# HFEA Executive Licence Panel Meeting

**5 October 2011**

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

## Minutes – Item 5

**Centre 0044 - (Centre For Reproductive and Genetic Health) – Variation of Licence to include HLA tissue typing in a specified patient couple with a child with Beta Thalassaemia (OMIM # 141900)**

| Members of the Panel: | Committee Secretary: |
|---|---|
| Peter Thompson, Director of Strategy & Information (Chair)<br>Mark Bennett – Director of Finance & Facilities<br>Juliet Tizzard – Head of Policy and Communications | Joanne McAlpine |

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 noted the papers for this item consisted of an executive summary, a redacted application form, previous Executive Licensing Panel minutes from 11 February 2010 and additional information in the form of a redacted Clinician's email dated 7 September 2011 in support of the application.

2. The Panel noted that this application had previously been presented to it on 27 January and 11 February 2010, at which the Panel adjourned its decision until either one of the following pieces of information was provided:

   - A medical letter from a clinician/doctor stating whether attempts had been made to HLA test the mother's siblings; or

   - A letter/email from the centre clarifying if attempts had been made to HLA test the mother's siblings.

3. The Panel noted that an email has now been provided by the specialist treating the affected child, and that the specialist is supportive of the application and states specifically that the mother's seven siblings have been HLA typed and none of them are a match for the affected child.

4. The Panel noted that the combination of PGD for Beta Thalassaemia with HLA had previously been authorised by the HFEA.

5. 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 at HF&E Act (1990) as amended, Schedule 2, para 1ZA (1) (d), and qualified by HF&E Act (1990) as amended, Schedule 2, para 1ZA (4).

6. The Panel noted from the original Clinician's letter (dated 5 May 2009) that the patient couple have a young girl with the condition, and want to undergo PGD with HLA typing with embryo selection in order for the family to have a new baby who is both free from Beta thalassaemia major and a HLA match.

8. The Panel noted that the Inspectorate recommended the variation of the centre's licence, to allow HLA for Beta Thalassaemia for the specified patient couple in the application.

**Decision**

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

10. The Panel noted that the letters and email from the treating clinician, demonstrated the high degree of suffering associated with the condition and the lack of viable alternative treatment options. Accordingly, the Panel agreed that it had sufficient information and that it was satisfied that HLA tissue typing was appropriate for the patient concerned.

11. The Panel was satisfied that that those seeking treatment and their families will have proper access to counselling about the implications of the procedure.

12. The Panel agreed to vary the centre's licence to include HLA tissue typing for the named patients specified in the application, for a child suffering from Beta Thalassaemia.

Signed: Peter Thompson Date: 18/10/11.
Peter Thompson (Chair)