British Fertility Society Response to the HFEA and ACGT Consultation Document on Preimplantation Diagnosis

MARCH 2000

The BFS has considered the Consultation document and a formal response is given below. The current practice is limited both in the UK and worldwide. There is no evidence available upon which the issues surrounding PGD can be fully evaluated. Therefore the response from the BFS reflects opinions of members rather than scientifically based evidence.

The Consultation document provides a comprehensive review of the main issues raised by the practice of preimplantation diagnosis.

Replies have been sought to several detailed questions. Most of these questions relate to the provision of regulation to determine:

- Who will be allowed to receive PGD
- What conditions can be detected and
- Under what circumstances can embryos be replaced when some genetic knowledge of the embryo is known

The BFS agrees that society has a legitimate interest in procedures that may ultimately influence the genetics of the human race. It follows therefore that society has a right to know what procedures are being carried out. There is a significant difference between monitoring practice and regulating it, particularly of the regulation is undertaken by a government authority. Great care must be taken to prevent the rebirth of eugenic movements. Any statutory regulatory authority that is given power by government to allow or prohibit birth of an individual based on identification of its genetic composition, effectively legitimises a role for the *state* in the definition of normality and “acceptable disabilities” .Such powers may be given with the best of intentions to prevent suffering and to prevent the potential use of this technology to allow couples to select genetically “perfect” babies. However, if the state were given the power to decide which genetic tests may be applied, it could be argued that this would legitimise discrimination against disabled individuals. This is not acceptable. For this reason, the BFS recommends that the HFEA should <u>not</u> be given the power to make judgmental decisions about the tests that can be offered for PGD. The HFEA should have regulatory authority (as already exists for IVF) to control the general standards of provision of service including clinical and genetic counselling and laboratory standards. It should monitor the procedures being carried our and their outcome. The decision about which genetic tests can be applied should be made by those who are best informed about the clinical syndrome and by those who will be directly involved with the long term care of the individual conceived. This will be the couple requesting treatment. Appropriate support and advise should be provided by clinicians and support agencies but the parents should make the final decision.

PGD cannot be considered in isolation from prenatal diagnosis (PND). A couple which has the option to choose the genetic makeup of their live born child by PND, as effectively already happens under existing clinical practice, is only disadvantaged by the imposition of restrictions on the practice of PGD.

The terms of reference of the working party were to “consider the practicalities of PGD licensing and the development of a licensing system”. These regulatory issues are covered in sections 53 to 59. It appears that the HFEA has already determined the practical aspects of the licensing procedures including the training and assessment of the biopsy practitioner. Section 57 relates to proposed accreditation mechanisms for genetic laboratories although no details are available. Since details of these systems are not included in the document, it is assumed that they are not to be included in the consultation process. The BFS regrets that it has not had the opportunity to comment on this.

Summary of BFS views

- The licensing process should ensure general standards of laboratory and clinical care including counselling. This approach is consistent with the current regulations under the HFEAct and Code of Practice.

- Centres should not be licensed for each specific test.

- The decision to apply any diagnostic genetic test should be made by the couple after appropriate genetic counselling and with informed consent.

- The HFEA should record the procedures carried out and their outcome.

- The BFS would welcome the opportunity to be involved in the setting of the licensing procedures and regret that these were not available for discussion in this document.