

Mr Thomas Carroll MB BCH BAO FRCSI (Neuro.Surg.) MD
Chairman
UK Fanconi Anaemia Clinical Network

18th July 2998

Dear Mr Carroll,

Thank you for your letter of 30th June regarding the HFEA licensing procedures for preimplantation testing for histocompatibility tissue typing (PGD/ HLA tissue-typing) for Fanconi Anaemia. Your concerns raise very important issues concerning how we handle these sorts of licence applications, which the Authority has considered on a number of occasions in the past and which we need to constantly keep under review.

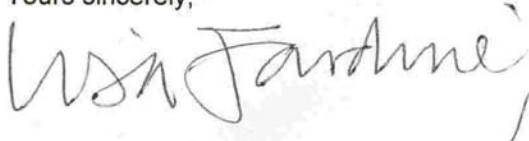
As you state in your letter, all applications to provide PGD/ HLA tissue typing are considered on a case-by-case basis by independent licence committees. This contrasts with certain (but not all) PGD licence applications, where the sole purpose for providing the test is to select non-affected embryos for treatment. However, PGD/ HLA tissue typing remains a highly controversial area of medical practice, as evidenced by the fact that Parliament had a free vote on relevant provisions during recent debates on the Human Fertilisation and Embryology Bill. During those debates, the Government argued against calls to restrict current practice, but stated that it would expect the HFEA's case-by-case decision making for such applications to continue (House of Commons Hansard; 19 May 2008; column 107).

This is consistent with the Authority's policy decision, in July 2004, following a detailed review of the area. This new policy removed any distinction between inherited and sporadic diseases. The Authority also maintained that, given the sensitive, complex and highly controversial nature of this area, licences should continue to be considered by the HFEA on a case-by-case basis.

However, we are aware that our current procedures for PGD/ HLA tissue typing applications sometimes create delays that can be stressful for families awaiting a decision. We therefore welcome provisions in the new Bill which, if enacted, will create new flexibilities for licensing decisions. Although we anticipate that applications for PGD/ HLA tissue typing will continue to be considered by the HFEA on a case-by-case basis, we will be exploring how these new flexibilities could enable us to streamline all licence decision making and ensure that all applications (including those for PGD/ HLA tissue typing) are considered in the most timely and efficient manner possible.

I hope this addresses your concerns ...

Yours sincerely,



Professor Lisa Jardine CBE