

PROCEEDINGS OF THE LECTURE SERIES
COMMUNITY AND THE NEW GENETICS
HUMAN GENETICS SOCIETY OF AUSTRALASIA
WESTERN AUSTRALIAN BRANCH

APRIL 1996

1996

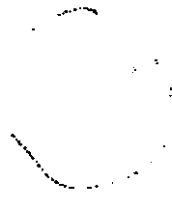
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**Human Genetics Society of Australasia
Western Australian Branch**

**The Proceedings of the Lecture Series
COMMUNITY AND THE NEW GENETICS**

**Edited by Ian Walpole, Betty Durston
and Diane Moore**

**Held at the MacDonald Lecture Theatre, Princess Margaret Hospital,
Perth, Western Australia.
February to December 1995.**

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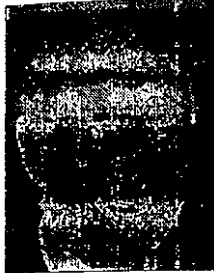
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Legal Issues Arising From the New Genetics

Legal Issues Arising From the New Genetics

Justice Michael Kirby BA, LL.M, BEc, Hon D. Litt (NCSH), Hon LL.D. (Macq)
President, New South Wales Court of Appeal, Sydney (1984-1986)
*Appointed to the High Court of Australia (1996)



Justice Michael Kirby

Past and other current appointments most relevant to this presentation include:

Deputy President of Australian Conciliation and Arbitration Commission (1974) Justice of Federal Court of Australia (1983). Foundation Chairman of Australian Law Reform Commission (1975-1984). Chairman on two Committees of the OECD on Privacy and Data Security. Member of Global Commission on AIDS of WHO. Special Representative of Secretary General of the United Nations on Human Rights for Cambodia (November 1993). Deputy Chancellor of University of Newcastle. Chancellor of Macquarie University (1984-1993).

**Recently appointed to National Institutes of Health and the Department of Energy Working Group on Ethical, Legal and Social Implications (ELSI) of the Human Genome Project (U.S.A.). and to the UNESCO International Bioethics Committee*

*Appointments since presentation of this paper.

I am very grateful to the HGSA, WA Branch for bringing me to Perth. Last night I was in Sydney at Macquarie University giving an address on drug law reform. There was a great mass of people there who were stirring and anxious. I could not understand why they all wanted to leave a discussion of such a fascinating topic. But of course it was the State of Origin match which was on last night! I am glad that I don't have any such competition over here in Perth tonight.

When I was a little boy at the Summer Hill Opportunity School on the far side of this continent. I remember a day vividly in about 1950 when two grey coated departmental officials came to the class room, handed us little documents and in them we were asked, "what do you want to be when you grow up?" After deep thought at the age of 10, I wrote, "I wish to be either a Judge or a Bishop" (one way or the other I was determined to spend my working day in fancy dress). Well, you've had a Bishop, indeed an Archbishop in this Lecture Series. Tonight I'm here as a Judge and citizen. Yet I want to start in the manner of a Bishop with a number of texts. Let me start with the following extract from *The Australian* which is headed, "Gene Debate Hijacked by Hysteria". It reads, "Illusionary fears of Frankenstein's laboratory have hijacked the debate over the use of genetic technology, clouding the positive aspects of gene therapy in the cure of disease, leading scientists told a technology forum this week". The Director of the Walter and Eliza Hall Institute of Medical Research and President of the Australian Academy of Science, Professor Sir Gustav Nossal said, "interference in genetic make-up of humans exists only in the imagination". "It's all fiction, it's not reality, not in any lab in the world". The Professor continued, "Let's keep this debate on what is possible now and will be possible in the next 30 years. Let's not allow the debate to get hijacked by people raising illusory fears, much of which can't happen". "I believe the gene therapy era is going to be something of huge benefit to humankind and something not to be portrayed to the lay

public as holding any terrors. I think there's a lot of mistrust in some sections of the community but I think it's misplaced. Scientists have a lot of constraints on them. It's quite a regulated industry". Professor Sir Gustav Nossal is President of the Australian Academy of Science. He is a most distinguished Australian. He is a friend.

Along the same lines have been comments in *Nature* by John Maddocks in an article, "New Genetics Means No New Ethics". Dr Maddocks in *Nature* in July 1993 expressed the view that there was no need to be alarmed and that there were no substantial dangers. That "it is usual for Hitler to be thrown into this debate". Yet he says at the end of his statement, "Geneticists are fond of saying, it will never touch the germ line"! But that is unwise.

