elected not to terminate the pregnancy, and the HMO considered withdrawal or limitation on medical coverage for the child. Billings et al. state that they were given an incentive to abort the child because of its genotype, a possible form of eugenics. This is ambiguous genetic discrimination at best. The genotype predicted a phenotype associated with high medical costs. The diagnosis was indeed made with a genetic test of a genetic disorder, but the reaction of the insurance company was based on the costs associated with the predicted phenotype.

Thus, only one of the nine cases offered as examples of purported genetic discrimination could be, I believe, condemned as such, whatever particular injustices might be committed with regard to insurance coverage or other matters because of disease or risk of disease.

It is strange that Billings et al. fail to note or complain of a widespread form of genetic discrimination that is, I believe, actually endorsed by The American Society of Human Genetics or one of its committees. This affects asymptomatic normal individuals who, purely because of their genetic makeup, are being denied financial opportunities open to others with a normal genotype. Carriers of chromosome translocations, those with even a family history of Huntington disease, and others with similar genetic at-risk status are, throughout the country, subject to such blatant discriminatory treatment. They are selectively screened out from and denied the opportunity to make money by donating sperm to sperm banks or for some other use in artificial insemination. At least, let us hope so!

Genetic information is important and has implications that society has a right to know of and act on in certain circumstances, as the examples of adoption and sperm donation illustrate. The issue of fair insurance coverage or employment is an issue related to all diseases, not just genetic ones. And genetic distinctions by society are not necessarily always socially foolish or irresponsible, nor, when legitimate, do they merit the pejorative implications of the term "genetic" discrimination.

ERNEST B. HOOK
School of Public Health, University of California, Berkeley, and Department of Pediatrics, University of California, San Francisco

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Genetic Discrimination and Insurance Underwriting

To the Editor:

The March issue of the *Journal* offered an editorial (Holtzman and Rothstein 1992), an opinion (Harper 1992), a review (Natowicz et al. 1992), and an original article (Billings et al. 1992), each of which targets a different aspect of the problems of the nonclinical use of genetic-test data. The articles are timely because, while there is much interest in this field on the part of nongeneticists, there are as yet no available tests that meet the criteria of wide application, positive predictive value, and low cost that would initiate their use outside of clinical medicine. One group following these developments with interest is the insurance industry, because the technology may bring new challenges in competition, in adverse selection, and in inappropriate legislation. Public perception of insurance industry practices is often far removed from reality, and thus these recent articles have prompted a reply.

The insurance industry is highly competitive. Brokers and agents work hard to find clients and to sell them various types of financial protection. The companies cannot afford to turn down many clients. They are not looking for new ways to lose business. Today, to my knowledge, there are no insurance companies in North America that use prospective DNA testing to assess their clients. Some may use tests results from previous studies, but most would have great difficulty determining the value of these tests because they have no past experience to guide them.

When underwriting an individual client, insurance companies are not all alike and do not always make the same decisions. Differences between companies

offering similar types of protection are often small, but it is clear that the major branches of the business (life, disability, and health insurers) are not all concerned with the same factors in the assessment of risk in their clients. For example, malignant melanoma poses a significant life risk but rarely leads to a long-term disability claim. In like manner, while it may be appropriate to discuss entitlement rights for access to standard health care for those with serious genetic mutations, do the same arguments hold for life insurance applications?

Life insurers base all their decisions on past experience. We predict life expectancy for an individual with a history of myocardial infarction, on the basis of what happened to previous clients with similar disease. The new genetic technologies could change this practice, for they will bring not only improved diagnostic capabilities but also the promise of new methods of management that may provide "cures" for some inherited diseases. At this time, insurance companies have adopted a wait-and-see approach to the use of these new tests. They welcome public discussion of the many problems the technology will bring.

On a number of occasions over the past several months I have heard Dr. Paul Billings speak about his collection of cases of individuals who have been unfairly considered by insurance companies. His remarks in public forums have been anecdotal and thus somewhat difficult to analyze. It was thus with interest that I approached his article in the recent issue of the *Journal* (Billings et al. 1992). Unfortunately, while the article gave many strong arguments in support of the genetically disadvantaged, it failed to provide much new information about the individual cases, and it suggested that an appropriate response to the situation is the imposition of further regulatory controls.

If there is a financial and social need for the insurance process, perhaps it is time, before a deluge of new laws are enacted, that we examine some facts. Before the insurance industry and the genetics community draw their lines in the sand, let us begin to communicate. Let us learn enough about each other's discipline, operations, and needs to resolve a potential conflict before it begins.

