DOCUMENTS POSITION PAPERS

COUNCIL FOR RESPONSIBLE GENETICS
186 South Street, 4th Floor, Boston, MA 02111, U.S.A.

Introduction — Research in human genetics today has become increasingly focused on the identification of genes associated with specific diseases. This focus has led to a dramatic increase in the number and range of genetic tests designed to predict future health of fetuses, children, and adults. As the number of tests grow, and as they become simpler to administer and their use expands, an increasing number of individuals will be, and are currently, labelled on the basis of predictive tests. Such individuals face the threat of genetic discrimination because genetic information is being generated much more quickly than legislative, legal, and social service systems can respond.

The following statements were written by the Human Genetics Committee of the Council for Responsible Genetics. Taken together, the statements present a critique of the scientific limitations of current research in human genetics and highlight the adverse social and economic implications of an increase in genetic testing. They were developed as the first step in the Council's campaign to prevent discrimination based on information generated by predictive genetic tests. Written for a broad audience, in particular those communities that will be affected by this new form of discrimination in our society, the statements were also written in the hope of stimulating discussion on the direction of current research in human genetics.

The Council for Responsible Genetics is a Boston-based national organization of scientists, public health advocates, trade unionists, women's health activists, and others who want to see biotechnology developed safely and in the public interest. The Council believes that an informed public can and should play a leadership role in setting the direction for emerging technologies. The Human Genetics Committee has 13 members with backgrounds in the biological sciences, public health, law, disability rights, occupational health and safety, and women's health. Members in clude: Ruth Hubbard, Professor of Biology at 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; Abby Lippman, Professor of Epidemiology, McGill University; Karen Messing, Professor of Biology, University of Quebec in Montreal; 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.

NACHAMA WILKER

POSITION PAPER ON GENETIC DISCRIMINATION[1]

During the past decade there has been a dramatic expansion in the number and range of genetic tests designed to predict future health. Whereas 10 years ago tests were only available for a few inherited conditions, now tests exist to diagnose cystic fibrosis, Huntington's 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 similar 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.

This kind of "predictive medicine" raises novel problems for affected individuals and they, together with their physicians and counsellors, 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 generated much more quickly than our legal and social service systems can respond. As our abilities to label individuals on the basis of genetic information increases, particularly through the efforts of the Human Genome Initiative,[1] there will be an even more urgent need to address these problems.

Employment discrimination

The tragedies of race and sex discrimination illustrate the dangers of basing

employment decisions on inborn characteristics. Like these, discrimination on the basis of genetics ignores the present abilities and health status of workers and substitutes questionable stereotypes about future performance.

Basing employment decisions on genetic status opens the door to unfounded generalizations about employee performance and increases acceptance of the notion that employers need to exercise such discrimination in order to lower labor costs. Indeed, without countervailing equitable forces, employers face economic pressures to identify workers who are likely to remain healthy. Less absenteeism, reduced life and health insurance costs, and longer returns on investments in employee training all reduce the costs of labor. To the extent that employers believe that genetic information can help identify workers who have a "healthy constitution," they have strong economic incentives to screen applicants and workers.

Employer discrimination on the basis of antibodies to HIV and of previous cancer history, despite current ability to work, demonstrates that employers take health status into account when making employment decisions to the detriment of individuals labeled as being at increased risk of ill health in the future.[2] Even more revealing is the history of discrimination on the basis of perceived genetic hypersusceptibility to occupational diseases.[3] For example, African-Americans who are healthy but have what is called sickle cell trait have been denied certain jobs despite the absence of scientific proof that any genetic characteristics are predictive of industrial diseases.[4]

Such policies victimize all workers. In the case of sickle cell trait, African-Americans have been "protected" out of jobs involving exposures to certain industrial chemicals, while remaining workers continue to be at risk from these chemicals. **Discrimination against individuals with particular genetic characteristics harms all workers by diverting attention from the need to improve and, if possible, eliminate workplace and environmental conditions that contribute to ill health for everyone.** Moreover, such genetic discrimination masks the fundamental need for adequate leave policies and insurance coverage, as well as for reasonable workplace accommodation for all workers who experience temporary or permanent disabilities, for whatever reasons.

