GENETIC DISCRIMINATION AS A CONSEQUENCE OF GENETIC SCREENING**

Paul R. Billings, Mel A. Kohn, Margaret de Cuevas and Jonathan Beckwith

Departments of Medicine, and Microbiology and Molecular Genetics

Harvard Medical School

Boston, MA. 02115

The Deaconess Hospitals

** Address reprint requests to: Paul R. Billings, MD, PhD, Clinic for Inherited Diseases, Deaconess Hospital, 110 Francis Street, Boston, MA. 02215

ABSTRACT

Rapid advances in the techniques of genetic medicine have improved the care of individual families burdened with hereditary conditions. We find evidence that discrimination typically reserved for the severely and chronically disabled is experienced by individuals labeled with genetic conditions. These prejudices and practices also affect close relatives of individuals with identified genetic traits. Since universal genetic screening programs would stigmatize many individuals who are asymptomatic or who will never become significantly impaired, caution in applying genetic screening protocols should be exercised to avoid creating a new social class, the "asymptomatic ill".

INTRODUCTION

Though human DNA-based diagnostic tests are a relatively new development, their technical power and intellectual allure have given the field of human genetics renewed influence. Individual families faced with agonizing reproductive or clinical decisions have been aided by techniques utilizing specific gene probes or disease-linked DNA sequences.[1] With further refinement of the human genetic linkage map,[2,3] genetic tests for the predisposition to common conditions such as cancer, cardiovascular disease, and mental disorders may be forthcoming.[4,5]

Insurance companies, private employers, governments and educational institutions have been mentioned as parties promoting large scale genetic screening to identify individuals carrying disease-associated genes.[6-12] In addition, economic pressures to apply genetic tests to broader sections of the population may have increased as biotechnology companies develop and sell genetic testing products.[13,14] Finally, the pace of development and application of DNA tests, and their acceptance by the public, may be influenced by the recent widespread media coverage of the work of human geneticists. Yet knowledge of how genes produce disease remains quite limited.

Given this situation -- a powerful and attractive new technique, social and economic forces pressing for its application, and incomplete basic investigations of inherited conditions -- concern about the burdens

engendered by widespread utilization of genetic tests seems justified. One conceivable outcome of these developments is a revival of eugenic social policies.[15]

While there have been theoretical concerns about prejudices surrounding genetic conditions and "genetic discrimination" -- stigmatization based on genetic inheritance -- investigations of these issues have not been published.[16-19] Evaluations of genetic screening programs for conditions such as phenylketonuria, Tay-Sachs Disease, sickle cell anemia and the XYY Syndrome have yielded mixed results when effectiveness and client satisfaction were considered, but have not assessed long-term, non-clinical outcomes.[20-25] The personal costs of consenting to genetic screening have not been studied, and therefore remain an ambiguous part of the "informed consent" process in genetic testing.

This paper describes the results of a preliminary survey of individuals labeled with genetic conditions. The survey's aim was to discover if incidents which may reflect genetically-based discrimination are occurring in the workplace, in access to social services, in insurance underwriting and in the delivery of health care. If such discrimination is occurring, widespread application of genetic testing and screening needs to be reconsidered.

THE SURVEY

A definition of genetic discrimination was developed for this preliminary study based in part on the work of the Genetic Screening Study Group of Science for the People -- a Boston area public interest group.[26-29] Discrimination stemming from supposed hereditary transmission of a condition can be obvious, as in the case of an individual who was denied a job because an old health record noted that the applicant's mother was "schizophrenic". In other instances, the distinction between discrimination based on clinical disability or illness, and that arising from genetic aspects of a condition, was difficult to determine.

For the purposes of this survey, genetic discrimination was defined as instances of differential treatment based on apparent or perceived human variation presumed to have a genetic origin. Using this definition, reports of discrimination involving individuals with hereditary disorders or close relatives were assessed. Furthermore, if incidents were reported by a disabled or clinically ill individual, evidence was required that prejudices about genetic conditions significantly influenced the reported discrimination.

