

# HFEA Executive Licensing Panel Meeting

1 March 2013

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

## Minutes – Item 6

**Centre 0070 – (The Bridge) – Variation of Licence Application to include PGD and HLA typing in a specified patient couple (Patient PQ and Patient FA) with a child suffering from Beta-thalassaemia (OMIM #141900)**

### Members of the Panel:

Mark Bennett – Director of Finance  
and Facilities (Chair)  
Jasper Squire – Computer Programmer  
David Moysen – Head of IT

### Committee Secretary:

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 noted the papers which included an executive summary, a completed application form and two clinicians' letters.
2. The Panel noted that this centre has considerable experience in providing pre-implantation genetic diagnosis (PGD) both with and without HLA tissue 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 noted from the clinician's letter (1 February 2013) that the patient has no HLA matched siblings and that the best donor would be a fully matched sibling donor, hence the reason for referring for PGD.
8. The Panel noted that the clinician's letter stated that unrelated transplantation is significantly inferior to related transplantation, which has disease free survival of 95% with transplant-related mortality of only 2-5%.
9. 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

10. 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.
11. The Panel agreed it had sufficient information about the patient couple's child's condition and was satisfied that HLA typing was appropriate.
12. 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:



Mark Bennett (Chair)

Date:

11 Nov 2013