Implications and Recommendations for U.S. Health Insurance Regarding Genetic Testing

The current status of genetic testing in health insurance and the need for further legislative and organization remedies to prevent genetic discrimination and severe psychosocial ramifications.

08 December 2003

James Bernard Glettler
james@elysianaudio.com

University of Michigan

This paper is available from:
http://elysianaudio.com/class/rc270/genetic_testing.pdf

Table of Contents

Forward

At the present, the legislation controlling the use of genetic testing by the health insurance industry is inadequate in the United States. I have been assigned to investigate issues with new biotechnology for RC Natural Science 270 and I chose this topic due to its high relevance and importance. This report documents the current status of these problems with genetic testing in health insurance and makes a number of recommendations to address these concerns.

> We must not allow advances in genetics to become the basis of discrimination against any individual or any group. We must never allow these discoveries to change the basic belief upon which our government, our society, and our system of ethics is founded - that all of us are created equal, entitled to equal treatment under the law.
>
> - President Clinton, 2000

Summary

Background

The field of genetics has advanced greatly over the past fifty years. In 2002, there were genetic tests for more than 800 diseases that doctors and geneticists could perform (Hoel, 254). According to Collins, "it should be possible to identify disease gene associates for many common illnesses in the next 5 to 7 years." Yet genetics and genetic testing is still a young science. Although we have sequenced the entire human genome, we do not yet know what it all means. Each person carries on average a half-dozen or so genetic defects that could place one at risk for disease, yet that doesn't guarantee illness ("Genetic Testing"). The National Human Genome Research Institute points out that just these slight mutations in all people mean that everyone should be aware of possible genetic discrimination.

Most genetic tests today only confirm the existence of disease, such as in newborn screening, while there are few tests that can predict late-onset adult illnesses (O'Neil, 718). But if one were to focus only on genetics, one would easily ignore outside influences such as environment, diet, and preventative measures especially where the link between the genes and the disease is tenuous (O'Neil, 718 & Everett, 56).

While the scientific utility of genetic testing remains immature, the possible utility for health insurance has become a major issue. In the United States, health insurance is voluntary and based on mutuality of risk. If pure genetic determinism was entered into the calculation of statistical risk, one can easily see the resulting segmentation of groups and therefore the segmentation of health insurance premiums. Those with low genetically determined risk would pay far less than those with higher genetic risks forcing some out of health insurance all together. (O'Neil, 716-7) Current laws, such as the Health Insurance Portability and Accountability Act of 1996 [HIPAA] have been put in place to guarantee access to health insurance, but have done nothing to prevent the use of genetic information to determining rates ("Baseline", Part II). The smattering of state genetic nondiscrimination laws are far from comprehensive ("Genetics Privacy") and no fully comprehensive federal law has yet been passed.

What is often lost in the political debate on genetic testing is its psychosocial aspects. Genetic tests are expensive, so only those with access to funding can realistically benefit from tests. But even among those that can afford testing, many actively choose not to be tested and forgo medical treatment out of fear of

disclosing genetic information. (Friedrich, 816) Others choose not to be tested because they truly do not want to know the results, especially for diseases for which there is no possible cure, or when the result will have other effects such as social stigmatization or other economic ramifications (Everett, 55 & "Genetic testing"). Lastly, genetic testing could be used as a further way to blame the individual for problems of which they have no fault for (Everett, 56), much like the arguments against assisting the poor class today.

It is very important to realize that genetic discrimination is not a possibility only in the future, but that it has occurred in the past and is continuing to occur at this time. Although documented cases seem to be rare, they do happen[1] and are only likely to increase (Friedrich, 815). O'Neil states on page 719 "Fears that commercial health insurance may fail for those with adverse risk factors, including adverse genetic risk factors, are not fanciful."

Recommendations

In order to deal effectively with the troubles of genetic testing and health insurance, there are courses of action that seem to be radically different but are not really that far apart. But in either case, it is very apparent that science education needs to be greatly increased in the United States to help the population understand the real meaning of biotechnology and human genetics at a less sensational level.

