HFEA Licence Committee Meeting

26 March 2009

21 Bloomsbury Street London WC1B 3HF

Minutes – item 5

Assisted Conception Unit, UCH (0044), application to conduct preimplantation genetic diagnosis (PGD) to avoid Bilateral Frontoparietal Polymicrogyria [OMIM# 606854]

Members of the Committee:	
Clare Lewis-Jones, Lay Member – Chair Ruth Fasht, Lay Member Roger Neuberg, Consultant Obstetrician and Gynaecologist, Leicester Royal Infirmary	Committee Secretary: Claudia Lally Legal Adviser: Graham Miles, Morgan Cole
Non-voting Specialist Adviser – present with the permission of the Chair: Sue Price, Consultant in Clinical Genetics, Oxford Regional Genetics Service	HFEA Members Observing: Jane Dibblin Lillian Neville Debbie Barber

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 (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 considered the description of Bilateral Frontoparietal Polymicrogyria presented in the Committee papers. The Committee also asked the Specialist Adviser to provide a verbal description of the condition. The Adviser informed the Committee that the condition is caused by a failure of the brain to organise the final complex layered structure of the cortex between 9 and 12 weeks of gestation. The abnormal structure of the brain which results means that children born with this condition have learning problems, difficultly controlling movement and frequent seizures. These seizures can be life-threatening and have a detrimental effect on the child's development, causing significant mental impairment. The Adviser also stated that there is no treatment available and the majority of individuals described have died in childhood.

2. The Committee noted the statement in the Executive Summary that this centre had an established PGD programme and had considerable experience in the techniques required. Furthermore, the Committee noted that the patients on behalf of whom the application had been made had been given access to appropriate counselling and advice and that patient information and consent forms for patients receiving PGD at the centre had previously been submitted and approved by a Licence Committee.

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 noted that without the proposed treatment there was a one in four chance that any child born to the couple would be affected by the condition. The also noted that the condition causes symptoms from birth and leads to a high degree of developmental impairment, usually leading to death before the onset of adulthood. The Committee agreed, on the basis of the information they had about the condition, that Bilateral Frontoparietal Polymicrogyria is a serious genetic condition, and there was a significant risk that the condition being passed on by the patients cited in the application.

5. The Committee agreed that, having regard to the information they had, they were entirely satisfied that PGD was an appropriate treatment for patients carrying the genetic mutation responsible for this condition.

6. The Committee was satisfied that a licence should be granted to carry out PGD for the avoidance of Bilateral Frontoparietal Polymicrogyria, 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 the avoidance of Bilateral Frontoparietal Polymicrogyria.

Signed……. … Date……..
Clare Lewis-Jones (Chair)