Basing employment decisions on genetic status may run afoul of the patchwork of state and federal laws that protect the employment rights of individuals with disabilities. To date, federal laws only cover workplaces receiving federal funds.[5] No state or federal court has ever determined whether such laws apply to the employment rights of individuals discriminated against because of their genetic status. Although a bill is pending in Congress that would provide comprehensive protection to workers who are disabled, there is disagreement among legislative experts over whether this bill would prohibit genetic discrimination.[6]

Screening individuals for genetic risk of late-onset diseases raises particularly difficult problems because such individuals may not be considered disabled at the time they are discriminated against and therefore may not be afforded protection under present or proposed federal and state laws protecting the rights of disabled individuals.[7] Ironically, someone who is stigmatized for being at risk for future genetic illness may, due to his or her asymptomatic status, fall outside the protection of laws prohibiting discrimination on the basis of disability. A clearly worded federal law is needed to prohibit discrimination on the basis of such information and to protect the privacy of genetic information.

The need for laws to protect the privacy of genetic information can be illustrated by the secrecy with which employers may use

medical information. There are few limits, for example, on employer discretion in deciding what pre-employment medical tests to perform on job applicants. Thus, once a sample of blood is taken from an applicant during the pre-employment physical, it can be tested for many conditions, including pregnancy, sickle cell trait, HIV antibodies, cholesterol, or drugs. Since employers do not have to give a reason for refusing to hire an applicant, many individuals never realize that they have been denied employment because of their medical status. Although it might be possible to challenge an employer's hiring policies which discriminate on the basis of medical status, it is very difficult to document such discriminatory practices.

Insurance discrimination

Insurers also face strong economic incentives to identify individuals perceived to be at increased risk for ill health in the future. Historically, such inherent characteristics as race and sex were used to deny African—Americans and women insurance 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 a 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 surveyed incidents of discrimination based on genetic status, without regard to the variability of the genetic condition and the fact that the applicant exhibited no identifiable clinical illness. Frequently, the presence of a genetic trait or condition was erroneously equated with disability by insurers and employers, despite the fact that the individual fulfilled the requirements for employment and could participate in a full range of activities with no, or reasonable, accommodations. This survey adds to the growing literature documenting that people with disabilities and perceived disabilities experience pervasive discrimination.[10]

In addition to reporting specific instances of genetic discrimination, Billings et al. also illustrate how "data banking" of genetic

information can lead to future abuses not only against at risk individuals, but also against their relatives. 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: (a) What information is stored; (b) who has access to the information; and (c) 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 pro-creative 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:

1. 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.
2. 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 in stitutions, cable television, and other media.
3. 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.
4. 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.
5. Propose absolute and legally binding guarantees of confidentiality to protect information obtained from genetic screening. The information should not be released to anyone without the informed consent of the screened person or her/his legal guardian.
6. Advocate nonbiased counselling about the option to refuse tests and about the benefits and risks of doing so to every individual offered genetic testing. Appropriate consent and refusal forms must explicitly state that refusal to undergo genetic testing will not lead to termination of medical care or insurance, denial of services, or to other discriminatory practices.

POSITION PAPER ON HUMAN GENOME INITIATIVE

Biologists and physicians as well as social theorists and politicians have tried to understand how physical and social traits are passed on to successive generations. This interest in heredity has had a range of motivations and effects:

1. Conservative and progressive thinkers alike have often labored under the mistaken assumption that our environment can be molded, but that our biology is unchangeable, and have therefore tried to identify fixed quanta of biological inheritance and to sort them from social and other environmental influences.
2. As scientists have devised methods to study the components of organisms at the molecular level, their focus has shifted from explanations at the level of organisms to chromosomes, genes, DNA molecules, and the nucleotide bases that give DNA its specificity.
3. Molecular geneticists assume that a better understanding of these smaller components will provide better insights into how whole organisms function, individually and in society. However, this reductionist view ignores the fact that molecules and subcellular structures, cells and tissues, and organisms and, indeed, societies all interact with each other and with every thing that goes on around them, so that it is impossible to predict how changes in the molecules or genes will affect what happens at other levels.

At present, molecular biologists in the United States, Europe, and Japan have begun to tackle the enormous project of identifying and mapping the 50 to 100,000 genes on the 23 human chromosomes and of sequencing the approximately three billion pairs of nucleotide bases of which these genes are composed. The international project, which goes under the name HUGO (for Human Genome Organization), was initiated by some 32 scientists from the participating countries. The U.S. project, known as the Human Genome Initiative, was begun at the instigation of the Department of Energy, but now has its headquarters at the National Institutes of Health and is under the direction of James D. Watson. The Department of Agriculture and the National Science Foundation plan to participate as well. The current budget for the NIH's part of the project is $100 million (*Science*, 7/14/89, p. 131).

