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## **Implications of “Donor-Linking” for Donors, Offspring, Recipients and Clinics: Past, Present and Future**

### **What is “donor-linking”?**

The concept “donor-linking” originated in Australia to describe the arrangements by which people involved in a donor procedure may be assisted to find out, and possibly make contact with, other people to whom they are related as a result of the procedure. Given the dual traditions of secrecy and anonymity which have provided the context in which donor conception has been practised in most countries, the ability to make these sorts of connections is itself a relatively recent phenomenon. “Donor-linking” is more developed in some countries than others. It is probably at its most developed in the Australian state of Victoria, which has developed protocols for “donor-linking” in relation to three distinct regimes:

- before there was any legislation at all, under which anonymity was assumed and the quantity and quality of information recorded varied according to individual clinic practice
- under the first regulatory regime in which anonymity was assured and specific information was recorded and lodged with the statutory regulator, the Infertility Treatment Authority
- under the current regulatory regime in which donors must be prepared to disclose their identity and specific information is recorded and lodged with the Infertility Treatment Authority.

In the United States, the Sperm Bank of California, which has been recruiting identifiable donors for about 20 years, has also developed protocols for “donor-linking”.

In countries where anonymity continues to characterise donor conception, and where connections between donors and their offspring are not encouraged, “donor-linking”

remains an unfamiliar concept. Within the last couple of years UK legislation regarding donor anonymity has changed and a voluntary contact register established, so we have recently begun to consider the implications of “donor-linking”.

Initially, “donor-linking” has drawn on the experience of handling requests for birth origins information in adoption and “reunions” between adopted people and birth parents. However, the essential differences between adoption and donor conception mean that the analogy is necessarily limited and it will be important to develop discrete policies and practices for “donor-linking”. In this presentation, I will draw on work that I carried out as a member of the British Infertility Counselling Association HFEA Register Counselling Project Steering Group, which produced a report in 2003, *‘Opening the Record’: Planning the Provision of Counselling to People applying for Information from the HFEA Register*, and some subsequent thoughts.

### **Who has an interest in “donor-linking”?**

Much of the debate regarding information in donor procedures has concerned the interests of a donor-conceived person in having information about his or her donor. However, while the extent to which a donor-conceived person may have an interest in such information itself remains contested, the debate in some parts of the world at least has moved on to consider the interests of a range of individuals involved in a donor procedure learning about another person to whom they may be connected as a result of the procedure. Barry Stevens’ video *Offspring*, for example, illustrates his quest to identify his donor in which he discovers a half-brother in England, David Gollancz (and has since discovered other half-siblings and the identity of his now-deceased donor).

Those whose interests may now be included encompass:

- donor-conceived individuals

- descendants of donor-conceived individuals
- individuals and couples who have conceived a child through donor procedures
- egg, embryo or sperm donors
- relatives of any of the above
- people wishing to establish whether they were born as a result of a donor procedure
- genetic siblings of donor-conceived individuals.

In different jurisdictions, where legislation exists, different groups may be afforded different rights to information. In the UK, for example, donor-conceived people *only* have a legal right to obtain information from the regulatory body, the Human Fertilisation and Embryology Authority. As part of its review of the Human Fertilisation and Embryology Act, the government is currently considering whether these rights should be extended to others. In Victoria, certain statutory rights to information are given to donor-conceived people, to parents of donor-conceived children, to descendants of donor-conceived people, and to donors.

Voluntary Contact Registers, which by definition rely on information that is given voluntarily, typically encompass a greater range of individuals.

In the UK, a government-funded pilot voluntary contact register, UK DonorLink ([www.ukdonorlink.org.uk](http://www.ukdonorlink.org.uk)), was set up in 2004 as a means of facilitating exchange of information and contact by mutual consent between anyone over the age of 18 who:

- was conceived using donated sperm or eggs
- donated in the UK or
- thinks that they may be biologically related to a donor-conceived person.

