

**PARLIAMENT OF VICTORIA LAW REFORM COMMITTEE**

**INQUIRY INTO ACCESS BY DONOR-CONCEIVED PEOPLE TO INFORMATION ABOUT DONORS**

**EVIDENCE PROVIDED BY**

Eric Blyth CQSW BA MA PhD  
Professor of Social Work  
University of Huddersfield  
Huddersfield HD1 3DH  
England  
[e.d.blyth@hud.ac.uk](mailto:e.d.blyth@hud.ac.uk)

Thank you for inviting me to provide evidence for this inquiry. I have been engaged in research into infertility and assisted conception for the past twenty years and have a particular interest in third party assisted conception. I have conducted research into surrogacy arrangements (UK); egg sharing (UK); sperm donation (UK); known oocyte donation (Canada), and embryo relinquishment via an embryo adoption program (USA). With Dr Ruth Landau of the Hebrew University of Jerusalem I co-edited *Third Party Assisted Conception across Cultures: Social, Legal and Ethical Perspectives* (Jessica Kingsley Publishers; London, 2004). Since 2009 I have been a member of the Victorian Assisted Reproductive Treatment Authority's Advisory Panel.

I welcome this inquiry by the Committee which is, as far as I am aware, the first in the world, to formally investigate the possibility of mandating retrospective disclosure of donor identity and well illustrates Victoria's pathfinding reputation in facilitating the ability of donor-conceived people to access information about their genetic history and genetic relatives resulting from gamete or embryo donation.

That being said, there is no existing system for accessing gamete donor information whose experience can be drawn on for the current inquiry.

A legislative frame of reference is provided by means of the principle enshrined in both the Infertility Treatment Act 1995 (S5(1)(a)) and the Assisted Reproductive Treatment Act 2008 (S5 (a)), that:

“the welfare and interests of any person born or to be born as a result of a treatment procedure are paramount”.

Both Acts (as indeed does similar legislation in other jurisdictions) equate such welfare and interests with the ability of a donor-conceived person to know the identity of his or her donor and (by mutual consent) other donor siblings who share the same donor. However, because the ability of a donor-conceived person to learn the identity of a third party necessarily impacts the welfare and interests of the third party, provisions have been made in all jurisdictions to ensure that the consent of any affected third party to disclosure of this information is given. This is easily effected as regards prospective donation of gametes or embryos by requiring all donors to give advance consent to disclosure of their identity if this is requested – and for which provisions are made in both the 1995 and 2008 Victorian statutes. Consequently, the welfare and interests of any person born as a result of a treatment procedure are “paramount” (i.e. to the extent that this enables them to access the identity of their donor) **only** if the procedure took place after 1996.

I note that when the Victorian Parliament debated the legislation that became the Assisted Reproductive Treatment Act 2008, it did not incorporate Recommendation 97 of the Victoria Law Reform Committee (2007) *Assisted Reproductive Technology & Adoption. Final Report*:

“If a person conceived with gametes donated prior to 1 January 1998 wishes to obtain identifying information about the donor and the donor has not registered his or her wishes on a voluntary register:

- The donor-conceived person should contact the agency managing the registers to request that it facilitate an approach to the donor.
- The agency managing the registers should contact the clinic where the person’s mother received treatment (if it can be identified) and ask the clinic to forward a letter from the Infertility Treatment Authority to the donor.
- The letter from the agency managing the registers to the donor should explain the donor’s options in respect of providing identifying information to the person conceived with his or her gametes, and should draw attention to the availability of counselling to explore those options further.”

I am not aware of the reasons why lawmakers did not see fit to incorporate this recommendation into the Assisted Reproductive Treatment Act 2008. I note from your Committee’s interim report that this proposal has the support of the Victorian Infertility Counsellors Group and Melbourne IVF and is considered to be consistent with the current ethical guidelines on the use of assisted reproductive technology in clinical practice and research published by the National Health and Medical Research Council. Implementing this provision would not put all individuals conceived from a donor-procedure undertaken in Victoria on the same footing as regards access to their donor’s identity, although it would provide donor-conceived people born before 1988 with the same access to information as those born between 1988 and 1996. As an absolute minimum, this provision at least should be incorporated into legislation, whether or not the Committee wishes to go further in advancing the rights of donor-conceived people. I am not aware that this would, in itself, pose any fundamental difficulties, although the following provisions would be essential to ensure effective implementation:

- Specify the steps to be taken by clinics to “make **an appropriate effort ..... to contact** the gamete donor and obtain his or her consent to the release of information” (National Health and Medical Research Council, 2007: 6.13 – my emphasis).
- Initiate a public education program (modelled on the program that preceded the launch of the *Time to Tell* campaign) in order to alert past donors to the importance of providing information to donor-conceived people.
- Provide a statutory basis for the provision of counselling for donor-conceived persons seeking information and for donors agreeing to exchange of identifying information and/or contact. Ideally this should be on a similar legal footing as counselling for adopted people seeking information about their birth origins.
- Extend legal and financial responsibilities towards donor-conceived offspring currently enjoyed by donors who donated gametes after 1 January 1998 to those who donated before 1 January 1998.

