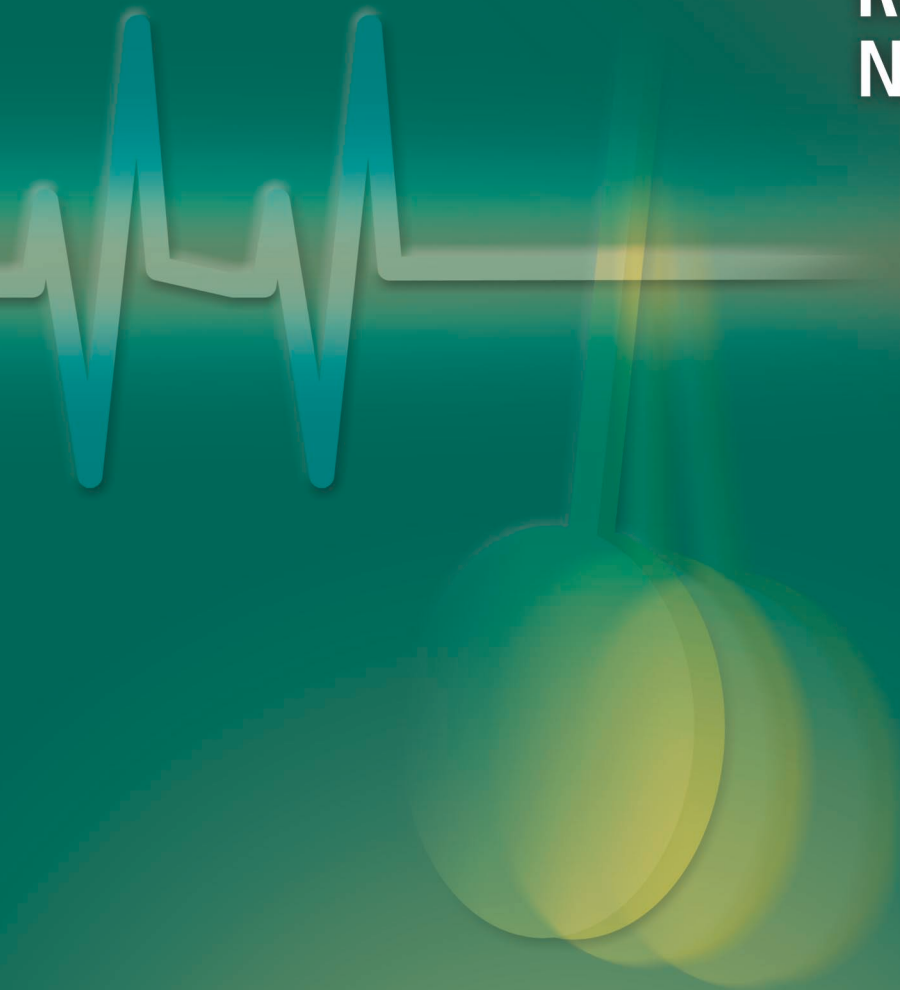


**2006 SUPPLEMENT**

To the position statement  
*Organ Donation and Transplantation:  
Ethical Dilemmas Due to Shortage*

**Paired Organ  
Exchange : Ethical  
Considerations  
Regarding a  
New Option**

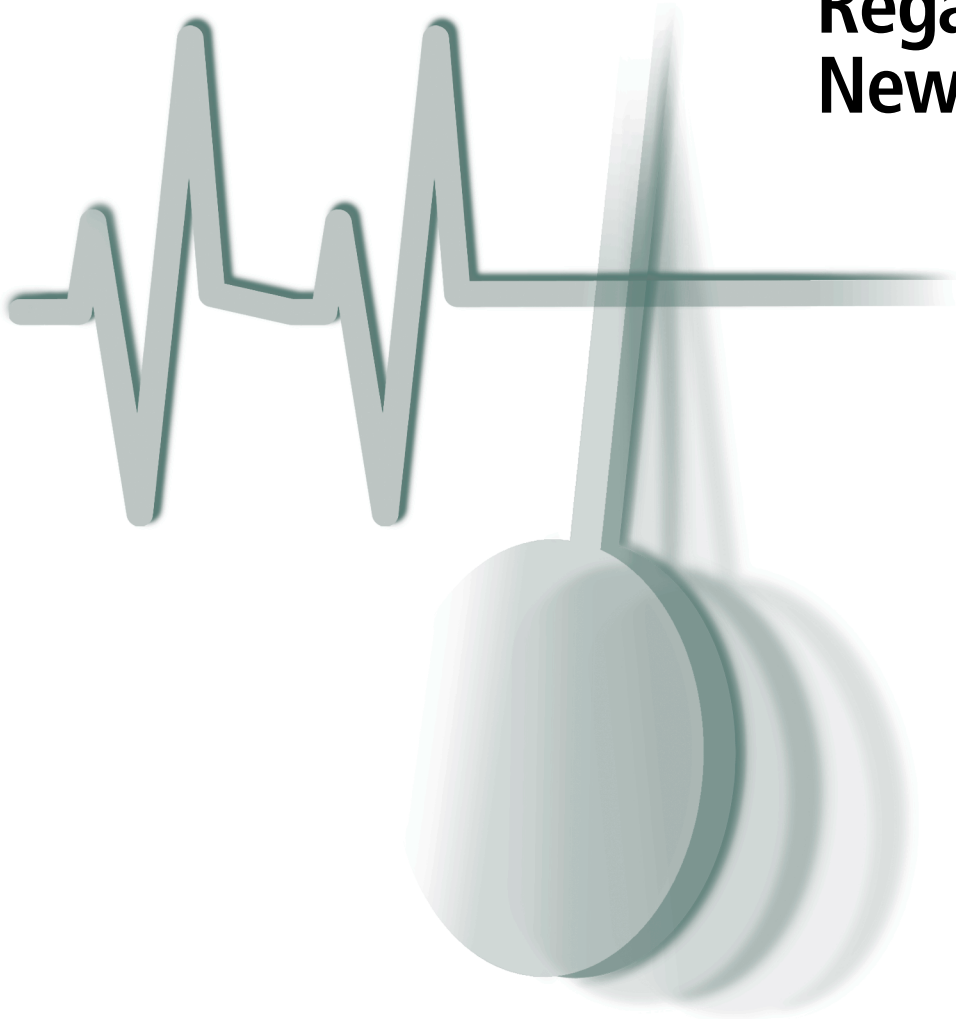




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# Introduction

Despite considerable efforts to alleviate the lack of organs for transplant, the discrepancy between the number of organs available and the number of patients on the waiting list continues to grow<sup>1</sup>. Complementary options to cadaveric<sup>2</sup> donation based on brain death criteria are now in place, i.e., cadaveric donation based on cardiopulmonary arrest criteria, living donation, and artificial organs. Among these innovations, kidney donation between living persons stands out for its scope and the quality of the transplanted organs (higher than that of kidneys harvested from cadaveric donors). In Canada, kidney donation between living persons since 2001 has been just as common a practice (if not more so) as kidney transplantation from cadaveric donors<sup>3</sup>. In 2005, Québec was the Canadian province with the highest rate of cadaveric donors per million inhabitants, but came last for living donations<sup>4</sup>.

One obstacle to kidney donation between living persons is the inability to find a compatible donor among the recipient's loved ones. Yet for

nearly a decade, a new option has been available to patients awaiting a kidney transplant in this situation: paired organ exchange. With this option, a living donor and recipient that are incompatible due to blood type (ABO incompatibility) or immunological reasons (human leukocyte antigen or HLA incompatibility) can be paired with another duo in the same situation. These people may proceed with an exchange in which the living donor's kidney goes to the recipient in the other pair (with whom he or she is compatible) and vice versa. In another hypothetical case, a person may give a kidney to an unknown (but compatible) patient on the waiting list, and, in exchange, the patient on the waiting list with whom this person is incompatible receives priority on the waiting list for a kidney from a cadaveric donor. Last, an altruistic donor (a person who donates a kidney without designating a particular recipient), also called a "good Samaritan", may also be included in a paired organ exchange in order to increase the benefits of this type of donation.

