

HFEA Executive Licence Panel Meeting

27 January 2012

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

Minutes – Item 7

Centre 0044 (Centre for Reproductive and Genetic Health (CRGH)) – Variation of Licence to include HLA tissue typing in a specified patient couple with a child at risk of Sickle Cell Anaemia and a child affected by the disease

Members of the Panel: Peter Thompson, Director of Strategy & Information (Chair) Mark Bennett, Director of Finance & Facilities Danielle Hamm, Senior Policy Manager	Committee Secretary: Joanne McAlpine
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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, and two redacted letters from the treating clinician in support of the application (dated 21 March 2011, 6 July 2009).
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 Sickle Cell Anaemia is on the list of conditions approved for PGD by the HFEA. In addition, PGD testing with HLA for this condition had previously been approved by the HFEA, for example by the Executive Licence Panel on 15 April 2011.
4. The Panel noted that embryo testing for HLA tissue type to provide a stem cell match for a sibling suffering from a serious medical condition, even without additional PGD testing of the embryo for the serious medical condition, is a lawfully defined purpose for embryo testing, as specified at HFE Act (1990) as amended, Schedule 2, para 1ZA (1) (d), and qualified by HFE Act (1990) as amended, Schedule 2, para 1ZA (4).
5. The Panel confined its consideration to the evidence before it. The Panel noted that the patient couple have a child with Sickle Cell Anaemia, and any child born to the couple without PGD screening has a 25% chance of inheriting the disease.
6. The Panel noted that the patient couple wish to undergo IVF treatment with PGD to conceive a child who will not be affected by Sickle Cell Anaemia and who will be an HLA match for the affected sibling. The child born will be a potential source of bone marrow and/or stem cells which may be used to treat the affected sibling in the future.
7. The Panel noted the letter from the clinician treating the affected child, and the suffering associated with the condition.
8. The Panel noted that the affected child has one sibling who is unaffected by the condition and has been tested along with the parents to see if they are a potential HLA match, but this has been unsuccessful.
9. The Panel noted the Inspectorate's recommendation to grant the variation.

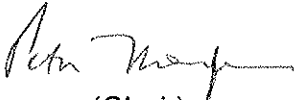
Decision

10. The Panel noted that the clinician treating the affected child was in support of this application and it considered the information provided.
11. The Panel referred to its PGD decision tree. The Panel concluded that stages 16d (i) – (iv), which set out a number of factors when considering pre-implantation tissue typing, had been demonstrated and met.

12. The Panel was satisfied from the supporting clinician's letter, and so took into account, the high degree of suffering associated with the condition.
13. The Panel agreed that it had sufficient information and that it was satisfied that HLA tissue typing was appropriate for the patient concerned.
14. The Panel agreed that it was satisfied that those seeking treatment and their families will have access to counselling about the implications of the procedure.
15. The Panel agreed to vary the centre's licence to include HLA tissue typing for the named patients with a child who has Sickle Cell Anaemia.

Signed:

Peter Thompson (Chair)

 Date: 6/2/12.