The most common reasons for excluding responses in this survey were:

1. Differential treatment was based on a physical variation or disability independent of conceptions concerning hereditary conditions (for example, individuals with Turner Syndrome who were discriminated against in employment settings because of their short stature).

2. Evidence that differential treatment arose from the hereditary nature of the condition was not presented (for example, working conditions or hours were altered by an employer, and an individual with a genetic and physical disability found it difficult to adjust to the new employment situation); or, there was inadequate information submitted to determine if discrimination had occurred.

An advertisement(for text, see ref.30.) was mailed to 1119 professionals and interested individuals listed by the Massachusetts State Genetics Office. This solicitation was also published in the American Journal of Human Genetics.[31] Similar appeals were reprinted in newsletters of organizations of individuals with genetic conditions including Friedreich Ataxia, Charcot-Marie-Tooth Disease, muscular dystrophy and possibly other such associations.

Many responses included supporting documentation. Personal communications between the authors and professionals practicing clinical genetics were considered without information reported directly to us by clients. Each described incident was reviewed independently by two of the authors (PRB and MAK) and a decision was reached as to whether it met the standard for inclusion in our survey. This preliminary investigation was closed after receiving responses for seven months.[32]

FINDINGS and COMMENTS

Of the 42 responses received, 13 (31%) were excluded from further study for reasons mentioned in the Methods section. The remaining 29 responses came from all regions of the United States and Canada. A variety of genetic conditions were represented in the study group including Huntington Disease, Freidreich Ataxia, Charcot-Marie-Tooth Disease, hemochromatosis, phenylketonuria and others. Most of the responses were elicited by the advertisement reprinted in newsletters.

The 29 evaluated responses described 41 separate incidents of possible discrimination. A categorization of these cases is presented in Table 1. The incidents involve private and group insurers, employers, physicians, and social institutions (federal and local governments, adoption agencies, etc.).

The respondents described attempts to get insurance coverage, difficulties in finding or retaining a job, and interactions with adoption agencies. Problems with insurance companies arose when individuals altered existing policies because of relocations or changes in employers. New, renewed or upgraded policies were frequently unobtainable even if individuals labeled with genetic conditions were asymptomatic. Assessment of the natural history of the genetic condition or evaluation of the fitness of the individual by physicians had little or no influence on the adverse outcomes presented by the responders. Because of fear of discrimination, several respondents withheld or "forgot" to mention potentially important medical or family history information to physicians, employers, insurers and

others." Even insurance agents advocated that clients give incomplete or dishonest information on insurance application forms.

Responses excerpted below illustrate themes found in the survey. They reflect three general dilemmas faced by individuals labeled with genetic conditions: the "Genetic Trait Versus Illness Dilemma", the "After Test Dilemma", and the "Asymptomatic Ill Dilemma". While the incidents suggest discrimination by specific institutions (for example, adoption agencies and insurance companies), the practices and attitudes of many business, social and political institutions are also likely represented in these anecdotes.

THE "GENETIC TRAIT VERSUS ILLNESS" DILEMMA

Several responses described situations in which people were victimized by rules which did not reflect their actual physical abilities, or the variability of genetic conditions. One respondent with Charcot-Marie-Tooth Disease (CMT), a non-fatal, clinically variable and genetically heterogeneous neuromuscular condition[84, 85] wrote:

I have been rejected for life insurance many times, but only once was CMT cited [explicitly] as the reason... [I appealed, informing the insurance company] that people do not die from CMT and that they had declared me automatically *eligible* [emphasis added] for accidental death insurance -- the one risk that can be assumed might be greater for people with CMT... [The insurance company's reply] repeated the statement that CMT is the reason for rejecting my application.

In 1979 my daughter was denied employment by the [name omitted] Company because she has CMT even though the case is not really noticeable. She had indicated on the form that she had CMT and the examiner asked her what it stood for; then, he looked it up in a medical book and denied her a job which she had been offered to her by the recruiter.

