

# **Financial incentives for organ donation**

**An investigation of the ethical issues**



Mr. G. van Dijk  
Dr. M.T. Hilhorst

**2007 ethics and health monitoring report**

**Centre for Ethics and Health**

*Financial incentives for organ donation. An investigation of the ethical issues*

Published by the Centre for Ethics and Health

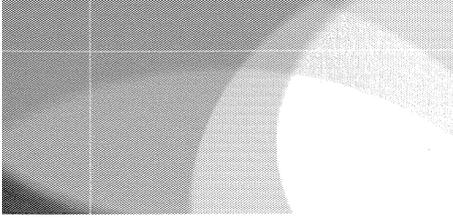
ISBN 978-90-78823-04-9

Copyright reserved

This publication can be obtained as follows:

Council for Public Health and Health Care. *Financial incentives for organ donation. An investigation of the ethical issues*. Ethics and Health Monitoring Report 2007/3. The Hague: Centre for Ethics and Health, 2007

You can download this publication via [www.ceg.nl](http://www.ceg.nl) / [www.rvz.net](http://www.rvz.net)



To the Minister for Health, Welfare and Sport

Dear Minister,

I have pleasure in submitting the report *Financial incentives for Organ Donation: an investigation of the ethical issues* to you. Two experts in ethics examined this topic on behalf of the Centre for Ethics and Health. The conclusions are surprising. Though the idea of offering rewards for organ donation may initially come up against resistance, it does appear that there are real and attractive options that could help reduce the dramatic shortage of organs.

Financial incentives for donations by living donors seems to be a particularly promising route. Rewards for post-mortem donation are less likely to produce tangible results, as the potential stock of post-mortem organs is continuing to decline. The RVZ [Council for Public Health and Health Care], which adopted the report at its meeting on 20 September, fully subscribes to its findings, which we set out briefly below.

#### **Rewards for post-mortem donation**

- There are no ethical objections to offering a small incentive to people registering as donors. The most suitable way of doing this is probably a small, one-off discount on health insurance premiums, or else giving potential donors a slightly higher priority on the waiting list for an organ if they should ever need one.
- Surviving relatives who give consent to organs being taken should also be eligible for a reward. This appears to be a more delicate issue, but a contribution to funeral costs could be considered.
- Individual payments to professionals is out of the question. However, healthcare facilities can spend some of their budgets on work to improve counselling services and communication for surviving relatives.

Parnassusplein 5  
2511 VX Den Haag  
Postbus 19404  
2500 CK Den Haag  
**Tel** 070 – 340 50 60  
**Fax** 070 – 340 75 75  
**E-mail** [info@ceg.nl](mailto:info@ceg.nl)  
**URL** [www.ceg.nl](http://www.ceg.nl)

Date  
12 November 2007  
Your letter of  
--  
Your reference  
--  
Our reference  
CEG/U07-017  
Direct line  
070-3405815  
Subject  
Organ donation report

### Rewards for living donors

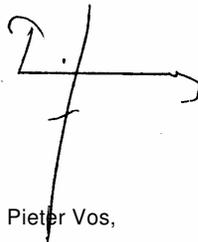
- Cash for kidneys: this seems repellent at first sight. However, it appears that altruism and incentives can co-exist. Our regulated system is also able to guarantee that the voluntary nature of the act is not compromised. Under these conditions, payment can be a strong encouragement to this form of donation, which is becoming increasingly important. Life-long exemption from health insurance premiums is the most suitable method in this case. It would show how committed the government is to reducing the organ deficit, demonstrate that the effort of donors is highly appreciated, and that the government is prepared to cover any health risks.

We hope that these conclusions, and especially the discussion of all arguments for and against, will be helpful in the run-up to the Organ Donation Master Plan due for publication in March 2008. This report investigates a route that has not received sufficient attention in policy so far, but that could be promising, particularly as an analysis of the ethical aspects now shows that there are no insurmountable obstacles.

Yours faithfully,



Rien Meijerink,  
Chairman of the  
Council for Public Health  
& Health Care



Pieter Vos,  
General Secretary of the  
Council for Public Health  
& Health Care

# Table of Contents

	<b>Summary</b>	7
1	<b>An urgent problem</b>	11
	1.1 Introduction	11
	1.2 Issues	12
	1.3 Hypotheses	13
	1.4 Outline	14
2	<b>Rewards in the post-mortem system</b>	15
	2.1 The value of offering rewards	15
	2.2 Rewards for registration as a donor	15
	2.3 Rewards for surviving relatives	19
	2.4 Rewarding the efforts of healthcare institutions	20
	2.5 Conclusion	22
3	<b>Rewards for live donation</b>	25
	3.1 The value of a kidney	25
	3.2 Various starting-points for the debate	26
	3.3 Key principles	27
	3.4 Towards a proposal for payments to living donors	39
	3.5 Conclusion	43
4	<b>Agenda points for policy and research</b>	45
	4.1 Offering rewards for organ donation can be morally justified	45
	4.2 Efficacy requires further investigation	45
	4.3 Particular points need further consideration	46
	<b>Bibliography</b>	48
	<b>Annexes</b>	50





# Summary

## Looking for ways to stimulate organ donation

Our society is facing a serious shortage of organs being made available for transplant. The number of post-mortem donations is continuing to fall in spite of what are often successful efforts made when counselling relatives of people who have died. Live donations, of kidneys in particular, are increasingly common but do not resolve the shortage.

This situation is translated into a great human and social cost. The cost is increasing rather than reducing, as people are more inclined to resort to illegal trade in kidneys from live donors, with all the abuse that this involves.

That is why ways of increasing the number of available organs are being explored. So far, little attention has been given in policy to one possible option: financial incentives for organ donation. This is easily explainable: the concept of paying for organs can initially appear repellent. The general view is that organs must be freely given. That is also the legal position.

## Are financial incentives for organ donation morally justified?

The question should really be whether we can ignore opportunities that, if carefully considered, can be integrated into our value-system from an ethical point of view and that are also worthwhile in practical terms, given what is at stake. Now that the drawbacks of the current situation are becoming more pressing, the question is whether we can afford to refuse to discuss the possibility of reward.

The time seems right for an in-depth ethical investigation of this topic. Two forms of donation need to be considered: post-mortem organ donation, and donation of a kidney by a living donor.

## Rewards for post-mortem organ donation

There are two ways of encouraging post-mortem organ donation by allowing reward: rewarding someone for registering as a donor, or rewarding his or her surviving relatives when the organ is taken.

An ethical analysis shows that there are no insurmountable ethical problems in either case. However, there are objections and risks. For example, would not certain measures, such as handing out a gift on registration or paying a considerable sum of money to surviving relatives, turn out to be counter-productive or lead to strategic behaviour? The stumbling-block here is therefore effectiveness rather than any moral objection. Another problem is the distorted cost/benefit ratio.

These objections apply less forcefully to incentives that do not take the form of cash payments but rather of discounts on medical expenses or funeral costs, for example. The link with healthcare is retained, which is not the case for something like a free passport. This also applies to the suggestion of a non-material incentive such as giving registered donors some advantage on waiting lists.

In the light of this, the following incentives for donor registration should be considered:

- giving a one-off discount on health insurance premiums, and
- giving registered donors a slightly higher place on waiting lists for any future organs they may need to receive themselves.

When the issue of donation actually arises, the benefit may come mainly from reducing the number of times that surviving relatives refuse to have their loved one's organs taken. The following incentives should be considered:

- rewarding surviving relatives who consent to organ donation, for example by paying funeral expenses, and
- offering (even) more support to professionals so that they can give good general information, help people taking decisions when they are about to die, and communicate with and provide counselling to surviving relatives.

Though these measures may have some impact, financial incentives to stimulate post-mortem donation are unlikely to produce a really significant effect. That is because the number of organs available for post-mortem donation is limited and continues to fall.

## Incentives for (kidney) donation from live donors

Live donation has become increasingly important as the number of organs available for post-mortem donation declines. The question which needs to be addressed is how financial incentives can help to increase the number of organs that are available.

The ethical analysis shows that under certain circumstances payment is morally justified, provided at least that the fundamental basic principles of it being a voluntary act and of equal access are maintained. Payment and the voluntary nature of the act do not seem to be mutually exclusive, and payment and altruism, an important feature of our donation system, can easily go hand in hand. There are therefore no decisive objections that by definition rule out the provision of financial incentives to live organ donation. There are certainly a number of difficulties, but these can be addressed by attaching conditions to implementation.

The best option is to arrange for life-long payment of health insurance premiums for live donors. This option does most justice to the moral intuition of many people who do not see organs as something for which you should receive money. Another benefit of exempting donors from paying health insurance premiums is that it is not so evident that it would lead people in financial difficulties to decide to donate an organ.

By making a financial incentive of this kind available the government further emphasises its commitment to reducing the shortage of donor organs, expresses the position that donation is morally justified and is valued by society and that it is doing what it can to cover all health risks.



# 1 An urgent problem

## 1.1 Introduction

### **Waiting lists for post-mortem organs are still long**

Around a thousand people were on the waiting list for a kidney in 2006, but the number of post-mortem organs available (i.e. those obtained from deceased donors) fell by 14 per cent from the 2005 figure to just 227. 95 people who were on the waiting list for a kidney transplant died in 2006 (2006 annual report of the NTS [Netherlands Transplant Foundation]). So in spite of the multiple initiatives undertaken over the past few years, practical improvements to the system and the good results they have achieved, the shortage of donor organs continues.

### **People are looking for solutions outside the waiting lists**

The shortage of donor organs remains a pressing problem precisely because a transplant can enormously improve the recipient's quality of life, and quite often means the difference between life and death.

We see that people are increasingly searching for ways to bridge the gap between what is medically feasible and what they need. Kidney donation from living donors is one such option. But even the dramatic growth in this procedure has not been able to resolve the shortfall in the Netherlands. It is becoming increasingly clear that a large, global illegal market in 'live' kidneys has developed. Donors often act out of despair and extreme poverty, and are often in a worse position after the donation (Goyal 2002, Scheper-Hughes 2000, Frontline 1997, Frontline 2002, Chugh 1996). That is because they do not have access to the health checks and good medical care that make organ donation by living donors so successful in this country. Dutch patients also seem to be choosing this solution.

The controversial donor show broadcast by BNN in June 2007 is a case in point. It no longer seemed inconceivable that someone could win an organ on a TV show. There was a great furor, because everyone thought that an organ really was going to be given away. When it became clear that the whole thing was a publicity stunt, the commotion

before and after the programme focused the spotlight clearly on the issue of organ donation, both at home and abroad.