1. According to QUÉBEC-TRANSPLANT statistics. [[http://www.quebec-transplant.qc.ca/QuebecTransplant\\_en/stats\\_en.htm](http://www.quebec-transplant.qc.ca/QuebecTransplant_en/stats_en.htm)]
2. The expressions "cadaveric donation" and "cadaveric donor" are synonymous with "donation from a deceased donor" and "deceased donor". The Commission chose to retain the terminology used in its position statement on donation and transplantation in order to maintain consistency between these two documents.
3. According to Canadian Organ Replacement Register statistics, Canadian Institute for Health Information, 2006. [[http://secure.cihi.ca/cihiweb/disPage.jsp?cw\\_page=statistics\\_results\\_topic\\_transplants\\_e&cw\\_topic=Problèmes%20de%20santé&cw\\_subtopic=Don%20d'organes/transplantations](http://secure.cihi.ca/cihiweb/disPage.jsp?cw_page=statistics_results_topic_transplants_e&cw_topic=Problèmes%20de%20santé&cw_subtopic=Don%20d'organes/transplantations)]
4. For example, in 2005, only 50 of the 225 kidney transplants completed in Québec were made possible by a living donor. However, it should be noted that cadaveric donors are able to give two kidneys each, while living donors cannot.

As this avenue seems promising, is beginning to spur discussion, could possibly be extended to lung and liver donation between living persons, and gives rise to ethical questions, Commission de l'éthique de la science et de la technologie (CEST) decided to issue a supplement on it in the wake of its 2004 position statement on organ donation and transplantation<sup>5</sup>. In this position statement, the Commission already expressed its interest in the ethical issues raised by organ donation between living persons.

After explaining in more detail the main types of possible organ exchange between incompatible living donors and recipients, the Commission looks at the impact this new practice could have on the organ shortage, healthcare costs, and donors and recipients. We then examine a series of ethical considerations, some of which give rise to recommendations for stakeholders. The monitoring and management of a national organ exchange program, donation anonymity, and exchange participant equity and consent are among the ethical issues discussed in this supplement.

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5. COMMISSION DE L'ÉTHIQUE DE LA SCIENCE ET DE LA TECHNOLOGIE, *Organ Donation and Transplantation : Ethical Dilemmas Due to Shortage*, Québec, 2004.

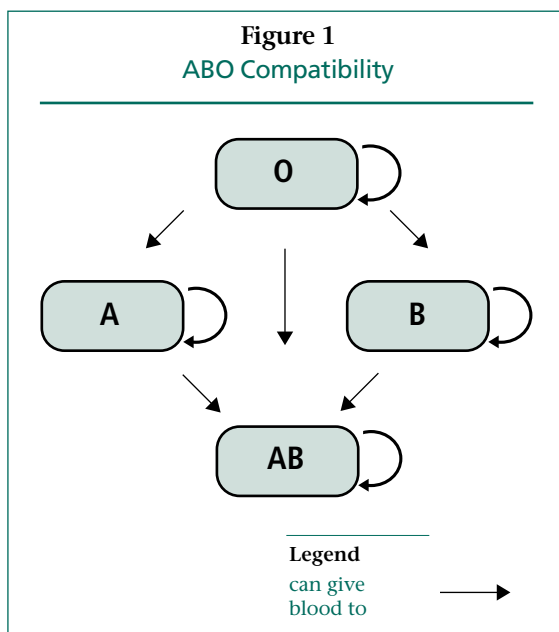
# Section 1 – Types of Paired Organ Exchange

Paired organ exchange is a new option that would enable patients on the single Québec-Transplant waiting list to receive a kidney from a living donor. Of the types of exchange possible, the Commission chose the following three, which are described briefly in order to bring to light the ethical questions raised.

Before proceeding, we will present figures illustrating the different blood types (A, B, AB, and O) and their compatibility. This basic knowledge is essential to understanding how paired organ exchange works and some of the ethical issues it entails. Note that ABO compatibility is the first criterion that must be met for kidney allocation. In the event of ABO compatibility, tests are then run to determine HLA compatibility. A donor and a recipient may be ABO compatible but not HLA compatible, which would prevent kidney donation between them.

Figure 1 indicates that :

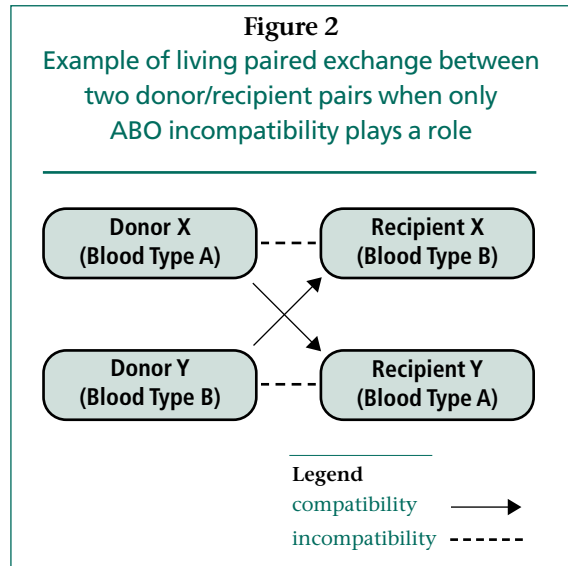
- Each blood type is compatible with itself
- As universal donors, Type O individuals can donate to all blood types, but can receive only from Type O donors
- As universal recipients, Type AB individuals can receive from all blood types, but can donate only to Type AB recipients



## Living Paired Exchange

Living paired exchange is possible when at least two patients on the waiting list for a kidney transplant each have a living donor who is ready to donate a kidney but cannot due to ABO incompatibility (e.g., a patient on the waiting list is Type A and the potential donor is Type B) or HLA incompatibility (i.e., the recipient has antibodies that could result in rejection of the transplanted organ, as demonstrated in a crossmatch test).

Figure 2 shows an example of living paired exchange between two donor/recipient pairs<sup>6</sup>. Donor X wishes to donate a kidney to Recipient X, but they are not ABO compatible. Donor Y wants to do the same for Recipient Y, but they are in the same situation as the first pair. However, Donor X's kidney could be transplanted to Recipient Y and Donor Y's kidney could be transplanted to recipient X.



Living paired exchange can also include individuals who are both ABO and HLA incompatible or only HLA incompatible. This type of exchange can have a greater impact, as it not only enables participation by a wider variety of patients (type A and B donors and recipients as well as type O and AB donors and recipients), but also the pairing of HLA-sensitized patients<sup>7</sup> with compatible donors.

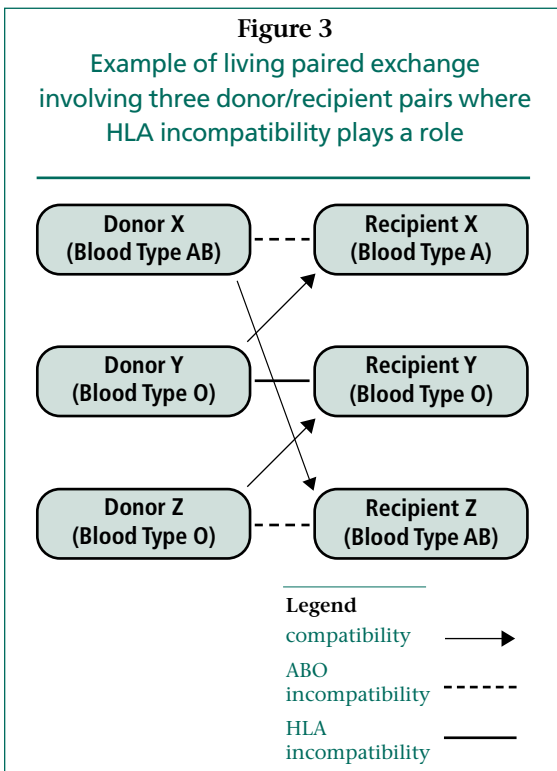
6. While this example shows an exchange between two pairs, living paired exchange can also include more than two pairs at once.
7. HLA sensitization can occur in people who have been exposed to foreign antigens before (e.g., previous transplant or blood transfusion patients, or women who have been pregnant). In such individuals, the immune system can become more sensitive and is therefore more likely to react negatively to a foreign body like an organ from another person. HLA sensitization may significantly increase the likelihood of rejection of a transplanted organ, unless special treatments are administered to weaken the immune system.

Figure 3 illustrates a living paired exchange involving three donor/recipient pairs where HLA incompatibility plays a role. Donor X wishes to donate a kidney to Recipient X, but their blood types are not compatible. Donor Y and Recipient Y are HLA incompatible. Donor Z is ready to donate a kidney to Recipient Z, but they are HLA incompatible. However, Donor X and Recipient Z can be paired because they are both Type AB and HLA compatible. Donor Y is HLA compatible with Recipient X. Lastly, Donor Z and Recipient Y are compatible.

To date, some 100 living paired exchanges have occurred in the United States<sup>8</sup>, while in Canada these exchanges are fairly rare<sup>9</sup>. However, this practice is increasingly spurring discussion. The Canadian Council for Donation and Transplantation (CCDT) published a consultation paper on the topic in October 2005 that was submitted to the Canadian Society of Transplantation annual meeting in March 2006. The paper primarily deals with eligibility criteria for a living paired exchange program and guidelines for this type of exchange. The Commission refers to this document in Section 3 on ethical considerations.

