

Dear Sir/Madam,

I write in response to the invitation for submissions to the Senate Inquiry into Gene Patents.

I write as a member of the public with the privilege of information and insight gained from my training as a medical and clinical genetic practitioner in the public health services, and have no financial interest in the issue of gene patents.

The arguments put forward include;

1 The gene was invented or manufactured by the companies applying for the patent.

To any lay observer this is nonsense. The gene sequence occurs in nature and was not manufactured or invented. It is comparable to patenting the course of a river or the topography of mountains. The technology used to do this or improve on access to such information should be patentable but not the information itself which always existed.

2 If gene patenting is not allowed it will stifle research and development in the area of genetic disease and stem cell research.

Medical research is not always driven by profit as every doctor who engages in it knows. Association of a company with a breakthrough in medical knowledge such as the human genome or the discovery of mechanisms in HIV infection has benefits to that company in terms of status, staff development and publicity. By comparison, profits could be made from the development of a HIV vaccine, which would and should be patentable. It would be wrong if someone were to patent knowledge of the virus itself such as its receptor binding sites. What is to stop companies making profit by being the best on the market at conducting the test through development of new technologies? Early discovery of a gene sequence will provide market status and a lead in this. The hope of patentable secondary discoveries such as therapies is emerging but real, and gene patenting should not be used as a 'stop gap' for profit.

3 The patenting of disease genes will not prevent good patient care as testing will be available through the company holding the patent.

How would we work if someone could patent the pattern of bony abnormality seen in a particular disease and not allow a doctor to diagnose it if they knew what to look for on an Xray? Patent the Xray technology by all means but not what it detects in the patient.

The patent on the BRCA gene sequence has caused clear and documentable harm to patients. Huge delays in diagnosis have resulted from the whims of the company changing. We have had to abandon trusted local laboratory staff for a distant commercial venture and mistakes have been made. We do not have the same level of communication or accountability for discussion and reporting of complex genetic variations which must be conveyed to the families. This testing is not simple and it has not worked as best practice under a distant monopoly.

4. Companies need rewards for finding the gene sequence.

It seems in all other areas of competition that keeping it to yourself until the opposition has caught up is the only reward, other than the status of being a forerunner in your field. Why should these companies be different?

5 It has already happened. If the US patents this we have to.

Only you can change this.

6 Look at the industry disadvantage in Europe when software was not patentable.

Software is an invention, they got it wrong. Genes are not an invention, this is not comparable.

In all the arguments the gene sequence is muddled with the technology that sequences it. The technology should be the issue of patents, and the gene sequence left in the public domain. To do otherwise will be a monumental loss to common sense and public good. Cadbury did not invent purple, and Myriad did not invent the sequence of the BRCA1 gene. Please do not let this go ahead.

Yours faithfully

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