

# HFEA Licence Committee Meeting

05 May 2011

21 Bloomsbury Street London WC1B 3HF

## Minutes – Item 1

### **Centre 0102 (Guy's Hospital) – PGD for Ehlers Danlos classic type (type I and II) OMIM# 130000 and 130010**

Members of the Committee: David Archard (lay) – Chair Debbie Barber (professional) Jane Dibblin (lay) Rebekah Dundas (lay) (via videoconference) Sue Price (professional)	Committee Secretary: Terence Dourado  Legal Adviser: Tom Rider, Field Fisher
---	--

Declarations of Interest: members of the Committee declared that they had no conflicts of interest in relation to this item.

The following papers were considered by the Committee:

- Revised Executive Summary
- PGD Application form
- Redacted first peer review
- New redacted second peer review
- New redacted correspondence with second peer review
- Genetic Alliance opinion
- Minutes of the Licence Committee meeting on 31<sup>st</sup> March 2011
- Paper by Beighton P (1998) Ehlers-Danlos syndromes: revised nosology, Villefranche, 1997. Ehlers-Danlos National Foundation (USA) and Ehlers-Danlos Support Group (UK). *Am J Med Genet.* 77(1):31-7

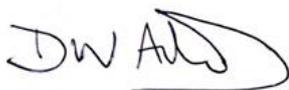
The Committee also had before it:

- 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)
- 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
1. The Committee noted that the item had been presented to the licence committee which met on 31 March 2011. At that meeting the Committee agreed to defer consideration of the item and requested receipt of a sufficiently complete peer review. In doing so, the Committee also requested a clearer explanation of why Ehlers Danlos classic type I and type II were being combined when previously they were treated as separate conditions.
  2. The Chair noted that a second peer review had since been submitted, alongside a paper in respect of the two separate for Ehlers Danlos – type I and type II, which the previous committee had requested clarification on.
  3. The Committee noted that although it bases its determination of how serious a condition is on its worst possible conditions, it did not see a clear statement within the paperwork on the severest effects of the condition, nor how the condition might meet the statutory test.
  4. The Committee was minded to defer the application and welcomed a clearer lay statement in respect of the following factors in order to properly assess the seriousness of the condition:
    - Age of onset;
    - Symptoms of the disease;
    - Whether the condition is treatable;
    - What type of treatment is available for those conditions that can be treated;
    - Effect of the condition on quality of life.

Signed

Date: 19/05/11

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

David Archard (Chair)