### **Can a controlled system of incentives offer a solution?**

These incidents create more support for regulation of this market (Cherry 2005, Taylor 2005). One argument often put forward in favour of giving serious though reluctant consideration to offering rewards is that regulation could curb the existing illegal trade.

Options for regulation have been on the agenda in the Netherlands for a considerable time. In 2003 the Health Council took the view that there were no good arguments for reviewing the ban on payments for live organ donation, but did take up the option of a form of payment regulated by the government (Health Council 2003). It pointed to a proposal from the Bellagio Task Force (USA), the system in Iran and developments closer to home in a number of Middle Eastern and Eastern European states such as Estonia, Yugoslavia, Romania and Turkey.

The Health Council also warned of what might happen: "This problem will only get worse if we are unable to achieve a significant increase in the number of donations in this country in the near future." If waiting lists do not become shorter, "a form of 'donation tourism' might develop in the Netherlands too, with people travelling to countries where there is no statutory prohibition on the sale of organs, or where any such ban is not enforced. We cannot ignore the fact that citizens today may interpret their freedom as having the right to buy or sell a kidney and that they may not be persuaded by the ethical views of doctors or the authorities." (Health Council 2003). This prediction has started to become reality over the past few years.

## 1.2 Issues

### **Can payment for organ donation be morally justified?**

Paying for organs: a thought that causes revulsion. That is because we hear so much about the rapid growth of the illegal sale of organs. And the basic principle of our current system in the Netherlands is that a donated organ is a gift for which no recompense, and certainly not money, can be made. And financial compensation for living donors, beyond the current limited payment of expenses is also subject to a taboo. According to present government policy, donation must be and must remain a gift. To provide something in exchange is reprehensible in ethical and legal terms. Paying for an organ is still prohibited by law (Article 2 of the Organ Donation Act):

Consent to removal of an organ which is given with a view to obtaining payment in excess of the costs, including loss of income, that are the direct consequence of removal of the organ, is void (Article 2 of the Organ Donation Act).

But the question really is whether we have to uphold this principle. Can there be no reason for allowing donors to receive a reward under certain conditions? If organs are scarce good, is it not realistic to determine their economic value?

These are controversial issues, but have long been the subject of debate in medical and ethical specialist literature. The option of paying donors is frequently raised as a real and morally defensible option. The debate focuses not only on the issue of scarcity and the human price that is paid in terms of premature death and impaired quality of life. There is a social price as well. Transplants save health insurance companies tens of thousands of euros a year when compared to dialysis.

In this report, written on behalf of the Centre for Ethics and Health (CEG), we explore the options for offering rewards for organ donation within our healthcare system. We approach this from a moral perspective: the central question is whether rewards for organ donation can be justified, and if so under what conditions.

### 1.3 Hypotheses

Although the government has a neutral position on organ donation in principle, 'more donations' has long been a policy aim in practice (Den Hartogh, 2004)<sup>1</sup>. This report supports that practice.<sup>2</sup> It is then up to legal experts to decide whether or not the proposals for offering incentives are legally acceptable. However, from an ethical point of view the current wording of the law is not a barrier: a law that is not satisfactory can be altered.

Our hypothesis is that our society regards both post-mortem organ donation and donation from living people as accepted, common practices. We realise that not everyone shares this hypothesis. Many people have doubts about post-mortem donation, and some people have insurmountable objections. Ethical experts and doctors say that they have difficulty with donation from living donors because of the harm that healthy individuals can experience as a result (*primum non nocere: first, do no harm*). These objections are legitimate, and may even be convincing. But it is beyond the remit of this report to discuss the moral justification of the current organ donation system. Anyone who has doubts about this practice will look in vain for an ethical defence of it in this report.

### 1.4 Outline

This report discusses the options for offering incentives for the two types of organ donation that exist: post-mortem donation and living donation. We first look at the options for

<sup>1</sup> "The central policy question ... is the question of whether the government wants to try to influence the decisions made by citizens and relatives to encourage donation: ... " The introduction of the petitioner role in hospitals makes this aim explicit "obtaining more consent to donation." Is it not time to apply this lesson to living individuals?

<sup>2</sup> Our investigation only addresses the issue of organ donation by adults. The question of organ donation by children or by mentally incompetent adults is excluded.

payment within the post-mortem system. We discuss the ethical considerations that are involved and investigate what incentives would be morally justifiable and might also be an effective way of reducing the shortage of donor organs.

We then talk about donation from living individuals. We analyse the principal objections to payment and show that many of these objections can be dealt with - but not fully eliminated - within a payment system regulated by the government.

Anyone who just wants to know our findings can simply read the summary and conclusions (chapter 4). Anyone who is interested in the debate, or would like to take part in it, would be well advised to also read the underlying considerations (chapter 2 and 3) that led to these findings.

## 2 Rewards in the post-mortem system

### 2.1 The value of offering rewards

Which ethical considerations are involved in rewarding people for registering as donors, making their organs available after their death, or working to increase the number of donations in the course of their professional activities? That question lies at the heart of this chapter.

We have deliberately decided to use the phrase 'offering rewards'. The phrase indicates that people would be receiving more than reimbursement of costs, as the Organ Donation Act probably intended. It is therefore not compensation, but an element that would be new to our system.

A 'reward' reflects an impression of value. It can be seen as a gesture of gratitude for someone's trouble. The message this puts across is that society is very appreciative of people who register as donors and are willing to offer their organs after death, and of people who actively support this system in their professional capacity. Offering a reward also shows that donation serves an important social interest, that post-mortem donation is morally justified, and that the government is committed to reducing waiting times.

In the light of this, a reward system should be considered even if it does not actually lead to more organs being donated. But that is in fact the aim. That is why we have looked at the options we discuss below both in terms of their ethical implications and in terms of their efficacy insofar as this can be assessed.

### 2.2 Rewards for registration as a donor

A first option to be examined is offering rewards for people who register to make their organs available after their death. There are various ways of doing this. We look at these below and discuss them in terms of their ethical implications and the contribution they could make to the aim of increasing the number of donor organs available.

#### **Giving a little present**

One way of encouraging people to register as donors is to show that this is appreciated, for instance by giving them a little present. There can be few ethical objections to this, as

it avoids any impression of paying for an organ. So long as the gift is small, the message is clearly that this is a gesture of thanks.

When you start to think of how this would work in practice, things become more difficult. What kind of present should be offered? A free first-aid kit? A discount card for their local drugstore? A large gift would quickly come to seem inappropriate, but an insignificant one-off present would not really convince many people to register. The costs of running the scheme should not be forgotten either. Sponsorship with a view to perhaps offering larger gifts would not be desirable either as it would easily give the impression that the sponsor is acting in order to attract customers.

There is a real danger of the wrong choice being made and the wrong signal being given. Trivial offers that have little to do with the aim would not be taken seriously by many people. This would be detrimental to the image of organ donation.

### **Giving a small sum of money**

A more businesslike way of rewarding donors would be to give people a cash sum, say € 25, when they register. There can be few moral objections to this. It is far removed from the idea of actually paying for an organ, because people would receive the money for registering, not for the organ itself. And the sum involved is so small compared to the economic value that an organ could represent that it would be difficult to describe this as a form of trade. Some of the traps involved in looking for appropriate presents could be avoided in this way.

One disadvantage is that the neutral character of a cash sum means that there is no connection between the aim and the payment. The absence of any such connection could create a bad impression, and so indirectly have a negative impact on the image of organ donation.

Another question is whether such a small payment would help achieve the aim of increasing organ donation at an acceptable cost. If we assume that 25,000 to 50,000 opt-in registrations are needed to bring about one extra donation a year, then the system would need to offer € 625,000 to € 1,250,000 for each additional donation.<sup>3</sup> In that case the cost/benefit ratio would probably not be favourable. There is also the risk of strategic behaviour, i.e. people who de-register once they have received the money.

An alternative system, in which people are paid for registering irrespective of whether they opt in or opt out of donation, is not at all a good idea in the light of this estimate.

<sup>3</sup> The Kidney Foundation assumes 25,000 additional registrations, but in fact we do not know whether someone who has opted in as a donor would not have been a donor if they had not done so. That is not necessarily the case. Someone who is not a registered donor might still become a donor on his or her death. It is therefore difficult to assess the efficacy of such an intervention with any accuracy.

The costs would be higher, and people who are leaning towards rejecting the idea of being a donor would actually be encouraged to formalise this view.

### **Offering a free passport**

Another option that has been suggested is rewarding people who register as donors by giving them a free passport. <sup>4</sup> This is certainly not a trivial gift. You could even argue that it is not a gift at all, but rather a form of payment. After all, most people need a passport at some time or another, and could save the costs of obtaining one by registering as a donor. But does this resolve the objections set out above in respect of offering an incentive in the form of a small gift or a small cash payment?

A reward taking the form of a passport would show even more clearly than a cash payment that the government wants to increase donation levels. The question is whether it is desirable to use proof of Dutch nationality for this aim. It might have some logic if the passport indicated that the holder was a registered donor, but that possibility has not yet been raised.

And while some people might see this as a reward, other people who have to pay for their passport might feel that they are being punished. This would then be an inappropriate tool, not connected to the aim, that might have counterproductive effects. Strategic behaviour could have a serious impact on efficacy in this case as well. And what about people who have already opted in on the donor register? If they were also to be given a free passport, the already significant costs would increase still further. In brief: there seem to be too many snags with this plan.

### **Giving a one-off discount on health insurance premiums**

Another way of rewarding people who register as donors is to offer them a one-off discount on their health insurance premiums. The great advantage of this is that the aim and the reward are connected: both are medical issues. This is important in terms of perception. It underlines the importance of solidarity. The message is that registration is something we do for ourselves and for everyone else.

However, looking at it from a financial point of view, the same objections as those raised against offering a small cash sum could apply. And the other issue is whether a small discount, set against a significant sum such as a health insurance premium, would prove a real incentive. Though not unattractive as an idea in principle, it is therefore not certain whether this option would be effective.

<sup>4</sup> Recently suggested by the Minister of Finance, Wouter Bos.

### **Waiting list priority**

Another approach would be to offer a reward in the sense of allowing people who register as donors to move up the waiting list if they ever need an organ themselves.

This kind of reward establishes the link with organ scarcity in very concrete terms (Den Hartogh 2003, Levi 2007). It is also a proposal that powerfully expresses the great importance that the government attaches to donor registration.

