

**Mapping Our Genes: The Genome Project and the Future of Medicine** by Lois Wingerson

(Dutton, New York, 1990), pp. xi + 338, \$US19.95, ISBN 0-525-24877-3.

Physically mapping the functional genes of humans has become an international industry with at least \$US3 billion already committed. This, the Human Genome Project, generates much intellectual activity in the Northern Hemisphere. It is one of those endeavours which, when completed, will change the way people see themselves in this world — in a manner comparable to Copernicus' observations on the universe, Darwin's theory of evolution and Voyager's transfer of men onto the moon. The ultimate gene map has enormous potential as the basis for strategies against disease. But clouds are already gathering and are expressed mainly as fears that the institutions of society may use genetic printouts and manipulative techniques to further erode the rights and freedoms of individuals.

Lois Wingerson, an American science graduate and journalist has produced one of those books in the US genre of scientific journalism that is not only informative about scientific processes and their impact on human subjects, but is also written in an unfortunate manner as stylised as Japanese court poetry. Her book was designed for the general public and her aim was to explain the principles of gene mapping together with the impact of genetic advances on members of families in which inherited disease was segregating.

She proceeds with a series of case studies, each involving an individual and relatives suffering from, or at risk to, a specific inherited disorder and those scientists who are investigating the disorder with an ultimate aim to localise genes or to clone them. Members from certain racial or religious population isolates feature prominently — the Cajuns of Louisiana, the Older Order Amish of Pennsylvania (whose main trading centre is the town of Intercourse), the Old Colony Mennonites of Alberta and the Mormons of Utah. These interbreeding groups with their consequently reduced gene pools tend to manifest rare genetic disorders more frequently than does the general outbreeding population. In the case of Mormons, there is the added attraction of extensive genealogical records. For over three decades these communities have been extensively mined by genetic researchers. The yield, part of which is discussed by Wingerson, has been high.

Although the author provides lucid explanations of gene linkage and mapping strategies and techniques, it is doubtful whether a reader without considerable understanding of genetic mechanisms could keep up with her. This applies particularly to the chapter on identification of oncogenes where the discussion is at a level comparable to that of the *Scientific American*, but without the benefit of the numerous illustrations employed so illuminatingly by that journal.

All in all, Wingerson has given a clear and accurate account of the experimental processes used for mapping genes. In this regard her communication skills reflect the best traditions of scientifically-informed journalism. The same cannot be said for the rest of the book. At its best, journalism can bring to life the thoughts and reactions of people. Sadly, Wingerson seriously handicaps her narrative by using the homogenised and sanitised prose style that appears to have become entrenched in US popular writing especially for reflecting the responses of ordinary people to extraordinary life situations. Her persona are described as stereotypes of appearance and personality that extend even to a photograph of the physician Herrick who in

1904 gave the first account of sickle-cell anaemia in the USA — his image appeared to Wingerson as if “he would have spoken gently to his patient”. Conversation is reconstructed full of clichés and pitched at a constant level of banal expression, so that scientists and the public speak and express their emotions in the same predictable way. It is as if a script had been prepared for the characters of a soap opera, and indeed, that may be the most promising way to market a generalist book on a “serious” topic in the contemporary USA. Occasionally there are patches of truly awful editorialising hyperbole in the style of *Time* magazine gone berserk.

All this is a shame because the individual and familial implications of inherited disease and the reproductive choices resulting from genetic advances raise all manner of personal and inter-personal dilemmas. Wingerson tries to convey the impact of this spectrum but is severely constrained by her style. Moreover, she is driven by scientific positivism and so the complexities and difficulties are somewhat underscored. An exception is with her description of a DNA sequencing project which did not proceed smoothly. Her emphases, however, were more on the trials of the postdoctoral scientists and the sociology of a leading laboratory.

