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# *NCOIL HOLDS HEARING ON GENETIC DISCRIMINATION*

**Albany, New York, May 7, 2002** – Genetic tests can determine a person’s predisposition to certain diseases, but they also pose tough insurance questions for legislators.  Should legislators allow insurers to use the results of genetic tests to decide whether a person is eligible for life or disability insurance?  Should insurers have the discretion to use test results to determine the terms and conditions of a policy?

In an effort aimed at resolving those questions, Sen. James Seward (NY), Chair of the National Conference of Insurance Legislators’ (NCOIL) Life Insurance Committee, announced today that the Committee will hold a hearing on a proposed *NCOIL Genetic Discrimination Model Act* on Saturday, July 13, at the Sheraton Boston Hotel in Boston, Massachusetts.  The Committee will hold the hearing in conjunction with its 2002 Summer Meeting on July 11 through July 14.

In making the announcement, Sen. Seward said, “This hearing should assist NCOIL in refining a model bill that will protect consumers’ confidentiality while allowing insurers to do their job, selling worthwhile insurance policies.  While genetic tests help in diagnostics and treatment, they may also present problems in terms of disclosure and privacy rights.  The Committee is interested in hearing the industry’s perspective on what information it deems necessary to write and issue policies.  The Committee would also like to hear from consumer protection advocates and from genetic specialists who may shed some light on these complicated new research capabilities.”

As proposed, the model, sponsored by Sen. Seward, would:

      apply to all life and disability insurance;

      bar an insurer from requesting or using genetic information without informed consent, with relation to limiting, canceling, refusing to renew, increasing the rate of, or affecting the terms and conditions of a policy;

      bar an insurer from using genetic information to identify potential customers or to induce the purchase of insurance;

      provide “informed consent” exemptions for the purposes of anonymous scientific or medical research, identification, newborn screening procedures and establishing paternity; and

      still allow an insurer to use family history when issuing policies.

The model would also contain special requirements for life insurance policies in excess of $100,000 and disability insurance policies in excess of $60,000.  And it would provide for the creation of a list of catastrophic diseases and related genes that insurers could use to determine risk when issuing coverage.  According to requirements outlined in the model, a listed gene must have an 80 percent chance of developing into its correlating disease, which must have a 50 percent mortality rate.  The model would also allow a person to present the results of a test as presumptive evidence that they are not predisposed to a disease.

The Committee seeks testimony on specific provisions of the model, rather than more general testimony on the issue of genetic testing.  The Committee will continue discussion of the model at the NCOIL 2002 Annual Meeting.

Those wishing to testify at the hearing must submit a Summer Meeting registration form and a request-to-testify form to NCOIL by mail: 139 Lancaster Street, Albany, NY 12210-1903, or by fax: (518) 432-5651.  Both forms are available on the NCOIL Web site at www.ncoil.org, or from the NCOIL National Office at (518) 449-3210.  Persons testifying must submit an electronic copy of their written testimony to NCOIL by Friday, June 28, 2002, and bring 50 copies with them on the day of the hearing.  NCOIL will accept written testimony from persons unable to testify at the hearing until July 31.

NCOIL is an organization of state legislators whose main area of public policy concern is insurance legislation and regulation.  Many legislators active in NCOIL either chair or are members of the committees responsible for insurance legislation in their respective state houses across the country.

Other members of the NCOIL Life Insurance Committee are Vice-Chair Gini Milkey (VT), Sen. Steven Geller (FL), Rep. Rich Golick (GA), Rep. Timothy Osmond (IL), Sen. James Lewis (IN), Rep. Ronald Crimm (KY), Rep. Greg Davids (MN), Sen. Ed Oliver (MN), Sen. Alan Nunnellee (MI), Rep. Chuck Surface (MO), Rep. Dan Ward (MO), Sen. Harold Burns (NH), Sen. Neil Breslin (NY), Assem. Nancy Calhoun (NY), Assem. Donna Ferrara (NY), Assem. Alexander Grannis (NY), Assem Howard Mills (NY), Rep. George Keiser (ND), Rep. Mark Young (VT), and Rep. Phil Montgomery (WI).

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