

## HFEA Licence Committee Meeting

28 March 2013

Finsbury Tower, 103-105 Bunhill Row, London, EC1Y 8HF

### Minutes – Item 3

#### **Centre 0044 (Centre for Reproductive and Genetic Health) – PGD for Alpha Thalassaemia OMIM #141800**

Members of the Committee: Sue Price (professional) Chair Debbie Barber (professional) Jane Dibblin (lay) Andy Greenfield (lay)	Committee Secretary: Lauren Crawford  Legal Adviser: Stephen Hocking, Beachcroft LLP
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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

- Cover sheet
- Executive Summary
- PGD Application form

The Committee also had before it

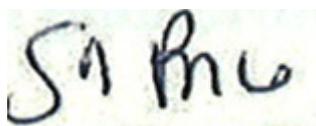
- HFEA Protocol for the Conduct of Licence Committee Meetings and Hearings
- 8th edition of the HFEA Code of Practice
- Human Fertilisation and Embryology Act 1990 (as amended)
- Decision trees for granting and renewing licences and considering requests to vary a licence (including the PGD decision tree); 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

## Discussion

1. The Committee had regard to its Decision Tree. The Committee noted that the Centre is licensed to carry out PGD. The Committee was also satisfied that the Centre has experience of carrying out PGD and that generic patient information about its PGD programme and associated consent forms had previously been received by the HFEA.
2. The Committee noted that the supporting documents with this application did not contain either a Peer Review or Genetic Alliance Opinion. The Committee were satisfied that they had, in any event, sufficient information before them on which to make a decision.
3. The Committee noted that the Centre's proposed purpose of testing the embryos was as set out in paragraph 1ZA(1)(a) of schedule 2 of the Act, ie. 'establishing whether the embryo has a gene, chromosome or mitochondrion abnormality that may affect its capacity to result in a live birth'.
4. The Committee noted that Alpha Thalassaemia (Haemoglobin- Alpha Locus 1; HBA1), OMIM #141800 is inherited in an autosomal recessive manner, although the trait is dominant. There is therefore a 1 in 4 chance of the embryo being affected by this condition with two carrier parents.
5. The Committee noted that Alpha Thalassaemia (HBA1) is a disorder which results from mutation of the alpha globin genes, of which there are four. If all four genes are mutated or deleted the result will be a baby who will die before or at birth.
6. The Committee was therefore satisfied that the condition meets the criteria for testing under paragraph 1ZA(1)(a) of Schedule 2 to the Act.
7. The Committee agreed to authorise the testing of embryos for Alpha Thalassaemia, OMIM #141800. The Committee confirmed that this condition will be added to the published list of conditions for which PGD may be carried out.

Signed:

Date: 15/04/2013

A handwritten signature in black ink, appearing to read 'Sue Price', is written on a light-colored rectangular background.

Sue Price (Chair)