

HFEA Licence Committee Meeting

23 February 2009

21 Bloomsbury Street London WC1B 3HF

Minutes – item 3

Application to provide PGD for the avoidance of Sandhoff disease (OMIM #268800), IVF Hammersmith (0078)

Members of the Committee:

David Archard, Lay Member (Chair)	Committee Secretary:
Sally Cheshire, Lay Member	Claudia Lally
Jennifer Hunt, Senior Infertility Counsellor, IVF Hammersmith	Legal Adviser:
Hossam Abdalla, Director, Lister Fertility Clinic	Mary Timms, Field Fisher Waterhouse
Attending via conference telephone:	
Neva Haites, Professor of Medical Genetics, University of Aberdeen	

Declarations of Interest: Jennifer Hunt withdrew from the meeting. Other members of the Committee declared that they had no conflicts of interest in relation to this item, although Hossam Abdalla stated for the record that he was the Director of a London fertility clinic.

The following papers were considered by the Committee:

- papers for Licence Committee (23 pages)
- no tabled papers.

The Committee also had before it:

- HFEA Protocol for the Conduct of Licence Committee Meetings and Hearings
- 7th edition of the HFEA Code of Practice
- Human Fertilisation and Embryology Act 1990 (as amended)
- HFEA (Licence Committees and Appeals) Regulations 1991 (SI 1991/1889)
- Decision Trees for Granting and Renewing Licences and Considering Requests to Vary a Licence; and
- Guidance for members of Authority and Committees on the handling of conflicts of interest approved by the Authority on 21st January 2009.

1. The Committee considered the description of Sandhoff disease presented in the Committee papers. The Committee noted that Sandhoff disease was a rare, genetic, lipid storage disorder resulting in the progressive deterioration of the central nervous system. Onset of the disorder usually occurred at around 6 months and death usually occurred by age 3.

2. The Committee noted the statement in the Executive Summary that this centre had an established PGD programme and has considerable experience in the techniques required. Furthermore, the Committee noted that the application had been reviewed by a peer reviewer, who had recommended that it be granted.

2. The Committee had regard to G 12.3.2 of the Code of Practice which states:

“PGD should be considered only where there is a significant risk of a serious genetic condition being present in the embryo. The perception of the level of the risk by those seeking treatment services is an important factor in the decision making process. The seriousness of the condition should be a matter for discussion between the people seeking treatment and the clinical team.”

3. The Committee also considered G12.3.3 of the Code of Practice, which states that in any particular situation the following factors are expected to be considered when deciding the appropriateness of preimplantation genetic diagnosis:

- the view of the people seeking treatment of the condition to be avoided
- their previous reproductive experience
- the likely degree of suffering associated with the condition
- the availability of effective therapy, now and in the future
- the speed of degeneration in progressive disorders
- the extent of any intellectual impairment
- the extent of social support available; and
- the family circumstances of the people seeking treatment

4. The Committee noted that no information had been provided on the patients seeking treatment. The Committee agreed, on the basis of the information they had about the condition, that Sandhoff disease is a serious and highly distressing genetic condition; it occurs early in childhood and is always lethal, usually leading to death by the age of 3.

5. The Committee agreed that, having regard to the information they had, they were entirely satisfied that PGD was an appropriate treatment for patients carrying the genetic mutation responsible for this condition.

6. The Committee was satisfied that a licence should be granted to carry out PGD for the avoidance of Sandhoff disease, being a practice designed to secure that embryos are in a suitable condition to be placed in a woman (Schedule 2 paragraph 1(1)(d) of the Human Fertilisation and Embryology Act 1990) and agreed that, taking into account all the matters set out above, this is necessary or desirable for the purpose of providing treatment services (Schedule 2 paragraph 1(3) of the Human Fertilisation and Embryology Act 1990).

7. The Committee noted that a signed application had been received from the centre and agreed that it was satisfied that it had sufficient and satisfactory information on which to make a decision on the application.

8. The Committee decided to vary the centre's licence to add PGD for the avoidance of Sandhoff disease.

Signed..... Date.....
David Archard (Chair)