Statutory Approvals Committee - minutes

Centre 0102 (Guys Hospital) – PGD application for Hereditary Sensory Neuropathy type 1A OMIM #162400

Thursday, 28 January 2016

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

Committee members	David Archard (Chair) Rebekah Dundas (Deputy Chair) Sue Price Margaret Gilmore Anthony Rutherford	
Members of the Executive	Trent Fisher	Secretary
External adviser	Dr Jenny Carmichael	
Legal Adviser	Tom Rider	Fieldfisher
Observers	None	

Declarations of interest:

- members of the committee declared that they had no conflicts of interest in relation to this item.

The committee had before it:

- 8th edition of the HFEA Code of Practice
- standard licensing and approvals pack for committee members

The following papers were considered by the committee:

- executive summary
- PGD application form
- redacted peer review
- Genetic Alliance opinion

1. Consideration of application

1.1. 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 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.

1.2. The committee noted that the condition being applied for is not on the approved PGD condition list.

1.3. The committee noted that the proposed purpose of testing the embryos was as set out in paragraph 1ZA(1)(b) of schedule 2 of the Act, i.e. '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'.

1.4. The committee noted that the condition is inherited in an autosomal dominant pattern and there is a 1 in 2 chance of an embryo being affected with the condition where one parent is affected.

1.5. The committee noted that the condition is a disorder that primarily affects sensory neurons. Symptoms may include prominent sensory loss leading to painless injuries. This can result in slow wound healing, chronic ulceration and subsequent bone infection that can require amputation.

1.6. The committee noted that other symptoms can include numbness, burning, shooting pains, dysesthesia and progressive sensorineural deafness. Individuals can experience mobility issues in later life due to muscle weakness and wasting.

1.7. The committee noted that the condition is variable and demonstrates a high penetrance with onset of symptoms from teenage years to later life.

1.8. The committee noted that there is no curative treatment for the condition, management of the condition aims to minimise the risk of injury and support mobility.

1.9. The committee noted that the application is consistent with the Peer Review.

1.10. The committee welcomed the advice of its specialist advisor, Dr Jenny Carmichael, who confirmed that the condition is as described in the papers.

2. Decision

2.1. The committee considered that the condition is serious due to the severity of symptoms associated with the condition and lack of any curable treatment.

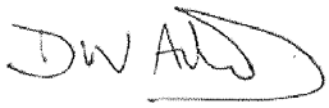
2.2. The committee had regard to its explanatory note and noted that on the basis of the information presented, given the condition's worst symptoms, it was satisfied that there is a significant risk that a person with the abnormality will have or develop a serious physical or mental disability, a serious illness or any other serious medical condition. The committee was therefore satisfied that the condition meets the criteria for testing under paragraph 1ZA(1)(b) and (2) of Schedule 2 to the Act.

2.3. The committee agreed to authorise the testing of embryos for Hereditary Sensory Neuropathy type 1A, OMIM #162400

3. Chair's signature

3.1. I confirm this is a true and accurate record of the meeting.

Signature



Name

David Archard

Date

11 February 2016