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Donor Registry Exploratory Workshop October 12 2007 Washington DC

UK donor registries

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Fertility services have been formally regulated in the UK since 1991, following implementation of the Human Fertilisation and Embryology Act 1990 (“The Act”). The Act established a statutory regulatory agency, the Human Fertilisation and Embryology Authority (HFEA), whose responsibilities include licensing certain forms of fertility treatment and to maintain a register of information (s31). The register includes details relating to donors, recipients of donated gametes and embryos, and children born as a result of all donor procedures provided by a licensed treatment centre¹.

Prior to 1991, no formal limit was placed on the number of offspring who could be conceived from the gametes of a single donor². The HFEA initially introduced a limit of 10 “live birth events” (defined as a single, twin or higher-order birth) from the gametes of any single donor. In 2005, the HFEA revised this limit, enabling the gametes of any

¹ The Act (s31(3)(b)) provides for counselling to be made available to applicants for information from the HFEA register. However, no individual or organisation has a responsibility to provide such counselling (see British Infertility Counselling Association (2003) *‘Opening the Record’: Planning the Provision of Counselling to People applying for Information from the HFEA Register*. Report of the HFEA Register Counselling Project Steering Group. http://74.220.203.213/bica/files/opening_the_record_0.pdf)

² It is commonly accepted that some individual donors were responsible for the conception of dozens of offspring – and more (see for example, Festing, S. (1999/2000) Brothers and sisters have I many. *DI Network News* 14 5).

single donor to be used to conceive children in no more than 10 families³. Since 1991, donors have always retained the right themselves to impose a lower limit.

The Act provides for a person intending to marry to enquire whether any information held on the HFEA register indicates that (s)he may be genetically related to their intended spouse⁴.

In addition, donor-conceived people may obtain further information from the HFEA register, dependent on when the procedure that resulted in their conception was undertaken:

- Procedures undertaken before August 1991
- Procedures undertaken between August 1991 and June 2004
- Procedures undertaken between July 2004 and March 2005
- Procedures undertaken after April 2005

In addition, separate provisions apply to an individual conceived as a result of a surrogacy arrangement and made the subject of a Parental Order under s30 of the Act.

Provisions relating to a donor procedure undertaken before August 1991

An individual conceived from a donor procedure undertaken before 1991 has no legal right to any information about his or her donor^{5,6}. However, a government-funded project, UK Donorlink, (www.ukdonorlink.org.uk), was established in April 2004 to exchange information and facilitate contact by mutual consent between anyone over the age of 18⁷ who:

³ Human Fertilisation and Embryology Authority (nd) *The HFEA Register for Donors*.
http://www.hfea.gov.uk/en/1213.html#What_is_the_HFEA_Register.

⁴ The earliest age that anyone could seek this information is 16, the minimum age for marriage in the UK.

⁵ Records relating to a donor procedure pre-dating the implementation of the Act have no legal protection.

⁶ Similarly, an individual conceived as a result of a donor procedure undertaken **outside** the state regulatory system since 1991 (i.e. where an informal arrangement has been made between a donor and recipient) has no right to access any information about their donor. However, neither do they fall within the remit of UK DonorLink.

⁷ Blears, H. (2003) Speech at HFEA Annual Conference. 28 January.
http://www.dh.gov.uk/en/News/Speeches/Speecheslist/DH_4031642

- was conceived using donated sperm or eggs,
- donated in the UK, or
- thinks that they may be biologically related to a donor-conceived person

UK Donorlink uses DNA profiling to establish a genetic match and offers dedicated counselling services to those using its services.

Provisions relating to a donor procedure undertaken between August 1991 and July 2004

On reaching the age of 18 years an individual conceived as the result of a donor procedure undertaken between August 1991 and July 2004 may request the following non-identifying donor information from the HFEA:

- Year of birth
- Country of birth
- Ethnic group
- Height
- Weight
- Eye, hair and skin colour
- Whether the donor had any children
- Any other details the donor may have agreed to provide, e.g. occupation, interests, religion, skills, “goodwill message”⁸.

⁸ The HFEA’s main priority in determining the nature of this information was not determined by considerations of a donor conceived person’s welfare. Rather it was perceived as: “ the minimum necessary to allow the Authority to answer questions from children born as a consequence of treatment services about their genetic backgrounds..... Great importance was given in the design of the data collection system to avoid unnecessary intrusion into the personal lives of patients and donors, and to avoid unnecessary cost to centres and to the Authority” (Human Fertilisation and Embryology Authority (1992) *Annual Report*. London: HFEA (p. 23). Several research studies undertaken during the 1990s indicated that donor information provided for the HFEA Register was subject to wide variations and may, in many cases, be extremely limited (Maclean, S. and Maclean, M. [1996] Keeping secrets in assisted reproduction – The tension between donor anonymity and the need of the child for information. *Child and Family Law Quarterly* 8, 243-251; Abdalla, H., Shenfield, F. and Latache, E. [1998] Statutory information for the children born of oocyte donation in the UK: What will they be told in 2008? *Human Reproduction* 13, 1106-1109; Blyth, E. and Hunt, J. [1998] Sharing genetic origins information in donor assisted conception: views from licensed centres on HFEA Donor Information Form (91) 4. *Human Reproduction* 13, 3274-3277).