The first possible course of action is to continue shoring up regulations on the insurance industry as it is in its present form. The first step would be the passage of The Genetic Information Nondiscrimination Act, known as S. 1053. This was recently passed by the U.S. Senate and remains to be passed by the House and signed by the President. (Vastag) The Genetic Alliance website has an excellent summary of the purpose of this act, which seeks to plug some of the holes in the HIPAA legislation. The main four points are to:

- Prohibit enrollment restrictions and premium adjustment on the basis of genetic information.
- Prevent health plans and insurers from requesting or requiring and individual take a genetic test.
- Prevent health plans from pursuing or being provided genetic information.
- Cover all health insurance organizations. This includes all private and public health insurance organizations including those that cover individuals. Not even the HIPAA legislation currently covers individuals ("Genetic Privacy").

The more radical, yet functional, approach to dealing with this issue is to transition to a nationally all-inclusive compulsory health insurance system with private supplemental voluntary insurance (O'Neil, 719). After some consideration, the restrictions that HIPAA and S. 1053 place on private insurance companies restrict their ability to determine premiums based on risk of individuals, it would seem that a national health care system could be more efficient, especially at distributing the genetic risks that at this time promise to cause severe segmentation of health insurance. A further study needs to be made on the feasibility of such a national health care system and is outside of the scope of this report.

> Without adequate safeguards, the genetic revolution could mean one step forward for science and two steps backward for civil rights.
>
> - Senator Daschle and Senator Jeffords, 2001

1 See *Oregonian.* 10 February 2001; Fuller. "Privacy in genetic research." *Science.* 285 (1999):1359; Hubbard & Wald *Exploding the gene myth...*(1999):1359; Martindale "Pink Slip in Your Genes." *Scientific American.* 284.1 (2001):19-20; Mulholland & Jaeger "Genetic privacy and discrimination..." *Jurimetrics*. 39 (1999):1317-1326; Murray "Social and medical implications of new genetic techniques." *The human genome project and minority communities* (2001):67-82

Discussion

The issues surrounding genetic testing and health insurance are complex. This technical discussion will cover the four major topics. First, the issue of genetics and testing is related to human health. Foundations and methods of health insurance is discussed on a broad basis. Current regulations on health insurance and genetics are explained and tied then together. Finally, the less quantifiable psychosocial and human factors are explained. An additional section at the end will discuss the proposed remedies.

Genetic Testing and Health

The growth of genetics has offered a unique insight into the workings of the human body. Over the past 20 years with the development of rapid gene sequencing techniques and the recent completion of the Human Genome Project, we as a society have access to vast knowledge of our individual genetic makeup. Many believe that one can predict the entire whole of a persons biology solely from their genes and by doing so also be able to predict the onset of heritable diseases.

Of course such a single-source isolated form of genetic determinism has been been throughly disproved by notable figures such as Richard Lewontin in his many books and Suzuki and Knudtson in *Genethics*. Still, if genes are able to play at least a partially predictive role, they are unique from all previously known forms of medical records (Everett, 54). Collins argues that almost every human illness at some level has a hereditary and therefore genetic factor. Therefore the effects on diagnosing and treating disease, especially preventative medicine "will be profound." (Collins, 540)

Genetic testing specifically refers to any procedure where the genes of a person are sequenced or tested in some way as to determine the presence or absence of a given allele. For instance, doctors can take a sample of blood and test a patient for the familial adenomatous polyposis (FAP) gene, which if present greatly increases one chance of developing hereditary non-polyposis colorectal cancer (HNPCC). Other standard tests are for hereditary hemochromatosis (body absorbs too much iron) and BRCA breast cancers. ("Genetic Testing") It is important to note here that the examples just given refer to single gene disorders.

Many genetic disorders are multi-factorial, meaning that many genes play a large part in the onset of symptomatic responses. Certain diseases are actually manifestations of a number of different genetic mutations that just so happen to have the same outcome. Because of this, some known genetic tests can actually have over a 50% failure rate. ("Genetic Testing")

Based on current knowledge, everyone carries a number of "genetic burdens" that may or may not be manifested as a disease or disability. Even if one has genes for a late-onset genetic defect (one where the disease does not take effect until later in life, usually beyond childhood), the carrier could easily become sick for some other reason prior to the genetic disease. (Friedrich, 815)

So from a health perspective, the main reason for performing a genetic test, ignoring any costs or implications of such testing, is to discover diseases prior to their onset and if possible take "preventative measures to reduce the probability of contracting the disease" (Hoel, 258). Although the focus of this report is not on newborn screening specifically, a study by Waisbren et. al. showed that there was a 50% reduction in hospitalization of newborns from screening and proper preventative medicine[2].

