

**Submission
No 24**

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

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Inquiry submission: Managing information related to donor conception in New South Wales (NSW), Australia

The Human Fertilisation and Embryology Authority (HFEA) submits the following information to assist the Legislative Assembly Committee on Law and Safety in its inquiry into managing information related to donor conception in NSW. The information set out in our submission addresses the areas outlined in the terms of reference for this enquiry and includes:

- Background to the HFEA
- Access to information
- Counselling and support services
- Management of donor registers
- Record keeping
- Useful links
- Annex A: Information provision to donors, patients and the donor-conceived regarding donor conception processes.

1. Background to the HFEA

- 1.1 The HFEA is the United Kingdom's independent regulator overseeing the use of gametes and embryos in fertility treatment and research. The HFEA was established in 1991 and was the first mandatory regulator of assisted reproduction in the world. The HFEA inspects and issues licences to fertility centres offering IVF and other assisted reproductive techniques and to centres undertaking human embryo research.
- 1.2 The HFEA collects information of all licensed treatments and outcomes for assisted reproduction, dating back to 1991 and stores it on its Register. This Register contains detailed information about all IVF and donor treatments and their outcomes. The data is provided by clinics, quality assured by the HFEA and then used to inform research, policy making and regulation. Information about donors and donor treatment is then disclosed by the HFEA upon receipt of an 'Opening the Register' request (OTR) from people who have a right to access the information.
- 1.3. The Authority has a duty to maintain a Code of Practice, issue Directions and add conditions to licences, so licensed clinics and laboratories meet appropriate standards of care for patients and donors and those for facilities and equipment in clinics or laboratories. This covers, for example, information to be provided to donors and patients undergoing donor conception treatment and requirements for clinics to collect and record donor information.

2. Access to information

Legislative requirements

- 2.1 The legislative framework which underpins the disclosure of donor information in the UK was established in 1991 with the introduction of the Human

Fertilisation and Embryology (HFE) Act 1990. Information provisions under the Act were amended in 2004 and in 2008 with the introduction of the Human Fertilisation and Embryology (Disclosure of Donor Information) Regulations 2004 ('The Donor Disclosure Regulations') and the Human Fertilisation and Embryology (HFE) Act 2008. Annex A sets out the current information access rights for donors, patients and the donor-conceived.

- 2.2. Originally the 1990 Act envisaged no contact between the donor and the donor-conceived person. People born as a result of donation could only access non-identifying information about the donor once they were over the age of 18. This changed in 2005 with the introduction of the Donor Disclosure Regulations which removed donor anonymity for donors donating after 1 April 2005, thereby making it possible for donor-conceived people to make contact with their donor.
- 2.3. Following the 2008 amendments to the Act, the statutory access rights were extended to allow donor-conceived people aged 16 and above to apply for non-identifying information about the donor. The amendments also made it possible for the HFEA to establish the Donor Sibling Link (DSL), a service to help donor-conceived siblings contact each other.
- 2.4. An important feature of the current legislation is the requirement on the HFEA to provide a "suitable opportunity to receive proper counselling about the implications of compliance with the request." This requirement is in recognition of the fact that the information contained on the Register is highly sensitive and has the potential to have a significant impact on the recipient.

HFEA policy making

- 2.5. Over time the HFEA has developed its thinking and policy around information disclosure. With the introduction of the Donor Disclosure Regulations in 2004 the HFEA shifted its approach, recognising the importance of information disclosure to people affected by donation. The HFEA gave donors non-statutory access rights to anonymous information about their genetic offspring, namely the number, sex, and year of birth of people born as a result of their donation (now a statutory right following the 2008 amendments to the Act).
- 2.6. The HFEA also gave parents of donor-conceived people access to non-identifying information about the donor from the Register. This was to enable parents to share information about the donor with their child as they grew up. This was reaffirmed by the HFEA in the 2009 (OTR) policy which further extended access rights to allow patients to access non-identifying information about the donor from the clinic where they received treatment.
- 2.7. In making these policy decisions the Authority considers finely balanced arguments of protecting the confidentiality of donors with the importance of information about donors to people affected by donation. In 2009 the Authority agreed core principles which should underpin the release of such information, which include:
 - Protection of the right of applicants to access information – to be open about the type of information the HFEA holds and to provide people with accurate information in a timely, secure and considerate manner.
 - Duty of Care – to treat all applicants sensitively and provide good

general information about the possible impact information can have on people's lives. To provide meaningful signposting to appropriate counselling and support services.

- Statutory Compliance – to implement the changes brought about by amendments to the Human Fertilisation and Embryology (HFE) Act 1990.

3. Counselling and support services

- 3.1. In light of the potentially complex psychological and social issues related to donor conception, the HFEA strongly recommends that donor-conceived people wishing to access the Register seek counselling or similar support services before making a formal application.
- 3.2. We provide signposting on our website to professional support groups who can provide counselling or similar support to donor conceived people on the implications of seeking donor information from the HFEA.
- 3.3. We have also taken steps to encourage the sector to provide adequate provision of appropriate counselling to donor-conceived applicants.

