

HFEA Licence Committee Meeting

23 February 2009

21 Bloomsbury Street London WC1B 3HF

Minutes – item 6

Application to conduct Preimplantation Genetic Diagnosis (PGD) for the avoidance of chromosomal rearrangements, Lister Fertility Clinic (0006)

Members of the Committee:

David Archard, Lay Member (Chair)
Sally Cheshire, Lay Member
Jennifer Hunt, Senior Infertility
Counsellor, IVF Hammersmith
Hossam Abdalla, Director, Lister
Fertility Clinic

Committee Secretary:
Claudia Lally

Legal Adviser:
Mary Timms, Field Fisher
Waterhouse

Attending via conference telephone:
Neva Haites, Professor of Medical
Genetics, University of Aberdeen

Declarations of Interest: Hossam Abdalla withdrew from the meeting. Other members of the Committee declared that they had no conflicts of interest in relation to this item.

The following papers were considered by the Committee:

- papers for Licence Committee (27 pages)
- no tabled papers.

The Committee also had before it:

- HFEA Protocol for the Conduct of Licence Committee Meetings and Hearings
- 7th edition of the HFEA Code of Practice
- Human Fertilisation and Embryology Act 1990 (as amended)
- HFEA (Licence Committees and Appeals) Regulations 1991 (SI 1991/1889)
- Decision Trees for Granting and Renewing Licences and Considering Requests to Vary a Licence; and
- Guidance for members of Authority and Committees on the handling of conflicts of interest approved by the Authority on 21st January 2009.

1. The Committee noted that this centre had applied to perform PGD for chromosomal rearrangements. PGD has previously been approved by Licence Committees for chromosomal rearrangements, therefore this application could have been approved by the Executive had the centre been currently licensed for PGD. The application had been brought before a Licence Committee because it represents this centre's first PGD application.

2. The Committee noted that this centre is not currently licensed to perform PGD, though it is licensed to perform PGS. The Committee noted that the centre has an embryo biopsy practitioner on its staff and all the necessary equipment to carry out embryo biopsies. The Committee also noted that the application, standard operating procedures, patient information and consent forms have been reviewed by the Executive and a peer reviewer and were judged to be satisfactory.

3. The Committee noted that the application was to perform PGD for a balanced reciprocal translocation. The couple on whose behalf the application had been made had previously had a baby who was affected by a chromosomal rearrangement and died at the age of 12 days. They were seeking PGD to select an embryo which will be unaffected by this chromosomal rearrangement.

4. The Committee noted the comment by the peer reviewer that the male partner has the balanced reciprocal translocation which caused the congenital malformation of his previous child which led to the death of the child at the age of 12 days. The peer reviewer stated that without PGD treatment this couple would have a high risk of conceiving a pregnancy with a serious genetic disease.

5. The Committee had regard to G 12.3.2 of the Code of Practice which states:

"PGD should be considered only where there is a significant risk of a serious genetic condition being present in the embryo. The perception of the level of the risk by those seeking treatment services is an important factor in the decision making process. The seriousness of the condition should be a matter for discussion between the people seeking treatment and the clinical team."

6. The Committee also considered G12.3.3 of the Code of Practice, which states that in any particular situation the following factors are expected to be considered when deciding the appropriateness of preimplantation genetic diagnosis:

- the view of the people seeking treatment of the condition to be avoided

- their previous reproductive experience
- the likely degree of suffering associated with the condition
- the availability of effective therapy, now and in the future
- the speed of degeneration in progressive disorders
- the extent of any intellectual impairment
- the extent of social support available; and
- the family circumstances of the people seeking treatment

4. On the basis of the information provided in the peer review, the Committee agreed that this was a case in which there was a significant risk of a serious genetic condition being present in the embryo.

5. The Committee agreed that, having regard to the information they had, they were entirely satisfied that PGD was an appropriate treatment for the patient concerned.

6. The Committee was satisfied that a licence should be granted to carry out PGD for chromosomal rearrangements, being a practice designed to secure that embryos are in a suitable condition to be placed in a woman (Schedule 2 paragraph 1(1)(d) of the Human Fertilisation and Embryology Act 1990) and agreed that, taking into account all the matters set out above, this is necessary or desirable for the purpose of providing treatment services (Schedule 2 paragraph 1(3) of the Human Fertilisation and Embryology Act 1990).

7. The Committee noted that a signed application had been received from the centre and agreed that it was satisfied that it had sufficient and satisfactory information on which to make a decision on the application.

8. The Committee decided to vary the centre's licence to add PGD for chromosomal rearrangements.

Signed..... Date.....
David Archard (Chair)