UK DonorLink is initially restricted to donor procedures that took place *before* 1991, i.e. before implementation of the Human Fertilisation and Embryology Act. As of 13 March

2006, 118 individuals had completed full registrations, i.e. had completed DNA testing. Of these, 41 are donor-conceived adults, 14 are donors, 2 are genetic siblings of donors and 25 are birth mothers. In addition a further 125 individuals have made initial enquiries and are at varying stages of considering or actually registering with UK Donorlink. Matches have been made so far between three groups of individuals sharing the same donor/genetic father:

- 8 half siblings and one birth child of the donor
- 3 half siblings and one birth son of the donor.
- 2 half siblings and possibly a third half sibling, subject to completion of tests.

Two internet-based registries have been established in the United States, but which are accessible internationally. The 'Sibling Registry', set up by Single Mothers by Choice, enables members to register their donor-conceived children for the purpose of locating other children who were conceived with the same donor sperm (<http://www.singlemothersbychoice.com>). The SMC Sibling Registry currently has 297 registrations, and 14 matches have been made, involving 33 individual children. (Single Mothers by Choice, personal communication, 3 April 2006).

The more recently-established 'Donor Sibling Registry' was established in September 2000 by Wendy Kramer and her donor-conceived son, to help individuals seeking to make contact by mutual consent with their biological relatives (their own or their child's half-siblings; their own or their child's donor; or their biological offspring) conceived as a result of either sperm or egg donation (<http://www.DonorSiblingRegistry.com/>). Contact may be made by anyone aged 18 or over on their own behalf and parents may make contact on behalf of their children aged under 18. By April 2006 membership of the Registry had grown to 7466 and matches between 1632 half-siblings and/or donors have been facilitated.

### **"Donor-linking" in practice**

The scope for “donor-linking” depends on the information that has been recorded, and the basis on which it was collected, including - of course – legal requirements and restrictions on the disclosure of information. Crucially, this will include whether the donation was made anonymously or whether the donor was aware at the time of donation that his or her identity could be disclosed. Most of the available evidence and “practice wisdom” relate to donor procedures that were conducted anonymously and where relatively little donor information has been recorded.

In the absence of legislation, it will be for individual clinics to develop their own protocols for “donor-linking”, including making the decision whether or not this is something they want to facilitate in the first place.

This decision may be informed by the, albeit limited, empirical evidence about practices and attitudes of those who are directly involved in donor-conception. While there are evident cultural differences, this shows that:

- Most heterosexual parents do not tell their donor-conceived children about their conception. However, recent studies suggest that an increasing proportion of parents appear to be telling their children. Same-sex couples are more likely to tell their children, as are heterosexual couples who have conceived children as a result of a surrogacy arrangement.
- Some parents of donor-conceived children and support groups have campaigned for the removal of donor anonymity.
- There is increasing evidence that some egg donors (in some studies a sizeable majority) wish to have information concerning the outcomes of their donation.
- There are varying reports about the proportion of existing egg/embryo donors who would be willing to meet offspring or disclose their identity.

- Somewhat fewer sperm donors than egg donors seem willing to be identified or to be contacted. However, the assumption that, having donated, sperm donors invariably have no continuing interest in their offspring, cannot be sustained, since some sperm donors wish to have information concerning the outcomes of their donation.
- Donor-conceived people who are aware of their conception generally want information about their donor and any half-siblings they may have, and some wish to make contact.

Assuming that “donor-linking” is to be facilitated, the request for information is most likely to be made by a donor-conceived person, a parent on behalf of a donor-conceived child who is a minor, or a donor.

A key underlying principle is to regard a request for information as a normal expression of interest in personal genetic history. It should not engender any presumption of psychopathological abnormality. However, it is insufficient merely to make information available. The person requesting information (the applicant) should be encouraged to consider their motivations, expectations, needs, hopes and the implications of receiving the information - including the possibility that any information they get might differ from their expectations, needs or hopes.

It is important to distinguish a request for *non-identifying* information from a request for *identifying* information and/or *contact*. Furthermore, the specific non-identifying information requested may not be available in the clinic’s records, and so obtaining it would require the clinic to engage in some form of mediating activity with the person about whom information is sought.