4. Record keeping

- 4.1. The HFEA is required by Section 31 of the Human Fertilisation and Embryology (HFE) Act 1990 (as amended) to maintain a Register of Information which records details of regulated assisted reproductive treatments and the use and storage of gametes and embryos.
- 4.2. The Register contains information about all notified births resulting from treatment services, including those where donated gametes and embryos were used. The Register also contains information on gamete donors, including a physical description, ethnicity and any additional information donors wish to provide. Since donor anonymity was removed in April 2005, the Register also contains the donor's name and address. Donors who donated prior to 1 April 2005 can also elect to lift their anonymity retrospectively.
- 4.3. The HFEA will soon be introducing a new process to make it easier for parents and donor-conceived people to check if their donor has re-registered by making their unique letter reference number available on our website. Currently 120 previously anonymous donors have chosen to re-register as identifiable.
- 4.4. There are statutory limits to what information the HFEA can disclose and to whom. The Donor Disclosure Regulations specify both what information the HFEA is required to give about donors and what information should not be given ie, information which would identify the donor.
- 4.5. Clinics collect donor information on donor registration forms¹ which are submitted to the HFEA. The current donor registration form asks the donor for non- identifying information, including:
 - the donor's parents' ethnic group

¹ Donor Registration form: <http://www.hfea.gov.uk/2505.html>

- whether the donor was adopted
- the donor's marital status
- how many children the donor already had (if applicable) and the gender of those children
- any physical illness or disability, history of mental illness or learning difficulties and any known medical conditions within the donor's biological family
- a goodwill message
- a description of themselves as a person (pen-portrait)

5. Management of donor registers

- 5.1. When an OTR request is received at the HFEA, a dedicated team interrogates the Register database, cross checking and referencing a woman's registration and treatment outcomes, and a donor's registration and use. This can also involve communications with the applicant and the clinic.
- 5.2. To give an idea of the number of requests we receive per year for information from the Register, please see the table below:

Requests for information in 2012

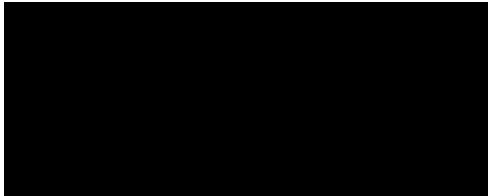
Type of applicant	Number of requests
Donor-conceived individuals	14
Donors	66
Parents	103
Total	183

- 5.3. Although relatively small in number, applications for information from the Register are rising steadily. This increase may be a result of more people reaching the age at which they are eligible to access information (the first donor-conceived people on the HFEA register had their 18th birthdays in May 2010). It may also be that an increase in applications is a result of a greater openness about donation within families and more generally within society. For example, HFEA staff see slight increases in applications when television programmes about donation are aired.
- 5.4. There are now 26 people registered to share their contact details with their donor-conceived genetic siblings, should any of them join the register. To date there have been no matches on the DSL, but all the processes and protocols are in place for future use. This service gives donor conceived people the opportunity to share experiences with someone in the same position as they are, and as more donor conceived people register the likelihood of finding a match will increase.

Useful links:

- 2009 Opening the Register Policy: www.hfea.gov.uk/535.html
- Information we provide to donor-conceived people accessing information about their donor: www.hfea.gov.uk/112.html
- Information we provide to parents who can find out about their child's donor and donor-conceived genetic siblings: www.hfea.gov.uk/118.html
- Information we provide for parents on talking to their child about their origins: www.hfea.gov.uk/116.html
- Code of Practice, information to be provided to donors: www.hfea.gov.uk/498.html#guidanceSection4290
- Donor Registration form: www.hfea.gov.uk/2505.html

This information has been submitted by Peter Thompson, Chief Executive, Human Fertilisation and Embryology Authority (HFEA).



Annex A: Information provision to donors, patients and the donor-conceived regarding donor conception processes

For whom?	About whom?	When?	From whom?	What?	Status
Donor-conceived people	Joint application from two donor conceived people who intend to enter into an intimate physical relationship	Age 16	HFEA	Whether the applicants might be related to one another	Statutory
Donor-conceived people	Joint application from two donor conceived people who intend to marry or form a civil partnership	Any age	HFEA	Whether the applicants might be related to one another	Statutory
Donor-conceived people	The donor	Age 16	HFEA	Non-identifying information	Statutory
Donor-conceived people	The donor	Age 18	HFEA	Identifying information (if the donor is identifiable)* Non-identifying information (if the donor is not identifiable)	Statutory
Donor-conceived people	Genetic siblings	Age 16	HFEA	Number of children Year of each birth Sex of each child	Statutory
Donor-conceived people	Genetic siblings	Age 18	HFEA (Donor Sibling Link service)	The identity and contact details of those genetic siblings, if consent to do so given	Statutory

For whom?	About whom?	When?	From whom?	What?	Status
Donors	The offspring	Any time after donation	Clinic or HFEA	Number of children Year of each birth Sex of each child	Statutory

For whom?	About whom?	When?	From whom?	What?	Status
Patients	The donor	Selecting a donor	Clinic	Any non-identifying information	Non-statutory
Parents	The donor	After successful treatment	Clinic or HFEA	Any non-identifying information	Non-statutory
Parents	Genetic siblings	After successful treatment	Clinic or HFEA	Number of children Year of each birth Sex of each child	Non-statutory

Code of Practice (8th edition)

- Paragraph 11.35: The centre should inform donors that anyone born as a result of their donation will have access from the age of 16 to the following non-identifying information provided by them: (a) physical description (height, weight, and eye, hair and skin colours); (b) year and country of birth;(c) ethnic group; (d) whether the donor had any genetic children when they registered, and the number and sex of those children;(e) other details the donor may have chosen to supply (eg, occupation, religion and interests); (f) the ethnic group(s) of the donor's parents; (g) whether the donor was adopted or donor conceived (if they are aware of this); (h) marital status (at the time of donation); (i) details of any screening tests and medical history; (j) skills; (k) reason for donating; (l) a goodwill message,(m) a description of themselves as a person (pen portrait).
- Paragraph 11.36: The centre should also inform donors who register or re-register after 31 March 2005 that anyone born as a result of their donation will have access to the following identifying information, from the age of 18: a) full names (and any previous names); (b) date of birth, and town or district where born, and (c) last known postal address (or address at time of registration).

* The HFEA will attempt to contact and inform a donor of the fact that that a donor-conceived person has requested identifying information about him or her.