2 The newborns were actually screened using tandem mass spectrometry. TMS actually looks at proteins in the blood that are the result of genetic defects, not the genetic defects themselves. The study looked at hospitalization rates within the first 6 months following birth of 258 newborns: 28% for screened newborns, 55% with standard clinical evaluation.

One can easily point to a number of genetic defects that currently have no known cure or preventive measure. For instance, removal of the colon can prevent the expression of the FAP gene and thereby prevent that specific form of colon cancer. On the other hand, there is no possible cure for Huntington's disease, a debilitating neurological disorder that destroys the brain. ("Genetic Testing")

Genetic testing carries another hidden burden on those tested. It is possible to be a carrier of a genetic defect and yet never express negative symptoms. Such an asymptomatic response is caused by any number of factors including but not limited to: having a copy of the non-mutant form of the gene on another chromosome, having a different gene that disables or masks the function of the mutant gene, not being exposed an environmental trigger that would cause symptoms.

In the end it is important to remember that although there are some genetic defects that can be alleviated through preventative treatments, no person ever chooses their DNA (Friedrich, 815). Furthermore, given that gene therapy currently remains a pipe-dream, no person can alter their DNA[3] and we should not hold people responsible for that which they have no control over.

Health Insurance

First, let us look at what exactly insurance is. O'Neil explains very eloquently that, "insurance is a way of mitigating the effects of harmful events of *uncertain* incidence by pooling modest premiums which provide the resources to make larger payments selectively to those who suffer such events." The italics on uncertain are intentional, and will be discussed below. O'Neil continues:

> Insurance is worthwhile for each person because the incidence of harm is uncertain: each benefits by contributing a premium in return for assurance that if misfortune strikes a claim can be made and met. If the incidence of harm could be fully known in advance there would be no context for insurance: those who knew for sure that they would not experience adverse events of a given type would not insure against them, and insurers would not offer worthwhile terms to those who were certain to experience such events.

Two models of organization for insurance exist based on this meme. The solidarity model treats all members of the insured group identically. Each member pays the same premiums and is entitled to claims in the same manner as all other members. No individual is disallowed from the group and the group's premiums are set based on the collective risk. Obviously, such a system must be governmentally controlled and compulsory because it relies on the participation of most of the population in order to share the risks effectively. Without forced participation, those with little risk would leave for alternate, and cheaper, insurance causing rates to increase for those at the most risk. (O'Neil, 716)

The other form of insurance is the mutuality model. Here, premiums are differentiated on the level of risk each person brings to the group, and groups are usually much smaller and already segmented by risk. Regulations, such as HIPAA prevent individuals of a group from being assigned different premiums from their group[4], but given the smaller group sizes, one can see how risk the mutuality model causes increased segmentation. (O'Neil, 716) The concern with severe risk segmentation is that insurers can use certain

3 This is not to say that DNA cannot be altered. Mutation is one of the main aspects of genetic defects. Exposure to certain mutagenic chemicals or ionizing radiation can also cause mutation, although one can assume that these mutations are negative and non-intentional. We will not be having any "Incredible Hulk™" stories here.

4 "Insurers cannot charge higher prices to high risk individuals in a group." ("Baseline", Part II)

medical information to require individuals or groups to pay prohibitively high premiums (Hoel, 254). Based on mutuality, it is likely that many people will be unable to obtain affordable private health insurance and therefore cannot afford health care (O'Neil, 717). Once effectively denied access to health insurance and therefore health care, an individual will find it impossible to get treatment for a disease that could be prevented but will result in death without assistance ("Genetic Discrimination").

O'Neil sums up with comparing the implementation of medical insurance, "It is not surprising that most developed countries have rejected mutuality-based health insurance models, and have established solidarity-based health insurance." The one major exception of course is the United States, which has at any time between forty to sixty million citizens without health insurance (O'Neil, 717).

The insurance companies have lobbied and argued that using the information from genetic testing to predict risks is no different from the procedures they use now. What is not mentioned is that the calculation of risk per individual and per group is statistical and again, based on uncertainty. As such, mutuality-model insurance schemes can often base premium rates off of risk assessments that are not particularly accurate. Because predictive genetic testing undermines the notion of uncertainty, even in the flawed concept of genetic determinism, it undermines the effectiveness of pooled risk and therefore health insurance in general. (O'Neil, 717,719)

Genetic Discrimination in Health Insurance

Discrimination can take many forms but genetic discrimination is particularly insidious. Dr. Paul Billings, describes genetic discrimination as "distinguished from discrimination based on disabilities caused by altered genes by excluding, from the former category, those instances of discrimination against an individual who at the time of the discriminatory act was affected by the genetic disease. (Reilly, 489)" Scientists were aware of the possibility of genetic discrimination and made the politicians aware as well. Unlike any other "Big-Science" venture before, the 3% - 5% of the budget for the Human Genome Project was set aside to study legal, social and ethical issues (Collins, 540).

