

Statutory Approvals Committee - minutes

Centre 0102 (Guy's Hospital) – PGD application for Matthew Wood-like Syndrome (also known as Microphthalmia syndrome 12), OMIM #615524

Thursday, 24 November 2016

HFEA, Level 2, 10 Spring Gardens, London, SW1A 2BU

Committee members	Margaret Gilmore (Chair) Rebekah Dundas (Deputy Chair) Anne Lampe Ruth Wilde Anthony Rutherford	
Members of the Executive	Siobhain Kelly Trent Fisher	Head of Corporate Governance (interim) Secretary
External adviser	Professor Mary Porteous	
Legal Adviser	Graham Miles – Blake Morgan LLP	
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
- one additional academic paper submitted with the application

- redacted peer review
- Genetic Alliance opinion

1. Consideration of application

- 1.1. The committee welcomed the advice of its specialist advisor, Professor Mary Porteous, who confirmed that the condition is as described in the papers.
- 1.2. The committee noted that the application is consistent with the Peer Review and Genetic Alliance opinion.
- 1.3. 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.
- 1.4. The committee noted that the condition being applied for is not on the approved PGD condition list.
- 1.5. 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'.
- 1.6. The committee noted that the condition can be inherited in autosomal dominant and autosomal recessive modes.
- 1.7. The committee noted that the condition is a very rare condition characterised by anophthalmia (no eyes) or severe microphthalmia (extremely small eyes), small underdeveloped or absent lungs, heart defects and a defect in the diaphragm which allows organs to move in to the chest and impair lung development.
- 1.8. The committee also noted that those affected can be stillborn or may die shortly after birth due to lung and heart abnormalities. A significant proportion of babies that survive the neonatal period will die during childhood. Survivors will usually suffer from severe intellectual and physical disability as well as blindness or severe visual impairment. The majority never walk and speech is frequently absent or limited.
- 1.9. The committee noted that treatment is supportive only and complex and multiple surgeries may be required with all the associated risks that would carry.
- 1.10. The committee noted that the symptoms present antenatally or at birth.

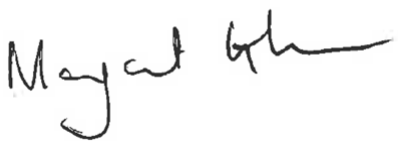
2. Decision

- 2.1. The committee considered that the condition is serious due to the severe physical and developmental problems and frequent death at an early age.
- 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 Matthew Wood-like syndrome (also known as Microphthalmia syndrome 12), OMIM #615524.

3. Chair's signature

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

Signature

A handwritten signature in black ink that reads "Margaret Gilmore". The signature is written in a cursive style with a long horizontal flourish at the end.

Name

Margaret Gilmore

Date

09 December 2016