

**This response was submitted to the evidence call held by the Nuffield Council on Bioethics on Donor conception: ethical aspects of information sharing between 21 March 2012 and 15 May 2012. The views expressed are solely those of the respondent(s) and not those of the Council.**

**Australian and New Zealand Infertility Counsellors Association**

**SUBMISSION TO NUFFIELD COUNCIL OF BIOETHICS**

**DONOR CONCEPTION: ETHICAL ASPECTS OF INFORMATION DISCLOSURE**

**Australian and New Zealand Infertility Counsellors Association (ANZICA)**

May 2012

The Australian & New Zealand Infertility Counsellors Association consists of social workers and psychologists working in Assisted Reproductive Treatment (ART) clinics across Australia and New Zealand. The group has been meeting for over 20 years and now consists of approximately 135 members. Together we have many hundreds of years' experience in working directly with donors and recipients through the provision of donor counselling, donor linking, running of support groups, education provision and our links with key consumer groups such as the Donor Conception Support Group. The Australian & New Zealand Infertility Counsellors Association is very proud that Australia and New Zealand leads the way in donor counselling practice. We welcome the opportunity to make a submission to the Nuffield Council of Bioethics Inquiry.

The Australian and New Zealand Infertility Counsellors Association is a subgroup of the Fertility Society of Australia. Whilst the laws and regulations for donor treatment vary across Australian states and territories and New Zealand, all counsellors working for ART clinics follow ANZICA counselling guidelines<sup>1</sup> and all ART clinics must adhere to the Reproductive Technology Accreditation Committee Code of Practice<sup>2</sup> which are routinely audited by an external body. ANZICA has also developed counselling guidelines for donor-linking practice.<sup>3</sup>

ANZICA is strongly supportive of the right of a donor-conceived individual to be informed of their donor-conception and to identifying information of their genetic origins. This principle is now enshrined in the practices and procedures of the Fertility Society of Australia and is subject to audit, with the Reproductive Technology Accreditation Committee Code of Practice, where the introduction states:

*“Fundamental to the delivery of ART services is that patients and their offspring remain the most important consideration in all decisions. Organisations aspire to deliver services in a manner that recognises patients’ cultural and individual values and beliefs, upholds their dignity and privacy, and acknowledges the rights of children born through ART to know their genetic origins and health outcomes.”<sup>4</sup>*

Requirements of the RTAC Code of Practice which are particularly relevant to this Inquiry include:

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<sup>1</sup> Australia and New Zealand Infertility Counsellors, Guidelines for Professional Standards of Practice Infertility Counsellors, October 2003

<sup>2</sup> Fertility Society of Australia, Code of Practice for Assisted Reproductive Technology Units, Reproductive Technology Accreditation Committee, Revised October 2010

<sup>3</sup> Australia and New Zealand Infertility Counsellors Association, ANZICA Guidelines for Professional Standards of Practice: Donor Linking Counselling

<sup>4</sup> Fertility Society of Australia, Code of Practice for Assisted Reproductive Technology Units, Reproductive Technology Accreditation Committee, Revised October 2010, p4

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#### **Australian and New Zealand Infertility Counsellors Association**

- The right of donor offspring to know their genetic origins
- Requirement of counselling of both donors and recipients (and their partners) by a full ANZICA member of prior to any donor process commencing.
- The organisation needs to explain the provisions, responsibilities and obligations associated with linking between donors, recipients and offspring<sup>5</sup>

The ANZICA counselling guidelines include detailed information what is to be covered in the counselling sessions. These include the recipient parents, ‘need to tell the offspring themselves about circumstances of their conception.’<sup>6</sup> It is the experience of ANZICA counsellors that families who talk to their children about how they became a family with the assistance of a donor; especially if they do so early and in a loving manner fare much better than those who do not. Secrets are often very difficult to keep and are often very damaging for families. Anecdotally we have heard many, many stories from donor-conceived adults who were not informed in this way and instead have found out about their conception later in life in a wide variety of ways. To give some examples, we have heard of people finding out from their parent at the time of the parent’s separation, from a third party who may be a relative or friend of the family ( this may be told kindly or in some cases vindictively), or who have guessed due to blood group or genetic information or an appearance very different to their father’s, where the parent has developed dementia and told inadvertently, where the young person has worked in a doctor’s surgery and looked up her mothers’ records. In some instances they have learned of their donor-conception after their non-biological parent has died and so have not had the opportunity to resolve this with them and tell them that they loved them whether they were biologically related or not.

Some (not all) donor-conceived people may be interested to know more about their donor. They may be interested to learn of medical history only, detailed non-identifying information or they may be interested to exchange letters or emails or eventually meet. This should be viewed as a normal healthy non-pathological interest and they should be assisted to do so. Many parents are also interested to learn more about the donor who helped them become a family and in our experience many wish to do so while their children are young so they can grow up knowing this information. Many are moved to want to thank the donor for the joy they have given them. ANZICA has developed guidelines<sup>7</sup> to assist with linking interested parties (donors, donor-conceived people and recipient parents). In this process the counsellor acts as an intermediary to support both parties establish roles and boundaries of contact. These guidelines are based on adoption reunion counselling practice.

Donor practice has changed substantially from early donor practice. Modern infertility practice using donated gametes should be based on an understanding of the needs of donor-conceived individuals and the consequent principles of being open with all participants about future identification and the consequences that follow from that.

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<sup>5</sup> Ibid p23-24

<sup>6</sup> Australia and New Zealand Infertility Counsellors, Guidelines for Professional Standards of Practice Infertility Counsellors, October 2003pp9-14

<sup>7</sup> Australia and new Zealand Infertility Counsellors Association, ANZICA Guidelines for Professional Standards of Practice: Donor Linking Counselling

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Kate Bourne

Chair of the Australian and New Zealand Infertility Counsellors Association