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19TH WORLD CONGRESS OF DERMATOLOGY

SYDNEY, AUSTRALIA, 16 JUNE 1997

LOOKING FORWARD - LOOKING BACK

The Hon Justice Michael Kirby AC CMG

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PROMISE OF THE HUMAN GENOME

I have become involved in work which takes me to the cutting edge of *your* profession. I suppose it would be roughly equivalent to your spending a couple of days a month in the company of Supreme Court judges - peering into the innards, as it were, of *my* profession. You will not do this. But I have that privilege.

Over the past two years I have become involved in the work of UNESCO the human genome. Within the Human

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[*] Justice of the High Court of Australia. President of the International Commission of Jurists. Member of the International Bioethics Committee of UNESCO. Member of the Ethics Committee of the Human Genome Organisation. One-time Member of the WHO Global Commission on AIDS.

Genome Organisation itself, I have been working with some of the top scientists and ethicists on the elucidation of the ethical quandaries which genomic research presents. I am excited about what I see. I want to start by sharing some of that excitement with you.

Like so many things in life, it happened accidentally. I went to a conference in Spain and found myself examining the future of medicine. History recounts that it was an accident that took James Watson to Max Delbrück's laboratory in Copenhagen to work on the chemistry of DNA. It was Watson and Francis Crick who, in April 1953, gave birth to molecular biology with their conception of a three dimensional structure of DNA which would afford insights into the nature of the gene. It was a breakthrough that ranked with the Darwinian theory of evolution[1]. We are still astonished by the medical, industrial and economic potential of it. Mark, will you please, that neither Watson nor Crick ever sought to patent their discoveries or their applications. Those were the days when such breakthroughs were regarded as the common heritage of humanity.

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[1] *New Scientist* (ANZ edition) 24 April 1993 at 23. See also M D Kirby, "The Human Genome Project - Promise and Problems" 11 *J Contemp Health Law & Policy* 1 (1994) at 5. Cf T H Murray *et al* (eds) *The Human Genome Project and the Future of Health Care* (1996), vii.

Speakers at this conference have been urged to look back a hundred years. To consider whether anything was thought about their subject in 1897 - the year of Queen Victoria's Diamond Jubilee. In that time, as Australia edged cautiously towards federal nationhood, nobody conceived of the double helix. X-ray crystallography, necessary to the breakthrough, was still 50 years away. Yet all scientists stand on the shoulders of their predecessors. Genetics was not new. Students of history were aware of the patterns of genetic diseases in famous families, including Queen Victoria's. Farmers experimented with primitive genetics in the breeding of animals. In 1865 Gregor Mendel's experiments with pea plants began to introduced system and discipline into the study of genetic variations[2]. But humanity still lacked the key that would unlock the door to genomic science. This did not mean that the genome did not exist. It did. Humanity simply did not know about it. Pause to reflect upon how many undiscovered territories there are which the inquisitive human mind has not yet visited, and cannot yet even conceive.

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[2] J C Alper, *Genetic Disorders of the Skin* (1990), vii.

After the double helix was revealed in all of its glory, the explosive growth of gene research and gene therapy still lay thirty years off. In 1985, for example, there were only 11 citations in world scientific literature on gene therapy. Between 1990 and 1995 almost 7,000 published papers on gene therapy appeared. By July 1996, there were 149 gene therapy clinical trials approved in the United States by the National Institutes of Health. Such rapid developments are the more remarkable given that the first successful transfer of foreign DNA to mammalian cells grown in tissue culture occurred less than 35 years ago[3].

The Human Genome Project itself was launched in 1988. Before that, for 20 years, informal cooperation had been going on. But over the past decade humanity has been engaging in the greatest scientific cooperative project in history. Its purpose is nothing less than to record the location of the estimated 100,000 human genes and to map the intervening sequences. At the very moment in history when the human imagination has taken our species out to the distant reaches of the universe, we are also peering down into the infinitesimal basic structures of our being. There we will find the markers which identify whether the subject will be tall or short, blue eyed or black

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[3] P A Khavari and G G Krueger, "Cutaneous Gene Therapy" 15 *Dermatologic Clinics* 27 (1997).

haired. More significantly, we will discover whether the subject has a susceptibility to common diseases such as cancer or heart failure or Altzheimer's[4]. The potential is there for discovering propensity to schizophrenia or diabetes or asthma, to the deficiencies that make us prone to alcoholism or catastrophic diseases including Huntington's, cystic fibrosis, fragile X, muscular dystrophy and so on.

