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Statement of the Declaration of Istanbul Custodian Group Regarding Payments to Families of Deceased Organ Donors

Alexander Morgan Capron, LLB,¹ Francis L. Delmonico, MD,^{2,3} Beatriz Dominguez-Gil, MD,⁴ Dominique Elizabeth Martin, MBBS, PhD,⁵ Gabriel M. Danovitch, MD,⁶ and Jeremy Chapman, MB, BChir, MD⁷

Abstract: Governmental and private programs that pay next of kin who give permission for the removal of their deceased relative's organs for transplantation exist in a number of countries. Such payments, which may be given to the relatives or paid directly for funeral expenses or hospital bills unrelated to being a donor, aim to increase the rate of donation. The Declaration of Istanbul Custodian Group—in alignment with the World Health Organization Guiding Principles and the Council of Europe Convention Against Trafficking in Human Organs—has adopted a new policy statement opposing such practices.

Payment programs are unwise because they produce a lower rate of donations than in countries with voluntary, unpaid programs; associate deceased donation with being poor and marginal in society; undermine public trust in the determination of death; and raise doubts about fair allocation of organs. Most important, allowing families to receive money for donation from a deceased person, who is at no risk of harm, will make it impossible to sustain prohibitions on paying living donors, who are at risk.

Payment programs are also unethical. Tying coverage for funeral expenses or healthcare costs to a family allowing organs to be procured is exploitative, not “charitable.” Using payment to overcome reluctance to donate based on cultural or religious beliefs especially offends principles of liberty and dignity. Finally, while it is appropriate to make donation “financially neutral”—by reimbursing the added medical costs of evaluating and maintaining a patient as a potential donor—such reimbursement may never be conditioned on a family agreeing to donate.

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The Declaration of Istanbul holds that successful and sustainable programs of organ donation and transplantation must embody “the principles of equity, justice and respect for human dignity” and cannot be built on “transplant commercialism.”¹ The latter, which occurs when those who provide organs receive “material gain,” inevitably “targets impoverished and otherwise vulnerable donors” and thus “leads inexorably to inequity and injustice and should be prohibited.”¹ The Declaration’s conclusion is consistent with the Resolution adopted in May 2010 by the World Health Assembly reaffirming that the principles of human dignity

and solidarity “condemn the buying of human body parts for transplantation and the exploitation of the poorest and most vulnerable populations.”² The international summit meeting at which the Declaration was adopted in 2008 addressed living donation.³ The present statement extends the Declaration’s ethical precepts to deceased donation.

I. BACKGROUND FOR THE CURRENT PROBLEM: MAKING PAYMENTS TO OR FOR THE BENEFIT OF NEXT OF KIN

In some countries in the Middle East, Asia, and the Americas, existing or newly established programs for obtaining organs from deceased persons provide cash payments to families that donate their deceased relative’s organs or pay sums on their behalf for funeral costs or for hospital expenses

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¹ Pacific Center for Health Policy and Ethics, University of Southern California, Los Angeles, CA.

² Harvard Medical School, Massachusetts General Hospital, Boston, MA.

³ New England Organ Bank, Boston, MA.

⁴ Organización Nacional de Trasplantes (ONT), Madrid, Spain.

⁵ Health Ethics and Professionalism, Faculty of Health, School of Medicine, Deakin University, Geelong, Victoria, Australia.

⁶ Kidney & Pancreas Transplant Program, Department of Medicine, David Geffen School of Medicine, University of California Los Angeles, Los Angeles, CA.

⁷ Division of Medicine and Cancer, Westmead Hospital, Sydney, NSW, Australia.

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Correspondence: Alexander M. Capron, Gould School of Law, University of Southern California, 699 Exposition Blvd., Los Angeles, CA 90089-0071. (acapron@law.usc.edu).

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beyond those generated in the process of obtaining organs for transplantation. Officials in these countries have set up such programs or allowed others to do so because, they argue, that without such financial incentives, sufficient organs would not be donated. They contend that money is needed to obtain agreement from people who otherwise feel no inclination to help facilitate organ transplants to which they lack access or who regard deceased donation as inconsistent with their cultural traditions. Officials have also explained the payments as appropriate reciprocity for the family's "gift" to the community, especially when the next of kin are poor or face large medical or other expenses.

Without doubting the sincerity of these beliefs, the Declaration of Istanbul Custodian Group has concluded that all programs that provide payments to or on behalf of families who have donated organs from their deceased relatives place the countries involved outside the circle of ethical transplant practices globally, as set forth in the Guiding Principles on Cell, Tissue, and Organ Transplantation⁴ of the World Health Organization (WHO), the Declaration of Istanbul, and other international standards.

