

HFEA Executive Licensing Panel Meeting

27th January 2010

21 Bloomsbury Street London WC1B 3HF

Minutes – item 5

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)

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

The Committee also had before it:

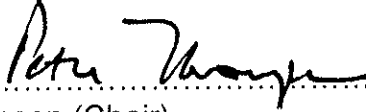
- HFEA Protocol for the Conduct of Licence Committee Meetings of the Authority's Executive Licensing Panel
- 8th edition of the HFEA Code of Practice
- Human Fertilisation and Embryology Act 1990 (as amended)
- Direction 0008 (where relevant), and any other relevant Directions issued by the Authority;
- 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, an application form for the variation to include Beta Thalassaemia with HLA typing, and a letter from the clinician in support.
2. The Panel noted that this centre has one of the largest PGD programmes of all the UK licensed clinics, and has considerable experience of carrying out PGD.
3. The Panel noted that the couple have one affected child and attempts at tissue-typing of near relatives, albeit not yet complete, had so far proved unsuccessful.
4. The Panel noted that this condition is a serious, transfusion dependent anaemia affecting people who have inherited the two abnormal beta Thalassaemia genes, one from each parent.
5. The Panel noted that a previous Licence Committee had approved this condition for another patient couple.
6. The Panel reviewed the references and noted that they recommended that the application be granted.
7. The Panel noted the points made in the clinician's letter and that whilst the father's siblings have been tested and they are not HLA matched, the mother's siblings have, at the time the letter was written, not yet been HLA tested although the clinician recommends that such attempts should be made.
8. The Panel were unclear as to whether, in the intervening period, such attempts had been made to carry out HLA testing on the mother's siblings, and would like the centre to clarify the matter.

The Panel's Decision

9. The Panel agreed it was not satisfied that it had enough information on which to make a decision and therefore deferred this item, until such time that the centre has provided one of the following;
 - A medical letter from a clinician/doctor stating that attempts have been made to HLA test the mother's siblings
 - A letter/email from the centre clarifying whether attempts have been made to HLA test the mother's siblings.

The Panel requested the inspectorate to act promptly on this matter.

Signed.....  Date..... 4/2/10.....
Peter Thompson (Chair)