

Statutory Approvals Committee - minutes

Centre 0102 (Guys Hospital) – PGD application for Hirschsprung disease OMIM #142623

Thursday, 25 February 2015

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

Committee members	David Archard (Chair) Anne Lampe Margaret Gilmore Anthony Rutherford	
Members of the Executive	Trent Fisher	Secretary
External adviser	Professor John Walter	
Legal Adviser	Dawn Brathwaite	Mills & Reeve
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
- three supporting research publications
- redacted peer review
- Genetic Alliance opinion

1. Consideration of application

- 1.1. The committee, on review of the paperwork submitted, found the application unclear as the application form and the peer review contained information on several different forms of Hirschsprung disease.
- 1.2. The committee was unable to establish whether the application is for PGD for Hirschsprung disease caused by a mutation in the RET gene only (the more common condition) or if the application is for PGD for Hirschsprung caused by mutations in the RET, SOX10, EDNRB or EDN3 genes. The committee considered whether in view of this lack of clarity it could form a view which condition the application related to or whether it needed to adjourn for clarification.
- 1.3. The committee welcomed the advice from the legal adviser, Dawn Brathwaite, who stated that the committee could, if it felt it had sufficient and clear information before it to be satisfied that this was an application for Hirschsprung disease caused by a mutation in the RET gene continue considering the application, or it could adjourn its decision and request further information.

2. Decision

- 2.1. The committee decided to adjourn its decision and to request clarification and further information.
- 2.2. The committee requests that the centre resubmits a more focused application and clarifies what condition/s the application for PGD relates to.
- 2.3. The committee also requests that the peer reviewer clarifies the review, focussing on the genetic subtypes of Hirschsprung contained in the revised application once the centre has resubmitted its application.
- 2.4. The committee would consider a revised application at the earliest feasible opportunity.

3. Chair's signature

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

Signature



Name

David Archard

Date

07/02/2016