Another respondent stated:

...My husband has a genetic disorder, Charcot-Marie-Tooth. We have just been turned down for automobile insurance with [name omitted] because of his disease. I have just recently sent them a letter from my husband's doctor...explaining that my husband is a far better driver than anyone I know...My husband has had NO accidents, or traffic violations since he has been driving from the age of seventeen [twenty years of driving].

A physician reported that:

An individual was found to have Gaucher Disease. His brother was screened and the results were consistent with unaffected carrier status [heterozygote]. The brother applied for a governmental job and included the history of his testing in the application. He was denied the job because of his being a "carrier, like sickle cell".

COMMENT:

Having a particular genetic trait is equated with the burden of a predetermined and severe illness in these incidents. Decision-making concerning these individuals is based solely on a diagnostic label, without regard to the variable meaning of the condition in each case. Errors in diagnostic decision-making or testing occur and are worsened by this irrational and unfair simplification of genetic conditions -- the equating of trait with significant disability. Inaccuracy in the diagnostic testing and labeling is increased when individuals with asymptomatic or mild genetic conditions are considered.

Once labeled (possibly erroneously), an individual may suffer serious consequences as highlighted in the examples. Furthermore, information related to genetic labeling may enter large scale data banks now used to store personal health-related information. Individuals' health "profiles", which can include genetic conditions, are available privately and are generated in a manner similar to the ubiquitous credit "checks" encountered in business. Breaches of confidentiality and non-consentual uses of this information may arise. Genetic data on certain groups within our society (for example, criminals) is already being stored by governmental agencies.[36-40]

These findings suggest that there are very important non-medical reasons why individuals may wish to avoid genetic screening. It is clear that the option "not to know" is being exercised now; many persons at risk for Huntington Disease have refused to be tested.[41, 42] The choice to refuse testing will become more difficult if such testing is required for employment, to obtain affordable medical care or as a qualification for insurance in the future. The widespread utilization of genetic testing as a prerequisite for obtaining social entitlements, in addition to its assumptions about the significance and infallibility of such tests, would also erode an individual's right to choose not to determine his or her genetic predispositions. Storing of the results of testing outside of an independent medical setting would likely increase chances that rights to privacy would be compromised.

Another aspect of the genetic trait versus illness dilemma is illustrated by the experiences of individuals thought to be "at risk" for a genetic condition. As a natural consequence of more genetic testing, the identification of individuals who are "at risk" either because of their family's medical history or as a result of screening will increase. The experiences of these individuals highlight important aspects of the difference between a genetic trait and a clinically apparent condition.

A respondent wrote:

I am at risk for Huntington Disease [age 31]. After many years of consideration, my husband and I decided not to bear our own children, but

rather to adopt children, so as not to take the chance of passing on the Huntington gene.

In 1987 we began investigating adoption. We encountered restrictions due to religion and availability of infants, but were finally invited to make application with [name and location of agency omitted]. We began our counseling process and our home visits, at which point the issue of my being at risk was discussed (I had disclosed in my original application the possibility of my developing the disease and why we had chosen adoption). Before completion of our home study, we were asked to withdraw our application, because of the Huntington Disease situation.

.....We understand the right to choose the BEST 50 couples out of some 500 applicants per year for placement. Availability of children is incredibly limited. And yet, should I be judged by a disease that I am only at risk for and that may not develop for some years to come? Does this make me different than anyone with diabetes or cancer, for example, in their ancestry?

Another couple at risk for Huntington Disease sent a letter they received from an adoption agency:

We have decided, in your situation, not to proceed with your application because there is a fifty-fifty chance of your getting Huntington Disease. Though you would be likely to get the disease around the age of fifty, it could be sooner. You would not receive a child from us, if we could proceed with your application, for several years, and therefore we would be risking the likelihood of not having you available to the child until he/she has reached adulthood. We feel that a fifty-fifty chance of getting a disease as serious as Huntington Disease is too great to risk, for our purposes and circumstances.

