PREVENTING INSURANCE DISCRIMINATION BASED ON GENETIC INFORMATION

Today the President pledged his commitment to enacting bipartisan legislation in this Congress to prohibit health plans from inappropriately using genetic screening information to deny coverage, set premiums, or to distribute confidential information. In so doing, he released a new report from the Department of Health and Human Services that summarizes the promise and perils of genetic screening. He also announced that the Republican Chair of the Senate Labor and Human Resources Committee, Senator Jim Jeffords, and the Public Health and Safety Subcommittee Chair, Senator and Doctor Bill Frist, have indicated their support for passing a bipartisan bill that is consistent with the goals and general recommendations of the HHS report.

The Promise of Genetic Testing. Genetic testing has the potential to identify hidden genetic disorders and spur early treatment. Tests for genetic predisposition to certain diseases -- such as Huntington's disease and certain types of breast cancer -- are already available and more such tests are on the horizon.

Genetic Discrimination: The Perils of This Progress. Genetic testing also can be used by insurance companies and others to discriminate and stigmatize groups of people. Studies have shown that:

- Over one-fifth of people in families where someone has a genetic disorder report that they, or a member of their family, had been discriminated against by an insurance plan.

- 85 percent of Americans report that they are extremely concerned with the possibility that their genetic makeup will be used to discriminate against them or a member of their family.

Building on Kassebaum-Kennedy. The Kassebaum-Kennedy law took steps to prohibit genetic discrimination by preventing insurers from using genetic information as a "pre-existing condition" and denying or limiting coverage in group markets. However, it does <u>not</u>: (1) prevent health plans in the individual market from denying coverage on the basis of genetic information; (2) assure that premiums settings are in no way based on genetic information; and (3) prevent health plans from disclosing genetic information to insurers, to plan sponsors, and other entities regulated by state insurance laws, such as life, disability, and long-term care insurers.

State laws are insufficient. Although 19 states have already enacted laws to restrict the use of genetic information in health insurance, state laws are insufficient to solve this problem. First, employer sponsored self-insured health

plans, which cover half of all Americans, are exempt from state insurance laws due to ERISA preemption. Second, current state laws generally focus on genetic tests rather than a broader definition of genetic information such as family history, medical records, and physical exams. Finally, the variability among state bills will lead to a lack of uniformity across the nation.

Building on the existing bipartisan commitment to the President's challenge. Bipartisan legislation introduced by Rep. Louise Slaughter (H.R. 306) and Senator Snowe (S. 422) addresses the three major gaps left by the HIPAA legislation and represents a strong foundation for this much-needed reform. It has already attracted over 130 cosponsors in the House. The legislation that the President will be forwarding to the Hill builds off the Slaughter/Snowe bill and strengthens it by explicitly specifying that genetic information cannot be disclosed to insurers, plan sponsors (the employer), and other entities regulated by state insurance laws, such as life, disability, and long-term care insurers. It also gives the Secretary the authority to define others situations where it is appropriate to allow genetic information to be disclosed. This modification will ensure that genetic information can still be used, where appropriate, to help improve important biomedical research efforts.

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Christopher C. Jennings
12/05/97 09:38:40 PM

Record Type: Record

To: Sylvia M. Mathews/WHO/EOP

cc: Bruce N. Reed/OPD/EOP, Elena Kagan/OPD/EOP, Paul E. Begala/WHO/EOP
Subject: Re: Genetic Screening.

We do have a genetic screening report; it is from the Labor the Department. It is not as good as the one we did earlier in the year, but it could be a good event if we combined it with something else on this subject. The bad news is there is not something available like that in December; the good news there is a major National Genome Conference on January 20th in D.C. that look tailor made for a great event. The VP has expressed a great interest in doing this, but of course would defer to the President if you all thought it was good enough for a Presidential event. I strongly advocate waiting for the January event. One caution: This potential event may not have as much news potential as some of those outlined below since we have already done one POTUS event on this issue, although anything on health and quality seems to be selling these days.

