HFEA Licence Committee Meeting
23 February 2009

21 Bloomsbury Street London WC1B 3HF

Minutes – item 5

Application to select female embryos for the avoidance of the x-linked condition childhood-onset Macular Dystrophy, Glasgow Royal Infirmary (0037)

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: 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 (14 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 considered the description of childhood-onset Macular Dystrophy presented in the Committee papers. The Committee noted that the condition causes gradual deterioration of vision which can ultimately lead to blindness. The Committee noted that the patient cited in the application has six male family members who were affected by this condition from childhood. The Committee further noted the statement in the peer review that this condition has a more severe presentation in this family than in the general population.

2. The Committee noted the statement in the Executive Summary that this centre has an established PGD programme and has considerable experience in the techniques required. Furthermore, the Committee noted that the application had been reviewed by a peer reviewer, who had recommended that it be granted.

2. 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."

3. 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. 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. The Committee took into account the fact that without treatment there is a 50% chance that any male child born to the couple would be affected by the condition. The Committee also took into account the fact that there is no

treatment for this condition which leads to progressive deterioration of vision and can ultimately lead to blindness.

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

6. The Committee was satisfied that a licence should be granted to carry out sex selection for the avoidance of childhood-onset Macular Dystrophy, 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 sex-selection for the avoidance of childhood-onset Macular Dystrophy.

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