

**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.**

## **Victorian Assisted Reproductive Treatment Authority**



**VARTA**

Victorian Assisted Reproductive Treatment Authority

### **SUBMISSION TO NUFFIELD COUNCIL OF BIOETHICS**

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

#### **VICTORIAN ASSISTED REPRODUCTIVE TREATMENT AUTHORITY**

**MAY 2012**

#### **Background**

The Victorian Assisted Reproductive Treatment Authority (formerly the Infertility Treatment Authority) is a statutory authority of Victoria, Australia which is responsible for administering aspects of the *Assisted Reproductive Treatment Act 2008* (Vic). The Authority:

- Administers a registration system for assisted reproductive treatment (ART) providers under the Act;
- Undertakes public education about treatment procedures and the best interests of children born as a result of treatment procedures;
- Undertakes community consultation about matters relevant to the Act;
- Monitors programs and activities carried out under the Act;
- Monitors programs and activities carried out relating to the causes and prevention of infertility;
- Monitors programs and procedures relating to treatment procedures carried out outside Victoria;
- Promotes research into the causes and prevention of infertility; and
- Approves import and export of donor gametes and embryos into and out of Victoria.<sup>1</sup>

Prior to the introduction of the *Assisted Reproductive Treatment Act 2008* in January 2010, the Authority (as the Infertility Treatment Authority) also managed the donor registers under the *Infertility Treatment Act 1995*. This consisted of a Central Register and a Voluntary Register which housed information about all donor-conceived births in Victoria since 1988. These registers are now managed by the Victorian Registry of Births, Deaths and Marriages. ART has been regulated in Victoria since 1988. The law has evolved over this time as technologies have developed and community views on family have evolved.

The Infertility Treatment Authority was established in 1996 under the *Infertility Treatment Act 1995* to:

- Administer the Central and Voluntary Registers;
- Administer a licensing and approvals system and grant exemptions where appropriate;
- Monitor compliance with licences, approvals and exemptions;
- Consider requests to approve the extension of storage time for gametes and embryos;
- Regularly review the progress of approved research;

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<sup>1</sup> *Assisted Reproductive Treatment Act 2008* (Vic).

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- Monitor programs and activities carried out under the Act and programs and procedures carried out outside Victoria;
- Promote research into the causes of infertility; and
- Approve the import and export of gametes and embryos into and out of Victoria.<sup>2</sup>

Victoria was the first jurisdiction in the world to establish donor registers with the introduction of the Central Register in 1988 and the Voluntary Register in 1997. Other countries have since used this model as a basis for developing their own donor registers. The Authority has almost 15 years' experience in dealing with issues related to donor conception, including the management of donor registers. As a result of this unique history, the Authority has a wealth of knowledge and experience in the area of donor conception, disclosure and donor-linking practice.

For the purposes of this submission, the term 'the Authority' refers to both the Infertility Treatment Authority and the Victorian Assisted Reproductive Treatment Authority. The terms of reference for the Inquiry list twelve consultation questions for review. This submission addresses each of those areas in the order in which they were raised.

#### **1. What ethical concerns arise in the disclosure, or not, of information in connection with donor conception**

In Australia reproductive technology is subject to State legislation. Under Victorian legislation, The *Assisted Reproductive Treatment Act 2008*, section 5 includes these guiding principles,

*'The welfare and interests of persons born or to be born as a result of treatment procedures are paramount'*<sup>3</sup>

*'Children born as a result of the use of donated gametes have a right to information about their genetic parents'*<sup>4</sup>

These guiding principles clearly articulate the commitment of Victorian legislators to donor-conceived people and to the importance of their being able to access information about their donor origins. Furthermore, under this Act, all donor-conceived children born after 1<sup>st</sup> January 2010, when applying for a birth certificate will receive an accompanying addendum indicating more information is available about their birth. If they request this further information they will learn that their name appears on the Donor Register.<sup>5</sup> This indicates a further commitment by legislators to ensure that donor-conceived people are informed about their conception.

#### **2. Is the disclosure of a child's donor conception essentially a matter for each family to decide? What if there is disagreement within the family? Who else should have a role in making this decision?**

Given, the birth certificate addendum described in the previous paragraph there is a significant legal incentive for parents to talk to their children about how they became a family; for if they do not their child is likely to find out in any case. There has also been a growing recognition among families and health professionals that secrets within families can be very detrimental and that it is easier for donor-conceived

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<sup>2</sup> *Infertility Treatment Act 1995* (Vic).

