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The Human Genome Project:
Cancer and the GeneStalk

In the past few years, scientists launched a fifteen- year biological investigation to map, sequence, and determine the functions of the distinct genes found in the cells of each of us and which comprise the human genome. The purpose of the genome project is to map a territory discovered in 1865, when Gregor Mendel first described hereditary 'elements.' Many claims are made about this effort. It is said that the information from the project will change the ways medicine is practiced, the ways science is performed, and will even change the ways we think about ourselves.

P.A. Flynn, *The Human Genome Project*

Less than a quarter century ago viruses, not genes, were thought to be responsible for cancer. Then the viral theory of cancer "evolved" into the oncogene theory of cancer. The oncogene theory of cancer initiation is the dominant one today. The initiating event is seen as the alteration of a gene in a chromosome within the nucleus of a normal cell. Most molecular biologists today are convinced that cancer occurrence is the result of alterations of DNA.

The search for the cancer gene(s) is undergoing rapid acceleration. And while many in the scientific and medical community have described the Human Genome Project as the biggest and best endeavor since the Manhattan Project, the international effort is not without its detractors. The costs/benefits evaluation and the problems produced by a huge investment in genetic research is often mentioned by activists and scientist/activists. Molecular biologist Prof. Richard Strohman at the Department of Molecular and Cell Biology at U.C. Berkeley states that, up to the present, genetics accounts only for 2% of cancer and cardiovascular diseases.

Other disputes concerning the Human Genome Project are focused on issues that involve the shift in direction of scientific research — from scientists to politicians — and many are concerned that :

... in mapping and sequencing the 50,000 or 100,000 genes in the 3 billion base pairs in the genome, perhaps 95% of this material is nongenic, and some object to spending time analyzing this "junk." (1)

If genetic research doesn't explain the causes of cancer, why is most of the cancer money devoted to basic genetic research? What does cancer research specifically have to do with an effort such as the Human Genome Project?

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Getting Reimbursed for Nutritional Services

Cinda Williams Chima

Working with insurance companies to obtain coverage for nutrition therapy can be a frustrating experience, because nutrition treatment may not be explicitly included in health insurance plans as a covered service. It may, however, be reimbursable as a "medically necessary service" ordered by a physician. Much depends on who reviews the claim and interprets the policy. During my years of advocating coverage for nutrition services, I have seen the same service covered and denied by the same plan.

In a data base maintained by the American Dietetic Association, of 1,146 claims for nutrition treatment submitted to insurers for a variety of diagnoses, 71% were paid. Many were paid at discounted or negotiated rates. The data base, however, is not a random sample of all claims nationally: data is submitted on a voluntary basis.

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Human Genome Project

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Genetic research is advertised through mass media as the big hope for cancer cure — and even for prevention. The Human Genome Project represents the theoretical and empirical frame affecting the methods and the aims of etiological research for the most important illnesses — ranging from heart diseases to reproductive problems.

Genetic Mapping

The result of the Human Genome Project would be the generation of a systematic body of scientific knowledge through a complete "genetic mapping." A genetic mapping is defined as:

the process of assigning genes to specific chromosomes. Genetic linkage maps determine where one genetic locus is relative to another on the basis of how often they are inherited together. A genetic locus is an identifiable marker on a chromosome, the presence of which indicates that a specific trait — eye color or blood type — will be expressed by the gene. (...) A map of the genomes tells you where genes are located, but does not disclose their function.[2]

Despite this explicit limit in the aims of the Human Genome Project, recently genetic research has obtained mass media coverage as a possible solution for a number of diseases such as cancer. Yet in contrast to this enthusiasm, *The Washington Post Health Supplement* (April 19, 1994), took a relatively critical stand toward genetic research. In the opening article, Rick Weiss explains in plain terms what it means that all cancers have a genetic component, and how this doesn't mean that most cancers are inherited.

Indeed most cancers are caused by genetic mutations that occur after birth. In breast cancer, for example, the vast majority of tumors are caused by an accumulation of genetic glitches acquired throughout a woman's life — perhaps from damaging compounds in the environment or the diet. Only 5 to 10 percent of all cases are the result of a mutant gene passed from parent to child at conception.[3]

Despite their proportionately small numbers, these hereditary breast cancers have attracted immense attention from both researchers and patients. Although scientists have identified two breast cancer genes, BRCA1 and BRCA2, they have no proof that these genes have anything to do with the other 90-95% of breast cancers that are not currently explained by hereditary causes.

If one goal is screening people for "cancer causing" genes — which sounds like a great business — there will be serious ethical dilemmas. Will some women choose to abort their BRCA1- positive fetuses even though breast cancer might never arise in the child — or might arise and be treated successfully? Will adults who harbor the gene be denied health insurance or be otherwise discriminated against? What about prophylactic mastectomy? In the global context of environmental crisis and limited resources, will poor people who carry the "wrong" genetic makeup be allowed to reproduce — if the cost-benefit analysts agree that "it is too expensive"?

The ability to screen for diseases but not to treat them raises interesting issues. Would identifying people with aberrant genes stigmatize them without helping? Many scientists consider the prospect of re-manipulating the oncogene as very far off, if not impossible. The Institute of Medicine at the Academy of Sciences issued a report on "Assessing Genetic Risks: Implications for Health and Social Policy" in 1993. As the report points out, the more genes are identified, the more "there is a growing pressure to broaden the existing screening programs and otherwise increase both the number of available genetic tests and the volume of genetic information they generate."

The report also notes that only one in 200 women inherits a defective gene. Yet, Don Hadley, genetic counselor at the HGP in Bethesda, predicts that a genetic test will be identified during 1995 and announced that it might be commercially available within two years.[4] This test will probably be very profitable for those who will be able to market it. Hopefully it will open the debate on the social utility of "large scale testing, when genetic susceptibility accounts for such a small proportion of common diseases."

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[1] P.A. Flynn, "The Human Genome Project," *Society for the Study of Social Problems Newsletter,* Vol. 24, N. 3, Fall 1993, pp. 4-8.

[2] Ibid.

[3] R. Weiss, "Scientists Track a Familial Gene for Breast Cancer, "*The Washington Post Health Supplement,* April 19, 1994, p. 3.

[4] A. Hott, "Can Genetic Testing Help Prevent Illness?" *American Medical News,* August, Vol. 37, N. 22-29, August, 1994.

This piece is edited and excerpted from a PhD. dissertation entitled "Malignant Profit: The debate on genetics and environmental causes of cancer among scientists, women survivors, and people of color."