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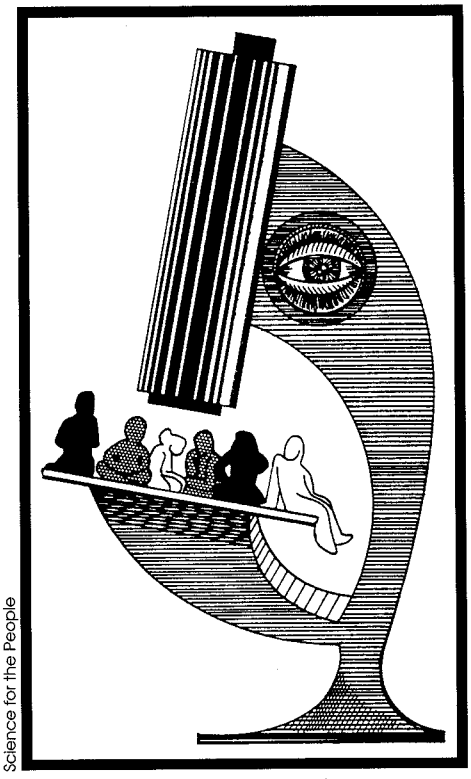
geneWATCH

Special Issue on
Human Genetics

Introduction by Ruth Hubbard

Much current research in human genetics is directed toward identifying genes associated with specific diseases. At the same time, some areas of human genetics are neglected or their exploration is actively discouraged. The articles in this issue of *geneWATCH*, which concentrates on human genetics, illustrate both these trends.



Science for the People

The identification of specific genes and their localization on the chromosomes is a major aim of the Human Genome Initiative. This megaproject was originally conceived by the Department of Energy, but the administrative offices of the Human Genome Initiative are now located at the National Institutes of Health, with James D. Watson as director. The project's intent is within the next fifteen years to specify the position of the fifty to one hundred thousand genes thought to be located on the twenty-three human chromosomes and to sequence the approximately three billion pairs of nucleotide bases of which these genes are composed. The project's proponents claim that this is the best way to find out how genes function and to improve the diagnosis and treatment of a wide range of diseases.

The Human Genetics Committee of the Council for Responsible Genetics (CRG) has prepared a critique of the Human Genome Initiative. This position paper analyzes some of the scientific flaws and adverse economic and ethical implications of the project and highlights the dangers it poses of genetic discrimination.

Briefly, the position paper challenges the notion that identifying the gene (or genes) involved with a particular disease significantly improves the outlook for a cure, except in rare cases. Furthermore, it argues that the genome project greatly exaggerates the importance of genes at a time when a deteriorating environment and economy make it increasingly difficult for people to live healthful lives.

The Human Genome Initiative is likely to lead to improved techniques of genetic diagnosis and DNA-based identification for a range of diseases and disabilities that could not be predicted before. Yet many of these diagnoses will offer only statistical predictions of future health outcomes. This is likely to raise a host of complex is-

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Position Paper on Genetic Discrimination

by the Human Genetics Committee of the Council for Responsible Genetics

During the past decade there has been a dramatic expansion in the number and range of genetic tests designed to predict future health. Whereas ten years ago tests were only available for a few inherited conditions, now tests exist to diagnose cystic fibrosis, Huntington disease, and several other gene-based diseases. Physicians are even projecting that they may be able to diagnose genetic predispositions for complex conditions such as cancer, cardiovascular disease and mental disorders.

As tests become simpler to administer and their use expands, a growing number of individuals will be labelled on the basis of predictive genetic information. This kind of information, whether or not it is eventually proved correct, will encourage some sectors of our society to classify individuals on the basis of their genetic status and to discriminate among them based on perceptions of long-term health risks and predictions about future abilities and disabilities. The use of predictive genetic diagnoses creates a new category of individuals who are not ill, but have reason to expect they may develop a specific disease some time in the future: the healthy ill.