Although the rate at which genes are being mapped inspires positivist thoughts (in September 1991, the totals for mapped genes and DNA segments stood at 2316 and 6831 respectively<sup>1</sup>), the challenge continues to grow. Comparative studies, especially by a British team on the cosmid from nematode *Caenorhabditis elegans* are revealing more genes than were expected. Extrapolation from this and other lower organisms to humans has increased the predicted number of genes to around 100,000. In gene-rich sequences of the genome new genes are being discovered, like Russian dolls, within larger genes. Gene mapping will provide some indication of function as already demonstrated by the inter-relationships among the 80-odd genes in the major histocompatibility region and the significance of gene order in the betaglobin complex. Yet the practical benefits that will ultimately justify the Human Genome Project cannot be achieved until each gene is cloned. Progress is uneven; for one extremely serious genetic disorder considered by Wingerson, Huntington Disease (HD), cloning has been elusive. Genetic linkage between the HD locus and the D4S10 gene marker on chromosome 4 was discovered in 1983. Eight years later, despite continual efforts in many laboratories, the HD gene has not been cloned although this goal may now be in sight as the location appears to have narrowed to somewhere along a sequence of 50 genes.<sup>2</sup>

Wingerson provides evidence of the revolution in genetic research stimulated by the Human Gene project. Classical experimental research, much of it driven by curiosity, has been replaced by task-oriented programs. Whereas formerly laboratories mastered single techniques such as the use of DNA probes and somatic cell hybridisation, now they routinely use batteries of different methods. Competition between the research groups has reached war-game intensity and Wingerson provides some interesting insights into these rivalries. There are fears that highly intelligent biological scientists will become bored and frustrated by repetitive work and reliance on machines and sophisticated software for analyses. James Watson told Wingerson he thinks otherwise and so far he is right. New challenges and inspired interpretations are features of virtually every recent scientific paper in this area.

One curious aspect of Wingerson's book is that she appears to accept that the US medical system will be able to accommodate the practical consequences

arising from gene mapping. She tells an anecdote about the father of a female researcher who had gained the trust of the Amish people among whom she was investigating inherited manic-depressive psychoses. The father had leukaemia and required 900 blood transfusions before he died. The researcher received a bill from the blood bank for \$27,000 which she could not pay. Hundreds of Amish people, however, donated blood to pay off the debt. Wingerson relates this tale merely to illustrate the Amish sense of duty to others in need. Although continually extolling predicted benefits, nowhere does she discuss how the bills will be paid for expensive genetic diagnoses and any subsequent reproductive or genetic re-programming interventions. There are currently 37 million Americans without any health insurance cover; tightly stretched public sector services exist for further millions of the poor and aged who are eligible for federal aid. Wingerson believes that US society would never tolerate any form of eugenic misuse of new genetic technologies. But if only the rich have access to the means for ensuring their children will not suffer from serious inherited diseases — surely that is a selective breeding advantage completely in accord with eugenic theory.

Being blinkered and uncritical about the established institutions of one's country is a typical manifestation of ethnocentric journalism. Another aspect of this stance is Wingerson's failure to note that the Human Genome Project is truly international with much input and leadership from the UK, Europe and more recently, Japan. Had she acknowledged this fact, she may have predicted the serious problem of information management the Project currently faces<sup>3</sup> along with differing national views on such matters as use of the new knowledge, patenting genes and ensuring privacy of genetic information.

The conclusion is that Lois Wingerson has written a book with some of the strengths and many of the weaknesses of the journalistic approach. Nevertheless it is worth reading especially by those interested in how American public opinion is shaped about a major field of scientific discovery.

#### REFERENCES

1. C. Pritchard, D.R. Cox, R.M. Myers, 'The end in sight for Huntington Disease?', *American Journal of Human Genetics*, 49, 1991, pp. 1-6.
2. P.N. Goodfellow, L. Sefton, 'Language of the genome', *Nature*, 353, 1991, pp. 117-18.
3. P. Aldhous, 'Human genome databases at the crossroads', *Nature*, 352, 1991, p. 94, J. Maddox, 'The case for the human genome', *Nature*, 352, 1991, p. 11.

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#### **Young Workers in Technologically Advanced Industries by Sue Whyte and Belinda Probert**

(National Clearinghouse for Youth Studies, Hobart, 1991), pp. 4iii + 76, no charge, ISBN 1-875236-10-4.

This report is the latest in a series for the National Youth Affairs Research Scheme, and addresses the question of

what, if anything, is special about [youth]employment in technologically advanced industries — and whether employment patterns, training provisions, skills and opportunities differed from other sectors of the labour market (p. vi).