It clearly indicates that organ donation is not regarded purely as a form of altruism. In this approach donation is indeed a matter of enlightened self-interest: a system from which anyone could derive personal benefit at a particular time. There can be no objection to this per se, rather the contrary. Society cannot function without fundamental moral concepts such as reciprocity and loyalty (Hilhorst et al., 2004).<sup>5</sup> In this variation, registration can then be regarded as a form of 'mutually assured help'. The question of when someone reaches the top of the list for a transplant would no longer depend purely on medical criteria but on how he or she had 'insured' him- or herself (Veatch 2000).<sup>6</sup>

Surveys show that many people are initially opposed to this suggestion. But that is not a decisive factor in ethical terms. It does require policymakers to present the issue carefully and to explain the reasons behind the proposal properly. They would need to persuade people that the alternatives are (even) less desirable.

Offering a reward in the form of a higher place on the waiting list, should it ever prove necessary, is therefore a morally defensible way of encouraging people to register as donors. But would it be effective? People might engage in strategic behaviour here as well.

People in high-risk groups who would not be able to donate because of their state of health might register en masse because of the benefits they could obtain, but their declared willingness would not in fact have any concrete results. Nobody would gain from this. On the contrary, the risk of unsuitable organs being used would increase. Young, healthy people might find the idea that they would end up on a waiting list for a transplant so far-fetched that they would not respond to this reward. And there are groups of individuals (children, people with HIV, people who engage in dangerous sexual contacts) who cannot be donors and so could not benefit from the scheme.

<sup>5</sup> "The rule 'fair distribution according to need' does not exist in a vacuum, but like the term solidarity assumes a clearly defined group ... A certain reciprocity can be expected within a group like this ... The rule is: if we insure ourselves, we are assured of mutual help."

<sup>6</sup> The obvious idea of giving people who donate a kidney during their lifetime priority at least if they need a kidney themselves, as practiced in the United States, does not apply in the Netherlands.

## 2.3 Rewards for surviving relatives

In addition to incentives for registration, the literature also contains references to the idea of paying (future) surviving relatives of potential donors for giving consent. This can be done in various ways, the implications of which we discuss below.

### **Giving a large sum of money**

Imagine that someone is brain-dead or their heart has finally stopped beating, but he or she is not a registered donor. It might then be conceivable to offer his or her relatives a significant sum of money if they consent to have organs removed for transplant. The principle here is that they would be doing what their partner or relative would have wanted, but the offer of a cash sum would stimulate them to consider donation. If they do give consent, then they would receive a sum of, for example, € 2,500 in total or € 1,000 per organ, irrespective of whether the organ turns out to be usable or not.

Thinking about this for a moment shows that there are significant objections. Firstly, this idea is in conflict with the system of pre-death registration as a donor. Relatives of non-registered potential donors would receive money for giving consent, while relatives of registered donors would receive nothing. Choosing a system like this would give a strange signal. It would be a financial penalty for registering as a donor, which is seen in current policy as a desirable and unselfish act.

But there are still serious objections to the possible solution to this problem, i.e. paying the relatives of all deceased people from whom organs are taken for donation. That is because asking consent for removal of organs when a loved one has just died is a very difficult thing to do. Asking relatives for consent in this charged situation (the worst possible question at the worst possible time) and mentioning money in the same context would often be repellent and might have the opposite effect to that desired.<sup>7</sup> It might lead relatives who are in favour of organ donation in principle to deciding not to give consent.

The objection is all the stronger because the payment would not be made to the potential donor, as with payment on registration (see preceding paragraph) or to someone who donates a kidney during their lifetime (see next chapter). It is the relatives who gain financially from the donation. Many people might take the view that that money should not come into their deliberations at all.<sup>8</sup> And people would not want to think that they had sold a part of their loved one.

<sup>7</sup> Even Robert Veatch (2000), who is not against the idea of cash payments, uses the word 'unseemly' in this context.

<sup>8</sup> If other insurers follow the example of the Monuta funeral insurance firm, giving a discount of less than € 200, this could be seen as a kind, symbolic incentive that is likely to have little effect. It will not affect people's decisions. At most, it raises Monuta's profile.

In brief: paying a significant sum of money to relatives who consent to having organs taken runs counter to important basic ethical principles. Offering money could undermine both the principle of voluntary consent and the idea of doing what the deceased person would have wanted. This is in itself a highly undesirable attack on important values. And in this case it would probably mean that the aim of obtaining more organs for donation would probably not be achieved.

### **Paying funeral expenses**

Another alternative that has been suggested is the idea of rewarding relatives not by offering cash but by contributing to the funeral expenses - € 2,500, for example.

But this is still an indirect financial reward. That is because the scheme would not be arranging the funeral, but passing over money 'earmarked' as a contribution to funeral expenses. The difference between this and a cash payment is minimal, and so this approach is subject to the same objections as those made against cash payments. And another form of reward would have to be devised for people who have funeral insurance. So this alternative entails risks as well.

## 2.4 Rewarding the efforts of healthcare institutions

A third way of increasing the supply of post-mortem donor organs by offering some kind of reward would be to pay hospitals for their efforts in obtaining organs for donation. What are the ethical implications here? And does this kind of financial incentive work?

### **Funding facilities**

A reward in this context could take the form of payment of the overheads incurred by a good donor programme. For instance, funds could be allocated to the work of donor coordinators and for transplant procedures. It is reasonable for departments to receive suitable payment for organ acquisition procedures that involve a large amount of irregular work, such as non-heart-beating procedures.

These kinds of incentives are often necessary in practice.<sup>9 10</sup> Much has been done and a lot has been achieved in this area over the past few years. Provided that the payment is more or less identical to the costs incurred, there is no legal objection to this form of financial incentive under the current system. Acceptability is not an issue either. The question really is whether anything can be gained at present by allocating larger budgets to donation programmes in healthcare institutions.

<sup>9</sup> Research in the United States shows that institutions are often unable to make 'optimum' use of a donor (as a result of lack of time and other factors); that the number of organs that could have been obtained exceeded the number that were removed; and that performance varies widely between institutions in this area. On the other hand it is important to avoid taking organs unnecessarily that later turn out to be unusable, as happens in Spain.

<sup>10</sup> The effect of Menzis' bonuses on GPs and the reaction of the pharmaceutical industry shows that professional standards are not always met.

This form of funding could be beneficial if it were necessary to bridge a gap between the number of post-mortem organs that could be removed in hospitals under ideal conditions and the number that are actually obtained at present. It is therefore important to know how many organs that could be obtained are being missed, and whether a financial contribution would improve a donation programme to such an extent that more organs would be obtained.

We suspect that very few suitable patients are not identified as potential donors. In that respect, more money would not be very helpful. Any benefit would come mainly from reducing the number of refusals by relatives. The hospital has an important part to play here as well.

Allocating funds for training medical staff and using them to give proper counselling to relatives could therefore be beneficial. It might increase the likelihood of actually obtaining consent from people who are in principle minded to give it. Good counselling might also help people who still have doubts to take a well-informed decision. There are no ethical complications in paying for this.

### **Rewarding performance**

Another way of offering financial incentives to healthcare institutions to promote organ donation is to pay sums that exceed the costs. This kind of scheme would lay considerable emphasis on performance, for instance by paying per donor, or in an even more targeted approach, by paying per organ taken or transplanted. Are there any objections to this? When answering this question we need to draw a clear distinction between creating optimum conditions and bonus-chasing, with healthcare institutions ignoring their professional duty of care, hounding relatives and conducting procedures without the proper care for the sake of the reward.<sup>11</sup>

Of course, a performance-based reward would aim to achieve the former effect. But it is not without difficulties. The question of image is a tricky issue, for instance. However carefully healthcare institutions handle the matter, patients and their relatives might be shocked to know that an institution receives a sum of money for each organ obtained. The interests of the patient and the interests of the institution do not necessarily always coincide in this kind of performance bonus scheme.

You might also wonder why a healthcare institution should be financially rewarded for good performance in this area. You might argue that if a healthcare institution regards organ donation and transplant as one of its activities, it is obvious that it should work to a

<sup>11</sup> These kinds of accusations are made with regard to the successful Spanish programme.

quality standard and try to optimise its performance. If improvements are still necessary, there must be other ways of encouraging them rather than financial rewards.

## 2.5 Conclusion

What should we conclude as to the options for using a reward system of one kind or another to increase the number of organs available for post-mortem donation?

There appear to be significant objections to financial incentives for people joining the donor register. We would make an exception to this view for the suggestion of offering people who register as donors a discount on their health insurance premiums. Another option is allowing them to move up the waiting list. Good reasons can be put forward for both ideas. However, it is unclear whether they would actually increase registration levels and result in more donations. This requires further investigation.

Payment of funeral expenses should also be considered. But there are significant objections and risks attached to the idea of rewarding surviving relatives who consent to organ donation from someone who is brain-dead or whose heart has finally stopped beating. An excessively direct link between consent and reward might be more likely to produce the opposite effect and should be avoided.

A more promising approach is making funds available to improve the procedures associated with end-of-life decisions and organ removal so that no organs that might have been available under more favourable conditions are missed. Investing in good communication and support in healthcare facilities for people who are facing the loss of a loved one and who might have to take a decision about organ donation would also be beneficial. Institutions that make considerable efforts in this direction could be rewarded, though a larger general contribution to training and the activities of professionals would be more appropriate than a bonus for each organ obtained.

The conclusion is that financial incentives for post-mortem donation can only make a limited contribution to the aim of making more organs available for transplant. Post-mortem potential is limited and is continuing to decline, and not many organs that might have been available from this pool are in fact missed. Consequently, the financial incentives for post-mortem donation that could be ethically acceptable are unlikely to lead to a substantial increase in the number of organs available.



## 3 Rewards for live donation

### 3.1 The value of a kidney

Financial incentives for post-mortem donation offer only limited opportunities for increasing the number of organs becoming available for transplant. That was the outcome of the investigation in the previous chapter. What about financial incentives for the second form of donation, that involving a living donor?

Living donation is gradually becoming more important as a result of the limited number of organs available from deceased donors. At present, around 40 per cent of kidneys available for transplant come from a living donor; the figure at the Erasmus MC hospital is even higher, at 60 per cent. This proportion is likely to rise still further, especially as surgical techniques continue to improve, the pool of post-mortem donors continues to shrink, and waiting lists for a post-mortem organ grow even longer.