Promises

The project promises to improve scientific knowledge about how both genes and organisms function. At the practical level, it promises to improve the ability to predict, diagnose, and cure genetic disease. The pharmaceutical industry is interested in developing molecular probes for specific genetic lesions, which could be used to diagnose "defects" in fetuses, children, or adults. It is hoped that therapies could be developed once it is possible to locate and isolate the genes involved in specific disease. For example, once a gene known to mediate a particular disease has been isolated, it might be relatively easy to identify its gene product(s) and use them to cure or ameliorate the disease. Alternatively, it might be possible to administer the gene in some form of gene therapy.

Critique

Scientific. Our critique of the Human Genome Initiative operates at several levels. A basic problem at all of them is the assumption that genes (the genome) are the "blueprint" of the organism and "control" the way the organism develops and functions. In this reductionist view, organisms are "readouts" of our genes, whose sequence and composition conceal a gold mine of information about our biology and behavior. Obviously, **genes are important components of an organism that**

make significant contributions to its metabolism. But they are not autonomous. Their structures and functions are affected by what goes on around them.

The office of the Human Genome Initiative will no doubt sponsor research that will advance the understanding of genetics and therefore of genetic components of health and disease. **However, knowing the sequence of an organism's genes will not make it possible to predict how that organism will function because genes are not "blueprints" of the organism.** They are merely one of many important elements that participate in its metabolism and development. Genes specify the amino acid sequence of proteins, which in this context are often referred to as "gene products." But each gene product (hence, each gene) can affect many traits of an organism; conversely, many gene products (hence, many genes) usually contribute to each trait. For example, when the gene that specifies the structure of human growth hormone (a protein) was transferred into the DNA of a mouse embryo, the animal grew to twice its normal size. However, when the same gene was transferred into a hog embryo, the animal's size did not change, but it was leaner than normal. In other words, the way the gene functioned depended on what was going on in the rest of the organism.

Also, in humans the same gene clearly can exert different effects in different individuals. For example, molecular biologists know how the gene for sickle cell hemoglobin differs from that for normal hemoglobin. For about 30 years they also have known the precise molecular difference between these two types of hemoglobin. Yet that has not made it possible to predict, or understand, why some people who have sickle cell anemia are seriously ill from earliest childhood, while others do not show symptoms till much later in life, and some of them only quite mild ones. Nor has any of this knowledge helped produce effective therapies, much less cures. Similarly, a few people with Huntington's disease, a gene-based progressive, degenerative disease of the nervous system, have experienced the first symptoms in childhood, while the majority experience them in their middle years, and a few not until old age. This is why it is erroneous to believe that knowing the sequence and composition of all the genes on the human chromosomes — a gigantic task — will tell us a great deal about ourselves or even will help cure many diseases.

Advocates of the Human Genome Initiative point to the fact that it will provide tools for the early diagnosis of gene-based diseases. They also claim that this will speed the discovery of cures. **But early diagnosis is of questionable value in the absence of therapies, and specifying the genetic basis of a disease will only rarely produce better therapies in the foreseeable future.** If scientists want to know more about the genetic basis of specific diseases, it would be better to concentrate on identifying the genes mediating those.

For the reasons we have discussed, information at the level of the gene cannot be readily translated into useful information at the level of cells, tissues, or whole organisms. Traditionally, scientists have deduced the presence of genes, as well as their functions, by looking at the way organisms differ from one another. It is not at all obvious that that scenario can be usefully played backwards, that is, that one will be able to identify a gene's critical function, or functions, once one has identified, located, and isolated it.

The main point is that even if we knew everything we could about the human genome, we would know only a tiny piece of the story. **The most that the complete sequence of an organism's genes can tell us is what proteins that organism can make. Such a list of ingredients cannot tell us how they will interact and operate together.** Anyone who has tried to prepare more than the simplest dish from a recipe knows that having a

complete list of ingredients, including the sequence in which to add them, does not guarantee the outcome.

Economic. At present, scientists, physicians, venture capitalists, and industrialists are involved with gene mapping and with genetic diagnosis and gene-based therapy. In their search for funding, they often describe genes as though they were all-important and determined who we are and what we do. This draws attention away from other biological processes as well as from the many societal factors that enter into the picture. Genes have their part to play in the ways people function, but they are always only part of the story. At a time of increasing conservatism and shrinking budgets for measures which could ameliorate the various problems that confront inherited traits for which compulsory sterilization was socially and medically approved as a "cure."

