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Obtaining information from the HFEA register: the facts

Why does the register exist?

In the Human Fertilisation and Embryology Act 1990, Parliament decided that there should be a central register of information about all donor treatments and births so that the question of whether a person had been conceived by donation could be authoritatively answered; and also so that people who are donor conceived could avoid marrying someone who is biologically related to them. The law also provided that people who donated sperm, eggs and embryos should remain anonymous unless they were known personally to the people having treatment.

What information is recorded?

The law came into effect on 1st August 1991. Since then the following information has been recorded on the register:

- identifying details of all donors donating at HFEA licensed clinics,
- some non-identifying information about donors,
- details of the patients who were treated using material donated by those donors,
- the outcome of those treatments.

The fact that a donor conceived child was born to a particular named patient on a particular day is therefore recorded, together with the name of the donor. The sex of the child is also recorded.

The forms on which information about donors was collected allowed for some non-identifying information also to be recorded, and some donors voluntarily added more personal information about themselves and why they had donated. The amount of non-identifying information that donors provided at the time varied a great deal because it was not compulsory and donors were not usually well-informed that it might be important to the children who were born. They were asked to give details of:

- whether they had their own children
- their height, weight, ethnic group, eye colour, hair colour, skin colour, religion, occupation, interests and a description of themselves (pen portrait).

But not all these details are recorded for all donors.

Has the recording of information been made more systematic?

Since 2004 non-identifying information about donors registering since then has been recorded in a fuller and more systematic way. The following non identifying information is recorded:

- the sex, height, weight, ethnic group, eye colour, hair colour, skin colour, year of birth, country of birth and marital status of the donor

- whether the donor was adopted
- if they have their own children, the number and sex of each
- ethnic group or groups of the donor's parents
- the screening tests carried out on the donor, and information on the donor's personal and family medical history
- whether they have any physical illness or disability, history of mental illness or learning difficulties and whether their biological family has any known medical conditions
- the donor's religion, occupation, interests and skills
- their reasons for donating
- a goodwill message to anyone born as a result of their donation.

The following identifying information is recorded:

- the donor's full names (and the name if different used at their birth registration)
- the date of birth and the town or district where born
- the appearance of the donor
- the donor's last known postal address.

Who is entitled to information?

The law only permits certain people to have information from the register – otherwise it is entirely confidential. It is a criminal offence for HFEA employees or others whose job involves handling information on the register to release it to anyone not entitled to it.

People over the age of 18 conceived after August 1991 can apply for information to find out whether they were conceived using donated sperm, eggs or embryos. If so, they will also be entitled to request whatever non-identifying information about the donor that is held on the register, and if they are planning to marry they can be told if the person they are proposing to marry is related to them. The main impact of this therefore will only come into effect from 2009 when individuals conceived after August 1991 will become 18. If people under the age of 18 are planning to marry they can also be given information and told if the person they are proposing to marry is related.

So the effect is that identifying information about donors who donated on the understanding that they would be anonymous, and who have not changed their minds about their wish to remain anonymous, will never be released. People who believe that they may have been conceived using donated material will be able to check if this is indeed the case, but they cannot be given information enabling them to trace their donor.

The information about whether a person has or has not been born as a result of donor treatment can only be given to individuals about themselves. It cannot be given to parents, grandparents or anyone else without an order of a court.

What if past donors change their minds about being anonymous?

The law has recently changed to allow previously anonymous donors to become identifiable if they choose to do so. If they are now content for identifying information about themselves to be made available to people conceived using their donated material, they can now record this. To do so they have to re-register their consent for the information to be released. This can be done either with the clinic at which they donated or at the HFEA. If a past donor re-registers as "identifiable", they are encouraged to also

provide additional non-identifying information as well as any new medical diagnosis that could be relevant.

Identifying information about a re-registered “identifiable” donor can still only be made available to those over 18 who were conceived using that donor’s donated material. Identifying information about a re-registered “identifiable” donor cannot be released to a parent or to a young person under 18.

However a parent who has a child conceived using donor treatment can be told if the donor whose material was used in their treatment has re-registered.

How has the law changed about donor anonymity?

In April 2005 the law was changed ending anonymity for donors who donated after that date. Identifying information about them can be given to people who have been conceived using their donated material. The identifying information will only be made available to people over 18 who were themselves conceived by donation – not to parents or others.

The broad effect of this change, so far as the release of information is concerned, will therefore come into effect in 2023.

The information that can be requested is the donor’s:

- name, or names if the person was conceived by both sperm and egg donation or by embryo donation
- address at time of registration
- ID number used at the centre where the donation was made.

How is the HFEA responding to the changes?

The HFEA recognises that, particularly after April 1, 2005 when all new donors must be identifiable to donor-conceived people when they reach the age of 18, there is likely to be an increased demand for information both from donors and from parents of donor-conceived people. Providing information may benefit those concerned, for example by allowing parents to make informed decisions about the controlled disclosure of information to their children and by allowing donors to prepare themselves and their families for possible contact with a donor-conceived person and their family

Will identifiable donors be informed when someone born as a result of their donation applies to the HFEA to receive information about them?

The HFEA will try to contact identifiable donors when someone born as a result of their donation applies for identifying information (but not non-identifying) about them, but donors will not be given information about the person making the request. So identifiable donors are encouraged to supply up-to-date contact and correspondence details.

Can parents obtain non-identifying information about donors whose material was used in their treatment?

Parents can request this from the clinic at which they were treated or from the HFEA. Clinics are encouraged to respond as fully as possible to patients’ requests for non-identifying information about the donors used in their treatment.

Can a parent of a donor conceived child find out if there are half-siblings conceived from the same donor, and if so how many?

A parent can ask the clinic at which they were treated for this information – or they can ask the HFEA. Parents can request clinics to give them any “donor code” number assigned to the donor by the clinic.

After 1991 there was a limit of 10 “live birth events” which meant that 10 different couples or individuals could have children from the same donor. They might have had a single child, twins or (very occasionally) triplets. They could also apply to use the same donor to have further children - who would be full genetic siblings to a first child - from the same donor even if the 10 limit had been reached. In 2005, this was simplified to allow 10 families to be created from any one donor. Clearly all the children will have a genetic relationship and this was the reason why the HFEA Act made sure that people could check with the register whether they could be related to the person they planned to marry.

What information is a donor able to obtain about the results of his or her donation?

Donors (whether identifiable or not) can request at any time to know:

- whether children have been born as a result of their donation
- if so, the number of children born
- whether they were girls or boys
- the year they were born.

This information can be given to a donor by the clinic at which they donated, or by the HFEA.

Are there any arrangements covering donor conception treatment before 1991?

Donors donating, parents treated and individuals conceived before 1991 are not covered by specific legislation. Donors were usually anonymous, and there was no legal requirement to maintain records.

To facilitate connection between donors and donor conceived people who would like to make contact, a register has been established by voluntary organisation – UK Donorlink - enabling people conceived through donor eggs or sperm, their donors or half-siblings to exchange information and where desired to contact each other.