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# Internet Organ Solicitation, Explained

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**The growth of internet-based communications and the increasing demand for living organ donors are resulting in more use of Web sites for organ solicitation. Web resources have the capacity to improve public awareness about both organ donations and transplant outcomes. Rules for organ donation and fair allocation must follow legal principles regarding organ solicitation. Categories of internet recipient/donor matching services include "clearing house," "membership," and "individual" sites. All these raise ethical concerns related to the individual recipient/donor relationship and to the current system of organ allocation. However, a lack of rules and regulations regarding internet solicitation exists. Several pragmatic steps are proposed.**

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**Index Words:** organ donation; transplant; internet; solicitation

Rising demand for Internet use has led to dramatic growth of Web-based communication in our society. Web-based communication is used by more than 200 million adults in the United States, which gave birth to both the Internet and the Web browser, and where computers are nearly universally available. In an unfortunate parallel, the demand for kidney transplants has also grown dramatically, as evidenced by recent United Network for Organ Sharing (UNOS) data. The waiting list for kidney transplants has grown to nearly 90,000 individuals, and the average waiting time has increased to 1,199 days. The list will be joined by 40,000 individuals this year. Over half of listed patients will die as their hopes for a transplant run out. The waiting list is growing at five times the rate of kidney donations.

Living-donation rates in the U.S. have recently increased to the extent that living kidney donation is the predominant form of kidney donation (Fig 1).<sup>1</sup> About 7,000 people became living kidney donors in the U.S. in 2004. About one third of the living donors are genetically unrelated to the recipient (Fig 2), which includes a spectrum of donor-recipient relationships, from spouse to friend to anonymous donors. A small segment, but one that shows growth potential, is the nonspouse, unrelated-donor group, a cohort that has dem-

onstrated 20-fold growth over the past 10 years and now totals twice as many donations as from spouses. Living donations might be further increased through more active pursuit of organ donors, including those solicited through media such as the Internet.

Those two very different trends—Internet demand and transplant demand—have recently intersected because of organ solicitation and donor-matching services on the Internet. In 1997, cases of directed organ donations by absolute strangers were documented,<sup>2</sup> but currently, dozens of such cases are known, and the number of Web sites used for solicitation continues to grow. The result is an intensifying debate about the role of the Internet in kidney-organ solicitation.

## Background

With kidney transplants now increasingly performed between individuals who are genetically dissimilar, the relationship between living kidney donors and transplant recipients has become more diverse. Historically, living donors have shared some genetic or emotional relationship with the organ recipient.<sup>3</sup> Data on the source of kidney-transplant donations were reviewed in the *New England Journal of Medicine* recently.<sup>4</sup> Categories of living donors include directed donations to a family member, loved one, or friend ("contingent" donations); nondirected living donations ("anonymous" donations); live-donor paired exchanges (which involves two living donors and two simultaneous transplants); and directed donations to a named stranger. The last may in some cases have a basis of religion,

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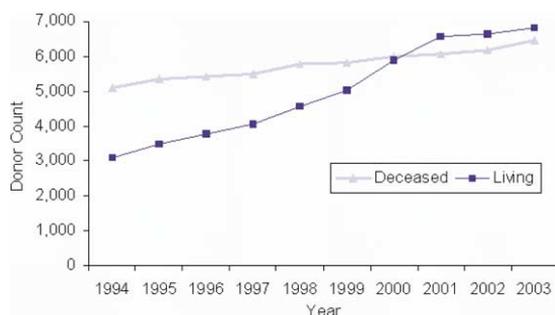
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**Figure 1.** Deceased and living donors. (Reprinted with permission from Davis CL, Delmonico FL: Living-donor kidney transplantation: A review of the current practices for the live donor. *J Am Soc Nephrol* 16:2098-2110, 2005.

ethnicity, or other personal characteristic that forms the donor-recipient relationship.

The role of the Internet in personal health continues to expand, with a growing number of Web sites offering a wide range of information sources, online chat rooms, and forums to consumers. The number of health-related Internet sites is growing exponentially. The positive effects of the Internet, including prescription medication information, clinical trials results, telemonitoring, and rapid patient-physician communication, have empowered patients to take a more active role in improving and maintaining their health. With regard to organ transplants, the number of persons who access the Internet specifically about transplantation has grown.<sup>5</sup> Web resources have the capacity to improve public awareness about both organ donation and transplant outcomes. Organ-donation registries, for example, have been used in some states to increase public awareness of the need for organ donations and to allow individuals to indicate their intention to donate. Visitors to an organ-donation Web site were more likely to join a registry, as shown by one study.<sup>6</sup> Free and commercial Web sites provide opportunities in which recipient and donor may initiate a relationship. Such information technology may help speed the rates of organ donation.<sup>7</sup> However, accreditation of Internet health sites<sup>8</sup> and guidelines for Internet use by patients are lacking.<sup>9</sup>