### List Paired Exchange

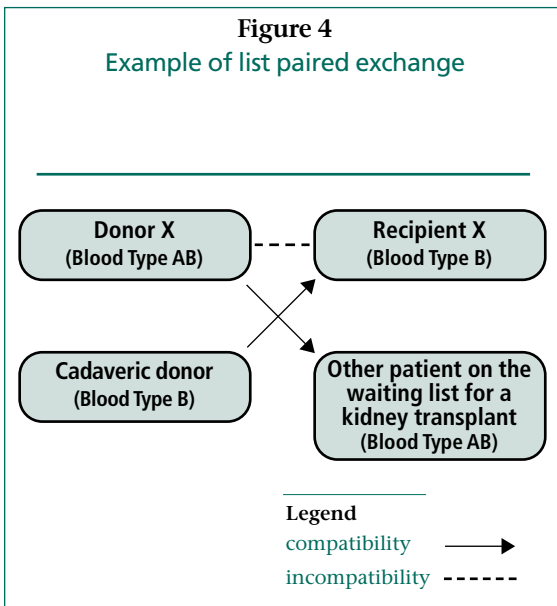
Paired organ exchange can also include cadaveric donors and a patient on the waiting list. In this type of exchange, a living donor who wishes to donate a kidney to another person but cannot due to incompatibility gives a kidney to the first compatible patient on the waiting list. In return, the recipient who is incompatible with the living donor receives priority on the waiting list and increases his or her chances of receiving an organ from a cadaveric donor.



8. According to UNITED NETWORK FOR ORGAN SHARING statistics, *Transplant: Donor Relation by Transplant Year*, data consulted July 14, 2006. [<http://www.unos.org>]

9. "Paired Kidney Exchange Offers Kidney Failure Patients a New Option", [online], March 31, 2006, Toronto, press release. [[www.uhn.ca/media/releases/2006/mar/paired\\_kidney\\_exchange.pdf](http://www.uhn.ca/media/releases/2006/mar/paired_kidney_exchange.pdf)]

Figure 4 shows an example of list paired exchange. In this case, Donor X, who cannot donate a kidney to Recipient X due to ABO incompatibility, donates a kidney to another patient on the waiting list for a kidney transplant. Recipient X then receives priority on the waiting list.



## Altruistic Donation Catalyzing Living Paired Exchange<sup>10</sup>

Altruistic donation catalyzing paired exchange always includes an altruistic donor, an incompatible living donor/recipient pair, and a patient on the waiting list. Initially, the kidney from the altruistic donor, unlike a kidney from a cadaveric donor (given to the first compatible patient on the waiting list), is given to a patient on the waiting list who is already paired with an incompatible living donor. This living donor then gives a kidney to another patient on the waiting list. Therefore, two transplants instead of one are possible thanks to the donation of a “good Samaritan.”

This type of exchange is not currently practiced, but given the growing number of altruistic donations—more commonly called “good Samaritan” donations—the Commission believes it should be included in the analysis. The number of people who donate a kidney during their lifetime without designating a desired recipient is on the rise in the United States<sup>11</sup>. In Canada, the phenomenon appears marginal; nevertheless, British Columbia has put in place a program to monitor the donation and allocation of organs from this category of donors<sup>12</sup>.

10. According to the description provided by Robert A. MONTGOMERY *et al.*, “Domino Paired Kidney Donation : Strategy to Make Best Use of Live Non-Directed Donation”, *Lancet*, vol. 368, n° 9533, July 27, 2006, p. 419-421.

11. The number of altruistic donations increased from 5 in 1999 to 86 in 2003, and has since remained stable (2004 = 89, 2005 = 89) according to UNITED NETWORK FOR ORGAN SHARING statistics, *Transplant: Donor Relation by Transplant Year*, data consulted July 14, 2006. [<http://www.unos.org>]

12. For an overview of this program, visit the BRITISH COLUMBIA TRANSPLANT SOCIETY website. [[http://www.transplant.bc.ca/LADS\\_main.htm](http://www.transplant.bc.ca/LADS_main.htm)]

The gymnastics of paired organ exchange must respect certain values. As regards logistics, paired organ exchange requires additional efforts by organ donation and transplantation teams, and entails certain costs (if only for management of the computerized living donor and recipient pairing system). The impact of paired organ exchange is just beginning to be measured, as this practice is very recent and still marginal. However, this impact should be considered in determining whether the human, material, and financial resources that would be dedicated to organ exchange are justified, especially when resources are limited. This issue of distributive justice is discussed in the Commission's position statement on organ donation and transplantation<sup>13</sup>.

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13. COMMISSION DE L'ÉTHIQUE DE LA SCIENCE ET DE LA TECHNOLOGIE, *op. cit.*, p. 9-11.



## Section 2 – Potential Impact of Paired Organ Exchange

When a person cannot donate a kidney to a genetically or emotionally related individual due to ABO or HLA incompatibility, this information is recorded in the patient file but is not necessarily indexed by the transplantation program for all cases. For this reason, there is no data to quantify the number of patients for whom a living potential donor could not be used due to incompatibility<sup>14</sup>. Consequently, it is difficult to determine the number of patients on the waiting list for a kidney transplant who could benefit from a paired organ exchange program. **The Commission believes that steps should be taken to address the difficulty of measuring the impact of paired organ exchange in Canada due to the lack of data on the number of people who wish to make a living donation but cannot due to incompatibility with the recipient.**

In the absence of Canadian data, it is still interesting to know the opinion of people who are ready to make a living donation. According to a recent U.S. survey<sup>15</sup> of 174 living donors who

could not be used due to incompatibility with a loved one on the waiting list, 64% said they would take part in a living paired exchange. Nearly 38% of respondents would consider list paired exchange. Only 12% said they would make an altruistic donation. For list paired exchange, respondents would be inclined to donate if it would move their incompatible recipient to the top of the list (38%) or to the top fifth (19%). According to the survey authors, and assuming the existence of a national pairing program, researchers might anticipate a possible increase of 1 to 11% in the rate of living donation — enough for 84 to 711 additional transplants each year in the United States<sup>16</sup>.

These numbers indicate that paired organ exchange could potentially offset — at least in part — the shortage of kidneys available for transplant. The foreign experiences presented below provide a glimpse of the possible impact of paired exchange on the organ shortage.

14. CANADIAN COUNCIL FOR DONATION AND TRANSPLANTATION, *Canadian Highly Sensitized Patient and Living Donor Paired Exchange Registries*, consultation paper, October 28-30, 2005, Toronto, Canada.

15. A.D. WATERMAN *et al.*, “Incompatible Kidney Donor Candidates’ Willingness to Participate in Donor-Exchange and Non-directed Donation”, *American Journal of Transplantation*, vol. 6, n° 7, July 2006, p. 1631.

16. *Ibid.*

## On the Organ Shortage

Most of the studies conducted on foreign experiences measure the impact of paired organ exchange on the organ shortage using two indexes: the number of additional transplants made possible by paired organ exchange and followup on these transplants. Thus, it is possible to determine how many patients on the waiting list for a transplant would leave the waiting list and whether the number of these transplant patients is comparable to the number of patients who receive an organ from a genetically or emotionally related living donor. Experiences in the Netherlands, South Korea, and the United States are certainly the best known.

Despite its recent adoption, living paired exchange in the Netherlands is well documented. After a year, the program included 60 donor/recipient pairs<sup>17</sup>. A compatible pair was found for 9 of the 29 ABO-incompatible pairs and 17 of the 31 HLA-incompatible pairs. According to the authors of this study, the program will enable some 30 additional transplants each year<sup>18</sup>. According to another study, Dutch researchers believe that one-third of living donors are incompatible with the people to whom they wish to donate<sup>19</sup>.

In South Korea, a paired organ exchange program was phased in gradually<sup>20</sup>. Initially, the program was only for patients with a genetically related HLA-incompatible donor. After the first two successful exchanges, the donor pool was expanded to include emotionally related incompatible donors and recipients. According to the authors of a South Korean study, living paired exchange has had positive spinoffs — between 1995 and 2003, 101 kidney transplants were made possible by such exchanges — and is helping ease the organ shortage<sup>21</sup>, particularly in countries like South Korea and Japan, where the number of cadaveric donors remains limited because the concept of brain death is not yet well accepted socially or legally.

In the United States, a number of transplant centers offer a living paired exchange program. The debate has now shifted to other types of paired organ exchange and their impact on the organ shortage. For example, list paired exchange would enable more transplants than living paired exchange. According to experts<sup>22</sup>, living paired exchange would result in a slight rise (1%) in the number of transplants each year in the United States.