Currently, genetic discrimination doesn't seem to be too common an occurrence, but Friedrich points out that there is an increasing potential for widespread discrimination as more information is extracted from the Human Genome Project (HGP). The Director of the National Center for Human Genome Research, Francis Collins, mirrored the same sentiment (Reilly, 491). In 2000, shortly before the completion of the HGP, 46% of poll respondents also felt that there would be harmful consequences[5] (Everett, 55).

In Rochester, New York a handful of middle-aged workers for Burlington Northern and Sate Fe railroads were genetically tested without their consent by their employers. They had filed claims for work-related injuries leading to the development of carpal tunnel syndrome. The employers argued that they were genetically predisposed to carpal tunnel syndrome and therefore ineligible to receive benefits. (Everett, 55) This occurred despite the fact that there is no known gene that would predispose someone to carpal tunnel syndrome and this was not viewed as a call to increase worker safety as opposed to blaming them. There was a lawsuit that was settled out of court which unfortunately resolved nothing. (Friedrich, 815) In another case, a young boy with Fragile X Syndrome was dropped from his health insurance coverage because the insurers argued it was a preexisting condition[6] ("Genetics Privacy"). Other recent accounts show that genetic information has been used to deny medical benefits to retirees (Everett, 55).

5 Poll was from CNN-Time Magazine in June of 2000.

6 See next section, current regulations prevent the existence of genetic defects as being classified as a preexisting condition.

A survey in 2001 of employers found that 7% of companies used genetic information in hiring decisions[7] (Everett, 55). Since regulations would prevent a company from denying access to group health care of a high-risk individual once hired, which would increase the premiums, companies chose not to hire people they determined to be high risk. This leads to the topic, equally important but not within the scope of this report, of genetic discrimination in employment and hiring practices.

The fear people have of losing their health insurance coverage or worse can be considered a major factor in their desire for genetic privacy within the current system. For instance, fewer than 5% of people at risk for Huntington's disease have chosen to be tested. In instances such as these, the "Fear of a loss of privacy can influence people to withdraw from full participation in health care." (Friedrich, 816). Yet at the same time, the fear of liability on the practitioner's side supports the desire to test everything available (Abbing).

Current Regulations

A number of regulations and laws exist that are specific to different types of health insurance such as Health Maintenance Organizations (HMOs), Preferred Provider Organizations (PPOs), Medicare/Medicaid, or even Fee-for-Service. However, very few laws actually cover them all and deal with genetic testing. The most pertinent legislation is the Health Insurance Portability and Accountability Act of 1996 (HIPAA), created under the Clinton administration. It is notable that many of the provisions of this act did not fully go into effect until April 2003.

The HIPAA legislation fixes a number of needed holes in health insurance and covers all health insurance providers. The one thing not covered is insurance coverage for individuals, which to date there has been no federal legislation for ("Genetics Privacy"). Although many, including doctors and insurance companies view HIPAA with disdain, with regard to the current discussion HIPAA has provided explicit instruction that a genetic predisposition is not definable as a preexisting medical condition ("Genetic Discrimination"). Because most genetic defects are determined at conception, the insurance industry had argued many times previously that a genetic defect was a preexisting condition and therefore it would always cause a delay in coverage (Reilly, 493). This does not cover genetic defects which are currently manifest, as that would be considered a preexisting condition. However, another provision allows for coverage to continue as long as the condition had been covered previously under some other insurance ("Genetic Discrimination").

Another part of HIPAA guarantees that insurers cannot charge higher premiums to individuals within a group and neither can they deny individuals or groups from coverage. However, no restrictions are placed on the way in which premiums are set. ("Baseline", Part II) Insurers are not barred from requiring individuals or groups to take genetic tests ("Genetics Privacy"). Insurers are still able to raise premiums to reduce the likelihood that a group will be able to afford health insurance if they deem a member of the group to be too high risk. This further feeds the issue of genetic discrimination for hiring raised in the previous section.