Comment:

What is the meaning of being "at risk"? As noted above, to have a genetic trait carries an aura of certainty, predestination, and severity.[43] Yet genes are thought to contribute to the development of many illnesses not

viewed as hereditary by social agencies. For example, siblings of individuals with juvenile onset diabetes mellitus who are genetically identical at the HLA locus to the affected individual have twenty-five times the risk for developing diabetes themselves when compared to the general population.[44, 45] Yet, a family history of diabetes is unlikely to result in an adoption application denial.

In the above anecdotes, the adoption agency's attitude illustrates how certain conditions categorized as "genetic" are viewed as special and handled differently in terms of social decision-making. DNA testing will not necessarily lessen the chances of similar hurtful incidents, since a positive test will not be an infallible predictor of the burden a genetic trait may place on an individual.

Many responses in this survey illustrated a lack of understanding of incomplete genetic penetrance, variable expression, pleiotropism, and genetic heterogeneity. Typically, evaluations of individuals with genetic conditions assume uniformly severe disease presentations -- while ignoring the range of presentations of genetic illness -- and no effective treatment. In these cases, the worst possible scenario seems to be the standard used for policy decisions concerning "at risk" individuals. These prejudices may therefore lead to discrimination against often healthy individuals who will never manifest the most clinically extreme scenario possible.

Huntington Disease, for instance, may be an unusual condition in that most of the affected individuals possess the same single mutant allele.[46, 47] Yet, the clinical illness demonstrates considerable variability in its manifestations. Age at onset ranges from 15 to 60, the disability can progress slowly, and there is variability in the type and severity of presentations (primarily psychiatric, dysmotoric, or both); paternal transmission is usually associated with more severe illness.[48] The implication of an adoption agency's rejection of these couples at risk for Huntington Disease is that they are at very high risk of developing a severe case of a disabling and fatal condition with early onset and rapid deterioration. A positive test or diagnosis does not necessitate this conclusion, nor does it predict the abilities of affected individuals as parents, or the qualities of a potential home.

These incidents also illustrate a larger eugenic prejudice -- the myth of genetic perfection.[49, 50] They assume that the best possible family is the one least likely to face medical adversity -- the "perfect" family with a disease-free genome. Unfortunately, all families are at risk. The comparison made by one respondent, of being at risk for Huntington Disease with susceptibility to diabetes or cancer, highlights a prejudice -- that the chance of developing a genetic condition is perceived differently from a similar probability of contracting an illness not produced by a gene.

THE "AFTER TEST" DILEMMA

The information derived from genetic testing may create personal situations requiring difficult and important decisions. Institutional involvement through employment, benefits or health care delivery relationships may influence individual decision-making.

A clinical geneticist caring for individuals with phenylketonuria (PKU) -- a potentially severe, genetic biochemical disorder which can affect growth and mental development -- wrote:

> [Name withheld] is an 8 year old [sex withheld] who was diagnosed as having PKU at 14 days of age through the newborn screening program...A low phenylalanine diet was instituted at that time...
>
> Growth and development have been completely normal. Height, weight, and head circumference all follow the 25th percentile. Routine developmental assessments done at 26 weeks, 53 weeks, and 54 months revealed skills solidly appropriate for age, and in many instances skills were above age-expected levels. The child continues to be developmentally normal and be healthy.
> The circumstances of the discrimination that this child has experienced involve rejection for medical insurance. She was covered by the company that provided group insurance for her father's previous employer. However, when he changed jobs recently, he was told that his daughter was considered to be a high risk patient because of her diagnosis, and therefore ineligible for insurance coverage under their group plan. She is currently being covered at the expense of her family, but this is a temporary solution at best. The family has written to the agency that administrates the group insurance plan to obtain details of the decision to deny coverage and also plans to write to the chairman of the large corporation for which the father works. All information will also be submitted to the [state] insurance commissioner...

