

# HFEA Licence Committee Meeting

25 August 2011

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

## Minutes – Item 5

### **Centre 0044 (The Centre for Reproductive and Genetic Health) – PGD for Severe Combined Immunodeficiency (SCID) (OMIM #601457)**

Members of the Committee: Anna Carragher (lay) - Chair Debbie Barber (professional) Sally Cheshire (lay) Mair Crouch (lay) (videoconference) Rebekah Dundas (lay) (via videoconference) Sue Price (professional)	Committee Secretary: Terence Dourado  Legal Adviser: Rosalind Foster, Beachcroft
--	--

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
- Research article
- Email from Consultant Paediatric Immunologist to centre 0044
- Licence Committee papers and minutes – X-linked Severe Combined Immunodeficiency
- Licence Committee papers and minutes – Autosomal Recessive Severe Combined Immunodeficiency with Bilateral Sensorineural Deafness

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)
- 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 it was in receipt of a PGD application for Severe Combined Immunodeficiency (SCID) which had not yet been processed. The Committee had been asked to consider whether PGD for all subtypes of SCID may be carried out under the existing approvals for X-linked SCID (OMIM #300400) and Autosomal Recessive SCID with Bilateral Sensorineural Deafness (OMIM#267500) both of which had been granted by previous licence committees.
  2. The Committee considered that PGD for all subtypes of SCID could not be carried out under the existing approvals for X-linked SCID (OMIM #300400) and Autosomal Recessive SCID with Bilateral Sensorineural Deafness (OMIM#267500). Those applications had been granted for very specific mutations and furthermore the licence committees which considered the items operated in a different context, under the previous statutory regime. As such those committees had been applying different tests to those which were required to be considered under the present Act, and had done so in relation to specific mutations. The approval in relation to the X-linked mutation had been for sex selection and as such had been granted following consideration of the tests applicable to such testing that were in force at the time. The approval in relation to Autosomal Recessive SCID with Bilateral Sensorineural Deafness (OMIM#267500) had been granted following consideration of the specific characteristics of that mutation, again applying the statutory tests in force at the time the approval was granted. As such it could not be said that those approvals authorised the testing of all mutations that caused Severe Combined Immunodeficiency (SCID) and a new application would be required to authorise such testing.
  3. The Committee confirmed that it would welcome an application from the Centre for all subtypes of SCID for it to consider at a future meeting.

4. The Committee considered more generally whether in future it might be appropriate to consider conditions similar in nature to SCID with reference to the general condition, or whether to continue to license by degree (i.e by a specific mutation). The Committee agreed that certain systems, such as the peer review process, would need to be more robust in order to fully review a general condition before such a change might take place. The matter was in any event a question of policy for the Authority to determine.

Signed

Date 14/09/2011

A handwritten signature in cursive script that reads "Anna Carragher".

Anna Carragher (Chair)