I have a few other ideas for you all to consider in December and January. First, January 1 marks the effective date of the new Medicare preventive benefits (mammography, colorectal screening, etc. coverage) that were included in the BBA. Announcing the effective date of new benefits would be a great holiday birthday present. (If POTUS does not want to do this, I am sure the VPOTUS or FLOTUS would.) Second, we are about to clear the mental health parity regulation (about December 18th). It appears as though the mental health advocates will likely be pleased with the result and an announcement around Christmas might be attractive not only because of the obvious positive message, but because the business community might think twice about being overly critical during that timeframe.

Third, in addition to the genetic event we believe could take place on January 20th, we believe there is great potential for an extremely strong and important event (in a child care or school setting) to announce a children's health outreach initiative. One of the greatest hurdles to reaching the President's 5 million covered children goal is the difficulty of targeting and enrolling this population. Both the POTUS and the FLOTUS have indicated significant interest in pursuing outreach and enrollment initiatives to do this. By January, we will have completed the development of a number of very marketable Administrative actions (and perhaps signed off on a number of budget options we are currently considering) to achieve this goal. Governors (whose successful programs in this area could be highlighted), state and local officials, health care providers and children's health groups could be counted on to strongly validate this type of public initiative.

Lastly, as you know, we have a race and health initiative that, pending budget approval, would probably be a great announcement/event before the State of the Union Address. This is becoming a very hot issue that we can get some validation that we are doing something serious to address.

All of these will take some effort to pull together and we need some lead time to assure successful events. However, they all have great potential. Please advise...

January - ——
Labor Dept. report

- what's going on

- principles of

what shld be done

in legislation

Endorsed Slaughter bill but had suggested changes. July 14

Jen — where is this?

Women's Legal Defense Fund

November 14, 1997

Melanne Verveer, Assistant to the President and Chief of Staff to the First Lady
Executive Office of the President
2nd Floor, West Wing
1600 Pennsylvania Ave., NW
Washington, DC 20500

Dear Ms. Verveer: Melanne

The job of deciphering every gene found in the human body, more than 80,000 in all, is proceeding at record speed. Today, genetic tests are available for over 400 disorders. Millions of women and their families stand to benefit from improved prevention, detection and treatment of diseases like breast and ovarian cancer alone. But without adequate protection against discrimination and misuse, the potential for real medical benefits from genetic advances may be outweighed by harmful consequences, such as the loss of health insurance or employment. For your information, the Women's Legal Defense Fund (WLDF) has enclosed a chart comparing pending legislation that would prohibit discrimination by employers and health insurers on the basis of genetic information.

The medical community and women's health advocates are working toward the same goal of improving women's health, and genetics research can bring us closer to this goal. However, there is growing concern that genetic information may be used in ways that hurt patients and research participants. Several researchers, in fact, are finding a shortage of volunteers willing to participate in studies, citing fear of discrimination as a significant deterrent.

Let us imagine a very plausible situation. Theresa is a 46-year old woman whose mother and sister both died in their mid-40s from breast cancer. She has heard of a research study being conducted by the National Institutes of Health on prevention of breast cancer. By participating in this study, she will learn whether she has inherited a gene that predisposes her to breast cancer and be closely monitored for any signs of the disease. While she would like to participate, she knows there are risks. Even though she does not have breast cancer, an insurance company may deny her coverage simply for having taken the test, assuming that by asking she has indicated her greater risk. In addition, she is worried that she may jeopardize her children's health insurance, since her genetic makeup influences her children's as well. If her employer or future employer learns about the genetic test, her ability to keep or get a job could be severely undermined by assumptions that she would be too costly to insure. Despite her desire to participate, she decides not to volunteer in the study, foregoing both the benefits to her own health and to the advancement of scientific knowledge.

1875 Connecticut Ave., NW ■ Suite 710 ■ Washington, DC 20009 ■ Telephone (202) 986-2600 ■ Fax (202) 986-2539

The Women's Legal Defense Fund is working hard to ensure that genetic information is protected from misuse. In 1996, WLDF helped shape key provisions of the Health Insurance Portability and Accountability Act (HIPAA) that benefit women, including those provisions that offer the very first federal protection against genetic discrimination. Now, if a woman like Theresa is in a group health plan covered by HIPAA, and she tests positive for the BRCA-2 gene, which may indicate a predisposition to breast cancer, she cannot be denied insurance or treated as if she has a "preexisting condition" solely because of her genetic profile.