In another case, a physician informed us that:

A family with a child who has cystic fibrosis received health care through an HMO. When a second pregnancy occurred, prenatal diagnosis using DNA analysis was instituted. Fetal DNA tested positively for two copies of the cystic fibrosis gene. Nevertheless, the family decided to proceed with pregnancy. After disclosure of the test result, the HMO considered withdrawal of or financial limitations on the health care coverage for the pregnancy, postpartum and pediatric care, as well as for the already affected child. Threats of legal action were required before this situation was resolved.

COMMENT:

The first incident illustrates constraints imposed by genetic labeling. The cost of a phenylalanine-restricted diet, an effective treatment for PKU,[51] is high. Without insurance, it is possible that the family would not be able to afford treatment for their daughter, with the consequent risk of developmental delay and permanent impairment. The family's life is restricted by the necessity for the father to maintain employment at the same job in the same state in order to have access to insurance. Otherwise, this family risks losing necessary health insurance coverage for the daughter. Therefore, the child's diagnosis has a major impact on the social status of other family members.

By preparing to take their situation to a governmental board, this family demonstrated "self advocacy" abilities. The poor, the uneducated, foreign nationals or those with fears about their job security may not be as willing to defend themselves publicly or negotiate the complexities of our legal and regulatory systems in order to secure their rights or present appeals.

In the second anecdote, the family was forced to consider that an unborn child with a certain genotype might alter their access to necessary health care entitlements and benefits. This situation could be viewed as incentive for the abortion of the fetus, an interpretation with eugenic implications. If legal threats are needed to maintain access to affordable health care, what happens to couples who can not afford legal assistance, who do not have non-group health insurance coverage or employment?

THE "ASYMPTOMATIC ILL" DILEMMA

Many individuals currently identified as having a hereditary condition are healthy. Some have undergone screening only because other affected family members have been identified. As screening tests become more readily available, an increasing number of individuals will discover that they harbor a disease-associated gene but have no identifiable clinical illness.

A respondent from a family with hereditary hemochromatosis wrote:

> In 1973, at age 27 and 1/2, I was diagnosed as having excessive iron in storage and was put on a regime of phlebotomies...
>
> ...[after several years] I have never had the slightest symptom, in part because early detection [and appropriate treatment] of iron overload in my case avoided damage...
>
> [after failing to get insurances because of his hemochromatosis]...I have supplied doctor's testimonies to no avail. I might as well have AIDS. Even though I have proven that I prevented health problems by early detection and prophylaxis, they condemn me to the same category as lost cases. I run 10 Km races, etc.. I am not a basket case, and will not be one, ever, because of iron overload.

COMMENT:

This anecdote illustrates both the promise and the burden of genetic screening. The respondent has most likely benefited in terms of his medical condition by being tested for the presence of a gene identified as affecting his family, and by undergoing treatment. Yet because of his screening test results, he has been stigmatized as if he were severely ill.

As larger numbers of individuals submit to or are coerced into testing (for instance, in order to get a needed job or insurance coverage), a new social class may be created -- the "asymptomatic ill". This new group may find that they are treated as if they were disabled or chronically ill by important segments of our society.[52, 53]

Access to jobs, insurance or social entitlements may be limited. Stigmatization and frustration ("I might as well have AIDS") may accompany the test result. The financial and legal burdens of maintaining a reasonable standard of living and basic entitlements could be significant.

Finally, trusted relationships within our society may be altered by screening. The responses to this survey suggest that health professionals, who should be recognized as experts on the natural history and variability of genetic conditions, have a striking lack of input into decisions made by social agencies and businesses about individuals with these diagnoses. Furthermore, routine numerical coding of diagnoses for billing and computer storage purposes may begin breaches of doctor/patient confidentiality, and publically identify individuals with genetic conditions. In response, many individuals may become reluctant to share personal information in medical settings for fear of its public ramifications. This will likely impede effective medical care and degrade important relationships with physicians.

