# Statutory Approvals Committee - minutes

## Centre 0102 (Guys Hospital) – PGD application for Familial Myelodysplastic Syndrome OMIM #614286

Thursday, 25 August 2016

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

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| Committee members | David Archard (Chair)<br>Rebekah Dundas (Deputy Chair)<br>Margaret Gilmore<br>Anne Lampe<br>Ruth Wilde | |
| Members of the Executive | Ian Brown<br>Trent Fisher | Head of Corporate Governance<br>Secretary |
| External adviser | Peter Turnpenny | |
| Legal Adviser | Ros Foster | Browne Jacobson 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
- redacted peer review
- Genetic Alliance opinion

## 1. Consideration of application

**1.1.** The committee welcomed the advice of its specialist advisor, Professor Peter Turnpenny, 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 the GA opinion paper.

**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 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.

**1.7.** The committee noted that Familial Myelodysplastic Syndrome is a very rare condition in which abnormal cells are created in the bone marrow. The condition causes an increased risk of developing acute myeloid leukaemia, a type of blood cancer, which may be fatal.

**1.8.** The committee noted that symptoms include anaemia which leads to fatigue, breathlessness and exercise intolerance. Individuals, due to a lack of white blood cells, have increased susceptibility to infection. Individuals can also suffer easy bruising and clotting problems due to a lack of platelets.

**1.9.** The committee noted that other symptoms include deafness, poor lymph drainage leading to swollen legs. A minority of patients can develop lung and breathing problems which can be life limiting.

**1.10.** The committee noted that the condition is likely to demonstrate a high penetrance. Symptoms can develop from childhood.

**1.11.** The committee noted that bone marrow transplant may be used to treat the condition however this involved surgical risks and is said not to be 100 percent effective.

## 2. Decision

**2.1.** The committee considered that the condition is serious due to severe symptoms associated with the condition which can be fatal.

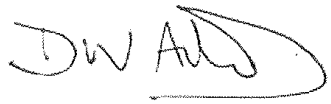
**2.2.** The committee had regard to its explanatory note and noted that on the basis of the information presented, given the condition's worst symptoms, it was satisfied that there is a significant risk that a person with the abnormality will have or develop a serious physical or mental disability, 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 Familial Myelodysplastic Syndrome OMIM #614286.

## 3. Chair's signature

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

### Signature



### Name

David Archard

### Date

8 September 2016