ALASKA LEGISLATURE COMMITTEE FILES 1995-1996 8672
8683 HOUSE LABOR & COMMERCE

BASIS 24 PAGES SELECTED Committee Minutes

In the course of further discussion of Sec. 10 provisions with Senator Donley and Mr. Sharrock, Mr. Farleigh reiterated problems resulting from lack of adequate supply furnished by distributors. He further advised that he could go to Costco and buy beer and wine cheaper than from a distributor. He acknowledged that Costco often does not carry the beers he needs, but he advised that he saw no problem with a free market. Mr. Sharrock noted that Mr. Farleigh's point was well taken.

In further discussion of the 9:00 p.m. deadline for entertainment in restaurants, Mr. Sharrock pointed to existing regulations. He advised that the majority of the revenue earned by such establishments is from dining, and traditional dining hours are 6:00 p.m. to 9:00 p.m. Mr. Farleigh advised that he had just appeared before the board on this issue and was turned down. He acknowledged that

Selection=>
PF1 HELP PF2 PF3 EXIT PF4 MENU PF5 PF6 PRINT PF7 BWD PF8 FWD PF9 PF10 FIRST PF11 LAST PF12 QUIT
SNA 02 A01CI17 NUM LPT1

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while 6:00 p.m. to 9:00 p.m. is the most common dining period, a number of people stop by later after a hockey game or other evening events. Mr. Farleigh stressed that he was attempting to increase the economically viable period in which a restaurant exists. He suggested that existing regulations force people to move their activities to bars after 9:00 p.m. He noted that he had had a number of such comments from customers.

Co-chairman Halford advised that he continued to have problems with sections of the bill relating to bottle clubs and advised that the bill would be held in committee for further review.

ADJOURNMENT

The meeting was adjourned at approximately 11:05 a.m.

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have to hold one election to change or remove or adopt an option they want.

MR. SHARROCK said there are other technical amendments, a few of which are somewhat new, that the board also suggested or desired. Those are insignificant in his mind, except maybe one that they had asked to be included in this version of the bill, which is a provision to convert restaurant licenses in the community if that restaurant business person wants to have entertainment. It does not create a new class of license, but allows a person to convert a beer and wine or restaurant license into what he refers to as a semi-tavern license. The reason the bill chose not to create a new license by regulation is because if it did, then that many more licenses would be available under the population limitation provisions and the board did not want to do that at all. The board thought it would be easier to address it under one class of license already. You may recall the Cirano case the board had a year or so ago, and this is the board's proposed solution to that kind of thing, to help people out that run into that problem, that run a different sort of business that is not a full-fledged restaurant.

House Judiciary Committee 5/5/95

Selection=>

PF1 HELP PF2 PF3 EXIT PF4 MENU PF5 PF6 PRINT PF7 BWD PF8 FWD PF9 PF10 FIRST PF11 LAST PF12 QUIT

SHA- 02 AD1C117 NUM LPT1 A

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He said the sectional analysis addresses the different things the board felt was appropriate.

Number 600

REPRESENTATIVE FINKELSTEIN asked what the outcome was of the Cirano case.

MR. SHARROCK answered that the proprietor submitted to the board what he believed was a sufficient menu for food to be served at the restaurant, which was somewhat expanded from what the board had looked at before, and the board accepted it.

REPRESENTATIVE FINKELSTEIN asked what the current composition of the board was.

MR. SHARROCK answered that, as required by law, there are two members from the industry.

Number 658

Selection=>

PF1 HELP PF2 PF3 EXIT PF4 MENU PF5 PF6 PRINT PF7 BWD PF8 FWD PF9 PF10 FIRST PF11 LAST PF12 QUIT

SHA- 02 AD1C117 NUM LPT1 A

HB

407

FISCAL NOTE

STATE OF ALASKA
1996 LEGISLATIVE SESSION

BILL NO. HB 407

Revision Date:
Department: Commerce and Economic Development
Title: Insuring Persons with Genetic Defects
BRU: Insurance
Component: Operations
Sponsor: Representatives Davies, Brown
Requestor: House Labor & Commerce Committee
COMPONENT SERIAL NO. #354

Expenditures/Revenues (Thousands of Dollars)

OPERATING EXPENDITURES	FY 97	FY 98	FY 99	FY 00	FY 01	FY 02
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0
CAPITAL EXPENDITURES						
CHANGE IN REVENUES						

FUND SOURCE (Thousands of Dollars)

1002 Federal Receipts						
1003 GF Match						
1004 General Fund						
1005 GF/Program Receipts						
1006 GF/MHTIA						
Other						
TOTAL	0.0	0.0	0.0	0.0	0.0	0.0

Estimate of any current year (FY 96) cost: $ 0.0

POSITIONS

FULL-TIME	0	0	0	0	0	0
PART-TIME						
TEMPORARY						

ANALYSIS: (Attach a separate page if necessary)
No fiscal impact.

Prepared by: Joan Brown, Administrative Officer
Phone: 465-2597
Division: Insurance
Date: 1/31/96
Approved by Commissioner: William L. Hensley
Date:
Agency: Commerce and Economic Development

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Individual, Family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis

Lisa N. Geller, Joseph S. Alper, Paul R. Billings, Carol I. Barash, Jonathan Beckwith, and Marvin R. Natowicz*

Keywords: genetic discrimination, genetic testing, Medical Information Bureau, state insurance commissions.

ABSTRACT

Background. *As the development and use of genetic tests have increased, so have concerns regarding the uses of genetic information. Genetic discrimination, the differential treatment of individuals based on real or perceived differences in their genomes, is a recently described form of discrimination. The range and significance of experiences associated with this form of discrimination are not yet well known and are investigated in this study.*

Methods. *Individuals at-risk to develop a genetic condition and parents of children with specific genetic conditions were surveyed by questionnaire for reports of genetic discrimination. A total of 27,790 questionnaires were sent out by mail. Of 917 responses received, 206 were followed up with telephone interviews. The responses were analyzed regarding circumstances of the alleged discrimination, the institutions involved, issues relating to the redress of grievances, and strategies to avoid discrimination.*

Results. *A number of institutions were reported to have engaged in genetic discrimination including health and life insurance companies, health care providers, blood banks, adoption agencies, the military, and schools. The alleged instances of discrimination were against individuals who were asymptomatic and sometimes imparted on other*

* All authors contributed equally to this work.

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asymptomatic relatives. Few surveyed respondents knew of the existence of institutions such as state insurance commissions or the Medical Information Bureau, Inc., which may play roles in redress of grievances or correction of misinformation.
Conclusions. Genetic discrimination is variable in form and cause and can have marked consequences for individuals experiencing discrimination and their relatives. The presence of abnormal genes in all individuals makes each person a potential victim of this type of discrimination. The increasing development and utilization of genetic tests will likely result in increased genetic discrimination in the absence of contravening measures.

The growing knowledge of human genetics, stimulated in part by the Human Genome Project, has engendered a societal need to understand potential hazards as well as benefits of this knowledge. With the increased ability to identify genetic differences, it is important to elucidate appropriate uses of genetic information from the perspective of both individuals and the public. At the same time, safeguards must be developed to minimize inappropriate uses of this information[1-4]. One area of concern is genetic discrimination.

The term "genetic discrimination" has been used to describe the differential treatment of individuals or their relatives based on actual or presumed genetic differences as opposed to discrimination based on phenotype[5-7]. Sources of genetic information that enable such discrimination include genetic and sometimes non-genetic medical tests, family histories, and information obtained from clinical examinations. Each of these sources has important limitations in terms of its reliability in predicting whether a particular genetic condition will occur and, if so, the clinical course of the associated disease. These limitations include but are not restricted to the sensitivity and specificity of genetic tests, the intrinsic clinical variability of many hereditary conditions, and the importance of environmental factors.

A pilot study of genetic discrimination showed this problem to involve more disorders than was previously revealed by isolated reports. The reported incidents involved a variety of social institutions such as life and health insurance organizations, and suggested that genetic discrimination may become a significant social policy problem[5]. Based on this work and reports of genetic discrimination by others, there is now serious concern regarding the importance of this problem[3-5, 8-11]. This concern is intensified by the proliferation and increasing utilization of genetic tests made possible in part by technological advances made by the Human Genome Project and by the application of these technologies by commercial interests[12-14].

Previous reports of genetic discrimination involved studies of relatively small numbers of individuals and, consequently, would not be expected to reveal a full range of the discriminatory experiences faced by affected individuals and their families. Here we report on case studies obtained in 1992-1993 of individuals living throughout the United States at-risk for or related to people at-risk for the following disorders: hemochromatosis, phenylketonuria (PKU), mucopolysaccharidoses (MPS), and Huntington disease. We describe the spectrum of discrimination reported by some of these individuals and discuss its implications through analysis of selected informative cases.

METHODS

Study Design

Individuals at-risk for genetic discrimination were sent questionnaires during 1992-1993. The definition of genetic discrimination has been previously presented and distinguishes genetic discrimination from discrimination based on phenotype[15]. Only those cases in which individuals appeared to have no symptoms (i.e. no apparent phenotype at the time of the reported discrimination) were included in this study.

Questionnaires and Interviews

Two questionnaires and an interview instrument were developed based on findings from our pilot study. They were reviewed by consultants experienced in qualitative research methods and questionnaire design and were approved by the Shriver Center's Institutional Review Board. The two questionnaires were distributed through the mailing lists of genetic disease organizations selected according to the criteria described below, and were accompanied by a letter describing the research group and the goals of the study. One questionnaire was directed at individuals who had or were at-risk to develop a genetic condition. The other questionnaire was directed at parents who had a child with a genetic condition. Both were designed to acquire information about whether an individual believed that she/he or a relative had experienced discrimination because of a genetic diagnosis or assumption of genetic predisposition to the disorder, as well as a brief description of the discriminatory event(s) (Table 1, see p. 85). The descriptions of the alleged discriminatory events were used to screen the returned questionnaires for cases that appeared to fit the definition of genetic discrimination used in this study. That is, the person alleging discrimination was not symptomatic for a genetic disorder (or any other disease which might confound the claim of discrimination) nor did the complaint appear to involve legitimate actions by companies or individuals that were construed as "unfair" by the individual claiming discrimination. Some cases were included where an apparent conflict between the perception of the individual and the apparent point of view of an institution illustrate areas of ambiguity concerning the "fairness" of the situation.

Telephone interviews were conducted with individuals who, from their responses to the questionnaire, appeared to have experienced genetic discrimination as described above. An attempt was made to interview all individuals whose questionnaire answers met the above criteria and who indicated on their returned questionnaires that they were willing to be contacted by telephone. The script (available by request) used to conduct the interviews was designed to obtain more detailed information about the perceived discriminatory event(s) (Table 2, see p. 86-87). For example, in cases of alleged discrimination by an insurance company, the interviewee was asked about how the company found out about his/her genetic status, what correspondence and conversations were held with individuals at the company, what reasons were given by the company for actions taken, whether outside support or counsel was sought, whether the case was reconsidered after communication with the company, length of time of response, who within the company handled the case, whether alternative policies were offered, etc. In addition, general information was elicited regarding the economic and educational status of the individual, as well as pertinent medical

information including whether the individual was asymptomatic. We also sought to determine the origin of the genetic diagnosis or supposed genetic risk factor, perceived ability to redress a grievance, the extent to which an individual challenged adverse decisions, and the impact of personal genetic information on the individual and her/his family. The Medical Information Bureau, Inc. (MIB) and state insurance commissions are institutions which may be useful to individuals seeking redress regarding insurance. After conducting a number of interviews, it became apparent that the respondents differed widely in their knowledge concerning avenues for seeking redress for complaints involving insurance. Consequently, questions concerning whether the individual knew of the MIB and state insurance commissions were added to subsequent interviews. Consenting interviewees were anonymously tape recorded to aid in the transcription of information. In addition, documentation of discriminatory events was sought, including such items as letters from insurance companies and medical and personal notes.

Study Groups

The specific disorders targeted for this study were Huntington disease, phenylketonuria (PKU), hemochromatosis, and mucopolysaccharidoses (MPS). They were chosen because they met the following criteria: (1) the genetic basis of the condition is known and unambiguous; (2) discrimination directed against individuals with these conditions would most likely be due to the genetic bases of these conditions, rather than due to physical symptoms; and (3) support groups for persons with these conditions exist so that individuals could be contacted easily. These conditions were also selected because they cover a spectrum of situations including dominant and recessive disorders, treatable and untreatable disorders, relatively common disorders for which screening programs exist, and rare disorders for which screening programs are not indicated. Note that the individuals with recessive disorders included both those with the genotype for the disorder and those who are simply carriers.

Huntington disease is a fatal, untreatable, autosomal dominant disorder whose symptoms generally appear in middle age. There is currently a molecular genetic test available to diagnose this condition. Hemochromatosis is an iron storage disorder with a variable phenotype, some individuals being completely asymptomatic. This autosomal recessive disorder is treatable by phlebotomy (drawing blood). PKU is an autosomal recessive disorder for which all newborns in the United States are tested. If left untreated the disorder results in mental retardation. However, PKU is successfully treated by placing the child on a special diet. MPS disorders are usually associated with mental retardation and organomegaly.

A total of 27,790 questionnaires were mailed by the following groups to their members: The Huntington Disease Society of America, The Hemochromatosis Research Foundation, The National M.P.S. Foundation, and the PKU Clinic at Children's Hospital, Boston, MA. These mailing lists included donors and interested individuals who were not appropriate respondents to the questionnaire, a factor which was expected to result in a low response rate. However, contacting individuals through a national organization was more likely to get a broader response than that obtained by contacting individuals through a few clinics. Respondents to the questionnaire

included individuals who were at-risk to develop a genetic disorder but who were not informed of their genotype, individuals who were presymptomatic for a specific genetic condition, and individuals who were asymptomatic because of receipt of a therapy or were heterozygotes and thus only "carriers" for an autosomal recessive condition.

RESULTS

Of the 917 returned questionnaires, 455 respondents asserted that they had experienced genetic discrimination and 437 that they had not. The remainder gave ambiguous answers that could not be specifically classified. Some respondents reported experiencing genetic discrimination in more than one setting. After screening the questionnaires for cases that appeared to fit the definition of genetic discrimination used in this study, we were able to contact for interviews 206 individuals who reported that they experienced genetic discrimination. Detailed breakdowns of the responses of all respondents to the questionnaire, categorized by disease group, are given in Table 3 (see p. 88).

A variety of different institutions allegedly discriminated against the respondents. The majority of cases involved discrimination by health and life insurance companies but there were a number of cases involved employers, adoption services, and blood banks. The cases reported below are grouped according to agents/institutions allegedly engaged in the genetic discrimination, followed by results of the impact of genetic discrimination on individuals and family members, responses and counter-measures taken to mitigate the effects of genetic discrimination, and information pertinent to the underlying bases of this phenomenon.

Agents/institutions engaging in discriminatory practices

- Health and Life Insurance Corporations

Four aspects of discrimination are illustrated by the cases involving health and life insurance: (1) discrimination against individuals who were asymptomatic; (2) differential treatment of asymptomatic individuals or families once a genetic diagnosis was established, thus treating the genetic diagnosis as a preexisting condition; (3) the failure of some group insurance plans to provide coverage for qualified individuals with a genetic diagnosis; and (4) the loss of insurability suffered by relatives of an individual with a presumed genetic disease. These issues are illustrated by the following cases.

Case a: A health maintenance organization (HMO) had covered the medical expenses of a child since birth but refused to pay for occupational therapy after she was diagnosed with MPS-I, claiming that the condition was pre-existing. All bills relevant to the condition had been paid up to the time of diagnosis. The occupational therapy had been pre-approved by the managed care corporation. The situation was remedied after the family complained to a customer service representative of the HMO.

Case b: A private insurer in Colorado notified the parents of a three year old who had been recently diagnosed with an MPS syndrome that the child's policy was terminated

although the family had been on the policy for nine months before the diagnosis. After an extended negotiation that included retention of a lawyer and the threat of a lawsuit, the insurance policy was reinstated. However, a rider was added to the policy excluding coverage for two common MPS-related complications.

Case c: A 24 year old woman was denied life insurance due to her "strong family history of Huntington's Chorea" and the fact that she has never been tested to determine if she is "currently a carrier." The rejection letter stated that if she "should be tested and if found to be negative," the company would issue a standard contract.

Case d: A mother submitted applications for employment-based life insurance policies simultaneously for her two children, one of whom had Hurler syndrome, a form of MPS. Both were rejected. The rejection letter indicated that the child with Hurler syndrome was denied a policy because the condition is fatal; no reason was given for the denial of a policy to the other child. She was later able to obtain coverage for the healthy child through a different employer.

• Clinical Professionals

In several cases medical professionals reportedly pressured patients or clients at-risk for having children with serious genetic conditions, to undergo prenatal diagnostic testing or to forsake having children.

