

# HFEA Licence Committee Meeting

1 March 2012

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

## Minutes – Item 2

### Centre 0102 (Guys Hospital) – PGD for L-2-Hydroxyglutaric aciduria (OMIM #236792)

Members of the Committee:	Committee Secretary:
David Archard (lay) Chair	Lauren Crawford
Anna Carragher (lay)	
Rebekah Dundas (lay) (videoconference)	Legal Adviser:
Mair Crouch (lay) (videoconference)	Tom Rider, Field Fisher
Sue Price (professional)	Waterhouse
Jane Dibblin (lay)	

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

- Cover sheet
- Executive Summary
- PGD Application form: Ref 1458
- Redacted Peer Review
- Genetic Alliance 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
- HFEA Pre-Implantation Diagnostic Testing (“PGD”) Explanatory Note For Licence Committee

## **Discussion**

1. The Committee had regard to its Decision Tree. The Committee noted that the Centre is licensed to carry out PGD. The Committee was also satisfied that the Centre has much experience of carrying out PGD and that generic patient information about its PGD programme and associated consent forms had previously been received by the HFEA.
2. The Committee noted that the Centre’s proposed purpose of testing the embryos was 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’.
3. The Committee noted that L-2-Hydroxyglutaric aciduria (OMIM #236792) is a disorder that is inherited in an autosomal recessive manner. There is a 1 in 4 chance of an embryo being affected by this condition.
4. The Committee noted that this condition is fully penetrant. L-2-Hydroxyglutaric aciduria is a neurometabolic which affects the brain, particularly the region involved in coordinating movements (the cerebellum). This is primarily associated with developmental delay, unsteady walking, epilepsy and macrocephaly.
5. The Committee noted that there is no curative treatment for L-2-Hydroxyglutaric aciduria. Symptoms usually present in early childhood. For affected individuals age of onset and symptoms may vary, however the progressive loss of function and neurological regression is likely to be severe. Patients live well into adulthood but become progressively dependant.
6. The Committee considered that the condition is serious because affected individuals have a very poor quality of life. The condition is untreatable and palliative management is the only option. The condition invariably leads to

severe progressive and neurological handicap, disability and requires life-long care.

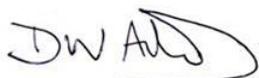
7. The Committee noted that the application is supported by the Peer Reviewer as well as by Genetic Alliance UK.
8. The Committee had regard to its explanatory note and noted that on the basis of the information presented, given the conditions worst symptoms, it was satisfied that there is a significant 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. Accordingly, it was appropriate to grant the application under paragraph 1ZA(1)(b) of Schedule 2 to the Act.

### **Decision**

9. The Committee agreed to authorise the testing of embryos for L-2-Hydroxyglutaric aciduria (OMIM #236792). The Committee confirmed that this condition will be added to the published list of conditions for which PGD may be carried out.

Signed:

Date: 13/03/2012

A handwritten signature in black ink, appearing to read 'DWA' followed by a stylized flourish.

David Archard (Chair)