Although the potential of HIPAA to protect millions of people from genetic discrimination is real, the law does not fully address the problem. For instance, HIPAA applies primarily to those with group insurance policies, but not the individual market. Several bills now pending before Congress would do more -- by prohibiting plans from requiring people to disclose genetic information, by providing better protection against being charged higher premiums because of genetic makeup, and by protecting all people seeking insurance in the individual market. Now is the time to build on HIPAA and take the next steps toward protecting women and their families. As of November, 1997, five bills have been introduced in Congress on the issue of genetic discrimination. Two of these bills aim to prohibit genetic discrimination in health insurance.[1] One bill is focused solely on preventing genetic discrimination in employment.[2] And two bills address both insurance and employment.[3] The enclosed chart compares these bills.

As you review the comparison chart, keep in mind three questions that will help us define how, as a society, we can protect genetic information:

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[1]H.R. 306/S.89: Genetic Information and Nondiscrimination in Health Insurance Act of 1997 (Representative Slaughter) and the Senate companion bill, Genetic Information Nondiscrimination in Health Insurance Act of 1997 (Senator Snowe); H.R. 328: Genetic Information Health Insurance Nondiscrimination Act of 1997 (Representative Solomon). In addition, Representative Furse has included the Slaughter-Snowe bill in H.R. 1726 (Children's National Security Act)

[2]S. 1045/H.R. 2275: Genetic Justice Act (Senator Daschle), and the House companion bill, Genetic Employment Protection Act of 1997 (Representative Lowey)

[3]S. 422: Genetic Confidentiality and Nondiscrimination Act of 1997 (Senator Domenici); H.R. 2198: Genetic Privacy and Nondiscrimination Act of 1997 (Representative Stearns)

- ✓ Should we ban genetic discrimination in health insurance, employment, or both?

- ✓ How should we define genetic information?

- ✓ How does the need to protect the privacy of genetic information fit in with broader concerns about the privacy of all medical information?

Should we ban genetic discrimination in health insurance, employment, or both?

Imagine Theresa has learned she has the gene mutation BRCA-2. First, Theresa needs protection from employment discrimination so that her employer cannot use this information against her. Second, while HIPAA will protect Theresa's health insurance as long as she remains in the group insurance market, the protections afforded by HIPAA are not comprehensive enough.

What if Theresa loses her job? Or she leaves her job for family reasons or to start a new business? If she cannot afford COBRA and lets her insurance lapse, she may later find it impossible to get health insurance in the individual market. Right now, there is no federal law to stop an insurer from using her genetic profile as a basis to deny her individual coverage or to charge an exorbitant premium, despite the fact that she may go through life without ever getting breast cancer.

Given these realities, it is crucial that we ban genetic discrimination in both health insurance and employment.

How should we define genetic information?

The definition of genetic information is important since it will determine the type of information that will be considered confidential and that cannot serve as a basis for insurance or employment decisions. The term "genetic information" can mean many different things. The definitions used in the pending legislation vary greatly -- from a specific definition that refers only to genetic tests, to a broad definition that also incorporates information about any inherited characteristic, such as a family history of Huntington's disease or high blood pressure.

How does the need to protect the privacy of genetic information fit in with broader concerns about the privacy of all medical information?

Privacy protections that restrict access to genetic information are integral to preventing discrimination in employment and health insurance. We must decide as a society how we want our medical information used and by whom -- including our genetic information. All of the bills before Congress have some provisions limiting disclosure of genetic information.

In addition to the effort specifically to protect genetic information, we can also deal with the issue of genetics in the context of the broader medical records privacy debate that is currently underway. In September, Secretary for Health and Human Services, Donna E. Shalala, testified before a Senate committee on confidentiality of medical information. A second hearing was held in October, and witnesses gave their reactions to Secretary Shalala's proposal. The discussion will likely continue in the months to follow since HIPAA requires that either Congress or HHS take action on this issue within the next few years. It is crucial that the urgent concerns of genetic privacy are incorporated into this broader discussion.