Case e: A PKU gene carrier reported that during a routine pediatric visit, her child's doctor advised her that it would be unwise to have more children and that she should consult a genetic counselor to understand "the implications of PKU".

Case f: A couple in which one member was at-risk for Huntington disease reported that physicians tried to compel them to undergo prenatal genetic testing and reportedly coerced them to sign a document agreeing to abort an affected pregnancy. They also reported being required by a health care provider to undergo genetic counseling despite their belief that they had comprehensive knowledge about the genetic risks and their decision to continue any pregnancy irrespective of Huntington disease status.

• Adoption

Three issues are illustrated by the cases of alleged discrimination by adoption agencies. They are: (1) a misunderstanding of the nature of the presumed genetic condition with consequent unfair treatment of the prospective parents; (2) the requirement that individuals "pass" a genetic test before being allowed to adopt a child; and (3) the assumption that individuals with genetic diagnoses should adopt only children at-risk of having a disability.

Case g: One respondent, a carrier for MPS, was required by an adoption agency to repeat the blood and urine tests routinely required of prospective parents. It was reported that agency personnel found it "inexplicable" that the original test results were normal in someone who was a carrier for a genetic disorder.

Case h: A married woman learned that she was at-risk for Huntington disease when she was 25 years old. A year later she and her husband decided to adopt a child on the advice of her physician. The latter told her it would be better for her not to have her own children and that she could easily adopt. She therefore underwent a tubal ligation and the couple began the adoption process. The adoption agency application asked why the couple was not able to have children biologically, inquired about the presence of hereditary disorders, and required certification from a doctor that the couple was sterile. Shortly after filing the application, the couple received a letter from the adoption agency refusing them the opportunity to adopt based on the woman's risk of Huntington disease.

Case i: A birth mother with Huntington disease was refused the opportunity to place her child up for adoption through a state adoption agency but the child was accepted by a private agency. A couple with one member at-risk for Huntington disease had been unsuccessful in trying to adopt a child who was assumed to be genotypically normal. However, that at-risk couple was permitted to adopt the at-risk infant.

• Armed Services

The case described below involving the armed services shows that even institutions as structured as the military may not have a consistent policy with regard to people at-risk for genetic conditions.

Case j: An individual enlisted in the Air Force and revealed his (approximately 50%) risk status for developing Huntington disease. When applying for reenlistment, he was discharged due to his risk status, although he was asymptomatic. The brother of this individual served in the Marines (who were aware of his risk status) until he became symptomatic for Huntington disease at which time he received a medical discharge and treatment at a V.A. hospital.

• Employers

In many of the cases involving employment, individuals believed that they were not hired or were fired because they were at-risk for genetic conditions. In other cases, individuals who were employed reported that they were reluctant to seek either a more desirable job or a job in a different location because they feared that they would be unable to obtain health insurance in their new position.

Case k: A 24 year old woman was fired from her job as a social worker shortly after her employers learned that she was at-risk to develop Huntington disease. In the eight-month period prior to her termination she received three promotions and outstanding performance reviews. However, while conducting an in-service training on admitting and caring for Huntington disease patients, she revealed that she had a family member with Huntington disease. Shortly afterwards, she was given a poor performance review. Her employers declined to give examples of poor performance. She was soon fired and told by a co-worker that the employer was concerned about her risk to develop Huntington disease.

Case f: A 53 year old man was interviewed for a job with an insurance company. During his first interview he revealed that he had hemochromatosis but was asymptomatic. During the second interview, the company representative told him that the company would be interested in hiring him but would not be able to offer him health insurance because of his hemochromatosis. He agreed to this condition. During the third interview he was told that although they would like to hire him, they were unable to do so because of his hemochromatosis.

• Educational institutions

Our study elicited a few reports of genetic discrimination occurring in educational institutions. As is the case for the examples described above, the examples of genetic discrimination by educational institutions involved the denial of opportunities to apparently qualified individuals because of a perceived genetic abnormality in those individuals.

Case ne: In a small town, two healthy children attended the same school as their disabled brother. That brother had MPS II and attended a special education class. When in second grade, one of the healthy children was judged to have poor penmanship. A teacher decided that this indicated the onset of MPS II and sent the child back to first grade without consulting the parents or a physician. The parents protested and the child was placed in the appropriate grade.

• Blood Banks

Twenty-two respondents with hemochromatosis reported that they were not able to donate blood. The American Red Cross has a policy of rejecting blood donations from all individuals with hemochromatosis arguing that the donations are treatments, not gifts[16]. A significant number of respondents stated that they donated blood because their health insurance would not pay for phlebotomy treatments. In some cases, blood banks were willing to perform phlebotomies as treatment for a fee. Several of these cases have previously been discussed[11]. In the case below, prejudice or ignorance of a medical condition apparently played a role in inappropriately denying a potential donor the opportunity to give blood.

Case n: A man who had regularly donated blood for a number of years was refused phlebotomy when the nurse responsible for scheduling at the local blood bank learned that he had been diagnosed with Huntington disease. Donating blood was important to this man as a way of making a contribution to society. His neurologic findings, if any, were apparently not an issue since the director of the blood bank invited him to resume his blood donations once that particular nurse retired.

Personal reactions among people at risk for genetic discrimination

Not unexpectedly, experiencing one or more episodes of genetic discrimination engenders a gamut of personal/psychological reactions for both the affected individual and, often, for other family members. These involve loss of self-esteem, alienation from family members and others, and alterations in family dynamics. For example, some individuals reported that they felt stigmatized and unworthy of marriage or that

membership of those groups. In addition, documentation of discrimination was difficult to obtain in many instances. Some types of discrimination such as employment discrimination cannot be documented easily. In other instances, records of discrimination were not kept, especially if the individuals believed that there was no recourse for appeal of an adverse decision. Thus, it is difficult to determine to what extent reports of genetic discrimination are of actual rather than perceived discrimination.

The low response rate to the questionnaires is due to several factors besides the actual incidence of genetic discrimination. No follow-up mailings of the questionnaire were done, a practice which greatly increases the response rate. In addition, the mailing lists of the disease organizations include many individuals who are not personally affected by the disorders and so would not respond to the questionnaire. This is reflected in the fact that some questionnaires were returned by people who noted that they were not appropriate respondents. It is also possible that the response rate reflects a real result; that while genetic discrimination exists at this time it is not a widespread phenomenon.

Finally, we emphasize that this study is not a survey, but rather and attempt to collect case studies in order to examine the varieties of genetic discrimination. Consequently any statistical analysis of the cases would be both inappropriate and unnecessary.

This first extensive study of genetic discrimination extends and confirms the results of earlier ones. The cases from this study are consistent with the interpretation that although not systematic, genetic discrimination does occur in a wide variety of contexts and can cause hardship to affected individuals and their families. Many instances of genetic discrimination described in this study are similar to other types of discrimination. However, the distinctive nature of this type of discrimination lies in its effect on individuals who are asymptomatic and may never become symptomatic. Because the number and use of genetic tests is expanding rapidly and will continue to increase, it is vital that standards be developed in the near future to ensure that genetic information be used fairly. As our society struggles to be more equitable in its treatment of people regardless of race, age, or gender, it cannot ignore or justify inequities based on genotype.

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Table 1. Questionnaire	
1.	What is your genetic diagnosis?
2a.	Do you think that you may have been refused social benefits or denied opportunities because of your diagnosed condition?
2b.	If no, do you have any concerns for the future, or other comments?
3.	In what year did the event/s occur?
4.	Around what issue did you experience difficulties? (Health insurance, life insurance, adopting children, military, social services, church/synagogue, community/neighbors, other (please specify).
5.	Please describe your experiences, explaining why these are discriminatory.
6.	Are there any other comments that you would like to make?
7.	Please note which institution sent you this questionnaire.
8.	May we contact you for more information? (name, address, telephone)

The above questions were distributed in a questionnaire to individuals associated with genetic disease support groups who were likely to have a genetic diagnosis (see Methods, pp. 73-75). In addition to the questions listed above, the questionnaire had a brief definition of genetic discrimination and an assurance of confidentiality. A nearly identical questionnaire was distributed to individuals likely to be carriers for a genetic disorder.

Table 2. Partial List of Questions from the Telephone Guide Used for Interviews on Genetic Discrimination

Number of children/family members affected by the condition
Pedigree
Presence or absence of confounding disabilities
Context of the occurrence or the event
(Insurance, employment, public entities & accommodations/housing, education, government, community, other)
Insurance
Type? (Health, life, disability, automobile, home/mortgage, commercial loan)
Obtaining, renewing, or switching insurance?
Company name?
Employment
(Hiring, promotion, transfer, job responsibilities, compensation, eligibility for benefits, provision for disability, association with someone disabled, other)
Company name?
Employer/title?
Type of job and relevance of the condition to job performance
Was physical accessibility to an activity curtailed in any way?
Were reasonable accommodations requested? If so, were they provided?
After the incident, where did you work?
If you changed jobs, why?
Describe educational background and qualifications for job
Jobs held before and after (title/duties/length of time/ why left)
Public entities and accommodation
(Adoption agency, public housing, obtaining a loan, professional licensing, other licensing, transportation services, place of education, day care center, recreational facility, other)
Education
(Admission, activity restriction, termination, health service, other)
Government
(Military, benefits, social security entitlement, federal, state, local, other)
Military
(Entrance, transfer, job responsibilities, activity restrictions, termination, promotion, other)
Army, Navy, Air Force, Marines, National Guard, other
Benefits
(type: eligibility criteria and dates)
Community
(Neighborhood, religious community, recreational facilities)

Table 2 continued: Partial List of Questions from the Telephone Guide Used for Interviews on Genetic Discrimination

Details of Discrimination

How was information about your condition revealed?
Did the institution get information from the Medical Information Bureau? What information did they get? How did you find out?
What did you request and why? (describe all events, contacts/correspondence which precede the institution's denial)
Who did you first contact? (include job title)
Type of correspondence (letters, phone, person)
What, if any, additional medical information were you required to disclose? (May we receive a copy of their request?)
Were you given a reason why this information was required?
Did you voluntarily submit additional information or medical letters of support? (May we receive documentation?)
Did you seek help from an outside source, such as personnel, other people you know, or a disease support group, etc.?
What was the nature of their reply?
(refusal to consider case, request for additional information—if so, what was requested?)
Were you or your physician requested to submit information? Other?
Did the person making the decision explain to you what they thought and why? How was this communicated to you?
How long did the institution take to respond to your initial inquiry?
Was the response made in person? By phone? By letter? (Personalized form or letter? May we obtain a copy? If not, why?)
Who replied? (job title)
Did this person continue to handle your case, or was it referred to a supervisor? If so, how high up within the organization did consideration of your case go? Did you ever request that a supervisor take charge?

Table 3. Tabulation of questionnaires

	Questionnaires (returned / sent)	Reporting genetic discrimination yes	no	ambiguous
Huntington disease	623 / 25,924	276	329	18
Hemochromatosis	138 / 1,250	53	85	0
MPS	57 / 420	44	10	3
Phenylketonuria	22 / 200	12	8	2
Other*	77 / none	70	5	2
Total	917 / 27,790	455@	437	25

* This category includes questionnaires with information regarding disorders other than those listed above and those where it was not possible to ascertain the disorder the individual had. Questionnaires returned blank are not included.

@ The 206 interviewees were from the 385 individuals in this category reporting an association with Huntington disease, hemochromatosis, MPS, or phenylketonuria. See Methods (pp. 73-75) for a more detailed description of the selection of individuals interviewed.

9-LS1209\C
Ford
4/10/96

CS FOR HOUSE BILL NO. 407( )

IN THE LEGISLATURE OF THE STATE OF ALASKA

NINETEENTH LEGISLATURE - SECOND SESSION

BY

Offered:
Referred:

Sponsor(s): REPRESENTATIVES DAVIES, Brown, Nicholia

A BILL

FOR AN ACT ENTITLED

"An Act relating to discrimination by certain insurers against a person with a genetic defect."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

* Section 1. AS 21.36 is amended by adding a new section to read:

Sec. 21.36.092. PROHIBITED DISCRIMINATION AGAINST PERSONS WITH GENETIC DEFECTS. (a) Except as provided under (b) of this section, an insurer may not

(1) refuse to issue, sell, or renew a policy of life or disability insurance if the refusal is based only on an asymptomatic genetic characteristic of the person to be insured;

(2) charge a higher premium, require a rebate, discount, or otherwise discriminate in the amount to be paid for insurance coverage issued to a person who has an asymptomatic genetic characteristic;

(3) insert a condition in a policy of life or disability insurance that

covers a person with an asymptomatic genetic characteristic unless the policy condition is also imposed on other persons with similar coverage; or

(4) fix a lower rate in agent or broker fees or commissions for issuing or renewing a policy of life or disability insurance if the lower rate is based only on the fact that the insured person has an asymptomatic genetic characteristic.

(b) The provisions of (a) of this section do not apply to an applicant or an insured person with an asymptomatic genetic characteristic and a medical condition, medical history, claims experience, or actuarial projection that establishes that substantial ~~differences~~ in claims are likely to result from the asymptomatic genetic characteristic.

(c) In this section,

(1) "asymptomatic genetic characteristic" means a scientific or medically identifiable gene or chromosome, or alteration of a gene or chromosome, that is known to be a cause of a disease or disorder, or is associated with a statistically increased risk of development of a disease or disorder, and that is asymptomatic of any disease or disorder;

(2) "insurer" includes

(A) an insurer as defined in AS 21.90.900;

(B) a group health plan as defined in 29 U.S.C. 1167(1)(Employee Retirement Income Security Act of 1974);

(C) a health maintenance organization as defined in AS 21.86.900;

(D) a hospital service corporation or medical service corporation as defined in AS 21.87.330;

(E) a writing carrier as defined in AS 21.55.500; and

(F) an entity offering a service benefit plan as referred to in 42 U.S.C. 1396g - 1.

November-December 1992

Stanford Observer

Genetic information poses quandary for insurance industry

Medicine's increasing ability to identify an individual's genetic disposition to disease may require the government to offer long-term national health insurance or prohibit insurance companies from using the information, says Nobel economist Kenneth Arrow.

Without one or the other of these policy changes, the Stanford professor emeritus said recently at a seminar on biomedical ethics, patients and their physicians increasingly will face an ethical conflict between medical truth and financial harm to patients.

In some cases, tests that determine an individual's disposition to a particular disease might lead to treatments that would prevent the disease from occurring, but at the same time, might cause the person's health insurance to be canceled, Arrow said.

"There are a few examples now, and very possibly, as the human genome project progresses, we will have people who are uninsurable at birth because they already have a high probability of very

See Genetic information, page 10

Genetic information

continued from page 1

costly diseases," he said.

In addition to the ethical conflict posed by these medical advances, he said, economic inefficiencies can be expected to increase. Already, new negative information about one's health status, such as the development of allergies or some other chronic condition, prevent people from changing jobs, retiring or becoming self-employed, he said. Because most U.S. health insurance is made available to people on a yearly basis through groups based on their place of employment, these people have trouble getting new insurance coverage if they change employers.

Employment-based health insurance is "analogous to the situation in communist societies where many benefits, such as health insurance and housing, are attached to the job. That's one of the reasons those countries tended to grow slowly," Arrow said.

"Restrictions on job mobility are really socially inefficient and individual depriving. The individual is deprived of an opportunity for a better position. Society is deprived of having the best person in the best job."

That inefficiency likely will occur on a larger scale if genetic dispositions to diseases become discoverable at birth, he said.

Arrow took the example of a 20-year-old individual whose medical tests reveal a cell tissue mutation known to be a precursor of colon cancer. The individual does not have the disease itself but is more likely to develop colon cancer over the next several decades than a 20-year-old without the mutation.

Before this medical information was known, he said, an insurer could rationally assume both 20-year-olds had the same chance of getting colon cancer and charge them, or their employer, equal health insurance premiums.

That was fair for all because no one knew who would get the expensive disease, and the premium cost was based on the overall probability of some people in the pooled group needing colon cancer treatment.

The new information would pose no dilemma if both 20-year-olds were insured for life, rather than one year at a time, he said.

Insurance is like a bet on the toss of a loaded coin when no one knows which way the coin is loaded, Arrow said. An even-money bet is fair

Kenneth Arrow

times and 15 heads come up," he said. "My willingness to place an even-money bet disappears."

Some might argue that insurance companies should voluntarily ignore changing individual risk factors, he said, because "in the aggregate, large group risks are smaller than for individuals separately." However, ignoring established individual differences in health insurance would be comparable to asking auto insurers to ignore individuals' driving records, he said. Ultimately, those with lower risk would pay for those with higher risks, and insurance companies who ignored the risk factors would face a competitive disadvantage.

"In effect, if an insurance company decides to take people known to be high risk without a special premium, the burden really falls on the other insured. The question is, is that what you want or not?" he said.

