



Human
Genetics
Commission

Lord Patel
Chairman
Science and Technology Sub-committee
on Genomic Medicine
House of Lords
London SW1A 0PW

3 July 2008

By email: hbgrd.guidelines@oecd.org

Dear Lord Patel,

I am writing, also on behalf of my fellow Commissioners, to thank you once again for the opportunity to give oral evidence to this important inquiry.

The Committee asked about HGC's activities in relation to the regulation of direct-to-consumer genetic tests. We gave a brief account of the HGC's recent seminar, to which we had invited commercial testing providers, regulators, professional bodies and other stakeholders, and at which we explored the desirability of a Code of Practice.

As promised at the evidence meeting, we will in due course send you a note of the outcome of the seminar once it has been agreed with all the parties involved in the process. In the meantime, a brief summary of the meeting is available on the HGC website.

During the evidence session, we also discussed the evaluation of new genetic tests and we quoted the example of free fetal DNA tests. A short discussion of costs of such tests ensued and we think it might be helpful to clarify that the



costs for some of these unevaluated genetic tests sit outside the tariff system. For a free fetal DNA test, for example, the sample is sent away and an invoice is raised which the referring hospital then has to pay – the cost for a free fetal DNA test currently is £250. The concern is that these tests are unevaluated and present an additional cost to the NHS.

I hope that this clarification is helpful.

Please do not hesitate to contact the Commission if you require any further information relevant to your inquiry.

Yours sincerely,

A handwritten signature in black ink that reads "John Sulston". The signature is written in a cursive, flowing style.

John Sulston
Acting Chair
Human Genetics Commission