CONCLUDING REMARKS

This anecdotal survey has identified multiple forms of possible discrimination experienced by individuals identified as having hereditary traits. It does not document the full range of the prejudices faced by those individuals nor does it establish the prevalence of these attitudes or discriminatory practices. A comprehensive study of the frequency and extent of genetic discrimination is critical for social planners designing strategies to ensure the ethical, humane and appropriate use of genetic testing in the future. Many of the institutions who may be involved in discriminatory practices have also expressed interest in improving their understanding and modifying rules and procedures in order to avoid making decisions which hurt people with genetic conditions.[54, 55]

Various constraints already exist on the uncontrolled expansion of genetic testing. These include the past failures and limited successes of attempts at expanding genetic screening; the dismal history of eugenic movements; general public suspicion of genetic and scientific incursions into normal daily life; organized opposition by interest groups (labor unions and disability advocates, for instance); and various laws including privacy acts, disability protections, Title 7, civil rights laws and other common law traditions.[20, 56]

Nevertheless, it is clear that unfair and discriminatory uses of genetic data likely occur under current conditions. There is considerable reason to fear that the rules and attitudes currently in place may be inadequate to restrain powerful interests which support larger applications of genetic techniques. The reaching of a broad-based public consensus on their appropriate use is necessary prior to the application of genetic screening programs. Many healthy and potentially productive members of our society, especially the poor, vulnerable and those unable to advocate for themselves, will suffer as the "asymptomatic ill" without further legal protections and changes in social attitudes.[7, 17-19, 52]

The results of this pilot survey suggest that advertising through the extensive network of newsletters serving individuals with genetic conditions will be a fruitful way to uncover further cases of possible discrimination. Once these cases are identified, they require careful evaluation which respects privacy and confidentiality issues. A team approach aiding the affected individuals with medical, legal and social service supports seems appropriate. Studies of genetically heterogeneous conditions -- those with significant clinical variability (for example, in age of onset and extent of disability) or requiring prolonged courses of therapy -- may be particularly illuminating.

Because of the important social and personal issues raised by this survey, the large appropriations for research into the sequencing of the human genome should be linked to funding assessing the outcomes of genetic

testing, the social impact of new DNA-based techniques, and to programs designed to improve the care of the already disabled. The impact of the expanding use of these techniques on medical confidentiality and on aspects of the physician/patient relationship needs to be considered. Caution in proceeding with universal genetic screening seems prudent until the screeners and the society to be screened become more aware of the significance and limitations of genetic information.

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REFERENCES

1. Sommer S and Sobell J. Application of DNA-based diagnosis to patient care: the example of hemophilia A. *Mayo Clin Proc.* 1987; **62**:387-04.

2. Donis-Keller H, Green D, Helms C, et al. A genetic linkage map of the human genome. *Cell.* 1987; **51**:319-37.

3. McKusick V. *Mendelian Inheritance in Man.* 8th Edition. Baltimore, Md: Johns Hopkins University Press; 1988.

4. Lander E and Botstein D. Mapping complex genetic traits in humans: new methods using a complete RFLP linkage map. *Cold Spr Harb Symp Quant Bio.* 1986; **51**:49-62.

5. Scott J. Molecular genetics of common diseases. *Br Med J.* 1987; **295**:769-71.

6. *The Role of Genetic Testing in the Prevention of Occupational Disease.* Washington, DC: Office of Technology Assessment, United States Congress; 1983.

7. Holtzman N. Recombinant DNA technology, genetic testing, and public policy. *Am J Hum Genet.* 1988; **42**:624-32.

8. Holtzman N. *Proceed with Caution: The Use of Recombinant DNA Technology for Genetic Testing.* Baltimore, Md: Johns Hopkins University Press; 1989.

9. *Genetic Testing in the Workplace.* Washington, DC: Office of Technology Assessment, United States Congress; in press.