"In a theoretically ideal market, the ethical dilemma would disappear by insuring people against future diagnoses," but that is not likely to be achieved by unrestricted free enterprise, Arrow said.

Government could help by enacting either of two policies:

- Creating national health insurance which would be long-term and would not tie individuals to a certain employer. There is no natural reason to base health insurance on yearly employment, he said. Lifetime health insurance for everyone would be "ethically fair and, in many ways, an efficient allocation of risk. Of course, we do know that compulsory insurance has drawbacks," particularly the lack of incentives to minimize treatment costs.
- Prohibiting insurance companies from using individual differentiation information in setting their rates. "The competitive motivation for using the information would then disappear," Arrow said.

Enforcement of the prohibition could be a problem, he said.

"I think for large companies, there's no great problem, but the problem comes around the edges for the self-employed and small firms – the ones where coverage is poor today," he said.

"There are a lot of problems with [small company and individual insurance plans], including their higher administrative costs," Arrow said. Trying to enforce a non-differentiation clause on them "gets into difficult problems with no simple an

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Representative John Davies
District 29

Sponsor Statement
HB 407
Prohibiting insurance discrimination based on genetic defects

Genetics have the potential to bring a great deal of good to human kind, through disease prevention, early detection, and new disease treatments (i.e. gene therapy). Researchers continue to narrow down the genetic indicators of diseases and as of today have identified over 4,000 single-gene disorders. A person may have predictive screenings for many of these disorders. However, a person who has a genetic marker may not ever develop the disease nor does it indicate the person's current health.

Although insurance discrimination based on genetic information is not known to be widespread, it will be a tempting area for competitive insurance companies to identify high risks and cut costs. In essence, it has the potential of becoming the 21st century's version of a 'preexisting condition.' In order to address this policy question before any abuse is widespread, I have introduced HB 407.

HB 407 prohibits insurance companies, that operate in the state of Alaska, from discriminating on the basis of gene information. Arizona, California, and Florida have similar laws.

Chapter Three
The Impact of Advances in Genetics on Insurance Policy

by
R. Steven Brown

As knowledge increases about human genes, information is becoming available that may fundamentally alter the premises upon which insurance is founded. State governments are the primary regulators of the insurance industries, and so are key players in how this technology will affect both the industry, and the people it serves.

Some have noted that advances in genetic technologies do not create new problems with the relationship between persons seeking insurance and the insurance industry, but that it is merely the newest chapter (Greely, 1992). This chapter explores the impact of new genetic technologies on the insurance industry, the effects the technologies have on individuals either covered under insurance policies or seeking coverage, and the role that state governments may play in the resolution of these changing relationships.

Persons who are familiar with the way insurance works may wish to skip ahead to the section entitled "Insurance and Genetics Information."

Insurance Principles and Types of Coverage[1]

People seek insurance to minimize financial losses that may arise from unexpected events. Policy holders who do not have a loss pay a small amount to cover the relatively large expenses of those few who do. Such a system is based on the premises that the general risk to the insured population is known, but that the risk to a particular individual is not, and that any loss (which usually must meet some test of significance) is beyond the control of the insured. The cost of the insurance is founded on the principle that the cost of insurance should be proportional to the risk involved. Individuals whose potential losses are large are expected to pay more in premiums than those whose potential losses are likely to be less.

Health, life, disability, home and/or auto insurance are those that most Americans are likely to seek or have at some point in their lives. Although at least four of these may be affected by genetic information (health, life, disability and auto), this chapter will focus on health insurance, and to a lesser extent, life insurance.

R. Steven Brown is the Director of the Centers for Health and Environment at The Council of State Governments.

Genetics and Insurance Discrimination

by
Paul R. Billings, M.D., Ph.D.

For human geneticists, these are strange and wonderful times. From a small, unpopular, unrecognized subspecialty, mostly known only to obstetricians and pediatricians, we have become the soothsayers and shamans of modern predictive medicine. The illnesses geneticists are asked to explain are more exotic and wonderful than ever before. But, underlying the media hype of the Human Genome Project (HGP) and DNA hysteria, the basic question remains the same; is what we observe and try to explain nature or nurture, from genetic or environmental origins?

The changes occurring in the field of human genetics are not just resulting in the identification of new disease factors. It is a revolution in method. Scientists now have more precise information about people's heredity, their actual DNA. Individual genetic variations can be characterized accurately and at virtually any time of life, even in fetuses and *in vitro* products of conception. The new Genetic Medicine heralds a time when this

Dr. Paul R. Billings is Chief of the Division of Genetic Medicine at the California Pacific Medical Center.

(Continued in the outside column on the following pages.)

Billings

precise DNA based information will be used to assess hereditary risk, make predictions about health in the future and hopefully result in new therapies and cures for the many intractable illnesses which afflict us.

Genetics is not that old a science, having really started about one hundred years ago. Around the turn of the century, it was already known that families differed in many ways including biologically. For example, Queen Victoria's family was unique in that the boys had hemophilia; this suggested that this disorder was linked to gender. Hemophiliac fathers never had affected children. The mothers of hemophiliac boys were always non-bleeders. When it was discovered that gender was associated with the X chromosome (females are XX; males XY), it became clear that a gene caused hemophilia, that it was on the X chromosome and was usually only detectable in XY individuals. This mapping on chromosomes of traits and diseases has been a major preoccupation of human geneticists over the years; recent advances in methods have increased the ability to conduct these experiments immensely.

The technological and information explosion in human genetics has now resulted in a massive Federal research program, the HGP. The goals of the project are to thoroughly understand our genes and make this information useful for the biomedical enterprise. HGP has many of the standard trappings of big, government supported efforts but it is also unique; it is the first scientific project to consider its social and ethical implications at the same time as it conducts its basic science experiments. Whether this new type of program will be productive and lead to more beneficial applications of science remains to be seen.

A direct result of HGP will be a proliferation of genetically based medical tests offered to the public. There are about five hundred thousand cases of the disorder called adult polycystic kidney disease in this country; there are a hundred thousand cases of Fragile X syndrome, a common form of mental retardation in males. Genetic tests can now be used in both these conditions. If DNA-based tests relevant to hypertension or common forms of cancer are forthcoming, the genetic testing industry will be an economic leader.

HGP and the genetic testing business sector will likely produce the personal genetic or DNA fingerprint. DNA fingerprinting usually refers to forensic applications of genetic technology. But these methods could be extended. As research

Brown

People obtain health insurance in one of four ways: group insurance, self-insurance, individual insurance, and publicly financed insurance (see Figure 3-1). The following material reviews each of these.

Group Insurance

People usually get group insurance as a cost-shared benefit through an employer, but this is no longer the most common form of insurance. The group sponsor, not the members of the group, is the insured party. Group insurance is a contract, is usually continuous in nature, and usually continues beyond the lifetime or membership in the group by any of the individual participants. Group insurance does not usually require medical information or other proofs of insurability by the individual members. Rather the group underwriters are usually interested in the whole group. Group underwriters will accept groups whose expected claims experience meets the standards established by an insurer for a plan of benefits and will set a rate to cover those expected costs. Most larger groups are "experience-rated," meaning that the insurer charges premiums based on the actual amount of claims payments made by the group in a prior period, usually the preceding year.

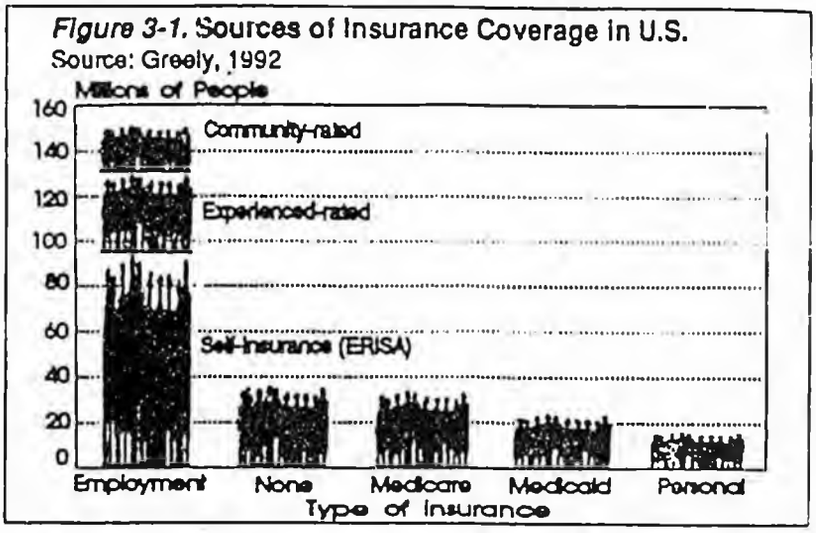

Figure 3-1. Sources of insurance coverage in the U.S. Source: Greely, 1992

The Blues

Another form of group insurance are the "Blues." The Blue Cross/Blue Shield insurance providers may appear to be commercial insurance companies, but they differ from commercial insurers in several ways. For example, most are exempt from the state laws covering commercial insurers, and are instead regulated by separate legislation (which is much the same from state to state). However, in response to growing competitive pressures, an increasing number of BC/BS plans are seeking legislative approval to reorganize themselves as mutual insurance companies.

Self-Insurance

Contrary to the sound of its name, "self-insurance" is not a term referring to policies bought by individuals (see "Individual Insurance"). People are covered under self-insurance plans through an employer, but self-insurance

are not the same as group insurance plans, differing in several very important areas. First, it is the company that is "self-insured," not the individual receiving the benefits. In this system, the company forms its own insurance pool, usually hiring an insurance company to administer the plan. Second, self-insurance plans are exempt from most state insurance law, falling instead under the oversight of a federal law originally designed to protect workers' retirement benefits, the Employee Retirement Income Security Act (ERISA).

Contrary to the sound of its name, "self-insurance" is not a term referring to policies bought by individuals.

Arising during the last 15-20 years as a competitive tool, self-insured plans offer several key advantages to employers. First, employers gain several financial benefits through self-insurance. They can use and retain earnings on amounts that would otherwise be paid to and held by insurers to create the claims reserves required by most state laws of insurance companies. Likewise, no premium taxes are applied to self-insured plans. Thus, much of the group benefits marketplace is virtually unregulated by the states. Self-insured plans need not follow any of the state laws that require health insurance contracts to include specific benefits or follow anti-discrimination restrictions applied to insured plans, need not pay state insurance premium taxes, and need not participate in state insurance pools for high-risk individuals.

The increased use of self-insurance complicates public policy on genetic information and insurance. The states have very little authority to regulate these plans, but the federal government leaves most insurance regulation to the states. The net effect is to create a public policy vacuum in the regulation of health insurance plans for self-insured companies (Murray, 1991).

Individual Insurance

Individual and group health insurance provide protection against similar types of medical expenses, but they are very different types of insurance contractually. An individual health insurance contract is one made by an insurer with an individual applicant and normally covers that individual, and, in some cases, his or her dependents. Although the health of persons applying for individual health insurance may not be much different from anyone else, they cannot demonstrate that they are a part of a well-defined, homogenous, and mostly healthy group. However, individuals are free to apply for various types and amounts of coverage.

When individuals apply for health insurance, they go through a process known as "medical underwriting," a process used by most insurers to determine whether and under what terms individual insurance coverage will be approved. The basic purpose of underwriting, from an insurer's point of view, is to assure that insured persons within each risk class have the same chance of loss and probable amount of loss. The goal of the underwriter is to determine whether and on what basis insurance can be issued at standard rates, offered at higher premium rates or with other limitations (such as excluding a specified medical condition from coverage), or whether insurance should be refused altogether. Each insurer prescribes its own range of acceptable risk selection factors.

For health insurance, age and current and future health status are the two most important risk factors. Claims costs for different benefits often vary by gender,

continues, genetic tests for hundreds of common conditions, risks and predispositions could be added to the "fingerprint." A panel of genetic assays is certainly technically feasible now and could be applied as part of neonatal or prenatal screening programs that are currently conducted by States. The goal of such programs would be to reduce the burden and cost of genetically influenced disorders on society by reducing the birth rate of affected individuals or preventing the expression of the disease trait.

Other benefits can be expected from HGP. New collaborations between the burgeoning biotechnology sector and the well-financed HGP will result in rapid advances in methods applied to questions in human genetics. Along with new genetic tests, novel pharmaceuticals may be produced.

HGP has been underway since 1988 and remains, even in recessionary times, a significant force in the biomedical research budget negotiations which occur yearly in Congress. Indeed, HGP has already announced itself a success; this presumably as a maneuver to help in the garnering of funding during the upcoming legislative year. HGP has been particularly skillful in charting the federal political process.

To conclude this brief and incomplete review of the Genetic Age, HGP can be seen as arising from a movement to genetic explanations, driven by a rapidly progressing set of technologies. The goal of this movement is to identify human genetic variations and using that information, create new ways to benefit society.

But there is a dark side to human genetics, genetic discrimination. Genetic discrimination is defined as discrimination arising from a response to actual or presumed information found in an individual's genetic inheritance. It is like other forms of discrimination, but its uses an individual's inherited genotype and characteristics as the differential mark by which to rank and stratify. It is not a new phenomenon in this country though most citizens are unaware of its existence or history. Public education on these issues often is reduced to sensational stories in *Glamour* or *Vogue*. The remainder of this paper will highlight important facets of genetic discrimination.

Eugenics

The intersection of genetics and social issues is not new. Eugenics is the pseudoscience of human betterment achieved through human genetic manipulation. It is the dark side of the science of human genetics. Modern genetics got started in Britain with Darwin and Austria with Mendel. Eugenics began at almost the same time with the work of Darwin's cousin, Frances Galton. As eugenic experiments and data accumulated, it became very popular in this country; its proponents influenced immigration legislation passed in the 1920s.

A famous Supreme Court decision written by Justice Oliver Wendell Holmes allowing forced sterilizations also reflected eugenic influences in American thinking. Holmes wrote that "three generations of imbeciles is enough" (1933) as he let stand a ruling calling for the sterilization of a woman who had given birth to several retarded children. The laws which this decision reenforced arose from the eugenists belief that certain human stock, especially those arising from central and eastern Europe was unfavorable for inclusion in American society.

Eugenics became unfashionable during the Second World War, primarily because the science was poor and as a reaction to the overtly eugenic Racial Hygiene Laws promulgated in Nazi Germany. It was revived in the 1960s when genetic screening was attempted for the genes responsible for sickle cell anemia, a disorder which in this country affects primarily blacks and some southern Europeans. The groups that were asked to undergo testing were already experiencing discrimination for other reasons — because of skin color or low socio-economic status. Genetic information derived from these programs was used as just another surrogate for prejudice and hurtful treatment — unfair apportionment of services and differential evaluations.

Discriminatory uses of genetic information are not limited to our country. Amniocentesis is used primarily for sex identification and selection in several countries including India. Recent reports suggest that forced sterilization of families, a classic eugenic strategy, afflicted with mental retardation occurs currently in parts of China. There seems to be a worldwide reemergence of eugenics (also called "ethnic cleansing"), with its hurtful siren call of genetic perfection. The modern eugenics may at times be as aggressive as its earlier forms, but also can use confusion and neglect to achieve its selection goals.

which is also a factor. Most health insurers deny any applicant whose probability of disease exceeds three times the standard risk for his or her gender and age, and most life insurers will refuse an applicant whose risk of death exceeds five times the mortality risk of a person with no health impairment (U.S. OTA, 1988). HIV infection, for example, far exceeds the limit of insurability for both life and health insurance.

The increased use of self-insurance complicates public policy on genetic information and insurance.

Applicants must supply two types of information for individual coverage: a health history and an evaluation of the current physical condition. The underwriter will give weight to a history of past illness or accident depending on the severity of the original ailment, degree of permanent impairment (if any), chance of recurrence, complications that may develop, and so on. Chronic conditions often have high costs and, therefore, large claims and so persons with chronic conditions may be refused coverage. Certain family health information may be requested about the health of relatives that may have some bearing on the applicant's health (e.g., family history of diabetes). Second, the underwriter reviews the applicant's current physical condition. Depending on this assessment, a life insurance underwriter may request certain tests or studies (e.g., blood chemistry, urinalysis, electrocardiogram), depending on the age or kinds of coverage that the applicant is seeking. These tests are rare for health coverage.

States regulate individual health insurance contracts more rigorously and in a more standardized way than group contracts. This is largely due to the view that individually insured people lack expertise about many insurance matters and are not able to negotiate the terms of contracts with the companies that specialize in this field. Some states require the advance approval of individual policies and related contractual materials (e.g., the application form). In many states, however, this approval process occurs automatically, unless the state insurance agency advises the insurance company to the contrary within a specified period.

