

CRG GENETIC DISCRIMINATION: Position Paper

INTRODUCTION

The Council for Responsible Genetics (CRG) is a national bioethics advocacy organization based in Cambridge, Massachusetts. The mission of the CRG is to educate the public about the ethical implications of new genetic technologies and to advocate for the socially responsible use of these technologies. One of the main goals of the CRG is to document cases of discrimination that occur as a result of predictive genetic information.

The science of genetics has been transformed into a major new industry, with public and private investment continuing to skyrocket. Much of this research is funded by the federal government, through the Human Genome Project. The goal of this multi-billion dollar project is to identify and sequence all of the genes that make up the human genome. Much of this research focuses on genetic diagnostics: tests designed to identify genes thought to be associated with various medical conditions. Scores of new genetic tests have been developed in recent years.

GENETIC TESTS CAN BE USED TO HELP . . . AND TO HARM

Genetic tests are rapidly becoming a routine tool for medical diagnosis. The information produced by these tests, while potentially valuable for medical treatment, is increasingly used out of context in ways that are contrary to the interests of the patient. CRG has found that an increasing number of healthy individuals have suffered discrimination on the basis of predictive genetic information, a practice known as genetic discrimination.

Cases of genetic discrimination documented by researchers include:

* Seven-year-old Danny is in perfect health, but a genetic tests reveals that he has a gene predisposing him to a heart disorder. Even though he takes medication that lowers his risk of a heart attack, he is denied health insurance. His insurance company argues that since his gene has been present since birth, this qualifies as a pre-existing medical condition.

* Lisa's young son has been having difficulty in school. Suspecting a learning disability, she consults her doctor. Her doctor performs some genetic tests, and tells her that Jonathan has Fragile X Syndrome, an inherited form of mental retardation. Her insurance company eliminates Jonathan's health coverage, claiming that his disability represents a pre-existing condition. Lisa searches unsuccessfully for another company that will be willing to insure her son. She ultimately quits her job so that she can qualify for Medicaid.

* Kim is a social worker with a large human services agency. During a staff workshop on caring for people with chronic illnesses, Kim mentions that she was the primary caretaker for her mother who died of Huntington's disease. Kim herself has a 50% chance of developing this fatal genetic condition. One week after she reveals her risk status, Kim is fired from her job – even though she has received outstanding performance reviews in the months prior to the firing.

* Mary has a family history of breast cancer: both her mother and her aunt have been diagnosed with it. She worries about her future and is considering getting tested for

BRCA-1, a gene associated with some forms of hereditary breast cancer. Ultimately, she decides not to take advantage of the test, because she fears a positive result will jeopardize her chances for promotion at her law firm.

These cases begin to tell the story of genetic discrimination. They are but a few of the hundreds of cases of genetic discrimination that have been documented. As genetic tests become simpler to administer and their use expands, a growing number of individuals are being stigmatized on the basis of their genetic makeup. Employers and insurers are using the results of genetic tests to discriminate based on perceptions of long-term health risks and possible future disabilities.

Not only is this discrimination unjust, it is scientifically inaccurate. Genes can tell us only part of the story about why some people get sick and others do not. Even if we were able to know exactly what genes a person has, we still would be unable to predict their future health needs. This is because many genetic tests predict—with limited accuracy—that a disease may become manifest at an undetermined time in the future. Because the severity of many diseases—such as sickle cell anemia and spina bifida—varies widely among individuals, a genetic prediction cannot foretell how disabling the disease will be for a specific person.

THE EXPANSION OF GENETIC TESTS MEANS THAT THE DISCRIMINATION WILL LIKELY INCREASE.

During the past ten years, there has been an explosion in the number of available tests for genetic conditions. Ten years ago we had only a handful of genetic tests; today we have hundreds. Doctors can screen for cystic fibrosis, Duchenne muscular dystrophy, fragile X syndrome, Gaucher's disease, Huntington's disease, Lou Gerig's disease, Marfan syndrome, Tay Sachs and many others.