While the new diagnostics will provide identification of genetic factors that may be responsible for evoking certain diseases or disabilities, it is not at all obvious how rapidly and to what extent this information will lead to treatments or cures for the diseases in question. Diagnoses unaccompanied by cures are of questionable value. This is especially true when the diagnosis can be made long before the person in question begins to notice any symptoms of disability or disease, as is often the case. Many genetic tests predict—often with limited accuracy—that a disease may become manifest at an undetermined time in the future. And although the severity of many genetic diseases varies widely among those individuals who develop the disease, the diagnoses usually cannot predict how disabling a specific person's disease will be. To this extent, the situation is similiar to the experience of people diagnosed to be infected with the human immunodeficiency virus (HIV), who know that they will probably develop one or more AIDS-associated diseases, but not when or which ones.

Gaetan Laroche

This kind of "predictive medicine" raises novel problems for affected individuals and they, together with their physicians and counselors, will have to learn how to approach them. Meanwhile the exaggerated emphasis on genetic diagnoses is not without its dangers because it draws attention away from the social measures which are needed in order to ameliorate most diseases, including equitable access to health care. Once socially stigmatized behaviors, such as alcoholism or other forms of addiction or mental illness, become included under the umbrella of "genetic diseases," economic and social resources are likely to be diverted into finding biomedical "cures" while social measures will be short-changed.

Individuals labeled as a result of predictive genetic tests face the threat of genetic discrimination. They and their families are already experiencing discrimination in life and health insurance and employment because genetic information is being generat-

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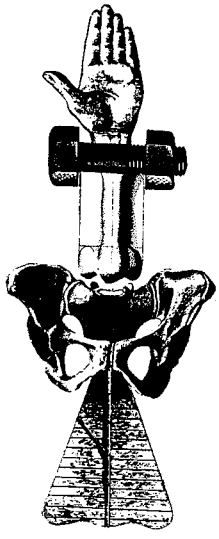
*The **Human Genetics Committee** has twelve members with backgrounds in the biological sciences, public health, law, disability rights, occupational health and safety, and women's health. Members include: Ruth Hubbard, Professor of Biology, Harvard University, Chairperson; Philip Bereano, Professor of Engineering and Public Policy, University of Washington; Paul Billings, Director of the Clinic for Inherited Diseases, New England Deaconess Hospital; Colin Gracey, Head of the Religious Life Office, Northeastern University; Mary Sue Henifin, Deputy Attorney General, State of New Jersey; Sheldon Krimsky, Associate Professor of Urban and Environmental Policy, Tufts University; Richard Lewontin, Alexander Agassiz Professor of Zoology, Harvard University; Karen Messing, Professor of Biology,Université du Québec à Montréal; Stuart Newman, Professor of Cell Biology and Anatomy, New York Medical College; Judy Norsigian, Co-Director, Boston Women's Healthbook Collective; Marsha Saxton, Director, Project on Women and Disability; and Nachama L. Wilker, Executive Director, Council for Responsible Genetics.*

coverage.[8] Some insurance companies did not end the practice of using explicit racial classifications in setting rates and benefits until the early 1960s. And, in the early 1970s healthy African Americans who were identified as having "sickle cell trait" once again experienced insurance discrimination, when some insurance companies charged them higher rates, despite the lack of evidence that such individuals were at greater risk than usual of ill health or shortened life span.



Life and health insurance companies are regulated by the states, and a patchwork of laws govern how rates are set and what types of discrimination are permissible. For example, Maryland and New Jersey, which limit unjustified discrimination, may permit discrimination on the basis of genetic status if increased actuarial risk of disease or decreased life span can be demonstrated.[9] Insurance companies argue that they have the right to make appropriate business and financial decisions based on their objective statistical determination of group risk. However, it is not equitable to stigmatize individuals on the basis of group risk, nor is it sound public health policy to deny life and health insurance generically to individuals with risk factors.

Without legislation mandating that all insurers cover populations at risk without discrimination, those who do provide comprehensive coverage are at a financial disadvantage. Insurance companies have successfully staved off legislative interference with their decisions to deny coverage based on actuarial risk and there is every reason to believe that they would lobby aggressively against laws which would prohibit genetic discrimination. The actions of the insurance industry regarding HIV antibody status are revealing. For example, states which have tried to regulate against discrimination on the basis of antibodies to HIV have met vigorous legal challenges by insurance companies, and several such state regulations have been invalidated by the courts.