Publicly Financed Insurance

Social programs such as Medicare and Medicaid, as well as entitlement programs like Champus, are also forms of insurance. Most of these have been created by federal enactments, which designate those eligible and the amount of funds available for the service. Of greatest interest to state governments is Medicaid, funded in part by state monies. State contributions to Medicaid have risen sharply in the last two fiscal years, and are expected to continue this trend for the foreseeable future. There has been little, if any, investigation of the impact of new genetic technology on the services or financing of these programs.

A Further Note About Insurance Regulation

Each state has enacted measures that require insurance companies to meet a variety of requirements to obtain a license to do business in the state. Laws are similar from state to state, but the exact requirements vary widely. In addition to multiple and varying financial and solvency requirements, states frequently prohibit certain types of discriminatory practices in issuing, continuing, or canceling insurance policies, or prohibit charging higher premiums solely because of certain physical handicaps such as blindness, mental handicaps,

etc., unless the discrimination can be justified by sound actuarial practice.

Many states have also adopted various mandated benefit laws. Alcoholism, drug addiction, and maternity coverage are frequently required. Some states require insurers to offer prospective buyers certain benefits, but the inclusion of those benefits in group contracts is often not mandatory.

Many states also have laws governing some aspects of group insurance contracts, such as who constitutes a group for group benefit purposes. Many states have also adopted laws requiring group contracts to contain certain types of mandatory conversion and/or continuation-of-coverage provisions, which permit members (and dependents) of a group to continue their insurance protection on an individual basis when their coverage under a group plan ceases. The continuation is an extension of the original group plan at the same premium, though the separated group members pay the full premium costs of coverage, including any employer contributions made for members still in the group. The continuation usually is for a limited time. The Federal Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985 (Public Law 99-272) has a similar provision regarding continuation of coverage.

While the McCarren-Ferguson Act (Public Law 15, 79th Congress) provides that the states have the major regulatory responsibilities for the business of insurance, several federal laws affect health benefit plans, particularly group plans. Under the federal tax code, employer contributions for health benefits are excluded from the taxable income of their employees. Legislation such as the Employee Retirement Income Security Act (ERISA), the Health Maintenance Organization (HMO) Act, and Medicare, each affect the design of many private health benefits for employees and their dependents. As mentioned above, the tax laws and ERISA were amended under COBRA to require that most group benefit plans continue coverage for workers and their dependents who would lose such protection due to job termination, death, divorce or legal separation, and for certain other qualifying events.

Why Should Genetic Information be Treated Any Differently From Other Medical Information?

Is genetic information any different from then any other piece of medical information? Some have assigned a special significance to genetic information based on a variety of historical, philosophical, and social reasons.

One argument made is that one's genetic make-up is beyond one's control, and that persons should not be punished for such involuntary conditions through denial of health insurance (Karjala, 1992). Others cite the special significance that genetics played in the eugenics movement, and in Nazi Germany. Genetics is widely thought -- correctly or incorrectly – to somehow identify the essence of what a person is.

Another argument is that genetic information has implications for other persons. For example, if a sibling tests positive for Huntington disease, all other siblings must be at a 50 percent risk for having the disease as well. The "positive" sibling may wish to keep this information private, which deprives others of knowledge about a possible serious health risk. On the other hand, the sibling may wish to warn his relatives, who may prefer not to know. Reproductive decisions may also be influenced by a person's or mate's genetic characteristics and knowledge of them.

Lastly, DNA is a very stable chemical, and samples taken for one purpose now, may be used for other, possibly unauthorized, purposes years later.

Genes and Insurance Policies

Ideally, insurance represents the efforts of a large group of payers to support the benefits required by individuals or their family members. Death benefits are paid to the survivors by those who are living. The sick collect from the healthy who finance health insurance. This is the basic tenet of insurance; there have been some important changes to the system erected on this principle recently.

An individual's experience with health care, rather than just involvement in the community pool, is increasingly used as a criterion for access to health insurance. Information contained in medical records and insurance companies perceptions of risk are crucial to a insurance system based on experience (past or potential future) and not designed to maximize pool size and cost spreading. In addition, concern with "experience" also leads to increased emphasis on prevention. It is notable that some insurance companies now subsidize preventive health protocols.

The discussion which follows is primarily concerned with issues in access to health insurance. Many of the concerns and methods described are applicable to other insurance products including auto, mortgage, disability and life coverages. The key idea is that a private business (insurers) form a community that is big enough to pay for the benefits to the individual designees and does not employ illegal or immoral practices in the conduct of its business plan.

The health insurance access system is failing in this country. There are thirty to forty million people who do not have coverage. Many of these individuals are unemployed. The health insurance system has grown less useful over the last years for those who have illness and thus most need it.

Why should our society care who has access to health care? There are many reasons: from a medical point of view, the uninsured get sick more frequently, use emergency rooms more regularly and die faster than their insured counterparts. All these phenomena cost states and counties public money.

Why is the system now in place failing? Certainly, the rising cost of health care puts pressure on payers to identify those predisposed to costly illness. But, there have also been developments in the system of health care access. For instance, health insurance has become the principle benefit

of employment. More than eighty percent of individuals who have health insurance in this country get this entitlement as a benefit of employment. Many large employers have decided to become self insurers — health insurance companies themselves. The administration of these benefit programs at the "self insured" workplace is often conducted by private insurers. The effect in terms of public policy and legislation is a blurring of employment and health care issues and problems.

Another trend in the insurance industry is a shift away from community based rating systems. No longer are rates set and costs spread over the largest possible group. Instead, the health care costs and illnesses experienced by small groups, often fellow employees, are assessed and managed. "Experience rating" of small groups often results in changes in coverage or rates from year to year. The trend can push up costs to employment based plans two to three hundred percent each year, particularly if a worker is using health insurance benefits.

In systems where experience rating predominates, employers have an incentive to identify and exclude those "at risk" for illness and workers may tend to behave like those threatened by and coping with a punitive social system. Under such conditions, "adverse selection" (an insurance term suggesting that clients with needs may buy insurance in ways which will hurt the insurance industry) may occur. The result will be that those who have insurance are only low risk, healthy people. The exclusion of the high risk makes business sense but may not be socially acceptable. One reason why the insurance industry has "redlined" and "skimmed" in this manner is the misconception that a federal or state safety net is provided by Medicare or Medicaid. Unfortunately, these programs are not working well either. More and more people are suffering from problems at the interface between the state safety net and the private sector health insurance system. The solutions to these situations require broad based political action to direct both government and the business sectors.

In summary, experience rating and the self insured employer represent new developments in the health insurance system over the last twenty years. Because of rising costs, problems posed by these innovations have been apparent. The system tends to insure only the best risks and assessment of risk can be viewed as a new technique to achieve business goals.

Insurance and Genetics Information

Although health and life expectancy are based on more than just a person's genes, information about the genetic make-up of a person potentially alters the basis of insurance in very fundamental ways. There is no consensus on when it is appropriate to use genetic information to determine eligibility for insurance coverage. Neither has it been easy to study the effects of genetic information on either adverse selection or unfair eligibility denials (House Committee, 1992). On the other hand, insurers can say that they would not want genetic information at all, if neither their applicants nor their competition has it (Karjala, 1992). That is, insurers see nothing broken that genetic testing would fix, only that genetic testing will complicate insurance matters (Bier, 1992).

States have variable procedures for ensuring the quality of clinical testing and there is no agreement on uniform procedures for doing so among the states.

Insurance is based on the expectation that, for the most part, risk is shared equally among all persons who purchase the insurance (the risk pool). The industry has some tools available to it to differentiate risk, for example medical and family history (a kind of genetic test), and behavior (i.e., whether the person smokes).

There is no consensus on when it is appropriate to use genetic information to determine eligibility for insurance coverage.

Genetic tests potentially change the basis of risk by providing information about an individual's risk for many medical conditions. The more precisely a person's genetic potential for various diseases and conditions is known, the more precisely an insurer could identify the risk of insuring that person. Carried to its logical conclusion (in which an insurer knows everything about a person's genetic risks), only persons with reduced risks of major diseases would be eligible for affordable insurance, and they would be the persons least likely to want to apply or to need it.

On the other hand, extensive information about people's genetic make-up may only reveal that most persons are genetically at risk for one disease or another on a relatively equal basis. In such a scenario, the basis of risk might remained equally shared, if insurers did not differentiate against the specific risks of specific persons. In addition, insurers will presumably only want to use genetic information if it gives them a competitive advantage.

For example, suppose a person wishes to apply for individual insurance. This applicant's family has a history of heart disease, but the applicant shows no medical history of heart problems and has appropriate behaviors (does not smoke, is not overweight, etc.). Such a person is not likely to be considered at an abnormally high risk for heart disease. However, suppose

...extensive information about people's genetic make-up may only reveal that most persons are genetically at risk for one disease or another on a relatively equal basis.

the same person undergoes a genetic test and finds that he carries a gene that is identified with life-threatening heart diseases. For this example, let us suppose that the person's physician advises him that he is at six times the normal risk for heart disease than the general population. This information, if revealed to the potential insurer, might jeopardize the applicant's eligibility or might raise the cost of the insurance.

Families might even avoid medically beneficial treatments and testing from fear that test results might precipitate the loss of insurance coverage. Testimony before Congress by representatives of the National Society of Genetic Counselors, Inc., cited an example of two families affected by adult onset polycystic kidney disease (see Chapter Two). These people refused to consent to renal ultrasound and/or DNA testing for family members known to be at a 50 per cent risk of having the kidney disease, for fear that if the diagnosis was confirmed they and eventually their children would become uninsurable (House Committee, 1992).

Why would an insurer want genetic information about an applicant? In short, underwriters will use this information like other data they use in the underwriting process. These data might include tests like electrocardiograms, blood sugar, urinalysis and so on. Along with personal and family medical histories, these factors are evaluated, and their potential impact on longevity and health are estimated. This information is used to determine how much risk the applicant entails to the overall insurance pool. The applicant's rates, or those of his employer, might be adjusted up or down to account for this risk.

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Genetic information would be one additional piece of risk classification information. Genetic information could be used to find whether a person was at low risk or high risk of heart disease, hypertension and so on, provided the genetic test has been developed. With this information, an insurance company may be able to set risk more precisely, which could determine in which risk pool, if any, an applicant should be placed. If one insurer can garner an economic competitive advantage over other insurers because of the use of genetic tests, other insurers will be more likely to use the tests to reduce the competitive advantage.

There is disagreement about what outcome might occur in this scenario. Some believe everyone will be worse off because of the use of this information -- insurance becomes less available (some people are excluded because of test results) and insurers can do nothing to improve their insurability (Karjala, 1992). Others believe that some people will be better off (because they tested negative for a disorder and got a clean bill of health), or will be unaffected (Bier, 1992).

To date, advances in genetic knowledge and testing have been limited mostly to those genetic characteristics caused by a single gene. These "monogenic" characteristics affect far fewer people than the diseases caused by a combination of genetic and environmental causes. These latter "multifactorial" diseases include most cancers and heart diseases, the top two causes of death

The Role of Genetic Testing in Risk Classification

There are various types of genetic information which are being included in the insurance system, including family history data, biochemical testing (for example, cholesterol screening), chromosomal and DNA analysis. A problem with the use of such genetic data in the insurance industry and especially for the establishment of risk categories is that there is little or no data concerning how good a predictor genetic information is for the cost of a clinical illness. There are many examples of people who have inherited a gene which can cause a debilitating and costly illness but who are well and may never experience health problems. These situations are in fact the rule not the exception.

Similarly, many people can inherit a gene which causes a severe illness but are treated (often by diet or other cheap interventions) and so never get sick. The inescapable conclusion is that genetic traits and disorders are not inevitably expressed or always severe. Much more research of the predictive value of genetic testing is necessary before its use in a wide range of clinical and non-clinical situations is justified.

Nonetheless, genetic testing and information making a greater fraction of the population undesirable to employers and insurers is expanding. It is creating with other kinds of testing a class of people called the "asymptomatic ill" — individuals who are treated as if they are ill by social agencies but who do not identify themselves as sick. As this group enlarges, a whole underclass identified by genetically based methods (like a newborn genetic fingerprint) will come in to existence. Members will not be entitled to the full range of social benefits.

Already, there are some genetic diagnoses which are entirely incompatible with the ability to purchase private health insurance. If a client is labelled by a genetic test or diagnostician as affected, access to coverages are curtailed. This list includes Huntington disease, sickle cell anemia and muscular dystrophy, for example. These are genetic conditions for which DNA type tests exist. The process that labels someone as "uninsurable" might simply be undergoing a genetic test or inquiring of a professional about genetic information.

Types of Genetic Discrimination

What kinds of discriminatory practices are currently occurring which use genetic information? A few examples can illustrate the problem:

A Californian told me that his son had recently had a seizure and was found to have a genetic disorder which most people associate with the "elephant man" — neurofibromatosis. This condition occurs in about one in three thousand people in this country. The child had a severe manifestation. During the child's hospitalization, the family had a disagreement with their insurance company over payment of benefits. The father was subsequently examined, and found to be a fifty year old asymptomatic carrier of the neurofibromatosis gene. He had never had health problems despite the fact that he carried the same gene that caused seizures in his son. After his genetic examination, the father was disqualified from obtaining private health insurance. The healthy children in his family were also uninsurable. The family was later covered by an HMO. These organizations do not generally use underwriting for eligibility and use genetic information differently (caps and limits) than private health insurers.

Another individual graduated from a police academy in the Midwest and applied for a position with a department in a local community. It became known to his prospective employers that the applicant's family had a history of Huntington disease. The department stated that the job offer was contingent on the new recruit undergoing testing for the genetic disorder. Such a request may be currently illegal or unfair, but occurs.

A woman had a nephew who had cystic fibrosis (CF), a common genetic disorder. She, by membership in her family, is more likely to carry a gene associated with CF.

Thus, if she marries someone else with the gene for cystic fibrosis, that couple could have a child with cystic fibrosis. She wanted to know whether she did in fact carry the gene for cystic fibrosis or not. She called up her local clinic in the small town where she lived and had a discussion about whether she could get tested for cystic fibrosis. The clinic said it did not perform the test very often but that it could be arranged. She said fine and forgot about it. She then got married. Her husband got a job at a local television company. The company used that clinic as their group health provider (PPO). A few days later an individual from the PPO called and asked the woman if she was the person who

in the U.S. As more information about multifactorial diseases is obtained, and if genetic tests are developed for these diseases, the problems discussed above will become of much greater concern and importance, primarily because of the economic impact to both insurers and the insured (Karjala, 1992). Chapter Two lists several common, adult diseases, including heart diseases and cancers, for which genetic testing is expected soon or is already available. Many people believe it would be unfair that persons should risk loss of insurance based on the results of genetic testing for common disorders, when the test was taken for the purpose of helping them promote their health.

If one insurer can gamer an economic competitive advantage over other insurers because of the use of genetic tests, other insurers will be more likely to use the tests to reduce the competitive advantage.

Other reasons for concern about how insurers may use genetic information are the factors insurers consider in deciding when to use new information. These factors include the cost and difficulty of obtaining the information, medical validity, competition from other companies, the number of diseases for which tests are available, and the cost-benefit to be derived. At present, these factors are unfavorable, so insurers are not likely to use genetic testing. Some believe it likely that this will change soon. The costs of testing will decline, possibly sharply; predictive value of the tests may increase; competition may intensify as some companies see a competitive advantage in using genetic predictors; and the cost-benefit ratio of genetic testing will become more appealing and insurers are likely to use them (Murray, 1991; OTA, 1988). The insurance industry disagrees that much change is imminent (ACLI-HIAA, 1991).

Many people believe it would be unfair that persons should risk loss of insurance based on the results of genetic testing for common disorders, when the test was taken for the purpose of helping them promote their health.

Adverse Selection

"Adverse selection" occurs when the persons seeking insurance will be those who will use it the most; that is, those with a greater than average chance of loss. Such a situation might be expected to occur when an individual is aware of a potentially expensive medical problem, but knows that the underwriter will not likely be aware of this problem. This is of concern in both group and individual insurance markets, but particularly in the latter. Because coverage under a group insurance plan is usually based on employment, adverse selection is less likely to be a problem. For example, group insurers usually write coverage only for groups that exist for reasons other than for the purpose of obtaining insurance. There is a flow of members into and out of such groups, so the average age and therefore the average risks of these groups do not change much over time. Employer-based groups are especially attractive to insurers, because employees whose health is good enough to meet employment standards are generally better-than-average risks for insurance purposes. (Adverse selection should not be confused with unfair discrimination. See "Unfair Eligibility Denial" below.)

Adverse selection is a greater problem for the individual market. Although most applicants are seeking coverage for the costs of unknown or unpredictable diseases, some applicants are especially motivated to get insurance, because they know they may have a higher than average chance or even a certainty that they will require medical treatment.

The insurance industry generally believes that adverse selection is a genuine concern, with serious implications for the ability of the industry to deliver its product to consumers.