<sup>3</sup> *Assisted Reproductive Treatment Act 2008* (Vic) s5 (a)

<sup>4</sup> *Assisted Reproductive Treatment Act 2008* (Vic) s5(c)

<sup>5</sup> *Assisted Reproductive Treatment Act 2008* (Vic) ss153,17B(2)

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children to learn of their origins at an early age and from their parents. In addition, there has been growing evidence from donor-conceived adults who found out later (often from people other than their parents) that disclosure would have been much easier if parents had told them at a young age in a loving way. This will be discussed in more detail later in the submission.

#### **3. What information, if any, do parents need about the donor in order them to carry out their parenting role? Please explain**

One of the major functions of the Authority (VARTA) is public education. As a result the Authority runs 'Time to Tell' education seminars for parents and people considering donor treatment to assist them to talk to their children. As people are often very private about this issue extensive information is also provided on the website ([www.varta.org.au](http://www.varta.org.au)) including podcasts of families of different constellations and who have used different forms of gamete donation. The Authority also provides individual education for parents of donor-conceived children via telephone consultations and face-to face sessions when requested.

Previously the Authority, managed the Donor Registers and so had extensive experience of recipient parents making applications to the Donor Registers for information about their donor. It is the experience of VARTA staff, that parents of donor-conceived children value comprehensive information about their donor including a detailed medical history, their interests, education, occupation and appearance. They also greatly value knowing the donor's first name as this makes it more personal when they are talking to the child e.g. rather than referring to 'the donor' they can refer to 'Peter' or 'DonorPeter'. Many parents also appreciate more personal specific information e.g. the reason why the donor donated and a message they have written for the child conceived from their donation and the donor's willingness and/or preference for information exchange/contact in the future. Many parents were primarily motivated to contact the donor to pass on their thanks to them for enabling them to become a family.

#### **4. What information might a donor-conceived person need about the donor, either during childhood or once they become an adult? Please explain**

The Authority also has experience of working with donor-conceived people who made applications to the Donor Registers to learn more about their donor. VARTA also currently facilitates an ongoing support group for donor-conceived adults. It is the experience of staff working for VARTA/ITA that the information needs of donor-conceived people are very similar to the parental needs described in the previous section. They include:

- Detailed medical information about the donor including genetic medical history of family members.
- Information about what the donor looks like.
- Information about the donor's personality.
- Why they donated?
- Any children the donor may have.
- Other people born as a result of the donor's donation.

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The donor-conceived person is often concerned about important medical information they might need to be aware of. They are also usually very curious to know whether or not they share any common characteristics with the donor or genetic half siblings. Many express a concern that they may inadvertently have a consanguineous relationship with a sibling.

**5. How significant is information about the medical history of the donor and the donor's family for the health and wellbeing of donor-conceived offspring? Do you know of examples or evidence in this area?**

In the recent Law Reform Committee *Inquiry into Access by Donor-Conceived People to Information about Donors*<sup>6</sup> there was evidence given of three examples of the need to pass on important medical information. These included a young donor-conceived woman who had been diagnosed with advanced bowel cancer, a donor whose father had a potentially fatal hereditary disorder, and a donor who had a serious heart condition which can result in sudden death with a 50% chance of passing this onto offspring. The committee recommended, 'That the Victorian government introduce a mechanism for medical information from a donor to be provided to a donor-conceived person, where there is evidence of hereditary or genetic disease or risks to the health of the donor-conceived person.'<sup>7</sup> The Victorian government has six months to respond to the recommendations.

The Authority also had experience of one donor applying to the Central register in order to pass on important medical genetic information to the person conceived as a result of their donation. The donor had a terminal condition and wanted the person to know so that they could have regular testing.

**6. Where information about inherited medical risk becomes apparent after donation has taken place, who should be told and by whom.**

The Law Reform Committee Inquiry Report cited in the previous paragraph, includes a case study of the donor who had the serious genetically linked heart disease which can result in sudden death, and described how the ART clinic managed this complex situation.<sup>8</sup> The clinic was initially contacted by the donor who was concerned about the risk of passing on the serious medical condition to genetic offspring his donation had produced. As the now adult donor-conceived people (aged in their late twenties and early thirties) may not have been aware of their donor-conceived status, the clinicians chose to contact the recipient parents and inform them of the serious medical risk to their sons and daughters and the need for medical testing. This needed to be done very sensitively as secrecy was the norm at the time of donor treatment. For one family, there was a great reluctance to inform their son and it took four years for them to do so. He was a pilot and did in fact inherit the serious heart condition. There were serious concerns raised as to what may have happened if he had died suddenly whilst flying.

