HFEA Licence Committee Meeting

31 March 2011

21 Bloomsbury Street London WC1B 3HF

Minutes – Item 4

Centre 0102 (Guy's Hospital) – PGD for Hereditary Motor and Sensory Neuropathy 1A (Charcot Marie Tooth type 1A) OMIM# 118220

Members of the Committee:	Committee Secretary:
David Archard (lay) – Chair Debbie Barber (professional) Anna Carragher (lay) Sally Cheshire (lay) Mair Crouch (lay)	Terence Dourado Legal Adviser: Tom Rider, Field Fisher

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

- HFEA Pre-Implantation Diagnostic Testing (“PGD”) Explanatory Note For Licence Committee

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

2. The Committee was satisfied 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 Hereditary Motor and Sensory Neuropathy 1A (Charcot Marie Tooth type 1A) OMIM #118220 is inherited in an autosomal dominant manner. Only one copy of the affected gene is required to cause the disorder, i.e. there is a 50% chance of the embryo being affected in a family where one parent is affected and the other is unaffected.

4. The Committee noted that there was a significant risk that a person with the abnormality will develop the condition in question because it is almost fully penetrant.

5. The Committee considered the seriousness of the condition. The Committee determined that it is not considered a fatal disease and that people with most forms of the condition have a normal life expectancy. The Committee agreed that the condition did not meet the statutory test in paragraph 1ZA(2) of Schedule 2 to the Act on the basis of the evidence before it. The condition affects both motor and sensory nerve function. It is characterised by a slowly progressive weakness and atrophy of the distal limb muscles. The Committee noted though that onset of symptoms tends not to be until adolescence or early adulthood, with some individuals not developing symptoms until mid-adulthood. Further, the Committee noted that the severity of symptoms varies greatly, with progression of symptoms being gradual. In a worst case, an individual suffers from severe mobility problems and severe pain. It is not though a fatal condition and people with most forms of it have a normal life expectancy. There is no cure for the condition but the Committee noted that it can be treated with physical therapy, occupational therapy, braces and other orthopaedic devices, and even orthopaedic surgery can help individuals cope with the disabling symptoms. In addition, pain-killing drugs can be prescribed for individuals in severe pain.

6. For these reasons, the Committee was not minded at this stage to grant PGD in respect of Hereditary Motor and Sensory Neuropathy 1A (Charcot Marie Tooth type 1A) OMIM #118220.

Signed..... Date...14.4.2011

David Archard (Chair)