# Organ Beneficiary Program: A Next Step

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## Abstract

A point based organ beneficiary (ORB) program is proposed to encourage deceased organ donations. In this program a deceased donor receives donation points upon donating their organ, which can be assigned to designated beneficiaries. The proposed ORB program assists altruism, while providing a non-monetary benefit. It is seen as a next step to the UNOS living donor point policy. A road map for implementing the proposed program is provided. Ethical aspects of this program are discussed. Several unanswered questions are also presented.

## 1. Introduction

The organ supply-demand imbalance problem is well known to the transplant community. Even though more than 478,000 organ transplants have taken place in US(1) since 1988, the organ demand has far out stripped the supply. Between 1995 and early 2009 the total waiting list at UNOS increased from 41,575 to 100,782 (up 142%), while the total number of donors increased from 8,857 to 12,934 (up by 46%) (1). This waitlist is continuing to grow and the unmet need is resulting in increased mortality[i]. A solution to this supply-demand imbalance problem is to increase organ donations from living and deceased donors[ii]. While increasing the living donor population is ideal, historically nearly 80% of donated organs are supplied by the deceased donors. The 2005 IOM committee report(2) conservatively estimated the yearly eligible deceased donor pool at 30 to 40 thousand (~22,000 donors satisfying circulatory determination of death, and ~10,000 to 17,000 satisfying neurologic death criteria(2)). From this estimated donor pool only 7,983 deceased donations were made in 2008(1). This is a success rate of 25% or less!

Modification of donor and donor family motivations, attitudes and beliefs is important to increase the donor pool. In fact, U.S population attitude towards organ donations has changed significantly over the years(2)[iii]. However, despite the change in population attitude, pro-active donor management protocols(3-5), state laws[iv], and the donor promotion campaigns by various OPOs, the total number of organ donors peaked at 14,753 in 2006(1). This number has declined for two years in a row among the living and the deceased donors(1). This major discrepancy between expressed willingness and actual donations may be due to factors such as stress surrounding death, misperceptions, mistrust about the medical system(6), and some yet to be understood reasons.

In management practices incentives are used to modify behavior. While the use of financial incentives has been advocated(7-9), such incentives are considered controversial(10). The

National Organ Transplantation Act(11) (NOTA) explicitly rules out organ commerce, and financial incentives are considered in violation of NOTA. Consequently, the current system relies on altruism, community spirit, and reciprocity as primary motivation for acceptable appeals for donations(2). Sade(12) argued, "…those with the power to give or withhold organs perceive little personal stake in donation." … "to agree to donation, such (donor)[v] families must be offered benefits that have greater value to them than those that weigh toward declining donation." This view is consistent with the findings and the decisional balance scale in Robbins et al.(13) evaluating donor stage of readiness. While NOTA rules out organ trade, it does not rule out a non-tradable, non-financial benefit. In fact, the UNOS kidney allocation policy(14)[vi] awards four points to a living donor giving them a priority on the waiting list if needed[vii](2). This point award can be viewed as a benefit to promote living donations. Similarly, the proposed ORB program provides a benefit to promote deceased donations.

Section 2 gives reasons to see the ORB program as a next logical UNOS step by putting it in the context of living donor point program, directed donations ORB program and the paired-exchange program(15). Potential benefits of the ORB program are discussed in Section 3. Section 4 gives an implementation roadmap. Section 5 argues that ORB program does not violate NOTA. Section 6 has an ethical discussion for the ORB program. Some unresolved research questions are discussed in the concluding section.

# 2. Organ Beneficiary (ORB) Program

In the proposed ORB program an individual whose organs are successfully recovered after death receives points (called ORB points) which are donated to beneficiaries of choice. These ORB points may be used for getting a priority on the waitlist in case of a future transplantation need. As a result chosen loved ones may potentially benefit from organ donations from a deceased donor.

ORB program can be seen as a strong motivator for individuals wanting to see their loved ones benefit from their donations. Given a choice such donors would much rather choose to preserve their organ for later transplantation to their loved ones, instead of acting altruistically. In the absence of the organ preservation technology, ORB program is a management/systems solution to the problem. We now explain why ORB program is the next step to the existing UNOS living donor point policies, the pair-exchange programs(15), and the practice of directed donation.