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In our own National Health and Medical Research Council Guidelines, which are part of the Statement on Human Experimentation, supplementary note number 7, Rule No. 2., says that all attempts to introduce pieces of DNA or RNA into human cells should be considered to be experimental and subject to the statement by the NHMRC, "Human Experimentation and Supplementary Notes". It further states in one of the instructions that as to the technique of insertion in the germ line experiments in animals is a prerequisite. It is necessary in humans to confine the insertion of DNA and RNA into intended somatic cells without entry into germ cells. This is supplementary note No. 7 titled: "Somatic cell gene therapy and other forms of experimental introduction DNA and RNA into human subjects".

When I was in New York for the presentation of my report as the Special Representative of the Secretary General for Human Rights in Cambodia, I was sitting at breakfast on the 22 November 1994 and opened my *New York Times* to find a front page story about a report which had been presented the day before to the American Academy of Sciences by a Dr Ralph Brinster, a researcher at the University of Pennsylvania. Dr Brinster had focused on a group of early stage sperm cells called stem cells which arise in the testes and are the source of sperm that males produce. Stem cells can divide to form more stem cells or more differentiated cells which continue along a developmental path and lead to the production of sperm. Dr Brinster was experimenting on mice. Since the stem cells are the genetic source of all sperm cells, genes inserted into the stem cells will appear in all the sperm derived from them and those known marker genes in turn will appear in every cell of the animal's offspring, altering its lineage. Dr Brinster and his colleagues found that they could gather stem cells with known gene markers from the testes of mice. They could then inject the sperm stem cells into the testes of other animals and see the marker genes' effects upon the next generation. The commentator who worked with Dr Brinster said that this could have far reaching clinical consequences for testing infertility and genetic disorders. I don't think he was considering only mice.

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I have four capacities in which I have some relevance to speak to you tonight. The first is as a Judge. Our legal system is a very interesting one. When I go to a country like Cambodia I see the great difference between a country like ours that can boast a continuous legal tradition of 8000 years and a country that can't. In our country, in our legal system (the common law) there is never a gap. If ever there is no law it's left to people like me to develop the law by analogy from earlier cases. That's the doctrine of precedent: expanding and developing old cases to meet new circumstances. If in any of the problems that I mention tonight there is no law and Parliament doesn't make a law, then it's left to the Judges to develop the law by analogy to past principles of the common law. This is the fail-safe system employed in our sort of society against having gaps in the law and silences about important matters. So that is my first relevance to comment upon

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the issues of human genetic developments, human genetic research and the problems that it presents to our society and the law.

My second relevance arises out of my work for nearly ten years as Chairman of the Australian Law Reform Commission. That Commission had the task, on projects which were assigned to it by the Federal Attorney General, to develop the law in areas which were often at the frontier of law making. For example, one of the first tasks which was given to the Law Reform Commission was to develop the law on tissue transplantation which was then becoming an important feature of medical science. The law on that subject had been pretty imperfect and often silent. Rather than leaving it to the chance that Judges would develop it and do ~~it~~ in a sensible and informed way, the Law Reform Commission was given the task to develop the principles. So it did. Those principles became the basis of the law on tissue transplants throughout our country. The way in which the Law Reform Commission achieved that success in a country that really cannot boast many laws which are uniform, I'll mention in a moment. It has quite important lessons, I think, for the way in which we ~~have to~~ ^{should} tackle the problems that are presented to us by human genetic developments.

The third relevant capacity relates to the fact that, at the moment, I am the Chairman of the Executive of the International Commission of Jurists (ICJ). The ICJ is based in Geneva. It's a world-wide body. Its commitment is to three things. Two of these are the protection of human rights and the rule of law. Both of those are very relevant to what I'm here to talk about tonight. So far as the rule of law is concerned, you can't have the rule of law if on important matters which touch features essential to society, the law is silent. Although in theory the Judges can develop the law, if the law is silent because the democratic legislature hasn't attended to the development of the law then we don't really have the rule of law. We have the rule of silence. The International Commission of Jurists a year ago was looking ~~to~~ ^{at} the next century and trying to decide what would be the important issues for human rights in the next century. One of the issues which it put on its agenda as one of the important questions for human rights in the century to come, was genetics, the Human Genome Project and its relevance to the human rights of people everywhere.

