

HFEA Licence Committee Meeting

31 March 2011

21 Bloomsbury Street London WC1B 3HF

Minutes – Item 3

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) Anna Carragher (lay) Sally Cheshire (lay) Mair Crouch (lay)	Committee Secretary: Terence Dourado Legal Adviser: Tom Rider, Field Fisher
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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:

- Executive Summary
- PGD Application form
- Redacted peer review
- Genetic Alliance opinion

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 chair of the Committee noted that a personal statement had been submitted. The Committee did not table the document as part of the documentation for consideration in relation to the application because the chair advised that the statement tended to read as if the author was personally making an application for PGD, which would not be considered appropriate given that the committee licences by condition and not on a case-by-case basis.
2. The Committee agreed, however, that it would welcome any additional information from the Centre that deals specifically with the effects of the condition including any anonymised statement from someone who suffers from the condition.
3. The Committee was dissatisfied with the supporting peer review for the application. It considered the peer review did not follow the standard form and had not provided the Committee with sufficient information regarding the condition.
4. The Committee therefore decided to defer consideration of the item until it was in receipt of a sufficiently complete peer review. In doing so, the Committee also wished to receive a clearer explanation of why Ehlers Danlos classic type I and type II were being combined when previously they were treated as separate conditions.

Signed  ... Date 14.4.2011

David Archard (Chair)