10. Murray T. Warning: screening workers for genetic risk. *Hastings Center Report.* 1983; **2**:5-8.

11. Motulsky A. Impact of genetic manipulation on society and medicine. *Science*. 1983; **219**:135-40.

12. The suggestion that genetic testing be used in educational settings arises from the current use of intelligence quotient and behavioral tests, argued to have a genetic basis, in these environments.

13. Hewitt M and Holtzman N. *The commercial development of tests for human genetic disorders.* Washington, DC: Staff Paper, Office of Technology Assessment, United States Congress; 1988.

14. *Genetic Testing in the U.S.A.* New York, NY: R. First Inc.; 1986.

15. Kelves D. *In the Name of Eugenics: Genetics and the Uses of Human Heredity* . Berkeley, CA: University of California Press; 1985.

16. The term "genetic discrimination" may have arisen from a workshop organized by P. Reilly for the American Society of Human Genetics, reported in: Rowley P. Genetic discrimination: rights and responsibilities of tester and testee: summary of a workshop sponsored by the social issues committee, American Society of Human Genetics, November 2, 1986. *Am J Hum Genet.* 1988; **43**:105-6.

17. Motulsky A. Brave new world? *Science.* 1974; **185**:653-63.

18. Motulsky A. Societal problems in human and medical genetics. *Genome.* 1989; in press.

19. For a discussion of the term "stigma" used in this context, see: Jones E. *Social Stigma: The Psychology of Marked Relationships.* New York, NY: W.H. Freeman Inc.; 1984.

20. *Screening and Counseling for Genetic Conditions.* Washington, DC: Report of the Presidential Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research; 1983.

21. Fraser F. Genetic counseling. *Am J Hum Genet.* 1974; **26**:636-59.

22. Hsia Y, Hirschhorn K, Silvergerb R, Godmilow L. *Counseling in Genetics.* New York, NY: A. R. Liss Inc.; 1979.

23. Lubs H and de la Cruz F. *Conference on Genetic Counseling.* New York, NY: Raven Press Inc.; 1977.

24. Evers-Kiebooms G and van den Berghe H. Impact of genetic counseling: a review of published follow-up studies. *Clin Genet.* 1979; **15**:465-74.

25. Lipkin M, Fisher L, Rowley P, et al. Genetic counseling of asymptomatic carriers in a primary care setting: the effectiveness of screening and counseling for beta-thalassemia trait. *Ann Int Med.* 1986; **105**:115-23.

26. Beckwith J. The negative side of a genetics discovery. *Boston Globe.* 1987; March 27:15.

27. Billings P. Genetic links say little for complexity of diseases. *Los Angeles Times.* 1987; March 18:II;5.

28. Dusek V. Bewitching science. *Sci for the People.* 1987; Nov/Dec:19-2.

29. The position papers of the Genetic Screening Study Group on genetic screening and discrimination are available from Professor Jon Beckwith, Department of Microbiology and Molecular Genetics, Harvard Medical School, Boston, MA 02115.

30. "Research in Genetic Discrimination. - For a study on societal attitudes involving genetics, I am soliciting reports of cases in which chromosomal or genetic variation may have been a consideration in obtaining insurance (life or health), employment, educational resources, or other human services (legal, governmental, or health). Any incident of possible discrimination is of interest. Affected individuals or others aware of possible examples are encouraged to contact me by phone or mail. Strict confidentiality will be maintained. Contact Paul Billings, M.D., Ph.D., Director, Clinic for Inherited Diseases, Harvard Medical School, New England Deaconess Hospital, Boston, MA 02215; phone (617) 732-9719".

31. *Am J Hum Genet.* 1988; **43**:225.

32. The use of self-reporting methods has recently been reviewed in: Strecher V, Becker M, Clark N, Pradasa-Rao P. Using patients' descriptions of alcohol consumption, diet, medication compliance and cigarette smoking: validity of self-reports in reseach and practice. *J Gen Int Med.* 1989; **4**:160-6.

