

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS\*

CEJA Report 3-A-06

Subject: Solicitation of the Public for Directed Donation of Organs for Transplantation

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Referred to: Reference Committee on Amendments to Constitution and Bylaws  
(Joseph H. Reichman, MD, Chair)

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INTRODUCTION

1 Recent public appeals for organ donors have received considerable attention and stimulated  
2 concern regarding the appropriateness of directed donation by a previously unknown person, that  
3 is, by a stranger.<sup>1,2,3,4</sup> In 2004, Todd Krampitz received a new liver donated by the family of a  
4 deceased donor, as a result of the media coverage generated by his advertising campaign on a  
5 billboard and the personal website [www.toddneedsaliver.com](http://www.toddneedsaliver.com).<sup>5</sup> More recently, Rob Smitty donated  
6 a kidney to John Hickey after learning information about Mr. Hickey and his need for an organ  
7 transplant through a posted profile on the commercial website [www.matchingdonors.com](http://www.matchingdonors.com).<sup>6</sup>  
8

9 The significant disparity between the large number of people in the United States awaiting an organ  
10 transplant and the much smaller number of suitable organs available for transplantation has left  
11 many transplant candidates desperate for ways to increase their chance of receiving a life-saving  
12 organ.<sup>7</sup> Through attempts to publicize their stories of need, individuals such as Krampitz and  
13 Hickey who are waiting for an organ through the national waiting list are seeking a directed  
14 donation to them, thus bypassing the national distribution algorithm. However, what may  
15 advantage one individual may have serious albeit unintended ramifications for others also awaiting  
16 an organ.  
17

18 This report explores some of the ethical issues arising from various approaches to connecting  
19 transplant candidates with potential organ donors, both deceased and living. It considers the  
20 impact of public appeals on donors, recipients, and other relevant parties, as well as on the values  
21 underlying the current system.

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1 BACKGROUND

2

3 *The Current Allocation System for Organs*

4 The United Network for Organ Sharing (UNOS) administers the system for allocation of organs  
5 from deceased donors on behalf of the Organ Procurement and Transplantation Network (OPTN).  
6 The system aims to ensure an optimal balance between equity and efficacy.<sup>8</sup> Specifically, it seeks  
7 to provide balance between equitable allocation of organs to transplant candidates and allocation  
8 according to appropriate medical criteria.<sup>9,10</sup> The allocation of organs from deceased donors  
9 follows algorithms developed by the OPTN/UNOS by broadly based, representative committees,  
10 using a process that is open, seeks broad public input, and is publicly transparent. The system for  
11 allocating organs to transplant candidates on various organ waiting lists has always allowed an  
12 important exception: the decedent or authorized decision maker may direct a medically suitable  
13 organ to a specific named individual or transplant center.<sup>11</sup>

14

15 Donations from living donors are not regulated in the same way that organs from deceased donors  
16 are; no nationwide system controls allocation of living donor organs.<sup>10</sup> In part, this is because most  
17 living donors come forward out of a desire to help a specific transplant candidate, even if there are  
18 other wait-listed individuals who have greater medical need or are a better biological match and  
19 who might also benefit from the donated organ.<sup>12</sup> Individual transplant centers make their own  
20 rules for accepting living donors and allocating their organs.

21

22 *Living Donation*

23

24 In recent years, the number of living kidney donors has exceeded the number of deceased donors.  
25 In addition, according to OPTN/UNOS, transplants from unrelated living donors have increased  
26 significantly.<sup>13</sup> In 2004, for example, most living kidney donors were biologically related to the  
27 recipient of their kidneys, but more than 30 percent were biologically unrelated (mostly spouses or  
28 friends).<sup>12</sup> The increase in biologically unrelated donors has been attributed to various factors,  
29 some medical and some cultural: grafts from biologically unrelated living donors have higher long-  
30 term survival rates than those from deceased donors, transplant centers are increasingly willing to  
31 perform transplants between donors and recipients who are not related, and innovative strategies  
32 have aimed at increasing the number of transplantable organs, including from living donors.<sup>14</sup>

33

34 It is uncommon for a living donor and recipient to have no previous personal relationship, but the  
35 frequency of such transplants is increasing as new approaches are used to connect potential donors  
36 with transplant candidates. OPTN/UNOS data for 2004 indicate that there were 87 Good  
37 Samaritan donations, 27 direct-paired donations<sup>1</sup>, and 16 list-paired exchanges.<sup>2,14</sup> OPTN/UNOS  
38 has not tracked living directed donation, so no national statistical data are available.<sup>14</sup>

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<sup>1</sup> In a direct-paired donation, for example, ABO incompatible donor-recipient pair Y and incompatible pair Z are recombined to make compatible pairs, donor-Y with recipient-Z and donor-Z with recipient-Y.