In February 2000, President Clinton issued an Executive Order that prohibited all federal agencies from using genetic information for hiring practices ("Genetic Discrimination"). Yet no federal legislation that would protect the private sector exists. A number of states have enacted their own legislation to address these issues of health insurance, genetic privacy and genetic discrimination. However, many states have also eliminated or neutered many of these laws. Oregon was the first to pass genetic property laws in 1995, but most of these have been dismantled (Everett, 60). Hawaii's Privacy of Health Care Information Act of 1999 was completely revoked in 2001 because the health industry found it too difficult to implement

7 Source: Martindale. "Pink Slip in Your Genes." *Scientific American*, 284.1 (2001):19-20

(Kelly, 309). Similarly, the HIPAA regulations could be pushed of the table with enough lobbying power. In the end, it is apparent that comprehensive federal laws are needed to address all these issues instead of the stopgap legislative acts of states and the federal government today (Reilly, 494).

On the legislative table is a good step forward, The Genetic Information Nondiscrimination Act (S. 1053). The U.S. Senate recently passed this in 2003, but it is still far from becoming a law. It addresses issues of both health insurance and employment practices. Copies of the bill can be found on the Federal Register[8].

Psychosocial Implications

Many point out the fact that genetic testing is not always useful and can be outright harmful, both physically and psychosocially (Wilfond, 243). Psychosocial refers to both the psychological (i.e. mental condition) and sociological implications of the human condition. Furthermore, the act of screening can put an "individual's autonomy under constraint" (Abbing). By this, Abbing means that a person can be robbed of choices in life they would otherwise be able to make.

Genetic testing runs into problems when it is used to put responsibility of social problems on individuals and deflect criticism of other social, economic or environmental factors. This results in genetics being used as an excuse for disease, the poor, violence, or any other "bad thing" while real causes are ignored[9]. Such behavior leads to changing the context of terms such as 'normal' and 'abnormal'. (Everett, 53-56) If this is taken to the limit, it can result in forms of eugenics and science-fiction like fantasies of "genetic purity."

One of the big issues regarding the impact and use of genetic testing is on the privacy of genetic information. Privacy in this sense not only includes the right to keep others from one's own genetic information but also the right not to know one's own genetic information. This allows an individual to select a course of action that is in line with one's values[10]. (Everett, 55) By providing an individual with control rights of their genetic information, they will be able to prevent the misuse of such data (Friedrich, 815). At the same time, not informing on individual may come at the expense of people who want to know (Wilfond, 245).

As mentioned before, knowing one's genetic predisposition to certain diseases can allow for prevention, but it can also cause anxiety and other more severe effects especially when treatments do not exist. As testing becomes more prevalent, these psychosocial issues will be greatly magnified as the nature of genetic defects means that for every identified carrier, many family members will also be identified with increased risk. This could lead in some instances that a physician or genetic councilor may recommend against sharing genetic information. (Wilfond, 245) An interesting study showed the parents of children who had tested positive (specifically false-positive) for certain defects were at risk for "increased stress and parent-child dysfunction" (Waisbren, 2564).

All of these issues combined with the current status of mutuality model health insurance result in a rather poor scenario for widespread genetic testing. Hoel has a very lengthy mathematical model to show that within the current system, genetic testing will be carried out when it is socially inefficient and testing will not occur when it is socially efficient. Part of the argument rests on the availability of genetic testing information to health insurance providers. Because individuals are fearful of negative economic and insurance repercussions of testing, those with high hereditary risk are least likely to undergo testing when it

8 http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=108_cong_bills&docid=f:s1053es.txt.pdf

9 Refer to Finkler. *Experienceing the new genetics: Family and kinship on the Medical frontier*. Philadelphia: University of Pennsylvania Press. (2000): 49

10 Refer to Lebacqz. "Genetic Privacy: No deal for the poor." *Dialog.* 33.1 (1994): 40

is possible. At the same time, those with little economic worry are most likely to be tested. But these people have the financial resources to afford direct health care in lieu of genetic testing. Obviously these are sweeping generalizations, but the assumptions do seem to be sound. Hoel then uses this to argue that health insurance providers should be allowed access to genetic information. What he does not bring up is the type of health insurance provider, mutuality- or solidarity-based.

Comparison of Remedies

At the current time, the best hope there is to prevent genetic discrimination in health insurance is the passage of The Genetic Information Nondiscrimination Act (S. 1053). Despite the fact that it passed through the Senate with a voting record of 95-0, it seems as if the House is less enthusiastic about genetic discrimination. S. 1053 is a good legislative fix, even if it is somewhat stopgap in the sense that it is only one small part of the total legislation that exists or is needed on health insurance and genetics.

