

Response from ASTS Regarding Declaration of Istanbul

The American Society of Transplant Surgeons applauds the efforts of the attendees at the International Summit on Transplant Tourism and Organ Trafficking (Istanbul, Turkey, April 30-May 2, 2008) and the general intent of the subsequent Declaration of Istanbul. The ASTS views this as a much needed attempt by the international transplant community to discuss an issue that concerns us all. There is much in the Declaration of Istanbul with which the ASTS strongly agrees; among those are the need to maximize the use of deceased donor organs, the need for countries with established deceased donor programs (or living donor, for that matter) to share their knowledge with countries without these programs, the need to protect vulnerable populations from abusive acts, the equitable allocation of donor organs based on sound ethical principles, and the prevention of organ brokerage and trafficking.

While we embrace the intent of the document, the ASTS is concerned that some statements and recommendations in the declaration are either not compatible with the current medical environment in the United States, are too vague (or in some cases too far reaching), or may be disallowed by the U.S. legal system. Examples include, but are not limited to, the following:

- 1. In Number 5, subsection a, it is stated that "the provision of disability, life, and health insurance related to the donation event is a necessary requirement..." This is neither practiced in the United States nor is it financially feasible in our current medical environment. This is a desirable state, but is not practical in our country. It is possible that a limited trial of rewarded gifting of live donors with an insurance policy, if permissible by Congress through an alteration of the National Organ Transplant Act, would address this issue (see 4. below).
- 2. Some statements are very vague and would require clarification before we could agree with the document. Page 3, number 2 refers to "the recovery of organs ...and the practice of transplantation, consistent with international standards." We are not aware of such standards. Page 5, number 6, letter d refers to "[the live donor's] out-of-pocket expenses should be administered by the agency handling the transplant rather than paid directly from the recipient to the donor." In a system that does not have a single payer, it is not clear which agency that might be in our case: a private insurance company, Medicare, Medicaid, or the OPTN? In the United States, there is a model program for live donor assistance, the National Living Donor Assistance Center (NLDAC). This program is funded by an agency of the U.S. Department of Health and Human Services, which provides for means-tested reimbursement of out-of-pocket expenses incurred by living donors. However, recipient coverage of donor out-of-pocket expenses is permissible under U.S. law, and, in fact, it must be shown that the recipient is

- incapable of providing this coverage before government funds for this purpose can be provided through NLDAC.
- 3. Page 3, number 6, subsection a, describes a "ban on all types of advertising (including print and electronic media) ... for the purpose of transplant commercialism..." While we agree that advertising for the purpose of financial gain by brokering organ transplantation is reprehensible, we are concerned that a broad ban on solicitation of any kind might run counter to the first amendment of our Constitution guaranteeing the right to freedom of speech. In dealing with websites like Matchingdonors.com, we have already taken the position as a society that we do not legislate how relationships get formed.
- 4. While the Declaration of Istanbul does not specifically prohibit a limited, controlled trial of rewarded gifting, the wording is such that support for this as a possible future endeavor is confusing at best. There are those who believe this can be done safely in a regulated environment in the United States and that this concept has not been rigorously tested in a clinical trial setting.
- 5. Further, endorsing such open ended statements such as "access to healthcare is a human right but not often a reality (P2)" in our opinion is off topic and surpasses the extent and purpose we believe this document ought to have, whether this is the case in a particular country or not.
- 6. Page 2, paragraph 1, states that, "A positive outcome for a recipient can never justify harm to a live donor." While we recognize the implication of this statement likely refers to the harm done to a vulnerable individual by any number of means, from a surgical perspective it carries with it a different connotation. When we operate on individuals whose only indication for surgery is the donation of an organ, there is always risk of harm; nothing we do can justify the harm that we might inflict. Our role is to define those risks clearly and present them to the patient, and society as a whole, for acceptance or rejection.

The ASTS agrees with the general goals and directions outlined in the Declaration of Istanbul, but cannot endorse the document in its current form without further input and changes from our society to make the document more relevant to the practice of organ transplantation in our country.