HFEA Licence Committee Meeting

28 October 2010

21 Bloomsbury Street London WC1B 3HF

Minutes – Item 4

Centre 0102 (Guys Hospital) – PGD for Simpson Golabi Behmel Syndrome Type 1 OMIM# 312870

Members of the Committee: David Archard (lay) – Chair Debbie Barber (professional) Anna Carragher (lay) Rebekah Dundas (lay) Sue Price (professional)	Committee Secretary: Terence Dourado Legal Advisers: Graham Miles, Morgan Cole

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:

- Executive Summary
- PGD application form
- Redacted peer review
- Genetic Alliance UK opinion

The Committee also had before it:

- HFEA Protocol for the Conduct of Licence Committee Meetings and Hearings
- 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); and
- 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 Directions 0000 – 0012
- Guide to Licensing

- Compliance and Enforcement Policy
- Policy on Publication of Authority and Committee Papers

1. The Committee had regard to its Decision Tree. The Committee was satisfied that the Centre has an established PGD programme and considerable experience of carrying out PGD.

2. The Committee noted that the application was made under the proposed purpose of testing the embryos as set out in paragraph 1ZA(1)(b) of schedule 2 of the Act, ie. 'where there is a particular risk that the embryo may have any gene, chromosome or mitochondrion abnormality, establishing whether it has that abnormality or any other gene, chromosome or mitochondrion abnormality'. The Committee noted that the application stated that the purpose of testing the embryo is not to establish the sex of the embryo in cases where there is a particular risk that any resulting child will have or develop gender-related illnesses, conditions or abnormalities. However, the Committee considered that the application suggested that the condition only meets the statutory test for males but not for females.

3. The Committee received legal advice to that, under paragraph 1ZA (1) of Schedule 2 to the Act a licence can authorise the testing of an embryo for one or more of the purposes set out in sub paragraphs (a) to (e). Accordingly, if the purpose set out in 1ZA (1) (b) applied, authorisation could be given even though testing would not also be for the purpose set out in 1ZA (1) (C). However, before testing could be authorised for the purpose set out in 1ZA (1) (b) the Committee had to be satisfied, in relation to the abnormality concerned, that that there is a significant risk that a person with the abnormality will have or develop a serious physical or mental disability, a serious illness or any other serious medical condition. If the Committee was of the view that this statutory test would only be satisfied in relation to male rather than female embryos, consideration could be given to whether it would be appropriate to limit the scope of any authorisation given.

4. The Committee was also advised that, under 1ZB (1) a licence cannot authorise any practice designed to secure that any resulting child will be of one sex rather than the other, but this does not preclude the testing of the embryos for sex, as set out in 1ZA(c) 'in a case where there is a particular risk that any resulting child will have or develop (i) a gender-related serious physical or mental disability, (ii) a gender-related serious illness, or (iii) any other gender-related serious medical condition.

5. The Committee concluded that it would be helpful to clarify with the Centre whether the purpose of testing was to detect the presence of the condition in males. The Committee agreed that should the Centre intend to test for the condition in females, it must clarify how the condition meets the statutory test in females.

6. In adjourning its deliberation, the Committee noted that it would hope to expedite an application for the condition at its meeting on 25th November 2010, should the required information be forthcoming.

Signed Date

As approved by David Archard (Chair)