This situation might be expected to happen for some genetic conditions if genetic testing becomes more prevalent, and if insurer access to the medical information is denied. On the other hand, many genetic conditions are not likely to result in significant adverse costs to an insurer.

The insurance industry generally believes that adverse selection is a genuine concern, with serious implications for the ability of the industry to deliver its product to consumers. Insurer efforts to avoid adverse selection may also threaten the access to insurance of consumers with some genetic characteristics who now may be able to get insurance.

According to the American Council of Life Insurance-Health Insurance Association of America (ACLI-HIAA), actuarial experts determined "the costs of adverse selection would vary widely depending on the particular disease, but that the cumulative cost of adverse selection for the total spectrum of genetic diseases could be quite significant...and the amount paid out in insurance claims could increase substantially and the result would be higher premiums for most policyholders." (ACLI-HIAA, 1991).

Insurer efforts to avoid adverse selection might also adversely affect persons who already have insurance. For example, suppose an insurer uniquely accepts persons with a certain genetic characteristic with relatively high claims, but whose total numbers are low enough not to have any significant impact on the claims of the company. Now suppose a genetic test for this condition becomes available for expecting parents, some of whom test positive as carriers for the disorder. Faced with the knowledge that they may be at risk for having a child with this disorder, they seek insurance coverage from the only company who will cover the condition. As this hypothetical test becomes used more and more, more persons testing positive seek coverage with this company. Eventually, an increase in claims faces the company, which must either refuse additional applicants, or raise premiums, or both. Additional genetic information has resulted in reduced coverage.

Of course, some persons submitting to genetic tests in this scenario will test negative. These persons now know their offspring will not be affected and so remove themselves from the group of persons who might be creating adverse selection. They become insurable on the same basis as everyone else.

Adverse selection may be most troublesome to the life insurance industry. Most persons view health insurance as more of a need than life insurance, and so persons seek health insurance on a routine basis. Life insurance, however, is generally viewed as less necessary. However, for a person who knows with some certainty that he or she will die before age 40, life insurance at ordinary rates becomes a bargain, even if one's beneficiaries are the only ones who will enjoy the results (Karjala, 1992).

had called about a year ago about the test for cystic fibrosis, to which she said yes. The PPO said, "We won't be able to cover you or your husband until this issue is resolved; until we know whether you are a carrier and whether your husband is a carrier." Now this is obviously a difficult and somewhat threatening process. These people were going to be without any health insurance at all until this issue was resolved. They went to the state health insurance board. Six months later the issue was resolved in their favor.

But this outcome might not be expected for everyone. They were very determined advocates for themselves. They spoke English, they could get a lawyer, they could write threatening letters. They did end up getting their health insurance, but they went six months without it, and if they had gotten in a car accident or had some other serious health problem, that family's finances would have been wiped out because of the health care costs.

Similarly, a genetic counselor told me that a woman with a disorder called adult polycystic kidney disease was pregnant. She had decided that she would like to know whether she had the gene for the disease, which can be determined by fetal testing. She went to her HMO and said that she would like to have this test done. They thought about it for awhile and said, "We won't pay for this test unless you tell us what you are going to do with that information. If the child is going to be affected with this disorder, we would like you to act on this information – in other words, to terminate that pregnancy." The HMO said it would withhold payment unless she agreed to that procedure. Of course, she fought that ruling. After some legal wrangling, the HMO recanted. Still, this is the kind of misunderstanding about appropriate use of genetic technology which is occurring in our insurance system.

My research has identified these as the major sites of discriminatory practices around genetic information:

1. Employment, both in the public and private sector
2. Access to social services, public and private sector.
3. Insurability, including life, disability, health and auto.
4. Health care.

There are other issues involved in the insurance industry using genetic information.

Billings

The insurance industry has a long tradition of sharing data among companies. There is a privately held national database called the Medical Information Bureau. Life insurers, primarily, but also health insurers, put people's records and health data -- 20 million Americans -- in the Bureau. That information is about your health and can limit your ability to have life or health insurance. Likewise, many Americans arrange private health insurance (that is, health insurance obtained by a source other than the employer). Usually they buy a policy from a local individual, the insurance agent. The insurance agent might sell you health, life, auto and mortgage insurance. That individual has a lot of information about you. Here is another actual example of how that information can hurt you.

An individual had applied for life insurance through his local agent. He had been known for 20 years to have a very mild manifestation of a genetic neurological disorder. He had been working and never really had any medical problems, but a clever physician had identified this disorder. The person applied for life insurance. This disorder does not have anything to do with life expectancy. He was accepted for life insurance, but it became known to his agent that he had been labeled as having this genetic disorder. The insurer canceled his auto insurance. His doctor wrote letters to the auto insurer saying there was no medical reason for this action, that the person had always had this trait, and that there was no medical reason to cancel the policy. The insurance was lost because the agent was the nexus of the information from the life insurance policy to the auto insurance process, and saw to it that his companies were protected before his client.

Gene Therapy

Gene therapy is an experimental treatment where the gene causing the disorder is modified directly. There have been many proposals for how we might conduct gene therapy for cystic fibrosis and other kinds of disorders. Gene therapy is a costly procedure as it is done now, and is still in the testing stages. Even if we reduce the cost, it is still going to be costly. Furthermore, it is going to exaggerate the difference between people who can afford and get to have these costly therapies and those who cannot.

Not so long ago there was a news story entitled "Man Needing Transplant in Blue Cross Dispute." This fellow had a genetic disorder and needed a transplant. His insurance company was disputing

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Unfair Eligibility Denial

There is unmistakable evidence that genetic information is misused in determining eligibility of applicants for life and health insurance.

"Eligibility denial" is a term used in Congressional hearings for irresponsible behavior by the insurance industry in denying coverage to an applicant (House Committee on Government Operations, 1992). It should be noted, of course, that insurers are not obligated to find each applicant eligible and there are legitimate reasons why insurers deny coverage. We have therefore modified this term slightly to include the word "unfair." Unfair eligibility denial occurs when an insurance company denies coverage to an applicant for no actuarially sound reason.

There is unmistakable evidence that genetic information is misused in determining eligibility of applicants for life and health insurance. Researchers recently found 32 cases of unfair practices, including the following cases:

- A woman who questioned her physician about the possibility of Huntington disease in her mother and later lost all her insurance when she applied for life insurance and her medical records were reviewed.
- A man with a mild, stable, and barely perceptible genetic characteristic applied for life insurance. His doctor attested to his good condition while sending his medical records to an insurance broker who serviced all the man's insurance needs. His life insurance application was rejected, as was his auto insurance, even though he had not had a traffic ticket or accident in 20 years of driving. Worse, his occupation was traveling salesman.
- Whole families are excluded from insurance when it is revealed that one male member of the family has a genetic form of mental retardation, even though there is no other effect on his health, and no significant manifestations of the condition in the women of the family.
- Upon changing jobs, the father of a girl with phenylketonuria (PKU) was denied coverage under the group insurance plan due to her "high risk," even though the child was developmentally normal, and her condition was treated by diet.
- Individuals with mild, remitted, or treated genetic traits or conditions may have records in national databases such as the Medical Information Bureau, Inc., and are usually unaware of its existence, or correctness, but may not be able to get insurance because of it. (Billings, 1992).

The validity of these cases, and the research methodology used in compiling them, is challenged by insurers (Bier, 1992). Although the researchers pointed out that these cases do not necessarily show the prevalence of discriminatory practices by insurers, they also point out that the cases cited do not necessarily document the full range of the prejudices faced by individuals with genetic diagnoses.

The U.S. Office of Technology Assessment surveyed 225 commercial health insurers, 72 Blue Cross/Blue Shield plans and 50 health maintenance organizations (HMOs). The purpose of this survey was to find out what the policies and attitudes of these organizations is regarding the present or future use of genetic information in underwriting (for individual health insurance policies) and reimbursement. These results indicate a distinct likelihood that genetic

information is or will be used to deny insurance to applicants. For example, 17 of 29 commercial insurers would decline an individual applicant who had tested positive for a pre-symptomatic serious, chronic future disease. The same was true for 11 of 25 Blue Cross/Blue Shield plans. Of the 11 HMOs that cover individuals, four would decline the applicant. A similar trend occurs when risk-oriented testing or carrier testing information was provided. Prenatal diagnosis of a serious, chronic disorder would cause 19 of 29 commercial insurers, 14 of 25 BC/BS plans, and four of 11 HMOs to decline coverage to individual applicants. Although not all insurers indicated they would decline coverage, most would. The prevailing attitude among insurers is that genetic information should not be treated any different than any other medical history information (U.S. Office of Technology Assessment, 1992).

Photo credit: The Council of State Governments

A federal government task force exploring these issues has noted that improved understanding among underwriters could reduce the number of baseless rejections -- that is, where there was no reason to expect that the individual was likely to be ill or die prematurely. But those individuals who do carry detectable genetic risks could still be rejected or charged higher premiums according to the definition of fairness used by the insurance industry. Education, then, might fix one problem -- mistaking inconsequential genetic conditions for severe ones -- but at the cost of possibly exacerbating another -- diminishing access to insurance for people at increased risk of significant disease (Murray, 1991).

One principle that has been used concerning other insurance issues is that of basing rates on factors under the individual's own control. The guiding premise of California's Proposition 103 is that auto insurance rates should be based upon factors within the individual's *own control*, such as safety and driving habits, rather than upon factors difficult or impossible for a motorist to control, such as age, gender, and, particularly for low-income individuals, one's place of residence (Rosenfield, 1992).

Genetics and the Dynamics between Insurers and the Insured.

The following sections examine the dynamics between the needs of insurers and the insured in an era of new and expanded medical information based on advances in genetic technologies.

A Corporate View of Adverse Selection

Adverse selection, also known as anti-selection, is a consideration that is of great importance to insurers. Adverse selection is a well-known phenomenon in which people with a likelihood of loss greater than what they are charged for tend to apply for or continue insurance coverage to a greater extent than do other people. It occurs when applicants withhold significant information from the insurer and/or choose amounts and types of insurance that are most

the need to pay for this transplant, saying that he knew all along that he was going to need this kind of therapy and that he had tricked them into insuring him and thus having the responsibility for paying for this disorder. But the fact is, this guy needed the very costly therapy to survive. This illustrates some of the inequities.

Likewise, as we start gene therapy, who is going to pay for the mistake when we do gene therapy and change a gene (for the worse) as well as correcting the problem gene? We may create individuals who have new kinds of illnesses. Who is going to pay for that? Should we expect people with genetic disorders to seek gene therapy? There may be people who are genetically predisposed to drug addiction or to alcoholism. What if they don't stop drinking? Are we going to say we are not going to give them any health benefits because they are not acting responsibly toward their genetic constitution? Are they going to be excluded from our health and insurance safety net because they refuse gene therapy to correct this situation? This is an important and difficult area of public policy concern.

Privacy

What are the solutions to the problems that I have been talking about? One of the solutions is a restatement by our society that each of us has a right to privacy. This means that organizations shouldn't be storing private health information about us that we don't know about and don't have control over, and that we have access to health and to safety no matter what our health condition -- or genetic constitution -- is.

Similarly, we need a public education policy that has to address what genetic information can and cannot tell us about normal human variation. We all vary in different ways. Some of our variation can be explained by genetic explanations and some by interaction between the individual and the environment. Such a message will increase public awareness about what the limitations as well as the prospects of the Genome Project and genetics really are. And this gets at the issue that ignorance is the root cause of much of the prejudice and discrimination that we see over a lot of the issues, including genetics.

Legislation

One of the final issues is legislation. Whatever legislation is present now at state and federal level does not appear to be working to protect individu-

als from unwarranted discrimination by the insurance industry. It is very easy for someone like me to find cases where people are being hurt by the way the system is working because they do not have access to legal relief the way the system is currently concocted. The Americans with Disabilities Act was thought to be a very big advancement for protecting people through the employment process. As the regulations have been promulgated, the act will probably not have that big an impact on issues of testing, particularly genetic testing, in terms of protecting people's access to employment and thus to health insurance.

California considered a bill that passed both the Senate and the Assembly before being vetoed by the Governor. This bill defined genetic information as a civil right in the state of California, much as other kinds of civil rights. It says, for the purposes of employment, for the purposes of group life and disability insurance, and -- for eight years -- for the purposes of writing health insurance, genetic information cannot be used as a criteria for access to those "rights" within the state of California.

What I think is particularly useful about this legislation is that it takes genetics out of work law and puts it squarely in the public civil rights tradition where I think this kind of issue really belongs.

In conclusion, we don't want to be controlled by our technology. We want the technology to be for our benefit and we want to exert our normal social controls as to how this technology is applied. In the field of insurance public policy is that insurers can't discriminate on the basis of gender or race. I think there is a movement to say we don't want insurers to discriminate on the basis of one's genetic constitution either.

Questions and Answers

➤ *Audience Comment:* The state of Massachusetts insurance department has proposed to collect incidences of insurance discrimination based on genetics makeup of the people involved. As I understand, that is the only state in the country that is going to methodically seek out that sort of information.

➤ *Dr. Hanson:* In the regulations issued pursuant to the Americans with Disabilities Act, the Equal Employment Opportunity Office has chosen to ignore the questions that were raised with them about genetic issues. In one area, dealing with

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beneficial to themselves. If the insurer is unaware of (or prevented from) getting important unfavorable information from an applicant, serious errors in risk classification can occur which would adversely affect the entire insurance pool.

A sound risk classification system for an insurance pool should be based on four principles:

- 1) Risk classification should reflect cost and experience difference. For example, employers of coal miners should pay more for unemployment insurance than employers of computer technicians because coal miners historically have much higher rates of unemployment.

- 2) The system should be applied objectively and consistently. For example, males of the same age and similar health histories should be charged similar rates for life insurance.

- 3) The system should be practical, cost-effective, and responsive to change. This means there are limits on how many resources can be directed toward classification of a risk, and it also means that systems are dynamic and can be changed. For example, when polio was no longer a public health hazard, insurers changed the system to reflect that development.

- 4) Anti-selection should be minimized. The system should limit the ability of an applicant to take an unfair financial advantage at the expense of the insurance company or policyholders.

-- After Pokorski, Robert J. "Genetic Advances: The Perspectives of An Insurance Medical Director," unpublished manuscript dated November 9, 1991.

The Relationship between Genetic Testing and Adverse Selection

For the purposes of discussing adverse selection, genetic tests may occur when either a patient's physician orders one, or when a potential insurer requires one for determination of eligibility for a policy.

In the former case, adverse selection occurs when a patient receives the test results, and after counseling decides that he or she is at higher risk for an adverse health condition associated with the test. To reduce the potential financial impact of this risk, the patient then seeks additional or different life or health insurance tailored for his or her potential needs. The patient (now the applicant), however, declines to share this risk information with the insurer, fearing that the application would be rejected. The use of genetic tests in clinical settings is increasing (see Chapter Two), but it is still unclear whether adverse selection based on the results of genetic tests is yet a significant problem for the insurance industry.

In the second case, an insurer may require an applicant to undergo a genetic test or tests for the purpose of assessing the applicant's risks. These sorts of genetic tests may result in an insurer declining coverage to the applicant, or offering a plan at a high premium. As "adverse" as such a result might be to

the applicant, such a decision is not "adverse selection" as the term is normally used. Life and health insurers have stated that their use of these tests for determining eligibility is "highly remote at this time" (ACLI-HIAA, 1991). The reasons why these tests are likely to be used at this time are given elsewhere in this document. Insurers believe that they should be allowed access to this information to assess an applicant's risk more accurately and to determine the applicant's eligibility and rates.

What Is a "Genetic Test"?

Genetic tests range from the scientifically precise (e.g., direct molecular manipulation of genetic material) to the historical (family histories). Each has its place in the repertoire of the various disciplines which use genetics information. Medicine is likely to use all five of the following broad categories of genetic tests. Forensic scientists are likely to use all but family history. The insurance industry is likely to use family history, and less likely to use the other tests, although does do so. States seeking to enact legislation which require a definition of genetic tests are encourage to consider the information in this section carefully.

1. Direct and Indirect determination of altered DNA composition, using molecular genetic techniques.

Researchers can carry out studies on DNA using blood or other cell samples. In those cases where the precise nature of the mutation that causes a condition is known, a direct probe with the appropriate DNA molecule can indicate whether the person has that mutation and whether he or she has one or two copies of the mutated gene. For any disease or condition, more than one mutation in the population is always responsible. That is, people suffering from the same disease (e.g., cystic fibrosis) will often carry different mutations in the "cystic fibrosis" gene. So, to determine whether an individual is a carrier for cystic fibrosis, many different DNA probes must be used to avoid false negatives as much as possible. In fact, it may be impractical to do large-scale screening for cystic fibrosis and avoid missing 5-10 percent of carriers. This is because so many different mutations in the "cystic fibrosis" gene can give rise to the disease that not all can be found. On the other hand, if someone being tested comes from a family in which there is a history of the disease, then the precise nature of the mutation in that family may be known. In this case, DNA tests would allow direct determination of whether that man or woman carries the mutation.