The focus on genes and the effort to discover genetic components or tendencies for all sorts of diseases that have obvious environmental components, is problematic not only because it draws attention away from the political changes needed to deal with them in other ways. These very political changes would also be required to render genetic and medical information useful. Economic barriers prevent large numbers of people from taking advantage of medical information that is already on hand. This is likely to get worse for gene-based medical information because it will necessarily be expensive to obtain and act on.

Prenatal diagnosis: A number of ethical issues are implicit in the use of prenatal diagnosis for inherited disorders. There are the problems of definition and labelling. There is also the obvious problem that, while many disabilities have a range of severities, prenatal tests give only yes or no answers, so that prospective parents are forced to make difficult procreative decisions in the face of limited, sometimes questionable, information. And at present, the only recourse for most people whose tests reveal that their future child will have a disability, which they cannot countenance, is abortion.

In the present climate of increasingly restricted access to abortion, especially for poor women, the decision to abort in the context of prenatal diagnosis is likely to be hemmed in in one of two ways, both of them bad. One is that diagnoses of inherited disabilities will be granted the status of exceptions in laws restricting access to abortion, thus increasing the stigma on people with inborn disabilities as well as the pressure to abort fetuses that manifest them. The other is that they will not be exempted, so that only affluent women will have access to prenatal diagnosis and abortion, by going to states in which these are available.

Privacy rights: Many ethical issues surround the disclosure of genetic information. What rights does an individual have *not* to disclose such information to present or prospective employers, insurers, or spouses, and to other family members? If someone who has a genetic disease decides to keep that fact secret, to which, if any, of these people should a health care provider be permitted, or indeed mandated, to disclose the information? These are some of the many thorny issues our society has not confronted and almost surely is not ready to deal with equitably. Yet the Human Genome Initiative will provide a host of such data, whether we are ready for them or not.

The NIH program has decided to allocate between 1 and 5% of its budget to research into ethical consequences of the Genome Initiative. Such research projects at best can yield worthy suggestions, with no assurance that they will be implemented. Yet it is certain that employers, insurers, and others who stand to gain financially or politically from obtaining genetic information about other people will make every attempt to gain access to it once it exists. It is irresponsible to acquire and store

such data before confidentiality can be assured.

Discrimination. Individuals experience discrimination whenever they are judged not for who they are or what they can do, but on the basis of their membership in a particular group, defined by skin color, sex, or some other characteristic. In addition, genetic discrimination may involve predictions about the future. Yet genetic predictions entail a considerable degree of uncertainty about the extent to which the trait in question will be expressed or whether it will be expressed at all. If the genetic trait confers evident disabilities, a person may be protected by civil rights laws that prohibit discrimination for reasons of disability. However, if someone shows no signs of disability, but a genetic diagnosis suggests that she or he may become disabled at some undetermined future date, that person may not be protected by current laws.

The Human Genome Initiative is bound to lead to improved techniques for various forms of genetic diagnosis and DNA-based identification for a range of diseases and disabilities that could not be predicted before. As procedures are simplified and used more widely, the opportunities for genetically-based discrimination will increase. This is most likely to become apparent in the areas of employment and insurance and in forensics. DNA-based, compulsory identification of specific groups (e.g., all those convicted of a sex offense or other violent crime) or individuals raises numerous unresolved ethical and political questions. Finger printing and social security numbers entered our society to facilitate identification in specific, limited contexts. They are now used widely and individuals have little, if any, recourse to refuse without drawing suspicion upon themselves. The same can be expected to happen with DNA-based identification, which potentially contains more information and therefore poses considerably greater risk to privacy and civil liberties.

ENDNOTES

1. This position paper is intended to accompany the Council for Responsible Genetics' Position Paper on the Human Genome Initiative, which describes the Initiative in greater detail, evaluates its goals and methods, and its implications for expanding the number and range of predictive genetic tests.

2. A survey of corporate views about AIDS was published in the January 1988 issue of *Fortune Magazine.* It revealed that 39% of the Chief Executive Officers surveyed would not hire individuals who were HIV positive, while 38% were not sure whether they would hire such individuals. Reported in Mark A. Rothstein, 1989, *Medical screening and the employee health cost crises*, p. 86, BNA Books. Job discrimination against recovered cancer patients is documented in Feldman, 1984, "Wellness and work," in C. Cooper (Ed.), *Psychosocial Stress and Cancer*, pp. 173–200.

3. A brief history of employment discrimination on the basis of genetic traits is presented in Ruth Hubbard and Mary Sue Henifin, 1984, "Genetic screening of prospective parents and of workers: some scientific and social issues," in James Humber and Robert T. Almeder (Eds.), *Biomedical Ethics Review,* pp. 99–111, Humana Press.