Provisions relating to a donor procedure undertaken between July 2004 and April 2005

From July 2004 the HFEA was required to collect **additional** non-identifying donor information which could be made available to any offspring seeking this information on reaching the age of 18⁹:

- Marital status
- Whether adopted
- Parents' ethnic group
- Details of any screening tests
- Personal and family medical history
- Number and sex of own children (if any)

Provisions relating to a donor procedure undertaken after April 2005

From April 2005 (with the exception of specific transitional arrangements) all new donors have been required to consent to their identity being made available to any offspring seeking this information who has reached the age of 18¹⁰. At such time, in addition to non-identifying information, a donor-conceived person may request from the HFEA the following donor information:

- Full names (and any former names)
- Date of birth and town or district where born
- "Appearance"
- Last known postal address (or address recorded at time of registration)¹¹

⁹ Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004. Statutory Instrument 2004 No. 1511 <http://www.opsi.gov.uk/si/si2004/20041511.htm>

¹⁰ Any donor who initially donated as an anonymous donor between 1991 and 2005 may re-register as an identifiable donor, either with a licensed treatment centre or directly with the HFEA. Any re-registration will be entered on the HFEA register. There is no formal encouragement for donors to change their status, nor advertising that they may do so other than on the HFEA website, nor any provision to advise recipients that the donor has changed his/her status. If a donor indicates a wish to re-register, counselling concerning the implications of so doing should be made available to him or her.

¹¹ Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004. Statutory Instrument 2004 No. 1511 <http://www.opsi.gov.uk/si/si2004/20041511.htm>

Donors' rights to information about the outcome of their donation

Donors are able to ascertain whether any children have been born as a result of their donation and if so, how many, their sex and the year of their birth¹².

Surrogacy Arrangements and Parental Orders

In the UK a woman who gives birth to a child is always recognised as the child's legal mother and should be registered as such on the child's birth certificate. S30 of the Act introduced provisions (modelled on existing adoption proceedings) enabling commissioning (intending) parents who meet specified criteria to secure legal parentage of a child conceived as the result of a surrogacy arrangement by means of a court order, a Parental Order¹³. An individual who is the subject a Parental Order has a legal right to obtain his or her original birth certificate at age 16 in Scotland¹⁴ and at age 18 in the rest of the UK¹⁵.

Human Tissue and Embryos (Draft) Bill

The government has proposed significant revisions to the legislation and published the Human Tissue and Embryos (Draft) Bill in May 2007¹⁶, containing several proposals regarding information and donor conception:

- Giving a couple in a same sex relationship intending to form a civil partnership the right to ascertain if any information on the HFEA register indicates that they may be related as a result of donor conception
- Giving a donor-conceived person the right to ascertain the existence, number, sex and year of birth and (by mutual agreement) the identity of any donor-conceived genetic half siblings

¹² *Ibid.*

¹³ Blyth, E. (1993) Section 30: The acceptable face of surrogacy? *Journal of Social Welfare and Family Law*, 4, 248-260.

¹⁴ The Parental Orders (Human Fertilisation and Embryology) (Scotland) Regulations 1994. Statutory Instrument 1994 No. 2804 (S.141) http://www.opsi.gov.uk/si/si1994/Uksi_19942804_en_1.htm

¹⁵ The Parental Orders (Human Fertilisation and Embryology) Regulations 1994 Statutory Instrument 1994 No. 2767 http://www.opsi.gov.uk/si/si1994/Uksi_19942767_en_1.htm

¹⁶ Department of Health (2007) *Human Tissue and Embryos (Draft) Bill*. Cm 7087. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsLegislation/DH_074718

- Giving a donor the right to access limited non-identifying information regarding any offspring and in “some circumstances” to allow a donor to be informed when his or her identifying details have been requested by any offspring
- Providing the regulatory body with the authority to provide, or arrange to have provided, Register services (including counselling) to those genetically related through donor conception if conceived prior to the enactment of the 1990 Act.

The Draft Bill has been reviewed by a Scrutiny Committee comprising members of both the House of Commons and the House of Lords. This Committee proposed further revision to the Draft Bill, which will be considered by the government before tabling a finalised Bill to be considered by parliament in the autumn of 2007¹⁷. The Scrutiny Committee has made the following recommendations regarding information and donor conception:

- Giving the right to a cohabiting couple and those planning an “intimate relationship” to ascertain if any information on the register indicates whether they may be related to each other as a result of donor conception, subject to the consent of each individual
- Permitting the regulatory body to establish a voluntary contact register for donor conceived people
- Reducing to 16 years the age at which information on the register can be accessed
- Annotating the birth certificates of donor-conceived people
- Ensuring the availability and funding of counselling services to “all who require them”.

¹⁷ House of Lords and House of Commons (2007) *Joint Committee on the Human Tissue and Embryos (Draft) Bill. Volume 1: Report*
<http://www.publications.parliament.uk/pa/jt200607/jtselect/jtembryos/169/169.pdf>

Postscript

On October 8 the government responded to the Scrutiny Committee's report¹⁸. It accepted the Committee's recommendation to:

- Give cohabiting couples and those planning an "intimate relationship" the right of access to the register to find out whether they are related to the other person subject to the consent of both individuals
- Allow the regulatory body to run the voluntary contact register, or to delegate the running of it.
- Reduce to 16 years the age at which *non-identifying* information on the register can be accessed – but to restrict access to *identifying* information to those reaching 18 – on the basis that (a) donors have consented to their identity being disclosed to any offspring reaching the age of 18 but have not consented to their identity being disclosed to a 16 year old and (b) this might adversely impact on donor recruitment

The government has not accepted the case for annotating birth records of donor-conceived people, noting however, that "the issues need to be considered carefully, including constructive dialogue with stakeholders, and we will keep the matter under review".

Neither has the government committed resources for counselling services, although it endorsed the "importance" of counselling and stated its expectation that "the process by which the HFEA handles requests by donor-conceived people for information will be included in the discussions that the Government will have with the HFEA about its annual business plan and priorities".

¹⁸ Department of Health (2007) Government Response to the Report from the Joint Committee on the Human Tissue and Embryos (Draft) Bill. CM 7209 8 October.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/dh_079127