In their survey of discrimination as a consequence of genetic screening, Paul R. Billings, Mel A. Kohn, Margaret de Cuevas and Jonathan Beckwith of Harvard Medical School illustrate how "data banking" of genetic information can lead to future abuses not only against at risk individuals, but also against their relatives.[10] Already companies that manage medical information for insurers track individuals identified as having specific genetic conditions so that such people may be denied insurance whether or not they reveal the relevant genetic information on their applications. In addition, government agencies have the capacity to retain records of "DNA fingerprints" on individuals who have been charged with committing violent crimes.[11]

Data banking increases the risk that genetic information will be used in ways that violate individual privacy and encourage irresponsible genetic epidemiology. To examine the full impact of genetic data banking we need to answer three questions: 1) What information is stored, 2) who has access to the information, and 3) how can such information be used?

An individual's right to refuse genetic screening is eroded when employers and insurers require such information as a precondition for employment or for life or health insurance. Even more chilling are instances where insurers have attempted to manipulate individual decisions about childbearing. Insurers have pressured potential parents to be screened or to have their fetuses screened, and then have tried to manipulate their procreative decisions by threatening to withdraw benefits to those who choose to give birth to children at risk of genetic disabilities.

Proposed Actions

The dangers of genetic discrimination may be lessened if advocacy groups and the relevant public and private agencies take the following actions:

- **Develop fact sheets that describe what is known** about genetic screening and why genetic status does not necessarily identify an individual's health or abilities. The fact sheets should be written by health and disability rights advocates and geneticists. They should encourage discussion of the dangers of stigmatizing individuals on the basis of future risks of ill health or disability.
- **Offer short courses on the uses and abuses of genetic screening** to the general public and to journalists, health care professionals, teachers, labor unions, and scientists by public interest groups, educational institutions, cable television, and other media.
- **Draft model laws** that can be proposed at local, regional, and, where appropriate, state and federal levels. These laws would prohibit discrimination in education, employment, insurance, housing, public accommodations, and other areas, based on present or predicted medical status or hereditary traits.
- **Design proposals to end disability discrimination** in all its forms, including proposals that will afford access and participation in all aspects of public life by individuals who are disabled. Coalitions should be encouraged between groups concerned with civil liberties, disability rights, women's rights, procreative rights, occupational health and safety, workers' rights, and the right to health care.
- **Propose absolute and legally binding guarantees of confidentiality** to protect information obtained from genetic screening. The informa-

Discrimination against individuals with particular genetic characteristics harms all workers by diverting attention from the need to improve workplace conditions for everyone.

Genetic Discrimination:
An Ongoing Survey

by Paul Billings, M. D.

The prejudices described in these reports included stigmatization not only of the individual labelled with the genetic disease, but also of close relatives including spouses.

The misuse of genetic data for social, political and economic purposes has plagued the field of human genetics. Though the origins of this problem require more investigation, the roots of this tradition probably are the same as those that have produced racism: an economic system dominated by a clannish ruling class.

A current version of this historical problem is reflected in the medical fallacy that suggests that human illness is encoded in mutant genes (changed DNA sequences) which can be transmitted within families to successive generations. Adherents of this position claim that virtually every trait or health condition, even those which are not inherited in a simple fashion, are either caused or significantly influenced by genes.

In reality, illness results from a multifaceted response of the human organism to a variety of circumstances and influences, some of which may be affected by genes. A gene does not produce illness; rather, it can confer a trait or a susceptibility which, given other intrapersonal and environmental factors, may become associated with a specific disease in the course of a lifetime.

The expression of genetically-influenced traits, and especially of those linked to illness, tends to be highly variable. Mutations (changes in a gene) may be easily noted, entirely masked by environmental influences, or not detectable for other, often unknown reasons. (Gene changes that are thought to have occurred, but that do not manifest themselves in the expected traits are said to be "non-penetrant.")