Donation from living donors is mainly of interest to kidney patients, but can also benefit patients waiting for a liver. But hardly any attention is paid in policymaking circles to this form of donation. Policy has concentrated mainly on reducing barriers. For example, in his response to the third evaluation of the Organ Donation Act the Minister said nothing at all about living donation. Why is there such reluctance in political circles to address this issue? Perhaps it is out of fear that the option of living donation might put pressure on relationships between people. But important opportunities are being missed here.

In its fund-raising campaigns, the Kidney Foundation focuses primarily on a distant - hypothetical - goal: artificial kidneys that can be implanted into people. But the immediately available solution - living donation - is underemphasised. The attitude is one of reticence: "It's an emergency measure: we would like to see research into the long-term effects on those who have donated an organ."

But there is already a significant body of research into this subject (Johnson et al., 1999, Westlie 1993). It shows that the (perceived) health of living donors returns rapidly to baseline values, and subsequently is actually better than the health of the general population in terms of quality of life. This of course is not to say that donating a kidney im-

proves health. That particular outcome is mainly due to the fact that donors are strictly screened and are only eligible if they are in very good health. But the research does show that donating a kidney is not necessarily detrimental to health.

Living donation is unlikely to entirely eliminate the waiting list for kidney transplants. After all, not everyone has a friend or relative who is able or willing to donate a kidney. But there are many missed opportunities here. The question of how far a policy aimed at encouraging living kidney donation should go always arises. For example, how should we react to the recent plea made by the Nijmegen lecturer in organ transplant and donation Andries Hoitsma to pay these donors € 50,000? (Hoitsma 2006)

### 3.2 Various starting-points for the debate

The debate on payment for living donations is conducted in various places and from a wide range of approaches. Before we start to address the fundamental issues, let us first consider the possible starting-points for the debate.

The hypothesis we selected for this report is the idea that offering rewards for donation might help reduce waiting lists. But some authors choose a more fundamental starting position in the debate. They ask what right the government has to prohibit citizens from trading in their organs amongst themselves.

According to Janet Radcliffe, this prohibition means that people are unable '*to enter freely into contract from which both sides expect to benefit, and with no obvious harm to anyone else*' (Radcliffe 1996). The (libertarian) norm here is that people are free to trade in their organs between themselves and that it is up to the government to put forward arguments justifying a prohibition on this practice. According to these authors, the prohibition on sale undermines our right to full ownership of our own bodies. Why is donation permitted but sale prohibited?

Looked at it from this position, the debate therefore turns first of all on the question of where the burden of proof lies. Does it lie with those who think that paying for organs is undesirable in principle, and that good arguments must be put forward to lift this ban? Or does it lie with those who think that people are free to do or not do whatever they want with their bodies, and that the government must have good arguments for prohibiting this activity?

Another starting point for the debate is that something must be done to combat the illegal trade in organs. We know that there is now a large, global illegal market in organs. Donors often act out of despair and extreme poverty, and are partly as a result of this in a worse position after the donation (Goyal 2002, Scheper-Hughes 2000, Frontline 1997, Frontline 2002, Chugh 1996). This vile 'organ tourism' creates more support for regula-

tion of this market (Cherry 2005, Taylor 2005). Canada recently decided to pay living kidney donors € 5,000 to compensate them for their expenses (Canadian Press 2007).

The main question when approaching the issue from this angle is not so much whether financial incentives should be introduced, but how we can put an end to this exploitative practice. *'If we are concerned about reducing the abuses of the black market for human kidneys, we should favour the legalisation of kidney markets, not their continued prohibition.'* (Taylor 2006)

Looking at it from this point of view, the problem is not that there is a market but that this market has objectionable aspects. The literature contains various proposals for transforming the current illegal market into a regulated system of payment. For instance, Erin and Harris assign a central role to the government in paying for and distributing organs within the country (Erin and Harris 2003). This could also prevent exploitation abroad.

The question: 'How can we put an end to the black market in organs?' is fundamentally different from the question 'What is the best way of reducing waiting lists in the Netherlands, and can payment contribute to this?' When assessing the various arguments it is important to bear in mind the perspective from which the debate is being conducted.

### 3.3 Key principles

A number of arguments come up time and time again in the debate on the moral acceptability of payments to living donors. These apparently include the core issues in the debate. We will set out the main arguments below and assess how tenable they are. It should be borne in mind that not all arguments can be easily described as for or against. The point on exploitation, for example, or of the voluntary nature of the act, can develop into an argument in favour of payment or against payment, depending on the perspective selected.

#### **'Payment for organ donation is repugnant'**

Some people believe that the idea of paying for an organ creates so much repugnance that we do not need to waste any further words on it. *'We intuit and feel, immediately and without argument, the violation of things we hold dear.'* (Kass 2004, Schepers-Hughes 2004). That should suffice in itself to prohibit payments for organ donation. The question of the reasons justifying payment, and whether it would be beneficial, do not even need to be discussed.

The problem with this argument is that many people do not agree with it. People who buy and sell organs clearly do not feel this repugnance, or they do, but do not let it determine their behaviour. From an ethical point of view, repugnance is not necessarily a decisive factor. Something may arouse repugnance without being immoral or something

that should be banned (Taylor 2007). Prostitution, pornography and the drugs trade can also be repugnant, but that is not a good enough reason to ban them.

And the present situation could be thought to be repugnant as well. If no other solution is found, the waiting list will continue to exist, with all this entails in terms of mortality, the burden of disease, and impaired quality of life. The black market and illegal trade will also continue under these circumstances. In other words: we need to consider not only the possible moral harm that introducing financial incentives might create, but also the moral harm caused by the current situation. As the Americans say: *'Do we buy or let die?'*

In brief: the argument of repugnance is not convincing in the debate over paid organ donation. Another interesting feature is that repugnance is often not clearly expressed, but replaced by ever-changing arguments against payment. If one argument appears to be untenable, then another is tried.

### **'An organ must not become a tradable object'**

Another argument is that an organ is not something for which you should be able to pay, as this makes the human body or part of it into an object, a 'thing' in its own right. The idea is that some things, including organs, should not be for sale. *'To sell an integral human body part is to corrupt the very meaning of human dignity.'* (Cohen C 1999). This is another fundamental point.

But it is unclear what exactly this argument involves and how it could win over people who do not share this idea of human dignity. The very fact that transplants are possible does actually make an organ into a commodity, something that has value also outside the body. It becomes a (potentially) tradable good. Whether you express that in financial terms or in another way appears to be a secondary question. The argument would be a reason for prohibiting all living donations, even unpaid ones, as there is - at least in emotional terms - a form of exchange taking place.

Anyone subscribing to this argument would have to explain why 'commodification' is not an objection to unpaid organ donation but is a barrier to paid organ donation. Another point is that this objection cannot be used to prohibit other people who do not share this view from selling their organs. And the argument offers no support if you wish to draw a distinction between different contexts and different forms of payment. In moral terms, selling a kidney to pay for a wedding is in a different class from doing the same thing to pay for a child's life-saving operation. The fact that money changes hands can never be the one and only decisive factor in a moral judgement.

And money does not automatically detract from the value of something for which payment is made. For example, in a plane crash involving fatalities the airline makes pay-

ments to surviving relatives. This does not degrade the infinite value of human life, or make the deceased person into a commercial object. The payment reflects that the airline recognises the loss or suffering the surviving relatives have experienced and they offer financial compensation for this. It would be unusual - and immoral! - for the airline to refuse to make payments because it is impossible to put a cash value on a human being. In other words, the fact that a price list is attached to something in certain situations does not mean that the value of that object in other situations is not recognised.

### **'Donation must be an altruistic act'**

One of the most widely-used arguments against payment is that donating an organ must be something that is done in a spirit of altruism; i.e. the donation must be a disinterested gift. This argument is also used by the Health Council (Health Council 2003). When assessing this argument we must draw a distinction between two interpretations.

The first (deontological) interpretation is that paying for organ donation would be contrary to important social or societal values, even if the effects were favourable: *'The fundamental truths of our society, of life and liberty, are values that should not have a monetary price. These values are degraded when a poor person feels compelled to risk death for the sole purpose of obtaining monetary payment for a body part.'* (Delmonico 2002)

In this case the important social value under attack would be altruism. Or as Richard Titmuss puts it: *"Well-established cultural norms of selfless giving can be seriously eroded by the commercialisation of some areas of social activity."* This is a fundamental point.

The other (utilitarian) interpretation is that paying for organ donation would lead to a decline in altruistic donation, and that as a result there would eventually be (even) fewer organs available. This is a pragmatic argument and mainly of interest in a discussion on the efficacy of payment as a means of achieving an end, such as reducing waiting lists. We discuss the tenability of these two interpretations below.

### **'PAYING FOR DONATION UNDERMINES ALTRUISM AS A SIGNIFICANT VALUE'**

How tenable is this argument? Various authors have pointed out that altruism as a value is overestimated. They believe that we set ethical standards far too high as a result.

In practice, people donate for many different reasons. Selling a kidney to secure medical care for your children is different from selling a kidney in order to pay for your wedding (Castro 2003). Altruism plays an important part in the first act, and a much less significant part in the second act. And why is it an act of altruism for a father in the Philippines to donate his kidney to his daughter who is suffering from a serious kidney disease, but

morally reprehensible for the same father to sell his kidney to a third party to raise money to pay for a life-saving operation for his daughter? (Radcliffe 1996)

The sale of an organ can take place for many different reasons, some of which are altruistic. Several motivations can co-exist. '*Selling in itself is not in itself at odds with altruism, it all depends on what the money is wanted for.*' (Ibid) Medical students like to earn money from taking part as subjects in medical trials: they are attracted by the money, they like to acquire experience of this kind of research, and it also makes them feel good about themselves. Someone might be very dedicated and self-sacrificing in working for a good cause, and also need money. This could apply to someone who earns a reasonable salary working for Médecins sans Frontières. It is still incorrectly thought that these motives are mutually exclusive.

The fact that the requirement for 'pure' altruism is too strict also becomes apparent when we look at the difference between 'related donations' (between people who know one another) and 'altruistic donations' (between people who do not know one another, usually via the waiting list). The first group is made up of donations between people who know each other, such as family and friends. The second group comprises people who are prepared to donate a kidney to someone they do not know, usually via the waiting list.<sup>12</sup>

This growing group of donors are described as 'altruistic' because their only motive is altruism (Netwerk 2007). In most cases they do not know the recipient. It is interesting to note that until very recently transplant centres did not accept people who wanted to donate to an unknown person on the waiting list because there were doubts as to the purity of their motives. And this group still undergoes very tight screening. It is clearly difficult to imagine people acting purely for altruistic reasons.

