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Regulating human genetics Transcript

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Regulating Human Genetics

by

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**Professor Hilary Rose and Professor Steven Rose
with Baroness Helena Kennedy, Chair, Human Genetics Commission**

Developments in the biosciences and biotechnologies move at almost frightening speed and present a host of ethical, legal and social prospects and problems. How are they to be controlled and regulated proactively and in the public interest? And can new forms of governance be developed to involve a wider citizenship in advising and decision-making? As part of its approach to these issues, the government has established three new Commissions and Agencies concerned respectively with: agriculture environment and biotechnology; human genetics; and food standards. The first two are advisory, the third, the Food Standards Agency, has regulatory powers. This is a significant difference. However all three new bodies differ from older advisory committees in that rather than their membership being composed of 'the great and the good' there has been an effort to make them more socially inclusive (although not in any direct sense representative), bringing in for instance, disability and environmental activists from relevant NGOs. They are also committed to openness and transparency, which is very different from traditional expertocratic and secretive models of giving advice on scientific issues. Last June Gresham College hosted a unique meeting bringing together senior figures from the three new Commissions together with members of NGOs, from Greenpeace to Genewatch, academics and individual activists to discuss how these experiments in more open and participatory forms were functioning.

This evening we have invited the Chair of one of these new bodies, the Human Genetics Commission, Baroness Helena Kennedy QC, a barrister by training and practice, to join us to discuss the HGC's mission and how it works. The HGC was set up in order to advise the government on how current and prospective developments in human genetics should be regulated in the broader social and political interest. For instance, should insurance companies or employers have access to an individual's genetic profile? What controls should there be on access to individual's DNA and health records? Should the Crime DNA bio-bank hold samples of innocent as well as convicted people?

The HGC has embarked on a wide scheme of public consultation on attitudes to these developments and issues. Amongst the questions we plan to raise with Baroness Kennedy are: What is the remit of the Commission? How are its members chosen? Do they adequately reflect the diversity of standpoints? For example, how many of the Commission have genetic disorders or are carriers of genetic disorders? How does the Commission set about securing wide citizen participation? And, in the light of a number of decisions by the Department of Health that impinge directly on issues of concern to the HGC, how far does the government listen to and respond to its recommendations?