Several inherited conditions can now be treated successfully. In such cases, the DNA sequence ("the gene") associated with the susceptibility continues to be present in all the body cells, but there may never be any sign of illness. A familiar example of this is PKU (phenylketonuria), a severely disabling genetic condition if left untreated. However, if PKU is diagnosed at birth and the children who have it are treated with a modified diet, they may never experience any symptoms of this disease. Thus genes do not necessarily determine the presence, course, severity, or ramifications of the illnesses with which they are associated.

Genetic discrimination in health matters can occur whenever the belief that an illness is encoded in the human genome is accepted. A recent survey I have conducted jointly with Jonathan Beckwith, Mel A. Kohn, and Margaret de Cuevas[1] suggests that this type of discrimination occurs in a variety of settings. By publishing an advertisement in the American Journal of Human Genetics and in the newsletters of several organizations of people with genetic disorders, we solicited descriptions of instances of discrimination from victims or health care providers. We received 42 responses of which 29 reports were evaluated carefully.

The prejudices described in these reports included stigmatization not only of the individual labelled with the genetic disease, but also of close relatives including spouses (who, of course, usually are not genetically related). The people who were discriminated against did not necessarily manifest clinical symptoms or disabilities. The discrimination was not remedied upon protests by outraged physicians or by evidence that effective preventive treatment was averting or controlling the disorder. Current laws did not offer adequate protection and individuals seemed afraid that they might suffer further losses if they sought legal redress. Offending agencies included employers, insurers, adoption agencies, educational institutions, and the government.

Several individuals with hereditary biochemical disorders who had been appropriately treated and were not ill, could not get insurance. One non-disabled respondent who has a genetically mediated neuromuscular disorder (Charcot-Marie-Tooth Disease or

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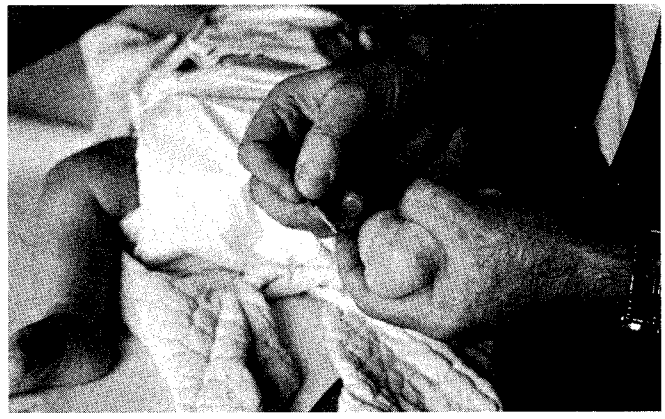

A few drops of blood from a heel prick are enough to identify most babies with the genetic condition PKU. Once diagnosed, such babies can be successfully treated with a special diet.

***Paul Billings** is a medical geneticist engaged in basic and clinical research in human genetics. He is the Director of the Clinic for Inherited Diseases, New England Deaconess Hospital, Boston, Massachusetts.*

shocked to find that genetic research was not just an abstraction, and they were shocked because, as one later told us, "I have worked all my life in this crummy plant to keep my family safe and healthy, and now you're telling me that I gave my son his heart problems."

Our difficulties in obtaining help from other scientists

As scientists, we could not affirm that there were genetic risks associated with the workplace based on the sample of five out of five. We therefore turned to other scientists with experience in human genetics. For example, at the birth of his second malformed child, one member of the executive had been told by the genetics counselor at a local hospital, "These things just happen, we'll never understand them. But they could not be associated with your work." We called the hospital many times, trying to reach this doctor, known as an expert in the field, and eventually to reach any one in the service, but our calls were never returned. In 1982, after our report had come out, the doctor finally called us: he had been retained by the employer and was threatening us with a lawsuit on their behalf.