17. Marry DE KLERK *et al.*, "The Dutch National Living Donor Kidney Exchange Program", *American Journal of Transplantation*, vol. 5, n° 9, September 2005, p. 2303.

18. *Ibid.*, p. 2304.

19. Leonieke W. KRANENBURG *et al.*, "Starting a Crossover Kidney Transplantation Program in the Netherlands : Ethical and Psychological Considerations", *Transplantation*, vol. 78, n° 2, July 27, 2004, p. 194.

20. Kim PARK *et al.*, "Exchange Donor Program in Kidney Transplantation", *Transplantation*, vol. 67, n° 2, January 27, 1999, p. 336-338.

21. Kim PARK *et al.*, "Exchange Living-Donor Kidney Transplantation : Diminution of Donor Organ Shortage", *Transplantation Proceedings*, vol. 36, n° 10, 2004, p. 2951.

22. Stefanos ZENIOS, Lainie FRIEDMAN Ross and E. Steve WOODLE, "New Model Could Increase Transplants", [online], May 2001. [<http://www.gsb.stanford.edu/research/reports/2001/zenios.html>].

The problem is ABO compatibility, particularly due to the fact that Type O recipients in these pairs will be overrepresented because they will only be paired rarely. It should be noted that these persons can receive a kidney only from Type O donors who are also HLA compatible. It is these patients on the waiting list who will participate most often in these programs, as they will have difficulty finding a living compatible donor among their loved ones. Consequently, it would be preferable and more efficient to use list paired exchange, a current practice in several American states. This study also states that some 10% of kidney transplants would be made possible by this type of exchange, i.e., between 1,000 and 2,000 additional transplants per year in the United States (or more than double the estimated benefits for living paired exchange). This would also result in a 15% decrease in waiting time for patients on the list and improve the life expectancy of recipients by 15%<sup>23</sup>.

Despite this prognosis, one in two pairs apparently cannot be matched with another pair, even in living paired exchange programs that use an algorithm to optimize pairing<sup>24</sup>. In a number of cases, living paired exchange pools include many Type O recipients and HLA-sensitized recipients.

This, in particular, is the reason the principle of altruistic donation catalyzing living paired exchange made possible by altruistic donation was suggested. According to a simulation, since the first living altruistic donor recorded in the United States, 583 transplants (instead of the 302 that actually took place) could have occurred using altruistic donation catalyzing living paired exchange<sup>25</sup>. In this regard, **the Commission nevertheless invites vigilance in order to prevent Type O people in the general public from feeling undue pressure to make an altruistic donation, since they alone can donate to Type O recipients, who are overrepresented on the waiting list.**

According to the CCDT, a future living paired exchange program in Canada would require at least 100-odd pairs registered nationally to be effective<sup>26</sup>. The CCDT believes this is possible, given the experience in the Netherlands (with a population of approximately 24 million, compared to approximately 32 million in Canada). At the moment, however, only 10 incompatible donor/recipient pairs are registered in the current Toronto program<sup>27</sup>.

23. *Ibid.*

24. Robert A. MONTGOMERY *et al.*, "Domino Paired Kidney Donation : Strategy to Make Best Use of Live Non-Directed Donation", *Lancet*, vol. 368, n° 9533, July 27, 2006, p. 419.

25. *Ibid.*, p. 420.

26. CANADIAN COUNCIL FOR DONATION AND TRANSPLANTATION, *op. cit.*, p. 23.

27. Elaine CAREY, "Paired Kidney Exchange Saving Lives", *Toronto Star*, April 1<sup>st</sup>, 2006, p. A13

## On Healthcare Costs

By enabling patients on the waiting list to receive transplants sooner, paired organ exchange reduces healthcare costs, particularly those for dialysis and certain prescription medication. In addition, by seeking a compatible donor for HLA-sensitized patients, paired organ exchange prevents these patients from having to undergo relatively risky and very expensive special treatments<sup>28</sup>.

Moreover, according to a group of U.S. researchers, a system to optimize exchange pair matching in a national program would result in savings of close to \$750 million<sup>29</sup>.

## On Living Donors and Recipients

Such being the case, the impact on both the physical and mental health of those concerned, i.e., living donors and recipients, must also be considered. As regards the physical health of living donors, the problem is the same as in compatible living donation, a topic the Commission discussed in its statement on organ donation and transplantation (see inset).

28. Robert A. MONTGOMERY *et al.*, "Clinical Results from Transplanting Incompatible Live Kidney Donor/Recipient Pairs Using Kidney Paired Donation", *Journal of the American Medical Association*, vol. 294, n° 13, October 5, 2005, p. 1657-1662.

29. Dorry L. SEGEV *et al.*, "Kidney Paired Donation and Optimizing the Use of Live Donor Organs", *Journal of the American Medical Association*, vol. 293, n° 15, April 20, 2005, p. 1883-1890.

### A contravention of the “do no harm” principle

“Living donation brings into play the “do no harm” principle. This principle states that “the potential harm to the other party, even with the person’s individual consent, imposes a prima facie obligation to ensure that the benefits outweigh the harm<sup>30</sup>.” In short, before removing an organ or part of an organ, it must be established that the benefit to the donor is greater than the damage of the procedure. The removal of an organ or part of an organ from a healthy person could potentially (but not necessarily) affect his or her quality of life immediately or in the longer term. The procedure may therefore seem unjustifiable, as a mutilation with no physiological benefit to the donor. However, the psychological benefits can be great.

Gutmann and Land introduced an interesting concept for weighing the costs and benefits of living organ donation. In their opinion, the calculation must take into account not only the benefits to the recipients, but also those to the donor<sup>31</sup>.

This concept was expanded on in the Consensus Statement on the Live Organ Donor, published in the U.S.<sup>32</sup> The benefit to the donor is psychological: saving the life of kin, a child, a spouse, or a friend or significantly improving the quality of life of a loved one is a considerable — and even vital — benefit to the donor. Although the donor may feel a certain pressure to donate<sup>33</sup>, the Commission’s consultation showed that helping a critically ill loved one is unquestionably a powerful motivator for donors. To compensate for the risks to the donor, a U.S. task force recently suggested giving living donors priority if ever they themselves need an organ transplant<sup>34</sup>.”

Commission de l'éthique de la science et de la technologie<sup>35</sup>

30. H.T. ENGELHARDT JR. and A. SMITH ILLIS, “Non-malfaisance (Principe de)”, *Nouvelle encyclopédie de bioéthique*, edited by Gilbert HOTTOIS and Jean-Noël MISSA, Bruxelles, DeBoeck Université, 2001, p. 616.
31. T. GUTMANN and W. LAND, “Ethics in Living Donor Organ Transplantation”, *Langenbeck’s Archives of Surgery*, [online], October 1999. [<http://trans.klinikum.uni-muenchen.de/ethics.htm>]
32. LIVE ORGAN DONOR CONSENSUS GROUP, “Consensus Statement on the Live Organ Donor”, *Journal of the American Medical Association*, vol. 284, n° 22, 2000, p. 2919-2926. [[http://www.kidney.org/transplantation/livingDonors/pdf/jama\\_article.pdf](http://www.kidney.org/transplantation/livingDonors/pdf/jama_article.pdf)]
33. For example, it is easy to imagine that parents would feel a certain duty to assist their child if his or her health condition required a transplant.
34. U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES ADVISORY COMMITTEE ON ORGAN TRANSPLANTATION, “Recommendations to the Secretary”, [online]. [<http://www.organdonor.gov/acotrecs.html>]
35. COMMISSION DE L’ÉTHIQUE DE LA SCIENCE ET DE LA TECHNOLOGIE, *op. cit.*, p. 23-24.

In its statement, the Commission recommends “that transplant centers, in cooperation with Québec-Transplant, follow up with donors and recipients to track transplant organs and compile information on the long term health of donors and recipients in living donor transplants<sup>36</sup>.” The Commission was concerned about the possible consequences for donors, especially due to the scope of living donation<sup>37</sup>. **The Commission can only reiterate its desire that special attention be given to following up with living donors, including those taking part in paired organ exchange. In addition, if such exchange were to result in adverse effects, the Commission believes it would be advisable to look to the vaccination victim compensation program as provided by the Public Health Act<sup>38</sup>.**

As regards the physical health of recipients, followup was possible only in the short and medium term, given that the practice of paired organ exchange is very recent. Followup after five years in South Korea shows similar results for transplant patients who took part in an exchange

and those who received an organ from an emotionally related living donor<sup>39</sup>. In the United States, a recent study conducted by Johns Hopkins Hospital (a paired organ exchange pioneer) shows comparable general results between recipients who took part in an exchange and those who received a transplant through a traditional donation between emotionally related living persons<sup>40</sup>.

