

**Report and Recommendation of Study Committee
On Misuse of Genetic Information
June 26 2005**

Recommendation

Your Study Committee recommends that creation of a Drafting Committee to draft a Uniform Act on Misuse of Genetic Information Act in the areas of insurance and employment.

Background

The current Study Committee is composed of D. Joe Willis, (Chair) Mike Getty, Peter Langrock, Genny Ohrensball, Art Peterson, Ken Takayama, James Wynn, Joan Zeldon and James Nelson. Henry Drummond was appointed but resigned his position from the Commission and did not participate. Robyn Shapiro participated as ABA advisor. Several current members were also members of the Study Committee that started this project and the Committee benefited from that continuity. The Current Committee began its work with a more narrow focus. It focused on that areas of employment and insurance and potential misuse of genetic information in those areas in and effort to make the task more manageable.

The Committee had the benefit of all prior work, exchange of ideas and suggestions, which did include some survey of existing law. The Committee also had the very able help of Professor Philip G. Peters (University of Missouri School of Law) and Professor Ellen Deason (Ohio State University School of Law). Professor Peters provided a survey of existing state law and a grid to better summarize various approaches. His work is attached as an Exhibit A. Most States have some law in this area but it is all over the board as to approach. Also included as Exhibit B is a summary from Professor Peters setting out "Creative Strategies from Europe" dealing with life insurance. Professor Deason, in addition to her law training helped the committee understand the technical aspects of the subject matter. Both Professors Deason and Peters deserve a well-deserved thank you. The Committee and the Chair also had the invaluable guidance and suggestions from both Fred Miller and Bill Henning and Martha Walters. This guidance was also invaluable in keeping the focus limited for now with the hope of completing the Study Committee work and any recommendation to be made in a timely and focused manner.

The Committee did its work through independent efforts assisted by those mentioned above through telephone conferences. Due to various scheduling problems and time zone constraints not all members made each telephone conference but most did. The participation level and diversity of viewpoint was very good. During the Committee's work the Congress took up an effort but it stalled. The Australian Law Reform Commission published it Genes and Ingenuity Report (June 2004) dealing primarily with patent issues but was an outgrowth of an earlier study dealing with Protection of Human Genetic Information. The information obtained demonstrates that neither the States in the United States nor the United States have a comprehensive

uniform approach to the subject matter. It also seems clear that we are well behind other countries in developing a comprehensive approach.

The Committee is aware that Federal Law does exist and apply. Discrimination in group policies is prohibited within its coverage and privacy protections attach.

The Committee believes that the science that identifies and allows application of genetic information will continue to grow exponentially. The Committee believes that the complexity of the dynamic interaction of various genes and exposure to almost infinite environmental circumstances and sequences currently belies some broadly held perceptions of the ability to predict future human condition based on genetic information. An example is the gene that all that have Huntington's disease carry. In that case it is universally accepted that if you have that gene you will have Huntington's. However, when the person will become symptomatic is yet unknown.

The Committee also believes that the Science must be allowed to continue to develop and flourish. Perhaps we will see the day when we gain a full and accurate understanding of all the dynamic interplay that could lead to avoiding tragic consequences due to exposure to various stimuli. The Committee also believes that the risk for misuse of Genetic information whether accurate and properly understood or not is substantial. If life health or disability insurers, for instance, could demand genetic testing and deny coverage to those carrying a certain gene that group would be denied coverage all together. Similarly, if an employer could demand genetic testing, and deny employment to a group having a particular gene because of a belief that group would drive up group insurance costs or workers compensation premiums it could lead to significant numbers of individuals becoming unemployable.

On the other hand if a person has a genetic propensity to develop a deadly disease when exposed to a particular compound used in the workplace should that person as well as the employer not be able to determine that?

The Study Committee had robust discussion of the potential for acceptance by State legislatures if and Act was promulgated and believes the potential is sufficient to merit use of the resources. A substantial majority of the Committee expressed strong belief in the need for NCCUSL to move forward in this area with this limited undertaking being only the first of several dealing with genetic information.

Thus the Study Committee believes that policy decisions should be made by a drafting committee with language to accommodate the decision:

(1) How to describe "genetic information". The Committee tends toward excluding medical histories that are in widespread use now and limit the definition to physical gathering and testing procedures.