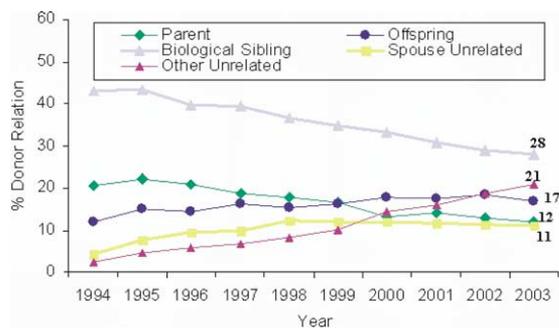
Helped by information on the Internet, those in need of organs are joining a grassroots movement of donor solicitation with

increasing frequency. A number of options exist for self-advertising by potential recipients in cyberspace. In fact, the movement is similar to recent trends toward self-representation by individuals within the legal system ("pro se" representation).

## Legal Background

Rules for organ donation and fair allocation are based on a well-known legal background that the renal-care provider should know. The current controversies regarding organ solicitation, while ethically complex, must take into account this legal background. Important existing legal principles include the following:

1. Buying and selling human organs is strictly prohibited by law in the United States. The landmark National Organ Transplant Act (NOTA),<sup>10</sup> passed in 1984, forbids "any person (to) knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in a human transplantation if the transfer affects interstate commerce."
2. It is against the law to benefit financially from organ donation. Of note, removal of certain financial disincentives for live kidney donors is in effect for some. The Organ Donor Leave Act permits federal employees to take paid leave toward donating an organ, a policy being adopted by some states and businesses. "Reasonable payments" are also permitted to cover ex-



**Figure 2.** Living donor relation to recipient for kidney, 1994 to 2003. In 2003, 11% of living donors fall under another relationship to donor group. (Reprinted with permission from Davis CL, Delmonico FL: Living-donor kidney transplantation: A review of the current practices for the live donor. *J Am Soc Nephrol* 16:2098-2110, 2005.

**Table 1.** Categories of Web Sites Used for Organ Solicitation

<i>Type</i>	<i>Example</i>	<i>Purpose</i>	<i>Objective</i>
"clearinghouse"	www.matchingdonors.com	Venue for advertising by potential recipients	Directed donation
"membership"	www.lifesharers.com	Voluntary network of potential donors	Directed donation
"individual"	www.toddneedsaliver.com	Plea from individual patient	Directed donation

penses incurred by a living organ donor, such as travel and subsistence expenses and lost wages, by NOTA. The recently enacted Organ Donation and Recovery Improvement Act provides a federal program to finance such payments.

3. Solicitation of an organ donation through advertising media, including billboards, television, and the Internet is not unlawful.
4. Directed donation is allowed by state and federal regulations. Federal regulations define and authorize directed organ donations, referring to "the allocation of an organ to a recipient named by those authorized to make the donation."<sup>11</sup>
5. State law (Florida) prohibits patients or their families from placing any restrictions on the allocation of a donated organ, living or cadaveric.<sup>4</sup>

### United Network for Organ Sharing

The more than 88,000 Americans waiting to receive a transplanted organ are registered through UNOS ([www.unos.org](http://www.unos.org)), the private, nonprofit agency that manages the U.S. organ supply. UNOS operates the Organ Procurement and Transplantation Network (OPTN) under contract with the U.S. government. It is also significantly funded through individual registration fees collected at the time of wait-listing of the recipient candidate. Only organs donated for transplantation from registered deceased donors whose families consent can be allocated through UNOS. UNOS provides the framework for matching recipient and cadaver donors in the U.S. As such, it operates under the following main kidney organ-distribution principle: equitable distribution of available organs on the basis of the length of time waiting. In implementing the policy, UNOS maintains recipient waiting lists and is

responsible for prioritizing listed patients. When a donated organ becomes available, information about the donor is entered into the UNOS computer system, which then creates a list of potential recipients for the organ on the basis of compatibility and waiting time.

As recently noted, however,<sup>11</sup> the OPTN was charged by the Department of Health and Human Services in late 2004 with becoming similarly active in transplantation involving living donors. The increase in jurisdiction is in recognition of the growing number and, in some cases, the complex nature, of living-donor donation.

### Internet-based Matching Services

Internet recipient/donor matching services have in common the direct purpose of bringing together a needy recipient with a sympathetic potential donor. Indirect benefits include an increase in the number of living-donor transplants and transplant awareness and a decrease in waiting times for at least some wait-listed patients. Because of significant differences, however, recipient/donor matching Web sites may be separated into at least three categories (Table 1).