As these tests become simpler to administer and their use expands, the CRG strongly believes that employers and insurers will continue to use genetic information in a discriminatory manner and that a growing

number of people will be stigmatized on the basis of their genetic makeup.

This potential for discrimination increased dramatically last year. Up until now, genetic tests were only available for relatively rare single-gene disorders. In the last year, however, scientists discovered genes associated with two forms of cancer, a disease that strikes millions of Americans every year.

Individuals who carry these genes are at increased risk for developing certain forms of colon and breast cancer. Many in the medical community advocate population-wide screening for these so-called "cancer genes," so that people who carry these genes can be closely monitored for early signs of cancer. While this may save lives through early diagnosis and intervention, it may also lead to stigmatization and discrimination. Insurance lobbyists from the American Council of Life Insurance (ACLI) have already stated that insurance companies should be allowed to use information about cancer predisposition to assign risk categories in medical underwriting and possibly refuse to insure those individuals who carry these genes.

THE SOCIAL COSTS OF GENETIC DISCRIMINATION

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.

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 that 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.

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.

Such policies victimize all workers. 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.

Currently, most Americans who have health insurance receive it through their place of employment. As the costs of health care continue to rise, employers may perceive an

economic incentive to hire employees who they believe are least likely to have future health problems. A 1989 survey commissioned by the Congressional Office of Technology Assessment (OTA) documented at least five Fortune 500 companies that were conducting genetic screening on their employees. As the technology improves and genetic tests become less expensive, we can expect that more employers will begin using them. Unless prevented by law, some employers will use these tests to avoid people they fear will be “bad risks.”

The Americans with Disability Act (ADA) forbids employers from discriminating against disabled individuals who are able to perform their duties with reasonable accommodation. In revised guidelines released in March of 1995, the Equal Employment Opportunities Commission (EEOC) stated that healthy individuals who have a genetic predisposition to a disease and are thus perceived as disabled fall within the scope of the ADA. There is no valid justification for employers to perform mandatory DNA testing on their employees, since they are forbidden by the ADA from using this information in employee evaluations.

INSURANCE DISCRIMINATION

Insurers also face strong economic incentives to identify individuals perceived to be at increased risk for ill health in the future. Insurance is a publicly regulated activity designed to meet broad community goals. In the case of health insurance, the goal is to ensure access to health care by providing adequate financing mechanisms. In the case of life and disability insurance, the goal is to provide families some measure of economic security following a tragic death or disability. Rating practices for all three types of insurance are becoming increasingly stringent, violate individual privacy, and seem geared to identify and insure only the healthy and long-lived. The number of individuals stigmatized as “substandard” risks or “uninsurable” has increased. Currently nearly 100 million Americans either lack health insurance or are underinsured. More and more consumers are now unable to obtain affordable life and

disability insurance products. Our current insurance market system is not meeting its primary publicly endorsed goal. This stratification of our community into “haves” and “have-nots” is neither morally or publicly acceptable.

As publicly regulated entities, insurance companies must adopt and enact practices which the community views as nondiscriminatory, fair and equitable both in order to survive in a competitive market and to retain their legal rights to operate. Because of the important public impact of the insurance business, the industry’s programs and practices should always be open to community scrutiny and specific control.

Thus, though from a business perspective fairness may dictate “treating similar risks alike,” it may be significantly in the public interest to insist that different risks also be treated as alike. The public’s view of fairness requires that groups that differ by race, ethnicity or religious affiliation, and who may have differing actuarial morbidity or mortality rates, be offered similar insurance contracts. Genetic information is another potentially discriminating factor that the public has indicated cannot be fairly included in insurance underwriting practices. Several national polls demonstrate this view and nearly 20% of Americans now live in states that prohibit by differing means the use of genetic information in rating insurance contracts. In this manner, the community through political and regulatory processes has asserted its view of fairness as dominant over the narrower insurance industry derived conception.