That is also true if you look more closely. Purely altruistic motives tend to be the exception rather than the rule. 'Altruistic donors' can in fact hope to become 'better' or 'richer' as a result of their gift, and may expect to develop, for instance, a stronger self-image, greater self-confidence, or a feeling of giving meaning to their lives. As far as related donations are concerned, donors may often have their own personal motives, such as a belief that donation is their duty or that it is in their own interests.

The argument that organ donation should be an act of pure altruism would therefore rule out other motivations for organ donation. For instance, Den Hartogh puts forward the idea that post-mortem organ donation is not (or does not have to be) so much an act of altruism, but should rather be understood as a form of insurance whereby everyone has to make his or her contribution in order to have an opportunity to acquire an organ in

<sup>12</sup> Since the year 2000, 21 altruistically-motivated Dutch people have donated a kidney as part of the Erasmus MC renal transplant department's altruistic donations programme.

turn. This brings us back to the proposal put forward earlier of allowing registered donors to move up the waiting list.

In this context, Den Hartogh prefers to use the term 'contribution' rather than 'gift'. Looked at from this point of view, people donate not from (disinterested) altruism but out of enlightened self-interest: they want to maintain a system from which they themselves might one day benefit. In this case, the term 'solidarity' is more accurate than that of 'altruism', and the idea of 'reciprocal duty' is more applicable than that of 'disinterest'. Taking this approach, campaigns should focus more strongly on appeals to reciprocity than they do at the moment. Policy should also take greater account of it.

In the case of living donations between relatives we should also not rule out the possibility that motives other than altruism may also be involved: self-interest, or a feeling that it is the individual's duty or a natural and obvious act. Kidney disease puts family life under great strain, and donating a kidney can improve the situation markedly, for the donor as well as for the recipient.

In short, people can have many different reasons for donating. It would be wrong to dismiss motives other than altruism as 'immoral' or 'morally reprehensible'.

But would it not erode the value of altruism too much? Would payment not undermine this important social value? It is hard to find much tangible evidence to support this concern. And there is evidence pointing in the other direction. Many people who work in the caring professions do so because of their sense of humanity or altruistic attitude, but this does not mean they are necessarily badly paid. And what if an unemployed person could sell a kidney and use the money to set up a business allowing him to provide for his family? Altruism and payment can go hand in hand here, rather than payment being detrimental to this important value.

Introducing money therefore does affect the way we act, but not necessarily in a negative fashion. Furthermore, in our society money has an important symbolic significance: it can (also) be a good way of expressing appreciation.

**'PAYMENT UNDERMINES ORGAN DONATION PROGRAMMES THAT ARE FOUNDED ON ALTRUISM'**

Altruism also plays another part in the debate surrounding rewards for organ donation. It has been said that payment for living donations would mean that people would no longer donate in a disinterested manner, for instance by registering as post-mortem donors.

This objection applies not only to financial incentives but to all efforts to stimulate living donation. It might give the impression that post-mortem donation is no longer necessary. If the waiting lists for kidneys (or livers) reduce as a result of more living donations, then the population might develop the incorrect impression that they no longer need to join

the donor register. In Iran, where there is a legal system of payment, only 10 per cent of donor kidneys come from post-mortem donors; though it has to be remembered that cultural and religious resistance to post-mortem donation also has a part to play (Bagheri 2006).

How serious is this objection? A less prominent role for post-mortem kidney donation is not necessarily to be regarded as a problem. The outcome of living donation is usually much better for the recipient than in the case of post-mortem donation (Hoitsma 2006). It is by no means obvious that post-mortem donation is preferable from a moral or practical point of view, or that it should receive priority in policy.

It is indeed possible that an increase in kidney donations from living donors, and so a decline in the urgency of post-mortem donation, might cause problems to patients waiting for a different organ, such as a heart. After all, post-mortem donation is the only option for them. Another objection might be that other altruistic donation programmes for bone marrow, blood or sperm, might suffer if a system of payments for kidney donation were to be introduced. Why pay the kidney donor and not the other donors?

However, these objections do not inevitably or by definition lead to problems. It might be possible to deal with them by selecting specific forms of rewards and continuing to emphasise the importance of post-mortem donation.

Willingness to donate between relatives or friends might also decline if the waiting list for kidney transplants becomes shorter as a result of paying donors. Why should you as a relative still donate if someone can obtain a kidney from an anonymous donor instead? It has been found that in India people would prefer to buy a kidney from a stranger than to ask a relative for a donation (Cohen L 1999). It is easy to understand this: an anonymous donation does not interfere with relations between relatives in the way that a specific donation does.

This effect should not necessarily be regarded as a problem. Anyone who thinks that transplants between people who know each other are more desirable than those between strangers, would see a decline in related donations as a drawback. But anyone who prefers anonymous donations, for example because they have less impact on family relationships, would see this effect as a benefit.

In short, the view that living donation is or should always be an act of altruism is incorrect in both empirical and moral terms. People can have many different reasons in practice for donating an organ without payment. The same would be true if payment was involved. Non-altruistic motives are not necessarily immoral or morally undesirable. Payment and altruism are not mutually exclusive.

So the objections contained in this argument of undermining do not lead to the conclusion that payment must be rejected. The risks that have been pointed out are not necessarily problems. And they are not necessarily inevitable either. It might be possible to deal with them by selecting specific forms of rewards and continuing to emphasise the importance of post-mortem donation.

### **'Rewards for donation pay for themselves'**

Another argument in the debate on payments to living kidney donors is that kidney transplants are an extremely cost-effective procedure, even if the sum of money involved is relatively large. The costs of treating patients who are on the waiting list for a kidney transplant are very high. In financial terms, the costs relate to dialysis and other hospital treatments. But there is also a high price to pay in personal and social terms: a lower quality of life, shorter life expectancy, and often partial incapacity for work. Transplants can bring about huge improvements in all these areas and are consequently particularly cost-effective medical interventions (Wit et al. 1998).

If a system of paid living donations could reduce the waiting lists for a kidney transplant, this would be a highly desirable outcome from an economic point of view. American calculations show that society would benefit financially even if the payment rate were set at 90,000 dollars per kidney (Matas 2004). Further investigation is needed to determine where this break-even point lies in the Netherlands. In this context Ardlene de Wit has calculated that kidney transplants cost € 12,000 per additional year of life, compared to € 60,000 per additional year of life for dialysis (De Wit 2002). Performing a transplant therefore saves € 48,000 per additional year of life. This means that transplants can be very cost-effective even if a significant sum of money is paid.

A crucial point here is the assumption made by both supporters and opponents of payment that people would actually be more likely to donate during their lifetime if a form of payment or financial compensation were in place. But how self-evident is this? (Rothman 2006)

The distinction between extrinsic motivations (money or other material rewards) and intrinsic motivations (a moral duty or an internally perceived urge) is important here. The anxiety or concern among opponents of payment is that extrinsic motivations would crowd out intrinsic motivations. The most frequently mentioned example in this respect is the work done by Titmuss on blood donation (Titmuss 1971). Between 1946 and 1968 the percentage of blood donors in countries where selling blood was banned increased, but fell in countries where people were paid for giving blood. This finding suggests that if people give enough blood by the altruistic route, then payment is not only unnecessary but may also be irrational.

The problem with organs is however that appealing to altruism does not seem so far capable of making enough organs available. Clearly, the moral commitment of people is

not strong enough, or - and this is more likely - the sacrifice is too great. Of course, this does not necessarily mean that payment would produce enough organs.

Titmuss is correct to say that some people would have donated their organs altruistically if the option of selling them did not exist. But as soon as selling becomes possible, they opt for that. There is therefore no reason for him to take the view that if selling was not possible large numbers of people would still donate an organ (Steiner 2004).

Titmuss' objections to payment are in the end utilitarian: he fears that the altruistic system would collapse if money entered the equation. The key point is which system works best. Further investigation is needed to find out whether the crowding-out effect would be produced in the case of organ donation. Perhaps this could take the form of an experiment in a particular region. Would paying for living donation really increase the number of organs available?

There are some indications of a favourable effect. Kranenburg's research shows that 18 per cent of people would find a financial incentive a persuasive element in convincing them to donate a kidney (Kranenburg 2007). This is in line with American figures: here again around 18 per cent of those surveyed said that they would be more likely to donate an organ if a financial incentive were available (Gallup Organization 2005).

Experiments with payment are always associated with risk. According to Titmuss, it is difficult to revert to the old system in which organ donation is seen as an altruistic gift if the experiment does not succeed: '*Once a commodity, always a commodity.*'

### **'The free will of the donor comes under pressure when payment is involved'**

Another important argument in the debate over paying living donors is that if payment is involved the free will of the donor comes under pressure. Those in favour of payment say that it is better to regulate the current illegal market in order to avoid people in developing countries being forced to part with a kidney. It is sometimes said that paid donation can ease the pressure on specific family donations because alternatives are now available: that is because payment increases the potential number of anonymous donations. Opponents take the view that introducing payment always compromises free will and puts it under unacceptable pressure.

The question of how money affects the behaviour of potential donors is crucial to any assessment of this argument. If a very large sum of money is offered for a kidney, this might be very attractive, even irresistible, to some people.

But there is an important difference between 'irresistible' and 'forced' (Veatch 2003). Putting a gun against someone's head to make them register as a donor is force; offering

someone a lot of money when they register is an attractive offer. The difference is that you can also say 'no' to an attractive offer. Offering someone money for a kidney is different from deciding that the same person is not entitled to social security benefits because his or her two kidneys represent a potential financial asset (Andrews 1986).

Supporters of payment take the view that the fact that money can persuade people is an advantage. They regard regulated payment as a way of dealing with the abuses in the current illegal market and relieving the shortage of donor organs. But they also insist on the donor's decision being voluntary. Otherwise the problem of donations made under pressure would simply be relocated.

Therefore, the fact that there is a risk of donations being made against the donor's will is not an argument against payment, but only against involuntary donation. Absence of free will is indeed a risk associated not only with paid donations but also with unpaid donations. If vendors can be forced by circumstances to sell a kidney, then donors can also be forced to donate by circumstances such as family pressure. To prevent that we do not need to ban all donations, only involuntary ones. It is a strict moral requirement that donors must not be put under severe pressure to donate a kidney, irrespective of whether payment would be involved or not.

It is also important to realise that money is only one element among many others that determines decisions. If payment is made, then people are donating their kidney in return for money, but not necessarily *only* for the money. We have already said that different motives can co-exist when we were discussing the question of altruism.