We called the genetics service of another hospital to see whether anyone would undertake a study of the workers. The service would not do a study, but offered to examine the newborn with the tracheo-esophageal fistula to see whether she or her parents had chromosomal anomalies. The test was negative, but this did not enable us to conclude that the baby's problems were unrelated to the workplace, since relatively few genetic anomalies are demonstrable with the technique they used. We talked to the head of a large department of human genetics and he informed us that offspring of *male* workers could not be affected by working conditions. On being asked why, in that case, he injected male rather than female mice when he studied mutagenesis, he responded that it was strange, wasn't it. (This fairly common scientific error is made less often now that many workplace exposures have been shown to affect male reproductive health. [3,4,5])

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In general, the local genetics community clearly was reluctant to get involved; it made us think of New Yorkers watching a mugging. We learned quickly not to use the word "union," but even "worker" sufficed to induce a negative reaction. (We have subsequently met the same response from a dozen scientists who refused when we asked them to testify in a court case involving compensation to an infant allegedly malformed by *in utero* solvent exposure.[6])

Preventing genotoxic effects on workers

Not finding anyone else to do the study, we got a tiny grant from our university (available due to the union-university agreement) for a study of chromosome aberrations among 15 workers and 15 controls, and for development of a questionnaire on workers' reproductive outcomes. We were extremely nervous about doing this, since in our work with fungi, we would never have used a technique about which we knew so little. Interestingly, once we suggested that their participation be anonymous, the scientific community became very helpful: an epidemiologist offered to help us write the questionnaire and check the results, and a cytogeneticist taught us how to check for chromosomal aberrations in white blood cells. The numbers of breaks are counted and compared to those found among an appropriate control group. Chromosomal breaks are thought to be an indicator of genetic damage. The union arranged to introduce us to 15 of the most exposed workers, a sample size adequate for studies of chromosome breaks with this technique, since many cells from each subject can be studied.

With the help of two undergraduate summer students, we analyzed the chromosomes and read the questionnaire results. The chromosomes, coded "blind", yielded a significant difference between exposed workers and controls of the same sex and similar ages selected from university personnel and their relatives. However, this test is not unambiguous and we did not have perfect confidence in our results, due to our own inexperience.

A well-known American researcher offered to check our results. He came, took samples, and returned with them to his laboratory, promising to

Doug Brugge / MassCOSH

working conditions, although we have recently submitted six such requests. When the studies have not been rejected outright, the parts involving questionnaires have been cut. We have unfortunately no idea how to gain information on working conditions without use of questionnaires, since employers are reluctant to let even non-union-affiliated researchers onto their property to do direct observation during working hours, and since workers are usually people who know most about their true, rather than ideal, working conditions.

- If we state that workers need and want desperately the answer to some question, this is a reason for a study not to be funded, on grounds of bias, although such reasoning is not applied to joint university-industry projects, which are actively encouraged by granting agencies.[19] We tried for four years to get funding for a study on reproductive outcome which was requested by a union of 1000 workers, designed with them, and addresses questions of daily concern to them. But when the study is explained, scientists tend to react negatively to this aspect, since subjects of a study are not supposed to have a stake in the results. We think, on the other hand, that a really effective way to ensure good-quality data is by involving the workers in the study. In fact, workers have much less interest than researchers in biasing the data. After all, it is in the interest of a scientist to find an interesting workplace risk to health in his/her study but the person who has to work there the next day is happier when no risk has been shown to exist.
- In the eyes of many scientists, workplaces do not lend themselves to scientific study. They consider it more accurate to model the workplace in the laboratory, and then state all the differences between the model and the real situation. (See for example the classic ergonomic studies on load lifting,[20,21] all done in the laboratory, where workers are modelled by college students or army volunteers, or the literature on how to assay genotoxic effects.[22])
- In fact, according to many scientists, humans do not lend themselves to scientific study. I spent a sabbatical year in a highly-regarded research institute examining mutant frequencies in blood cells of people exposed to ionizing radiation and exploring methods for differentiating radiation-caused from other DNA damage. The most frequent comment I received on my project was that it would be much better to do this with Chinese hamster cells. When I replied that I was interested in living human blood, which circulates, and varies in its exposure to radiation in ways that cells in culture don't, people replied that it was impossible to control all the parameters affecting human blood, and that work with isolated cells was more reliable.

