

HFEA Licence Committee Meeting

26 January 2012

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

Minutes – Item 2

Centre 0102 (Guys Hospital) – PGD for Canavan Disease (OMIM #271900)

Members of the Committee:	Committee Secretary:
David Archard (lay) Chair	Lauren Crawford
Anna Carragher (lay)	
Rebekah Dundas (lay) (videoconference)	Legal Adviser:
Sue Price (professional)	Graham Miles, Morgan Cole
Debbie Barber (professional)	
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
- 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

Decision

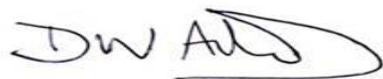
1. The Committee had regard to its Decision Tree. The Committee noted that the Centre is licensed to carry out PGD. The Committee was also satisfied that the Centre has much experience of carrying out PGD and that generic patient information about its PGD programme and associated consent forms had previously 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 Canavan disease (OMIM #271900) 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. The condition presents in at 2-4 months of age with head lag, hypotonia and macrocephaly, progressed to marked developmental delay, seizures, optic nerve atrophy, progressive spasticity and opisthotonic posturing.
5. The Committee noted that there is no curative treatment for Canavan Disease. For affected individuals in the 2nd year of life seizures often develop, together with irritability and sleep disturbance. Muscular hypotonia gives way to spasticity reminiscent of cerebral palsy.
6. The Committee considered that the condition is serious because affected individuals have a shortened life expectancy even though age of death is variable. Death usually occurs within a few years, although survival in a vegetative or near-vegetative state may extend to the 2nd decade.
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 condition’s 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.

9. The Committee agreed to authorise the testing of embryos for Canavan Disease (OMIM #271900). The Committee confirmed that this condition will be added to the published list of conditions for which PGD may be carried out.

Signed:

Date: 20/02/2012

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

David Archard (Chair)