GENETIC DISCRIMINATION

File Gen. Discrim.

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.

	#Administration's Health Insurance Proposal December 17, 1997	*H.R. 306/S.89 Slaughter/ Snowe	*H.R. 328 Solomon	*H.R. 1726 Furse (Same as H.R. 306)	#H.R. 2216 J. Kennedy	*H.R. 2198 Stearns	*S. 422 Domenici	#H.R. 2215 J. Kennedy	*S. 1045/H.R. 2275 Daschle/ Lowey	#Administration's Workplace Proposal January 20, 1998
Title	Administration's Health Insurance Proposal	"Genetic Information Nondiscrimination in Health Insurance Act of 1997"	"Genetic Information Health Insurance Non-discrimination Act of 1997"	"Children's National Security Act"	Genetic Protection in Insurance Coverage Act	"Genetic Privacy & Non-discrimination Act of 1997"	"Genetic Confidentiality and Non-discrimination Act of 1997"	Genetic Non-discrimination in the Workplace Act	"Genetic Justice Act"/ "Genetic Employment Protection Act of 1997"	Administration's Workplace Proposal

*Indicates the original comparison prepared by the Women's Legal Defense Fund (August 26, 1997)
#Indicates an addendum prepared by the National Human Genome Research Institute (February 1998)

	#Administration's Health Insurance Proposal December 17, 1997	*H.R. 306/S.89 Slaughter/ Snowe	*H.R. 328 Solomon	*H.R. 1726 Furse (Same as H.R. 306)	#H.R. 2216 J. Kennedy	*H.R. 2198 Stearns	*S. 422 Domenici	#H.R. 2215 J. Kennedy	*S. 1045/H.R. 2275 Daschle/ Lowey	#Administration's Workplace Proposal January 20, 1998
Original Co-Sponsors	N/A	**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		Clayton, DeGette, Hooley (OR), Jackson-Lee (TX), Lofgren, Lowey, McKinney, Maloney (NY), Millender-McDonald, Mink (HI), Norton, Slaughter, Waters, Woolsey	None	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	Jeffords, Dodd	None	**House:** Lazio	N/A
Date Introduced	July 14, 1997	January 7, 1997 (House) January 21, 1997 (Senate)	January 7, 1997	May 22, 1997	July 22, 1997	July 17, 1997	March 11, 1997	July 22, 1997	July 22, 1997 (Senate) July 25, 1997 (House)	January 20, 1998

	#Administration's Health Insurance Proposal December 17, 1997	*H.R. 306/S.89 Slaughter/ Snowe	*H.R. 328 Solomon	*H.R. 1726 Furse (Same as H.R. 306)	#H.R. 2216 J. Kennedy	*H.R. 2198 Stearns	*S. 422 Domenici	#H.R. 2215 J. Kennedy	*S. 1045/H.R. 2275 Daschle/ Lowey	#Administration's Workplace Proposal January 20, 1998
Committee	N/A	**House:** Commerce, Ways and Means, Education and the Workforce **Senate:** Labor and Human Resources	Commerce, Education and the Workforce	Commerce, Ways and Means, Education and the Workforce, Judiciary, Transportation and Infrastructure, Banking and Financial Services, Budget	Commerce, Education and the Workforce	Commerce, Government Reform and Oversight, Education and the Workforce, Veterans' Affairs	Labor and Human Resources	Education and the Workforce	**Senate:** Labor and Human Resources **House:** Education and the Workforce	N/A
Defines genetic information	Yes. Defined as "Information about genes, gene products or inherited characteristics that may derive from the individual or a family member."	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 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."	Yes. Defined as "Information about genes, gene products or inherited characteris-tics that may derive from an individual or a family member."	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 from a human DNA sample about molecular genotype, information from mutation analysis, or information about nucleotide sequence of a gene."	No	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."	No

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Defines genetic test	Defined as "the analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect heritable disease-related genotypes, mutations, phenotypes, or karyotypes.	No	Defined as "a test for determining the presence or absence of genetic characteristics in an individual."	No	Defined as "a test for determining the presence of absence of genetic characteristics in an individual, including tests of nucleic acids such as DNA, RNA and mitochon-drial 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, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to diagnose a genetic characteristic."	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	N/A	No	No	No	N/A	As defined by section 701 of the Civil Rights Act of 1964.	"Employer" defined as under section 3(5) of ERISA.	No	As defined by section 701 of the Civil Rights Act of 1964.	Not specifically defined, employer/but applies to public employee and private-sector employers, unions and labor management groups that conduct joint apprenticeship and other training programs. Employment agencies and licensing agencies that issue licenses, certificates and other credentials required to engage in various professions and occupations.

