AUSTRALIAN BROADCASTING CORPORATION

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HE CHALLENGE OF THE HUMAN GENOME PROJECT

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is a little more than forty years since the great scientists and Crick revolutionised our knowledge of genetics and d forever our understanding of living things. In their in April 1953 to the scientific journal *Nature* they ed the outcome of their research which showed that all of e about a hundred thousand genes. Hidden away on the helix are the genes which carry the markers which tell r we will grow to be tall, have blue eyes or manifest other d characteristics and diseases that will affect our life's and, perhaps, predict its end.

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stice of the High Court of Australia. Member of the ESCO International Bioethics Committee, Paris. Member the Ethics, Law and Social Issues Committee of the man Genome Organisation, Bethesda. Formerly Chairman the Australian Law Reform Commission. Personal views.

ombined with the remarkable capacity of information
logy to isolate, analyse, test and describe these markers,
e now reached the brink of truly amazing developments in
research and therapy of great importance to animal
and also to humans.

Kath Walker, the great Australian Aboriginal poet, who
d to the name of Oogeroo of the Nunuccal described more
than my words can how all of us are hostage to the past
tions from whom we are derived:

"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."

people have only the dimmest idea of the double helix
ure described by Watson and Crick, or of the 100,000
and the 3.3 billion base pairs which affect and define what
ok like, how we feel and live and, to a large extent, who
. I confess that I do not fully understand the mysteries of
But I do know that it is about time that we all came to be
about the directions of genetic research. They promise
lous opportunities of medical therapy. But they also
t the most puzzling dilemmas for morality, society and the
We cannot leave these puzzles to scientists alone. Hard as
e must face up to the dilemma of the genes.

Already genetic research is isolating many of the 5,000 or tic diseases which arise from single gene defects as well r more complex polygenic traits. We live in hope that research will identify and help us to cure (and to prevent) erious and painful inherited conditions which, until now, fflicted humanity and been resistant to treatment or cure. month seems to go by but scientists somewhere in the nnounce that they have isolated the marker which signals esence of a cancers or other genetic conditions. Clearly, t step on the path to medical attention to such conditions, of them serious and even potentially fatal, is identification errant gene. Find it, and you are on the way to gene y in this generation and, possibly, manipulation to extrude ifying the offending gene, in future generations.

became interested in the double helix and its messages I attended a conference in Bilbao, Spain in 1993 to mark 0th anniversary of the famous letter announcing DNA. The ence was specifically addressed to the legal and ethical ons presented by genomic research. Judges and lawyers many parts of the world examined some of the implications the new research presented:

ow do we protect the confidentiality of genetic nformation? Does such data belong to the individual or to

family and relatives who may also be affected by its
ntents?

es proof of a genetic propensity to violence help to
culpate the criminal who may be merely acting out
netic pre-disposition? To what extent must our criminal
w revise its postulate of free will as the foundation for
minal responsibility?

ould scientists be able to obtain patents upon segments
the map of the human genes known as the genome - even
fore they have identified the significance of the markers on
at map for particular characteristics or medical conditions? Or
ould the genome belong to all humanity being a gift of God or
ture to us all?

ould employers and insurers be entitled to conduct intensive
nomic investigations to reveal the potential risks which may be
ced in the distant future by the employee or the insured?

ould a person be entitled to refuse to unlock his or her genetic
ture, preferring to live in happy ignorance of genetic disorders
ther than to take the risk of melancholy discoveries?

w should we control manipulation of animal and human
nes? Are there risks which we cannot yet predict in
terfering with the germ-line by which genetic messages are

t from one generation to the next? Four Nobel Laureates at Bilbao conference urged a complete moratorium on genetic pulation of future generations. They said that scientists just not know enough about their potential irrevocably to alter racteristics which are the product of millennia of natural elopment. In times of pestilence and plague it has been the y diversity of the gene pool which has protected humanity m destruction. Keep it like that for the moment, they urged;

may be content to permit, and even encourage, the genetic search which is finding the markers for muscular dystrophy, tic fibrosis, "fragile-x" syndrome in babies, various forms of lanoma, breast cancer, Alzheimer's and Parkinson's Disease the latest: the propensity to nicotine addiction. But what out baldness? Or obesity? Or programming out perceived ws on beauty? If the deafness marker were found and minated, might we possibly lose a Beethoven? If the blindness rker were found and removed, would we lose a Milton? The eat Gustav Mahler suffered from a genetic heart disorder which mately claimed his life at 51. Yet before he died he left us rs to his immortal music. How many great spirits of the past, d the present, would have been eliminated (if that option were ailable) on discovery of the so-called "gay gene": identifying propensity to homosexuality? Is this quest for genetic erfection" simply the latest twist in eugenics - achieving by ience a stereotype of humanity that even the Nazi doctors uld not procure?

Australia such fine scientists such as Sir Gustav Nossal have
ged us to resist irrational fears about science-fiction in
. He points to the marvellous potential of genetic research to
the pain and suffering that come from so many inherited
. So indeed we should. But the lesson of history is that
science fiction all too soon becomes tomorrow's reality. We
begin thinking and working now towards the answers to the
legal and social dilemmas which genetic research presents.
re not matters for scientists alone. Because they touch the
ture of our species, they are matters for society - for us.
society speaks with clear and principled guidance, the natural
veness of scientists will be largely unrestrained by law or
. Already there are reports of human-animal hybridisation
the fertilisation with human sperm of polcat eggs as part of
into male infertility. There has even been *in vitro* fertilisation
panzee eggs with human spermatozoids, although interrupted
stages. A framework of rules is required. It will not come
by ignoring the difficult issues and putting blind faith in the
government funding bodies and scientific laboratories. In
which affect our genetic makeup, humanity has a legitimate
. We must find the ways to ensure that the voice is heard -
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The Human Genome Organisation ("HUGO"), with its main
Bethesda, near Washington in the United States of America,
dinating the work of scientists all over the world in mapping

y of human genes and identifying the billions of markers with yet, mostly unrevealed secrets. This is the greatest ve scientific endeavour in history. It is bigger by far than the an Project which produced another scientific phenomenon of ury; nuclear fission. This year, an Australian, Professor Grant nd of Adelaide, has been elected President of HUGO. In for the first time, HUGO will convene its annual meeting in . Professor Sutherland will preside.

have been elected to the Ethics, Law and Social Issues tee of HUGO. More recently I have been appointed to the O International Bioethics Committee. The latter is preparing an tion to lay down international law for the global regulation of c research. The Director-General of UNESCO has asked me to this convention to the HUGO conference in October. When r people criticise the growth and influence of international st consider how painfully inadequate the law of any single would be to deal, unaided, with the problems presented by tional research such as is now occurring under the umbrella of . We are on the brink of a new millennium where the map of nes will be completed. This will become the encyclopaedia for e in the centuries ahead. Whether it becomes a completely olled experiment or advances to the benefit of humanity within which humanity itself sets, is the big question which soon we nswer.

lost of the issues which distract our political life and ons in Australia pale into utter insignificance in comparison to ortance, urgency and difficulty of the problems presented by genomic research. But who is looking into those problems? nobody. Of the mega-bucks which hang on genetic patents, uch is devoted to the ethical, legal and social questions? a trickle. The Human Genome Project will overwhelmingly humanity. But humanity must pay attention to the ethical, d social issues which it brings in its train. At stake is nothing n the definition of what humanity will be like in the next um. It is time that we in Australia began to be aware of the as which the Human Genome Project presents and to build ons which, in harmony with those of other land, will help to hose dilemmas.

"Let no-one say the past is dead
The past is all about us and within."