

## The human genome: public not private, global not national

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*The Salzburg Seminar, established in 1947, provides an ongoing forum for international dialogue on contemporary issues of global concern. The Hon. Justice Kirby reports on the seminar that led to the Salzburg Statement on Biotechnology (19 July 2000)<sup>1</sup> and argues that in the matter of human genetics, as for the internet and nuclear non-proliferation, no country can go it alone – nothing less than a global approach to genetic issues will suffice.*

### The setting magnificent

Picture the scene: one of the most beautiful natural settings on earth today; a palace, Schloss Leopoldskron, at the foot of the mountains at Salzburg in Austria – in the distance, the Bavarian Alps. Bus tours circle the lake in front of the palace, for this is where Mozart's patron lived and where, more recently, *The Sound of Music* was filmed. Inside the palace, serious debate is taking place on some of the most important and urgent problems facing humanity – surrounded by gilt and marble, we were discussing the issues presented by human genomic research.

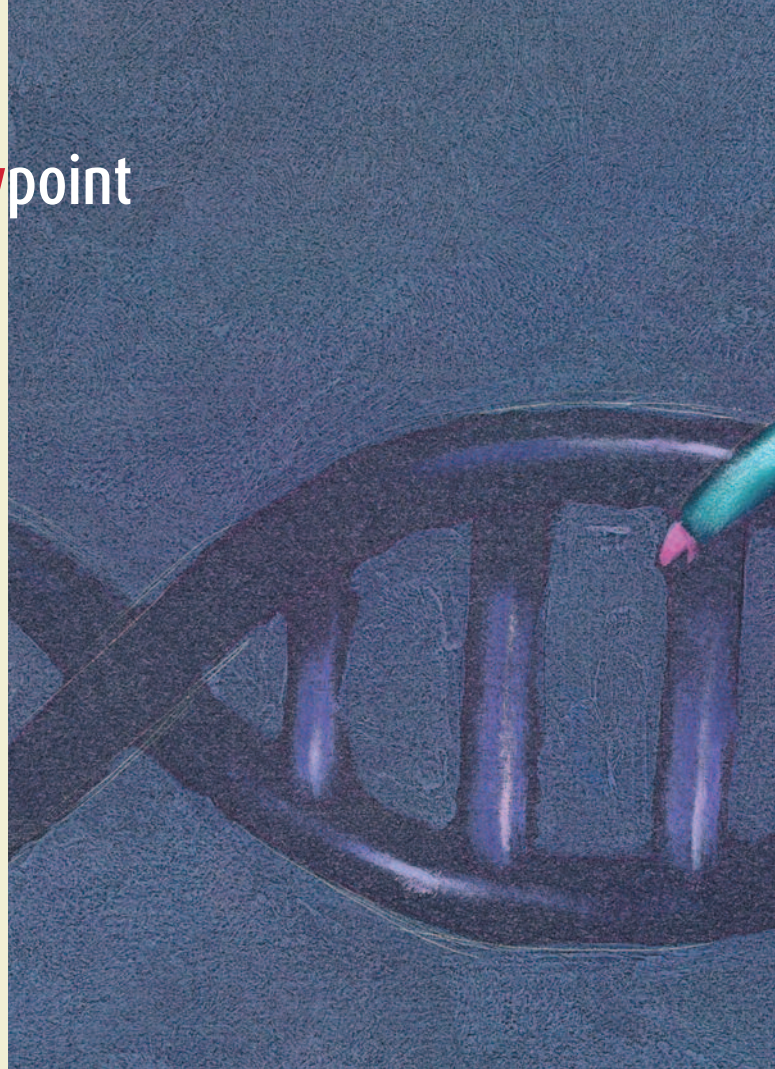
### The participants eminent

Dr James Watson – famed co-discoverer with Francis Crick in 1953 of DNA, the basic source material of life, the double helix on which are found the genes that control our existence – led the debate. Other luminaries attending were:

- Dr Michael Morgan of the Wellcome Trust in the UK – who *Time* magazine has credited with rescuing the publicly funded Human Genome Project when private enterprise enthusiasts in the USA threatened to complete the genetic map for private profit.
- Dr Alan Colman – who, with a brilliant team of scientists in Scotland, produced the cloned sheep 'Dolly'. Dolly and her cousins peered down at us sweetly from his computer

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graphics. 'We don't know how long she will live but we know she loves posing for TV cameras', said Colman. I could not be sure whether he was pulling our collective leg.

- Judge Pauline Newman from Washington DC in the USA – who, at the cutting edge of legal decision-making, decides big patent cases.
- Huanming (Henry) Yang, an exuberant Chinese scientist – who constantly reminded the participants that the human genome belongs to the human species everywhere, not just to those living in the advanced countries who stand to profit quickly from genetic discoveries.

In all, there were about sixty participants from thirty countries, both developed and developing; every continent was represented. Figure 1 shows some of the key participants.

### The dilemmas profound

Organised a year in advance, this Salzburg Seminar, held from 12 to 19 July 2000, could hardly have been better timed. About two weeks earlier, on 26 June 2000, a working draft of the total human genome sequence had been unveiled in Washington DC – the first step to mapping all the genes within the human species.

A sense of wonderment and excitement filled the palace as the scientists carefully and methodically described the human genome project – where we are and where we are going. The identification of these genes is expected to eventually reveal the causes of hundreds of human diseases and the conditions that





make people susceptible to disease. The Salzburg participants were all aware that this breakthrough is likely to lead to therapies that will save human lives and reduce pain. However, they were also acutely aware of the dilemmas that such new knowledge will present. Dolly's photograph was an ever-present metaphor for the potential ethical and legal challenges if the cloning of *Homo sapiens* proves possible.

