Submission No 8

INQUIRY INTO INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS

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The Committee Manager
Committee on Law and Safety
Parliament House
Macquarie St
Sydney NSW 2000

Dear Committee Manager,

RE: Submission on the inquiry into inclusion of donor detail on the register of births

The Hawkesbury Nepean Community Legal Centre (**HNCLC**), located in Windsor NSW, is a non-government community-based legal service providing free legal information, advice and casework to people living in the Hawkesbury, Riverstone, Nepean and Hills areas and is one of thirty community legal centres (**CLCs**) in NSW.

CLCs are actively involved in human rights by:

- having a human rights focus;
- working within human rights frameworks;
- advocating for human rights on behalf of our clients and communities of interest;
- informing, advising and representing individuals and groups where human rights are at issue;
- educating individuals, groups and communities of interest about human rights and related legal and societal processes; and
- undertaking law reform activities to improve human rights protections and processes.

Our Services

HNCLC has 3 services - a legal service, a women's domestic violence court advocacy service and an Aboriginal legal access program.

1. Legal Service

The Legal Service provides free legal services to people living in the Hawkesbury, Hills and Nepean areas. We provide legal advice and representation on a broad range of legal issues and in particular, target our casework services to those clients who are the most economically and socially disadvantaged in our community.

Our client base consists of Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, women, prisoners, young people and other people who, because of mental illness, disability or social or economical disadvantage, find it difficult to access legal services.

In addition to advice and casework, the Legal Service also provides community legal education and advocates for reform to laws and practices which negatively impact upon our clients.

2. North West Sydney Women's Domestic Violence Court Advocacy Service

HNCLC has been the auspice of a Women's Domestic Violence Court Advocacy Service (WDVCAS) since 1995. The service provides a holistic support, referral and legal advocacy service for women experiencing domestic violence and who are applying for Apprehended Domestic Violence Orders at Windsor Court and Blacktown Court.

3. Aboriginal Legal Access Program

HNCLC has provided an Aboriginal Legal Access Program (ALAP) for more than ten years. The program is involved in a variety of groups and committees advocating for increased access and participation to legal and community services for Aboriginal families and individuals in the Hawkesbury. The ALAP also provides outreach services at locations South Windsor and Riverstone.

While providing legal services to individuals, the descriptions above also illustrate that we work beyond the individual. Our centre undertakes community development, community legal education and law reform projects that are based on client need, are preventative in outcome, and that develop the skills of individual clients and strengthen our communities.

HNCLC welcomes this opportunity to provide a submission to the inquiry into the adequacy of the current system for recording donor information and whether donor details should be included on the register of births.

Please do not hesitate to contact me on [redacted] if you have any questions regarding our submission.

Yours sincerely,
Hawkesbury Nepean Community Legal Centre

[redacted]

Kellie McDonald
Solicitor

SUBMISSION ON THE DONOR DETAILS INQUIRY

Summary of recommendations

We submit that the following recommendations strike an appropriate balance between the rights of donors, donor conceived people and their parents:

Recommendation 1: Donor conceived people should continue to be able to access identifying and non-identifying information about their donors.

Recommendation 2: The Act should not apply retrospectively to donors who made donations prior to 1 January 2010.

Recommendation 3: The management of the Central Registry be transferred from NSW Health to the Registry.

Recommendation 4: If a donor conceived person conceived prior to 1 January 2010 wants access to information about their donor and their donor has not provided identifying information voluntarily, the agency managing the Central Registry should contact the ART provider where the donor provided gametes, if known, and ask them to forward their letter to the donor explaining the donor's options about providing identifying information to the donor conceived person.

Recommendation 5: Legal parent/s of donor conceived people should have the right to choose to list their child's donor on their donor conceived child's birth certificate, if the donor consents.

The current system in NSW

1. The NSW *Assisted Reproductive Technology Act 2007* (**the Act**) was amended in 2010 to establish a Central Register, authorising NSW Ministry of Health (**NSW Health**) to manage it. The purpose of the Central Register is to enable the exchange of identifying and non-identifying information between donors, donor conceived people and parents of donor conceived people.

2. Donors who donate eggs, sperm or embryos after 1 January 2010 must now provide certain identifying and non-identifying information (**mandatory information**) to ART providers for inclusion on the Central Register. This information must be provided to a donor conceived person over the age of 18 or their parent upon an approved application for the information.

3. The requirement to provide mandatory information does not apply retrospectively to donors who made donations prior to 1 January 2010 but these donors are still encouraged to register identifying and non-identifying details on the Central Register. Under these circumstances, information provided by donors will only be disclosed to a donor conceived person or their parent with the express consent of the donor.

Rights of donor conceived people

4. The rights of donor conceived people are enshrined in the *International Convention on the Rights of the Child* (**CRC**). The CRC states that every child has the right to non-discrimination, to an identity, to know their parents and their

best interests must be the paramount consideration when making decisions that affect them.[1]

5. We refer to submissions made by donor conceived people to the Victorian Parliamentary Inquiry[2] and Commonwealth Senate Inquiry[3] about access to information about donors and submit that access to information about donors is important to donor conceived people for the following reasons:

   - Developing their self identity;
   - Understanding their medical history;
   - Understanding their genetic and cultural heritage; and
   - Forming relationships with biological relatives.