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Defines group health plan	No	No	No	No	No	Group health plan/Health insurance issuer/Health insurance coverage as defined in section 733 of ERISA.	No. See definition below of "insurer."	N/A	N/A	N/A
Defines insurer	Yes. Defined as "insurance provider refers to an insurance company, employer, or any other entity providing a plan of health insurance or health benefits including group and individual health plans where fully insured or self-funded."	No	No	No	Yes. Defined as "an insurance company, health care service contractor, fraternal benefit organization, insurance agent third party administrator, insurance support organization or other person subject to regulation under state insurance laws. Includes self-funded health plans and health plans regulated under ERISA."	No	Defined as "an insurance company, insurance service, or insurance organization" (including HMO) licensed and regulated by state law. **Does not include a "group health plan."**	N/A	N/A	N/A

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HEALTH INSURANCE DISCRIMINATION PROHIBITIONS	Yes. Insurers should be prohibited from varying rates charged to a group based on *presymptomatic* genetic information and from releasing genetic information for non-treatment purposes without prior authorization. Insurers in the individual market should be prohibited from requesting or requiring genetic information except where the information relates to a disease or condition for which the individual has been positively diagnosed; from using genetic information in the absence of a diagnosis to deny, limit or vary coverage or to set rates; and from requiring individuals to undergo testing.	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."	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. On the basis of genetic information, insurers should be prohibited from: refusing to enroll; determining a rate; offering or providing different terms, conditions or benefits; or otherwise consider genetic information in the provision of insurance coverage or benefits.	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 . . . ."	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 request for or receipt of genetic services by an individual/family member."	N/A	No	N/A

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Amends HIPAA "nondiscrimination" provision	Yes. Expands nondiscrimination to rates charged to a group.	No	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	Yes. Cannot determine a rate based on genetic information.	Yes. Expands "genetic information" provision of HIPAA non-discrimination section by inserting "or a request for, or receipt of, genetic information or a genetic test" after "genetic information."	No	N/A	N/A	N/A
Applies to group plans	Yes. Amends ERISA	Yes--amends ERISA.	Yes--amends ERISA.	Yes--amends ERISA.	Yes	Yes--amends ERISA (also applies to programs administered by the VA).	Applies to "insurers" (see definition section above) but <u>not</u> to "group health plans." Insured ERISA plans would be covered but not self-insured ERISA plans.	N/A	N/A	N/A

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Prohibits plans from varying premiums on the basis of genetic information in the group market	Yes. Insurers shall not adjust premium or contribution rates on the basis of presymptomatic genetic information or a request for or receipt of genetic services.	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.	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. Insurers cannot determine rates on basis of genetic information.	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.	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	N/A	N/A
Applies to individual coverage	Yes. Expands HIPAA protections to the individual market.	Yes	The bill does not contain a nondiscrimina-tion 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	Yes	Yes	N/A	N/A	N/A

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Prohibits plans from varying premiums on the basis of genetic information in the individual market	Yes	Yes	No	Yes	Yes	Yes	Yes	N/A	N/A	N/A
Prohibits plans from requiring people to disclose genetic information	Yes, but in individual market, insurers can request genetic information relating to a disease or condition which has been positively diagnosed.	Yes	Yes	Yes	Yes	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	N/A	N/A	N/A
Prohibits plans from requiring people to take genetic tests	Yes	No mention of the taking of a genetic test, but plan is prohibited from requiring people to disclose genetic information (see above).	Yes	No mention of the taking of a genetic test, but plan is prohibited from requiring people to disclose genetic information (see above).	Yes	No	Yes	N/A	N/A	N/A

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Requires written authorization before plans can disclose genetic information	Yes. Authorization required for any entity that is a member of the same controlled group; any other insurer; the MIB; any plan sponsor; or any other person the Secretary may specify in regulations.	Yes. Required for each disclosure and must include identification of person to whom disclosure would be made.	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.	No	Yes. Description of the information, to whom, and purpose.	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	N/A	N/A