The results of these recent experiences are highly encouraging. **The Commission nevertheless believes we should remain cautious and that recipients taking part in paired organ exchange must be followed up as carefully as recipients who receive a kidney from an emotionally or genetically related compatible living donor.**

**Furthermore, the Commission wishes to draw the attention of researchers and stakeholders to the psychological and social repercussions of paired organ exchange on both donors and recipients. To its knowledge, there is no data on this matter.**

36. *Ibid.*, p. 27.

37. *Ibid.*, p. 26-27.

38. *Public Health Act*, R.S.Q., Chapter S-2.2, 2001, c. 60, particularly sections 70 to 78.

39. Kim PARK *et al.*, “Exchange Living-Donor Kidney Transplantation : Diminution of Donor Organ Shortage”, *op. cit.*, p. 2950.

40. Robert A. MONTGOMERY *et al.*, “Clinical Results from Transplanting Incompatible Live Kidney Donor/Recipient Pairs Using Kidney Paired Donation”, *op. cit.*, p. 1662.

## Section 3 – Ethical Considerations

In most cases, the new practice of paired organ exchange is enthusiastically welcomed, as we will see in the following discussion of the perspective of a number of organizations regarding the ethical acceptability of this practice. This discussion is followed by a certain number of ethical considerations that are worth analyzing here.

### Position Statements Over Time

Already in 2000, the Live Organ Donor Consensus Group, including representatives from the National Kidney Foundation (United States) and U.S. transplantation, surgeon, and nephrologist societies, came out in favor of living paired exchange<sup>41</sup>. In 2003, two British organizations announced their position, with the British Transplantation Society calling living paired exchange an extension of living donation<sup>42</sup>.

According to the Society, living paired exchange does not pose new ethical issues and is therefore just as acceptable. The Unrelated Live Transplant Regulatory Authority, which authorizes emotionally related living donations in Great Britain, agrees with living paired exchange provided that a procedure for ensuring proper donor protection is developed<sup>43</sup>. The Health Council of the Netherlands believes living paired exchange is acceptable both medically and ethically<sup>44</sup>. In addition, the Council maintains that this practice should be encouraged through national and international paired organ exchange mechanisms. In 2005, the American Society of Transplant Surgeons expressed its support for living paired exchange as well as list paired exchange<sup>45</sup>. However, for list paired exchange, it stresses that the negative impact of this practice on Type O recipients should be considered in certain cases.

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41. LIVE ORGAN DONOR CONSENSUS GROUP, *op. cit.*, p. 6.

42. BRITISH TRANSPLANTATION SOCIETY, *Approved Position Statements: Paired Organ Exchange*, [online], September 2003. [<http://www.bts.org.uk/approvedstatements.htm>]

43. UNRELATED LIVE TRANSPLANT REGULATORY AUTHORITY, *Excerpt of minutes of the 34<sup>th</sup> session of ULTRA*, held September 30, 2003, London.

44. HEALTH COUNCIL OF THE NETHERLANDS, *New Options for Organ Donation*, [online], June 19, 2003. [<http://www.gr.nl/adviezen.php?ID=716&highlight=>]

45. AMERICAN SOCIETY OF TRANSPLANT SURGEONS, *Statement on Solicitation of Donor Organs*, [online], January 20, 2005. [<http://www.astsonline.org/donorsolicitation.cfm>]

The American Society of Transplantation (AST) supports initiatives to expand the pool of organ donors, such as living paired exchange and list paired exchange, provided that operations are supervised by United Network for Organ Sharing (UNOS)—the organization that monitors organ donation and transplantation in the United States<sup>46</sup>. More recently, AST promoted the development of a national organ exchange program<sup>47</sup>. To this end, UNOS endorsed plans to create a national living paired exchange program<sup>48</sup>.

While donation and transplantation stakeholders seem to agree on the ethical acceptability of paired organ exchange<sup>49</sup>, certain ethical issues must be examined more closely, particularly as regards the monitoring and management of a national organ exchange program, as well as donation anonymity, equity, and consent.

## National Organ Exchange Program Monitoring and Management

If a national organ exchange program were introduced in Canada, the monitoring and management of this program and the register of participants would clearly become an issue. Without revealing the details, CCDT is already

defining the role and main tasks of a possible organization in charge of monitoring and managing such a program. Although it is not in a position to express an opinion regarding the technical or organizational details of the process, the Commission nevertheless sees fit to make the following recommendation.

### Recommendation 1 :

#### The Commission recommends

**That minister de la Santé et des Services sociaux (health and social services) ensure that if a national organ exchange program is put in place in Canada,**

- **An independent public body be mandated by the federal government to monitor and manage this program and the register of participants; and**
- **This organization develop a framework of good practices, particularly in order to guarantee the transparency required in this type of activity**

46. AMERICAN SOCIETY OF TRANSPLANTATION, *Position Statement on Paired Organ Exchanges*, [online], July 27, 2005. [[http://www.a-s-t.org/PublicPolicy/KeyPosition\\_pdfs/PairedOrganExchange.pdf](http://www.a-s-t.org/PublicPolicy/KeyPosition_pdfs/PairedOrganExchange.pdf)]

47. AMERICAN SOCIETY OF TRANSPLANTATION, *Key Position Statement : Living Organ Donation*, [online], April 26, 2006. [[http://www.a-s-t.org/PublicPolicy/KeyPosition\\_pdfs/LivingOrganDonation06.pdf](http://www.a-s-t.org/PublicPolicy/KeyPosition_pdfs/LivingOrganDonation06.pdf)]

48. OPTN/UNOS, *Executive Summary of the Minutes OPTN/UNOS Board of Directors Meeting*, [online], November 18-19, 2004, Reston, Virginia, United States of America. [[www.unos.org/sharedcontentdocuments/executive\\_summary\\_nov\\_2004.pdf](http://www.unos.org/sharedcontentdocuments/executive_summary_nov_2004.pdf)]

49. Papers do not always present the underlying rationale.

## Donation Anonymity

The Commission again raises the issue of donation anonymity in the context of living donation. The lack of anonymity was a cause for concern for the Commission in its statement on donation and transplantation:

*This lack of anonymity raises a number of ethical issues, especially with regard to freedom of consent. For example, people are always free to consent to donating or refuse to donate a kidney or part of an organ, but if the recipient is related genetically or emotionally, the potential donor may feel tremendous pressure to donate, reducing the autonomy essential to freedom of consent<sup>50</sup>.*

However, the reason for this concern — the fact that donations cannot be anonymous between two living persons because they necessarily know each other — disappears with paired organ exchange: contact between donors and recipients is not inevitable.

Still, some challenge the principle of donation anonymity. A number of U.S. transplantation centers provide an opportunity for living paired exchange participants to meet once the exchange is complete. In addition, the nonprofit organization Organ Swap makes a database available to members (see inset).

### Organ Swap

First, people interested in taking part in a living paired exchange register on the Organ Swap website. Each patient can register a number of incompatible potential living donors with whom to form a pair. Patients can then submit a request to be matched with another pair in the same situation. A list of compatible exchange pairs is provided without their contact information. Patients can then contact pairs on this list through a messaging system provided by Organ Swap. After initiating correspondence, people can exchange contact information when they feel comfortable. Organ Swap suggests that members disclose only information deemed “necessary.” The organization assures that correspondence can be read only by the correspondents.

From Organ Swap website<sup>51</sup>.

Meetings and contact between organ donation and transplantation participants or their loved ones can have both positive and negative effects. There are benefits, but also disadvantages and risks. In considering the issue, the Commission made a distinction between pre- and post-transplant contact.

50. COMMISSION DE L'ÉTHIQUE DE LA SCIENCE ET DE LA TECHNOLOGIE, *op. cit.*, p. 24.

51. See : <http://www.organswap.org/aboutSwap.php>.

On one hand, in paired organ exchange, **pre-transplant** contact raises significant ethical questions. What impact will a participant's perception of the other pair have on his or her desire to participate in the exchange? Might this contact be seen as a good time to exert pressure or make inappropriate demands? After the exchange, how can respect for one pair's desire to discontinue contact with the other pair be ensured?

On the other hand, **post-transplant** meetings pose certain risks, but may also benefit participants. Contact between the families of cadaveric donors and transplant recipients are sometimes possible with the consent of all parties. Close examination of this issue led to a recommendation by the Commission in its statement on organ donation and transplantation (see inset). The spirit of the Commission's statements can also be applied to paired organ exchange between living persons.

### The issue of anonymity: Maximizing benefits and minimizing risks

“In some cases, donors’ and recipients’ families feel the need to talk. Families are motivated primarily by the desire to see the good that came from their loved one’s death and confirm that the organs were in fact donated and transplanted. It is important to note that some families are hesitant to consent to donation due to a lack of trust in the transplant system. As for recipients, contact with donor families is an opportunity to thank the people who saved their lives or helped them greatly improve their quality of life.

