HFEA Licence Committee Meeting

25 March 2010

21 Bloomsbury Street London WC1B 3HF

Minutes – Item 6

Centre 0044 (Centre for Reproductive and Genetic Health) – Variation application to perform PGD for Non-Classical Congenital Adrenal Hyperplasia (CAH), OMIM# 201910

Members of the Committee:	Committee Secretary:
David Archard (lay) – Chair Rebekah Dundas (lay) Sue Price (Professional)	Terence Dourado Legal Advisers: Graham Miles, Morgan Cole

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:

- Executive summary
- Signed application form (including appendix)
- Redacted peer review
- Additional redacted response from peer reviewer to further information from centre

The Committee also had before it:

- HFEA Protocol for the Conduct of Licence Committee Meetings and Hearings
- 8th edition of the HFEA Code of Practice
- Human Fertilisation and Embryology Act 1990 (as amended)
- Decision trees for granting and renewing licences and considering requests to vary a licence (including the PGD decision tree); and
- Guidance for members of Authority and Committees on the handling of conflicts of interest approved by the Authority on 21 January 2009.
- Guidance on periods for which new or renewed licences should be granted
- Standing Orders and Instrument of Delegation
- Indicative Sanctions Guidance
- HFEA Directions 0000 – 0012

- Guide to Licensing
- Compliance and Enforcement Policy
- Policy on Publication of Authority and Committee Papers

1. The Committee had regard to its Decision Tree. The Committee was satisfied that the Centre already has considerable experience of carrying out PGD and had conducted 46 PGD cycles between 1 January 2008 and 31 December 2009.

2. The Committee noted that the purpose of testing the embryos was set out in paragraph 1ZA(1)(a) 'establishing whether the embryo has a gene, chromosome or mitochondrion abnormality that may affect its capacity to result in a live birth; or 1ZA(1)(b) 'where there is a particular risk that the embryo may have any gene, chromosome or mitochondrion abnormality, establishing whether it has that abnormality or any other gene, chromosome or mitochondrion abnormality'.

3. The Committee noted that Non-Classical Congenital Adrenal Hyperplasia (NCAH) was described as a variation of the condition Classical Congenital Adrenal Hyperplasia (CAH). However, it had not been presented with any information about CAH. Furthermore, it was unclear whether both conditions are covered by the same OMIM number.

4. The Committee adjourned consideration of the item for receipt of further information about the condition and clarity about which OMIM number relates to the condition. The Committee requested that the Executive take utmost care in associating the correct OMIM number with the condition type.

5. In adjourning the Committee also wished to give the PR an opportunity to provide information as to whether the embryo has a gene, chromosome, or mitochondrion abnormality that may affect its capacity to result in a live birth as this had been noted on the application form but had not been supported in the papers.

Signed..... Date.31/3/2010....

David Archard (Chair)