6. Caroline Lorbach from the Donor Conception Support Group Australia (**DCSG**) states in her submission to the Commonwealth Senate Inquiry:

   "[t]he denial of such rights of access to one group can have severe adverse effects on their perception of themselves and their position in the world… The federal government has a responsibility to protect the existing records… and ensure that donor conceived people have the same rights that everyone else in the population has."[4]

7. We submit that the NSW Government has an obligation to comply with the CRC and to protect and promote the fundamental human rights of all children, including children who are donor conceived.

8. We submit that it is in the best interests of donor conceived people to be able to access information about their donors. Such information can help them develop a fuller sense of self-identity which will in turn enable them to better participate in society.

Recommendation 1: Donor conceived people should continue to be able to access identifying and non-identifying information about their donors.

Rights of donors

9. We submit that the right to information for donor conceived people should be balanced against the rights of donors to privacy.

10. Prior to the introduction of the Central Registry, donors were not required to consent to the disclosure of identifying information to donor conceived people and often entered into private contractual arrangements with ART providers on the basis that they would remain anonymous.[5]

11. The Fertility Society of Australia said in their submission to the Commonwealth Senate Inquiry that it would be a violation of privacy to require donors to consent to the release of identifying information through legislation that applied retrospectively to them:

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[1] Articles 2,3,7 and 8 of the *Convention on the Rights of the Child.*

[2] Parliament of Victoria, Australia, Victorian Parliament Law Reform Committee, *Interim Report on the Inquiry into access by donor-conceived people to information about donors*, September 2010.

[3] Commonwealth of Australia, Senate Legal Constitutional Affairs References Committee, *Report on the Inquiry into donor conception practices in Australia*, February 2011.

[4] Ibid, p 81 – 82.

[5] Above n 2, 25.

> *"It would be a grievous violation of their privacy, with potentially devastating consequences for their own families, to now compulsorily change these arrangements in retrospect."*[6]

12. We submit that it would be unjust to apply reforms to the Act retrospectively to donors who made donations prior to 1 January 2010, as they may have made a decision to donate based on their right to anonymity.

Recommendation 2: The Act should not apply retrospectively to donors who made donations prior to 1 January 2010.

Management of donor details

13. As discussed above, the Central Register is currently maintained and managed by NSW Health.

14. We note that this inquiry is seeking submissions on whether the management of the Central Registry should be transferred from NSW Health to the NSW Registry of Births, Deaths and Marriages (**the Registry**).

15. In Victoria there are two Central Registers and two Voluntary Registers. Both contain identifying and non-identifying information about people associated with donor conception. Until 1 January 2010 the Infertility Treatment Authority (ITA), a statutory body created under the *Infertility Treatment Act 1995,* managed these registers.

16. The management of the donor registers was transferred to the Victorian Registry of Births, Deaths and Marriages in 2010 following a recommendation by the Victorian Law Reform Commission (**VLRC**).[7]

17. This recommendation was based on the principle that information about donors is for the benefit of donor-conceived people, and that their parent's fertility should not define them throughout their life. Accordingly, it was deemed inappropriate that donor information be held by the ITA.[8]

18. The VLRC also indicated that centralising information about a donor conceived person's conception, parentage and cultural heritage would help normalise the method by which they were conceived.[9]

19. We acknowledge that some donor conceived people want to access information about their donor for medical purposes and on the face of it, NSW Health appears to be the appropriate agency to hold that information. However donor conceived people also want to access information about their donor for much broader reasons pertaining to the development of their self identity.

20. As discussed above, donor conceived people often want to access information about their donor so they can better understand their genetic and cultural heritage and their donor's family history.

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[6] Ibid, 26.
[7] Victorian Law Reform Commission, *Assisted reproductive technology & adoption* (2007), 5.
[8] Above n 2, 14.
[9] Above n 7, 158.

21. We submit that it is common practice for people to approach their Registry of Births, Deaths and Marriages when they want to find out information about their family's history and cultural heritage.

22. The majority of submissions made to the Victorian Parliamentary Inquiry and Commonwealth Senate Inquiry state that donor conceived people want to access information about their donor to help develop their self identity.

23. We submit that because the medical history of their donor is only one aspect that assists in shaping a donor conceived person's identity, the Registry is the more appropriate agency to maintain and manage the Central Register.

24. We further note that the current system requires donor conceived people to apply to NSW Health for information about their donor and if they want further information about their donor's family they must then apply to the Registry for that information.

25. Transferring the management of the Central Register to the Registry would centralise information about parentage and treat donor conceived people who want information about their parentage in the same way as other children seeking information about their family.

Recommendation 3: The management of the Central Registry be transferred from NSW Health to the Registry.

Accessing information about donors

26. The current system enables people who were donor conceived **after** 1 January 2010 to access identifying and non-identifying information about their donors after they turn 18 and allows their parents to access this information in the event of a medical emergency or life-threatening situation, where the donor conceived person is under 18 years of age.