### 2.1 ORB Program as a Next Step to the Current Living Donor and Directed Donation Policies

UNOS/OPTN follows a point system in making kidney allocation decisions. A living donor may choose the recipient, and the donor is given four points for use in the kidney allocation system in case of a future need. These points received by a living donor[viii] give this donor a preference in the waitlist. The proposed ORB program takes this concept further in two conceptual steps: (i) it provides points to a deceased donor upon harvesting their organs; (ii) it allows a restricted gifting of points from a deceased donor to a beneficiary. We discuss these below in the context of current UNOS policies and practices.

We first show that the current **UNOS living donor policy is equivalent to rewarding and gifting donation points** using a quantitative argument. Assume an alternate system where a living donor is only assigned points (say ten) and instead of choosing the donated organ recipient he is given a choice of gifting some of these (in this case six) points to a person on the waitlist. The addition of 6 points to the chosen person on the waiting list effectively bumps this person to the top of the list, allowing them to receive the desired organ (in this case the one made available by the donor). The remaining four points are kept by the donor for a future need. The just described approach exactly replicates the current UNOS policy.

UNOS allows a directed donation practice in which a deceased donor or donor family can choose the organ recipient(16). This practice is legally authorized by the uniform anatomical gift act (UAGA(17)) and by most state anatomical gift laws, which use UAGA as a guide(18). From the above discussion on living donor policy also suggests that the **directed donation practice also implicitly assigns points to a deceased donor and allows gifting of these points to the recipient of choice!** In fact, by identifying the organ recipient, the directed donation practice gives an even more preferential treatment to the beneficiary than possible in the ORB program. We will discuss this further in the section on ethics.

### 2.2 ORB Program as an Extension of the Paired-Exchange Program

We now compare the ORB program with the established paired-exchange programs on the basis of the central problem they solve. A similar argument will draw parallels with the non-simultaneous organ exchange program as well. The concept of living donor paired kidney exchange program was set forth by Rapaport(19). It gained greater acceptance since the report of Ross et al.(20). The rationale behind the paired exchange program is that genetically unrelated but emotionally involved donors are often not histocompatible. It may be possible, however, to make two (or more) pairs of compatible donors, from two (or more) pairs of incompatible donors. For example, person A may want to donate his kidney to B, but is incompatible. Similarly person C may want to donate her kidney to D, but is incompatible. However, A is compatible with D and C is compatible with B. Hence, an exchange, if agreed upon, results in two transplantations, when there was none possible in the beginning. This is shown in Figure 1. The desired donations are shown by broken arrows, and the actual transplantations are shown by solid arrows.

Now assume that persons S and T are emotionally involved, and S would give his kidney to T if T is in need, and S is living. Similarly, at a future date U and V are emotionally involved, and U will give his kidney to V if V is in need, and U is still living. S (U) can't give his kidney to T (V), since S (U) is dying for other reasons, and T (V) does not need it now! This is shown in Figure 1. The actual donations are shown by solid arrows. S does not know the person receiving his organs. At some time in the future (time separation shown by dotted line) because of ORB points T receives U's kidney. Also, V's need will arise at some time further in future. The situation is similar to that in the paired-exchange program, except instead of histocompatibility, the time lag between the availability and need of a perishable resource is the problem[ix]. However, through the ORB program by providing a preference to T in the future, S has potentially given a gift of life to T. This solution is then similar to the paired-exchange solution to the histocompatibility problem.

## 3. Potential Ways the ORB Program Can Promote Organ Donation

The living donor system is clearly an incentive to promote organ donations. It provides an immediate benefit to the chosen (in case of non-anonymous donations) loved one, and provides some security to the donor for future need. Similarly, the ORB program is an incentive to promote deceased donations, and it gives priority to the loved ones of such donors should they need a kidney in the future.

The knowledge that a loved one may benefit from our actions is a powerful incentive. While discussing alternative methods to increase donation based on their telephone survey and focused group study Peters et al.(6) state, "Many in both donor and non-donor groups felt as though preferred status (families having donated a loved one's organs would receive preferential care if subsequent need for an organ arose) was a reasonable incentive." The ORB program formalizes this incentive for the deceased donors. For the family members this possibility also allows for an open discussion under normal circumstances, while making choices. In addition, since points are allocated only for healthy donated organ, it may help expedite organ recovery.