✢ ✢ ✢

The benefits to medical science and women's health presented by genetics research are invaluable. We cannot afford to risk continued progress because people rightly fear for their insurance or their jobs. Federal legislation must be put in place today to ensure better health for women and their families tomorrow.

We hope this information is helpful. If you have any questions, please feel free to contact either Joanne Hustead or Erin Raccah at (202) 986-2600.

I hope you find this interesting
J.

Enclosure

Sincerely,

Judith L. Lichtman

Judith L. Lichtman
President

Women's Legal Defense Fund

1875 Connecticut Ave., NW
Suite 710
Washington, DC 20009

Comparison of Genetic Information Non-Discrimination Bills in the 105th Congress

Several bills dealing with genetic information and discrimination in the health insurance and/or employment context have been introduced in the 105th Congress. This chart summarizes the major provisions in each bill.

	H.R. 2198 STEARNS	H.R. 328 SOLOMON	H.R. 306/S. 89 SLAUGHTER/ SNOWE	S. 422 DOMENICI	S. 1045/H.R. 2275 DASCHLE/LOWEY	H.R. 1726 FURSE (SAME AS H.R. 306)
Title	"Genetic Privacy & Nondiscrimination Act of 1997"	"Genetic Information Health Insurance Nondiscrimination Act of 1997"	"Genetic Information Nondiscrimination in Health Insurance Act of 1997"	"Genetic Confidentiality and Nondiscrimination Act of 1997"	"Genetic Justice Act"/ "Genetic Employment Protection Act of 1997"	"Children's National Security Act"
Original Co-Sponsors	Armey, Bishop, Brown (OH), Canady (FL), Davis (VA), DeFazio, Duncan, Faleomavaega, Farr (CA), Foley, Fowler, Gekas, Gillmor, Gilman, Gonzalez, Green, Herger, Hyde, Johnson (CT), Kennedy (MA), Lofgren, McCollum, McHugh, McKinney, Nadler, Oberstar, Oxley, Sensenbrenner, Shadegg, Smith (NJ), Stump, Taylor (NC), Traficant, Upton, Waxman, Weldon (FL), Woolsey		**House:** Abercrombie, Ackerman, Barrett (WI), Brown (FL), Brown (CA), Clayton, Danner, DeFazio, Dellums, Eshoo, Evans, Gejdenson, Gonzalez, Green, Hilliard, Hinchey, Jackson-Lee (TX), Kennedy (MA), Kildee, LaFalce, Lewis (GA), Lofgren, Lowey, Maloney (NY), McDermott, Meek (FL), Morella, Nadler, Payne, Pelosi, Rivers, Sanders, Serrano, Smith (NJ), Stark, Thurman, Towns, Waters, Waxman, DeLauro, Matsui, Watt (NC), Roybal-Allard	Jeffords, Dodd	**House:** Lazio	Clayton, DeGette, Hooley (OR), Jackson-Lee (TX), Lofgren, Lowey, McKinney, Maloney (NY), Millender-McDonald, Mink (HI), Norton, Slaughter, Waters, Woolsey
Date Introduced	July 17, 1997	January 7, 1997	January 7, 1997 (House) January 21, 1997 (Senate)	March 11, 1997	July 22, 1997 (Senate) July 25, 1997 (House)	May 22, 1997