<sup>2</sup> In a list-paired exchange, a patient waiting for a transplant receives priority status for a deceased donor organ in exchange for a living donation into the general organ pool on his or her behalf.

1 CONCERNS

2

3 Solicitation of the public for an organ to be directed to a particular candidate has the potential to  
4 increase the number of available organs and thereby alleviate the disparity between supply and  
5 demand. However, if the current system's attempt to achieve an optimal balance between equity  
6 and efficacy is to be preserved, the effect of public solicitation on achieving this goal merits  
7 consideration.

8

9 *The Code Of Medical Ethics*

10

11 In its recent report, "Transplantation of Organs from Living Donors," the Council recognized that  
12 variations in donation and allocation schemes for transplantable organs from living donors required  
13 further study, and concluded this: "ultimately, only variations that produce a net gain of organs in  
14 the organ pool and do not unreasonably disadvantage others on the waiting list are ethically  
15 acceptable."<sup>15</sup>

16

17 With regard to how organs from deceased donors should be allocated, the AMA's *Code of Medical*  
18 *Ethics* has had clear policy since 1993: allocation should follow "ethically appropriate criteria  
19 relating to medical need"—the same criteria that guide allocation of scarce resources.<sup>16</sup> Moreover,  
20 it specifically excludes the use of non-medical criteria, such as "ability to pay, age, social worth,  
21 perceived obstacles to treatment, patient contribution to illness, or past use of resources should not  
22 be considered."<sup>16</sup> However, it does not exclude directed donation of organs. Similarly, directed  
23 donation has never been prohibited by national policy.<sup>16</sup>

24

25 The AMA's *Principles of Medical Ethics* articulates physicians' responsibility to contribute to the  
26 improvement of the community (Principle VII), the physicians' paramount responsibility to their  
27 patients (VIII), and physicians' obligation to support access to medical care for all (Principle IX).<sup>17</sup>  
28 These Principles and the aforementioned standards from the Code should guide deliberation on the  
29 moral permissibility of public solicitation of directed donation.

30

31 *Statements by Transplant-Related Organizations*

32

33 The OPTN/UNOS Board of Directors is on record as opposing any attempt by an individual  
34 transplant candidate (or her/his representative) to solicit a deceased donor's organ(s), if doing so  
35 would place the transplant candidate ahead of others on the waiting list in a way that subverted the  
36 system's commitment to equity.<sup>18</sup> Counterbalancing the Board's concern is the possibility that  
37 directed donation may increase the number of organs available for transplantation, a significant  
38 goal of the organ donation and procurement system.

39

40 The American Society of Transplant Surgeons also has expressed its opposition to the solicitation  
41 of organs, both from potential living and deceased donors, if the intent is to direct the donation to a  
42 specific individual rather than to allocate it according to waiting list policies.<sup>3</sup> It does support,  
43 however, directed donation (by living and deceased donors) to family members, friends, and

1 individuals with whom a relationship exists through a community (e.g., school, place of worship, or  
2 place of employment), except when solicitation is involved.<sup>3</sup> It is not clear why an individual from  
3 a shared community, whom the transplant candidate does not know directly, is morally different, as  
4 a donor, from an individual from an unshared community.

5  
6 *Perceptions of Trust and Fairness of the Transplantation System*  
7

8 Another concern about public appeals that aim to connect a transplant candidate with a living or  
9 deceased donor is that such appeals might undermine trust in the allocation fairness upon which the  
10 current system has been built and depends.<sup>3, 19</sup> Individuals might be perceived as circumventing the  
11 accepted system when they obtain an organ transplant before others on the waiting list, despite less  
12 urgent need, shorter waiting times, or a less desirable organ-recipient match.<sup>19</sup> However, transplant  
13 programs encourage transplant candidates to seek potential donors among relatives, friends, and  
14 colleagues, despite the subverting effect of such donation on the equity and fairness of the waiting  
15 list. Transplant-related organizations praise solicitation of donation from living friends and  
16 relatives; if they did the same for directed donation solicited from the public, perhaps trust in  
17 allocation fairness would be strengthened rather than threatened.

18  
19 Actual or perceived preferential access to scarce life-saving resources has raised several concerns.  
20 First, perceived injustice in the national organ donation system might deter some from participating  
21 in the transplant enterprise in general.<sup>9</sup> The transplant community has invested great effort in  
22 developing the public's trust in the fairness of donation in order to minimize such perceptions.<sup>5</sup>  
23 However, at least some of the publicly perceived injustice of public appeals would disappear if  
24 solicitation were shown to generate more donations overall.