In your own branch of medical science, dermatology, the potential for gene therapy - and thus of genomic research that underpins it - is enormous. A paper by Dr Paul Khavari and Dr Gerald Krueger in January 1997 observed[5]:

> "Skin is a uniquely attractive tissue for gene therapy. The skin is amenable to uncomplicated harvesting of tissue for growth and gene transfer of tissue culture. Keratinocytes and fibroblasts can be expanded in tissue culture and high-efficiency gene transfer to these cells is possible using a variety of approaches. Genetically engineered keratinocytes and fibroblasts can be successfully grafted back onto the donor using established protocols that have been developed, in part, for the treatment of patients with burns and cutaneous ulcers. The risks from neoplastic transformation from gene insertion inducing mutogenesis are markedly reduced in the skin where tissue can be readily inspected and neoplasms detected and rapidly excised. The skin may also offer a sight for control of therapeutic

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[4] R Williamson, "What is the New Genetics?" in *Chiron*, Vol 3 No 5 (May 1997) at 5.

[5] Khavari and Krueger, above n 3.

> molecule dosage by topical regulators. Percutaneous absorption of topically applied molecules ... can be used to regulate therapeutic genes controlled by inducible promoters. Finally, the skin is attractive in that it is capable of delivering polypeptides to the systematic circulation and thus offers potential as a therapeutic 'bioreactor' for production and delivery of therapeutic genes to the systematic circulation. In spite of these attractive features, the skin has lagged behind other tissues in the actual implementation of trials for human gene therapy; the time now appears ripe for the development of this field".

So here we stand on the brink of a remarkable adventure. There has been nothing quite like it before in medicine. One has to reach into the metaphor of mapping and the work of the great cartographers of medieval times who mapped our planet and mapped the stars and told us about ourselves as creatures of the universe we live in. Now we have turned the eye inward. We are peering into our own very nature. What do we see there? Certainly, we see the encyclopaedia of medical practice in the millennium which we are about to enter. The hit and miss of the past will gradually give way to scientific knowledge, accuracy and high predictability, even certainty.

All of this was said much better than I could do in the words of one of Australia's great poets, Kath Walker. She later reverted to her Aboriginal name, Oogeroo of the Nunuccal. She wrote a poem, "The Past", which illustrates how each one of us has a line, which we never think of, tracking our daily existence in 1997 back to our forebears, back to Biblical times, back to the times beyond knowing - the dreamtime of Aboriginal legend[6]:

> "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."

The past is indeed within us. We bear in this generation, and project into the next, the genetic messages which we carry within us. But is that all we will do? Or are we on the brink of actually changing genetic reality? Will future generations say that this was the moment when dermatologist, judge and every person stood on the shoulders of Watson and Crick and conceived the very possibility of creating a new and "improved" species? Would that itself be something that grows out of the intelligence of humanity? Would it take the genome project and gene therapy beyond useful adjuncts to medical practice? Does humanity have the knowledge and the wisdom to utilise our new-found treasure house of information? Will we like Prometheus steal fire from heaven? I try to engage my fellow lawyers in an appreciation of the critical challenges which we will have to

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[6] K Walker (Oogeroo of the Nunuccal) "The Past" in *The Dawn is at Hand* (1996) at 25.

resolve in the decades immediately ahead. They turn away: returning to the comfortable world of leases and car accidents. Of bills of sale and custody suits. I protest that I am talking of nothing less than the human rights of future generations. Of whether they will be "humans", as we know humans. Of fundamental and deep questions which deserve our best collective thought. But it is so much easier to ponder on the familiar problems of daily life which we can help to solve. No doubt dermatologists have the same inclinations.

LEGAL AND ETHICAL QUESTIONS

In the few minutes allotted to me, I cannot even begin to explore the multitude of ethical and legal problems which the genome project, potentially, presents to us. Leave aside the grand themes and the complex questions of altering germline cells by introducing to them genetic information that goes to future generations as far from us today as our ancestors in the caves are. Just concentrate on the quandaries which we must solve now, or in a year or two:

- Does the individual have a right to confidentiality in the use of that individual's genetic information?