The ORB program may also help counter negative perceptions regarding donation. Some of these perceptions have to do with mistrust of the medical community in general, or mistrust resulting from a perceived conflict of interest of an organ recovery organization/agent by viewing their donation requests as self-serving(12). Education and dissemination of information about donation and transplantation that counter these negative perceptions will be facilitated by the ORB program by providing additional talking points for community education by individuals with no conflict of interest in promoting donation. Furthermore, since a loved one is identified as a potential beneficiary of the program, individual doubts about the transplantation equitability across communities can be countered. In summary the ORB program:

- Assists altruism while giving potential preferential treatment to a loved one
- Provides a talking point to initiate interpersonal communications around donation.
- Provides a new promotion and advertising tool for local or national organ recovery organizations.
- Provides opportunity for a third party, with no apparent conflict of interest, to educate general population regarding the benefits of organ donation.
- It gets around the "yuk" factor associated with providing monetary incentives for donation.

## 4. A Roadmap for Implementing the Proposed ORB Program

The concept of ORB points is new, and it raises new legal questions. We now provide a tentative time-phased plan for implementing the ORB point program while taking into account the current US legal process of administering the estate of a deceased. This should be considered a draft proposal, open to further debate and discussions.

**Implementation Phase I: Indicate ORB Point Allocation Beneficiaries in the State Donor Registries**

In Phase-I implementation a potential donor will indicate ORB beneficiaries at the time of registering to donate through the state registries (http://www.organdonor.gov/), or such state dependent mechanisms. The system will allow only designated individuals as beneficiaries with the option of designating no beneficiaries. A fixed number of points can be distributed over several beneficiaries. The system may cap the number of designated beneficiaries (for example, four) that can be input by a donor in the system. A potential donor may change beneficiaries at any time. Trading or exchange of ORB points will be strictly prohibited. Any unused points available to a beneficiary expire, should the need for using these points does not arise during their lifetime.

If no beneficiary is designated, then no ORB points are allocated. Also if a designated beneficiary is deceased before donor's death the points indicated for this beneficiary are not reallocated (gifted). In the event that all designated beneficiaries are deceased before donor's death the ORB points will not enter into a probate court. Also, organ donations through second person consent will have no designated beneficiaries, and will not enter into a probate court. The information on beneficiaries, together with donor information, will be maintained at a central registry after receiving the ORB points. There will be no cap on the number of individuals who can donate to a beneficiary. Similarly, there will be no cap on the total number of benefit points received by a recipient.

The concept of designating ORB point beneficiaries through donor registry has some similarities with that of designating beneficiaries when buying a term life insurance. In term life insurances the financial institution promises to pay the insurance money to the beneficiaries upon death. The life insurance beneficiaries get money based on the insurance policy without probate[x]. The treatment of ORB points as a 'non-probate asset' is consistent with the philosophy of designating beneficiaries on an insurance policy. In both cases the intended purpose is to provide some security to the loves ones.

Only in certain situations a life insurance policy may enter into the probate court. One such case is when no beneficiary is designated, or a designated beneficiary is deceased. By not allocating points in this case, and in the case of second person consent donations, the system will avoid dealing with the complexities of the probate law and process. Also, by requiring beneficiaries to be individuals the system will not allow organizations or living trusts to become beneficiaries.

**Implementation Phase II: Establish ORB Beneficiary Laws for Unregistered Donors**

Allocation of ORB points for donations through second person consent is a complex legal issue. The mechanisms for such allocations can benefit greatly from the existing laws for handling financial assets of a deceased. The laws differ among states within U.S. For example, several state jurisdictions recognize a married couple's property as a community property. In this case, if a person dies intestate, the surviving spouse becomes an automatic beneficiary.

The distribution of financial and material wealth after death to beneficiaries is well accepted. This act of giving can be viewed as an expression of love from the deceased to the living. It is considered ethical in the western society, and brings emotional fulfillment to the giver as well as the receiver. One would contend that while living the human body is the most important

possession one has. If a human body is considered as part of a portfolio of possessions, and not separated from the financial and material wealth, the ORB point giving becomes a logical extension of the concept of financial and material giving upon death. In principle, concepts that apply to personal estate can be extended to ORB points, with appropriate legal restrictions to ensure that ORB points are not commoditized.

# 5. ORB Program and NOTA

The proposed program does not violate the U.S. 1984 National Organ Transplant Act(11), which prohibits "any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce." The intent of the law is to ensure that major "human body parts should not be viewed as commodities."

By strictly prohibiting the trading of beneficiary points the program does not affect the interstate commerce. The ORB program does give importance to the human organs without associating any monetary value. As a result it provides donation benefits without commoditizing the human body.

