HFEA Executive Licensing Panel Meeting

12 April 2013

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

Minutes – Item 2

Centre 0044 – (The Centre for Reproductive and Genetic Health) – Variation of Licence application to include HLA typing in a specified patient couple with a child suffering from Beta Thalassaemia (OMIM #141900)

Members of the Panel:	Committee Secretary:
Juliet Tizzard – Head of Policy and Communications (Chair) Rachel Hopkins – HR Manager Ian Peacock – Analyst Programmer	Rebecca Loveys

Declarations of Interest: members of the Panel declared that they had no conflicts of interest in relation to this item.

The Panel also had before it:

- HFEA Protocol for the Conduct of Meetings of Executive Licensing Panel
- 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)
- 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 Direction 0008 (where relevant), and any other relevant Directions issued by the Authority
- Guide to Licensing
- Compliance and Enforcement Policy
- Policy on Publication of Authority and Committee Papers

Consideration of Application

1. The Panel considered the papers, which included a completed application form and clinicians' letters.

2. The Panel noted that this centre has considerable experience of carrying out PGD, both with and without HLA typing.

3. The Panel noted that Beta thalassaemia is on the HFEA list of approved conditions for PGD testing and, furthermore, that PGD for Beta thalassaemia with HLA typing has previously been authorised by the HFEA.

4. The Panel noted that embryo testing for HLA typing to provide a bone marrow/stem cell match for a sibling suffering from a serious medical condition is a lawful defined purpose for embryo testing, as specified in the HF&E Act (1990, as amended), Schedule 2, paragraph 1ZA (1) (d), and qualified by Schedule 2, paragraph 1ZA (4).

5. The Panel noted that the specified patient couple has a child with Beta thalassaemia, and that any child born to the couple in the future without PGD screening would have a 25% chance of inheriting the condition.

6. The Panel noted that the specified patient couple wish to undergo PGD with HLA typing in order to have a new baby who is both free from Beta thalassaemia and an HLA match for the affected sibling.

7. The Panel was satisfied that the child has no suitable related donors, as explained in the clinicians' letters, hence the reason for referring to PGD.

Decision

8. The Panel had regard to its decision tree. The Panel noted the purpose of the application did not include research. The Panel noted stages 16d (i-v), which set out the factors that needed to be addressed when considering pre-implantation tissue typing, had been demonstrated and were met.

9. The Panel agreed it had sufficient information about the patient couple's child's condition and was satisfied that HLA typing was appropriate.

10. The Panel agreed to vary the centre's licence in accordance with the application to allow HLA typing for the specified patient couple with a child suffering from Beta thalassaemia.

Signed: Date: 18 April 2013

Juliet Tizzard (Chair)