While such measures can temporarily constrain current known problems with genetic testing, we are given an opportunity to explore other solutions. O'Neil points out very explicitly that, "The demand that health insurance not use genetic information, interpreted in this way, is so sweeping that it comes close to a demand that health insurance be based on solidarity rather than on mutuality" (719). And as Hoel has stated, allowing insurance providers access to genetic information is more socially efficient towards promoting health of a population (255). Wilfond comments that the "the tension between commercial interests in promoting testing and managed care interests in minimizing costs point to a broader issue" (247).

What is the broader issue? From the material so far presented in this report, it is easy to postulate that if the United States converted to a solidarity based health insurance system, many issues with genetic testing, privacy and discrimination would be for the most part wiped clean.

If one needs some empirical evidence this is so, one only needs to look at the European health care system, or even that of Canada. The United Kingdom has a solidarity-based health insurance system. Although there is ongoing public dialog and issues surrounding genetic testing in the United Kingdom, it has not focused on health insurance. Instead it has been aimed more at life insurance. The issues are similar for sure, but not necessary to illustrate the point.

References

Journals:

Abbing, HR. "Some legal aspects of genetic screening." *Medicine and Law*. 22.3 (2003): 401-9.

Collins & McKusick. "Implications of the Human Genome Project for Medical Science." *Journal of the American Medical Association*. 285.5 (7 February 2001): 540-544.

Everett, Margaret. "The social life of genes: privacy, property and the new genetics." *Social Science and Medicine*. 56 (2003): 53-65.

Friedrich. "Preserving Privacy, Preventing Discrimination Becomes the Province of Genetics Experts." *Journal of the American Medical Association*. 288.7 (21 August 2002): 815-819.

Hoel & Iversen. "Genetic testing when there is a mix of compulsory and voluntary health insurance." *Journal of Health Economics*. 21.2 (March 2002): 253-270.

Kelly, Carly. "HIPAA compliance: Lessons from the repeal of Hawaii's patient privacy law." *The Journal of Law, Medicine & Ethics*. 30.2 (2002): 309-312.

O'Neil, Onora. "Insurance and Genetics: the current state of play." *Modern Law Review*. 61.5 (1998): 716-23.

Reilly, Philip R. "Public Concern About Genetics." *Annual Review of Genomics and Human Genetics*. 1 (September 2000): 485-506.

Vastag, Brian. "Genetic Discrimination Ban." *Journal of the American Medical Association*. 290.18 (12 November 2003): 3396.

Waisbren et. al. "Effect of Expanded Newborn Screening for Biochemical Genetic Disorders on Child Outcomes and Parental Stress." *Journal of the American Medical Association.* 290. (19 November 2003): 2564-2572.

Wilfond et. al. "Cancer genetic susceptibility testing: Ethical and policy implications for future research and clinical practice." *The Journal of Law, Medicine & Ethics*. 25.4 (1997): 243-252

Internet:

"Genetic Discrimination in Health Insurance" March 2002. National Human Genome Research Institute
< http://www.genome.gov/page.cfm?pageID=10002328 > (01 December 2003)

"Genetic testing: Weighing its benefits and risks." 14 May 2002. Mayo Foundation for Medical Education and Research.
< http://www.mayoclinic.com/invoke.cfm?id=FL00076 > (01 December 2003)

"Genetics Privacy and Legislation." 20 Nov. 2003. Human Genome Project Information & DoE Office of Science.
< http://www.ornl.gov/sci/techresources/Human_Genome/elsi/legislat.shtml > (30 Nov. 2003)

"The Genetic Information Nondiscrimination Act." 31 October 2003. Genetic Alliance.
< http://www.geneticalliance.org/PDF/GINA_summary.pdf > (01 December 2003)

Long, et. al. "Baseline Information for Evaluating the Implementation of the Health Insurance Portability and Accountability Act of 1996: Final Report." The Rand Corporation for Centers for Medicare and Medicaid Services. October 1998. < http://aspe.hhs.gov/health/reports/hipabase/ > (01 December 2003)

"Protecting the privacy of patients' health information." 14 April 2003. United States Department of Health and Human Services.
< http://www.hhs.gov/news/facts/privacy.html > (01 December 2003)

(Note: All sources have been stored electronically and can be provided on request)