

March 2006

Obtaining information from the HFEA register: things for donor conceived people, donors, parents and patients considering donor treatment to think about

For donor conceived people

It is entirely understandable that you are interested to know more about the person or persons who helped you to be born. How you feel and how much you want to know will depend on your personal circumstances and needs. Your parents may have been able to tell you a great deal about the donor or have had no information at all. Perhaps you do not feel able or are not certain about letting your parents know you are contacting the register. Whatever the situation, it is normal to feel some anxiety as well as excitement about what you will learn.

Think about

- the possibility that there will be less information than you would like or that it is very different from what you expected
- getting the information may affect you unexpectedly
- parents and other relatives could be affected and you need to take time to plan how best to deal with this
- contacting a donor 18 or more years after he, she or they donated has implications that need careful thought and preparation
- you might need support in deciding to make this decision and in carrying it through.

What support can I expect to have?

You may already be talking to parents or other relatives and friends who can offer the support you need. However, we know that this can feel like a difficult and complicated decision so people often need extra help to plan and prepare for the information they will receive. You have a legal right to be offered counselling and we will provide you with details of the counsellors who you can contact. A counsellor will help you talk through any aspect of your situation that could be troubling as well as support you through the experience of applying and receiving information. Counsellors can be particularly important if you decide that you want to contact the donor and may offer to act as an intermediary on your and the donor's behalf.

If you were conceived before the register came into being in August 1991 and are interested in making contact with your donor or half-siblings, you can register with UK

Donor Link. This government funded organisation has the potential to bring together donors, offspring and half-siblings via DNA testing.

For donors

You may have donated many years ago, or only just recently. Either way the fact that you are reading this means that you are conscious that your donation may have resulted in the birth of one or more individuals who will now be growing up and may seek information about you.

You may deliberately have decided not to find out whether your donation resulted in the birth of children. And you may have decided to keep the fact that you were a donor from your close family.

If you donated anonymously, your identity will remain protected for as long as you want – for ever unless you consciously decide otherwise. No one is entitled to pressure you to reveal anything.

But you may want to think about the following:

If you donated in the few years following August 1991, the non identifying information held on the register may well be sketchy. Some donor conceived people find even the tiniest items of information about their donors of great value. This can help them to fill in what they feel is a real gap in their lives. So you may want to consider updating your non-identifying information. The HFEA will tell you what is there so that you could add to it.

Some donor conceived people would be even more grateful if you would consider re-registering as an identifiable donor. Before doing so you have the right to be offered a chance to talk this over with an experienced counsellor, and the clinic at which you donated should be able to facilitate this entirely confidentially.

If you donated before the register started in August 1991 and would now like to be available to be contacted by any young people and adults you helped create, you can register with UK DonorLink. This is a government funded organisation that can potentially bring together donors, offspring and half-siblings using DNA testing.

Have you told your own partner or spouse that you were a donor? If you now have children of your own, you may want to consider telling them that they may have half-siblings. If there is any risk that this information could come out by accident, it may be best to tell them before they learn about it from elsewhere.

For parents

You are entitled to as much non-identifying information as there is about the donor with whose material you were treated. Sometimes, particularly in relation to those who donated in the early 1990's, there is frustratingly little non-identifying information for you to give your children. Remember that your clinic is likely to have better information than the HFEA. But the fact that there may be little information to give your children is not a good reason for not telling your children the fact that they are donor conceived. Our leaflet [[link](#)] explains why telling children is the right thing to do.

Some parents feel that their young child would benefit knowing half siblings, and are sad that they do not have a right to make connections with other families. With the use of

donor codes, it may be possible to find links through voluntary organisations such as the Donor Sibling Registry – a US web-based network. Other parents may not wish their children to focus on the fact that there may be other families who have used the same donor.

If your son or daughter approaches the HFEA for information from the register at or after age 18 and discovers that they were conceived with the aid of a donor, but this is information that they had not known before, this may well have implications for family relationships. Although precise details of what will be available from 2009 are not yet known, the HFEA is likely to be able to refer you and other family members to a counsellor for support with adjustment to this situation.

For patients considering donor treatment

Parliament has decided that any child of yours would have the right to information about how he or she was conceived, and this is therefore something over which you have no choice. But remember that in future it is likely that greater availability of DNA testing would mean that young people would be able to check this for themselves anyway.

The fact that your child could access information about, and possibly make contact with, their donor may seem uncomfortable now. Many parents find that once their child is a few years old and they feel secure in the relationship they have established, they recognise their child's right to this information and feel it is less of a threat. It is impossible to predict the extent to which donor conceived children will want to make use of the possibility to make contact – the experience with adoption is that around half of all adopted people seek information about their birth parents, but a much lower proportion go on to make contact. Donor conceived adults say that they want to know more about the person who gave something of his or herself to make them, in order to be able to understand more about themselves. Wanting this information is not a rejection of their parents.

Support Organisations

UK DonorLink

www.ukdonorlink.org.uk

Donor Conception Network

A network of parents with children conceived with donor sperm, eggs or embryos, adult offspring and those contemplating or undergoing treatment. Its website includes news, information about meetings, leaflets and library resources, personal stories, and a member forum.

www.dcnetwork.org

British Infertility Counselling Association (BICA)

The professional association for infertility counsellors and counselling in the UK. Its website includes a list of counsellors providing services and a downloadable leaflet on choosing a counsellor. Call Tel 0114 263 1448 or visit www.bica.net

Donor Sibling Registry

www.DonorSiblingRegistry.com