HFEA Licence Committee Meeting

05 May 2011

21 Bloomsbury Street London WC1B 3HF

Minutes – Item 2

Centre 0102 (Guy's Hospital) – PGD for Spinal and Bulbar Muscular Atrophy X-linked (Kennedy disease) OMIM# 313200

Members of the Committee:	Committee Secretary:
David Archard (lay) – Chair Debbie Barber (professional) Jane Dibblin (lay) Rebekah Dundas (lay) (via videoconference) Sue Price (professional)	Terence Dourado Legal Adviser: Tom Rider, Field Fisher

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
- Application form
- Genetic Alliance opinion
- Redacted peer review

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
- HFEA Pre-Implantation Diagnostic Testing ("PGD") Explanatory Note For Licence Committee

1. The Committee had regard to its Decision Tree. The Committee was satisfied that the Centre has considerable experience of carrying out PGD.

2. The Committee noted that the Centre's proposed purpose of testing the embryos was as set out in paragraph 1ZA(1)(b) of schedule 2 of the Act, ie. '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'.

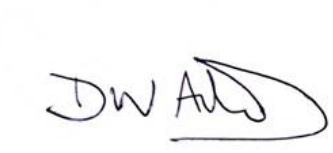
3. The Committee was aware that in effect only males suffer from the condition but females carry the condition and was concerned that the application did not make explicit whether the Centre will only seek to exclude affected male embryos from implantation.

4. After much discussion the Committee decided to refer the application back to the Centre in order that the ambiguity is clarified.

5. The Committee requested that the Centre resubmit an application with a clear explicit statement that the Centre seeks a licence variation in respect of PGD Spinal and Bulbar Muscular Atrophy X-linked (Kennedy disease) OMIM #125310, for male embryos only.

6. The Committee noted that it would consider a resubmitted application from the Centre at the soonest opportunity.

Signed Date 19/05/11



David Archard (Chair)