

## Commentary

# Would 'all-inclusive' compensation attract more gamete donors to balance their loss of anonymity?

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### Abstract

The UK Government has determined that children born from egg donation have the same right to know their biological parent as adopted children on reaching the age of 18. There is concern as to the effect of loss of anonymity on egg donor recruitment, since a wait of 1 or 2 years is not unusual even under present circumstances. Some fertility programmes have introduced egg-sharing (involving 'subfertile donors') to circumvent the delays. However, with this method both the donor and the recipient may have reduced overall success. The shortage of sperm donors has led the Human Fertilisation and Embryology Authority (HFEA) to consider increasing the allowable expenses payment and a consultation exercise is underway to review payments and other issues for sperm, egg and embryo donors. Fundamental new initiatives regarding gamete donation need to be implemented to avoid further restrictions on an already unsatisfactory service. An 'all-inclusive' financial allowance is proposed for donors to promote donor recruitment and shorten the waiting time to treatment predicted to increase with the loss of anonymity.

**Keywords:** *anonymity, children's rights, egg donation*

### Introduction

When our Centre first performed egg donation in 1986, anonymous and known donors were used to suit different patients' circumstances. Nothing seemed more acceptable than sister to sister donation, but public awareness of these actions (Steven, 1987) promoted an outcry in the lay press (Stirat, 1987), even though the terms of reference of the then supervising body, i.e. the Voluntary Licensing Authority (VLA), covered this consideration in exceptional circumstances. New legislation mandates that all gamete or embryo donors need to be aware that, from 1st April 2005, children resulting from the donation of gametes or embryos have the right to know their biological parent(s) on reaching the age of 18 (HFEA, 2004b). This decision was based upon responses to a previous Department of Health (DOH, 2001) consultation document with the premise that all donors be known to children conceived using donor gametes. The changes resulting from the loss of anonymity need to be considered in relation to changes in the international trends on gamete donation (Frith, 2001).

The HFEA's response to the DOH consultation paper recommended that (i) there should be a move towards loss of donor anonymity; (ii) any change in donor anonymity should not be applied retrospectively; (iii) the double track system (Pennings, 1997) should be rejected and (iv) stronger guidelines should be developed on the counselling needs of those considering treatment with donor gametes and of donor offspring seeking information on donors (HFEA, 2002). The DOH circulated a summary of responses to the consultation

document received over the 8-month consultation period. However, there were only seven responses from egg donors, nine from sperm donors and two from embryo donors and only 18 from those who had received donated eggs (DOH, 2003). Such a poor response rate does not suggest that the views of the major stakeholders (i.e. the patients) have been well represented.

### Mechanism for implementing the legislation

In a recent HFEA circular (2004c) concerning disclosure of information to donors and recipients of gametes and embryos, certain specified information, can be made known to donors and recipients "as long as the disclosure could not lead to the identification of a person (presumably the resultant child) whose identity should be protected". The information allows donors and recipients to be aware that children conceived from the use of donated gametes or embryos will be in contact with donors when the HFEA provides identifying information of the donors following the offspring's request at the age of 18. The HFEA will inform donors that an application has been made to the Authority by a person conceived as a result of their donation, but the HFEA will not give the donor any information about the person making the application.

It is not clear how efficient contact by the HFEA (or equivalent regulatory authority) will be with donors once the child reaches the age of 18, since this is dependent on up-to-date communications existing which may be influenced by altered lifetime events, change of address etc. Even now, 100%

response to the outcome of fertility treatments cannot be guaranteed, whether these involve using the patient's own, or donated, gametes and when one considers the difficulties clinics currently have to maintain contact with patients who have gametes or embryos in storage. Nevertheless, in the modern age of sophisticated telecommunications, it is far easier to locate registered persons by date of birth and national insurance numbers.

In Sweden, where loss of anonymity of sperm donors was made law in 1985, more than 80% of parents have not told their children of their biological origins (Gottlieb *et al.*, 2000), which raises the question as how such a law could be enforced in practical terms save by marking the birth certificate in a particular way.

