

“NEVER MAKE FORECASTS, ESPECIALLY ABOUT THE FUTURE”

Sam Goldwyn

**Notes for a speech prepared by
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1. Sam Goldwyn’s apparent misuse of the English language is wise counsel when speculating about the impact of much greater availability of the use of human genetic tests, and the implications for observance of human rights.
2. It is now exactly 50 years and one month since Francis Crick walked into the Eagle Hotel in Cambridge and announced that he and James Watson had, “found the secret of life”. Watson’s recollection is somewhat different.
3. Whatever was said by whomever it clearly was a momentous day. As the golden anniversary of the discovery of the structure of DNA is celebrated what is clear is that Watson and Crick accelerated the search for answers to questions about what is it that makes us what we are.
4. From a human rights perspective subsequent research on the human genome establishing that we are so essentially all the same is worth noting. The moral entitlement to be born free and equal in dignity and rights by the simple virtue of being human is sustained by research which establishes that every human being is 99.9% the same.
5. At the same time research into the function of DNA throws up challenges to the right of every one to be treated with the dignity that underlies the concept of human rights.
6. As is ever the case with learning one needs to be aware of developments outside the area under immediate consideration.
7. A very quick consideration of two other areas of learning is helpful. Genomics is not the only area where developments in science and technology could give rise to concerns that a better knowledge of how our bodies work and function could have an adverse impact on human rights.
8. Proteomics represents a bigger revolution in biology than the mapping of the human genome sequence. Proteomics is the science of identifying proteins and understanding what proteins do inside cells.
9. Genes are the instructions for making proteins. DNA is a very long string of instructions written in a chemical code. The instructions are broken up into sections, called genes. The string of letters in each gene translates into a string of amino acids that make up a protein. Nearly all drugs act on proteins, not genes, so understanding proteins is the key to effective new medicines.

10. The understanding of proteins will be much harder than understanding human genes. While there are about 35,000 human genes there are in excess of a million proteins. Each protein has a separate function and is active at varying times according to what the cell is doing. Different cell types have different proteins. Alun Anderson, the editor of *New Scientist*, uses the following analogy. The list of all human genes is equivalent to a roll of all the people who live in a town with a population of 35,000. The list contains names but does not tell you occupations or how the people interact or how the town is run or how its economy functions. Nor does the list identify who are the crooks – the equivalent of the malfunctioning proteins that need to be dealt with to stop disease.
11. Advances in technology are making the identification of proteins and the mapping of what they do faster and more accurate.
12. In November 2002 the Human Proteomics Organisation (HUPO) conducted its inaugural meeting at Versailles. HUPO is a not for profit scholarly society whose mission is to consolidate national and regional proteome organisations into a worldwide organisation. HUPO is creating standards for projects so that scientists can work together on a large scale. One project is on blood plasma which is seen as providing the basis for the ultimate diagnostic tool given that blood circulates everywhere. A complete list of all the proteins in the plasma will give clues to the health of organs throughout the body.
13. Advances in neurotechnology also give rise to concerns about their potential consequences for human rights.
14. Over the past decade machines for measuring brain activity have proliferated. They range from the well known such as electro-encephalography to magneto-encephalography to single-photon-emission computerised tomography to functional magnetic-resonance imaging (fMRI). fMRI uses powerful magnetic fields to monitor the rate of blood flow in the brain and thus determine which parts are particularly active.
15. Research done at Stanford University involving the use of fMRI scans has allowed researchers to detect problems with brain development in children that question-based psychological evaluation does not. Few would object to such worthy enterprise.
16. What, however, if the features of brain scans can be linked to a wide variety of mental states? One can, despite the words of caution of Sam Goldwyn, forecast that there will be a desire to use the information in ways which could lead to discrimination against individuals.
17. Whether one considers the implications of the mapping of the human genome or proteomics or advances in neurotechnology or any other method of learning more about how our bodies function there are concerns which remain constant:
 - (i) How much screening should be allowed for certain genetic traits?
 - (ii) Who should have access to such information?
 - (iii) Should the information be told to people if they do not want to know?
 - (iv) Will the information be used against someone?
 - (v) What will happen when those traits can be modified at will?