For the time being, the donor and recipient are kept anonymous so that neither one knows the other’s identity. They can communicate anonymously in a letter, which is forwarded by a third party (e.g., Québec-Transplant or the attending physician).

Communication between the people involved is usually mutually beneficial, and the risk of complications is generally avoided. However, letters exchanged between donor families and recipients can at times lead to inappropriate requests or remarks. For example, families may ask of recipients that they act in a very specific way to perpetuate the behaviour or personality of the donor through the organ. Likewise, recipients may ask for personal information about their donors that families do not wish to share — or even for financial support. In the opinion of the Commission, such requests are out of line and must be prevented. **The Commission considers it essential to protect the gratuitous nature of donation, prevent any attempt to extort property or money, prevent harassment in any form, and protect the right to privacy.**

Given the importance of receiving something in return in the donation process, the Commission does not wish to close the door to the possibility of consenting adults (recipients and donor families) coming together to express their appreciation and offer encouragement. It would be overcautious and inappropriately overcontrolling to prevent these meetings on account of a few unacceptable situations that have occurred in the past. However, it would appear best for the parties to allow a certain period of time to pass in order to let things settle so they can think clearly about any potential meeting.

#### Recommendation no. 1 :

**The Commission recommends that Québec-Transplant and physicians involved in the organ donation and transplantation process —**

- a) **Maintain the current donation anonymity policy**
- b) **Consider requests for the organ donor’s family and the recipient(s) to meet and, if both parties agree, clearly inform the parties involved of the risks associated with such a practice and ask them to sign a consent form to this effect**
- c) **Follow up on and assess the benefits of these meetings.”**

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52. COMMISSION DE L'ÉTHIQUE DE LA SCIENCE ET DE LA TECHNOLOGIE, *op. cit.*, p. 22-23.

In the Netherlands, a survey of 14 exchange pairs provides an interesting perspective on how these people perceive pre- and post-transplant contact. Respondents unanimously preferred to remain anonymous and not meet the pair with whom they were matched<sup>53</sup>. The most commonly cited reasons were the desire to focus on living a normal, healthy life without becoming emotionally involved in the lives of other people experiencing the same health problems. Respondents also wished to avoid the psychological pressure of knowing the other pair. They also wanted to avoid any pressure or conflict that may arise if the transplants had different results. The risk of pairs perceiving each other negatively before the exchange and withdrawing their consent was another reason respondents cited for not wanting to meet the other pair participating in the exchange.

The very logistics of the exchange can jeopardize donation anonymity. If exchange must occur in the same center, it becomes more difficult to ensure the confidentiality of donor and recipient identity<sup>54</sup>.

As regards paired organ exchange, the British Transplantation Society<sup>55</sup>, like CCDT<sup>56</sup>, believes that donation anonymity should be protected. However, both organizations remain open to the possibility of post-transplant meetings. The Unrelated Live Transplant Regulatory Authority suggests that living paired exchange participants undergo their operations in different centers in order to better protect confidentiality<sup>57</sup>. Certain U.S. transplantation centers allow and organize post-transplant meetings following the same

principle: In order for such meetings to be held, all parties involved in a given paired organ exchange must consent to them. **The Commission supports the CCDT proposal of surveying living paired exchange participants regarding their opinion on the issue. Nevertheless, it believes that the decision whether to authorize post-transplant meetings should take into account the needs of exchange participants and past experience in cadaveric donation, as well as the risks and disadvantages of this type of meeting. Moreover, the Commission reiterates that exchange participants must provide free and informed consent regarding post-transplant meetings, and transplant teams must advise participants of the potential risks and disadvantages of this type of meeting.**

## Equity Among Patients Awaiting Transplant

Currently, equity among patients awaiting transplant is subject to allocation criteria for organs from cadaveric donors. For living donation, this is not really an issue. Whether one patient is surrounded by three compatible living donors while another does not have this good fortune is, by and large, a matter of chance. Such being the case, the issue of equity could arise if a national paired organ exchange program is put in place, i.e., at the time of program registration or with respect to Type O patients in a list paired exchange program. We must also consider the issue of the potential commercialization of organ donation.

53. Leonieke W. KRANENBURG, *op. cit.*, p. 195.

54. LIVE ORGAN DONOR CONSENSUS GROUP, *op. cit.*, p. 6.

55. BRITISH TRANSPLANTATION SOCIETY, *op. cit.*

56. CANADIAN COUNCIL FOR DONATION AND TRANSPLANTATION, *op. cit.*, p. 26-27.

57. UNRELATED LIVE TRANSPLANT REGULATORY AUTHORITY, *op. cit.*

### Eligibility Criteria for a National Paired Organ Exchange Program

Access to a living paired exchange register for patients on the waiting list for a kidney transplant could raise the issue of equity. For this reason, the Commission believes that the eligibility criteria for a register for matching exchange pairs should be the same for everyone, known by everyone, and free of unjustified discrimination. In its consultation paper, CCDT suggests eligibility criteria for such a register, like the presence of at least one incompatible living potential donor and the absence of major risks related to donation or transplantation for donor or recipient health<sup>58</sup>.

Nevertheless, certain questions remain unanswered: Can a patient on the waiting list participate in another exchange if a kidney is rejected? In list paired exchange, can a patient on the waiting list use a series of living donors in order to receive priority on the waiting list more than once (e.g., following organ rejection) or must he or she give others a chance?

### A Step Toward Commercialization?

In certain countries, such as Australia<sup>59</sup>, list paired exchange is prohibited, as it represents — within the meaning of the law — a form of commercialization of organ donation. Note that in this type of exchange, a donation from a living person enables a patient awaiting transplant to receive priority on the waiting list for a kidney from a cadaveric donor. According to this argument, the donation is not free, since a patient designated by the donor receives valuable consideration in return. This argument led UNOS to request a legal opinion on the issue with respect to U.S. legislation. According to this opinion, living paired exchange and list paired exchange do not constitute commercialization within the meaning of U.S. legislation on organ donation and transplantation<sup>60</sup>. These exchanges take nothing away from the altruistic nature of the donor's gesture. Furthermore, in such exchanges, all patients on the list move up, since there is one fewer recipient above them.

With living paired exchange, the living donor's motivation is the same as that of a living donor who is not taking part in an exchange. Both want their donation to help a loved one survive or considerably improve his or her quality of life. Some believe that living paired exchange recipients in fact receive nothing more than traditional direct living donation recipients<sup>61</sup>.

58. CANADIAN COUNCIL FOR DONATION AND TRANSPLANTATION, *op. cit.*, p. 25-26.

59. Anthony P. MONACO and Peter J. MORRIS, "Care of the Live Kidney Donor : Consensus on the Ultimate Gift", *Transplantation*, vol. 79, n° 2S, March 27, 2005, p. S62.

60. WILLIAMS MULLEN, *Position Statement : Intended Recipient Donations, Paired Donations and NOTA § 301*, [online], May 5, 2005. [[www.unos.org/contentdocuments/section\\_301\(NOTA\).pdf](http://www.unos.org/contentdocuments/section_301(NOTA).pdf)]

61. Leonieke W. KRANENBURG, *op. cit.*, p. 195-196.

Still, the donor's kidney is not transplanted into their loved one. Emotionally, this difference — which reduces the intimacy of the gesture — is not perceived in the same way by everyone, even if the essential objective is achieved and the incompatible pair satisfied. **Consequently, and in agreement with UNOS, the Commission believes that paired organ exchange does not constitute a form of commercialization of organ donation.**

### Blood Type O Patients

Contrary to living paired exchange, list paired exchange could penalize Type O patients on the waiting list, for two reasons. First, Type O living donors (universal donors) can donate a kidney to another person of any blood type, provided they are HLA compatible. Consequently, chances are that few of them would take part in list paired exchange, instead opting for living paired exchange. Second, as Type O recipients can, conversely, receive a kidney only from a Type O donor, they are overrepresented among patients on the waiting list.

Thus, in list paired exchange, a Type O patient on the waiting list **who has** an incompatible living donor (who can donate a kidney to another patient on the waiting list) will receive priority for a kidney from a Type O cadaveric donor. But Type O patients on the waiting list **who do not have** an incompatible living donor and, consequently, cannot receive priority would

be penalized. They could continually see available Type O cadaveric kidneys allocated to recipients taking part in an exchange. This extends the waiting time<sup>62</sup>, creating a serious inequity for Type O recipients waiting for a cadaveric kidney, especially Type O patients from certain cultural communities, e.g., African Americans, a much larger proportion of whom are Type O<sup>63</sup>.

