Statutory Approvals Committee - minutes

Centre 0102 (Guys Hospital) – PGD application for Autosomal Dominant Hypocalcaemia OMIM #615361 #601198

Thursday, 17 December 2015

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

Committee members	David Archard (Chair) Rebekah Dundas (Deputy Chair) Sue Price Margaret Gilmore Bishop Lee Rayfield	
Members of the Executive	Trent Fisher	Secretary
External adviser	Dr Edward Blair	
Legal Adviser	Graham Miles	Blake Morgan
Observers	Polly Todd	

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 that 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 causes low calcium levels in blood. As a result of the low calcium levels, individuals can be affected by pins and needles, muscle cramps, muscle spasms and seizures.

1.6. The committee welcomed the advice of its specialist advisor, Dr Edward Blair who informed the committee that if the calcium levels in an individual's blood are regularly monitored then significant and severe symptoms of this condition would not develop.

1.7. The committee noted that where there is a family history of the condition and thus a risk of a child inheriting the condition, any child born is likely to be tested. Where the condition is present the child will be regularly monitored and through monitoring the condition can be managed to avoid the child developing the serious symptoms associated with the condition.

2. Decision

2.1. The committee could only authorise the testing of embryos for this condition if 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.

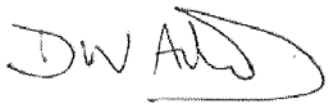
2.2. The committee, in considering the worst case scenario of the symptoms associated with the condition and taking into account the treatment and management options available, concluded that the threshold for the statutory test of seriousness was not met.

2.3. The committee accordingly refused to authorise the testing of embryos for Autosomal Dominant Hypocalcaemia OMIM # 615361 #601198.

3. Chair's signature

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

Signature



Name

David Archard

Date

6 January 2016