**Risks for Illegal Point Trading**

Although the trading of ORB points is restricted, there is a risk of individuals paying money to become beneficiaries of a potential donor. These risks are similar to having an illegal organ trade market that finds living donors, or directed donations through monetary compensations. Furthermore, since it is not known with certainty that organs will be harvested from a deceased donor, an agent acting illegally will find it difficult to act.

# 6. Ethics of the Proposed ORB Program

ORB program promotes *the right to choose* a beneficiary. This right is given to a living donor and a living/deceased donor through directed donation. But, it is taken away if the directed donation is not an option for a deceased donor. This is an inconsistency in the current system. The existing system forces altruism on a deceased donor. Isn't it unethical to force altruism, when alternatives are possible? We do not force people to donate their material wealth to charity after their death – we give them options to choose beneficiaries!

This ethical dilemma would not arise if all living donor organs went to a general pool, and people on the waitlist received allocation based on organ availability in this pool – or, if the organs could be preserved. If the organ preservation technology was there, many deceased individuals and their loved ones may find it emotionally more fulfilling to preserve their organ, perhaps by paying a price, for later use by their loved ones. For a deceased donor the choice of wanting to act purely altruistically (or not) should be left to a donor and not forced by the system. The ORB program resolves this ethical dilemma by allowing donors to choose the mode of their emotional fulfillment – through a purely altruistic donation, or through a donation with designated ORB beneficiaries.

The proposed ORB program does not compromise the four guiding principles set by the IOM committee(2): "*common stake in a trustworthy system*," "*acceptable appeals for organ donation*," "*respect for persons*," and "*fairness.*" The proposed program continues to maintain respect for the human body by giving individuals the freedom to choose, and right to assign beneficiaries. It does not question an individual's belief system, and those wishing not to opt in the program can simply do so by not becoming a part of the program, or not assigning a beneficiary.

Another ethical argument favoring point reallocation follows by reinterpreting the word *living*, and viewing a beneficiary as *an extension of the life of a deceased*. The donation points are used for preserving this life-extension, should there be a future need. If it is fair to pass on the financial and material wealth to the loved ones after death, then one would argue that it is equally (and perhaps more) fair to pass on the opportunity to use remaining healthy organs for use by the loved ones. Otherwise, an idealistic purely altruistic system should give all material wealth of a deceased to the state. Altruism, community spirit, and reciprocity have continued importance in the proposed program, much the same way they hold importance in allowing anonymous charitable donations.

One may ask: Does the relative increase in priority obtained through the ORB program discriminate against patients with greater clinical needs but who were unfortunate to obtain points? For example, would ORB beneficiaries be young people, or would members of a social group or race benefit more than others? A scientific answer to such questions need estimates of organ donation increase resulting from the ORB program, and any social bias it creates. As discussed in the Introduction section, today only ~8,000 of the estimated 30 to 40 thousand eligible donors actually donate. There were ~7,000 death removals from the UNOS waiting list in 2008. Since a deceased donor provides three organs on the average, it is then estimated that a 5 to 10% increase in donations from the deceased donors will equal the number of death removals from the UNOS wait list.

We expect that in the short term ORB program's impact on creating a system bias will be minimal. A deceased donor will *supply multiple organs much before* the designated beneficiaries will be put on the waiting list. Moreover, the beneficiary may never have a need to be on the waiting list. Hence, if a bias is created it will be in the future. By that time, ideally, the entire population would know and have an opportunity to participate in the ORB program. In the mean time, many lives will be saved. Finally, the technological developments (for example, research on artificial organs, tissue engineering, and organ preservation) may make the issue redundant in the future.

**Coercion, Right to Withdraw, Privacy and Confidentiality**

The right to withdraw from the program, change beneficiaries, maintaining strict privacy and confidentiality should obviously be part of a fair and trustworthy system that is respectful of donor's wishes. One may fear that the ORB program may compromise the decision ability of those with knowledge of them being the beneficiaries. While maintaining confidentiality protects one, the decision process of providing end-of-life therapy and withdrawing life-support of a dying patient should not change, irrespective of a patient's donor status. The role of the

physician team determining death, the family decision to terminate life-support, and discussions with local OPO representatives should be strictly separated. Furthermore, since the decision makers are healthy individuals with limited knowledge of their future needs, it is unlikely that they will make a decision that is not in the best interest of a patient. We believe that with a well managed decision system any residual risk of coercion are outweighed by the potential benefits of the ORB program.

