

HFEA Statutory Approvals Committee

25 September 2014

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

Minutes – Item 3

Centre 0102 (Guy’s Hospital) – PGD application for Achondroplasia (OMIM# 100800)

Members of the Committee: David Archard (lay) Chair Debbie Barber (professional) Rebekah Dundas (lay) Jane Dibblin (lay) Hossam Abdalla (professional)	Committee Secretary: Sam Hartley, Head of Governance and Licensing Legal Adviser: Dawn Brathwaite, Mills & Reeve
Advisor: Dr Edward Blair	

Declarations of Interest: The Members declared no conflicts in relation to this item.

The following papers were considered by the Committee:

- Executive summary
- PGD application form
- Redacted Peer Review form

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) (“the Act”)
- 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

Discussion

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.
2. 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’.
3. The Committee noted that Achondroplasia (OMIM #100800) 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.
4. The Committee noted that Achondroplasia is characterised by skeletal abnormalities. Individuals have a marked curve of the spine and narrowing of the spinal canal which can cause nerve compression leading to pain, paralysis and incontinence. They may also have malalignment of the joints, ear, nose and throat abnormalities such as deafness, speech delay and respiratory obstructions.
5. The Committee noted that the condition may be detected in the second trimester of pregnancy. However, typically symptoms of Achondroplasia are apparent from birth.
6. The Committee noted that there is no curative treatment for Achondroplasia but the symptoms can be managed with surgery, orthopaedic supports and drug therapy.
7. The Committee welcomed the advice of its advisor, Dr Edward Blair, who confirmed that the condition was as described in the papers
8. The Committee considered that the condition is serious because there is no curative treatment and can adversely affect the patient’s quality of life. The

Committee further noted that in some cases, when narrowing occurs in the upper spine and skull base, spinal cord compression may occur, which can lead to quadriplegia and death.

9. 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.

10. The Committee agreed to authorise the testing of embryos for Achondroplasia (OMIM #100800).

Signed:

Date: 07/10/2014

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

David Archard (Chair)