

International Workshop on 'Human Genome Project: Legal Aspects'

Empire Day, Madrid.

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EMPIRE DAY 1994

The Hon. Justice Michael Kirby AC CMG*

On Thursday last, in faraway Sydney, Australia, I was dressed in crimson robes. I was confirming or upholding appeals from people who are in prison at this moment, because of decisions by me. On Friday last I was sitting in civil appeals. My first legitimacy to speak to you is because I am a judge. At the bottom line, at least in the common law system, which the English speaking people have followed, the decisions in relation to genetics, in relation to the human genome project, for default of any other law, will be decided by people like me. Judges will have to fill any gaps in the law. Self-evidently, this is a pretty defective system. But it is the result of failing to act efficiently to develop well thought out and principled law. How could that be done? At the national level, the resistance results from the fact that the politicians in Parliament find that the problems of the kind presented by the human genome project are very daunting. No votes in them. Perhaps votes to be lost in them. Nothing tends to be done.

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In Australia, for ten years, I chaired the Law Reform Commission. It helps the Federal Parliament in developing the law. Justice Jean-Louis Boudouin did the same thing in Canada. The Australian Commission, early in its life, was asked to look at the new law on human tissue transplants. That task presented a very crude, but somewhat analogous problem to the problem we are dealing with here. The Commission got together the experts. We consulted the community. We consulted the people who were most involved, as Frits Hondius said we should. We ultimately produced a report which faced up to the hard questions: the definition of death; do you allow infants to donate organs; do you adopt opting in or opting out; do you permit the sale of body parts? Problems of the kind which are being presented in the human genome project in much greater multiplicity and complexity.

On the international level, because this is an international problem, we have an even greater problem. At that level there is a diversity of cultures, religions and legal traditions. But things can be done. In an earlier manifestation of the impact of the technology on the law, I chaired a committee of the OECD looking at the development of guidelines for trans-border data flows and the protection of privacy. Those guidelines were adopted by the OECD. They were accepted by the OECD and recommended to the member countries. Now, almost every member country including my own, Japan, the Netherlands, New Zealand — countries with utterly different legal traditions — have adopted legislation, binding and enforceable in their countries, for the protection of privacy in the context of the trans-border data flows. These laws are based upon, or at least greatly influenced by, the OECD guidelines. It gets a little irritating, to a person from Australia, to sit and listen to what is being done in Europe. Or to sit and listen to what is being done in the United States. The human genome project, like informatics, is a *global* concern. It is not simply a concern to Europe or North America. It is of concern to all humanity: perhaps much more acutely so than informatics. So we have to develop global institutions to deal with this issue. It can be done. In the Global Commission on AIDS, for example, principles are being developed for how to deal with prisoners who have HIV/AIDS. Those principles,

formulated in Geneva, are being reflected in local policy and legislation. So with all due respect to HUGO, I think we have to get something with the legitimacy of governments behind it, which can give the impetus, in a transcontinental way, to the problems of the kind we have been hearing about today and about which we will hear more tomorrow.

There are other matters which should concern us. We have heard of some this morning. The concern of government attitudes. When Karl Brandt, one of the Nazi doctors, went to his death, he said, "I only did what I did for my country in a time of war". And that was the suggested justification for him for breaching the basic principles of international humanitarian laws in relation to scientific experimentation. We may dismiss that. The Nuremberg Code may say that Dr Brandt's excuse was not good enough. But in the recent Operation Desert Storm, in Iraq, the United States government excepted from the principle of informed consent, its soldiers and other operational personnel. It did so because it said this was necessary for the defence of the national interests of the United States.

So when we look at the problems ahead of us, we have lessons to learn from what has gone before. And we also have lessons to learn from this meeting. Most of us are all comfortably off people from the occidental tradition. Almost all of us. This is a problem which concerns, as we have heard, the Japanese. If the South Koreans and the Singaporeans and the Chinese are not there in the scientific developments in great numbers now, they soon will be. Most of them do not share all of our fundamentals. The Confucian renaissance, which we face in the world, starts from utterly different premises: Not the individual, but the community. Not rights, but duties. Not the rule of law, but the rule of powerful men of virtue. So when I hear that the scientists are coming together to talk about the human genome project, I am very glad. But I will be gladder still if we could get together lawyers and ethicists with the scientists. I would be most glad if there were lots of oriental faces about, and black faces about, to deal with issues which are common to all humanity.

As I came here, and no-one came to this conference from further, I thought about the great social experiments of our century. There was prohibition, and it failed. Yet we still bear the scars of it on an international level in our response to drugs. There was communism, and it failed. There is self-determination of peoples. The principles of self-determination are still working their way out. Today, ladies and gentlemen, was Empire Day. This is Queen Victoria's birthday. When I was a boy in Australia, we celebrated it as a symbol of the Empire upon which the sun would never set. Well, the sun did set. The self-determination of peoples works its powerful messages in Yugoslavia and in the Soviet Union.

The other great experiment was eugenics. We have to learn from history, lest we repeat its mistakes.

I have five commandments with which I will finish this session. I would have ten, like the Almighty, but the Chairman has not given me time enough. Perhaps the Almighty should have been similarly limited. He might have left one or two of them off His list.

The first is that not to act, not to make legal principles to deal with the problems presented by the human genome project, is to make a decision. Science will then rush ahead and it will not be controlled in a way in which perhaps, in retrospect, we as human beings would want. Secondly, we should seek to frame our laws on the subject consistently with international human rights law. In these two points I reflect what Frits Hondius has said to this Workshop. Thirdly, and Frits Hondius said this too, we have to consult not only the general community, but we have to consult all involved. All people who are actually or potentially going to receive the benefits and suffer the problems of the human genome project should have a chance to be heard. Fourthly, as in AIDS, we must base our laws and policies on good science, not on ignorance or mythology or even, with respect, religion. But on good science. And fifthly, in order to be effective, we have to find global mechanisms.

In a way, the last command presents the greatest challenge of all. However, it can be done. For the sake of the human genome project and for the sake of humanity,

it should be done. We, who meet here in Bilbao, must play a part to make sure that more is done and that there is a greater sense of urgency in providing society's response to this great scientific advance.