#### "Clearinghouse" Web Sites

The emergence of the prototype "clearinghouse"<sup>12</sup> Web site, MatchingDonors.com ([www.MatchingDonors.com](http://www.MatchingDonors.com)), in 2004 has had the greatest impact on solicitation and directed donations. The Web site provides a venue by which recipients can advertise their needs globally, and potential recipients and donors can communicate. Potential donors can browse the listed patient profiles without joining. An interested donor can e-mail and arrange to meet the patient. Pursuant to donation, the interested party then contacts the transplant center that

coordinates the recipient's care. Initial blood sampling can then be arranged.

This nonprofit entity was created by a Boston-area physician and his patient, whose father was in urgent need of a kidney transplant. (At least one for-profit alternative, [kidneymatch.com](http://kidneymatch.com), also exists.<sup>13</sup>) Recipient profiles and pleas for organs are posted for a monthly fee, which provides its basis of operation. The fee may be waived for those unable to afford the service. All money paid by patients is applied to operation of the Web site. Other revenue comes from money donated to the corporation, which goes toward helping pay for patient memberships, and money from advertising sold to physicians and hospitals. About half of recipient candidates profiled pay the full monthly fee. Donor testing is typically covered by the patient's insurance. [MatchingDonors.com](http://MatchingDonors.com) can also provide expert biography assistance for an additional fee. However, the site performs no validation of the recipient information; provides no screening for potential donors for medical, psychiatric, or other problems; and bears no responsibility for the outcomes of matches achieved through its Web site. It does not attempt in any way to uncover or prevent extortion involving members.

The nonprofit site has paired more than 25 living organ donors and recipients since 2004, and more than 10 transplants, all kidneys, have taken place. With more than 2,000 registered potential donors, others are reportedly matched and waiting for surgery. Of note, the first transplant procured through the Web site, in Denver, Colorado, received wide media attention and was initially postponed over ethical concerns of commercialism. A specific concern was the acknowledgement that the recipient paid the donor \$5,000 for travel expenses, although payment to the donor family for expenses is allowed by U.S. law, as noted above.

#### *"Membership" Web Sites*

The Internet has also made possible the implementation of a voluntary network of organ donors, whose members form an advanced directive-donor registry.<sup>14</sup> Lifesharers ([www.lifesharers.com](http://www.lifesharers.com)), formed in 2002, is a nonprofit voluntary organization with free membership,

whose members act in their own self-interest, not altruism. Members pledge to donate their own organs upon their death and give fellow members first access to their organs. In turn, members get preferred access to other members' organs, in case a need arises. Allocation occurring before the organ goes into the nationwide waiting pool of recipients. The obligation of the local organ-procurement organization to offer the organ to Lifesharers members is based on legal principle and the language on the donor card. The next of kin are relied upon to monitor the process. Members retain the right to donate organs to their family as first choice, and if the organ is not accepted by a suitable Lifesharer match, it will be offered to nonmembers. With less than 3,000 members, however, this Internet source is not large enough yet to provide a significant source of organs for transplantation. Its major feature is the principle that organs are in such cases the private resource of the donor, not a public resource to be allocated.

#### *"Personalized" Web Sites*

In personalized Web sites created by and for individual recipients only, case-by-case solicitation is sought. Individualized Web sites allow patients to independently solicit organs from the general public. Although the number of such sites is impossible to determine, they are born solely of the quest to establish a recipient-donor relationship for the purpose of transplantation.

#### **Ethical Concerns**

The ethics of organ donation by living donors, including Internet solicitation of organs, was recently reviewed for the general medical readership in three articles in the *New England Journal of Medicine*.<sup>4</sup> To varying degrees, all three types of Internet-based solicitation raise similar concerns that range from issues related to the individual recipient/donor relationship on the one hand to the impact on the current system of organ allocation on the other. The predominant concerns are (1) ethical questions about financial exploitation in individual cases and (2) subversion of the current network of organ allocation in the

United States.<sup>15</sup> These issues have generated input from experts in transplantation and ethics and created a necessary debate, out of proportion to the numbers of patients affected at least at the current time.<sup>16</sup>

Three primary ethical issues involve the donor/recipient. First, the potential exists for current Web sites to discriminate against recipients already disadvantaged by the "financial shock of serious illness,"<sup>17</sup> because of inadequate resources to pay for the service, lack of computers or computer skills, or a biographical profile that is unappealing. Second, further discrimination is possible when the recipient is selected on the basis of a donor's preference for a race, a religion, or an ethnic group.<sup>4</sup> Third, historically, the leading principle of kidney transplantation has been that donated organs are a voluntary "gift of life." Even legislation that approves payment for donor expenses has provided some public policy controversy. Financial compensation directly through cash payment, or through a variety of indirect means, converts organs into commodities to be purchased, which creates the potential paradox of financially needy donors receiving payment from well-off recipients. Legally, financial coercion would break the federal law against organ trafficking,<sup>12</sup> and payments "under the table" would be unethical.