^{about} But it is the fourth capacity which really brings me to speak to you tonight. It arises out of the fact that because of the three capacities that I earlier mentioned, I was invited exactly two years ago to attend a conference in Bilbao, Spain, on the subject of the Human Genome Project. I went there with the relative ignorance of the Human Genome Project that probably most lawyers have. In a sense, my eyes were opened to the tremendous importance of this project for humanity, for science, for medical research, for medical assistance, indeed for all of us. I was really rather alarmed at the lack of knowledge in my own profession, the law, and of the lack of debate in my own country about the implications of the Human Genome Project and the genetic research technology which it signals and which it facilitates.

At the conference there were four Nobel laureates, Carleton Gajdusek who is ^a Nobel laureate for 1976 in medicine, Jean Dausset, Nobel laureate in medicine, Sir Ervin Klug, Nobel laureate in chemistry, Dr Hamilton Smith, Nobel laureate in medicine. There were other people from different legal traditions. Of course there were a lot of Spanish jurists and scientists. But one of the most important people there was a member of the French Constitutional Council, Madam Noëlle Lenoir, who is now the Chair of the UNESCO Committee which is looking at the legal and ethical implications of the Human Genome Project and of genetic research.

The occasion was the 40th anniversary of the famous letter by Watson and Crick to *Nature* in April 1953. It was then that they wrote their letter in which they indicated that genetic messages, important for our genetic composition, were to be found in the DNA. They defined the ways in which the DNA could be unravelled. They indicated its importance in terms of the future of life sciences. The human genes which Watson and Crick disclosed number approximately 100,000. Since their discovery the Human Genome Project has been developed as probably the most remarkable international cooperative scientific endeavour, certainly in the life sciences and probably of this century. Its purpose is to map the human genome. Many analogies were drawn between the great Spanish cartographers who had mapped the then known world and the cartographers of today who, turning inward upon the human genome, are mapping it entirely by a cooperative endeavour across the continents involving scientists in all parts of the world.

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Genetic research is not only important for human beings. It is also important in animal husbandry in the development of pigs, chickens, "super cows" and the perfect lamb. However, in terms of the human genome and human genomic research, the research has already led to the discovery and identification of important markers for very serious human medical conditions such as Huntington disease, muscular dystrophy, cystic fibrosis, sickle cell anaemia, "Fragile X" syndrome, Alzheimer's disease and various forms of cancer such as melanoma, breast and colon cancer. The search is on for the gene markers which identify all such conditions. The issue which was examined at the conference in Bilbao was what implications this had for the legal system and for the principles of ethics which underlie the development of any legal system. What implications did it have for the development of the law? What should we, as lawyers, know about it? What should we do about it?

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During the course of the debates by participants from various parts of the world and different legal traditions, a number of issues were identified as critically important. Over riding them all was the issue of democracy itself. How in a society of parliamentary democracy, do we ensure that our representatives in parliament face up to the growing number of problems and issues for the law which are presented by the Human Genome Project and the human genomic research technology that goes on around it? Various ways in which this should be done were identified and discussed. Various degrees to which it should be done or not done were discussed. Whether the development should be left entirely to self regulation, as Sir Gustav Nossal had suggested, was hotly debated. Whether, at least in certain areas, the law should step in and set the standards was a matter for anxious concern.

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A second critical issue was the question of human rights. How do we identify the human for the purpose of human rights. How do we ensure that the fundamental integrity of each human being is being respected and preserve and protect for each human being the right to knowledgeable informed consent about medical procedures which affect him or her. The whole principle of human rights is founded on the integrity of the individual. In the last month or so we've been seeing the shocking pictures of the opening up of the camps at Auschwitz and Dachau fifty years ago. We can see how sometimes in human history, evil people and gangsters get control even of civilised societies. They present a warning to us which we ignore at our peril.

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Bilbao

Much of the time in the conference was addressed to issues which were specifically lawyers' issues, relevant to human genetics and new genetics. For example, the question

of confidentiality. At the very time that privacy is becoming such an important issue in societies such as our own, along comes a means of intruding into the very being of individuals and finding out aspects of the individual's genetic make up which will provide markers which will provide accurate predictors as to the future medical history of the individual. Should the individual have an absolute right to prevent others having access to such information? What principle should govern the right of access to the information? Should a person for example, sometimes be under some legal obligation to provide it, given that we can now get this data, to inform a future spouse or partner of the data, as being relevant to the future development of the person and their children? What risks of genetic discrimination exist? What if a person doesn't want to know the genetic markers? Should such information only be provided to the individual at that individual's knowing informed request? Or are there some circumstances where at the request of others, for example members of the family, such information should be able to be obtained? What are the principles of consent and authority of law that should provide for access to such information? The importance of confidentiality was generally acknowledged. The importance of informed consent in undergoing genetic testing was also acknowledged. But the way in which these principles of a general character would be worked out in particular cases was accepted as presenting issues of great complexity and difficulty.