25  
26 Second, resources that may be necessary for public appeals are not available to everyone.<sup>10</sup> Recent  
27 campaigns, for instance, have relied on billboard advertisements and personal or commercial  
28 websites; all of these services require at least modest financial resources.<sup>7</sup> Solicitation also is  
29 facilitated by practical knowledge, relationships with key individuals, social status, media appeal,  
30 and membership in certain communities.<sup>19, 20</sup> Thus, condoning public solicitation may reinforce  
31 disparities in health care, because those without the means to advertise must wait and possibly be  
32 passed over for an organ that could otherwise have been theirs.<sup>7</sup> However, such an organ might  
33 not otherwise have been theirs because it might not have been donated at all if not solicited. How  
34 many organs are transplanted solely because they were solicited (that is, they would not have been  
35 donated without solicitation) is unknown. The concern about lack of resources to advertise should  
36 be lessened by the fact that websites such as [www.matchingdonors.com](http://www.matchingdonors.com) have waived the listing  
37 charge for individuals who could not afford it.<sup>21</sup> Moreover, there is benefit to those on the waiting  
38 list who are below the recipient of an organ from directed donation when the recipient ahead of  
39 them moves off the list, thus advancing their positions by one rank.

40  
41 Finally, solicitation might facilitate unacceptable discrimination if potential donors identify  
42 intended recipients to whom they will donate based on race, color, religion, national origin, sexual  
43 orientation, gender, ethnicity, age, religion, sexual preference, or any other basis that would

1 constitute invidious discrimination.<sup>10, 22</sup> Some, however, have suggested that directed donation on  
2 the basis of such criteria actually could help balance a system that already is discriminatory.<sup>23</sup>  
3 Currently, no mechanism exists to monitor such occurrences in order to better understand their  
4 impact.

5  
6 *Coercion and Inducements*

7  
8 Exploitation might occur if those seeking to obtain an organ through public appeals are subjected to  
9 demands for payment or other remuneration at the time of solicitation.<sup>10</sup> These payments would be  
10 unethical except for reimbursement for travel, lodging, lost wages, and the medical care associated  
11 with donation.<sup>24</sup> Indeed, because anyone can reply to a public solicitation, some potential donors  
12 may have ulterior motives such as gaining access to the recipient's personal information.<sup>9, 10</sup>  
13 Safeguards to monitor and prevent this kind of activity would be needed.

14  
15 Coercive inducements could be minimized if organizations such as the OPTN/UNOS or transplant  
16 centers served as brokers between potential donors and transplant candidates. Anonymity,  
17 however, could not be fully protected if the potential donor were responding to a particular  
18 individual's media appeal, leaving open the possibility for future donor demands.<sup>19</sup> This possibility  
19 also would need to be monitored and prevented.

20  
21 Inaccurate or Inadequate Information

22  
23 No simple verification is available for the accuracy of the stories put forward by individuals at  
24 either end of the recipient-donor connection. In the context of unregulated solicitations, potential  
25 donors could be swayed by incomplete or false information.<sup>9, 10</sup> Some of the commercial websites  
26 that aim to connect potential donors with transplant candidates do not include any information or  
27 only inadequate information about the risks of donation.<sup>10</sup> Individuals may volunteer as donors  
28 before carefully exploring and understanding the risks of donation;<sup>25</sup> this is likely to result only in  
29 temporary inconvenience to the potential donor, however, as all risks will be fully explained by the  
30 transplant team before any volunteer is accepted as a donor.

31  
32 It is not inconceivable that a transplant candidate would misrepresent some information in an  
33 attempt to make a personal story more compelling to attract willing donors. Likewise, potential  
34 donors might not represent themselves accurately if their motivation for donation extended beyond  
35 altruism. Most such misrepresentations are likely to be corrected during the preliminary and  
36 preoperative evaluations and disclosures by the transplant team.

37  
38 **POTENTIAL TO INCREASE THE NUMBER OF ORGAN DONATIONS**

39  
40 A particular recipient's publicly told story could increase overall organ donation; by associating the  
41 story with the suffering of tens of thousands waitlisted individuals, public pleas for donor organs  
42 may bring about donations that would not otherwise have been made. Personal accounts can  
43 generate sympathy and action in a way that statistics and fact sheets cannot.<sup>26</sup> Moreover,

1 solicitations could well have the effect of increasing public awareness of the need for organ  
2 donation, potentially generating more donations in general.<sup>27</sup>

3  
4 If public appeals result in higher donation rates, solicitation of organ donation could benefit  
5 everyone on the national waiting lists.<sup>27</sup> The potential effect of public solicitation on overall  
6 donation rates is unknown, as is the extent to which waitlisted individuals are disadvantaged as a  
7 result of solicitation.<sup>28</sup> Given these unknowns, it seems wise to generate information to answer  
8 these questions rather than make an uninformed judgment based on assumptions that may or may  
9 not be valid.