Support of known donation encourages recipients to tell their children about their biological background from an early age, since children accept information for what it is as they grow up. Finding out one's true biological entity later by a chance event, sometimes from a third party, is likely to be devastating, bringing about anger, frustration and feelings of being deceived (Snowden and Snowden, 1998; Turner and Coyle, 2000; Frith, 2001; McWhinnie, 2001). However, despite the openness and right to know afforded to all children under the new legislation (HFEA, 2004b), some consider disclosure may not be best for all donor gamete families (Klock, 1997; Frith, 2001).

Even if a donor is prepared to be known to a prospective child at the age of 18, it is pertinent to consider if it is preferable that the recipient knows the donor at the time of donation, even if this has not been thought to be an end consequence of the recent legislation. If the donor and recipient agree to know each other, thereby changing an anonymous arrangement to a known donation, it may enrich both parties if success occurs. It also allows the recipient to be prepared that her child will become aware of the donor's identity at the age of 18, if not beforehand. In addition, this arrangement almost certainly increases the likelihood of a child knowing their biological parent at 18. In this sense, the HFEA mechanism would be simply a back-up.

Certainly recipients and donors need to feel comfortable with any intended arrangement and be counselled rather than have an adverse reaction when their offspring, and possibly they, meet the donor for the first time some 18 years later if they have been anonymous to each other at the time of donation.

This concept of an 'all-inclusive' allowance allowing both altruism and limited compensation was first raised by our Centre at an HFEA sponsored meeting nearly a decade ago (St Anne's College, Oxford, 1 June 1995). Some donors may not wish to receive any reimbursement of their own expenses, or any financial gain and others could accept a total allowance, if agreed. It can be questioned if there is any real philosophical difference in letting a recipient pay for an egg sharer's treatment, and a fertile donor receiving an 'all-inclusive' allowance as compensation for her involvement. It behoves the DOH, the HFEA and indeed the profession, to come up with new and effective ways to improve recruitment from fertile, rather than from subfertile, donors so that UK patients do not need to travel overseas for one fertility treatment method. It

may also facilitate treatment within the NHS using donated gametes for those who cannot afford private treatment now that one NHS-funded treatment cycle is at long last becoming a reality.

Should the child's right to know its biological origins take absolute precedent, at all costs, over an infertile couple's rights to found a family? Moreover, it may not be appropriate to use adoption as an analogy for egg donation (Klock, 1997; Frith, 2001). It has also been questioned whether legislation enacted prior to this issue being considered, e.g. United Nations Convention on the Rights of a Child (1989) and the Human Rights Act (1998), which incorporated the European Convention on Human Rights into British Law in October 2000, is appropriate to this present situation (Frith, 2001).

## What is 'known donation'?

Some uncertainty exists as to what should be known about a donor and the level of contact that may exist with the gamete donor when the young adult reaches the age of 18. In its complete sense 'known donation' means meeting, and potentially remaining in contact for life, besides becoming aware of the personal, family and medical history of the donor. It is understood that legislation enshrines the prospect that offspring may physically meet their biological parent(s). One can speculate that many recipients would accept the principle of contact if 'contact' meant 'communication' and actually stopped short of physically meeting, since recipients may consider communication only as less of a threat to their own relationship(s).

The identity of donors will, as now, be known to the HFEA with the assumption that the HFEA expects donors to be anonymous to recipients at the time of donation, except for those who elect to be known. However, if donors are successfully recruited by recipients directly or indirectly through a third party, it is possible that some contact will occur between them, they may become known to each other, know that a child has been born, and the child him/herself may become aware of the relationship before the age of 18. Some recipients may prefer this situation, considering it less of a threat to their relationship as their child grows up than a donor, anonymous to them, meeting their offspring for the first time as a young adult. The possible downside of such arrangements is that the donor may know who the child is before the child knows their biological parent, which is not the purpose of the legislation.

## The benefits of known donation

Current work supports the concept that children conceived from donated gametes, or embryos, should have the option of knowing their biological parents. Furthermore, London Fertility Centre has always encouraged known donation provided counselling ensures donors are not pressurised to act in this capacity and that the welfare of the child is secure. This philosophy is supported for two reasons. The first is the belief that children benefit from knowing their biological origins (McWhinnie, 2001; Anon, 2002; Blyth, 2002; Montuschi, 2002; Wray, 2002). The second is the result of witnessing the profound delays of up to 2 or more years for anonymous donation. Such delays prompt some patients to give up their

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