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A second lawyer's question ^{which} that was debated at considerable length was the issue of culpability. Our criminal law works very much on the principle of free will. That is to say that those who do antisocial acts have a free will to determine whether they will do an antisocial act or not/do so. Yet in the face of genetic markers, for example a genetic marker which might identify some cause for aggression in a particular person, is the notion of free will still a viable ~~notion~~ ^{foundation} on which to build our criminal law? Can we really assume that people voluntarily and with the evil intent that the criminal law postulates, commit crimes against society? Or at least in some cases, ~~with~~ ^{is} the individual ~~is~~ simply the victim of the genetic messages? I think nowadays we're noticing, especially with Attention Deficit Disorder (ADD), that there are some children who, ^{by reason of this} condition, are committing antisocial conduct. Whether this is of a genetic origin or simply determined by their environment, I am not competent to say. But certainly some people, by predisposition, appear much more likely than others to commit antisocial conduct and to end up in courts before people like myself.

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I suppose the hottest debate at the Bilbao conference and in much of the literature relates to patents. It is in patents that can be found the economic incentive for much of the research which is taking place. In the United States there are 35,000 applications for patents pending at the moment in respect of genetic research. In Europe 13,000 are ^{lodged} at the European Patent Office in Munich. The development of the law of intellectual property has not kept pace with the development of genetic research. It's ~~the~~ interesting ~~thing~~ to reflect upon the fact that Watson, when he wrote his famous letter ~~in~~ in 1953, took no steps to seek any form of patent or any other protection for his discovery. He simply provided it as part of the common scientific information of humanity. At the conference in Bilbao there was a great deal of criticism, especially from developing countries, at the pressure to secure patents particularly in the United States of America. These were criticised as being an endeavour to introduce a form of neo-colonialism of a new variety whereby American corporations would have effective control over the development and access to much of the product from research upon genes which, it was said, were the common property of all humanity. ^{Participation} Countries such as Argentina felt that far from promoting access to new benefits, it was likely that they would not have ready

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access, nor would their scientists be able to pursue the research. If genetic discoveries were patented, they would be closed off from that form of research.

Insurance was also a matter which was extremely, hotly contested because the conference came at a time when a report had just been produced in the United States of America on the relevant rules that should govern the insurance industry of that country. Whether there should be any limits upon access by insurers to genetic data was disputed. Some people said, "Of course there should be access to such information. We permit insurers to get raw data at the moment about whether a person smokes or doesn't smoke". Those of the contrary view pointed out that the whole object of insurance was to spread the risk of unhealthy conditions and life threatening conditions, so that amongst the policy holders the policy holders were pushed into a pool which would be provided to spread the risk in a way that was based on the best possible available information. There were many critics who said that if the principle of access were pushed into the field of genetic markers, people who had not received proper genetic counselling could be forced into securing information on their health which they didn't particularly want to know. This would burden them with information that they didn't need and prevent them getting access to insurance, or increase their premiums in a way which, in their former state of ignorance, would not have occurred. Is this something that should be permitted, or should it be restricted? What principles should govern access to such information about gene markers? and any obligation of the policy holder to undergo such tests? All of this was the subject of a very hot debate which was informed by the report of the United States committee.

Many other issues which included the question of DNA identification, evidence and the like (were discussed) But the general feeling at the end of the conference was one of optimism. It was generally believed that we should look forward to the benefits of human genetic research. We should remember the importance of diversity and should not seek to promote or even permit a monochrome uniformity.

When issues of the future arose as to whether parents would be able to insist upon children of a particular height, or a particular skin colour, or eye colour, there that was something upon which the law could draw a line. The most telling moment came at the end of the conference when the four Nobel laureates made what for them was an impassioned plea. They said the one thing we must not do is to permit scientists to touch germ cell lines because we don't currently know enough about this area to anticipate unpredictable developments that might occur with the manipulation of human germ cells.

