

HFEA Executive Licensing Panel Meeting

11 February 2010

21 Bloomsbury Street London WC1B 3HF

Minutes – item 8

Centre for Reproductive and Genetic Health (CRGH) (0044), Application to vary to include beta Thalassaemia major with HLA typing for named patients

Members of the Panel:

Peter Thompson, Director of Strategy & Information (Chair) Committee Administrator:
Joanne McAlpine

Mark Bennett, Director of Finance & Facilities

Trish Davies, Director of Compliance

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 (3 pages)
- no papers were tabled for this item

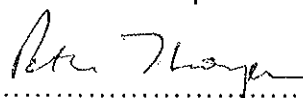
The Committee also had before it:

- 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 noted that this item had previously been put before them at the meeting of the 27 January 2010, and that the item had to be adjourned due to insufficient information to determine a decision.
2. The Panel noted in the previous minutes that they had asked the centre for clarification of either: A letter/email from the treating clinician/doctor stating if attempts have been made to HLA test the mother's siblings; or written confirmation from the centre clarifying if such attempts had been made to HLA test the mother's siblings.
3. The Panel noted that the centre has had further contact with the clinician treating the sick child, and the clinician has submitted an email updating the Committee.
4. The Panel noted that the clinician states in his email that he has not heard anything more from the patient couple and therefore could not say if any attempts had been made by the family to test the mother's siblings for a HLA tissue match.
5. The Panel noted that the clinician reported that had only had a verbal conversation with the patient couple during which he was not presented with documentary evidence.
6. The Panel noted that the condition has been approved by a Licence Committee for use in PGD. However, the Panel felt that they still did not have sufficient clarification that the mother's siblings had been tested, in order to establish if there is a HLA tissue match, or that this option was not possible.
7. The Panel referred to the Code of Practice section 10(19)(e) guidance which states "the availability of alternative sources of tissue for treating them, now and in the future". The Panel agreed that they still were of the view that they had insufficient information to know whether that element of the Code had been complied with.

The Panel's Decision

- 8 The Panel agreed that for the above reasons that they were not satisfied that they had enough information on which to make a decision and therefore decided to defer this item, until such time that the centre has provided one of the following;
 - A medical letter from a clinician/doctor stating if attempts have been made to HLA test the mother's siblings
 - Or a letter/email from the centre clarifying if these attempts have been made to HLA test the mother's siblings.
9. The Panel concluded that they are willing to consider this application as soon as the centre has provided one of the above.

Signed.....  Date..... 1/31/10.....
 Peter Thompson (Chair)