	H.R. 2198 STEARNS	H.R. 328 SOLOMON	H.R. 306/S. 89 SLAUGHTER/ SNOWE	S. 422 DOMENICI	S. 1045/H.R. 2275 DASCHLE/LOWEY	H.R. 1726 FURSE (SAME AS H.R. 306)
Committee	Commerce, Government Reform and Oversight, Education and the Workforce, Veterans' Affairs	Commerce, Education and the Workforce	**House:** Commerce, Ways and Means, Education and the Workforce **Senate:** Labor and Human Resources	Labor and Human Resources	**Senate:** Labor and Human Resources **House:** Education and the Workforce	Commerce, Ways and Means, Education and the Workforce, Judiciary, Transportation and Infrastructure, Banking and Financial Services, Budget
Defines genetic information	Defined as "information about the genes of the individual or a member of the individual's family or about any gene products or inherited characteristics that may derive from the individual or a member of the individual's family."	Defined as "information about genes, gene products, or inherited characteristics that may derive from an individual or a blood-relative of the individual."	Defined as "information about genes, gene products, or inherited characteristics that may derive from an individual or a family member of the individual."	Defined as "information from a human DNA sample about molecular genotype, information from mutation analysis, or information about nucleotide sequence of a gene."	Defined as "information (including information regarding carrier status and information derived from a laboratory test that identifies mutations in specific genes or chromosomes, a physical medical examination, a family history, and a direct analysis of genes or chromosomes) about a gene, gene product, or inherited characteristic that derives from the individual or a family member of the individual."	Defined as "information about genes, gene products, or inherited characteristics that may derive from an individual or a family member of the individual."

	H.R. 2198 STEARNS	H.R. 328 SOLOMON	H.R. 306/S. 89 SLAUGHTER/ SNOWE	S. 422 DOMENICI	S. 1045/H.R. 2275 DASCHLE/LOWEY	H.R. 1726 FURSE (SAME AS H.R. 306)
Defines genetic test	Defined as "a test for determining the presence or absence of genetic characteristics in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes, or proteins in order to diagnose a genetic characteristic."	Defined as "a test for determining the presence or absence of genetic characteristics in an individual."	No	No	Not specifically defined, but included in the definition of "genetic services," which is defined as "genetic evaluation, genetic testing, genetic counseling, and related services."	No
Defines employer/employee	As defined by section 701 of the Civil Rights Act of 1964.	No	No	"Employer" defined as under section 3(5) of ERISA.	As defined by section 701 of the Civil Rights Act of 1964.	No
Defines group health plan	Group health plan/Health insurance issuer/Health insurance coverage as defined in section 733 of ERISA.	No	No	No. See definition below of "insurer."	N/A	No
Defines insurer	No	No	No	Defined as "an insurance company, insurance service, or insurance organization (including HMO) within meaning of section 514(b)(2) of ERISA. **Does not include a "group health plan."**	N/A	No

	H.R. 2198 STEARNS	H.R. 328 SOLOMON	H.R. 306/S. 89 SLAUGHTER/ SNOWE	S. 422 DOMENICI	S. 1045/H.R. 2275 DASCHLE/LOWEY	H.R. 1726 FURSE (SAME AS H.R. 306)
HEALTH INSURANCE DISCRIMINATION PROHIBITIONS	Yes. Plan/issuer "may not use genetic information to reject, deny, limit, cancel, refuse to renew, establish differential rates or premium payments for, or otherwise affect benefits . . . ."	Only expands "genetic information" provision of HIPAA nondiscrimination section by inserting "or a request for, or receipt of, genetic information or a genetic test" after "genetic information."	Yes. Plan/issuer may not "deny, cancel, or refuse to renew such benefits or such coverage, or vary the premiums, terms, or conditions for such benefits or such coverage, for any participant or beneficiary under the plan--(1) on the basis of genetic information; or (2) on the basis that the participant or beneficiary has requested or received genetic services."	Yes. Insurer shall not "1) terminate, restrict, limit, refuse to renew, or otherwise apply conditions to the coverage of an individual or family member under the health policy or plan involved, or restrict the sale of the health policy or plan to an individual or family member; 2) deny coverage or exclude an individual or family under the health policy or plan; or 3) impose a rider that excludes coverage for certain benefits or services under the health policy or plan for an individual/family member; 4) establish differentials in premium rates or cost-sharing for coverage under health policy or plan for an individual/family member; or 5) otherwise discriminate against an individual or family member in the provision of health insurance coverage; on the basis of any molecular genetic information about a healthy individual or a healthy family member, or on the basis of a	No	Yes. Plan/issuer may not "deny, cancel, or refuse to renew such benefits or such coverage, or vary the premiums, terms, or conditions for such benefits or such coverage, for any participant or beneficiary under the plan--(1) on the basis of genetic information; or (2) on the basis that the participant or beneficiary has requested or received genetic services."