27. Access to information for donations made **before** 1 January 2010 requires the express consent of the donor before this information can be disclosed to a donor conceived person or their parent. This means that people who were donor conceived before 1 January 2010 may not be able to access any information about their donor.

28. Lack of access to information about their donor means donor conceived people risk having consanguine relationships with unknown relatives, may not have a full understanding of their medical history and might not be able to obtain a full sense of self identity.[10]

29. While we acknowledge that NSW Health encourages donors to provide information and consent to the disclosure of information, we submit that more can be done to facilitate access to information for donor conceived people while still protecting the rights of donors to privacy.

30. The VLRC recommended that where a donor conceived person who was conceived before donors were required to provide mandatory information wants information about their donor and the donor has not voluntarily provided their information, the agency managing the Central Register should try to facilitate

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[10] Above n 1, 80.

contact by contacting the ART provider where the donation was made and requesting they forward the agency's letter to the donor which explains options about providing identifying information to the donor conceived.[11]

31. This VLRC recommendation was supported by former Register Officers of the Victorian ITA in their submissions to the Victorian Inquiry.[12] The Victorian Infertility Counsellors Group also supported the VLRC recommendation and thought that it would strike 'the most appropriate balance between protecting the rights of the donor conceived person to have access to information and protecting a donor's privacy'.[13]

Recommendation 4: If a donor conceived person conceived prior to 1 January 2010 wants access to information about their donor and their donor has not provided identifying information voluntarily, the agency managing the Central Registry should contact the ART provider where the donor provided gametes, if known, and ask them to forward their letter to the donor explaining the donor's options about providing identifying information to the donor conceived person.

Registration of the birth of donor conceived people

32. According to the NSW *Status of Children Act 1996*, when a child is born to a woman who is married or cohabiting with a man between 44 weeks and 20 weeks before the birth of the child or in a de facto relationship with a woman who consents to the conception of a child through ART, both parties are presumed to be the legal parents of the child.[14]

33. Sperm and egg donors are not presumed to be legal parents of a donor conceived person, unless they are listed as a parent on the donor conceived person's birth certificate.[15] However, this is a rebuttable presumption.[16]

34. There is no provision for the inclusion of names of donors who do not consider themselves parents on NSW birth certificates.

35. The VLRC submits that birth certificates can have legal consequences and as such, the inclusion of information that does not assist in identifying a person for legal and administrative purposes would create confusion about a person's legal status with respect to a child.[17]

36. We agree with the VLRC, however we submit that birth certificates also have a significant symbolic value to donors, donor conceived people and their parents, insofar as they are seen to represent the structure and make-up of their families.

37. The 2003 community consultation report by the NSW Gay and Lesbian Rights Lobby (**GLRL**) found that some families would like the option of listing a donor on their child's birth certificate:

> *"A number of women stated that they felt unhappy leaving the biological father [the donor] off the birth certificate, as they wanted the child to know his or her heritage and felt that the birth certificate had enormous symbolic and emotional importance to a child's sense*

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[11] Above n 7, Recommendation 97, 158

[12] Above n 2, 30.

[13] Ibid, 30-31.

[14] Sections 9, 10 and 14.

[15] *Status of Children Act 1999* (NSW), section 11.

[16] Ibid, section 15.

[17] Above n 7, 146.

> *of identity… The parents who expressed these views did not want legal consequences to follow from the naming of the biological father [the donor] on the certificate."*[18]

38. Prospective Lesbian Parents said in their submission to the VLRC that:

> *"Many families would like to have the option of listing their known donor on the certificate…They have chosen to conceive through a known donor, and often to also involve him to some extent in their family, though contact that can vary from annual or occasional or weekly. They want their child's birth certificate to reflect the reality of their conception and the make up of their family."*[19]

39. We submit that the option to list a donor's name on a donor conceived person's birth certificate may serve to assist a donor conceived person better understand their family structure and develop a fuller self of self-identity.

40. We submit that because the role that donors play in families varies significantly[20], a donor should not be listed on a donor conceived person's birth certificate as a matter of course. Instead, the legal parent/s of the donor conceived person should have the right to choose to include the donor's name on the their child's birth certificate.

41. The donor should be required to consent to their name being listed on the donor conceived birth certificate however should not be able to compel the inclusion of their name on the certificate.

42. Presently there is a space for the 'informer', usually the doctor or another person present at the birth. We submit that another title, such as 'Donor', could be inserted on a birth certificate.

43. We submit that if it is made clear that a person named on a birth certificate is a donor, a donor's name could be named on a donor conceived person's birth certificate without raising any legal presumptions of parentage for the donor or the legal parents of the child.

Recommendation 5: Legal parent/s of donor conceived people should have the right to choose to list their child's donor on their donor conceived child's birth certificate, if the donor consents.

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[18] NSW Gay and Lesbian Rights Lobby and Millbank, Jenni, *And then… the brides changed nappies: Lesbian mothers, gay fathers and legal recognition of our relationships with the children we raise* Final Report (April 2003), 11.

[19] Above n 7, 142.

[20] Above n 15, 5 – 6.