**7. What is the impact on donor-conceived offspring of finding out about their donor conception at different ages: for example medically, psychologically and socially. Do you know examples of any examples or evidence in this area?**

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<sup>6</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information about Donors* March March 2012 p103

<sup>7</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information about Donors* March March 2012 p 107

<sup>8</sup> Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor-Conceived People to Information about Donors* March March 2012 p54

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Emerging research suggests that parents who tell their children while they are young that they are donor-conceived are more at ease with the process than parents choosing a later time for disclosure.<sup>9</sup> This study also indicated that parents wished for greater support from peers or professionals to assist them with the process, both initially and well after the birth of their children were born. Parents in this research study did not express regret, or report a negative outcome, after telling children (aged less than 10 years) that they were donor-conceived. This is consistent with more recent evidence that the majority of parents who disclose, do before their children are four to five years old.<sup>10</sup> Parental feelings of sadness and anxiety about 'telling' is sometimes experienced with worries about whether they had told children at the right time with the right amount of information. Positively, children told early about their donor conception respond in a factual non-emotional way.<sup>11</sup>

Having information about the donor can be important for donor-conceived people's sense of identity<sup>12</sup> and being unable to find the donor can lead to feelings of loss and grief.<sup>13</sup> Mental health professionals who are working with people seeking information about their donor agree that donor-conceived people need specialised assistance to successfully assimilate, accommodate and positively evaluate new information about their identities as donor-conceived persons.<sup>14</sup> Donor-conceived people who are not told by their parents about the way they were conceived but instead find out from someone else or under adverse circumstances often feel betrayed and lose trust in their parents.<sup>15</sup> Based on the estimation that at least 50% of donor-conceived people have not been told about their donor origins<sup>16</sup> and that parents often tell someone outside the family about using a donor,<sup>17</sup> some donor-conceived people are likely to learn about their donor origins from someone other than their parents. This is of serious concern.

Parents who have shared information with their teenage or adult donor-conceived offspring have reported that keeping donor conception a secret is both burdensome and a pressure.<sup>18</sup> Invariably these parents wished they had shared the information with their children earlier. While the optimal time to tell

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<sup>9</sup> MacDougall K, Becker G, Scheib JE and Nachtigall RD, "Strategies for Disclosure: How Parents Approach Telling Their Children That They were Conceived with Donor Gametes" (2007) 87(3) *Fertility and Sterility* 529.

<sup>10</sup> Blake L et al "Daddy ran out of tadpoles': how parents tell their children that they are donor-conceived, and what their 7-year olds understand" (2010) 25 (10) *Human Reproduction* 2527-2534.

<sup>11</sup> Blake L et al 22.

<sup>12</sup> Donor Conception Support Group, *Let the Offspring Speak, Discussions on Donor Conception* (Donor Conception Support Group of Australia Inc, NSW, 1997); Turner AJ and Coyle A, "What Does It Mean to Be a Donor Offspring? The Identity Experiences of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy" (2000) 15(9) *Hum Reprod* 2048; Hewitt G, "Missing Links: Explorations into the Identity Issues of People Conceived Via Donor Insemination" (2002) 9(3) *Journal of Infertility Counselling* 14; Daniels K and Meadows L, "Sharing Information with Adults Conceived as a Result of Donor Insemination" (2006) 9(2) *Human Fertility* 93; Daniels K, *Building a Family with the Assistance of Donor Conception* (Dunmore Press, Palmerston North, 2004) pp 87-94.

<sup>13</sup> Turner and Coyle, n 34 at 2050.

<sup>14</sup> Turner and Coyle, n 34 at 2050.

<sup>15</sup> Turner and Coyle, n 34 at 2045-2049; Riley HJ, "Listening to Late Discovery Adoption and Donor Offspring Stories: Adoption, Ethics and Implications for Contemporary Donor Insemination Practices" in Spark C and Cuthbert D (eds), *Other People's Children: Adoption in Australia* (Australian Scholarly Publishing, Melbourne, 2009) pp 145-160; Donor Conception Support Group, n 34 at 39-42.

