Statutory Approvals Committee - minutes

Centre 0101 (CARE Nottingham) – PGD application for Pena-Shokeir Syndrome Type 1 OMIM #208150

Thursday, 29 October 2015

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 Sam Hartley	Secretary Head of Governance and Licensing
External adviser	Dr Alan Fryer	
Legal Adviser	Graham Miles	Black Morgan
Observers	Anna Quinn	Scientific Policy Officer

Declarations of interest:

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

The panel 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)(a) of schedule 2 of the Act, i.e. 'establishing whether the embryo has a gene, chromosome or mitochondrion abnormality that may affect its capacity to result in a live birth'.

1.4. The committee noted that the condition is inherited in an autosomal recessive pattern and there is a 1 in 4 of an embryo being affected with the condition where both parents are carriers of the mutation.

1.5. The committee noted that Pena-Shokeir syndrome type 1 is a very rare genetic condition. It is characterised by loss or impairment of voluntary movement due to malformation in the brain. The condition is lethal and can result in stillbirth. Babies that are born are not expected to survive past the first few weeks of life.

1.6. The committee noted that other symptoms associated with the condition include heart defects, incomplete development of the lungs, excess amniotic fluid, joint contractures, short umbilical cord and anomalies of the and hands.

1.7. The committee noted that the condition demonstrates a complete penetrance and symptoms can be observed during pregnancy.

1.8. The committee noted that there is no curative treatment for the condition.

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 Alan Fryer who confirmed that the condition is as described in the papers. Dr Fryer also confirmed that the clinical name for the condition is Fetal Akinesia Deformation Sequence.

2. Decision

2.1. The committee was satisfied that the condition meets the criteria for testing under paragraph 1ZA(1)(a) of Schedule 2 to the Act.

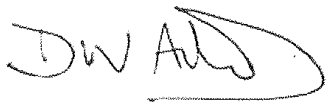
2.2. The committee considering the advise of the clinical advisor decided that the condition will be listed as on the HFEA approved PGD condition list as Fetal Akinesia Deformation Sequence (Pena-Shokeir syndrome type 1), OMIM #208150.

2.3. The committee agreed to authorise the testing of embryos for as Fetal Akinesia Deformation Sequence (Pena-Shokeir syndrome type 1), OMIM #208150.

3. Chair's signature

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

Signature



Name

David Archard

Date

11 November 2015