If we can believe the statement of the President of the Australian Academy of Scientists, then that is a problem which we don't have to worry about for 30 years. Yet we can look at the research of Dr Ralph Brinster at the University of Pennsylvania where already he is dealing with the primitive sperm cells of mice and sending into future generations, genetic characteristics which may be traced through the progeny of the mice over future generations. There being no scientific reason or technological reason to prevent it, I think the question is acutely posed, "Is this something that can be translated into the human species?" Well, what is stopping such developments at the moment? Is self regulation guidelines such as are produced in Australia by the National Health and Medical Research Council. It may be that there are also certain contractual obligations, in particular laboratories. It may be even that there are trust obligations or employment duties. But Australian society has not spoken on this matter. It has certainly not spoken through its Parliament. Therefore, the question is I think, presented to us, whether or not it is safe "for 30 years" simply to allow this matter to proceed in laboratories around

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the world. Or whether there may not be many Ralph Brinsters who, looking at the development, are seeking to pursue their intellectual curiosity, also perhaps for their economic advantage or that of their institution? It's notable that Dr Brinster announced that steps had been taken by his laboratory to seek a patent on the development which he was pursuing. It was explained to me during my attendance at the conference in Bilbao, why so many American scientists are breaking with the traditions of the past and had pursued patents. The answer is really quite simple. About 10 years ago the Congress at the United States enacted a law that imposed a duty on institutions who receive Federal funds in the United States to apply intellectual property protection to the novel developments and inventions that they make. If they don't, they run the risk of losing the Federal funding ~~that~~ they receive. Therefore, there is acute pressure upon those institutions to pursue the protection of the intellectual property. Of course once that pressure was applied, and it was soon seen that there were very large profits to be made out of the commercial exploitation of the biotechnological developments, the pressure which was at first that of the Federal Act in the United States became a commercial pressure. It's the combination of these two things that has led to the 35,000 applications for patents in biotechnological developments in the United States which are pending at this time.

On the 4th March 1995 a development occurred in the European Parliament which is important to call to your notice. The European Parliament had before it a draft Directive from the Commission of the European Union, the organisation we used to call the European Economic Community. The Directive was the result of six years work amongst the bureaucrats consulting the industry groups and consulting other bureaucrats. The matter went through the process of consultation which was laid down by the Maastricht Treaty. It went up to the European Parliament for formal ratification. But it was rejected by a vote of 240 to 186 with 23 abstentions. The rejection was unexpected. It was the first time the European Parliament with new powers to reject Directives from the Commission of the European Union exercised its powers. The pressure against adoption of the Directive came largely from the environmental groups, including the Greens. But ultimately they were joined by a large section of the socialists in the European Parliament. I think there's a lesson for us in Australia and in other Western countries of this development. It indicates that you can have the consensus of industry, the agreement of the bureaucrats, the wise nodding approbation of the lawyers, but ultimately, in a democratic society, you have to bring developments on the issue of the law as it touches genetic research, to the representatives of ordinary members of the community. That's as it should be. That is the rule of law. The Directive was concerned with a provision which would have permitted the patenting of life forms. The environmentalists said that was an insult to humanity, an offence to the common property of humanity. It was permissible to patent an invention such as a particular drug but not actual gene markers, a part of the genome itself is. ~~that it is valid to patent an invention (gene construct) that will affect the genetic makeup of a human being, but not possible to actually patent the marker or the genome because that belongs to nature; to humanity. It doesn't belong to any particular scientist or research institute and still less does it belong to any particular corporation. The corporations have a right to be protected for their investment in their inventions but they don't have a right to patent part of the genome itself.~~

The Times newspaper made the point that I've just made to you. Without proper thorough public debate you're not going to be able to get legislatures, which are responsive to the anxieties of the kind that were mentioned in the European Parliament,

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to agree to Directives of the kind that the bureaucrats and the experts in intellectual property law had developed. Not everybody took the absolutist stance that the environmentalists did. Some just didn't like the particular measure that had been developed. Others said that what was needed was some form of intellectual property protection which was different in quality from the patent. They felt that a patent provided protection which was too complete and too long and that what was needed was something which would not prevent other basic research on the human genome for the benefit of humanity. But whatever the reason for the dispute, the Directive failed to come as something of a surprise to a lot of bureaucrats after six years of work on it.

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What can be done about the problem which is presented in microcosm by the experience of the European Union and which if we in Australia address issues of the same kind will present themselves to us as well? When I spoke at the conference in Bilbao I suggested that the answer was to be found in procedures such as the Australian Law Reform Commission had adopted in its work on the highly controversial issues of human tissue transplant in 1977. Procedures included were not unlike this meeting tonight, the use of consultation with experts, with the community, the use of the media. But there is more. The use of the discussion papers, the drafting of legislation, thorough debate, carrying the community and identifying the controversial areas. Should we have an "opt in" or an "opt out" system for tissue donation? Should you have to actually volunteer that your organs will be available or should you be deemed to be a donor unless to have opted out of the system? Should there be a provision for somebody to give consent for children? Should there be access to cadaver body parts for use for the development of serum? Should there be a system of paying or not paying for body parts? All of these issues were identified, debated, discussed. Within the Law Reform Commission there are often disagreements. But they were presented clearly. The political process was helped to resolve many of the issues. We got, at the end of the day, a uniform law which is still in force in this country.