Considering the potential positive impact of list paired exchange and the possibility of narrowing the gap between the number of patients on the waiting list and the number of kidneys available for transplant, a number of solutions have been proposed in order to correct this inequity toward Type O patients on the waiting list. An initial solution<sup>64</sup> consists of giving preference to Type O living donors when a number of donors volunteer for the same patient on the waiting list and all are incompatible. This would give patients on the waiting list who do not have an incompatible living donor a better chance of obtaining a Type O kidney and patients who have an incompatible Type O donor a better chance of being paired faster, since Type O donors are universal donors (provided they are HLA compatible). This measure would create a certain challenge for donation and transplantation stakeholders, as special attention would need to be given to living donor freedom of consent. Steps would have to be taken to ensure that additional pressure to donate is not placed on Type O potential living donors and other Type O individuals among the loved ones of the patient on the waiting list.

62. Stefanos A. ZENIOS, E. Steve WOODLE and Lainie FRIEDMAN ROSS, "Primum Non Nocere : Avoiding Harm to Vulnerable Wait List Candidates in An Indirect Kidney Exchange", *Transplantation*, vol. 72, n° 4, August 27, 2001, p. 648-654.

63. Stefanos ZENIOS, Lainie FRIEDMAN Ross and E. Steve WOODLE, "New Model Could Increase Transplants", *op. cit.*

64. Stefanos A. ZENIOS, E. Steve WOODLE et Lainie FRIEDMAN ROSS, *op. cit.*, p. 648.

**To prevent such a situation, the Commission believes that patients on the waiting list and their loved ones must be notified as soon as possible of the existence of such a criterion, to ensure that only people who genuinely wish to make a living donation apply and that they know, if they are Type O, that they will receive priority to take part in the exchange as the incompatible donor.**

In terms of impact, according to a simulation using this measure, a national list paired exchange program could provide 884 to 2,155 additional kidneys each year in the United States, reducing the waiting time for a kidney by 58 to 145 days<sup>65</sup>.

Another solution would be to limit list paired exchange for type A, B, or AB patients on the waiting list when their donor is ABO incompatible, as this would prevent Type O recipients from receiving priority on the waiting list for a kidney from a cadaveric donor<sup>66</sup>. However, recipients of all blood types whose donor is HLA incompatible could be accepted, as this would

enable Type O living donors to donate kidneys to patients on the waiting list who do not have compatible or incompatible living donors. According to a simulation, not only would this proposal benefit patients of all blood types on the waiting list, it also would not negatively affect Type O patients<sup>67</sup>.

In terms of impact, this solution would provide 414 to 1,150 additional kidneys each year in the United States, reducing the waiting time by 49 to 146 days on average<sup>68</sup>. In this simulation, the authors took for granted the existence of a national pool of incompatible pairs of living donors and patients on the waiting list — although one does not currently exist in the United States. Consequently, the results overestimate the number of exchanges and the reduction in waiting time<sup>69</sup>.

Blocking access to list paired exchange to pairs in which the patient on the waiting list is Type O may seem inefficient or even unfair. However, proponents of this solution believe this inequity is ethically acceptable, as it benefits all patients on the waiting list, including Type O patients<sup>70</sup>.

65. *Ibid.*, p. 653.

66. Lainie FRIEDMAN ROSS and Stefanos ZENIOS, "Restricting Living-Donor-Cadaver-Donor Exchanges to Ensure that Standard Blood Type O Wait-List Candidates Benefit", *Transplantation*, vol. 78, n° 5, September 15, 2004, p. 641.

67. *Ibid.*, p. 642.

68. *Ibid.*, p. 643 et 645.

69. *Ibid.*, p. 645.

70. *Ibid.*

Equity is also an issue with altruistic donation catalyzing living paired exchange. While the many benefits of “good Samaritan” donation should not initially change the motivation of the donor in question (since his or her donation benefits a number of people instead of just one), we must be careful to ensure that this type of donation does not result in inequity toward patients of certain blood types, as may occur with list paired exchange<sup>71</sup>. For example, if the altruistic donor is Type O and his or her donation ultimately leads to a Type A kidney donation, inequity toward Type O patients may again result. Ideally, this donation should provide maximum benefits for patients with a blood type that is difficult to match (like O and B).

## Equity Among Pairs

Once pairs register to be matched, steps must be taken to ensure that each registered pair is matched fairly. A consensus has emerged that organs should be harvested simultaneously. CCDT<sup>72</sup>, the Live Organ Donor Consensus Group<sup>73</sup>, the National Kidney Foundation (United States)<sup>74</sup>, Dutch transplantation centers<sup>75</sup>, and the British Transplantation Society<sup>76</sup> all agree with this approach. If operations are not begun simultaneously, once the first transplantation is completed, the donor who has not yet donated a kidney could withdraw, knowing that his or her incompatible recipient has now received a kidney. In short, simultaneous harvest reduces the chance of such a situation occurring.

Still, an operation may not occur as planned for medical reasons. In such cases, CCDT suggests solutions for the main hypothetical cases that could arise (see inset).

### Recommendation 2 :

#### The Commission recommends

**That minister de la Santé et des Services sociaux (health and social services) ensure that the organization that may potentially be asked to monitor and manage the national organ exchange program put in place a mechanism to ensure equity among patients awaiting a kidney transplant prior to implementation of a list paired exchange program.**

71. Lainie FRIEDMAN ROSS, “The Ethical Limits in Expanding Living Donor Transplantation”, *Kennedy Institute of Ethics Journal*, vol. 16, n° 2, 2006, p. 166.

72. CANADIAN COUNCIL FOR DONATION AND TRANSPLANTATION, *op. cit.*, p. 26-27.

73. LIVE ORGAN DONOR CONSENSUS GROUP, *op. cit.*, p. 6.

74. NATIONAL KIDNEY FOUNDATION, *Waiting for a Transplant*, New York, 2005, p. 12. [<http://www.kidney.org/atoz/pdf/waitingforatx.pdf>]

75. UK TRANSPLANT, *Bulletin Summer 2006*, [online], summer 2006. [[http://www.uktransplant.org.uk/ukt/newsroom/bulletin/current\\_bulletin/using\\_international\\_experiences.jsp](http://www.uktransplant.org.uk/ukt/newsroom/bulletin/current_bulletin/using_international_experiences.jsp)]

76. BRITISH TRANSPLANTATION SOCIETY, *op. cit.*

**Table 1: If an operation cannot occur: hypothetical cases and solutions suggested by CCDT<sup>77</sup>**

*Consider Donor 1 giving to Recipient 2 and Donor 2 to Recipient 1*

**If a problem arises during surgery with Donor 1**

|  |  |
|--|--|
| If early enough...   | ...then both donor procedures and transplants should be aborted. This decision will be made by telephone by the surgeon performing the uncomplicated donor procedure.  |
| If later...  | ...then proceed based on previously obtained Donor 2 consent to either autotransplant the kidney back to Donor 2 (cancelling both transplants), or proceed with giving Donor 2 kidney to the top compatible patient on the Recipient 1 local list and have Recipient 2 receive the first available compatible normal risk deceased donor kidney from region of Recipient 1.  |
| If Recipient 1 is temporarily unable to receive the kidney after donor operations have occurred... | ...Donor 1 gives to Recipient 2 as planned. Donor 2 kidney is given to top compatible patient on local list (of Recipient 1). If and when Recipient 1 is subsequently able to receive a kidney, they will be prioritized for a deceased donor kidney within Region 1. Consent should include the rare possibility that if one recipient becomes seriously ill during the procedure and does not recover he/she may never be able to be transplanted. |
| If the graft is lost within 48 hours of surgery...   | ...the recipient retains priority for the next suitable kidney as above.   |

77. CANADIAN COUNCIL FOR DONATION AND TRANSPLANTATION, *op. cit.*, p. 27.

Clearly, for each hypothetical case that may arise, there is a proposed solution for restoring some degree of equity between the pairs. **While its mandate is not to express an opinion on the technical details of these solutions, the Commission wishes to reaffirm the importance of the principle of equity among pairs taking part in paired organ exchange. When operations do not go as planned, the Commission believes that the authorities in charge must ensure equity among pairs.**

## Freedom of Consent

In living donation, donor freedom of consent is a major issue. Agreeing to donate an organ or part of an organ to another person is a decision that may have serious repercussions on physical and psychological health, as well as socially and financially. In addition, ties between the living donor and the recipient may heavily influence the living donor's volition and freedom of consent. Harm to the donor's physical integrity cannot be compensated only by the potential benefit to a emotionally or genetically related recipient, and only free and informed consent can justify such harm. These aspects are discussed in the Commission's opinion statement on organ donation and transplantation (see inset).