	H.R. 2198 STEARNS	H.R. 328 SOLOMON	H.R. 306/S. 89 SLAUGHTER/ SNOWE	S. 422 DOMENICI	S. 1045/H.R. 2275 DASCHLE/LOWEY	H.R. 1726 FURSE (SAME AS H.R. 306)
Amends HIPAA "nondiscrimination" provision	Yes. Expands "genetic information" provision of HIPAA nondiscrimination section by inserting "or a request for, or receipt of, genetic information or a genetic test" after "genetic information."	Yes. Expands "genetic information" provision of HIPAA nondiscrimination section by inserting "or a request for, or receipt of, genetic information or a genetic test" after "genetic information."	No	No	N/A	No
Applies to group plans	Yes--amends ERISA (also applies to programs administered by the VA).	Yes--amends ERISA.	Yes--amends ERISA.	Applies to "insurers" (see definition section above) but not to "group health plans." Insured ERISA plans would be covered but not self-insured ERISA plans.	N/A	Yes--amends ERISA.
Prohibits plans from varying premiums on the basis of genetic information in the group market	Probably. Plan/issuer may not use genetic information to "establish differential rates or premium payments for, or otherwise affect benefits provided . . . ." Presumably this would restrict premium differentials within a group as well as premiums charged to an entire group.	Only to the extent that HIPAA provides this protection. HIPAA prohibits premium differentials within a group; HIPAA does not restrict the premium charged to the entire group.	Probably. States that plan/issuer "may not . . . vary the premiums, terms, or conditions" on the basis of genetic information. Presumably this would restrict premium differentials within a group as well as premiums charged to an entire group.	Yes. Insurer shall not "establish differentials in premium rates or cost-sharing for coverage under health policy or plan for an individual or family member."	N/A	Probably. States that plan/issuer "may not . . . vary the premiums, terms, or conditions" on the basis of genetic information. Presumably this would restrict premium differentials within a group as well as premiums charged to an entire group.
Applies to individual coverage	Yes	The bill does not contain a nondiscrimination ban applicable to insurers in the individual market. Provisions relating to collection and disclosure of genetic information apply to insurers in the individual market (see below).	Yes	Yes	N/A	Yes

	H.R. 2198 STEARNS	H.R. 328 SOLOMON	H.R. 306/S. 89 SLAUGHTER/ SNOWE	S. 422 DOMENICI	S. 1045/H.R. 2275 DASCHLE/LOWEY	H.R. 1726 FURSE (SAME AS H.R. 306)
Prohibits plans from varying premiums on the basis of genetic information in the individual market	Yes	No	Yes	Yes	N/A	Yes
Prohibits plans from requiring people to disclose genetic information	Not explicitly. Plan/issuer may not use genetic information to discriminate against employees, but there is no specific language prohibiting plans from requiring people to disclose.	Yes	Yes	Yes	N/A	Yes
Prohibits plans from requiring people to take genetic tests	No	Yes	No mention of the taking of a genetic test, but plan is prohibited from requiring people to disclose genetic information (see above).	Yes	N/A	No mention of the taking of a genetic test, but plan is prohibited from requiring people to disclose genetic information (see above).

	H.R. 2198 STEARNS	H.R. 328 SOLOMON	H.R. 306/S. 89 SLAUGHTER/ SNOWE	S. 422 DOMENICI	S. 1045/H.R. 2275 DASCHLE/LOWEY	H.R. 1726 FURSE (SAME AS H.R. 306)
Requires written authorization before plans can disclose genetic information	Yes. Description of the information, to whom, and purpose.	Yes. Description of the information, to whom, and purpose required for each disclosure.	Yes. Required for each disclosure and must include identification of person to whom disclosure would be made.	Yes. Requires signed, dated, identification of person authorized to make disclosure; description of the specific information to be disclosed; identification of person to whom disclosing; description of purpose of disclosure; expiration date of authorization; revocation/ amendment statement. The bill also states: "A general authorization for the release of medical records shall not be construed to be an authorization for disclosure of genetic information about the molecular genotype of an individual with respect to any genetic trait."	N/A	Yes. Required for each disclosure and must include identification of person to whom disclosure would be made.