In brief: If we are concerned about the free will of the donor, then we should not prohibit payment but design a screening process that protects the free will of the donor to the greatest possible extent. This is standard practice, though never entirely conclusive, in normal (unpaid) living donations.

With sufficient care it would be possible to prevent payment leading to unjustified pressure. For example, the need to be meticulous has led to a properly-functioning system of checks and balances in the case of euthanasia. In the early days it was feared that people might be forced to ask for euthanasia by their families, for example. It is conceivable for a system to be devised that protects the free will of the donor in the case of living kidney donations, as is already the case for 'ordinary' living donations.

So free will and payment are not mutually exclusive. The requirement that donations must be voluntary is a rational, tangible requirement. But the conclusion that because of this payment should not be allowed, is excessive. And the present situation has led to a lack of free will and to exploitation. Preventing such excesses was one of the main reasons why prostitution, pornography, abortion and soft drugs were legalised in the Nether-

lands. Not in order to make these things available to everyone, but because regulation is often preferable to an illegal system. The same applies to paid organ donation.

### **'Payment leads to exploitation of the poor'**

A related argument against payment is that 'poor people', especially in developing countries, will be forced to sell their organs. This brings us back to free will. Permitting payment '*signals a willingness to accept a policy environment that would make exploitation of the worst off a societal-endorsed rule rather than the exception to be avoided.*' (Kahn et al. 2004)

Other authors do not see this problem in these terms. They ask why you should deprive poor people of a way of escaping their poverty. (Radcliffe et al. 1998). It is a double injustice towards them: '*you can't have what most other people have, and we are not going to let you do what you want to have those things.*' (Savulescu 2003). In the literature this is referred to as '*leveling down-egalitarianism*' (Radcliffe 1996): 'prohibiting someone from improving their own position because otherwise someone else would make a great deal of money out of it'. These authors also see the sale of organs as a legitimate way for poor people to escape their poverty or resolve a financial problem - temporarily, in any case. Dutch kidney patients who go abroad to buy an organ appear to seek moral support from the argument that the money they pay allows people to make a better life for themselves.

But is this really true? Various studies in fact show that most donors in developing countries who have sold a kidney are eventually in a worse position - medically, psychologically, and also financially (Goyal et al., 2002). In India, for instance, there is an unregulated and illegal market with brokers, and the very real possibility that people who are in debt are put under pressure by their creditors to sell a kidney. Furthermore, this market operates without any psychological screening of donors, the medical after-care is poor, and no assistance is provided in how to make best use of what is for Indian conditions a relatively large sum of money (€1,000 on average).

So it may well be that free trade leads to exploitation of the poor. However, this is not an argument against payment in itself, merely against its negative aspects. As Den Hartogh says: 'the existence of poorly-functioning markets is not a valid objection to the existence of markets.' (Den Hartogh 2003). Concern over exploitation should lead to a regulation of the market rather than to a ban on payment. Various ways of preventing abuses have been suggested in the literature (Steinberg 2002).

The main question is not so much whether financial incentives should be introduced, but how we can put an end to this exploitative practice. '*If we are concerned about reducing the abuses of the black market for human kidneys, we should favour the legalisation of kidney markets, not their continued prohibition.*' (Taylor 2006) Various proposals for

transforming the current illegal market into a regulated system of payment have been made. For instance, Erin and Harris assign a central role to the government in paying for and distributing organs within the country (Erin and Harris 2003). This could also prevent exploitation abroad.

The objection still remains, but in a slightly weaker form. Even if we stop blatant exploitation of individuals, it will mainly be less well-off people who are attracted by a financial offer. So there would be inequality.

But inequality is not necessarily the same as injustice. What kind of inequality are we talking about here? The reason why living donation is permitted at all in the Netherlands is that we find the difficulties and risks of this procedure acceptable. Once this has been established, 'the fact that poorer people are more likely to undergo it cannot be regarded as a problem.' (Den Hartogh 2003). Many authors find it rather patronising to deprive the less well-off of an opportunity to improve their own situation by taking a small risk.

In this context comparisons are often drawn with dirty or unpleasant work, or with participating in medical research as a trial subject. Here again the burdens and risks are borne by particular groups in the population. But in this situation we say that it should be well paid, not that we want to ban dirty and unpleasant work or that we will only pay the expenses of people doing it.

#### **'Only the rich could afford it'**

Another argument that is raised in the debate over payment is that it would lead to unequal access to the supply of organs. A system of paid organ donation might mean that rich people would have better access to organs which become available than poor people. This would be the case particularly if people were able to buy an organ directly. Is this unjustifiable and undesirable, or permissible? We can look at this in two ways. In the first place we could argue that this is true of so many other things too. Many things are accessible to rich people but not to poor people, such as better jobs, housing and health. So why should there be equal access to organs then? If you find this comparison acceptable, you could argue for a free market.

But most authors go for a different solution. Erin and Harris opt for equal access to organ transplants rather than for a free market (Harris 2002). The hypothesis here is that the risk of unequal access is not an argument in favour of a ban on payment, but in favour of a *monopsony*: a market with multiple vendors but only one purchaser. A monopsony is the opposite of a monopoly, where there is only one vendor and multiple purchasers.

In the Netherlands, this would mean that just one organisation, the monopsonist (such as the Netherlands Transplant Foundation) would be able to make payments and only one organisation would be able to allocate organs. This would guarantee equal access for both donors and recipients. Introducing a system of paid organ donation in the Neth-

erlands would be a way of abolishing the current illegal system in which 'rich' people buy organs from 'poor' people in a 'free' market.

Equal access is a complex concept. Within the current system of living donations, people with close-knit families or strong social networks are better placed to obtain a kidney from a living donor than others. They do not rely on the post-mortem waiting list. However, people who do not have this kind of network also benefit in the long run as more donations from living individuals means that the waiting list gets shorter. But a kidney from a living donor lasts for twice as long as a kidney donated post-mortem (Hoitsma 2006). A system of paid living donation could reduce this inequality by offering everyone a real chance of a kidney from a living donor.

#### **'Transplants would be less safe'**

A final point that is often raised in the debate over payments to living donors is a practical but serious one: the offer could be so attractive that potential donors conceal medical problems or behaviours (drug use, high-risk sexual contacts). This would lead to them being selected for kidney donation in spite of the fact that they are medically unsuitable, resulting in danger to both the donor and the recipient.

The possibility of unsuitable donors being drawn to organ donation by money means that medical and psychological screening of donors has to be very strict. For that reason the reward cannot be too great. The risk of many unsuitable donors coming forward has indeed always been one of the arguments against paying for blood donation (WHO 2007).

### 3.4 Towards a proposal for payments to living donors

In the preceding section we have examined a variety of arguments for and against payment for living donation. We have seen that there are no decisive objections to it. Some objections are fundamental in nature but are not universally shared, while others are legitimate but do not appear to be insurmountable. Finally, some objections and risks could be dealt with by creating the right conditions.

#### **Criteria for a system of regulated payment**

What system of regulated payment for living donors would best deal with the objections? A responsible system of payments for living donation must meet the following criteria:

- Payments to donors for living donations can only be made by the government or a government-appointed organisation, 'the monopsonist'. This means that a single body would be responsible for obtaining and distributing these organs. In the Netherlands, this could be the Netherlands Transplant Foundation, for example. Insurance companies and the government would contribute to the fund from which payments would be made.

- The offer is only open to people living within certain geographical boundaries; for instance, residents of the Netherlands, the Eurotransplant region or the EU.
- The principle of reciprocity must be upheld: anyone who is a potential donor must also be a potential recipient. Potential donors and recipients belong to the same (geographical) group.
- The payment system must be effective, i.e. it must ensure that everyone has a greater chance of an organ. The sum must therefore be large enough to convince people to become donors where this would not otherwise have been the case.
- The government must take steps to ensure that a system of paid kidney donation does not make the situation worse for patients who are waiting for another organ, such as a heart.
- Anonymously donated organs are assigned according to set criteria that are determined and monitored by an independent body, such as the Netherlands Transplant Foundation or Eurotransplant.
- The payment is set at a specific sum, so that people with a rare blood group or tissue type do not receive more.
- Potential donors undergo extensive medical and psychological screening prior to the transplant.

### **Practicalities**

A regulated system would have to meet the requirements listed above to prevent payments to people who donate an organ during their lifetime having undesirable effects. A number of practical choices will consequently have to be made when devising such a system.

### **WHO IS ELIGIBLE FOR PAYMENT?**

Three groups are eligible for payment: related donors (such as relatives, partners and friends), anonymous donors (who donate to whoever is top of the waiting list) and targeted donors (who donate to someone with whom they had no relationship previously but whom they get to know during the process of donation) (Hilhorst 2005).<sup>13</sup> Should donors from all these groups receive payment, or are there reasons to exclude certain groups from payment?

A distinction is often made between donations between people who know each other or are related to one another and what is called altruistic donation, i.e. donation to strangers who may or may not remain anonymous. Are there any reasons for paying one group of donors and not the other?

<sup>13</sup> We could define other groups (people who take part in the cross-over programme, or who donate conditionally to a certain targeted group of patients), but it would be going into too much detail here.

One option is to pay only unrelated donors, the idea being that they are acting purely altruistically and would not otherwise donate. But we have pointed out that self-interest does indeed have a part to play in this form of donation as well, so the distinction does not really stand up.

But there is a more practical issue too. If payments are made only to unrelated donors, then this might eventually prove detrimental to the system of living donations between relatives and friends. If payment is successful and donations to strangers do increase significantly, then the need for related donations will fall. The question is whether that would be a problem. Earlier on we said that this depended on whether one form is regarded as morally superior to the other. If you think that related donations puts too much strain on relationships, then a decline in the number of such donations would be welcomed. If you are in favour of related donations, then you would regard this as an undesirable effect.

It is therefore difficult to draw a distinction between groups that should be paid and those that should not be paid. The real question is why we would want to do so. Why should related donations be excluded from financial compensation? After all, what these donors are doing is far from a routine act. They are making a considerable sacrifice, no less great than that made by altruistic donors.

Furthermore, paying related donors might be an effective way of increasing the number of organs available. We could expect the potential pool of willing donors in the recipient's social and family circle to increase significantly. Money might make a real difference to this group as well.

Turning the question around, there are few reasons for not paying non-related donors. They would soon lose motivation if payments were to be made to related donors and not to them. The risk of strategic behaviour is high as well: people who might in principle be willing to donate anonymously would look for a recipient via the Internet or using other means, and then pretend that they know each other so that they become eligible for payment.