II. ETHICAL PRINCIPLE

Providing money to people to encourage them to consent to organ removal or reward them for doing so weakens organ donation programs by treating the human body as a commodity used for financial gain, exploits the economic vulnerability of living donors and deceased donor families, and undermines equality and justice by reinforcing rather than reducing socioeconomic inequities.

III. APPLICATION OF THE PRINCIPLE TO DECEASED DONATION

A. Payments to Next of Kin Fall into the Category of Organ Commercialism

1. Direct or indirect payments to donor families constitute transplant commercialism. Payments made to or on behalf of donor families amount to purchasing organs because consent to organ donation "gives rise to financial gain or comparable advantage."⁵ Such transactions are sales, and it is deceptive to present the payment as a "gift" or "reward."⁶ As stated by the WHO, countries "should ensure that any gifts or rewards are not, in fact, disguised forms of payment" for organs and 'rewards' with monetary value that can be transferred to third parties are not different from monetary payments."⁴

2. The payment source is irrelevant. The origin and method of the payments—whether the government, a public or private foundation, or individuals (such as organ recipients)—are unimportant ethically, because in all cases the financial arrangements depend on the family agreeing to donate a deceased relative's organs.

3. Once payments to next of kin are permitted, no ethical principle exists for determining whether the amount is appropriate or excessive. Unlike reimbursing hospital and other expenses that donors incur in the process of being evaluated or in actually donating, which are acceptable when based on actual costs, the amounts paid to the next of kin have no inherent limit. Payments to incentivize donations will be

set based on market forces (that is, the payers will choose the amount needed to obtain consent, which will vary based on donor families' financial needs); "charity" payments depend on the extent to that officials choose to relieve donor families' poverty; and payments for funeral costs and hospital care (beyond any added costs for organ donation) can vary widely and, moreover, those items are not distinguishable from other debts that the family might prefer to have paid. In sum, the amounts paid to families on any of these grounds are inherently arbitrary and subject to manipulation and abuse.

B. Adverse Effects on Society and Legitimate Transplant Programs

4. Payments undermine trust in death determinations.

Although it is physicians who diagnose death, the next of kin also have a role to play when the diagnosis will be followed by organ donation. With brain-based determinations of death, the family must accept the diagnosis and allow medical interventions to be withdrawn before organs can be recovered, and with circulatory-determinations of death, the diagnosis is made only when the patient's circulation and respiration have permanently ceased, following the family's agreement to the withdrawal of life-support. As experienced organ procurement staff recognize, families' involvement must be handled with sensitivity and always framed in terms of their deciding what is in the patient's best interests. Further complexity is added when the methods that physicians use to diagnose death, especially based on loss of brain functions, are unfamiliar to or not yet broadly accepted by the general population. Making payments to the next of kin who consent to donate organs, which has to be preceded by their decision to withdraw medical interventions, creates an obvious conflict of interest and raises questions for the public about whether decisions about care are being made in patients' best interests and whether death has truly occurred before organs are removed.

5. Paying for deceased donation will adversely affect living donation. When next of kin receive financial incentives and rewards, it becomes impossible to refuse to pay living donors both because the money provided to the families legitimates exchanging organs for material gain, and because a society that allows payments to next of kin, who bear no physical risk, cannot reasonably refuse to allow at least equal payment to living donors, who take on actual burdens and risks in donating.

6. Payments to next of kin undermine public support of transplant programs. Most basically, payments suggest to the public that all types of organ donation are not acts one should undertake as a matter of civic duty and in solidarity with the needs of one's fellow citizens but instead something that a person should do only for a financial benefit.

7. Payments for organs raise doubts about fair allocation. When organs are obtained through payments, they have become commodities, which—for good reason, in light of experience in systems where organs are treated that way—fosters a public perception that their distribution will also be determined by financial considerations, thereby weakening general support for organ donation as a community resource that is necessary if transplant programs are to fully and equitably meet the needs of patients.

8. Giving next of kin money does not produce the highest donation rates. The countries with the highest or most rapidly increasing donation rates do not provide financial incentives or gratuities for deceased donation.⁷ Instead, better donation rates depend on improved organ procurement practices, engagement of the critical care community, and public education.^{8,9} The exclusion of payments in these countries, which are found in most regions of the world, is not based on particular cultural norms but on universal principles of ethics and human rights that uphold the dignity of human beings and aim to protect them against exploitation.