- Does such confidentiality stand against an insurer or an employer or the State?

- Will genetic research alter our notions of the culpability of criminal offenders?

- Will we be able to cling to the idea of individual responsibility when we know that some people are genetically pre-disposed to conduct deemed anti-social?

- What of the law of patents and intellectual property? How do we preserve the idea of a common heritage of humanity in the age of hugely expensive scientific research and potentially vastly rewarding gene therapy?

- Do we impose legal limits on genetic experimentation deemed bizarre or unacceptable to the human community? Hybrids? Cloning? Or must we allow science to take us where it will, given that attempts in one place to ban such experiments may simply lead to their occurring in another place on earth less tender to objections?

- Do we permit the state or banks or anyone else to identify us by genetic testing, thus giving way to the universal identifier which could come back to haunt or oppress us?

- What role has the law to play in upholding human standards? How will such a law be drafted? Can our democratic systems of government, limited to the understanding of the ordinary men and women, cope with the complexities of the genomic revolution?

- Will we permit the unqualified termination of human life found, by genetic tests, to be susceptible to unwanted genetic characteristics? Do we permit mass screening? Already this is occurring. In Cyprus it was realised that the thalassaemia marker was carried by 1 in 7 people. Unless the number of the affected population was reduced, within 25 years roughly 40% of the total Cypriot community would suffer from severe anaemia and need extremely expensive blood transfusion and other therapies. A national control programme to detect carriers of thalassaemia has been instituted in Cyprus and to offer prenatal diagnosis was instituted. But where does this path lead us? What of predisposition to obesity? To homosexuality? To cosmetic deformity? History records that it is the very diversity of the gene pool that protects humanity in time of disease. Goya and Beethoven became deaf. Milton became blind. Mahler died of congenital heart disease. Each one of us carries genetic features that adds to the diversity of humanity. Where will the lines be drawn in the future? And, more importantly, who will have the power and the choice?

LOOKING BACK

I bring you no answers to these quandaries. But if we are serious about human rights, the democratic polity and rule by law, we must ensure that means are created which will agitate these global questions and produce, if humanity can, global responses. That is why I gladly participate in the work of UNESCO and of the Human Genome Organisation. To their great credit they are at least asking the right questions. It depends on us to contribute to the answers.

Yet I want to conclude with the suggestion that the future of your profession lies not only in the laboratory. Its future depends as much on generous communication as on gene therapy. Its survival as a noble profession depends as much on old-fashioned verities as on the cutting edge of genomic research.

Let me therefore take you, looking back, at what it is that lies in the essence of the healthcare professional. No lawyer in the courtroom can ever quite come close to it. No engineer with his bridges, no architect with her buildings can quite capture the special dependence which we have on another human being - and the skills and science that lie at their command - when we are sick or when our loved ones are in need of medical care.

It is that special dependence - going to the essence of human existence or well-being - that elevates the healthcare professions to a particular nobility. In the age of gene therapy, of CAT scans, of countless pathological tests, there still stands beside the bed or in the surgery or out in the field the concerned human being with the *will* to provide relief, if they can, from pain and death. It is like the *will* of the judge to do justice. No computer and no technology which we have yet devised, or can yet imagine, can exhibit that human quality. In the age of cut-backs, of economic rationalism and of technology we should be constantly reminded - and constantly remind ourselves - of the elements that set the old professions apart. They include the skill and knowledge that come from training. But more importantly, they require an ultimately selfless caring spirit, an insatiable curiosity, a concern for fellow human beings and a capacity to communicate with them.