10  
11 A justification for allowing individuals to direct their organs to family members and close friends is  
12 the special bond of these intimate relationships; the same bonds do not exist between people who  
13 have no prior relationship.<sup>9</sup> Some have argued that there is a prima facie obligation for family  
14 members to donate, and that a campaign that seeks to further the cause of one individual by  
15 reaching into a large community with many similarly suffering individuals is, on egalitarian  
16 grounds, unjust.<sup>29</sup> A different view of justice, however, has led others to argue that individuals in a  
17 free society may reach agreements with others, by right, without outside interference; thus, there is  
18 no warrant to prohibit public solicitation of organs.<sup>30</sup>

19  
20 Currently, individual transplant centers have to determine how to allocate non-directed donations  
21 from living donors. Regardless of how a potential living donor and a transplant candidate came to  
22 be connected, the health care team must evaluate the suitability of the potential donor and the  
23 transplant candidate.<sup>31</sup> A physician should resist pressure to participate in a transplant that he or  
24 she believes to be ethically improper and should not pressure others to participate if they refuse on  
25 ethical or moral grounds.<sup>32</sup>

## 26 27 CONCLUSION

28  
29 Although the effect of public solicitations for donor organs has yet to be fully established,  
30 physicians should support policies that can increase the quantity of available donor organs without  
31 unreasonably disadvantaging individuals already on transplant waiting lists. Physicians may also  
32 participate in the transplantation of publicly-solicited organs when appropriate ethical safeguards  
33 outlined in this report and its recommendations have been followed. Alternatively, physicians may  
34 refrain from participation in such transplantations on the basis of their own ethical or moral beliefs.

## 35 36 RECOMMENDATIONS

37  
38 The Council on Ethical and Judicial Affairs recommends that the following be adopted and the  
39 remainder of this report be filed:

40  
41 The obligation of physicians to hold their patients' interests paramount and to support access to  
42 medical care requires that maximizing the number of medically suitable solid organs for  
43 transplantation by ethical means should remain a priority of the medical profession. Donation of

1 organs to specified recipients has been permitted by donation policy since the beginning of organ  
2 transplantation. Although directed donation is permitted under current national policy, solicitation  
3 of organs from potential donors who have no preexisting relationship with the recipient is  
4 controversial. The Council offers the following guidelines regarding solicitation of organ donors.

- 5
- 6 (1) Solicitation of the public for organ donation on the organ supply or on transplant waiting  
7 lists has unknown effects. Policies should be based, as far as possible, on facts rather  
8 than assumptions, so physicians should support study of the current system and  
9 development of policy based on the results of such studies.
  - 10
  - 11 (2) Directed donation policies that produce a net gain of organs in the organ pool and do not  
12 unreasonably disadvantage others on the waiting list are ethically acceptable, as long as  
13 donors receive no payment beyond reimbursement for travel, lodging, lost wages, and  
14 the medical care associated with donation.
  - 15
  - 16 (3) The health care team must fully evaluate the medical and psychosocial suitability of all  
17 potential donors, regardless of the nature of the relationship between the potential donor  
18 and transplant candidate.
  - 19

20 A physician should resist pressure to participate in a transplant that he or she believes to be  
21 ethically improper and should not pressure others to participate if they refuse on ethical or moral  
22 grounds.

23  
24 (New HOD/CEJA Policy)

Fiscal Note: Staff cost estimated at less than \$500 to implement

## ACKNOWLEDGMENTS

The Council gratefully acknowledges the following individuals and organizations for their contributions to this Report:

The American Society of Transplant Surgeons Ethics Committee (comments submitted by Charles Miller, MD, Chair); Francis L. Delmonico, MD, President, United Network for Organ Sharing; Professor of Surgery, Harvard Medical School, Visiting Surgeon, Transplantation Unit, Massachusetts General Hospital, Medical Director, New England Organ Bank; Timothy Murphy, PhD; Professor of Philosophy in the Biomedical Sciences, University of Illinois College of Medicine; Mary Simmerling, PhD, University of Chicago, Social Sciences Division; Northwestern/Northwestern Memorial Hospital Organ Transplantation Ethics Group.

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