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Since the Law Reform Commission dealt with issues such as corneas, kidneys and body parts, other similar problems have arisen in the world. There has been development of IVF and the transplantation of life itself. This raises issues that are, in many ways, generically different from the issue of transplanting a cornea. The Canadians set up a Royal Commission in 1988 to look at the issues that were presented to the Canadian society by reproductive technology. The result was a tremendous disagreement within the initial Commission. Of the seven initial Commissioners, four came to the conclusion that the Commission was not approaching the matter in a proper way. They went first to the Privy Council Office in Canada. They asked what they could do to stop the other Commissioners from reporting. The Privy Council Office said that there was no way the government could interfere with the running of the Commission, and it would just have to be left to them. Subsequently, the government sacked four of the Commissioners and appointed new ones. The result was tremendous controversy in the Canadian community and the production of a report which has been very severely criticised. So I don't underestimate the difficulty, especially in a matter as controversial as genomic research, of consulting the community meaningfully and getting an informed opinion from the community, as distinct from immediate reactions.

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Not to take a step is to make a decision to simply leave genetic research and development entirely to self regulation. This is to accept that the Dr Ralph Brinsters of this world in their laboratories, working with their imagination and in the hope of the economic advantage that will come from the intellectual property protections that they can secure,

will go ahead anyway. They will do what they think is right. Now there may be some who will say, "Well, that's something we have to tolerate", and in effect that genetic research is in the mind of human beings *and to that extent safe.*

Product of genome research

It is simply the next stage of the development of science which is itself a product of the human species. *In this sense*, the human species ~~is itself not~~ capable of stopping a dynamic process so important, so radical, so universal, so global. That may, in the end, be the conclusion that we reach. But if it is a conclusion, let us reach it rationally after a full appreciation of its implications, both for ~~individuals~~ *the* and for our society and for our species. That really is what I came to say to you tonight. Before I conclude I would like to give you a little poem which will be in my mind as I cross this continent again tonight. It is by the great Australian Aboriginal poet, Oogeroo (Kath Walker) *It's relevant to our topic:*

*Let no-one say the past is dead
the past is all about us and within
haunted by tribal memories, I know this little now
this accidental present is not the all of me
whose long making is so much of the past.*

*No walls about me, the stars over me
the tall surrounding trees that stir the wind,
making their own music
Soft cries of the night coming to us there,
where we are one with all old nature's lives
known and unknown
A thousand thousand campfires in the forest are in my blood*

*Let no-one tell me the past is wholly gone
now is so small a part of time
so small a part of all the race years
that have moulded me
Each individual, each one of us
is the product of all those race years
that have moulded us*

THIS IS PART OF MY TEXT NOT OF POEM

The four Nobel laureates explained their opposition to interference with the germ line by saying that the way in which humanity had survived the many assaults on it, of pestilence and plague, ~~was~~ because of its variety. We have to be very careful that we don't embark upon manipulation, at least at the germ line, without very great forethought. It would be prudent, said the four laureates, not to touch the germ line. I think that's an important lesson which we should reflect upon. It is one which I support.

Discussion

Professor Fiona Stanley, Institute of Child Health Research, Perth

Thank you very much for a very erudite talk. I have two questions. The first, I just wonder what your opinion is of how we've done in other areas of medical endeavour? Are there parallels which we can call upon? How do we rank in the past as to how we've managed to control ourselves and what research has done. The second question arose from your interesting talk about the meeting in Bilbao and I wondered how much the

differences between countries in their legal systems and ethical and cultural differences played in your discussions. I'm interested in the current litigation and how much more litigious the American system seems to be and how it drives decisions in medical science and in public health. I think there are some frightening and concerning issues there for us who are trying to get good debate about important decisions in medicine and when you have the fear of the individual litigation overriding the public good. I think that there are messages there, not just for genetic research but for much research. I'm just interested in those two areas.