A second way in which DNA tests can be used to detect the presence of mutations is by linked markers. In general, this can only be done within families. If a genetic marker is found on the chromosome that tends with high probability to segregate with the disease in a family, then this can be used to predict with high probability whether a family member has the gene for the disease. For instance, the gene for Huntington disease has not been found yet, so the precise nature of the mutations responsible is not known. However, a marker has been found on Chromosome 4 that is close enough to the "Huntington disease" gene so that nearly all members of a family who have the disease have the marker. Nevertheless, since the marker is not in the gene itself, an individual will occasionally be born with the disease gene but without the marker. That is because of recombination (see Glossary). The reverse is also possible; a person may be born with the marker but not the disease gene. Thus, there will always be certain probabilities of false negatives and false

employment practices, the regulations say that a potential employer cannot withdraw an offer of employment based on a person's medical problem unless the employer can show that it would be directly job related. But the government chose not to deal with the issue of how genetic factors might be used in denying even already-offered employment. There was some concern that employers might choose applicants that they thought were most desirable and then mandate that they have certain kinds of medical tests done as a condition of employment. They might uncover information that might affect that person's employment status.

➤ *Audience Comment:* One way of putting this is that we used to have a health insurance system based on shared risk because nobody knew what their shared risk was for most medical conditions. Now we have tests for some of these genetic conditions and we can remove that shared, but unknown, risk and now have individuals where we know their individual risks. There is then a tendency to exclude those people from health insurance. Unfortunately, the public policy result of that is that they eventually fall on the public health funds like Medicaid to pay for their problems.

➤ *Audience Comment:* Other than for accidents, the logical extension of the Human Genome Project is that we will find that all of us carry a number of deleterious genetic factors and the logical extension is that nobody can be insured. No one has "perfect genes."

➤ *Dr. Billings:* Genetics testing will find certain genes that are more common in Jews or blacks or other groups and, in a worse case, this information will be used as a reason to justify differential treatment.

On a practical basis, more and more physicians like me are refraining from submitting people for medical testing until we know their insurance is taken care of. Or we don't put a diagnosis in the chart when we know that chart can become part of an insurance rating process or database.

As far as what genetic information is concerned -- you can cast your net very widely or very specifically. The insurance industry says that it doesn't really care about genetic information. The number of people with genetically caused illnesses is the same in this society as it was 50 years ago. If they cast their net widely enough, they can factor out the cost of genetic illnesses.

➤ *Dr. Hanson:* One of the unique things that genetic knowledge does add to the equation is what testing one person tells about other people, namely relatives. If I have a test done, the information has implications for me, but it also says something about my parents and my offspring and cousins and aunts and others. The sharing of that information can have consequences for others that are often not intended.

➤ *Audience Question:* Did the health insurance industry oppose the California bill?

➤ *Dr Billings:* They opposed it at the beginning, but when we agreed for a ban on the use of genetic data for only eight years, they dropped their opposition because they felt that in eight years we'll know more about genetics and how these tests should and should not be used for health purposes. Also they are hoping for federal relief over this issue of health coverage.

In terms of health insurance behavior and the use of genetic information, there is a great deal of variation from state to state. California has a lot of laws relating to this behavior, but other states have virtually no laws relating to this.

positives when this technique is used. But, picking markers that are very close, or using two markers that surround the gene in question, can reduce the false results to a very low frequency.

2. Examination of chromosomes by microscopy.

Again, by obtaining a blood sample or a sample or body cells (e.g., skin), researchers can readily analyze the chromosomes of an individual with a microscope. Such analysis allows the detection of a number of conditions that are due to an abnormal number of chromosomes or to chromosomes with aberrant structures. These include Down syndrome (an extra copy of Chromosome 21); Turner syndrome (females missing one X chromosome); or Klinefelter syndrome (males with an extra X chromosome). Fragile X syndrome, which causes mental retardation, can be detected in some cases by examination of chromosomes, but recently a DNA test was developed for this condition.

3. Chemical, immunochemical or biochemical analysis.

A number of genetic conditions can be detected by measuring chemicals or enzymes in the body. Phenylketonuria is ascertained by measuring the concentration of phenylalanine in the blood. Included among other conditions that can be analyzed in this way are galactosemia, Tay-Sachs disease and hypercholesterolemia. These tests can be done prenatally or postnatally. Such genetic tests have been done with various groups including married couples, single people, pregnant women and certain ethnic groups.

4. Medical or physical examination.

If a genetic disease can be diagnosed directly from medical examination, then the diagnosis itself provides genetic information. For certain people who have neurofibromatosis, the symptoms are quite characteristic; a diagnosis of that disease can be made with high certainty. Since neurofibromatosis has been shown to be genetic in all cases studied, the diagnosis can be said to have revealed a genetic disease. A number of other conditions, including von Hippel-Lindau syndrome and tuberous sclerosis, can be specified with confidence from medical examination.

5. Family history.

Since genetic conditions can run in families, family histories can be indicators. For instance, if, in a family, a number of men have died from heart attacks before age 50, it is likely that a genetic susceptibility to heart disease runs in the family. Similarly, if many women in a family have died from breast cancer, a disease-free woman member of the family is at higher risk than the general population of developing the disease. Thus, family histories can be used to help determine risk.

Even though family histories can help in assessing risk, they cannot say which of the family members will contract the disease and which will not. This is one important difference with genetic tests. Since Huntington disease is a dominant genetic condition, one can predict that, on the average, one out of every two progeny of a person with Huntington disease will themselves suffer from the disease. Thus, from family history one can only say that each child in such a family is at 50 percent risk of developing the condition. In contrast, a DNA test, in principle, can say with fairly high accuracy which of the children will -- and which will not -- develop Huntington disease.

Brown

Anderson, Betsy, Jonathan Beckwith, Rob Bier. Memorandum to National Institutes of Health's Ethical, Legal, and Social Implications Program's Task Force on Insurance. May 31, 1992.

A Debate: Will Genetic Information Affect a Person's Ability to Obtain Insurance?

NO: There are several reasons why we should not expect that genetic information will affect many people's access to private health or life insurance.

First, most of the health insurance and 40 percent of the life insurance obtained in the U.S. is from employers. In these cases, insurers do not usually do individual underwriting.

Second, for the smaller group of people seeking individual private health insurance policies, insurers will have little reason for conducting genetic tests. This reduces a small group to an even smaller group. From that group, even fewer are likely to get information from a genetic test that would adversely affect their eligibility for private insurance. A few might even get information that will *increase* the likelihood of coverage (for example, they might find out that they do *not* have an adverse genetic condition that is known to occur in their family).

Third, much information about genetic conditions is already obtained through means other than DNA-based genetic tests. These means include physical examination, biochemical tests, chromosome examinations, and so on.

Finally, the cost of the genetic tests may be too high for insurance companies to use routinely anyway. Companies are not likely to require genetic tests costing a hundred dollars or more for every applicant, if the total cost of all tests on all applicants will exceed the loss from additional risks of a few applicants.

YES: There are two major reasons why we should expect that genetic information will adversely affect many people's access to private health or life insurance.

First, there is no reason to believe that employers are bound to extend health insurance coverage to an employee. For example, an employer can undergo a technique known as "churning." Churning usually occurs when an employee has a medical condition that results in the insurer raising the employer's insurance rates substantially. The insurer then offers open enrollment for a "new" insurance plan at the old (lower) rate, with the caveat that the new plan does not cover the ailment in question, or covers it for a very low amount. Most employees jump to the new plan, leaving the old plan only for the employee whose ailment is covered only by it. Because most employees have to make an insurance co-payment, this one

Photo credits: The Council of State Governments

employee's co-payment is now so high that he or she can no longer afford it. Employees with genetic conditions which are expected to have significant adverse health effects are at risk for this practice.

Some states have banned the practice of churning. Another way employers and insurers avoid covering certain employees is to "self-insure." By providing its own insurance pool, an employer falls under the federal Employee Retirement Income Security Act (ERISA). ERISA "insurance" is exempt from state insurance laws, so an employer can drop its insurance plan, retain the same insurer as the "administrator" of its ERISA plan, and set whatever limits to coverage it likes.

Another way that employees are excluded from employer-provided insurance is via "pre-existing conditions." These conditions supposedly are medical conditions for which the employee was undergoing treatment before joining an employer-provided health care plan. However, pre-existing conditions have been expanded to include all sorts of "medical conditions." For example, for some women over 40, age alone is a pre-existing condition for risk of Down Syndrome (a genetic disorder). This situation has been used as a reason why an insurer would not pay for an amniotic cell culture/test to detect Down Syndrome in a fetus. On the other hand, otherwise healthy women age 33 and 34 having a child for the first time have been denied coverage for the test because their insurer felt there was no risk for Down Syndrome (Cable, 1991).

For these reasons, arguing "individual underwriting does not occur for employer-provided insurance" is moot. Individual underwriting may not occur, but individuals may be removed from coverage by other means.
The second reason we should expect that genetic information will affect many people's access to private health or life insurance is a multiple chain of events: 1) insurance companies would like the information to pinpoint risks, 2) more molecular genetic tests are being developed, 3) more of these tests will likely be conducted for medical practice reasons, 4) insurance companies do and will have access to this data, 5) underwriters do not understand specialized medical data and will likely use it to exclude applicants. Each of these reasons is discussed in the following paragraphs.

The first reason (insurance companies would like the information to pinpoint risks) is explained in the "NO" section above.

The second reason is that the number of genetic tests, that is tests using direct gene probes or tests for genetic markers, is growing rapidly (Miller, 1989). One genetic scientist has speculated "an avalanche" of tests will be available in a few years (Reilly, 1992), and one trade journal estimated that by 1992 over 30 million DNA probe tests would be performed annually (*Genetic Technology News*, 1986).

The third reason is, as some physicians have argued, that genetic tests will have to be used in the practice of medicine (Holtzman, 1989), at least as a defensive practice.

The fourth reason is that insurance companies have access to individual's medical records. The foremost reason for this is that applicants must agree to allow the insurer access to their medical records to apply for insurance. In theory and by law insurers are not allowed access to certain data: mental health information and AIDS/HIV information, for example. These records are generally segregated in hospital settings; that is, the records for these items are simply kept in separate locations from other records. This is not generally true

physician's offices. Because potential insurers usually get their medical information about an applicant from a primary care physician, information about the applicant is readily available, even information which is in theory protected by law.

Finally, empirical evidence (see Billings, 1992) demonstrates that underwriters often do not understand the specialized medical information often found in these files. For example, underwriters may not be sensitive to the difference between a genetic "carrier" and a person who "expresses" (that is, "has") a genetic condition. For example, a person may carry a gene for Huntington disease, but may not "have" the disease. Carriers will never develop the disease, but may pass it on to their offspring. Underwriters may not be likely to distinguish the difference. As tests for more and more genetic conditions are developed and used, the ability of underwriters to keep up with this information will be overwhelmed.

States, Genetics, and Insurance.

The following sections examine the states' role in genetics and insurance, and the policy issues and options facing states

State Understanding of Genetic Information --Insurance Issues.

There is little research investigating state policy makers' understanding of the issues surrounding genetic information and insurance. At least one is underway at Florida State University, and one other was completed in Spring, 1992. This latter research, conducted at Eunice Kennedy Shiver Center in Massachusetts surveyed each of the state insurance commissioners in 1991 concerning the practices of life insurers in using genetic testing (McEwen, 1992).

The results of that survey suggest the following:

- those who regulate the life insurance industry do not yet perceive genetic testing to pose a significant problem in how insurers rate applicants;
- that life insurers have much legal latitude to require genetic tests on those who apply for coverage;
- that few consumers have formally complained to commissioners about the use of genetic data by life insurers.

However, the survey results also suggest that most state officials simply do not know the extent of testing, the use of test results, or how their own state laws might regulate these activities. For example, of the 42 states responding to the survey:

- 32 states answered that they did not know whether life insurers used genetic information from medical records in determining eligibility or rates for applicants and
- 32 states answered that they did not know whether life insurers directly conducted genetic testing on persons who apply for life insurance.

Brown

- When asked how insurers would react under state law to five hypothetical applicants having significant genetic disorders, from 20 percent to over 33 percent of the state insurance agencies were unable to provide that information.

Policy Options for States

Some states have already taken or proposed legislative action on the relationship between genetic information and insurance. Other than taking no action, some of the legislative options include:

1. ***Moratorium on Genetic Testing for Insurance.*** A moratorium is a suspension of use of the results of genetic tests by all insurers to determine eligibility of applicants for a specified time. The advantages of this option are that it suspends the real or perceived difficulties of persons applying for insurance, and it removes genetic information as a competitive issue among insurers. The disadvantages are that it may be difficult to define a "genetic test" (see "What is a Genetic Test?"), and that it may promote adverse selection, because applicants would still be able to have genetic tests performed, but would not have to share that data with insurers. Even if the moratorium is limited to DNA testing, there are a series of other possible obstacles (see Karjala, 1992). California attempted to enact this option in 1991.

2. ***Prohibiting Unfair Eligibility Requirements.*** Another option is to prohibit insurers from practicing unfair eligibility and rating reviews with respect to genetic information. This option might permit the use of data from genetic tests only when the tests have been validated to assure high sensitivity (few false negatives) and high specificity (few false positives). Essentially, this provision requires underwriters to act rationally in interpreting genetic information. Alternatively, a separate, disinterested group could be used to review the validity of genetic tests for use by insurers.

   This policy option may remove some of the most egregious abuses of insurers in denying eligibility. Insurers would not be able to deny eligibility or set abnormally high rates to an applicant just because the applicant has an identified genetic characteristic.

3. ***Privacy Determinations.*** This option assigns privacy rights to genetic information and attributes ownership of the information to the person on whom tests were performed. This policy option might stipulate who is entitled to see the information and under what circumstances. For example, privacy rights may be lost for criminal investigations, or the data may be used by researchers, providing the identification of the donor is kept confidential. It might be argued that this option promotes adverse selection, because individuals are under no obligation to provide medical information (that is, genetic information) about themselves to an insurer.

   On the other hand, at least one state (Wyoming) considered legislation which would have required individuals genetically tested for forensic purposes to disclose any and all pertinent genetic information to potential insurers.

4. ***Health Care Reform.*** This option involves including genetic testing issues in a general health care reform package. Options include community-based rating and small market reform. (National health care insurance is also an option, but cannot be addressed by the states.)

Opting for community rating removes most incentive for insurers to use genetic information because they could not use this information in rate setting (although they might use it to deny coverage). Community rating, however, introduces its own set of difficulties, including a definition of "community," and questions of payment equitability.

Small market reform would allow a range of insurance prices within a community. This reform would set a limit on the cost of insurance for those with adverse genetic test results. Questions about test validity (with respect to their use for insurance purposes) would, however, go unanswered.

5. ***Ban Use of Genetic Information to Determine Insurance Eligibility.*** Alternatively, a state might ban insurers from using genetic information to determine eligibility outright, or might permit use only if the insurer can demonstrate significant variances in the claims experience of the applicant, or in the applicant's actuarial projections. This is Wisconsin's and Arizona's approach.

6. ***Permit Insurers to Use Genetic Information.*** Insurers are permitted to use genetic information in ways similar to other medical information to determine an applicant's insurance eligibility. Alternatively, states may require that applicants give permission for insurers to examine their medical records to determine eligibility. This is the current policy position of most states. This position favors the insurers, because applicants will automatically be ruled ineligible if they fail to grant permission for the insurer to examine medical records.

Recent State Legislation on Insurance and Genetic Information

As of mid-1992, none of the national organizations which might be expected to develop model state legislation on genetics information and insurance have yet done so, including the Suggested State Legislation Committee of The Council of State Governments, the National Association of Insurance Commissioners, or National Conference of Commissioners on Uniform State Laws. In very recent years, the following states have considered or enacted legislation on genetics and insurance:

> ARIZONA, HB 2517 (1989). "An act relating to insurance; proscribing unfair discrimination on the basis of a genetic condition, developmental delay or developmental disability...."

This bill provides that "no insurer shall refuse to consider an application for life or disability insurance on the basis of a genetic condition...." and further notes that such a denial would constitute unfair discrimination, unless "the applicant's medical condition and history and either claims experience or actuarial projections establish that substantial differences in claims are likely to result from the genetic condition...." There is also a clause prohibiting "unfair discrimination" in other types of insurance.

STATUS: Signed into law, June 5, 1989.

> CALIFORNIA, A.3152 (1992). "An act to amend ... the insurance code, relating to discrimination." Sponsor: Assembly Member Connelly.

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This bill was a revision of a similar bill which passed in 1991 (A.1888), but was vetoed by the Governor. In general, the bill prohibits unfair insurance eligibility and rating based on genetics.

STATUS: Withdrawn.