(2) When, if at all, gathering and use of genetic information should be banned. Should a ban on just group health and life policies be considered? Discrimination is already prohibited by those covered by the Federal law. Such a ban would fill a gap for individual policies to prevent adverse selection.

(3) If not banned, what balance needs to be struck concerning obtaining the information and being able to use it and the protection of individuals from:

- (a) Incompetent use of the information. Should this be addressed by setting standards of competence and/or placing a burden of demonstration on the proponent of the information that it is indeed reliable?
- (b) Competent use of the information. Should an individual be able to demand employment in the face of reliable science demonstrating a clear negative impact? Should an employee armed with this information be able to demand accommodation or unemployment benefits if no accommodation is available? Should a pattern of the European Countries that have not outright banned the use of genetic information in life insurance be followed, i.e. caps on the amount of coverage available-banning required testing but requiring sharing of information already obtained – providing longer waiting periods for coverage to become effective.

(4) If not banned what is the proper balance to place any limit on mandatory testing?

(5) If not banned, what is the proper balance to place on sharing of information, notice of such sharing if allowed, and destruction or retention of the genetic material?

The Committee believes from its work that a Drafting Committee that works its way through the above issues and other related issues that always arise during the process will produce a product that meets all the Criteria stated in NCCUSL Statement of Policy Establishing Criteria and Procedures for Designation and Consideration of Acts (January 13 2001).

Summary of Recommendation

Your Study Committee on Misuse of Genetic Information recommends that a drafting committee be created to draft a Uniform Act on Misuse of Genetic Information in the areas of Employment and Insurance. Although not a part of a recommendation for additional Drafting Committees at this time a substantial majority of the Drafting Committee urges Scope and Program to view this effort as the first step toward a more comprehensive effort if the first is successful.

Respectfully Submitted on behalf of the Committee.

Exhibit A

Will Forward Under Seperate Cover

Creative Strategies from Europe¹

In Europe, life insurance is seen as a basic social need because it is necessary in order to get a mortgage. Thus, it is often characterized as a right, not a privilege. As a consequence, twenty-two European countries reportedly have instituted either partial or complete bans on the use of genetic data by life insurers. In a few other European countries, the insurance industry has voluntarily instituted a full or partial moratorium on the use of genetic information.²

Because adverse selection is an obvious risk when you restrict the use of genetic information, a number of these countries have adopted compromise or “partial” prohibitions designed to reduce the risk of adverse selection. In addition, legal scholars have suggested two other ways of reducing this risk. The four options are:

1. **Caps.** One European strategy is to cap the amount that can be purchased free of genetic testing. The insurance industry in Germany, Ireland, Sweden, and the UK apparently have instituted moratoria using this approach. The ceiling can be a fixed amount (the lowest in the EU is about \$100,000), or a sum that is proportionate to the level of income. A cap strategy allows people to own a home, while at the same time eliminating the most serious instances of adverse selection (e.g., where an applicant learns that he is high risk and belatedly acquires large sums of insurance at what amounts to a huge discount).³
2. **Mutuality of information.** Another interesting approach to the risk of adverse selection is to bar insurers from requiring genetic tests, but also require that applicants divulge the results of any genetic tests that they have taken. The moratoria in Australia, Canada, Greece, New Zealand and South Africa reportedly take this approach. In theory, the resulting mutuality of information eliminates the information asymmetry that fuels adverse selection. (In the future, however, direct sales of at-home test kits to consumers could make this approach difficult to police because the test results will not be in the applicant’s medical records.)
3. **Longer waiting periods.** An option suggested by a US working group is to offer life insurance without medical underwriting, but with a five year waiting period except in the case of accidental death. For this idea to work, all life insurance would have to be offered in this manner.

¹Information contained in this memo is derived from Bartha Knoppers, Beatrice Godard, and Yann Joly, “A Comparative International Overview,” and Mark Rothstein, “Policy Recommendation,” in *Genetics and Life Insurance* 173 (Mark Rothstein, ed., MIT Press, 2004)

²Note: In the US, insurers would need to take the antitrust laws into account when deciding whether to adopt one of these approaches voluntarily.

³I don’t know how these insurers/countries protect against the purchase of multiple policies from different companies.

4. **Limit the ban on testing to group plans.** Adverse selection risk could also be reduced by limiting the prohibition on genetic discrimination to group policies, much like current federal law in the US prohibits discrimination in group health insurance. However, group plans currently account for only one-third of the life insurance policies sold in the U.S.