C. Adverse Impact on Donor Families

9. Dynamics among donor relatives can be destructive. Making payments to the next of kin for donating organs can provoke arguments within families over the manner in which the money is distributed among family members and over the adequacy of the amount received—for example, if permission were given to remove more organs from the deceased could family members receive a bigger financial expression of “gratitude” or “charitable relief”? Such disputes at the bedside of potential donors are harmful to a dignified dying process for the donor as well as to other patients and families in the hospital unit. After the fact, disgruntled family members may institute legal proceedings against the physicians, nurses, hospitals, organ procurement agency, and others involved in making or condoning the payment to a particular next of kin.¹⁰

10. Payment programs can stigmatize all donors. Especially in countries where deceased donation is not yet widely adopted, receiving financial incentives or rewards sets members of donor families apart from others in society; even family members who do not accept payment may be seen—or fear they will be seen—as having done for money something that successful and reputable people would not do.^{11,12}

11. Payments to next of kin change the relationship between society and donors. What would otherwise be a praiseworthy act of gift-giving is transformed into a commercial transaction, which explains families bargaining for increased payment if they allow more organs to be harvested.

D. Ethical Objections to Payments

12. Achieving basic dignity should not require people to provide donor organs. Ensuring proper burial or cremation for all those who die is a basic feature of decent societies. In settings where this does not occur because of the general conditions or the poverty of some families, it is coercive for a deceased donation program to offer to cover funeral expenses only for families that allow organs to be procured from their deceased relatives. It likewise is wrong to condition access to health care—or relief from bearing the cost of such care—on the next of kin agreeing to donate organs. All such practices violate the requirement of voluntary informed consent to donation set forth in the WHO Guiding Principles and the Declaration of Istanbul. Further, a just society would never condition the important benefits it makes available to grieving families upon their agreeing to part with a relative’s organs.

13. Payments based on the recipient having donated organs are the antithesis of charity. Attempting to justify

payments as “charitable gifts” merely underlines the exploitation because acting generously toward the poor can never involve extracting something of material value from the supposed beneficiaries. Further, whenever a person has truly made a gift, responding with money turns the act of giving into a pecuniary exchange, in which case either party would then be justified in saying that the gift deserved more money or the payment merited a bigger gift.

14. Paying for funeral or medical expenses of deceased donors is doubly unjust. Making payment depend on consent not only exploits the financial need of donor families but also provides nothing to other needy families who did not authorize donation or are perhaps not even able to do so because their deceased relative was not a suitable donor.

15. Payments designed to get people to act against their beliefs are especially wrong. When some people have strong cultural, moral, or personal reasons why they are unwilling to do something, it especially offends principles of liberty and dignity to induce them to act against their beliefs by offering them an amount of money that would be difficult or impossible for them to refuse, given their financial straits. The offense is especially pronounced in societies with wide variations in wealth, where financially privileged persons would have no need to compromise their objections to acting in the way that poor persons are induced to act.

16. Reimbursement of donation-related expenses should not turn on giving consent. As both the WHO Guiding Principles and the Declaration of Istanbul make clear, prohibitions on paying for donation do not preclude keeping organ donation a financially neutral act by reimbursing the reasonable and verifiable expenses incurred.¹³ In the context of deceased donation, it is therefore wholly acceptable for a transplant program to pay the hospital where a potential deceased donor has received medical care for any *added* costs of evaluating and maintaining the patient as a donor and to cover any costs the next of kin incur to participate in decisions about whether or not to donate organs, such as the cost of coming to the hospital to speak with organ procurement personnel. It is not, however, acceptable to withhold such reimbursement of expenses should the family decide not to donate, nor to include in those expenses anything for funeral costs or hospital charges not connected with the donation of organs—that is, expenses that would have arisen even if organ donation were not being considered for that patient.

IV. CONCLUSIONS

For all of these reasons, countries should not establish or allow others to operate public or private programs that pay money to, or for the benefit of, next of kin who consent to donate their deceased relative’s organs, whether such payments are for funeral expenses, to cover charges for predonation hospital care, to relieve their poverty, or especially to incentivize their decision. Countries that rely on such financial gifts, rewards, and incentives for deceased donation undermine their chance of building a transplant program that accords with global ethical and human rights standards; instead, they are in effect announcing that the economic and social marginalization of large portions of their population precludes them even trying to create such a program. Moreover, experience shows that a later decision to stop paying will necessitate

organ donation programs having to expend great—and not necessarily successful—efforts to reverse the public expectation that such a payment will be forthcoming for organs from deceased relatives.

In place of payment programs, the Declaration of Istanbul Custodian Group works to support transplant professionals and government officials around the world who share a commitment to creating national systems of voluntary, unpaid organ donation that are adapted to local conditions and that can successfully advance each country toward “self-sufficiency” in transplantation without exploiting its poorest and most vulnerable citizens.¹⁴ To be truly effective and sustainable, as well as ethical, the incentive to donate cannot be external, in the form of a payment on behalf of those who have access to transplants to those who do not, but rather internal, in the form both of the psychic rewards of demonstrating generosity toward those in one’s community who need a life-saving organ, and of reciprocity, which occurs when all those asked to be donors are also eligible to be recipients.

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