<sup>16</sup> Kirkman M, Rosenthal D and Johnson L, *Telling It Your Way: A Guide for Parents of Donor-conceived Adolescents* (Infertility Treatment Authority, Victoria, 2007) p 9.

<sup>17</sup> Durna EM, Bebe J, Steigrad SJ, Leader LR and Garrett DG, "Donor Insemination: Attitudes of Parents Towards Disclosure" (1997) 167 *MJA* 256; Gottlieb, Lalos and Lindblad, n 24; Murray and Golombok, n 31.

<sup>18</sup> Daniels n 11, pp 95-111.

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children that they are donor-conceived is when they are young, the lack of supportive literature available for parents of donor-conceived teenagers or adults has been a problem.<sup>19</sup>

Research conducted by the ITA in partnership with researchers from the University of Melbourne, revealed that adolescents understand that it might be difficult for parents to tell them that they are donor-conceived. At the same time, adolescents wanted their parents to be the ones to tell them.<sup>20</sup> Research has shown that information about a donor is important for young donor-conceived adults in developing a sense of identity.<sup>21</sup> Donor-conceived adults have reported a sense of loss and grief when unable to find their donor.<sup>22</sup> It is therefore considered that specialised assistance is needed for donor offspring to successfully assimilate, accommodate and positively evaluate new information about their identities.<sup>23</sup>

These research findings have been consistent with VARTA's experience of extensive contact with recipient parents and donor-conceived people as a result of managing the Donor Registers, conducting the 'Time to Tell' campaign and facilitating a group for donor-conceived adults. In the Authority's experience it is far easier for children to learn of their donor-conception early. Teenagers and young adults who speak at the Time to Tell seminars, who have learned of this early and who can't remember ever not knowing, commonly describe their situation as, 'not a big deal' and present as relaxed and comfortable about being donor-conceived, and describe a close relationship with their parents.. The contrast between these young people and those who discovered later is marked. They commonly describe the shock and disbelief they felt when learning of their origins, feeling they had been lied to and deceived. They have described taking years to process the information and incorporate it into their identity.

#### **8. What is the impact of donor-conceived offspring of making contact with either the donor or any previously unknown half siblings? Do you know of any examples or evidence in this area?**

It is still very early to comment on the experience of donor-conceived people making contact with the donor or half siblings. There is limited research to date, however early findings indicate a positive experience.<sup>24</sup> The Authority hoped to evaluate the outcomes of applications to the Donor Registers, however was unsuccessful in obtaining funding to do so. Anecdotally we can report that the experience of the applicants was consistent with the findings of the research. The counsellors' experience suggested that making contact was emotionally challenging for all concerned given that this is such a new

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<sup>19</sup> Daniels and Meadows, n 11 at 93-99.

<sup>20</sup> Kirkman M, Rosenthal D and Johnson L, " Families working it out: adolescents views on communicating about donor-assisted conception" (2007) *Human Reproduction*

<sup>21</sup> Donor Conception Support Group, *Let the Offspring Speak, Discussions on Donor Conception* (Donor Conception Support Group of Australia Inc, NSW, 1997); Turner AJ and Coyle A, "What Does It Mean to Be a Donor Offspring? The Identity Experiences of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy" (2000) 15(9) *Human Reproduction* 2048; Hewitt G, "Missing Links: Explorations into the Identity Issues of People Conceived Via Donor Insemination" (2002) 9(3) *Journal of Infertility Counselling* 14; Daniels K and Meadows L, "Sharing Information with Adults Conceived as a Result of Donor Insemination" (2006) 9(2) *Human Fertility* 93; Daniels K, *Building a Family with the Assistance of Donor Conception* (Dunmore Press, Palmerston North, 2004) pp 87-94.

<sup>22</sup> Turner and Coyle, n 11 at 2050.

<sup>23</sup> Turner and Coyle, n 11 at 2050.

<sup>24</sup> Jadvá V, Freemant T, Kramer W and Golombok S, "Experiences of offspring searching for and contacting their donor siblings and donor" (2010) *Reproductive BioMedicine Online* 20,523 Beeson, D. R., P. K. Jennings, et al. (2011). "Offspring searching for their sperm donors: How family type shapes the process." *Human Reproduction* 0(0): 1-10.