Moving beyond this, any suggestion that all donor-conceived people born before 1996 resulting from a donor procedure undertaken in Victoria should be afforded the same rights as those born after 1996, a course of action that I endorse, does raise several significant considerations. I will explore these in relation to the issues identified by your Committee.

**The legal, practical and other issues that would arise if all donor-conceived people were given access to identifying information about their donors and their donor-conceived siblings, regardless of the date that the donation was made**

*Legal issues:* This proposal could risk a legal challenge from a donor or from any donor-conceived sibling who had not formally consented to the disclosure of their identity (and, indeed in the case of

a donor-conceived sibling, they may not even be aware that they are donor-conceived prior to being approached for information). It is noted that empirical evidence suggests that at least some donors who donated under a regime of anonymity would be willing to disclose their identity to offspring, but not all would necessarily be willing to do so. To extend an absolute right of access identifying information about a donor, regardless of his or her express consent, might be justifiable on the grounds that the donor-conceived person's right to this information trumps the donor's right to privacy, on the basis that the welfare and interests of the donor-conceived person are "paramount" and therefore those of the donor must, inevitably, be secondary (although to my knowledge this has never before been tested in any court of law). This might be considered to be broadly analogous to the retrospective application of the right of an adopted person to access her or his birth records, including the identity of her or his birth mother – information to which the birth mother had never consented.

The legal and financial responsibilities of donors who donated gametes before 1 January 1998 towards donor-conceived offspring should be the same as donors who donated gametes after 1 January 1998.

However, it is difficult to justify extension of such a right to information about a donor-conceived sibling who has not given consent to the release of this information. Each donor-conceived person's welfare and interests enjoy equal standing under the law, and supporting the rights of the person seeking information would both transgress current conventions regarding informed consent and trump the privacy rights of a non-consenting donor sibling. In my view, arrangements regarding information about donor siblings should continue to be based on voluntary registration and mutual consent.

*Practical issues:* A public information campaign – possibly modelled on the *Time to Tell* campaign and drawing on lessons from that campaign – would be necessary to alert former donors to any proposed change in legislation and the availability of necessary support etc (see below for more details). Investigations should also be undertaken to ascertain the contribution that clinics might make to establish discreet and confidential contact with their former donors and the expertise they possess to make such contact.

*Other issues:* Information provided by the Committee suggests that at least some individuals who donated gametes in past years (before implementation of relevant legislation) may have received limited or no counselling or any other services, or given insufficient opportunity to consider the implications of their donation. By today's standards, few of these donors probably gave effective informed consent to their donation. It is imperative therefore, that any change in legislation that could expose them to unanticipated – and especially unwelcome – contact from a donor-conceived offspring needs to be accompanied by the provision of adequate information, intermediary services, support and counselling. Donor-conceived people seeking their donor's identity and potential contact would also need access to such services, especially to consider the potential implications of their wish for information not being welcomed by the donor for themselves, their family, the donor and her or his family. Such support services should also be available to members of the donor's and the donor-conceived person's family networks. It also needs to be acknowledged that expertise in providing such services – especially as regards "unwelcome" contact – is virtually non-existent, although some expertise may be available in analogous settings, such as adoption and counsellors with donor-linking experience. Resourcing such a service needs to acknowledge that professional support to people seeking information and/or information exchange will not necessarily be a 'one-off' event.

**The relevance of a donor's consent or otherwise to the release of identifying information and the National Health and Medical Research Council's ethical guidelines on the use of assisted reproductive technology in clinical practice and research**

The relevant sections of the NHMRC's guidelines state:

"Assisted Reproductive Treatment (ART) procedures must be conducted in a way that is respectful of all involved. Clinical decisions must respect, primarily, the interests and welfare of the persons, who may be born, as well as the long-term health and psychological welfare of all participants, including gamete donors" (5.1)

"If the consent form does not include permission for release of identifying information ..... the clinic should make an appropriate effort, consistent with the original consent document and the privacy rights of the donor to contact the gamete donor and obtain his or her consent to the release of information" (6.13).