In the light of these practical and strategic considerations, and in terms of justice, it would therefore appear advisable to pay all three groups of donors equally.

#### **HOW DO WE DEFINE THE PAYMENT?**

Another question is what exactly does paying living donors mean. Are we talking about paying for an organ, offering a reward for a particular act, or compensation for harm suf-

ferred? (Castro 2003). This question is also relevant in the context of the Organ Donation Act, that rules out payment for an organ but does allow for reimbursement of expenses.<sup>14</sup>

Some authors use the term 'rewarded gifting' to pick up on the idea of a gift. From this angle, the organ is still a gift, but society offers a reward to express its gratitude.

Is this term being used correctly here? Occasional awards of money to someone who has done something really exceptional (saving a child from his neighbour's house, with the consequence that his own house burns down) is rather different from a system in which money will in future be available for people who have done something exceptional. In the first case the award of money is an exception, but in the second case it is standing policy that encourages people to perform an exceptional act. Veatch therefore regards the term 'rewarded gifting' as a 'blatant corruption of the language.' (Veatch 2003). If you are paying for an organ you have to recognise that it is being bought and not try to conceal the fact.

Payment for living donation could also be regarded as appropriate compensation for a loss suffered. Someone who loses a kidney as a result of a car accident caused by another driver receives compensation for the loss from the insurer of the party at fault. The term 'loss' has a broad meaning in that sense.

By analogy with this, broader and more 'generous' compensation could be offered for living donation within the current context of the Organ Donation Act than the limited payment of expenses which is currently permitted. A crucial issue here is how the term 'costs', which appears in the Act, should be understood. However, answering this rather legalistic question goes beyond the scope of this report.

#### **HOW MUCH SHOULD BE OFFERED?**

Andries Hoitsma mentioned a sum of € 50,000 in his speech. By doing so he emphasises that each transplant produces a significant financial benefit to society and the insurer, and that it is right to share this benefit with the donor. But other viewpoints are conceivable.

The risk of offering too large a sum of money is that the wrong people, or people with wrong or dubious motives, would register as donors. These might be people who are medically unsuitable, or people who are not acting freely. This can make the transplant more dangerous. It would therefore be better to stay on the safe side, and not to offer too large amounts of money for the time being. The only question is whether a small amount would still prove effective in making more organs available. A relatively small,

<sup>14</sup> Article 2 of the Organ Donation Act: Consent to removal of an organ which is given with a view to obtaining payment in excess of the costs, including loss of income, that are the direct consequence of removal of the organ, is void.

symbolic reward may not be sufficient to persuade a large amount of people to become donors.

A tangible 'indirect' reward, such as life-long exemption from medical insurance premiums, could be an attractive alternative. This form of reward 'matches' the aim of donations (preventing illness, promoting health, saving costs) while establishing a clear link between an individual's action (donating) and the benefit this produces for society as a whole and medical insurance companies in particular.

This indirect but significant reward (a 30-year-old donor would be exempted from paying premiums for maybe 40 years or more, easily saving € 40,000 as a result) takes greater account of the moral intuition of many people who do not regard organs as objects for which you should be able to receive money.

Another particular benefit of exemptions from health insurance premiums is that it is much less likely to prove an incentive to donate for people who are living in poverty or have heavy debts.<sup>15</sup> Research shows that payments to living donors in the form of life-long exemption from health insurance premiums would have strong support among the Dutch population (Kranenburg 2007). It is also a real alternative, given the high costs that renal dialysis represents to insurance companies and the savings that could be made from transplants.

### 3.5 Conclusion

We see offering a generous financial incentive to living donors as a real and morally defensible option. The objections against payments to living donors are not conclusive. The arguments of principle do not justify a ban, and serious ethical objections and various practical problems can to a large extent be overcome.

This is particularly true if the system chosen involves the government offering a fixed sum to (Dutch) donors and then allocating the organs obtained on the basis of strict criteria. Practical difficulties still remain in connection with introducing a system of this kind, and care must be taken to resolve them.

Most of the discussion will focus on the option of life-long payment of health insurance premiums. This option does most justice to the moral intuition of many people who think that you should not be paid for organs. Another benefit of exemption from health insurance premiums is that it is less obvious that this would be likely to tempt people living in poverty or who have heavy debts to opt for living donation.

<sup>15</sup> For some, that is actually an argument in favour of making cash payments.

## 4 Agenda points for policy and research

### 4.1 Offering rewards for organ donation can be morally justified

In this report we have showed that there are no decisive ethical objections to offering rewards for organs. However, the acceptability of such a scheme would depend to some extent on how it is implemented.

Careful consideration must therefore be given to what rewards mean in practice, what the possible effects might be, and which of them are regarded as desirable or undesirable. Empirical and normative questions are closely interconnected in this investigation.

### 4.2 Efficacy requires further investigation

There are no insurmountable moral obstacles. However, it is difficult to assess how effective financial incentives would be in achieving the goal of increasing the number of organs available. There is little international experience with a regulated system of payments to donors.

However, it is already clear that payments to living donors are likely to prove most effective. It is important to treat all living donors equally, including those who have donated a kidney in the past. This means that payments to donors must also apply retroactively.

The actual effects will have to become apparent through experience. Specific proposals will allow a much more focused investigation than was possible in the past. So far, the debate has been held mainly through informal opinion surveys.

Answers can be found by investigating public opinion and by proposing, implementing and testing various forms of payment. These specific proposals must be absolutely clear as to the aims, the moral basis on which they rest, and the arguments that have led to the proposal being made. The government, patients' associations and insurance companies must be in accord on these matters.

### 4.3 Particular points need further consideration

This report is intended as a starting point for debate, focusing mainly on the moral aspects of offering rewards for organ donation. This is of course only the beginning. Many other points need to be investigated in more detail. We list the principal issues below.

– **WHAT IS THE EXTENT OF SUPPORT IN THE GENERAL POPULATION?**

What is the attitude of the Dutch population to paid living donations? What financial incentives are regarded as acceptable? Under what circumstances would people be willing to donate a kidney themselves? Does the primary loyalty lie mainly with friends or relatives, or can it also extend to anonymous strangers? How do views about paying health insurance premiums differ from views on other forms of payment?

– **WHAT IS THE EXTENT OF SUPPORT AMONG SPECIAL-INTEREST GROUPS?**

Are special-interest groups persuaded that things need to change? Do they see the continued importance of a good post-mortem system, but also its limitations? Do they realise the limits of a policy that was based on the conviction that donation must be an act of altruism, a disinterested gift?

– **WHAT ARE THE EFFECTS ON THE DONOR/RECIPIENT RELATIONSHIP?**

How do relatives experience mutual dependence, and how do they interpret the phrase 'free will'? How does payment change the relationship and the feelings that friends or relatives have about each other? And what does payment mean for altruistic donations? How can we expect donor profiles and motivations to change?

– **WHAT ARE THE EFFECTS ON RECOURSE TO FOREIGN DONORS?**

We do not currently know how many Dutch patients engage in organ tourism. How many people go abroad for a transplant each year, how good are the operations, and what do these patients think about their decision after the event? Research into the precise extent and the consequences of these foreign transplants could give us a greater insight into the effect of a payment-based programme in the Netherlands.

– **WHAT ARE THE LEGAL IMPLICATIONS?**

It is not clear what payments could be made in accordance with article 2 of the Organ Donation Act and how the phrase 'consent to removal' should be understood. The scope of this article needs to be examined in greater detail in order to determine whether the Organ Donation Act needs to be revised.

– **WHAT ETHICAL PRINCIPLES NEED FURTHER INVESTIGATION?**

Practical investigation of key moral terms, particularly the concepts of free will, altruism and injustice, is urgently needed. Although free will is a strict criterion, its meaning in the context of related individuals and their mutual dependence is often unclear; after all, do-

nors have a personal interest in the well-being of the recipient. The broadly shared view that donation must be a disinterested gift, motivated by altruism, creates a distorted image of reality and appears to stand in the way of changes to policy. It is a striking feature of this situation that a (truly) altruistic donor is often regarded as odd.

– **WHAT ETHICAL DILEMMAS NEED FURTHER EXAMINATION?**

In current transplant practice there are significant differences between patients on the waiting list for a post-mortem organ, caused by various factors including their blood group. People who have a living donor can often receive help quite quickly, either directly or via the cross-over system. And some donors would like to give their partner a kidney but cannot do so because a suitable match cannot be found and for understandable reasons exchanges with the waiting list are not permitted. So in terms of justice there appears to be a conflict between the post-mortem public system and the private living donation programme. Which inequalities do we accept as inevitable, and which do we regard as unjust?

# Bibliography

- Andrews L. My body my property. *Hastings Center Rep.* 1986; 16: 28-38
- Bagheri A. Compensated Kidney Donation. An ethical review of the Iranian Model. *Kennedy Institute of Ethics Journal* 2006; 16, 3: 269-282
- Canadian Press. Ontario would pay organ donor's expenses. August 3, 2007
- Castro L. Commodification and exploitation: arguments in favour of compensated organ donation. *Journal of medical ethics* 2003; 29: 142-146
- Chugh K.S., Jha V. Commerce in transplantation in third world countries. *Kidney Int.* 1996; 49: 1181-1186
- Cherry M. Kidney for sale by owner. *Human organs, Transplantation, and the market.* Washington, 2005
- Cohen C. Selling bits and pieces of humans to make babies: the gift of the magi revisited. *The Journal of medicine and philosophy* 1999; 24: 288-306
- Cohen L. Where it hurts. *Indian material for an ethics of organ transplantation.* *Daedalus* 1999; 128: 135-165
- Delmonico F.L., Arnold R., Schepers-Hughes N., ea. Ethical incentives - not payment - for organ donation. *The New England Journal of Medicine.* 2002 Jun 20; 346(25): 2002-5
- Den Hartogh G. Gift of bijdrage; over morele aspecten van orgaandonatie. Den Haag: Rathenau Instituut, 2003
- Den Hartogh G. Verleiden tot donatie. In: *Medisch Contact* 2004; 36: 1401-1404
- De Wit A. Economische evaluatie van niervervangende behandelingen. Proefschrift Erasmus MC oktober 2002
- Erin C., Harris J. An ethical market in human organs. *Journal of medical ethics* 2003; 29: 137-138
- Frontline 2002. Karnataka's unabating kidney trade. Beschikbaar op: <http://www.frontlineonnet.com/ktrade.htm>.
- Frontline 1997. Kidneys still for sale. Beschikbaar op <http://www.flonnet.com/fl1425/14250640.htm>
- Gallup Organization, The. National Survey of Organ and Tissue Donation Attitudes and Behaviors. The Gallup Organization, 2005. Te downloaden vanaf: <http://www.organdonor.gov>
- Gezondheidsraad. Nieuwe wegen naar orgaandonatie. Den Haag: Gezondheidsraad, 2003: 140-144
- Goyal M., ea. Economic and health consequences of selling a kidney in India. *JAMA* 2002; 288: 1589-1593
- Harris J. An ethically defensible market in organs: a single buyer like the NHS is the answer. *BMJ* 2002; 325: 114-115
- Hilhorst M., Kranenburg L., Busschbach J. van. Loyaliteit moet je koesteren; de miskende rol van solidariteit bij orgaandonatie. *Medisch Contact* 2004; 28/29: 1172-1175
- Hilhorst M.T. Directed altruistic living organ donation: partial but not unfair. *Ethical Theory and Moral Practice* 2005; 8: 197-215
- Hoitsma A. Een kwestie van geven en nemen. *Oratie*, 23/12/2006
- Johnson E., ea. Long term follow-up of living kidney donors: quality of life after donation. *Transplantation* 1999; 67: 717-721
- Kahn J., ea. The consequences of public policy to buy and sell organs for transplantation. *American Journal of Transplantation* 2004; 4: 178-180
- Kass L. The Wisdom of repugnance, <http://www.catholiceducation.org>.
- Kranenburg L. Public survey on financial incentives for living kidney donation. In: Kranenburg, L. *Psychological and ethical aspects of living kidney*