33. The failure of patients to report important past clinical history has been recently documented in: Byrne J, Lewis S, Halamek L, et al. Childhood cancer survivors' knowledge of their diagnosis and treatment. *Ann Int Med.* 1989; **110**:400-3.

34. Bird T, Ott J, Giblett E, et al. Genetic linkage evidence for heterogeneity in Charcot-Marie-Tooth Neuropathy (HMSN Type I). *Ann Neurol.* 1983; **14**:679-84.

35. Baraitser M. *The Genetics of Neurological Disorders.* Oxford, England: Oxford University Press; 1982.

36. *Summing Up.* Washington, DC: Report of the Presidential Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research; 1983.

37. Norton C. Absolutely not confidential. *Hippocrates.* 1989; **2**:53-9.

38. Dezell M. It's 1984: do you know where your medical records end up? *Bost Bus J.* 1984; **4**:1,12-3.

39. Descriptions of the activities of the MIB, Inc., a company which stores medical information for use by insurers, are available from MIB, PO Box 801, Boston MA 02103.

40. The State of California and the Federal Bureau of Investigation have initiated programs for storage of DNA identification information on criminals.

41. Meissen G, Myers R, Mastromauro C, et al. Predictive testing for Huntington's disease with use of a linked DNA marker. *N Eng J Med.* 1988; **318**:535-42.

42. Brandt J, Quaid K, Folstein S, et al. Presymptomatic diagnosis of delayed-onset disease with linked DNA markers: the experience with Huntington's disease. *JAMA.* 1989; **261**:3108-14.

43. Murray T. Genetic testing as a social sorting device: justice and genetic differences. Philosophy and Medicine. 1989; in press.

44. Eisenbarth G. , *N Eng J Med.* 1986; **314**:1360- .

45. The absolute risk of these HLA identical siblings to develop diabetes is about twenty percent, which is similar to the recurrence risk of an

autosomal recessive condition (for example, cystic fibrosis or phenylketonuria) in a family.

46. Folstein S, Phillips J, Meyers D, et al. Huntington's disease: two families with differing clinical features show linkage to the G8 probe. *Science*. 1988; **229**:776-9.

47. Hayden M, Robbins C, Allard D, et al. Improved predictive testing for Huntington's disease by using three linked DNA markers. *Am J Hum Genet.* 1988; **43**:689-94.

48. Hayden M. *Huntington's Chorea.* New York, NY: Springer-Verlag Inc.; 1981.

49. For discussion of genetic myths, see: Suzuki D and Knudtson P. *Genethics.* Cambridge, MA: Harvard University Press; 1989.

50. Billings P. Debunking the genetic myth. *Tech Rev.* 1989; **6**:75-6.

51. Scriver C, Beaudet A, Sly W, Valle D. *The Metabolic Basis of Inherited Diseases.* New York, NY: McGraw Hill Inc.; 1989.

52. Nelkin D and Tancredi L. *Dangerous Diagnostics: The Social Power of Biological Information.* New York, NY: Basic Books Inc.; 1989.

53. Marx G and Sherizen S. Monitoring on the job: how to protect privacy as well as property. *Tech Rev.* 1986; **8**:63-72.

54. Alexander W. Insurance and genetics. *J Insur Med.* 1988; **20**:35-41.

55. *The Potential Role of Genetic Testing in Risk Classification.* Washington, DC: American Council of Life Insurance Report; 1989.

56. Russell-Einhorn M and Rowe M. Employer screening for genetic disease: current legal problems. in: Foulkes F., editor; *Current Issues in Strategic Human Resources.* New York, NY: Prentice Hall Inc.; 1989.

TABLE 1

TYPES OF INCIDENTS NOTED IN 29 EVALUATED RESPONSES

	INSURANCE[1]	EMPLOYMENT[2]	OTHER	TOTAL
INCIDENTS:	32	7	2	41

1. Includes incidents related to applications or coverage changes for health, life, disability, mortgage and auto insurance.

2. Includes examples of pre-employment evaluation, unexpected termination and difficulties related to promotion or transfer.