

Request for Public Input Regarding OPTN/UNOS Facilitation of Living Unrelated Kidney Donation

Kidney transplantation from live unrelated donors (“unrelated” defined as the absence of biological, familial or emotional relationship) has increased significantly. In 2004, more than 30 percent of live kidney donors were biologically unrelated to the recipient of their kidney. Spouses and friends now frequently donate a kidney with every expectation that the transplant will be successful, despite the absence of a genetic match. Kidney transplantation has become so successful that an altruistic stranger who is medically well and has a blood type compatible with a potential recipient can be a live kidney donor.

Nevertheless, some kidney transplant candidates cannot find a compatible donor within family or friendships because of biological incompatibilities. The OPTN/UNOS is seeking to help such kidney transplant candidates identify compatible live donors. To do so, OPTN/UNOS is proposing to develop a distinct Internet web site to assist patients in need of a kidney transplant and individuals considering live kidney donation. This site could include three free features for potential live unrelated donors and candidates, and we invite comment on each of these potential features:

- A moderated forum for people interested in being living unrelated donors to post information about themselves that has been approved by OPTN/UNOS staff as appropriate
- A moderated forum for transplant candidates seeking an unrelated donor to view information posted by potential donors and/or post information about their own needs, which has been approved by OPTN/UNOS staff as appropriate
- A resource area regarding the living donation process and applicable laws

In addition, this new OPTN web site would be linked to the UNOS Transplant LivingSM web site (<http://www.transplantliving.org>), which is being modified to include more extensive information about live donor transplantation.

All of these resources must be subject to the important caveat that the OPTN/UNOS would show no preference to any individual request, and that the decision

for determining donor, candidate and organ acceptability remains with the transplant center. Public input on the feasibility and desirability of these additional services will be appreciated.

In addition, the OPTN/UNOS will develop an organizational statement regarding the public solicitation of live unrelated kidney donors. Some of the issues underlying these considerations are listed for reference in Appendix A of this document. The committee's deliberations will benefit greatly from public input on this important subject. Whereas the OPTN/UNOS Board of Directors has previously expressed concerns about the solicitation of deceased donor organs (see Appendix B), the circumstances that surround living donation are markedly different. An ad hoc OPTN/UNOS committee is studying this issue, focusing on whether the potential living donor is able to make a willing and fully informed decision to give his or her organ to an unrelated individual. It is now evident that there are a variety of ways that an altruistic donor may develop a relationship with a potential recipient, including an Internet interaction.

Individuals with significant expertise on this issue will be invited to present their perspective at a public hearing to be held June 6, 2005, in Chicago, Illinois (pending reservation of meeting space). Specific questions are identified below for which written comment is solicited.

Call for Public Input and Notice of Public Hearing

The OPTN/UNOS seeks public input with the goal of assembling a series of recommendations for consideration by the Board of Directors. Specific commentary is invited on the following questions:

1. What is the potential effect of solicitation of potential living donors on donation rates overall? Please supply objective data to support your conclusions.
2. Would the solicitation of potential living donors affect the operation of the current allocation system and impact public trust in that national transplant system?
3. How would the potential for coercion or illegal monetary gain be addressed when a solicited donor comes to the attention of a transplant center? Should the transplant program's protocol for living donor evaluation be different if the donor has no previous relationship to the candidate? If so, how?
4. Should forms of solicitation that involve a financial cost to the user (fee-based services, paid advertising, etc.) be considered differently from services that are

- free to the user (personal web sites, non-sponsored news coverage, etc.)? If so, how?
5. Does a transplant center have an obligation, legal or otherwise, to perform a living donor transplant when the living donor has no pre-existing personal relationship to the candidate? If so, on what authority is the obligation based?
 6. How should a transplant center weigh a potential live donor's autonomy to make an informed decision with his or her medical suitability for donation and an identified medical risk to the donor?
 7. How should living-unrelated donation be promoted and supported in ways that respect donor choice and guard against exploitation of potential donors and transplant candidates?

Please address written comments in one of the following formats:

Electronically. Please use the public comment response option on the OPTN web site (<http://www.optn.org/policiesAndBylaws/publicComment/submitYourComment.asp>).

By mail. Address your response to: UNOS
attn: Ad Hoc Public Solicitation Committee
P.O. Box 2484
Richmond, VA 23218

The deadline for comments and requests relating to the public hearing (described below) must be received at UNOS by 5:00 p.m. Eastern time Wednesday, May 18, 2005. Comments received after that date may still be considered but may not affect invited testimony at the hearing.

To gather additional public input, the Ad Hoc Committee on Public Solicitation of Organs will convene a public hearing June 6, 2005, beginning at 10 a.m. Central Daylight Time, in Chicago, Illinois (pending reservation of meeting space). The specific meeting location will be announced separately, using the same distribution as this announcement. Depending on the number and type of comments submitted, the Committee may invite specific individuals to testify in a panel format. The Committee reserves the right to determine all panel assignments and the length and format of presentations each panelist may present. Due to budgetary limitations, travel and lodging expenses must be the responsibility of the individual panelist. The Committee will contact all invited panelists no later than Friday, May 20, 2005 with further details. Each panelist will be asked to submit written testimony in addition to his or her spoken remarks.

Public attendance is encouraged at the hearing, and there is no registration fee. As time permits after discussion with invited panelists, questions and comments will be taken from attendees.