Discrimination, as used in the title of the article by Billings et al., has an unfortunate connotation. It appears as a pejorative. Yet discrimination can also be defined as differentiation. On the basis of signs, symptoms, and laboratory (including genetic) tests, geneticists discriminate when they make diagnoses. Discrimination is also what insurance companies do when they assess risk. There is a clear difference in risk between an Olympic athlete and a 70-year-old with congestive heart failure. In the insurance industry, we call this discriminative process "underwriting." It is not prejudicial in an unfair manner, but, on the basis of available information, it does attempt to determine the expected life and health risks for a particular client. The cost of the policy is then calculated when the individual risk is compared with actuarial data for a large group of people of the same age. Underwriting is inherently fair because it spreads risk among a large cohort but requires those who are expected to make early or excessive claims to bear some of the financial responsibility. On the basis of past experience, the underwriter determines what it will cost the insurance company to provide each individual with the insurance protection the client seeks.

If regulations are imposed that remove or restrict the underwriting function, current policyholders are placed at a disadvantage. Premium costs will rise, and some companies may be unable to meet the cost of increased claims. If an insurance company offers a policy to a man who has hypertension and angina, without knowledge of these medical impairments, the company will almost certainly pay an early claim and will lose money. That loss must be borne by the other policyholders. It is thus reasonable for those policyholders to expect their insurer to identify the increased risk represented by the applicant's medical condition and to protect their interest.

The situation is not much different for an otherwise healthy applicant who has a mutated bit of DNA that will lead to a premature demise. If that information is known by the client or the physician, it must be also available to the insurer in order to protect the other policyholders' interests. If the insurer is prevented from acquiring the information, then the client can use it to unfair advantage by purchasing excessive amounts of insurance. The process is called "adverse selection" because the client is purchasing insurance with the expectation of an early claim.

Dr. Billings has identified 29 cases in which he believes there was genetic discrimination against an individual on the basis of aberrations in his genome. The cases were identified over a 7-mo period and apparently are derived largely from the northeastern United States. If one discounts cases of unfair employment or those from auto insurance companies, this number is remarkably small. In a 7-mo period, hundreds of

thousands of life insurance policies would be issued in the same region, and yet only 42 clients felt strongly enough about their insurer's decisions to respond to Dr. Billings's survey. Of these, only 29 qualified as examples that met Dr. Billings's definition of genetic discrimination.

From the few details presented on 8 of 29 cases, it appears that some bad decisions were made, but I do not believe that they represent typical insurance-industry practice. They may represent mistakes in judgment based on lack of information. Most underwriting is carried out by skilled technical staff who have acquired their medical knowledge during their training programs and from subsequent years of experience. Their tools include medical texts as well as underwriting guidebooks, which are extensive compendia of medical impairments, developed by all major insurance companies. The guidebooks also provide suggestions about ratings, but they are not complete medical libraries, and they focus on common diseases.

To assist or monitor lay underwriters, most insurance companies also employ a medical director who may have access to more complete and current information. Sometimes these medical directors are not omniscient! Their expertise is in the assessment of risks that cause most insurance claims—heart disease and cancer. They need assistance in maintaining a current knowledge base in new, rapidly changing fields such as genetics. Without help they will make some poor decisions.

Poor decisions can be avoided by developing regulations that remove the underwriters' right to make the decision. Perhaps, however, it would be better to educate the insurance companies' medical directors and underwriters so that they can do their job of risk assessment from an informed position rather than from a guess. This knowledge must come from the genetics community. I am sure it will be well received.

J. A. LOWDEN

Crown Life Insurance Company
Toronto, Ontario

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Reply to Hook and Lowden: The Definition and Implications of Genetic Discrimination

To the Editor:

In our recent article "Discrimination as a Consequence of Genetic Testing" we discussed cases in which genetic information was used to discriminate against individuals or families (Billings et al. 1992). In that report, as well as in an accompanying review (Natowicz et al. 1992*a*), the opinion was expressed that abuses of genetic information are likely to markedly increase in the near future as a result of the proliferation of new genetic tests, the Human Genome Initiative (HGI), and corporate and societal pressures to develop and utilize genetic testing. The results of our preliminary survey indicate that genetic information is already used to deny social benefits such as insurance. They therefore raise serious concerns about the consequences of genetic testing and screening.

Drs. Hook and Lowden (Hook 1992; Lowden 1992) question both our definition of genetic discrimination and the appropriateness of the case examples chosen from the survey. They also argue that the discrimination noted may not have been unfair. In addition to addressing these issues in the present letter, we discuss some of their concerns at length in an accompanying letter and in other articles (Natowicz et al. 1992*b;* Alper and Natowicz, submitted).

Dr. Hook argues that, in most of our examples, we confuse genotype with phenotype. One example he points out is the individual with the genotype associated with hemochromatosis who was discriminated against because the health insurance company erroneously believed that he would incur substantial medical costs. In view of the fact that there is no medical or actuarial basis for that belief, we maintain that the discrimination arose because, in our society, genetic conditions are often perceived as being either more severe or less amenable to treatment than are nongenetic conditions. In several of the other examples of discrimination that are described and criticized by Dr.