Dr Watson – who has never sought to make a cent for himself out of his brilliant scientific discovery – has long been a proponent for vigilance about the outcomes of genetic research. It was Watson who had insisted that between three to five per cent of the budget of all US enterprises investing in genetic research should be spent on analysis of the ethical and social issues resulting from genetic discoveries. It was a demand – like the customs of Hamlet's Denmark – that has been honoured more in the breach than in the observance.

### The decisions global

By the end of the seminar, the participants agreed that the issues presented were extremely complex and urgent and more dialogue was needed. Nevertheless, they had quickly concluded that the approaches to genetic research adopted in different countries would have to be developed within the framework of a common international approach.

What is involved here is the very question of what it is to be a human being, how our species is made and how it may be

altered. In a remarkably short space of time – no more than God had taken to create the heavens and the earth, according to the Book of Genesis – the seminar agreed to a statement, the Salzburg Statement on Biotechnology. Among other things, the statement outlined a number of principles to guide the world's responses to the challenge of the genome (see the box on this page).

Given the involvement of a number of participants from developing countries – those that are not among the leaders in the research into human genetics – it is perhaps understandable to see the statement's emphasis on respect for the rights of indigenous peoples. Likewise, the insistence on ensuring that 'the benefits of the genome accrue to all humanity' and a related recommendation that 'technology transfer' to developing countries be stepped up.

### Law and government

Patent law was one of the most vexed subjects discussed, on which tempers commonly flared (including Watson's). The Salzburg participants insisted that international and national patent law should be developed 'to the greatest public benefit'. Rather than long term private monopoly rights, the object of any laws permitting patenting of life forms should be just reward for risk-taking in the creation of new drugs for the benefit of humanity. (But will the big pharmaceutical companies share these fine aspirations?)

At the top of the list of recommendations the statement addressed to national governments was a call to establish multi-disciplinary advisory bodies to address the legal, social and ethical issues presented by gene technology. Such bodies would consider what, if any, regulation or deregulation is required in

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### The Salzburg Statement on Biotechnology: guiding principles for human genomic research worldwide

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- To observe respect for fundamental human rights and human dignity, including respect for the special interests of indigenous peoples
- To ensure health and environmental protection
- To base proposals on a detailed understanding of the relevant science
- To engage in effective multidisciplinary dialogue
- To initiate an appropriate involvement of the public in decisions affecting them
- To maintain respect for different ethical, philosophical, and religious viewpoints
- To recognise the differing legal traditions and institutions that will necessarily affect our responses.



Figure 1. The hills are alive...with the human genome. Some of those who participated in the Salzburg Seminar on biotechnology (policy issues and regulatory frameworks) including Huanming Yang (third from left), Dr James Watson (fourth from left), Dr Michael Morgan (fifth from left), Justice Michael Kirby (sixth from left) and Judge Pauline Newman (seventh from left). About sixty scientists, legislators, policy-makers, public opinion leaders and private sector representatives participated.

this area. Needing special study would be the introduction of new regulations to:

- safeguard individual and family privacy in relation to access to genetic data, particularly when collected by genetic testing
- prevent and redress discrimination against persons on the basis of their genome or the results of genetic testing
- facilitate risk assessment and safety evaluation when new genomic developments are introduced.

### Communication and education

The Salzburg statement also urged improved communication by scientists and technologists around the world about their genetic discoveries, for example, by using language that the general community can understand. Obviously the media has an important role in stimulating meaningful public debate beyond superficial 'gee whiz' reports and alarmist entertainment.

The Salzburg Seminar also urged the improved provision of:

- education concerning the basic nature of the human genome and its implications for science and society
- general knowledge for the community so that informed decisions may be made concerning genomic developments
- courses and information for decision-makers in the legislative, executive and judicial branches of government so that decisions might be informed rather than based on uninstructed intuition.

### What happens now in Australia?

Is Australia affected by these issues? Further, given that Australia is a comparatively small time player in the science and technology of genetics, could anything we do in this country affect the achievement of the Salzburg Seminar's objectives?

On my return to Australia, I found media reports that bore out the importance of these themes. Several gave specific instances of alleged discrimination against patients – the refusal of loan facilities or of full superannuation and insurance cover based on the results of genetic testing. Insurers were said to be offering discounted premiums to people willing to subject themselves to a spectrum of genetic tests but what inference would such a person draw if insurance was then refused? The problems considered in theory at Salzburg have already arrived in Australia. The need for a response is clear and urgent.

On 9 August 2000, the Australian Federal Government announced a national inquiry into the role of gene technology and related human rights, privacy and discrimination issues. The inquiry is to be conducted by the Australian Law Reform Commission and the Australian Health Ethics Committee of the National Health and Medical Research Council – precisely the kind of multidisciplinary body that the Salzburg Seminar proposed.

As the Federal Attorney General Darryl Williams remarked, 'the issues are complex and significant, the science is only in its infancy but the...issues raised are...far reaching'. The involvement of the public and experts is to be welcomed. The established track record of the Australian Law Reform Commission in addressing bioethical issues promises a timely and effective national debate. Some interim laws might be needed to safeguard the rights of vulnerable people while the wheels of law-making grind slowly on.

Science surges ahead. Making sure that our democracy can respond in an informed and timely way to the genome is a major challenge. The Australian inquiry could do worse than to launch its investigation on the basis of the Salzburg Statement on Genetic Regulation. One thing is sure. In the matter of genetics – like the internet and nuclear non-proliferation – no country can go it alone. We are studying the future of our species. Nothing less than a global approach will do.

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### Reference

1. <http://www.salzburgseminar.org/>