18. The forerunner to the New Zealand Bioethics Council was the Independent Biotechnology Council (IBAC). In an excellent summary publication released last year IBAC identified the risks and limitations associated with genetic testing. One of the most pertinent issues identified was the need to ensure that our right to be free and equal in dignity and rights is not devalued. Any devaluation of that right could lead to social and economic discrimination.
19. One of the issues IBAC posed for consideration is the question of whether human rights legislation in New Zealand adequately covers the immediate and longer term implications of human genetic testing, together with its effect on both individuals and society. That is a reasonable question and one to which we as a society need to respond. In its strategic plan the Commission specifies work on “appreciation of the human rights implications of bioethics and emerging knowledge of the human genome.”
20. Amendments to the Human Rights Act which came into force on 1 January 2002 gave the Commission responsibility for the development of a National Plan of Action for the promotion and protection of human rights in New Zealand. The Commission launched this project on Human Rights Day, 10 December, last year. The Commission expects to develop the National Plan of Action by the end of 2004. The national plan of action will cover issues associated with human genetic testing. We hope to be able to draw on the major project being undertaken by Otago University’s Centre of Excellence in Law and Bioethics.
21. The New Zealand Law Foundation has commissioned the University of Otago to undertake an international study into the legal implications of the Human Genome Project for New Zealand. The study will focus on:
- biotechnology and patents
 - genetic engineering
 - testing and cloning
 - population screening
 - designer babies
 - property rights
 - stem cell research data protection
 - human rights
 - Indigenous populations.
- An analysis will be made of the law and its ability to adapt to the implications of the Human Genome Project and make recommendations for change.
22. In addition to monitoring the work that will be produced by the University of Otago the Commission has been closely monitoring the papers being jointly produced by the Australian Law Reform Commission and the Australian Health Ethics Committee on *Protection of Human Genetic Information*. Their final report with recommendations is due to be published on Monday 31st March. The Commission will, along with numerous other individuals and organisation on both sides of the Tasman and throughout the world, be a keen and eager reader of what is a most impressive piece of research and analysis. Our attention is likely to be initially on recommendations relating to employment, insurance, kinship and regulation of human genetic testing. No doubt my colleagues at the Health and Disability Commission and the Privacy Commission will be taking a keen interest in the report.

23. In their issues paper IBAC in discussing the balancing of the risks and benefits of genetic testing identified the use of human genetic tests by governments, insurers, banks, employers, and educational institutions as an area requiring careful thought in order to prevent possible discrimination.
24. An aspect of the far more widespread use of testing of human genetic information that is of concern is the pressure being brought to bear on such fundamental rights as the right not to be tried twice for the same crime. Proposals put forward in New Zealand, New South Wales, England and Wales in recent times argue for the use of the results of human genetic tests after someone has been acquitted of a serious crime to be an exception to this fundamental right. As often is the case there is a conflict between this right and the right of all of us to live free from the fear of violence. Wherever the line is drawn it is imperative that there be a full, proper, reasoned and reflective discourse which gives due recognition to both rights.
25. There are a wide range of implications for our privacy as human genetic testing becomes more widely based and available. I shall say no more than that as the privacy issues will be covered by others during the course of the day.
26. At a recent public forum in Auckland, Dr Hendrik Callesen from the Danish Institute of Agricultural Sciences expressed his opinion that we have now reached a point where the question is not so much what is it possible to do but what is it acceptable to do. This view leads me to express what I believe should become a norm for governments throughout the world and particularly those of New Zealand and Australia. Each should pledge that they will make every effort to ensure the principles set out in the UNESCO Universal Declaration on the Human Genome and Human Rights and the Council of Europe Convention for Human Rights and Biomedicine are implemented through legislation; codes of ethics; codes of practice; official standards; best practice standards and other appropriate means. Adherence to the universal and timeless principles set out in these instruments will avoid the pitfall of designing legislation around any specific technology used for human genetic testing.
27. Professor Michael Ignatieff of Harvard University provides wise counsel that human rights are not a panacea; they are the basis from which we can begin to negotiate our differences. Widespread discussion of the issues needs to be encouraged and the Human Rights Commission will be contributing to that discussion. Discussion will help in removing the lack of trust which is a paramount feature of so much of the public debate to date. In the area of bioethics and research the Danes have developed a model which seeks to ascertain public attitudes and the barriers to dialogue. The Centre for Bioethics and Risk assessment in a January 2002 report on “Dialogue on biotechnology in relation to plants” noted that in order for there to be a comprehensive, specific and fundamental dialogue between biotechnology researchers and the general public there needed to be a multifaceted and long-term effort to remove barriers to communication. When one makes the necessary changes for context this is an approach that I whole heartedly support.
 - a. New Zealand and Australia showed by their significant contributions to the establishment of the United Nations and the creation of the Universal Declaration of Human Rights that they can be a force in creating landmark developments on the path towards a better world for all. There is now a fresh opportunity to once again to show leadership in this very important area of human rights.

- b. I wish to acknowledge use of the following in the preparation of this speech:
- a) “The New Frontier of Biomedicine” – Alun Anderson in “The World In 2003” published by the Economist
 - b) “The Secret of Life” – Nancy Gibbs, Time Magazine – 17 February 2003
 - c) “A Twist of Fate” – Michael D Lemonick, Time Magazine – 17 February 2003
 - d) “Open Your Mind” – the Economist – 25 May 2002
 - e) “Trial and Trial Again” – Daniel Williams – Time Magazine – 24 February 2003
 - f) “Genetic Testing – An Introduction to the Technology that is changing our lives” – Independent Biotechnology Advisor Council – June 2002
 - g) “Protection of Human Genetic Information: - Discussion Paper 66 – Australian Law Reform Commission/Australian Health Ethics Committee – 28 August 2002.
 - h) “Dialogue on Biotechnology in Relation to Plants” – Centre for Bioethics and Risk Assessment – January 2002.