# Statutory Approvals Committee - minutes

## Centre 0102 (Guys Hospital) – PGD application for XMEN Syndrome (X-linked, magnesium defect, EBV, neoplasia) OMIM #300853

Thursday, 28 January 2016

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

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| Committee members | David Archard (Chair)<br>Rebekah Dundas (Deputy Chair)<br>Sue Price<br>Margaret Gilmore<br>Anthony Rutherford | |
| Members of the Executive | Trent Fisher | Secretary |
| External adviser | Dr Jenny Carmichael | |
| Legal Adviser | Tom Rider | Fieldfisher |
| 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
- two supporting articles submitted by the centre
- 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 characterised as being inherited in an x-linked pattern where there is a 1 in 2 chance of an embryo inheriting the condition where the mother is a carrier.

**1.5.** However, the committee noted further, from the papers provided, that the condition is an extremely rare condition with an extremely small number of cases reported.

**1.6.** The committee noted that the condition affects the body's immune system especially the ability of the body's T-cells to fight disease and often leading to cancers.

**1.7.** The committee noted that due to a compromised immune system individuals do not develop protection on exposure to Epstein-Barr virus and viral persistence affects the immune system adversely. As a result there is a higher risk of developing cancers of the immune system including lymphoma. Individuals are also prone to recurrent respiratory infections.

**1.8.** The committee noted that the condition is likely to demonstrate a high penetrance by late adult life. Age of onset is variable and malignancy appears to develop after puberty.

**1.9.** The committee noted that there is no curative treatment for the condition. Treatment for the management of the condition is considered to be extremely invasive and can be fatal.

**1.10.** The committee noted that the application is consistent with the Peer Review.

**1.11.** The committee welcomed the advice of its specialist advisor, Dr Jenny Carmichael, who confirmed that the condition is as described in the papers adding that it is an extremely serious condition and is life limiting.

## 2. Decision

**2.1.** The committee considered that the condition is serious due to severity of symptoms and lack of any curable treatment

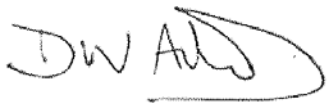
**2.2.** The committee had regard to its explanatory note and noted that on the basis of the information presented, given the condition's worst symptoms, it was satisfied that there is a significant risk that a person with the abnormality will have or develop a serious physical or mental disability, 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 XMEN Syndrome (X-linked, magnesium defect, EBV, neoplasia) OMIM #300853.

## 3. Chair's signature

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

**Signature**



**Name**

David Archard

**Date**

11 February 2016