- donation. Proefschrift Erasmus Universiteit, juni 2007
- Levi Y. On Israel's New Organ Transplant Bill. Haaretz, 12 February 2007
- Matas J. Payment for living donor (vendor) kidneys: a cost-effectiveness analysis. *American Journal of Transplantation*. 2004 February; 4 (2): 216-21
- Nederlandse Transplantatie Stichting. Jaarverslag NTS. Leiden: NTS, 2006
- Netwerk. Uitzending Netwerk d.d. 17 juli 2007
- Radcliffe J. Nephrological goings on. Kidney sales and moral arguments. *The Journal of medicine and philosophy* 1996; 21: 375-416
- Radcliffe J., ea. The case for allowing kidney sales. *Lancet* 1998; 351: 1950-1952
- Rothman S.M., Rothman D.J. The Hidden Cost of Organ Sale, *American Journal of Transplantation* 2006; 6 (7): 1524-1528
- Savulescu J. Is the sale of body parts wrong? *Journal of Medical Ethics* 2003; 29: 138-139
- Scheper-Hughes N. The Global Traffic in Human Organs. *Current Anthropology*. 2000; 41: 192-224
- Scheper-Hughes N. Rotten trade. *Anthropological Quarterly* 2004; 77: 197-202
- Steinberg A. Compensation for Kidney Donation: a price worth paying. *IMAJ* 2002; 4: 1139-1140
- Steiner H. the right to trade in body parts. In: Seglow, J. (ed). *The ethics of altruism*. London, 2004
- Taylor J. Stakes and kidneys: why markets in human body parts are morally imperative. Aldershot: UK, 2005
- Taylor J. Black markets, transplant kidneys and interpersonal coercion. *Journal of Medical Ethics* 2006; 32: 698-701
- Taylor J. A. "queen of hearts" trail of organ markets: why Scheper-Hughes's objections to markets in organs fail. *Journal of Medical Ethics* 2007; 33: 201-204
- Titmuss R. *The Gift relationship: from human blood to social policy*. New York, 1971
- Veatch R.M. *Transplantation Ethics*. Washington, 2000
- Veatch, R. Why liberals should accept financial incentives for organ procurement. *Kennedy Institute of Ethics Journal* 2003; 13, 1: 19-36
- Westlie L., ea. Quality of life in Norwegian kidney donors. *Nephrol Dial Transplant* 1993; 8: 1146-1150
- WHO. Blood safety and donation. WHO fact sheet N°279, June 2007
- Wit, G., ea. Economic evaluation of end-stage renal disease. *Health Policy* 1998; 44: 215-232
- Wet op de Orgaandonatie (WOD): Artikel 2. 'Toestemming voor het verwijderen van een orgaan, verleend met het oogmerk daarvoor een vergoeding te ontvangen die meer bedraagt dan de kosten, daaronder begrepen gederfde inkomsten, die een rechtstreeks gevolg zijn van het verwijderen van het orgaan, is nietig'.

# Appendix 1

## **Council for Public Health and Health Care**

### **Composition of the Council for Public Health and Health Care (RVZ)**

The activities of the CEG/RVZ come within the remit of the Council for Public Health and Health Care (RVZ). The report *Financial incentives for organ donation. An investigation of the ethical issues* was adopted by the RVZ at its meeting on 20 September 2007.

#### **CHAIRMAN**

Mr. M.H. Meijerink

#### **MEMBERS**

Ms. A.M. van Blerck-Woerdman, LL.M

Mr. H Bosma, LL.M

Prof. Dr. D.D.M. Braat, vice-chairman

Prof. Dr. W.N.J. Groot

Ms. J.M.G. Lanphen, GP

Prof. Dr. J.P. Mackenbach

Mr. A.A. Westerlaken, LL.M

Prof. Dr. D.L. Willems

#### **GENERAL SECRETARY**

Mr. P Vos

### **Composition of the Centre for Ethics and Health (CEG)/RVZ Forum**

The Forum was established to support the work of the CEG/RVZ in compiling reports. The Forum acts as a sounding board and fulfils the function of raising issues, giving advice and initiating action in the drafting of reports.

**MEMBERS**

Ms. G. Abrahamse-van den Bosch, healthcare policy officer, Protestant Christian Senior Citizens' Association, Zwolle

Mr. H. van Dartel, assistant professor in medical ethics and law, LUMC, Leiden

Prof. Dr. G. Glas, professor by special appointment in reformational philosophy and psychiatrist, Leiden University and Zwolse Poort, Zwolle

Prof. Dr. M.H.F. Grypdonck, professor in nursing science, Utrecht UMC

Ms. M Morskieft, Kantel Konsult, Nijmegen

Dr. A. Pool, nurse and psychologist, Krimpen aan den IJssel

Ms. F.H. Stegehuis, manager of care provision, Menzis Zorg en Inkomen, Zwolle

Prof. Dr. M.J. Trappenburg, professor by special appointment in the patient's perspective, EUR, Rotterdam

Ms. M.I. Verstappen, director-general, GGD Amsterdam

Prof. Dr. G.A.M. Widdershoven, professor of medical ethics, Maastricht University

**FROM THE RVZ**

Prof. Dr. D.L. Willems, professor of medical ethics, AMC, Amsterdam

member of the RVZ and chairman of the Forum

J.M.G. Lanphen, GP, member of the RVZ and vice-chairman of the Forum

Dr. A.J. Struijs, senior advisor and project coordinator for CEG/RVZ

Ms. I. Doorten, advisor to CEG/RVZ

Ms. L Romein, CEG/RVZ project secretary

# Appendix 2

## Past publications of the CEG

### Reports

#### 2003 ETHICS AND HEALTH REPORTS:

##### *Council for Public Health and Health Care*

- Eisend gedrag en agressie van zorgvragers
- Drang en informele dwang in de zorg
- Culturele eigenheid en zelfbeschikking van allochtone zorgvragers
- Zelfbeschikking en eigen verantwoordelijkheid van mensen met een verstandelijke handicap

##### *Health Council*

- Handelingen met geslachtscellen en embryo's
- Screening van pasgeborenen op aangeboren stofwisselingsziekten
- Geneesmiddelen voor kinderen
- De maakbare mens

#### 2004 ETHICS AND HEALTH REPORTS:

##### *Health Council*

- 'Vruchtbaarheidsverzekering': medische en niet-medische redenen
- Terminale sedatie
- Bestrijdingsmiddelen, cosmetica, verf: de bescherming van proefpersonen in blootstellingsonderzoek
- Geavanceerde thuiszorgtechnologie: morele vragen bij een ethisch ideaal

##### *Council for Public Health and Health Care*

- Intermezzo
- Geavanceerde thuiszorgtechnologie: morele vragen bij een nieuwe zorgpraktijk
- Mantelzorg, kostenbeheersing en eigen verantwoordelijkheid
- Economisering van zorg en beroepsethiek

#### **2005 ETHICS AND HEALTH REPORTS:**

##### *Health Council*

- Embryonale stamcellen zonder morele pijn?
- Ethische aspecten van kostenutiliteitsanalyse
- Nu met extra bacteriën! Voedingsmiddelen met gezondheidsclaims

##### *Health Council/Council for Public Health and Health Care*

- Opsporing verzocht? Screening in de huisartspraktijk

##### *Council for Public Health and Health Care*

- Zorgverlener en opsporingsambtenaar?
- Ethiek in zorginstellingen en zorgopleidingen

#### **2006 ETHICS AND HEALTH REPORTS:**

##### *Health Council/Council for Public Health and Health Care*

- Vertrouwen in verantwoorde zorg? Effecten van en morele vragen bij het gebruik van prestatie-indicatoren

##### *Health Council*

- Testen van bloeddonors op variant Creutzfeldt-Jakob?

#### **2007 ETHICS AND HEALTH REPORTS:**

##### *Health Council*

- Overwegingen bij het beëindigen van het leven van pasgeborenen

##### *Council for Public Health and Health Care*

- Formalisering van informele zorg.  
Over de rol van 'gebruikelijke zorg' bij toekenning van professionele zorg
- Financiële stimulering van orgaandonatie. Een ethische verkenning

#### **Background studies**

- Economisering van zorg en beroepsethiek, 2004
- Ethiek in zorgopleidingen en zorginstellingen, 2005

#### **Investigations**

- De vertwijfeling van de mantelmeeuw, 2004
- Over keuzevrijheid en kiesplicht, 2006

These publications can be obtained via [info@ceg.nl](mailto:info@ceg.nl) or downloaded via [www.ceg.nl](http://www.ceg.nl) or [www.rvz.net](http://www.rvz.net)

# Appendix 3

## **AUTHORS**

- Mr G. (Gert) van Dijk, ethics policy worker with the Royal Netherlands Society for the Promotion of Medicine [KNMG], Utrecht and secretary of the Medical Ethics Issues Committee at Erasmus MC, Rotterdam
- Dr. Ir. M.T. (Medard) Hilhorst, senior lecturer at the Medical Ethics and Philosophy Department, Erasmus MC Rotterdam