Let me give three illustrations of this theme:

* A recent Australian essay on doctors as patients revealed some rather harsh insights into the failings of some medical professionals to understand and talk through the things that are concerning the patient. One doctor, reassured about a lump in her breast, went for pathology after a second lump appeared under her armpit. Her hopes rose briefly when the surgeon left the room following the biopsy. But she knew the news was bad as soon as the pathologist's voice

changed. She sat alone, sobbing, waiting for the surgeon to return. Her "normal confident doctor self" was reduced to an incoherent patient who waited alone, in vain, for the surgeon to offer reassurance and explanation and who wished she had been touched "with something other than a fine needle"[7]. Studies in malpractice suits in the United States have demonstrated that silent doctors are more likely to be sued[8]. Painful though it sometimes is, communication is wise. It is also the essence of the professional relationship. That is why decisions of the highest courts of Australia have insisted upon the legal duty of explanation and communication to the patient[9]. But far greater than any law or more important than malpractice insurance is the ethical duty that comes with the high calling which you have joined.

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[7] Dr R McKenzie quoted in M Sweet "Bad Patients, Better Doctors" in *Sydney Morning Herald,* 22 August 1996 at 15.

[8] S G Boodeman, "Silent doctors more likely to be sued" in *Washington Post Health Report,* February 25 1997 at 9. See also R North, "Why Health Professionals Get Sued - Lessons for Lawyers" in *Law Society Journal* (NSW), March 1997 at 35.

[9] *Rogers v Whitaker* (1992) 175 CLR 479. Cf R Milstein, "'Informed Consent': The Envelope Expands (Again)" in (1997) 5 *Australian Health Law Bulletin* at 65 commenting on *Chappel v Hart*, Supreme Court (NSW), unreported, 38/94.

- Fortunately, the medical profession, including in this country, is enriched by many who know these simple truths. Last year, the Australian Medical Association gave the President's Award for the best individual contribution to healthcare in Australia to Dr Wendell Rosevear of Queensland[10]. It says a lot about medical practice in this country that he was chosen as the model and the mentor. He worked for a time in developing countries to Australia's north. When he returned, he established in Brisbane the Gay and Lesbian Health Service. He was soon overwhelmed with people living with HIV/AIDS. He went into the prisons to help victims of rape and sexual abuse. He set up a counselling service to respond to an epidemic of suicides. To his assembled colleagues of the AMA he declared that his greatest fear was that "If I was honest about my sexuality I would be rejected". He came from a caring, conservative, religious family who taught him honesty. He overcame his own fears. He nursed his partner until he died at home of AIDS. He turned his life's experience to the benefit of the disadvantaged. His colleagues in the medical profession of this country

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[10] Australian Medical Association, Presentation Speech by Dr Keith Woollard and response by Dr W Rosevear (1996).

honoured him. No gene therapy there. Just old-fashioned doctoring, listening and being concerned.

* Finally, a personal anecdote. Long ago in my schooldays my mother fell ill. Her condition as it happened was a severe dermatitis. The year was 1953. She was allergic to the so-called "wonder drugs". Her specialist dermatologist carried on his practice in Sydney. My father begged him to come to our suburban home. Specialists in those days rarely did this. But he pronounced that it was no problem. He was going that night to a veterans' hospital nearby. And so he arrived, resplendent in full military uniform. It was quite a sight for a 13 year-old child. Gently and skilfully he went about his consultation. He treated each one of us, in our small family group, with courtesy, kindness and understanding. He entered my room to look at my study chart. He gave a few words of encouragement. And then he went off into the dark. This dermatologist left an indelible memory on my impressionable mind. To take the extra step. To offer the extra help. To live by the professional golden rule. To treat every person under your professional attention as special, unique, a whole human being with a life extending far beyond the professional problem in hand. To show compassion, tempered with detachment. To strive to be worthy of the highest ideals of those who have gone before. I hope that Dr Geoffrey Finley, dermatologist of

Sydney, still practising, is in this audience and does not mind this public acknowledgment. I made it at a Law Graduation last year to encourage the future members of my own professional to live by the same high standards. I have said it to his face. I now say it to his peers. Basic verities taught by example.

CONCLUSION

So that is the challenge. To reach out into space. To look down into the very essence of our composition. To understand that we are much more than the building blocks of the double helix. To appreciate that we, uniquely, are creatures with a moral sense. To ponder upon our duties to each other and our obligations to the generations yet to come. To master the technology. To listen to the auditors, the economists and the accountants. But never to forget that with the noble calling come old-fashioned obligations that are impervious to time and that transcend the miracles of science. If these things are realised we can face the new millennium with confidence. Let no one say the past is dead. The past is all about us and within.