Justice Kirby

Thank you very much for those two questions. First, analogies. I've given one analogy and that is to human tissue transplants. I think there are some lessons to be learned in that rather less controversial, much more self contained, smaller and identifiable problem area. Another area that I think has a lot of lessons for the way in which we deal with the provision of information and the provision of counselling is in connection with HIV. After all that involves the introduction of a virus into a human being. It presents some of the same problems as are presented by the new genetics. For example, should we test or not? If a person doesn't want to know their status, is it nonetheless important for them that they know their status? Is it important for them so that they can warn and protect others? Is it important for them so that they can get the best possible treatment which is available to mitigate, though not at the moment to cure the condition as it develops? Is it important that they have the test so that their family can be informed or so that steps can be taken for the preparation of the development of the condition? What counselling do we give before the test is undertaken? What counselling do we give a person immediately after the test is taken?

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There were some absolutely heartless stories in the early days of the epidemic. I hope it doesn't happen now. They involve people simply being told in a brutal way the results of their HIV test if they were positive and having to bear that burden without assistance, advice, counselling, support or information.

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There have been cases for example in Sydney (I hope this isn't repeated) where family and friends coming to visit a particular prisoner have been told, "Oh, yes, he's over in the AIDS ward". They learn in that way for the first time, that the person is HIV positive.

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I think generally speaking we in Australia have done well in coping with the AIDS epidemic. I suspect that's because we had at a critical moment in our history in the early 1980s when there were two people in Federal Parliament who I regard as princes among politicians, Neal Blewett and Peter Baume. It just happened that we had on the opposite sides of the Parliament at a critical moment, two people who were willing to take a position which was above party politics in support of our community and in support of the people who were infected. They are the sort of analogies that I would draw. I would hope that we can find similar leaders who will take an interest in this issue. I don't see many of them around at the moment. I hope that this series which is really a remarkable series, which is so thoroughly admirable that needs to be replicated in all parts of our country dealing with the greatest issue of the human health sciences of this century, will promote a public debate. It should engage people from religion, like the Archbishop of Perth, and jurists, medical scientists. It's a wonderful thing that this is being done here. It's what got me to come here tonight.

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You raised the question of the different cultures. That's a very important issue because I have to say that the people who gathered in Bilbao were basically people of the Western

tradition. There were a very small number from Japan. Overwhelmingly they were people, as one might expect from a conference in Spain, from the Spanish speaking countries of Latin America and from the United States, Canada, Europe and Australia. It's very important that we ~~try~~ engage the other communities in the world. There can be little doubt that the countries of East Asia which have such skills in this sort of area, will very soon enter major genomic research and technological development flowing from it. Then it will be more difficult to gain a consensus as to moral principles. At least we in the West begin from the position of a generally shared moral recollection of principles of a common religion. In terms of other communities, whether they are Buddhist or Confucian or Islamic or just people who don't have any religion at all, ~~who are~~ humanists, it's not at all certain that it will be easy to secure a common approach to the ~~sort of~~ problems ~~that~~ I have presented. For example, in many of the Asian communities I think they might well wonder what all the fuss is about in terms of confidentiality and privacy. Notions of individual privacy are not as important in those traditions generally as they have been in ours. No doubt there are some matters that are more important in their tradition than in our tradition. Their concerns and perspective will be different. But ultimately we all come together in a common human species with a common human genome which is completely undifferentiating and undiscriminating and which presents in the new genetic research a challenge to the whole of humanity. That's why bodies such as UNESCO have set up committees to look at the legal and ethical and social implications. We should support their work and seek to follow it.

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Unfortunately HUGO (the Human Genome Organisation) despite lots of prodding from people like me is really just basically scientific. ~~They're not really interested and they don't have the money or expertise to evaluate~~ the legal, ethical, moral questions. It will be a tragedy if the scientists rush ahead, ~~because~~ the net result of it, at least in societies like ours, is what happened in Europe. The scientists and the bureaucrats will be able to agree. Industry will smile. But it will get to the point of the people in their legislatures and it will be stopped. That, I think is the peril of which I must warn in the light of the development in March in the European Parliament.