	H.R. 2198 STEARNS	H.R. 328 SOLOMON	H.R. 306/S. 89 SLAUGHTER/ SNOWE	S. 422 DOMENICI	S. 1045/H.R. 2275 DASCHLE/LOWEY	H.R. 1726 FURSE (SAME AS H.R. 306)
Exceptions to written authorization	Yes---if authorized under certain criminal laws; required by specific court order; authorized under law for establishing paternity; for identifying a body.	Yes--if authorized under certain criminal laws; required by court order; for testing paternity; for purpose of providing genetic information to blood relatives for a medical diagnosis; for identifying a body.	No	Yes. Information can be disclosed "to the extent reasonable in the exercise of judgment for professional medical consultation for the direct benefit of a patient," or as otherwise required by federal or state law. Section 204 of the bill also includes extensive procedures relating to compulsory disclosure of genetic information in court proceedings brought against people who "store" genetic information in "clinical records." This may include health plans and employers if they "store" genetic information in "clinical records."	N/A	No
Creates private cause of action by individual for damages	No	No	Yes. Plan/issuer "may in the court's discretion be liable . . . for compensatory, consequential, and punitive damages."	No	N/A	Yes. Plan/issuer "may in the court's discretion be liable . . . for compensatory, consequential, and punitive damages."

	H.R. 2198 STEARNS	H.R. 328 SOLOMON	H.R. 306/S. 89 SLAUGHTER/ SNOWE	S. 422 DOMENICI	S. 1045/H.R. 2275 DASCHLE/LOWEY	H.R. 1726 FURSE (SAME AS H.R. 306)
Authorizes Attorney General to pursue civil penalties/injunctive relief	No	No	No	Yes. AG may bring action to restrain a person violating or about to violate provisions of the Act via TRO or preliminary/permanent injunction. If person knew/should have known violating Act, court can require civil penalty of not more than $50,000 for each violation and may require reasonable costs, including atty fees.	N/A	No
Requires insurers to provide applicants/enrollees with an understandable, written statement of their rights	No	No	No	Yes	N/A	No

	H.R. 2198 STEARNS	H.R. 328 SOLOMON	H.R. 306/S. 89 SLAUGHTER/ SNOWE	S. 422 DOMENICI	S. 1045/H.R. 2275 DASCHLE/LOWEY	H.R. 1726 FURSE (SAME AS H.R. 306)
EMPLOYMENT DISCRIMINATION PROHIBITIONS	Yes. Employer may not "attempt to acquire, acquire, or use the genetic information of an employee or applicant for employment or require a genetic test of an employee or applicant for employment for the purpose of distinguishing among employees or applicants for employment or for the purpose of discriminating against or restricting any right or benefit otherwise due or available to an employee or applicant for employment . . . ."	No	No	Yes. Employer shall not "request, require, or use the genetic information" of an employee/potential employee for the purpose of restricting any right or benefit otherwise due.	Yes. Employer shall not: "1) fail or refuse to hire or to discharge any individual, or otherwise to discriminate against any individual with respect to the compensation, terms, conditions, or privileges of employment of the individual . . .; or 2) limit, segregate, or classify the employees . . ." because of "genetic information with respect to the individual, including an inquiry by the individual regarding genetic services." Bill also has similar sections regarding labor organizations, employment agencies, and training programs. In addition, an employer shall not "3) request or require the collection for the employer or disclosure to the employer of genetic information . . . ." except under certain circumstances (see below for exceptions).	No

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Exceptions	Yes. If genetic information or genetic test is "job-related and consistent with business necessity, or is required under Federal or State law."	N/A	N/A	Yes. Employer "may request or require or use" the genetic information of an employee for the purpose of: "(1) permitting a genetically susceptible employee to avoid occupational exposure to substances with a mutagenic or teratogenic effect; or (2) determining a genotype that is otherwise directly related to the work and is consistent with business necessity."	Yes. Employer may "request or require collection . . . of genetic information" if: "1) the employer made the request or requirement after making an offer of employment; 2) the information is job-related for the position in question and consistent with business necessity; and 3) the knowing and voluntary written consent of the individual has been obtained for the request or requirement, and the collection or disclosure."	N/A