There is a strong community sentiment against using “pre-existing medical condition” exclusions to deny people insurance. The removal from insurance pools of those who clearly need the benefits which insurance based financing affords strikes a blow to the social purpose of insurance. In fact, the spreading of risk across a community (community rating) is exactly what the public intended when it first allowed private insurers to provide such an important social product.

Unlike infectious diseases, genetic conditions exist at a fairly stable incidence in our society.

There is no epidemic of genetic conditions. Thus, they are already reflected in the actuarial tables used by insurers to establish rates. It is misleading for insurers to suggest that their financial solvency will be jeopardized if they are obligated to insure people at risk for genetic conditions. In fact, insurers have always insured people at risk for genetic conditions. Previously, however, it was not possible to identify those people at risk for genetic conditions before they become they became ill with the disorder.

The insurance industry has offered no compelling reason to specifically exclude this group from the insured pool now. Early identification of risk status may actually lead to insurer cost savings as a result of preventative care and longer life spans during which premiums can be collected.

Recent developments in human genetic science and the technology of testing are not identifying new costly diseases that were not previously accounted for by the insurance industry’s actuarial data. Rather, these developments are only facilitating the identification of those individuals who carry disease-associated genes at earlier times; many of these people will never have a related illness, or will experience a lifetime of the asymptomatic, presymptomatic or minimally symptomatic phases of the condition. It is not, therefore, the cost of financing the care of genetic conditions which is driving the call for access and inclusion of genetic information in insurance practices. There is no reason for insurers to begin to use this new predictive information now, merely because it is available.

GENETIC DISCRIMINATION SETS A DANGEROUS PRECEDENT

Genetic testing is not only a medical procedure. It is also a way of creating social categories. As a basic principle, we believe that people should be evaluated based on their individual merits and abilities, and not based on stereotypes and predictions about their future performance or health status. In most cases, genetic testing can only reveal information about probabilities, not absolute certainties. We believe that individuals should

not be judged based on stereotypes and assumptions about what people in their class or status are like.

Insurance or employment practices that employ these stereotypes in underwriting inadvertently reinforce them in other arenas as well. There is a strong public policy precedent for avoiding the negative social consequences of such a practice. For example, statistics demonstrate that African Americans do not live as long as Americans of Northern European descent, even when one controls for socio-economic factors. And yet no life insurance company in the country rates applicants differentially on the basis of race. To do so would violate deeply held community values about equality and equal access.

Skin color, like other genetic traits, is mediated by genes. These lie entirely outside the individual's control. Whereas individuals can exercise choices about whether to smoke, how much exercise they get, and how much fat is in their diets, they cannot change the

contents of their genes. To make employment or insurance decisions on the basis of genetic characteristics determined at the moment of conception is to discard cherished beliefs in justice and equality.

STRONG LEGISLATION IS NEEDED NOW TO COUNTER GENETIC DISCRIMINATION

Genetic information is being generated much more quickly than our legal and social service systems can respond. The Council for Responsible Genetics maintains a database of current state laws protecting citizens from genetic discrimination in health insurance and employment. While many states have now passed some form of legislation, much of it is inadequate and does not go far enough to protect the genetic privacy of individuals.

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ABOUT CRG The Council for Responsible Genetics fosters public debate on the social, ethical, and ecological implications of genetic technology. Founded in 1983, CRG is a non-profit/ non-governmental organization based in Cambridge, Massachusetts (USA). In addition to producing educational materials on various issues raised by biotechnology, CRG also publishes a bimonthly magazine, **GeneWatch**, the only national magazine that continually monitors the ethical, social, and ecological impacts of biotechnology as they apply to both humans and the environment. CRG has **position papers and question-answer sheets** on a variety of topics, including genetic discrimination, human cloning, predictive testing, genetically engineered food, the "gay gene," life patents, and germline engineering. Other resources include **The Genetic Bill of Rights**, a **Genetic Discrimination Legislation database**, and **selected books** on biotechnology and genetics. CRG also runs a **competitive internship program** for exceptional college and graduate students.

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