judgment that relies on the best available objective evidence, to determine the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices, or procedures will mitigate the risk" (56 Fed. Reg. 35701 [July 26, 1991]). This paragraph goes on to say that this assessment "is essential if the law is to achieve its goal of protecting disabled individuals from discrimination based on prejudice, stereotypes, or unfounded fear, while giving appropriate weight to legitimate concerns such as the need to avoid exposing others to significant health and safety risks."

In view of the above discussion and statement of the law, we can summarize our position as follows: Genetic discrimination is discrimination against an individual or a member of the individual's family solely on the basis of that individual's genotype. This type of discrimination, like sex, race, age, sexual orientation, and disability discrimination, is unfair because it treats individuals as though they are defined by membership in some particular group. In some circumstances, it is legitimate to make distinctions between individuals on the basis of their individual characteristics. Thus, in making decisions about whether to hire an individual, it is legitimate to consider genetic factors if these factors are relevant to the performance of the job and to the health and safety of others. But, as the law states, in order to avoid illegal discrimination, it is necessary to assess each case individually, and it is necessary that there be no reasonable accommodations that would enable a (genetically) disabled person to perform the job.

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Muddling Genetic Discrimination

To the Editor:

The paper by Billings et al. (1992), purporting to address genetic discrimination, contains a great number of problems that undermine their analysis. These include, among others, conflation of genotype with phenotype and of penetrance with expressivity. Billings et al. define genetic discrimination as discrimination of—i.e., against—an individual solely because of real or perceived differences of his or her genotype from the "normal" genome. They exclude discrimination against an individual who was affected by the genetic disease at the time of the event. Billings et al. do not tell us precisely what they mean by "affected," however, and therein lie difficulties.

I consider here the alleged instances of genetic discrimination offered by Billings et al. and show that all but one of their examples either are not examples of their definition, illustrate that their definition is muddled, or establish that what they denounce as discriminatory actually has some social justification as a legitimate genetic distinction. I deal with their examples in the order they present them.

The first is a man with hereditary hemochromatosis who was diagnosed in 1973 as having excessive iron storage and has been receiving phlebotomies. He can't get health insurance even though he is asymptomatic and runs 10-km races. Billings et al. state that, regarding this case, "it was through genetic testing that this individual was diagnosed" (p. 479). They classify him as an example of genetic discrimination. First, in 1973, genetic testing for hemochromatosis was not available. And while he may have been investigated because of his family history, genetic testing—even if it were used in the diagnosis—is irrelevant to the issue involved. He is asymptomatic, and the disorder has a

genetic basis. But he is affected in the sense that he needs regular treatment. There are no grounds to believe that it was the genetic etiology of the condition that led to the insurance company's decision, however unfair it was.

The second case, a carrier of Gaucher disease denied a government job because of his "being a 'carrier, like sickle cell'" does fit unequivocally their definition of genetic discrimination. (It sounds so bizarre that I, for one, would seek further details to assure me that this was an accurate report of what happened.)

The third case is one of an 8-year-old child with phenylketonuria whose family could not get health insurance after the father changed jobs. While the disease has a genetic basis, again there is no ground to regard its genetic origin as the grounds for the lack of insurance coverage. Billings et al. state that the child is completely asymptomatic and that her only abnormality lies in her genotype. But one may argue that she needs ongoing treatment, so she is affected, in this sense.

The fourth, fifth, and sixth cases of alleged genetic discrimination all have Charcot-Marie-Tooth disease and have been denied life insurance, employment, or automobile insurance, respectively. Now these individuals *are* symptomatic. Therefore, by the definition of Billings et al. they are *not* examples of genetic discrimination. Their problems result from misconceptions about the disease. The genetic etiology has nothing to do with the decisions by the insurance companies. Moreover, it is interesting that one respondent says that he or she actually *is* at risk for accidental death in an automobile because of the condition. On those grounds, he or she seems to imply the insurance company might legitimately classify him or her at higher risk (i.e., discriminate) regarding this type of insurance at least.

Billings, et al. state, regarding these cases, that "having a particular *genotype* is equated with the presence of a severe illness and the lack of effective treatments" (emphasis added) (p. 479). However, it was not the genotype but the (probably) false understanding of the phenotype that led to their rejection. Billings et al. also state: "This evaluation of genetic conditions illustrates a lack of understanding of the concepts of incomplete genetic penetrance, variable expressivity, and genetic heterogeneity" (p. 479–480). But the disease *is* penetrant in these individuals. Whose misunderstanding of incomplete penetrance is illustrated?

The seventh and eighth cited cases are of couples in which one parent is at risk for Huntington disease. In both cases, they were rejected as adoptive parents. One woman, in implicitly criticizing the adoption agency, asked rhetorically whether she is "different than anyone with diabetes or cancer, for example, in their ancestry?" (p. 480). For the other case, a letter is cited from the adoption agency saying that a "fifty-fifty chance of getting a disease as serious as Huntington disease is too great a risk, for our purposes and circumstances" (p. 480) because of the great likelihood that the affected parent would not be available to the child for all the preadulthood years. The logic makes sense to me at least (even if the odds are closer to 1:2 because the person at risk has reached, probably, her mid 30s). There are just so many babies to be placed. Why place infants in families where there is not only a serious risk of losing the function of one parent, but also the serious possibility of the adverse behavioral effects of the disorder itself on the parent-child relationship?

Billings et al. claim that these cases illustrate a "eugenic prejudice—the myth of genetic perfection" (p. 480). They claim that "the agencies assume that the best possible family is the one least likely to face medical adversity . . . unfortunately, all families are at risk" (p. 480). Yes, but medical geneticists, one hopes, should be the first to recognize that some families are at more risk than others, in particular those in which a parent has Huntington disease.

Billings et al. also state "the comparison made by one respondent, of being at risk for Huntington disease with susceptibility to diabetes or cancer, highlights the prejudice—that the chance of developing a genetic condition is perceived differently from a similar probability of contracting an illness not produced primarily by a gene" (p. 480). But the distinction here is not because of the origin of the disease but because of the magnitude of the associated risk of manifesting a phenotype. And it's simply erroneous to imply, as Billings et al. do, in making this argument, that the effects of her developing these disorders, certainly of diabetes, would have the same qualitative effect upon the parent-child relationship as her developing Huntington disease. Further, the genetic etiology of Huntington disease is irrelevant to the issue of adoption here. The adoption agency would, presumably, take the same approach if a parent were at a perceived high risk of developing dementia because of environmental factors.

The ninth case cited was of a family in which cystic fibrosis was diagnosed prenatally but the family

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.

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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