HFEA Executive Licensing Panel Meeting

11 February 2010

21 Bloomsbury Street London WC1B 3HF

Minutes – item 7

The Bridge Centre (0070), Application to Vary to include pre implantation genetic diagnosis (PGD) for Sickle Cell Disease (OMIM #603903) with HLA tissue typing for named patients Mrs SI and Mr AI

Members of the Panel:	
Peter Thompson, Director of Strategy & Information (Chair) Mark Bennett, Director of Finance & Facilities Trish Davies, Director of Compliance	Committee Administrator: Joanne McAlpine

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:

- papers for Licence Committee (15 pages)
- no papers were tabled for this item

The Committee also had before it:

- HFEA Protocol for the Conduct of Licence Committee Meetings of the Authority's Executive Licensing Panel
- 8th edition of the HFEA Code of Practice
- Human Fertilisation and Embryology Act 1990 (as amended)
- Direction 0008 (where relevant), and any other relevant Directions issued by the Authority;
- Decision Trees for Granting and Renewing Licences and Considering Requests to Vary a Licence
- Guidance for members of Authority and Committees on the handling of conflicts of interest approved by the Authority on 21 January 2009
- Indicative applications guidance on the time period for which licences should be granted approved by the Authority on 21 October 2009
- Indicative sanctions guidance approved by the Authority on 18 March 2009
- Licence application and any relevant documentation

1. The Panel considered the papers for this item which included an executive summary, a redacted application form for the variation to include HLA typing for sickle cell disease for named patients, and a redacted letter from the treating clinician.

2. The Panel noted that this is a large PGD centre and has considerable experience of carrying out PGD and has a large PGD programme.

3. The Panel noted that Sickle Cell Disease has already been licensed by the HFEA for use in PGD.

4. The Panel noted that the combination of PGD for Sickle Cell Disease with HLA typing has previously been authorised by the HFEA.

5. The Panel noted that the patient couple have one affected child. Neither parent is HLA matched to the child and as there is no consanguinity in the family, no other relative will be suitable to act as a donor.

6. The Panel noted that the patient couple wishes to have more children, but would like to ensure that further pregnancies are not affected by the condition. The couple is from a developing country which cannot offer the standard of medical care expected for Sickle Cell Disease in the UK.

7. The Panel noted that the proposed treatment has been supported by the clinician responsible for the care of the sibling child and a letter to this effect is enclosed in the papers.

8. The Panel noted that Embryo testing for HLA typing to provide a bone marrow tissue match for a sibling suffering from a serious medical condition is a lawful 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).The Panel noted that although the centre has considerable experience in PGD this is its first application to conduct PGD for HLA Tissue Typing.

9. The Panel noted the letter from the clinician supporting this application provides appropriate detail about the medical history of the couple's child.

10 The Panel noted that this condition has been licensed by a previous Licence Committee for use in PGD.

<u>The Panel's Decision</u>

11. The Panel agreed that they were satisfied that they had enough information on which to make a decision and therefore decided to approve this application to vary the licence to include PGD for Sickle Cell Disease (OMIM #603903) with HLA tissue typing for named patients.

Signed.....Date.....1/3/10.

Peter Thompson (Chair)