



“Optimizing Informed Consent Processes to Educate Donor and Recipient Candidates about Psychosocial Risks” - Additional Q&A  
From Wednesday, January 16, 2019  
<https://ast.digitellinc.com/ast/sessions/2210/view>

Do you suggest having a donor advocate team independent of the recipient team?

**A donor advocate team is not part of the regulatory requirement (whereas an ILDA is a required component). A designated donor care team has the advantage of reduced risk of conflict of interest, and expertise in the specific care needs of this special patient population—but not all programs have the resources/ volume to designate a separate team. For additional information on this model, see: Rudow DL, Prog Transplant 2009 Mar.**

How to manage a potential recipient related donor who decides to withdraw? How do you convey this information to the recipient?

**All donor candidates have the right to confidentially withdraw from the donation process. Transplant program processes vary: some provide a general statement about donor candidate “unsuitability”; others create a “medical alibi”. For descriptions of the range in practice, please see: Thiessen et al. J Med Ethics. 2015 Jul.**

How does a patient's level of honesty about their psychosocial history impact candidacy? (i.e.: donors not being forthcoming about their inpatient psych stays, or diagnoses, or medications - but is ultimately discovered by the team)

**Informed consent is predicated on a reciprocal process of disclosure and information-sharing between patient and care provider. Without a shared understanding of risk factors, it is impossible to reach a meaningful agreement about anticipated outcomes/risks of donating. See Hays RE, Curr Transplant Reports 2015 Jan 20.**

**Psychosocial candidacy criteria is beyond the scope of this webinar, so we hesitate to weigh-in. It is rare but not unknown for donor candidates to avoid sharing history of psychosocial problems/vulnerability; individual program processes may vary in this situation. For additional information about psychosocial evaluation strategies and candidacy assessment, along with a ‘red flag checklist’, see: Massey EK et al. Transplant In 2018.**

I'm also wondering about your opinions on compensation for living donors (financial or otherwise), and if this should be reconsidered, and if so, at what level and in what way.

**This is a terrific, complicated question that is unfortunately well beyond the scope of this webinar; we'd encourage you to suggest this as a future topic, as much has been written/ debated on this question. There is widespread agreement that living donors should at least be reimbursed their costs. See Hays et al. AJT 2016 Jul.**

What if Donors insist on going forward with the donation despite having some soft calls such as borderline prediabetic and Pre-hypertension? Understanding all risks

**Each transplant center must develop its own candidacy criteria and communicate these to donor candidates. Some have recently proposed integrating donor candidate strength of motivation and/or willingness to undergo risk into donor candidacy processes, but methods to implement this concept have not yet been tested. See Thiessen et al, AJT 2015 Sept.**

We try to thoroughly present psychosocial risks to our patients, but we have struggled with many recipients being so focused on needing a transplant, that they do not hear/absorb the information. Then they are transplanted and overwhelmed with the finance.

**This is a common challenge! There is often a gap between presented information and patient integration/retention. To support meaningful informed consent processes, we encourage utilizing a combination of health education best practices, including use of plain language, varied modalities, repetition, teach back, & peer mentoring. Education should be provided in culturally relevant ways and in the patient's language of choice. See Tan JC et al, CJASN, 2015 Sept 4.**

**In terms of financial risks specifically, we encourage use of concrete worksheets; with donor candidates, use the cost estimation worksheet at [livedonortoolkit.com](http://livedonortoolkit.com) For recipients who wait awhile for transplant, repeated anticipatory guidance can be helpful, as readiness to hear/ learn may change over time.**

Can you comment on SIPAT, STSW or other standardized tools to better assess patients?

**Standardized tools offer consistency between different psychosocial providers and patients. They may also document risk assessment findings in a way that is easier for medical team members to integrate. That said, standardized tools may lack clinical nuance/ depth, and may not meet cultural competency standards. Some tools are also copyrighted. For more on standardized tool utility, see Maldonado et al. Psychosom Med 2015 Nov-Dec**

Do you have a psychosocial assessment tool for evaluation of recipients?

**Standardized tools include the SIPAT. (see above).**

"How do you get the entire transplant team to agree on the risks level with these sorts of subjective issues?"

**This is a tough question, and worthy of its own webinar! We recommend achieving multidisciplinary team consensus on donor/recipient candidacy criteria and contraindications, as well as teamwide understanding of UNOS/OPTN contraindications. We recommend evidence-informed psychosocial assessment of risk factors, and a culture at donor selection meetings that honors multidisciplinary input. See Rudow DL et al. J Clin Psychol Med Settings 2015 Sept**