As regards a donor-conceived person's wish to learn the identity of a gamete donor who has not consented to the release of this information, the NHMRC guidelines indicate that the donor's wishes should trump those of the donor-conceived person. Clearly any legal measures that enable the donor-conceived individual's interests and welfare to trump those of the donor would run counter to the NHMRC's current position, which would need to be revised to reflect the changed emphasis in priority.

**Any practical difficulties in releasing information about donors who provided their gametes before 1 July 1988, because in many cases records are not available either because the procedure was carried out privately or records were not stored centrally**

Inevitably, there is a risk that records of a donor procedure conducted prior to 1 July 1988 that was carried out privately or were not centrally stored may be unavailable or very difficult to track down. Every effort should be made to ascertain the existence of relevant records through appropriate medical networks and – where feasible – retrieved records should be stored centrally with current records for donor procedures in Victoria.

Such records may also be at special risk of destruction. The Supreme Court of British Columbia in Canada recently prohibited the destruction of such records and such steps could also be taken in Victoria.

Clearly nothing can be done about records that do not exist or cannot be found, although donor-conceived people for whom records cannot be found may well need access to competent information, support and counselling services.

**The options for implementing any changes to the current arrangements, including non-legislative options**

Three options for changing the status quo were summarised in the Committee's interim report (p. 30):

1. All donors to be contacted and asked to re-consent to being identified;
2. Donors' identifying information to be released without donors' consent upon request from approved persons, for example, donor-conceived people or donor recipients, as occurs with retrospective access to identifying information about birth details for adoption people;
3. Donors to be contacted and asked to consent to the release of information only upon request for information by a donor-conceived person.

Option 2 alone would result in all individuals conceived from a donor-procedure undertaken in Victoria being placed on the same footing as regards access to their donor's identity. Self-evidently this is also the most controversial path and, if it were to be introduced, contact between donor-

conceived people and their donors should be mediated via an official intermediary equipped with the necessary skills.

As I have indicated above, current arrangements for facilitating communication and contact between donor-conceived siblings should be extended to individuals born as a result of a donor-procedure undertaken before 1 July 1988.

### **The impact that any such changes may have on the donor, the donor-conceived person and future donor programs**

*potential impact on the donor:* It is noted that those who donated gametes before 1988 are likely to have contradictory views regarding the retrospective disclosure of their identity. There are clearly problems associated with forcing contact with offspring on unwilling donors – not only for the donors, but potentially for members of their family and also for the donor-conceived person her or him self. Since the Committee’s interim report also suggests that the informed consent of at least some pre-1988 donors was compromised (pp. 25-27), these issues need to be taken into account by those providing support, intermediary and counselling services.

*potential impact on the donor-conceived person:* There is a risk that the hopes and expectations of donor-conceived persons may be raised unrealistically and that contact with a donor may have a deeply negative impact on the donor-conceived person. This needs to be taken into account by those providing support and counselling services.

*potential impact on future donor programs:* I do not envisage any impact on future donor programs, but in any event supply issues should not trump matters of principle.

### **The impacts of the transfer of the donor registers currently held by the Infertility Treatment Authority to the registrar of births, deaths and marriages**

The evidence provided in the Committee’s interim report (which is not contested by contrary evidence) is that this transfer has been accompanied both by a loss of specialist counselling services and a reduction in information provided to parents of donor-conceived children and to donor-conceived people themselves (p. 24). In my opinion there was no good reason for the transfer of such responsibility in the first place, and the risk that the expertise built up by the Infertility Treatment Authority would be lost appears to have materialised. Steps need to be instituted urgently to rectify this retrograde impact. Consideration should be given either to transferring these responsibilities to the Victorian Assisted Reproductive Treatment Authority or to compelling the registrar of births, deaths and marriages ensure the provision of necessary information and specialist counselling services.

### **The possible implications under the Charter of Human Rights and Responsibilities Act 2008**

The Charter’s provisions contain within them the possibility of conflicting rights, notably a donor’s right to privacy and non-interference in his or her family life and the donor-conceived person’s right to information about her or his genetic origins. The Charter provides no obvious means of resolving such a conflict since no one individual’s rights are given priority. The justification for favouring the interests and rights of a donor-conceived person are to be found in S5 (a) of the Assisted Reproductive Treatment Act 2008:

“the welfare and interests of any person born or to be born as a result of a treatment procedure are paramount”.