Thus, the closer we were to questions asked by workers, the less likely we were to encounter a sympathetic response from other scientists. But it was not only the content of projects which offended other scientists. For example, one of us included in her CV, in an application for work on radiation effects, co-authorship of a 100-page booklet on radiation in the workplace, published jointly by the unions and the university. This single reference led to the remark, "Why does she bring up the unions everywhere (sic) in her application?" In contrast, a member of a committee considering a grant request for work with cells in culture in collaboration with hospital staff, said, "Oh, now she's a good little girl!"

We were told by a biochemist, member of a committee which considered a grant request by another one of us, "Someone asked, 'Isn't she the one who has a relationship with unions?' Of course, that didn't influence our [negative] decision, but it made a funny atmosphere around the table." In contrast, the fact that the chairman of a major Canadian epidemiology department regularly does *paid* consulting for companies does not appear to affect negatively his considerable ability to obtain grants. He recently accepted money from a company to critique a project proposed by the union, and then was selected by a granting agency to review the same project for funding. (Funding was refused.)

We also didn't understand why the company's geneticist continued to be well respected in scientific circles while frequently accepting money from management, while we were regarded as untouchables because of our *non-lucrative* relationship with unions.

Consequences

Unions lack access to scientific expertise. Our experience is just one example of the pressure exercised on non-conforming scientists and especially those who "mix" other than middle-of-the-road politics with their scientific endeavours. Donna Mergler has experienced pressure to abandon studies of the neurotoxic effects of solvents; two doctors at the Ontario Workers' Health Centre were asked to choose between their university appointments and their participation in a labor-sponsored organisation.[23] A labor-initiated study at the US National Institutes of Occupational Safety and Health (NIOSH) on the effect of VDTs on pregnancy was stalled by labour-management conflict for so long that the proposed control group started using VDTs, making the study impossible! [24]

Consequently, unions in joint labor-management committees or adversary situations have limited access to highly trained and respected scientific resources. This is so, not only because unions have much less money than management to pay for resourc-

Interestingly, once we suggested that their participation be anonymous, the scientific community became very helpful.

Dangerous Diagnostics:
The Social Power of Biological Information

Reviewed by Marsha Saxton

Dorothy Nelkin and Laurence Tancredi
Dangerous Diagnostics: The Social Power of Biological Information
New York: Basic Books, 1989 (224 pp., $18.95)

Dangerous Diagnostics is an exploration of the history of testing and of how the rapidly increasing range of tests can be used and abused. Nelkin and Tancredi focus on medical tests, psychiatric evaluations, educational tests such as are used for identifying learning disabilities and classifying intelligence, and genetic tests which may detect susceptibility to disease or sensitivity to workplace hazards. The authors discuss the impact of these tests on social institutions. This review will focus primarily on the issues surrounding genetic tests.

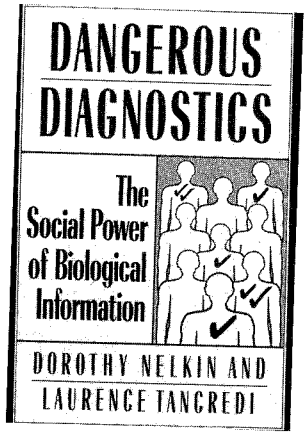
The public tends to regard the new biotechnologies as amazing examples of modern science, something akin to space travel. There is little comprehension among the general public that these technologies will have profound effects on the everyday lives of ordinary people.

With current increases in the expense of health care, hospitals and clinics are under pressure to function as profit-making institutions. Diagnostic technologies that predict disease before the onset of symptoms are increasingly being used to determine which patients are poor financial risks. Nelkin and Tancredi report:

> In 1987, 20 per cent of insurance applicants were classified as substandard; their policies excluded particular conditions, or they paid higher than usual rates.... Some genetic conditions are considered unacceptable for either medical coverage or disability insurance. These include autism, spina bifida, duodenal or gastric ulcer, narcolepsy and active rheumatoid arthritis.

Such health care "rationing" increases the gap in the care available to rich and poor, and denies care to people who need it most.