FLORIDA, Committee Substitute for S.980 (1992). "An act relating to DNA analysis."

This bill provides that, except for criminal investigations, DNA analyses may only be performed with informed consent, and that test results are the exclusive property of the person tested, are confidential, and may not be disclosed without consent. The bill also states that any person who conducts a DNA test must provide a notice to the person tested stating whether the information was used "in any decision to grant or deny any insurance, employment, mortgage, loan, credit, or educational opportunity." In the event of denials, the test "must be repeated to verify the accuracy."

STATUS: Signed into law April 8, 1992.

NEW YORK, S.1667, A.2643 (1991-1992). "An act to amend the civil rights law, in relation to genetic testing." Sponsors: Senator Kuhl and Assemblyman Davidsen.

This short bill adds a new section to the state civil rights act which mandates the confidentiality of genetic testing. Genetic testing is defined as "medical and biological examination and analysis of a person to determine the presence and composition of genes in such person's body. such term shall also include DNA profile analysis." All genetic information is "deemed the exclusive property" of the person to whom it relates. The information "may not be released" (it is unclear to whom this applies) to "insurance companies, employers, or potential employers." Finally, the privacy measures are exempted for criminal investigations.

STATUS: Bill is still pending as of this writing.

NEW YORK, A.11056 (1992). A bill prohibiting discrimination based on genetic predisposition.

STATUS: Died.

NEW YORK, S.1432 (1992). A bill establishing a sickle cell anemia screening program and prohibiting discrimination based on same.

STATUS: Died.

OHIO, LSC 119 0920-7 (1992). A bill limiting genetic information use in underwriting.

STATUS: Bill is still pending as of this writing.

WISCONSIN, A.749 (1991). "An act ... relating to prohibiting insurers from using genetic test results for insurance coverage." Sponsors: Seery, *et al.*

This bill prohibits insurers and certain government and quasi-government agencies from requiring genetic tests, requesting information about previous tests, or conditioning coverage on having a test or the results of any test. Rates

Brown may not be determined based on any of this information. Life insurers may not require that a test be performed, otherwise they are exempt from all other prohibitions. Life insurers may not further disclose the information, and must provide for rates that are "reasonably related to the risk involved." A genetic test is "a test using deoxyribonucleic acid extracted from an individual's cells in order to determine the presence of a genetic disease or disorder or the individual's predisposition for a particular disease or disorder."

STATUS: Died.

WISCONSIN, A.515 (1992). An act similar to above and prohibiting collection of all genetic information for insurance purposes.

STATUS: Enacted as Act 117.

WYOMING, S.0098 (1992). "An act ... relating to genetic testing." Sponsor: Senator Burke.

A bill primarily relating to forensic matters, but including the following clause: "No person who has undergone forensic DNA testing and whose test results indicate the person has a genetic characteristic determined to be associated with a statistically increased risk of development of a disease or disorder may apply for, or obtain, insurance coverage without first disclosing the results of the testing to the insurance carrier."

STATUS: Died.

NOTES

1. For a more detailed discussion of insurance and the insurance industry, see the U.S. Office of Technology Assessments' *Medical Testing and Health Insurance*, 1988.

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HB

414

FISCAL NOTE

STATE OF ALASKA
1996 LEGISLATIVE SESSION

BILL NO. HB 414

Revision Date:
Department: Commerce and Economic Development
Title: An Act requiring conciliation panel review in a civil action against an architect, engineer, or land surveyor;....
BRU: Occupational Licensing
Component: Operations
Sponsor: Representative Green
Requestor: Representative Green
COMPONENT SERIAL NO. 1844

Expenditures/Revenues (Thousands of Dollars)

OPERATING EXPENDITURES	FY 97	FY 98	FY 99	FY 00	FY 01	FY 02
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	0.0	0.0	0.0	0.0	0.0	0.0
CAPITAL EXPENDITURES						
CHANGE IN REVENUES						

FUND SOURCE (Thousands of Dollars)

1002 Federal Receipts						
1003 GF Match						
1004 General Fund						
1005 GF/Program Receipts						
1006 GF/MHTIA						
Other 1091 Designated PR						
TOTAL	0.0	0.0	0.0	0.0	0.0	0.0

Estimate of any current year (FY 96) cost: $ 0.0

POSITIONS

FULL-TIME						
PART-TIME						
TEMPORARY						

ANALYSIS: (Attach a separate page if necessary)

HB 414 creates malpractice provisions against design professionals. The bill does not affect licensing requirements for architects, engineers, and land surveyors, therefore, funding is not required.

Prepared by: Jennifer Strickler, Administrative Officer
Phone: 465-2144
Division: Occupational Licensing
Date: January 16, 1996
Approved by Commissioner: William L. Hensley
Date: 1-19-96
Agency: Commerce and Economic Development

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FISCAL NOTE

DRAFT

STATE OF ALASKA
1996 LEGISLATIVE SESSION

BILL NO. CSHB 414

Revision Date:
Title: An Act requiring conciliation panel review prior to filing a civil action against an architect, engineer, or land surveyor...
Sponsor: Representative Green
Requestor: Representative Green

Department: Commerce and Economic Development
BRU: Occupational Licensing
Component: Operations

COMPONENT SERIAL NO. 1844

Expenditures/Revenues (Thousands of Dollars)

OPERATING EXPENDITURES	FY 97	FY 98	FY 99	FY 00	FY 01	FY 02
PERSONAL SERVICES						
TRAVEL	9.3	9.3	9.3	9.3	9.3	9.3
CONTRACTUAL	1.3	1.3	1.3	1.3	1.3	1.3
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	10.6	10.6	10.6	10.6	10.6	10.6
CAPITAL EXPENDITURES						
CHANGE IN REVENUES	10.6	10.6	10.6	10.6	10.6	10.6

FUND SOURCE (Thousands of Dollars)

1002 Federal Receip's						
1003 GF Match						
1004 General Fund						
1005 GF/Program Receipts						
1006 GF/MHTIA						
Other 1091 Designated PR	10.6	10.6	10.6	10.6	10.6	10.6
TOTAL	10.6	10.6	10.6	10.6	10.6	10.6

Estimate of any current year (FY 96) cost: $ 0.0

POSITIONS

FULL-TIME						
PART-TIME						
TEMPORARY						

ANALYSIS: (Attach a separate page if necessary)

CSHB 414 provides a conciliation review process for claims against design professionals. Both the claimant and the design professional(s) whom the claim is against are required to pay $750.00 each to initiate the process. Starting with a funding source of $1,500.00, all expenses related to a claim will be paid by the parties involved before the panel decision is released. This fiscal note identifies the costs involved with establishing a conciliation review panel and funding its activities. Attached is a detail of the costs identified above.

Prepared by: Jennifer Strickler, Administrative Officer
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Division: Occupational Licensing
Date: February 20, 1996
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Date: 2-20-96
Agency: Commerce and Economic Development

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DRAFT

This fiscal note is based on utilizing at least six conciliation review panels each year. Each panel consists of three members. This fiscal note also assumes that each panel will require one day to conduct its business.

Assumptions are made that at least three reviews will be held in the Anchorage area, and three in Juneau or non-Anchorage locations. Each claim will start with a funding source of $1,500.00 and costs exceeding this amount will be paid by parties involved before the panel decision is released.

TRAVEL

Anchorage: An assumption is made that only one panel member will be entitled to meal allowance payment, a result of commuting beyond the 50 mile radius of the meeting site making the member eligible to claim a meal allowance.

Stipend	$300.00 x 3 members =	900.00
Per Diem	$42.00 meal allowance for 1 member =	42.00
Travel		0.00
	Sub-Total Per Claim (for Anchorage):	942.00
	x	3 events
		2,826.00

Juneau (or other non-Anchorage locations): An assumption is made that at least two panel members will be required to travel.

Stipend	$300 x 3 members =	900.00
Per Diem	$80 hotel + $42 meals = $122.00 x 2 =	244.00
Travel	$500.00 x 2 members =	1,000.00
	Sub-Total Per Claim (for Juneau or non-Anchorage):	2,144.00
	x	3 events
		6,432.00

TOTAL TRAVEL: 9,258.00

CONTRACTUAL

If rental of meeting space becomes necessary, space rent is anticipated to cost at least $125.00 per event x 6 events = $750.00.
Communication costs for postage, telephones, etc. are anticipated to cost at least $100.00 per event x 6 events = $600.00.

TOTAL CONTRACTUAL: 1,350.00

TOTAL COSTS: $ 10,608.00

SUMMARY:

Staff time involved with selecting a Chairperson for each panel, operating supplies, and equipment costs are anticipated to be absorbed by the division.

Each event in Anchorage can be expected to cost:

Travel:	942.00
Contractual:	225.00
Total Costs per event in Anchorage:	1,167.00
x	3 events
	3,501.00

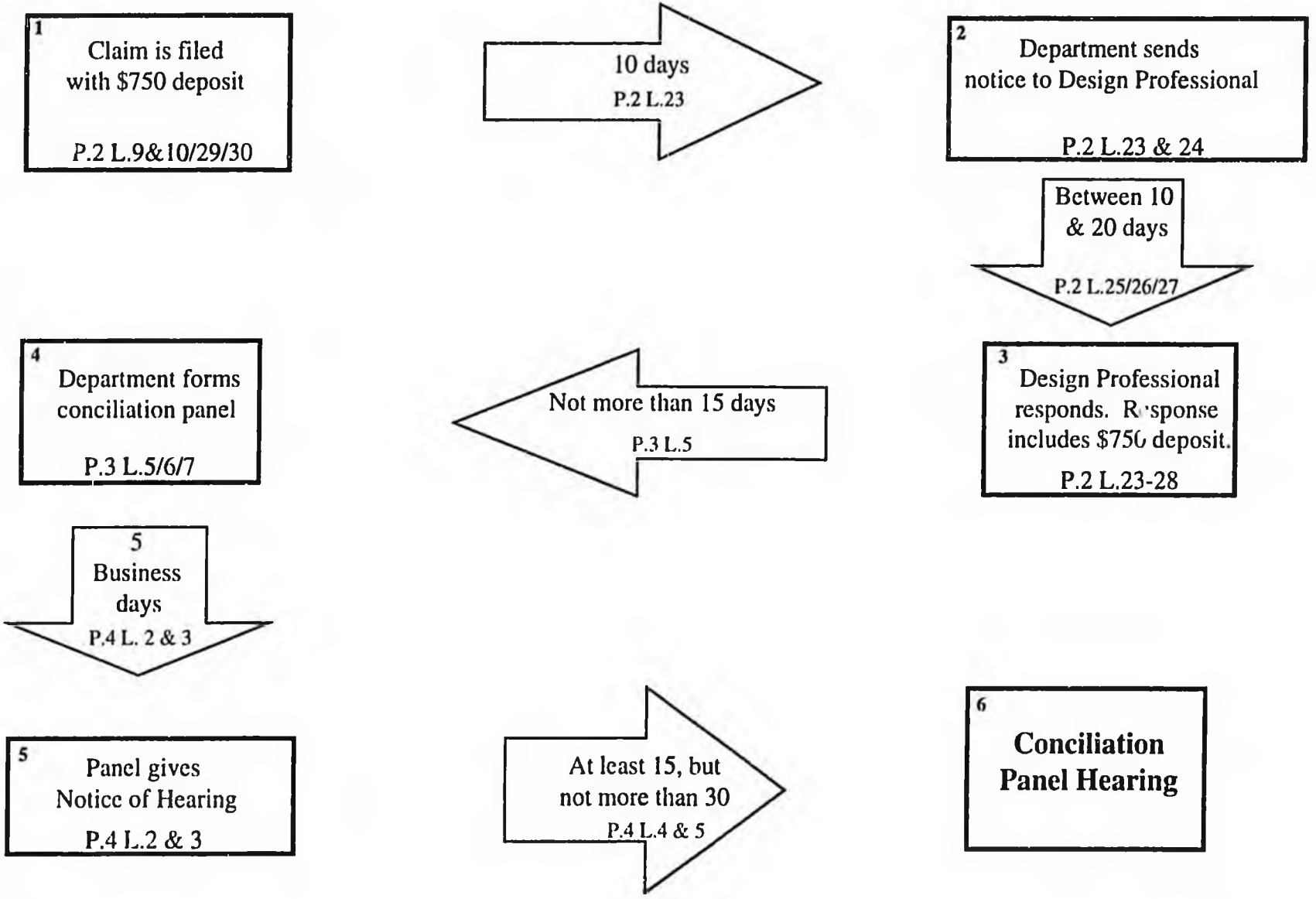
Each event in Juneau or non-Anchorage location can be expected to cost:

Travel:	2,144.00
Contractual:	225.00
Total Costs per event in Juneau or non-Anchorage location:	2,369.00
x	3 events
	7,107.00

This fiscal note does not include travel and per diem costs that may be incurred from consultants whose services are requested by the panel. This and any other costs must also be paid by parties to the claim before the panel decision is released.

Design Professional Reconciliation Panel Process

Proposed in CS HB414



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DEPT. OF NATURAL RESOURCES
DEPT. OF COMMERCE & ECONOMIC DEVELOPMENT
DEPT. OF ENVIRONMENTAL CONSERVATION

Representative Joe Green
District 10

Sectional Description - HB 414 (Version "K")

Conciliation Panel Review for Actions Against Design Professionals

Section 1

Sec. 08.48.111 Allows the AELS board to suspend, refuse to renew, or revoke a license for failing to comply with AS 09.55.750 (d), the provision that requires additional payment to be made, if necessary, before the panel's decision is released.

Section 2

Sec. 09.55.700 (a) Requires a plaintiff with a legal claim against a design professional to submit the claim for review by the design professional conciliation panel. (b) Allows the design professional to waive the conciliation process and proceed straight to court.

Sec. 09.55.710 (a) States that the claim must be submitted to the department in writing, and with the fee. Sets the time frame within which the design professional against whom the claim is made to respond. (b) Sets the fee at $750. (c) Directs the department to form a panel comprised of a mediator, an attorney, and a design professional. (d) Sets the compensation rate at $300. (e) Directs the department to furnish office space and equipment. (f) Directs the board to prepare a list of design professionals.

Sec. 09.55.720 (a) Requires the panel to give notice of the hearing within five business days after it is formed. (b) Allows the claimant to proceed to the appropriate court at any time by mutual consent of the parties.

Sec. 09.55.730 (a) States that the panel meetings are not open to the public. (b) States that panel hearings shall be informal. (c) Grants the panel and the commissioner the power of subpoena. (d) Establishes what information the panel can consider during the hearing. Limits compensation for expert witnesses to the state rate for per diem and travel expenses. (e) Allows the panel to encourage settlement at any time in the process.

Sec. 09.55.740 Requires the parties to attend panel hearings.

Sec. 09.55.750 (a) Requires the panel to forward their decision, including the issue of liability, in writing to the commissioner. Prohibits the panel from deciding on the issue of damages. (b) Requires panel members to sign the decision, and allows for dissenting opinion, and states that the panel must find one of four conclusions. (c) Allows the panel to forgo the written opinion if the claim is settled before the decision. (d) Directs the panel to ensure that sufficient funds been deposited to cover the costs of the proceedings. Prohibits a panel decision from being released until all costs are covered.

Sec. 09.55.760 (a) Requires the defendant to formally reject the findings of the panel before an action can be filed in the appropriate court. Prohibits a decision, conclusion, finding, or recommendation of the panel, made during the conciliation process, from being used in court.

Sec. 09.55.770 Holds panel members immune from liability for action taken as a panel member.

Sec. 09.55.780 Stops the clock from running on the statute of limitations during the conciliation process, however, the clock may not stop for more than 6 months.

Sec. 09.55.790 (a) Directs a party to the conciliation process to cooperate. (b) Allows the court to assess penalties if they fail to do so.

Sec. 09.55.800 Directs the department to include information about claims brought before the panel in their annual report.

Sec. 09.55.810 Definitions.

Section 3 Amends Alaska Rule of Evidence 402 relating to the admissibility in court of decisions, conclusions, findings, or recommendations made during the panel process.

Section 4 Application date.

Section 5 Effective date.

9-LS1508\K
Ford
2/6/96

CS FOR HOUSE BILL NO. 414( )

IN THE LEGISLATURE OF THE STATE OF ALASKA

NINETEENTH LEGISLATURE - SECOND SESSION

BY

Offered:
Referred:

Sponsor(s): REPRESENTATIVE GREEN

A BILL

FOR AN ACT ENTITLED

"An Act requiring conciliation panel review prior to filing a civil action against an architect, engineer, or land surveyor; amending Rule 402, Alaska Rules of Evidence; and providing for an effective date."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

* Section 1. AS 08.48.111 is amended to read:

Sec. 08.48.111. POWER TO REVOKE, SUSPEND, OR REISSUE CERTIFICATE. The board may suspend, refuse to renew, or revoke the certificate of or reprimand a registrant or corporation who is found guilty of (1) fraud or deceit in obtaining a certificate; (2) gross negligence, incompetence, or misconduct in the practice of architecture, engineering, or land surveying; or (3) a violation of AS 09.55.750(d), this chapter, a regulation adopted under this chapter, or the code of ethics or professional conduct as adopted by the board. The code of ethics or professional conduct shall be distributed in writing to every registrant and applicant for registration under this chapter. This publication and distribution of the code of ethics or professional conduct constitutes

due notice to all registrants. The board may revise and amend its code and, upon doing so, shall immediately notify each registrant in writing of the revisions or amendments. The board may, upon petition of the registrant or corporation, reissue a certificate if a majority of the members of the board vote in favor of the reissuance.