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Exceptions to written authorization	Yes. For treatment purposes and claims payment or benefit coordination.	No	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	N/A	Yes---if authorized under certain criminal laws; required by specific court order; authorized under law for establishing paternity; for identifying a body.	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	N/A	N/A

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Creates private cause of action by individual for damages	Yes	Yes. Plan/issuer "may in the court's discretion be liable . . . for compensatory, consequential, and punitive damages."	No	Yes. Plan/issuer "may in the court's discretion be liable . . . for compensatory, consequential, and punitive damages."	No	No	No	N/A	N/A	N/A
Authorizes Attorney General to pursue civil penalties/injunctive relief	No	No	No	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	N/A	N/A
Requires insurers to provide applicants/enrollees with an understandable, written statement of their rights	No	No	No	No	No	No	Yes	N/A	N/A	N/A

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EMPLOYMENT DISCRIMINATION PROHIBITIONS	N/A	No	No	No	N/A	Yes. Employer may not "attempt to 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 .."	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.	No. Restricts access to genetic information, but does not have discrimina-tion provisions.	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).	Yes. Employers should not require or request that employees or potential employees take a genetic test or provide genetic information as a condition of employment or benefits. Employers should not use genetic information to discriminate against, limit, segregate or classify employees in a way that would deprive them of employment opportunities.

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Exceptions	N/A	N/A	N/A	N/A	N/A	Yes. If genetic information or genetic test is "job-related and consistent with business necessity, or is required under Federal or State law."	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."	N/A	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."	Yes. (1) Employer shuld be permitted to monitor employees for the effects of a particular substance found in the workplace. Infored consent required. (2) The statutory authority of a federal agency or contractor to promulgate regulations, enforce workplace safety and health laws, or conduct occupational or other health research should not be limited. (3) An employer should be able to disclose genetic information for research and other purposes with the written, informed consent of the individual.

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Confidentiality provision	N/A	N/A	N/A	N/A	N/A	Yes. Employer shall not "1) allow access to genetic info of employees . . .;" (see exceptions below).	No	Yes. No employer may obtain from any source genetic information about an employee unless authorized as follows: authorization is in writing, signed by the individual and dated on the date of signature. The authorization is not on a form used for any other purpose. The employer authorized to receive the information must be specifically named in the authorization. The employer must provide the employee with a written statement of the uses which the employer intends for such genetic information.	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).	Yes. Employers should not obtain or disclose genetic information about employees or potential employees under most circumstances.

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Exceptions to confidentiality provision	N/A	N/A	N/A	N/A	N/A	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	None	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.	Yes. Exceptions for: (1) Genetic testing and use of genetic information to monitor employees for effects of a particular workplace substance. (2) Statutory authority of a federal agency to conduct occupational research. (3) For research and other purposes with the written informed consent of the individual.

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Requires written authorization before employer can disclose genetic information	N/A	N/A	N/A	N/A	N/A	The bill does not have a clear prohibition on disclosure of genetic information by employers.	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.	No specific requirement for authorization, but provides for a penalty if employer discloses without authorization.	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.	Yes. See above

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Exceptions to written authorization	N/A	N/A	N/A	N/A	N/A	See above.	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. See above	No	No

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Creates private cause of action by individual for damages	N/A	N/A	N/A	N/A	N/A	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).	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. Civil action for actual damages and equitable relief.	Yes. Employee may bring action in federal or state court. Court may award any appropriate legal or equitable relief.	Yes. Private lawsuit in federal or state court.
Statute of limitations	N/A	N/A	N/A	N/A	N/A	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.	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	No specific provision in bill, so state law would generally apply (average 2-3 years).	No

	#Administration's Health Insurance Proposal December 17, 1997	*H.R. 306/S.89 Slaughter/ Snowe	*H.R. 328 Solomon	*H.R. 1726 Furse (Same as H.R. 306)	#H.R. 2216 J. Kennedy	*H.R. 2198 Stearns	*S. 422 Domenici	#H.R. 2215 J. Kennedy	*S. 1045/H.R. 2275 Daschle/ Lowey	#Administration's Workplace Proposal January 20, 1998
Authorizes Attorney General to pursue civil penalties/injunctive relief	N/A	N/A	N/A	N/A	N/A	Enforcement through sections 705-09 of Civil Rights Act of 1964, which provides for action by the Attorney General in limited circumstances.	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	No	Recommends relief through EEOC, DOL or other appropriate federal agency.