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Confidentiality provision	Yes. Employer shall not "1) allow access to genetic info of employees . . .;" (see exceptions below).	N/A	N/A	No	Yes. If an employer/labor organization/employment agency has genetic information, it "shall maintain the information on separate forms and in separate medical files, and treat the information as a confidential medical record . . . " (see exceptions below).	N/A
Exceptions to confidentiality provision	Yes. Employer can "allow access to genetic information . . . to persons whose duties and responsibilities in connection with the employer require access to such information for purposes consistent with subsection (a) . . . " (subsection (a) includes determinations of job-relatedness and business necessity). It is unclear if provision requiring "prior, written, and informed consent of the employee" applies here.	N/A	N/A	N/A	Yes. If employee provides "knowing and voluntary written consent," employer may 1) inform supervisor regarding necessary restriction of work/duties of, or a necessary accommodation for, the employee; 2) inform first aid/safety personnel; and 3) provide relevant info to government official investigating compliance with this Act, on request.	N/A

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Requires written authorization before employer can disclose genetic information	The bill does not have a clear prohibition on disclosure of genetic information by employers.	N/A	N/A	Yes. "A person may disclose genetic information characterized from the DNA sample of an individual only with the written authorization of the individual." Written authorization requires signed, dated, identification of person authorized to make disclosure; description of the specific information to be disclosed; identification of person to whom disclosing; description of purpose of disclosure; expiration date of authorization; revocation/amendment statement.	Yes. Written authorization required for release of information under confidentiality provision (see above). Otherwise, disclosure other than to employee (at the employee's request) is prohibited.	N/A

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Exceptions to written authorization	See above.	N/A	N/A	Yes. Information can be disclosed "to the extent reasonable in the exercise of judgment for professional medical consultation for the direct benefit of a patient," or as otherwise required by federal or state law. Section 204 of the bill also includes extensive procedures relating to compulsory disclosure of genetic information in court proceedings brought against people who "store" genetic information in "clinical records." This may include health plans and employers if they "store" genetic information in "clinical records."	No	N/A
Creates private cause of action by individual for damages	Enforcement through sections 705-09 of Civil Rights Act of 1964, so employee must exhaust administrative remedies before filing suit. These sections of Title VII do not provide for damages--only equitable relief (i.e., backpay, reinstatement, injunctive relief, attorneys fees and costs).	N/A	N/A	Yes. Liable for actual damages sustained as a result of the violation or $50,000, whichever is greater. If violation resulted in profit/monetary gain, treble damages. If successful action, costs and reasonable atty fees as determined by the court. **Bill also states: "may be enforced in accordance with title VII."**	Yes. Employee may bring action in federal or state court. Court may award any appropriate legal or equitable relief.	N/A

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Statute of limitations	Enforced through sections 705-09 of Civil Rights Act of 1964, which requires that charges be filed within 180-300 days of the alleged violation.	N/A	N/A	Yes. 6 years after date alleged violation was/should have been discovered. If disabled (i.e. minor, incapacity b/c mental illness) tolling is 10 years after disability is removed. **Bill also states: "may be enforced in accordance with title VII," which has a different statute of limitations.** (See Stearns)	No specific provision in bill, so state law would generally apply (average 2-3 years).	N/A
Authorizes Attorney General to pursue civil penalties/injunctive relief	Enforcement through sections 705-09 of Civil Rights Act of 1964, which provides for action by the Attorney General in limited circumstances.	N/A	N/A	Yes. AG may bring action to restrain a person violating or about to violate provisions of the Act via TRO or preliminary/permanent injunction. If person knew/should have known they were violating Act, court can require civil penalty of not more than $50,000 for each violation and may require reasonable costs, including atty fees. **Bill also states: "may be enforced in accordance with title VII," which provides for actions by the AG in limited circumstances.**	No	N/A