For *all* requests for information, the following issues should be discussed with the applicant before information is provided:

- their motivation for seeking information
- the background to their decision to seek information. Since many parents of donor-conceived children do not tell their child about their conception, where the applicant is a donor-conceived person, they may have discovered their status ‘accidentally’ or from a source other than their parents. Alternatively, they may simply suspect that there may be information about their conception that has been withheld from them.
- any legal and formal requirements and restrictions relating to the disclosure of information, the process of such disclosure, and any legal rights or obligations between the parties.
- the options available to them and the implications and potential consequences of proceeding with the application for information on themselves and others. In the case of a donor-conceived person, this will include whether their parents are aware of their request, the applicant’s understanding of the impact of their request on their parents (if they are aware of it), to what extent this will reactivate their parents’ feelings about their infertility, whether their parents may feel threatened by the application, and what impact the request and/or the information will have on their relationships with their parents. The request, and any information provided, may have implications for any donor-conceived siblings of the applicant; siblings’ interests in information may be different and different siblings may have access to different levels of donor information. The request may also disclose information about the existence of other – previously unknown – genetic relatives, such as other donor-conceived half siblings or the donor’s children.



- their expectations about the outcome of their request and how they will deal with potentially varying emotional reactions arising from the disclosure of information - or discovery of the lack of information.
- their need for additional and/or longer-term support, which may require the involvement of another service or support group – if they are not already in contact.

The clinic needs to have an agreed policy for dealing with situations in which it believes that the release of the information requested may place the applicant or another person in danger.

Where the non-identifying information requested is unavailable or where the request is for identifying information, the clinic needs to ascertain if it is prepared to make contact with the person about whom the information is requested. If not, it will need to carefully discuss its rationale with the applicant and be prepared to respond to the applicant's distress and anger and offer or make available support as necessary.

The clinic may be prepared to pursue some requests but not others. For example, it may be willing to try to contact a donor, but not a recipient or a donor- conceived child.

If the clinic is prepared to try to locate the individual about whom the information is requested, it needs to establish the extent to which it is prepared to make enquiries, and invest time and resources into the investigation, bearing in mind that any available contact details may be considerably out of date.

The applicant needs to be prepared that it will not be possible to contact the individual about whom information is requested, that the individual may have died, or that, once contacted, the potential informant is unwilling to provide the requested information. In

the latter instance, the clinic needs to respect the rights of the potential informant to privacy and determine how far it is prepared to advocate on behalf of the applicant; will any effort at making contact and obtaining information be limited to “one shot”? In any event the clinic needs to ascertain what information the informant is prepared to disclose, and be prepared to discuss the informant’s feelings, thoughts, expectations and wishes in relation to the inquiry.

If the informant is prepared to use the clinic as an intermediary for the exchange of information, and which may be a vehicle for developing communications in preparation for direct contact or meeting, the clinic must decide if it is prepared to assume this role.

In endeavouring to make contact with a person about whom information is requested, the clinic will need to take account that current members of her or his household may not be aware of her or his involvement in a donor procedure, and so great care needs to be taken in ensuring confidentiality.

A request for identifying information is most likely to be made by a donor-conceived person or a parent acting on a child’s behalf requesting information about the donor’s identity. In such instances the potential impact on the person about whom the information relates and members of their social and kinship networks must also be considered. In particular:

- the impact on the donor – the donor’s expectations and needs and how these might be managed in the context of his or her current life circumstances.
- the impact on the donor’s partner (who may not be aware of the donation)
- the impact on half-siblings - the donor’s children and any other siblings - who may have different needs which the request may trigger

- the impact on the applicant’s family, especially parents and siblings – the issues previously discussed will be relevant and may be intensified if the possibility of contact arises
- the impact on the applicant – the impact of any new information on self-perception; any mis-match between reality versus fantasy; the discovery of other genetic relatives (especially of half-siblings who may have made similar requests for information); the implications of a request for contact being denied, a failure to contact the donor or discovering that the donor has died.

## **Conclusion**

“Donor-linking” is an emerging practice in donor assisted conception, so we are far from being able to produce definitive protocols or to draw on extensive empirical research or practice wisdom. While the lessons of adoption clearly have some relevance to this work, the limits of these must be acknowledged. It is important, therefore, that practices and policies relating to “donor-linking” in different countries and under different regimes are properly researched and evaluated.

© Eric Blyth: 17 April 2006

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