4. Individuals who have one sickle cell gene (a condition called sickle cell trait) are free of symptoms and do not know that they have the gene, unless they have been tested for it. However, those who have two sickle cell genes have sickle cell anemia and may experience severe symptoms. Approximately 1 in 500 African–American babies is born with sickle cell anemia, and about 1 in 10 carries the sickle cell gene. Although no scientific evidence exists to show that African-Americans with sickle cell trait experience increased morbidity or mortality, their identification through screening programs in the 1970s led to job and insurance discrimination against them.

For example, Charles Reinhart, Director of the DuPont Laboratory for Toxicology, reported in 1978 that DuPont gave pre-employment blood tests to African-Americans to screen for sickle cell trait. He stated that at the Chambers Works plant, in Deepwater, New Jersey, individuals with sickle cell trait who had hemoglobin levels of less than 14 grams per 100 milliliters of blood (normal levels are usually given as 13 to 16 g per 100 ml) were restricted from work that involved handling nitro and amino compounds. Charles Reinhart, 1978, "Chemical Hypersusceptibility," *Journal of Occupational Medicine* 319–322.

5. Specifically, the Rehabilitation Act of 1973, as amended, protects individuals with disabilities who are otherwise qualified, from employment discrimination at the hands of the federal government, federal contractors or businesses receiving federal funds. 29 U.S.C. Sees. 701–795 (Supp. 1989).

6.The Americans with Disabilities Act, (Public law 101–336) was signed into law by President Bush on July 26, 1990. The law bars discrimination on the basis of disability in employment, public services and public accommodations.

7.For example, in *School Board of Nassau Co. v. Arline,* 480 U.S. 273 (1987), the Supreme Court declined to decide whether the Rehabilitation Act would protect a person from employment discrimination who has no symptoms but whose medical tests indicate that a disease might develop in the future. 480 U.S. 282, n.7. In *Arline*, an elementary school teacher was fired after a relapse of tuberculosis. The Court ruled that the Rehabilitation Act covers those who are able to work, but "are regarded as impaired and who, as a result, are substantially limited in a major life activity."

8.In the early 1900s women had trouble getting insurance due to misconceptions about increased female mortality due to child birth hazards. See Note 66, (1979–1980) Challenges to sex-based mortality tables in insurance and pensions, *Women's Rights Law Reporter*, 59; Heen, 1985, Sex discrimination in pensions and retirement annuity plans after *Arizona Governing Committee* v. *Norris, Women's Rights Law Reporter,* 155, p. 161. African—Americans also experienced insurance discrimination. See M. James, 1944, *The Metropolitan life: a study in business growth,* Lexington, MA: Humana Press, p. 338; G. Myrdal, 1944, *An American dilemma: the negro problem and modern democracy,* New York, NY: Harper & Brothers, pp. 316–317, 955, 1262–1263; M.S. Stuart, 1940, *An economic detour: a history of insurance in the lives of American negroes,* New York, NY: W. Malliett & Co.

9.The utility of such laws is explored by Neil A. Holtzman, 1989, *Proceed with caution: predicting genetic risks in the recombinant DNA era,* pp. 199–200, Johns Hopkins University Press.

10.The invidious nature of discrimination is the same whether an individual *has* a disability or *is perceived* as having one. Both types of discrimination are demeaning in that they stereotype the individual and deny his or her abilities.

11.According to a recent news report, the FBI is laying the groundwork for a computer information network that would contain genetic information on all violent offenders who have been incarcerated. The network would permit prosecutors to search DNA data banks to match evidence from rapes or murders against a list of DNA taken from convicted offenders. At least four states, California, Colorado, Nevada, and Virginia, have drafted laws that would require that blood be taken from prisoners convicted of violent crimes so that their genetic profiles can be entered into such a DNA data bank. Rorie Sherman, Dec. 18,1989, "On the horizon: a DNA data bank," *National Law Journal,* p. 25. Arkansas, Georgia, Louisiana, Maryland, Arizona, Florida, Michigan, and Massachusetts also enacted or introduced legislation during 1989 concerning DNA identification systems. See Table 1, "DNA identification bills before state legislatures," *geneWATCH,* **6**(1). See also the testimony of Professor Philip Bereano before the Subcommittee on Civil and Constitutional Rights, US Senate Judiciary Committee, March 1989. Copies of Professor Bereano's testimony are available from the CRG office.