## 7. Future Research Questions and Concluding Remarks

Proposal of any new system raises many questions. It is beyond the scope of this paper to answer them all. However, we describe some of these questions requiring consideration prior to implementing this program. The point system is easier to manage for the prior living donor, since typically only one vital organ (or organ segment) is donated. It is not clear if the same point system is fair in case of a deceased donor. We need to answer questions such as: How many points should be given to a deceased donor? This is further complicated by the fact that in the past on the average a deceased donor provided more than three organs[xi], and some of these (e.g., heart) organs are scarce. Should extra points be given to a deceased donor providing multiple organs? Should there be organ type and quality considerations while assigning points? In Phase-II should the system allow roll-over of points from one generation to the next generation? What is an equitable point allocation approach for second person consent donations?

The proposed ORB program requires some foresight from potential donors in seeing the benefits of donation. However, herein exists an educational opportunity. It is easy to compare the ORB program with buying a term life insurance policy. Both are for the benefit of love ones. They both provide a resource for emergency, which may never arise and this resource may never be truly needed.

In summary, the ORB program is an ethical next step to current UNOS practices and it meets the guiding principles of the IOM committee. It does not violate NOTA, and in fact, it makes the directed donation practice consistent across deceased donors. It achieves a greater social justice by recognizing donors (deceased or living), and increasing the potential of organ donation.

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[i] Year 2008 saw 6,118 death removals from the transplant waiting list as compared to 3,723 in 1995 (up 64%) from this waiting list.
[ii] As of early 2009 381,571 of the 48,044 transplanted organs were provided by the deceased donors.

[iii] A 2005 Gallup survey showed that since 1993 the number of Americans granting permission for organ or tissue donation on their driver's license or an organ donor card has grown from 28% to 52.7%. An additional 19% were willing to donate. Nearly all the survey respondent (97%) said they would donate a family member's organs if the family member's wishes were known, and 71% (up from 47% in 1993) would donate even if they did not know the family member's wishes. Also 71% (up from 52%) of Americans have told a family member about their wish to donate their organs or tissues or a family member has told the respondent about their wishes. 16.5% of the population said that they would be more likely to donate their organ if paid a financial incentive to them or their families, and 18.7% say that they would be more likely to donate a family member's organs if given an incentive. A similar proportion say that they would be "more likely to donate a family member's organ if paid an incentive.

[iv] Several U.S. states have laws that make the first person consent legally binding, and do not require family consent for deceased donors.
[v] (donor) added
[vi] According to article 3.5.11.6 of UNOS policy and by laws, "A candidate will be assigned 4 points if he or she has donated for transplantation within the United States his or her vital organ or a segment of a vital organ (i.e., kidney, liver segment, lung segment, partial pancreas, small bowel segment). To be assigned 4 points for donation status under Policy 3.5.11.6, the candidate's physician must provide the name of the recipient of the donated organ or organ segment, the recipient's transplant facility and the date of transplant of the donated organ or organ segment, in addition to all other candidate information required to be submitted under policy. Additionally, at the local level of organ distribution only, candidates assigned 4 points for donation status shall be given first priority for kidneys that are not shared mandatorily for 0HLA mismatching, or for renal/non-renal organ allocation irrespective of the number of points assigned to the candidate relative to other candidates. When multiple transplant candidates assigned 4 points for donation status are eligible for organ offers under this policy, organs shall be allocated for these candidates according to length of time waiting."
[vii] In 2004 the U.S. Health Resources and Services Administration asked the Institute of Medicine (IOM) to study this problem. A committee of experts from a wide range of areas was formed. This committee arrived at its recommendations after making careful ethical, legal, and medical considerations. The IOM committee ruled out a financial incentive based system. Additionally it recommends, "Individuals who have recorded a willingness to donate their organs after their death should not be given preferential status as potential recipients of organ."
[viii] Article 3.5.11.6 of the UNOS policy and bylaws also gives a priority at the local level, but for the purposes of our discussion we will ignore this.

[ix] Note that this will not be a problem if it was possible to preserve the organs of donors S and U.
[x] Probate is the legal process of administering the estate of a deceased person by resolving all claims and distributing the deceased person's property.
[xi] 381,571 transplant organs were provided by 122,355 deceased donors1. OPTN. Organ Procurement and Transplantation Network. 2009 [updated 2009 February 20; cited]; Available from: http://www.optn.org/latestData/rptData.asp. between 1998 and 2008