Communication approaches

• Offer **feedback** to patient
• **Consult** coordinator
• At selection:
  – Summarize findings
  – **Recommend** interventions
  – Be willing to sit with tension, and be ‘unpopular’ - particularly for ambivalent donors
Resolving differences in the team

• Define ILDA role narrowly
  – particularly when it comes to ‘contraindications’
• Identify whether/not barriers are intervenable
  – understanding v cognitive capacity
  – mid-decision v sustained ambivalence
• Use resolution strategies, but have grievance policy in place
Benefits of gradual/ repeated assessment

An Example:

1. Introductions, outline of donor rights/process
   - Assess donation motivation
   - Assess learning needs

2. *(later in the process)* Semi-structured interview
   - Assess desire to proceed
   - Review understanding

3. *(just prior to donation)* Confirm desire to proceed and reiterate right to withdraw

4. *(after donation)* Check in re: satisfaction and unmet needs
Clinical skills= finding balance

1. Listen
2. Assess and share findings
3. Represent and communicate
4. Check back
5. Rinse and repeat
2 general role constructs for ILDA practice are a matter of emphasis.

Is it Independent Donor Advocate or Independent Donor Advocate?

Embedded donor care clinician as ILDA

**Benefits**
1. Assesses donor readiness over time
2. Facilitates nuanced assessment of informed consent components
3. Advocacy within team may function better

**Challenges**
1. Dual role may be confusing
   - Clinician may be functioning as both the coordinator and the ILDA
2. Risk of conflict of interest
   - May be affected by transplant center pressures

External consultant ILDA

### Benefits

1. Role is clear
2. Independence is transparent
3. An impartial view of the donation process
4. Donor may be less inhibited in expressing concerns

### Challenges

1. Knowledge base may be limited about donation or about specific donor risk factors
2. Assessments are typically one-time only
3. Advocacy within donor care team may be challenging

Strategies to minimize limits to the external consultant ILDA

Focus on training

Integrate role throughout donor process

Structure advocacy aspects

- Role in donor candidacy is defined
- Appeals process for when there is disagreement within the team
Strategies to minimize limits to the embedded donor clinician ILDA

Clarify role:

- To patient
- To team
- To self

Implement external reporting structure

Narrow field of focus in ILDA assessment
• **May 27**: History of ILDA: Regulatory Oversight and Basics of the ILDA Role
• **June 17**: Basics of Kidney Disease and Transplantation
• **July 15**: Living Kidney Donation A to Z: Understanding the Basics
• **July 29**: Basics of Liver Disease and Transplantation
• **August 19**: Living Liver Donation A to Z: Understanding the Basics
• **September 16**: Basics of Informed Consent for Living Donors
• **October 21**: Navigating the ILDA Role: Challenges and Responsibilities
• **November 18**: Medical Ethics: Concepts and ILDA Practice
• **December 16**: Difficult Living Donor Decisions

Visit [www.myAST.org/ILDA](http://www.myAST.org/ILDA) for more details