Although no public allocation system exists for organs from living donors, equally important ethical issues are nonetheless raised when unregulated public solicitation of living donors threatens the fairness inherent in the allocation system that does operate under UNOS. The leading principle of deceased-donor allocation within the current anonymous and nonprofit system is to establish the best outcomes for the maximum number of patients (ie, a social distribution of the resource). Internet solicitation, on the other hand, suggests that allocation is part of the problem, not the solution. Ethicists charge that when solicited organs are going to those less disadvantaged and not those in greatest need, others may be unwilling to donate to the system. The ultimate effect of this disparity could be a "public" allocation system diminished by a shrinking number of donors, whereas a separate "private" system flourishes.

## Reexamination of Policies

Notwithstanding the governing principles of transplantation listed earlier, a void currently exists in the rules, regulations, and penalties regarding directed donations and Internet solicitation. Appropriately, UNOS and professional organizations are reexamining, if not modifying, their policies under the pressure of longer waiting times and broader Internet utilization.

UNOS discourages patients from soliciting organs from nonrelated donors. UNOS "will not participate in efforts to solicit living donors for specific transplant candidates." The UNOS Board of Directors is on record opposing directed donations that are based solely on a class or group of individuals who share some nonmedical characteristics.<sup>18</sup>

The American Society of Transplant Surgeons (ASTS) states, "Living donors . . . ought not to profit financially . . . from donation." The ASTS is strongly opposed to "buying, selling, or brokering of organs for transplantation. The ASTS is also strongly opposed to the solicitation of organs by recipients or their agents . . . through commercial Web sites."<sup>19</sup>

The National Kidney Foundation (NKF) recommends that living donation be arranged through transplant centers rather than by public solicitation. The NKF has advocated against federal funding of demonstration projects to evaluate whether financial incentives would increase non-living organ donations. The NKF strongly supports paid leave from work for living-organ donations.

## Conclusion

The current kidney-transplant shortage constitutes a health-care crisis. The profound waiting times have spawned grassroots Internet-based, controversial efforts to improve organ availability for individuals through organ solicitation and directed donations. While empowering the individual, this new paradigm has forced key institutions to reexamine, if not reconsider, their policies on living donations.

As noted by Truog,<sup>4</sup> Internet solicitation of organs is probably here to stay. What is the optimal use of the Internet for organ solicitation? Given the success rates of transplants from living unrelated kidney donors, any in-

dividual who is “competent, willing to donate, free of coercion, and found to be medically and psychosocially suitable”<sup>1</sup> may be a living-donor candidate. Categories of Internet sites for solicitation will likely grow in the future and provide an entire portfolio of options that could attract the majority of potential recipients. If Web-based solicitation grew to be universally available in a format sanctioned by the transplant community, the charge of unfairness would lose credence.

Directed living donations are also here to stay, and they represent a net gain of organs to the system. As evident from the response to organ solicitation, hardly any general regulations regarding screening and assessment of directed donors exist. Much remains to be learned about the impact of directed donations on wait-listed patients in the case of Internet solicitation. For example, are recently listed patients more likely to be matched with a donor? How many listed patients have their status affected? Will altruistic living donations really decrease if solicited transplants come to dominate? These questions bring out the private and public nature of organ donation as a resource.

Leading ethicists will continue to debate the philosophical issues. However, pragmatic changes that will further increase this resource while preserving the public trust in its allocation do not require final policy resolutions. In fact, one can argue that a significant increase in organ donations is by itself fundamental to enhancing trust at this time of profound shortage. As noted by Truog,<sup>4</sup> 20 years of experience in managing the cadaver donor system puts UNOS in a unique position to expand its jurisdiction into living donation; more is likely to be expected from UNOS in the future. Proper regulations over solicitation will help to increase the public endorsement of the existing allocation system in the current crisis. As for the transplant community, it can exert more influence over supervision of organ solicitation by taking the following steps:

1. Continuing to develop and disseminate resource information for persons considering living-directed donations
2. Developing a “seal of approval” for selected Internet sites used for organ solicitation

3. Establishing safeguards and restrictions to assist living-donor programs when a “match” is made between recipient and solicited donor
4. Creating a standardized process for evaluating prospective kidney donors<sup>1</sup>

These pragmatic steps will improve conditions for Internet-based donations and indirectly for all wait-listed patients.

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