

Counselling information supplement for couples undergoing treatment by Donor Insemination (May 2009)

by Mr. Jonathan West FRCS FRCOG, Consultant Gynaecologist, Royal Devon & Exeter Hospital

Introduction:

All UK centers offering treatment by Donor Insemination (DI) are subject to regulation by an authority called the Human Fertilisation & Embryology Authority (HFEA). As well as ensuring certain minimum standards so far as the technical and medical aspects of treatment are concerned, they also require clinics to ensure that couples undergo counselling prior to treatment in order amongst other things to be informed of certain implications of the law as it relates to this form of treatment. Our routine practice is to ask couples to arrange a counselling session after the first visit with the clinic doctor.

About Counselling:

The aim of the counselling session is not that it should be some form of 'assessment', but just to ensure that couples are fully informed about their treatment, have a chance to talk through some of the medical and other issues, and feel fully comfortable with it. It includes a meeting with a fully qualified independent counsellor in case there is anything before, during or after your course of treatment that you may feel more comfortable discussing in confidence with someone other than our clinic staff. The discussion will cover many of the points on the information card written by the HFEA, but there are certain things about our clinic in particular which need mentioning.

Screening of donors:

The procedure for donating sperm is regulated by the HFEA. Donors are screened and counselled according to set guidelines for risks of hereditary and potentially infectious diseases (including HIV infection and cystic fibrosis). These are amended from time to time according to expert opinion but recipients should be aware that tests may not be 100% reliable and also that there may also be a small risk of themselves or their child contracting a transmissible disease for which there is as yet no suitable screening procedure. Donors are asked to notify clinics if they become aware subsequent to their donation that they are affected by a previously unsuspected genetic condition. In such a case recipient couples who have conceived or have had children from that donor may be informed and offered suitable counselling and assistance. It should also be noted that although an effort is made to match physical characteristics between the donor and recipient couples it is not possible to guarantee the resultant characteristics of the child.

Implications relating to the eligibility of couples for treatment:

Centers are required to take into account not only the request of couples seeking fertility treatment, but also the welfare of any child who may be born as a result as well as that of existing children in the household or family. Our criteria relating to this are set out in the Clinic's leaflet 'What to expect at the Exeter Fertility Clinic'.

Legal Parenthood:

The legal mother is the woman who gives birth to the child. The husband or Civil Partner of the woman who gives birth after donor insemination treatment obtains the same rights and responsibilities as if he was the biological father. If the couple are not married or in a Civil Partnership there is a special Consent Form that must be completed by the woman and her partner to ensure that the woman's partner has parental rights and responsibilities. If by any chance the couple were to split up without letting us know and the woman were to carry on having treatment the woman's husband or partner might still be legal parent if she was to have a child from treatment. The clinic **MUST** be informed if the woman's husband or partner longer wishes to become the legal parent of the woman's child and there is a special form to be used for this.

The Children's' Rights:

The HFEA has to be supplied with information about all UK sperm donors and couples receiving DI treatment. Changes to the law relating to egg or sperm donation were introduced in April 2005 that allow children born from DI treatments performed using sperm donated after the change to discover the identity and last recorded address of the donor from the HFEA. This information may be made available to them on reaching the age of 18 years, or 16 if they are contemplating marriage. When using sperm donated before the legal changes parents did not necessarily have to tell children that they have been conceived as a result of DI, but the HFEA are in any case concerned that parents should know that it is their view that children should have the right to know something of their biological origins. Our counsellor(s) would be happy to discuss with you the issue of when and how to tell your child. Those conceived from treatments performed before the proposed change to the law who cannot be told the identity of the biological father may ask if they likely to be biologically related to someone with whom they may be considering having a child. It may also be possible for them to be told some limited information about the biological father (e.g. roughly what he looked like, interests etc.). Information of this sort may have been supplied by the donor at his own discretion when he made the donation.

A special situation may arise if a child was born with an inherited disability from a donor who had deliberately concealed information about the relevant risk, in which case he or she would be allowed to apply to the HFEA to seek to discover the donor's identity and possibly to sue him. We are legally obliged to do our best to ensure that the HFEA knows whether the woman becomes pregnant during the course of treatment and also some details of the birth. Couples are requested to let us know this information therefore.

Confidentiality:

Once DI has started it is treated with an even greater degree of confidentiality than other forms of medical treatment. Only staff of licensed clinics and the HFEA are allowed to know details unless couples themselves have passed the information on or given express permission. Sometimes it is necessary for others (e.g. a general practitioner) to know about the treatment in which case we might either write a letter and ask the couple to pass it on, or else we may ask that a form be signed giving written consent to pass information on directly. Information passed on in this way would still be confidential but would be subject to the more usual degree of medical confidentiality. Our clinic in

particular, operating on NHS premises and treating some NHS patients, may require the release of some general details of treatment to hospital and health authority staff who may be involved with the administration of its funding.

Success Rates:

Unfortunately not all women will conceive as a result of their course of DI treatment. Sometimes this may be for reasons that are hard to explain. Statistics regarding our success rates are regularly updated. The HFEA publishes a 'Patients' Guide', which includes details of success rates of all licensed UK fertility clinics in a standard format but they should not be seen as a 'League Table' since there are considerable variations and fluctuations due to random factors and differences in the characteristics of couples being treated.

NHS resources and limitations to treatments:

Historically Exeter was one of the first centers in the UK to offer DI treatment and there has been a DI clinic here ever since it was pioneered in the 1940's by Dr. Margaret Jackson. We have traditionally been one of very few centers nationally to provide DI treatment on the NHS. Unfortunately this may sometimes result in long waiting-times for treatment. NHS fund-holding organisations want and need to know how best to allocate the resources for DI - which with the best will in the world are not unlimited. Criteria for access to NHS DI treatments locally in the Devon/Cornwall Peninsula are similar to those for IVF treatments.

The introduction by the HFEA of regulations regarding the payment of donors and donor anonymity has led to a critical shortage of donated sperm. This may result in delays or possibly even prevent treatment proceeding at all if no source of supply can be found. Couples may wish to consider alternatives such as: importation of sperm from abroad under license from the HFEA (overseas donors have to comply with the same HFEA regulations as would apply to UK donors); use of a 'known' donor supplied by the couple being treated; and, travel abroad for treatment. In the latter case the couple would be advised to take their own legal advice about the paternity status and nationality of children born as a result.