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phenomenon it involved stepping into the unknown. As applicants were unsure about the possible response of the other party, this was daunting for them, however the situation could also be perceived as exciting as they may soon learn more about their genetic relation. It was important that the donor-conceived person and the donor be supported through this process with counselling and intermediary support. Recipient parents may also need support as they may have concerns about contact. A service model was developed to ensure this occurred. See Attachment 1.

The counsellors were informed of many positive results of contact. The common ingredients to successful contact/information exchange seemed to include: honesty, acceptance of difference, respect, and good will. People who proceeded slowly and carefully, and who clarified their roles and boundaries also appeared to have a better outcome. The Authority found the 'letterbox' system in which sealed letters were passed from the applicant to the other party (this could be the donor, recipient parent or the donor-conceived person) by the counsellor so the parties do not need to exchange identifying information was a very popular way to communicate with each other and allowed the parties to get to know each other in a safe way. Once they felt comfortable, either party may choose to include contact details in their letter and then may go on to write/email independently.

#### **9. What interest do donors and donors' families have in receiving any form of information about a child born as a result of the donation?**

From 2001 to June 2011, 346 people lodged information and made applications to the Voluntary Register in Victoria. Of these, 153 (44%) were donors followed by 133 (38%) recipient parents and 60 (18%) donor-conceived people. This indicates that donors are interested to both volunteer information and to find out information about the people born as a result of their donation. They however rarely applied to the Central Register to contact the donor-conceived person. This occurred on only one occasion described previously when the donor wanted to pass on medical information. Four donors made applications to the Central Register via the recipient parents so that they could ensure that their application did not result in the donor-conceived person learning of their conception via a government body.

Research by Jadva et al indicates that it is important for donors to be able to access information about the children born as a result of their donations.<sup>25</sup> This was confirmed by the experience of the Authority's donor-linking counsellors. Donors wanted and were given non-identifying information such as the number of children who had been born as a result of their donation, the children's gender and year of birth. In addition to wanting to know the outcome of their donation, donors often wanted to be reassured that people born as a result of their donation were healthy, happy and well-loved and were curious about whether or not they shared any resemblance with the donor physically or in their personality or interests.

#### **10. What responsibilities arise in connection with the disclosure of information? Where do these responsibilities lie?**

The Victorian government provided funding for sensitive education so that the general public could be informed of changes to legislation. The Authority ran a 'Time to Tell' campaign as a result and the ongoing public education. This campaign is further described in an upcoming *Journal of Law and Medicine* article, "Donor conception legislation in Victoria, Australia: The "Time to Tell" campaign, donor-linking and

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<sup>25</sup> Jadva V, Freeman T, Kramer W, and Golombok S, "Sperm and Oocyte Donors' Experiences of Anonymous Donation and Subsequent Contact with Their Donor Offspring" (2011) 26 Hum Reproduction 638.

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implications for clinical practice”<sup>26</sup> The Authority has endeavoured to work closely with ART clinics to deliver this public education.

#### **11. What support is required in connection with these responsibilities?**

It is interesting to note that in the United Kingdom and Australia considerable funding support and education has historically been given to families created from adoption. There has been a corresponding lack of support and education to families created via donor-conception. This is despite these families having some common issues to contend with. Families may need education and/or counselling support to assist them to talk with their children and to find information about their donor and/or half siblings (if they choose to do so). In VARTA’s experience sensitive intermediary counselling is essential in mediating information exchange and/or contact which feels comfortable for each party. A letterbox service has been very useful to facilitate highly specific information exchange without exchange of identifying information unless either party wishes to reveal this.

#### **12. Any other comments?**

Examples of public education brochures and information are provided to help to demonstrate resources VARTA has developed to assist donor-conceived people, recipient parents and donors with disclosure and also to make an application to the Donor Register.

See attachment 1 on the following page: Process for accessing information from the Donor Registers.

Louise Johnson  
Victorian Assisted Reproductive Treatment Authority

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<sup>26</sup> Johnson L, Bourne K, and Hammarberg K, <sup>26</sup> “Donor conception legislation in Victoria, Australia: The “Time to Tell” campaign, donor-linking and implications for clinical practice” Journal of Law and Medicine, to be published June 2012

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Attachment 1. PROCESS OF ACESsing INFORMATION FROM THE DONOR REGISTERS

