

Whose information is it anyway?

Information rights after donor conception in the UK

If you have conceived a child in the UK with donated eggs or sperm (or are thinking of doing so), then you may want to understand what information will be available to your child throughout their life.

The HFEA as keeper of the keys

For children conceived through donation in the UK before 1st August 1991, there was no HFEA and central record kept. Finding out information about the donor or any genetic siblings (of which there may be any number, since there was no cap on the numbers of families created by any one donor at this time) is usually a matter of detective work: tracking down medical notes and getting in touch with organisations like UK Donor Link which help match genetic relatives through DNA testing and other means.

For children conceived in the UK since 1st August 1991, there is much more structure, since information about the conception is recorded on the central HFEA Register of Information. Information on the Register includes the identity of the donor and any donor conceived siblings (i.e. the donor's genetic offspring in other donor conceived families). How much of this information is available, to whom, and when, depends on how the law applies to the circumstances.

Information about siblings

All donor conceived people conceived in the UK since 1991 can access information about their 'donor conceived siblings' (which means people conceived by other families using the same egg or sperm donor – although not the donor's own children). In practice, people conceived with donor sperm often have lots of genetic half siblings, since donors in the UK can be used to help up to ten different families (with each family possibly having several children). It is in practice, rarer to have lots of egg donor conceived siblings, simply because of the practicalities involved – bluntly, sperm is easier to donate in bulk than eggs.

At age sixteen (or before if their parents support it), donor conceived people can find out how many siblings they have on the Register, and their sex and approximate age. They can also, at age eighteen, join the HFEA's Donor Sibling Register to ask to make contact with siblings. If any are over eighteen and have also joined, the HFEA will help them get in touch with each other.



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Information about the donor

Donor conceived people who were conceived between 1st August 1991 and 1st April 2005 are usually only able to access non-identifying information about their donor via the HFEA (such as hair colour, eye colour, occupation, etc – the kind of information most parents get on matching). They can access this from age sixteen in their own right, or with the support of their parents beforehand. However, it is possible for pre-2005 anonymous donors to choose to change their status to being identifiable. Although rare so far, it will be interesting to see how many do so in the decades ahead, particularly with growing openness and understanding of donor conception. If a pre-2005 donor chooses to register as identifiable, his or her offspring are then effectively in the same position as children conceived after 2005.

Donor conceived people conceived in the UK after 1st April 2005 usually have an 'identifiable' donor. This means that, as well as the non-identifying information available to them at age sixteen (or before), they (and only they) can ask the HFEA for the donor's name and address once they get to the age of eighteen.

There are a few limited exceptions in which a child conceived after April 2005 may still have an anonymous donor. Most importantly, patients with stored anonymous donor gametes can use them to conceive a genetically matched sibling for an existing child. The younger child (like the older sibling) will not be able to contact the donor.

Conceiving outside the UK

If you have conceived outside the UK (or are considering doing so), then none of this statutory framework applies, since the HFEA's Register of Information only covers children conceived within the UK's borders. What information is available to you and your child will depend on how things work in the country where you conceive, and this can vary considerably.