### The issue of donation authenticity: Evaluating donors

"Transplant centers require that anyone expressing a desire to make a living donation undergo a physiological and psychological evaluation. The ultimate objective of the evaluation is to establish whether the benefits expected by the donor and recipient outweigh the anticipated risks. It is also a means of ensuring the validity of the process leading to the donor's consent. [...]

[...]Lastly, interviews with evaluators can provide donors with the opportunity to speak in confidence. Donors can express their doubts or even unwillingness to donate, or discuss any moral obligation they may feel<sup>78</sup>. Potential donors must be free to change their minds at any time. The interval between initial evaluation and organ removal is generally long enough for donors to fully reflect on their wish to donate. Notably for reasons of doctorpatient privilege, physicians are not required to justify a donor's withdrawal. However, to avoid exposing potential donors to probing by recipients or loved ones, physicians can state that a number of factors make the organ donation impossible.

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78. For example, this obligation may be felt particularly strongly when the donor is the father or mother of the recipient.

79. COMMISSION DE L'ÉTHIQUE DE LA SCIENCE ET DE LA TECHNOLOGIE, *op. cit.*, p. 26-27.

Paired organ exchange could increase the potential pressure on donors. With this type of exchange, there is no longer just one person involved (however dear to the donor). Now, a number of people are delighted that they or a loved one will soon receive an organ. A donor's hesitations no longer affect a single transplant, but many.

In addition, we must remember that while certain loved ones of patients on the waiting list for a transplant may express interest in donating, they may do so under pressure from family or those around them. The donor evaluation is a key opportunity for donors to confide in professionals regarding any pressure they may feel. If paired organ exchange becomes possible, hesitant donors will face a delicate situation, as donor/recipient incompatibility can no longer be used as an excuse for withdrawal, or at least will no longer count among the “many reasons” that make organ donation impossible. And while the actual reason why the donation did not proceed need not be stated, the recipient and those in the donor's or recipient's circle may be more suspicious about the reasons it did not. The situation is roughly similar to traditional donation between living persons: HLA-compatible donors who withdraw also have no other reason to hide behind. For people who submit to an evaluation regretting that they cannot point to HLA incompatibility as a reason for withdrawal, physicians seeking free and informed consent in confidential interviews and evaluations have the same duty as if these “potential donors” were compatible with the recipient in a traditional organ donation between living persons, i.e., recognize the real desires of donors and protect them without lying.

**In agreement with the experts<sup>80</sup>, the Commission believes that the disappearance of HLA incompatibility as an excuse for the withdrawal of certain living donors is not sufficient cause to disregard the option of paired organ exchange, especially since this type of situation already exists in traditional donation between living persons. However, the Commission wishes to reaffirm that while assuming their duty of confidentiality toward potential donors, organ donation and transplantation professionals must ensure that such donors provide free and informed consent and are not under pressure. Furthermore, the Commission makes the following recommendation in this regard.**

### **Recommendation 3 :**

#### **The Commission recommends**

**That the health professionals concerned explain the option of paired organ exchange to patients on the waiting list and their loved ones very early in the process of the patient's registration on the waiting list. If paired organ exchange becomes a viable option, those who did not wish to donate or who only wanted to donate directly to the patient on the waiting list will not have indicated their interest and will not be considered. Only those who have consented to an evaluation for organ donation would remain, knowing that paired organ exchange could occur in the event of incompatibility.**

80. Lainie FRIEDMAN ROSS et Stefanos ZENIOS, *op. cit.*, p. 645 ; Leonieke W. KRANENBURG, *op. cit.*, p. 195.

## Informed Consent

Paired organ exchange considerably alters the symbolic relationship inherent in living donation. As the donated organ does not go directly to the person designated by the donor, the tie between the donor and the recipient — two people who know each other and understand that the donor's kidney is in the body of the recipient — is clearly no longer the same in the case of an exchange. At the moment, there is no data on the psychological repercussions on donors and recipients participating in paired organ exchange. However, a very limited number of studies show the importance of organ origin for recipients<sup>81</sup>.

In organ exchange, the donated kidney is transplanted into a stranger, while the kidney of another stranger is transplanted into the recipient. Given this change in the donor/recipient relationship, can the **donor's** consent be just as informed?

Some believe that the **recipient** should be able to consult certain relevant medical data concerning the donor in order to be able to provide informed consent<sup>82</sup>. Conversely, the British Department of Health questions the appropriateness of disclosing anonymous information about the recipient's condition to the donor<sup>83</sup>.

**The Commission believes that paired organ exchange participants must place enough trust in medical specialists and health professionals to provide the information needed to**

**make a decision. This trust is central to the physician/patient relationship. While patients must always be the ones to make decisions regarding their health condition and suggested treatments, their physician is in the best position to convey clear and accurate information in this regard.**

Many agree that certain information regarding the procedure and the benefits, risks, and disadvantages of paired organ exchange should be disclosed to exchange participants in order to ensure their informed consent. For example, participants should know what will happen if an organ is quickly rejected by one of the recipients while the other does fine<sup>84</sup>. In addition, the consent form must clearly state that the operation may not go as planned<sup>85</sup>. In such a case, participants should know the organ allocation procedure that will be followed. List paired exchanges must specify exactly when the patient on the waiting list will receive priority and whether the recipient will retain priority in the event of rejection. **In short, the Commission believes that these scenarios must be explored and the proposed solutions clearly explained to participants to enable them to make informed decisions.**

81. Lainie FRIEDMAN ROSS, *op. cit.*, p. 153.

82. LIVE ORGAN DONOR CONSENSUS GROUP, *op. cit.*, p. 6. ; ORGAN SWAP [<http://www.organswap.org/aboutSwap.php>]

83. U.K. DEPARTMENT OF HEALTH, *Human Bodies, Human Choices, The Law on Human Organs and Tissue in England and Wales*, consultation paper, [online], July 12, 2002. [<http://www.dh.gov.uk/assetRoot/04/06/02/64/04060264.pdf>]

84. Arthur J. MATAS and David E.R. SUTHERLAND, "The Importance of Innovative Efforts to Increase Organ Donation", *Journal of the American Medical Association*, vol. 294, n° 13, October 5, 2005, p. 1692.

85. U.K. DEPARTMENT OF HEALTH, *op. cit.*

# Conclusion

For a number of years, the organ shortage has led many health professionals to explore new avenues in order to maximize the number of transplantations. Paired organ exchange comes in the wake of these efforts to increase the number of kidney transplants from living donors and, sometimes, cadaveric donors.

To begin with, the Commission believes it is important to evaluate, in Québec and across Canada, the potential impact of paired organ exchange on the organ shortage and healthcare costs, and, more fundamentally, on the physical and psychological health of recipients and donors who take part in paired organ exchange.

While this type of exchange may be considered an extension of the practice of living donation, it raises significant, specific ethical issues that cannot be ignored. For this reason, the Commission decided to develop a position regarding the monitoring and management of a national organ exchange program, donation anonymity, equity, and consent. As regards monitoring and management, the Commission has issued a recommendation aimed at ensuring the independence and transparency of such a program. As regards donation anonymity, the Commission has reiterated the position in its statement on organ donation and transplantation: While anonymity prevents a great many possible quandaries, it could potentially be broken, but

under certain conditions and, especially, in light of the anticipated benefits for exchange participants and with their free and informed consent. The Commission has observed that equity is an issue with regard to exchange participants, other patients on the waiting list who are not involved, and the most vulnerable groups. It has invited the health professionals concerned to be particularly vigilant in this regard. Lastly, the Commission has examined and identified the conditions required to ensure that organ exchange participant consent is free and informed.

Paired organ exchange is a new option that supplements more traditional types of organ donation. While at first blush it appears promising, we must remember that this practice raises its own ethical concerns, as well as the same ethical issues associated with living donation. The Commission hopes it has helped spur ethical thinking in both cases by suggesting possible solutions for ensuring the development of a fully ethical process.



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87. When the present position statement was adopted









Paired Organ Exchange: Ethical Considerations Regarding a New Option is a supplement to the position statement by Commission de l'éthique de la science et de la technologie entitled Organ Donation and Transplantation: Ethical Dilemmas Due to Shortage. Following a brief description of the various types of paired organ exchange, the Commission discusses the potential impact of this new practice on the organ shortage, healthcare costs, and organ donors and recipients. In addition to providing an overview of position statements regarding paired organ exchange, the Commission raises several ethical considerations, including the values that should guide the monitoring and management of a national organ exchange program, donation anonymity and equity, and conditions aimed at ensuring free and informed donor and recipient consent. The Commission makes three recommendations.

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The CEST's **mission** firstly consists in informing, sensitizing, gathering opinions, fostering reflection, and organizing debates on the ethical issues raised by developments in science and technology and, secondly, proposing orientations to guide stakeholders in their decision-making.

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