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We in Australia ought to do better. We ought to have the ^{assurance} legitimacy that our voice can be lifted in this debate, by being an important country in the new genetic research. If we're simply raising our voice in the ethical and legal debate and not doing very much of the research, then people will say, "who are you to speak on this subject"? They won't then pay much attention to our voice. Let us have legitimacy in the research and in the application of the research. But let us share the problems and issues with our community so that we can develop principles which are ~~hid down~~ by the whole of our society and hopefully reflect universal values. Whether our societies were Islamic, Confucian, Buddhist, Christian or simply humanist there would be consensus, for example that there can be no crossing of a human and animal species. There would be probably consensus that certain developments on the human species should not be permitted. But where do we draw the line? Research in England in the last couple of years has shown that the number of parents who said they would like to know if their child had a marker for alcoholism rose in the space of two years from 5% to 12%, and therefore if that is possible, what is next? A marker for fair hair? A marker for proneness to obesity? Five percent of parents asked the question said, "yes, we would like to have knowledge of a marker for good looks". Whether there is such a marker or not, the fact that 5% of parents have said yes to that question is an indication of the sort of peril that lies ahead and the difficult ~~and~~ drawing that will be presented to society of what is permitted and what is not permitted, and who will draw those lines? Is it to be left entirely to scientists?

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Or will there be institutional arrangements in our society to help the scientists provide principled answers?

Jack Goldblatt, Director, Genetic Services of Western Australia

Is there any legal forum in the country when these issues are being proactively debated or are test cases awaited?

Justice Kirby

There is a test case in the Federal Court at the moment which is the Australian reflection of litigation I think it's by the Shiron Corporation in respect of the Hepatitis C vaccine which they are seeking to prevent others from invading as they say, their patent. So there are test cases of that kind principally in the area of intellectual property law, protection of patents. That's where, if I can be excused for saying it, the big bucks are. As to whether there's a legal debate in the community I think I have to say to you that there isn't. *is not.*

When I came back from Bilbao I felt it to be my ~~moral~~ obligation to do something about it. So I wrote an essay which was published in the *Australian Law Journal*. It drew a lot of attention. In fact, a lot of people commented on how important and complex the matters were. But then they went on to the articles of association of shopping centres which are rather more easier to cope with and to solve. It is important that we raise the debate in the legal profession. I'll keep on going away and stumping the country to try and get not only the legal profession, but the community generally and the scientific community to engage in debate such as we're having here tonight. We need that going on all over the country. This is the greatest development in the health sciences, the human sciences this century. It has legal implications. *we should be aware of them.*

Brenda McGibbon, Student, Murdoch University

What I was wanting to know was whether you think that the law in Australia with respect to abortion is adequately equipped to deal with the increasing diagnostic and prognostic abilities in the medical field because it seems that the prohibition against abortion is in our criminal law but it's developing in case law at different rates in different jurisdictions. Do you think that's an adequate system to deal with it?

Justice Kirby

Can I give that question an answer with two points. First, I'm an old stager who's been around for 20 years in public office. You would realise that that's a matter upon which there are very strong community differences about which a Judge has to be a little cautious. Secondly, as it happens, I have reserved at the moment in my Court, an appeal from a Judge who held that a woman who was not informed of ~~her rights for abortion~~ had no cause of action. ~~Therefore, that is a matter on which I will have to give a judgement, and I think if I started talking about the subject now, people might say, "Well, maybe one day he'll share his views with us in the judgement. But why did he go over to Perth to talk about the case?"~~ If you would like to give me your name I'll send you a copy of the judgement when it comes down, which will be in a few weeks time. I've just got to be a little cautious on some topics. You're absolutely right of course that the issue of abortion, termination of pregnancy is very much raised by this research. I think there would be a general consensus in the Australian community that in terms of gross brain damage of a fetus demonstrated by amniocentesis, that was an understandable instance for termination for pregnancy. There would of course be many very sincere people in our community who would say that, even then, the termination of pregnancy was a moral offence and not, permitted. However, the overwhelming majority of the Australian

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community would, I think, accept such a case. Then you go down the line to the point of good looks. That's where people would say, "Well, that is completely unacceptable". Where on that line we draw the boundary is the controversy that's presented in the ~~case~~ of abortion by the new genetics. Of course, the critics of abortion say, "well this is the slippery slope". Do we permit ~~it~~ for the alcohol marker? No. Do we permit it for Huntington disease? Possibly. Do we permit it for tallness or proneness to obesity? No. Do our institutions permit a change of view on the importance of particular topics over time? There would be many who would say we should just hold the line and say, "No" absolutely. But that is a matter which is not yet fully thought out. The point I've come here to make tonight is that we simply don't have the institutions, unless it be the Judges, to sort those problems out. I suggest to you that it's better that they be sorted out by Parliaments, representative of our community, than by the judiciary doing the best they can. The limited material that's presented in a typical case to resolve such delicate and heartfelt controversies makes it better to solve these problems in an open way, involving the whole interested community. *That is what we should aim at.*

I view this series as a contribution to open debates on difficult and important topics. Such debates are the hallmark of a mature and civilized society.

abortion

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