The authors point out that while many characteristics such as height and longevity are recognized to be the product of interactions between genetics and environment, this interactive model is not applied when a disease is discovered to be "genetic". Instead, clinicians tend to interpret all conditions known to have a genetic component as if genes were the determining influence. But "Valid and useful diagnosis ... must not confuse the presence of a genetic or biological condition with the actual disease. Most genetic disorders, in fact, are polygenic, the product of the interaction of several genes with a person's environment." Nor will a test "provide information about the timing or severity of a disability or how it might affect the normal functioning of the afflicted individual." There may be little correlation between a positive test result and impaired performance. Also, many genetic tests diagnose or predict potential illness where hope for treatment or cure may be decades away. Since diagnoses affect the course of therapy in only eight to thirty per cent of cases, their usefulness is questionable.



The possibility of false positives raises complex concerns. An institution carrying out a screening procedure may consider a low or moderate level of reliability adequate. But for the individual being screened, the consequence of error may not only be personally distressing, but also result in stigma or ostracism.

Employers are major financial beneficiaries of the new tests, since under the pretext of protecting workers characterized as genetically "ultrasensitive" to occupational hazards, a company can refuse to hire certain categories of people, rather than instituting perhaps more costly policies that would protect all workers. Employee screening programs that eliminate women of childbearing age, in particular, have come under criticism for their discriminatory intent.

The genetic tests have begun to create yet another class of people vulnerable to employment discrimination, denial of medical or life insurance and a host of other social privileges.

Such discrimination is not new to people with disabilities and critics of the new diagnostic technologies need to explore the history and current policy regarding denial of social privileges and civil rights on the basis of *perceived* physical, mental or emotional limitations, which usually are markedly, if not completely, different from the individual's *actual* abilities.

Negative assumptions about people with disabilities have led to the increased use of prenatal screening techniques designed to identify a "de-

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DISCRIMINATION STUDY

(continued from page 7)

CMT), which is notorious for its highly variable clinical manifestations, could not get automobile insurance. This occurred despite a letter from his physician emphasizing his lack of disability and the fact that he has had no traffic accidents or violations in twenty years of driving. Another respondent with CMT could not get life insurance even though this disorder does not shorten lifespan. Yet another was refused a job for which she had been recruited. She listed CMT on a pre-employment form. The interviewer asked her what the initials stood for, looked the disease up in a medical book, and denied her the job.

A healthy individual, who carries only one gene for a recessive genetic condition (Gaucher Disease—a liver disorder which is never manifested unless both genes that mediate the trait are present) was not allowed to enlist in the Air Force. This suggests that the military still does not understand that people who have only one copy of a gene producing a recessive disorder are at no increased risk for illness. Yet, a great deal of publicity about this has been directed at the armed services ever since the 1970s when the Air Force improperly denied admission to African-American recruits with sickle cell trait.

Several people who responded are at risk for Huntington disease. They have a one-in-two chance of contracting this disorder, and if they do, it can be very debilitating. Huntington disease usually does not exhibit symptoms until people reach mid-life and sometimes not until old age. Two of our respondents were barred from adopting children and one of them was told the reason was that she might develop the disease before the child was fully grown. Another asked: "Does this [possible inherited susceptibility] make me different than anyone with diabetes or cancer ... in their ancestry?"

We also received reports of two instances in which women carrying fetuses, which had been diagnosed as having genetic disorders, decided to continue their pregnancies. They then had to fight to retain full insurance coverage for the future care of their babies.

Though our survey method does not allow us to estimate the frequency with which persons with inherited disorders experience discrimination—a key fact if we wish to ascertain whether agencies have active policies of genetic discrimination—our findings suggest that such policies exist. To establish this will require further investigation.

Individuals with hereditary biochemical disorders who had been appropriately treated and were not ill, could not get insurance.

A systematic effort by geneticists and others to educate the public about the limited predictive value of genetic diagnoses is essential to prevent further genetic discrimination. Unfortunately, the Human Genome Initiative, as it is currently conducted, is likely to worsen these problems since it may generate genetic tests long before appropriate therapies are developed or public understanding improves. As we have seen, even the existence and conscientious use of adequate therapies may not prevent the occurrence of genetic discrimination.

Notes

1. Paul R. Billings, Mel A. Kohn, Margaret de Cuevas, and Jonathan Beckwith, "Genetic Discrimination as a Consequence of Genetic Screening." Unpublished.