* Sec. 2. AS 09.55 is amended by adding new sections to read:

ARTICLE 9. MALPRACTICE CLAIM AGAINST DESIGN PROFESSIONAL.

Sec. 09.55.700. MANDATORY CONCILIATION PANEL REVIEW; JUDICIAL DETERMINATION OF EXCEPTIONS. (a) Except as provided under (b) of this section, a person who has a claim against a design professional for civil damages resulting from professional negligence shall, before filing the claim with the court, submit the claim for review by the design professional conciliation panel.

(b) A claim is not required to be submitted to the panel if the design professional against whom the claim is asserted agrees, within seven days after receiving notice of the claim as required under AS 09.55.710(a), to waive review by the panel. If a claim is asserted against more than one design professional and one or more design professionals refuse to waive panel review, panel review may not be waived and the claim shall proceed as provided under AS 09.55.700 - 09.55.810.

Sec. 09.55.710. FILING OF CLAIM; DESIGN PROFESSIONAL CONCILIATION PANEL. (a) A claim required to be reviewed by a panel under AS 09.55.700(a) shall be submitted to the department in writing with the fee required by (b) of this section. The claimant shall set out facts upon which the claim is based, and shall include the names of all design professionals against whom the claim is made who are known to the claimant. Within 10 days after receiving a claim, the department shall provide notice of the claim and of the deposit requirement under (b) of this section to all design professionals against whom the claim is made. The notice must include a date, at least 10 but not more than 20 days after mailing the notice, within which a design professional against whom a claim is made may file a written response to the claim.

(b) A claim may not be accepted by the department for filing unless the claimant deposits $750 with the department when the claim is filed. The design professional shall deposit $750 with the department not later than the date specified under (a) of this section for filing a written response to the claim. If the design professional fails to

deposit the funds required by this subsection, the claimant may proceed with a civil action in the appropriate court. If a claim is withdrawn or otherwise terminated without participation by a panel, the department shall return all money collected to the respective parties.

(c) Not more than 15 days after the date for receiving the response from the design professional under (a) of this section, the department shall form a design professional conciliation panel to consider the claim. A panel shall consist of one individual acting as the chair, selected from among individuals who are familiar with and experienced in the tort claims settlement process, one attorney licensed in this state and experienced in trial practice, and one design professional. The chair shall be appointed by the department. The attorney panel member shall be appointed by the chair from a list of not less than 20 attorneys experienced in trial practice submitted annually to the department by the Alaska Supreme Court. The design professional member shall be appointed by the chair from a list of not less than 20 design professionals submitted annually by the State Board of Registration for Architects, Engineers and Land Surveyors established under AS 08.48. After a panel renders its decision or the claim is otherwise disposed of, the panel shall be disbanded.

(d) The chair shall preside at the meetings of the panel. Panel members shall be compensated at the rate of $300 per claim and per diem and travel expenses authorized for boards and commissions under AS 39.20.180. Panel member compensation is due when the decision of the panel is submitted to the department. The department shall pay panel members from funds collected from the claimant and defendant.

(e) Office and meeting space, office equipment, and office supplies for the panel shall be furnished by the department.

(f) The board shall prepare a list of design professionals, along with their respective specialties, who shall then be considered consultants to the panel in their respective fields. Panel members may also consult with other legal, technical, and insurance specialists. A consultant called by the panel to appear before the panel shall be paid per diem and travel expenses authorized for boards and commissions under AS 39.20.180. Per diem and travel costs for a consultant shall be paid by the department from funds provided under AS 09.55.710(b) or 09.55.750(d).

Sec. 09.55.720. REVIEW BY PANEL; VOLUNTARY TERMINATION. (a) Within five business days after the panel is formed, the panel shall give notice of the hearing, by certified mail, to all design professionals and others who are parties to the claim. Notice of the hearing must include (1) a date and time, at least 15 but not more than 30 days following the date the notice is mailed, for a hearing by the panel; (2) a description of the nature and purpose of the panel's proceedings; and (3) the location of the place for the hearing. The time and location originally set out in the notice may be changed by the chair on due notice to all parties for good cause, provided that a party requesting the rescheduling of the hearing within seven days of the scheduled date may be required by the panel chair to compensate the panel in an additional amount equal to the fee panel members receive under AS 09.55.710(d).

(b) At any time, by mutual consent of the parties involved, the department, before the appointment of the chair, or the chair after the chair's appointment, may terminate the proceedings and the claimant may proceed in the appropriate court.

Sec. 09.55.730. PANEL HEARING PROCEDURES. (a) A person, other than the panel, witnesses, consultants called by the panel, and the persons listed in AS 09.55.740, may not be present at a panel hearing except with the permission of the chair. The panel may, in its discretion, conduct an inquiry of a party, witness, or consultant without the presence of a party.

(b) A panel hearing shall be informal. The panel may record its proceedings for the use of the panel, but the record may not be made available to the parties and is not admissible in any other action or proceeding, except that a record of a statement made at a panel hearing is admissible as provided under AS 09.55.750. The panel may receive oral or documentary evidence. Questioning of parties, witnesses, and consultants may be conducted by the panel, and the panel may, in its discretion, permit a party or counsel for a party to question other parties, witnesses, or consultants. The panel may designate who, among the parties, shall have the burden of going forward with the evidence with respect to the issues it may consider. Unless otherwise designated by the panel, when a design professional's records have been provided for the claimant's review, the burden of going forward with the evidence shall initially rest with the claimant at the commencement of a hearing.

(c) The panel has the power to require by subpoena the appearance and

testimony of witnesses and the production of documentary evidence. When subpoena power is utilized, notice shall be given to all parties. The testimony of witnesses may be taken either orally before the panel or by deposition. In cases of refusal to obey a subpoena issued by the panel, the panel may invoke the aid of the appropriate court. A member of the panel or the commissioner may sign subpoenas. A member of the panel may administer oaths and affirmations, examine witnesses, and receive evidence. The panel shall attempt to secure the voluntary appearance, testimony, and cooperation of parties, witnesses, and consultants without coercion.

(d) At the panel hearing, and in arriving at its opinion, the panel shall consider statements or testimony of witnesses, construction documents, inspection reports, calculations, and other records kept in the usual course of the practice of the design professional without the necessity for other identification or authentication. Statements of fact or opinion on a subject contained in a published treatise, periodical, book, or pamphlet, or statements of experts may be considered by a panel without the necessity of the experts appearing at the hearing. The panel may, upon the application of a party or upon its own decision, appoint as a consultant an impartial and qualified design professional or other professional person or expert to testify before the panel or to conduct necessary professional or expert examination of the claimant or relevant evidentiary matter and to report to or testify as a witness. A panel consultant may not be compensated or reimbursed except for per diem and travel expenses authorized for boards and commissions under AS 39.20.180. Consultant per diem and travel expenses shall be paid by the department from funds provided under AS 09.55.710(b) or 09.55.750(d). The parties may not conduct discovery.

(e) During a panel hearing and at any time before the release of an advisory decision under AS 09.55.750, the panel may encourage the parties to voluntarily settle or otherwise dispose of the case.

Sec. 09.55.740. REQUIRED PANEL ATTENDANCE. Unless excluded or excused by the panel, the following persons shall attend hearings before the panel:

(1) the party or parties making the claim;

(2) any design professional against whom the claim is made or a representative of the design professional, other than counsel, authorized to act for the design professional; and

(3) counsel representing the parties, if any.

Sec. 09.55.750. PANEL DECISIONS; ADDITIONAL PAYMENTS. (a) Except as provided under (c) of this section, within 15 days after the completion of a hearing, a panel shall file a written advisory decision on the claim with the commissioner. The commissioner shall mail copies to all parties concerned, counsel of the parties concerned, the board, and the representative of each design professional's liability insurance carrier authorized to act for the carrier. The panel shall state its conclusions in writing. The panel may not decide the issue of damages.

(b) Each member of the panel shall sign the decision, and the decision may include concurring or dissenting opinions. The decision must contain one of the following conclusions:

(1) the evidence does not indicate that the design professional failed to comply with the applicable standard of care;

(2) the evidence does indicate that the design professional failed to comply with the applicable standard of care and that failure is the proximate cause of the alleged damages;

(3) the evidence indicates that the design professional failed to comply with the applicable standard of care, but the failure is not a proximate cause of the alleged damages; or

(4) the evidence indicates that there is a material issue of fact, not requiring an expert opinion, bearing on liability that should be considered by a court or jury.

(c) The advisory decision required by this section need not be filed if the claim is settled or disposed of before the decision is written or filed.

(d) Before filing an advisory decision as required under (a) of this section, the chair of the panel shall determine if sufficient funds have been deposited with the department to pay all expenses allowed under AS 09.55.710 and 09.55.730. If funds on deposit are insufficient, the parties to the conciliation proceeding shall contribute sufficient funds to pay all panel expenses as provided under (e) of this section. A party shall deposit the required funds within 10 days after receiving notice of the deposit requirement. A panel decision may not be released until the department has sufficient funds to pay all panel expenses.

(e) If the decision of the panel contains the conclusion described

(1) under (b)(1) of this section, the claimant shall deposit all additional funds required under (d) of this section;

(2) under (b)(2) of this section, the design professional shall deposit all additional funds required under (d) of this section; and

(3) under (b)(3) or (4) of this section, the parties to the conciliation proceeding shall, in equal shares, deposit additional funds required under (d) of this section.

(f) A design professional who fails to deposit funds as required under (e) of this section has committed misconduct in the practice for which the design professional is licensed, and the department shall provide notice of the misconduct to the board.

(g) If a claimant fails to deposit funds as required under (e) of this section, the department shall impose a civil penalty of $1,000 against the claimant.

Sec. 09.55.760. SUBSEQUENT LITIGATION; EXCLUDED EVIDENCE. A claimant may institute litigation based on a claim heard by a panel in an appropriate court only after a party to the design professional conciliation panel hearing rejects the decision of the panel. A statement made in the course of the hearing of the panel is admissible in a subsequent civil action to the extent allowed under the Alaska Rules of Evidence. A decision, conclusion, finding, or recommendation of the panel may not be admitted into evidence in a subsequent civil action, nor may a party to the panel hearing, or the counsel or other representative of a party, refer to or comment on a decision, conclusion, finding, or recommendation of the panel in an opening statement, an argument, or at any other time, to the court or jury, except that a decision, conclusion, finding, or recommendation may be admissible under AS 09.55.790.

Sec. 09.55.770. PANEL MEMBER IMMUNITY. A member of a panel is not liable for civil damages for action taken or for a decision, conclusion, finding, or recommendation made by the member while acting as a member of a panel.

Sec. 09.55.780. STATUTE OF LIMITATIONS TOLLED; LACK OF A DECISION IN SIX MONTHS. Notwithstanding any other provision of law, the filing of a claim with the department tolls any applicable statute of limitation until 30 days after the date the decision of the panel is mailed or delivered to the parties. However, the applicable statute of limitations may not be tolled for more than six months. If a

decision by the panel is not reached within six months after the claim is filed, the applicable statute of limitations shall resume running and the party filing the claim may commence a suit based on the claim in the appropriate court.

Sec. 09.55.790. DUTY TO COOPERATE; ASSESSMENT OF COSTS AND FEES. (a) It is the duty of a person who files a claim with the panel and of a design professional against whom a claim is made to cooperate with the panel for the purpose of achieving a prompt, fair, and just disposition or settlement of a claim, provided that the cooperation may not prejudice the substantive rights of the person.

(b) On application of the department, the court may award as a civil penalty against a party all or a portion of the costs and expenses of the panel attributable to a claim involving the person if the court finds that the person failed to cooperate with the panel.

Sec. 09.55.800. ANNUAL REPORT. The department shall prepare annually, 20 days before the convening of a regular legislative session, a report containing the department's evaluation of the operation and effects of AS 09.55.700 - 09.55.810. The department shall notify the legislature that the report is available. The report must include a summary of claims brought before a panel and the disposition of those claims.

Sec. 09.55.810. DEFINITIONS. In AS 09.55.700 - 09.55.810,

(1) "board" means the State Board of Registration for Architects, Engineers and Land Surveyors;

(2) "commissioner" means the commissioner of commerce and economic development;

(3) "department" means the Department of Commerce and Economic Development;

(4) "design professional" means an architect, engineer, or land surveyor licensed under AS 08.48;

(5) "panel" means the design professional conciliation panel;

(6) "professional negligence" means a negligent act or omission by a design professional in providing professional services;

(7) "professional services" means services provided by a design professional that are within the scope of the services for which the design professional is licensed as an architect, engineer, or land surveyor.

* **Sec. 3.** AS 09.55.760, enacted by sec. 2 of this Act, has the effect of amending Rule 402, Alaska Rules of Evidence, by providing that a decision, conclusion, finding, or recommendation of the panel is not admissible in a subsequent civil action.

* **Sec. 4.** This Act applies to causes of action that accrue on or after the effective date of this Act.

* **Sec. 5.** This Act takes effect July 1, 1996.

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DEPT. OF COMMERCE & ECONOMIC DEVELOPMENT
DEPT. OF ENVIRONMENTAL CONSERVATION

Representative Joe Green

District 10

Sectional Description - HB 414

Conciliation Panel Review for Actions Against Design Professionals

Section 1

Sec. 09.55.700 (a) Requires a plaintiff with a legal claim against a design professional to submit the claim for review by the design professional conciliation panel. (b) Allows the design professional to petition the court that panel review is inappropriate. (c) Lists the reasons why a panel review can be considered inappropriate. (d) Allows the design professional against whom the claim is asserted to waive the proceedings.

Sec. 09.55.710 (a) States that the claim must be submitted to the department in writing, and with the fee. (b) Sets the fee at $750. (c) Directs the department to form a panel comprised of a mediator, an attorney, and a design professional. (d) Disbands the panel after a decision is reached. (e) Sets compensation for panel members at $300 per claim. (f) Directs the department to furnish office space and equipment.

Sec. 09.55.720 (a) Directs the panel to notify the defendant that a claim has been filed. (b) Allows the proceedings to be terminated if both parties agree.

Sec. 09.55.730 (a) States that the panel meetings are not open to the public. (b) States that panel hearings shall be informal. (c) Grants the panel and the commissioner the power of subpoena. (d) Establishes what information the panel can consider during the hearing. Limits compensation for expert witnesses to the state rate for per diem and travel expenses. (e) Allows the panel to encourage settlement at any time in the process.

Sec. 09.55.740 Requires the parties to attend panel hearings.

Section Description
HB 414

Sec. 09.55.750 (a) Requires the panel to forward their decision, including the issue of liability, in writing to the commissioner. Prohibits the panel from deciding on the issue of damages. (b) Requires panel members to sign the decision, and allows for dissenting opinion. (c) Allows the panel to forgo the written opinion if the claim is settled before the decision. (d) Directs the panel to make sure enough money has been deposited to cover the costs of the proceedings. Prohibits a panel decision from being released until all costs are covered.

Sec. 09.55.750 (a) Requires the defendant to formally reject the findings of the panel before an action can be filed in the appropriate court. Prohibits a statement made during the conciliation process from being used in court.

Sec. 09.55.770 Holds panel members immune from liability for action taken as a panel member.

Sec. 09.55.780 Stops the clock from running on the statute of limitations during the conciliation process, however, the clock may not stop for more than 12 months.

Sec. 09.55.790 Directs a party to the conciliation process to cooperate, and allows the court to assess penalties if they fail to do so.

Sec. 09.55.800 Directs the department to include information about claims brought before the panel in their annual report.

Sec. 09.55.810 Definitions.

Section 2 Amends Alaska Rule of Evidence 402 relating to the admissibility in court of decisions, conclusions, findings, or recommendations made during the panel process.

Section 3 Amends Alaska Rule of Evidence 613 relating to the admissibility in court of statements made during the panel process.

Section 4 Application date.

Section 5 Effective date.

AMERICAN CONSULTING
ENGINEERS COUNCIL

CERTIFICATE OF MERIT

BRIEFING PACKET

Background

AMERICAN CONSULTING
ENGINEERS COUNCIL

AMERICAN CONSULTING
ENGINEERS COUNCIL

JOHN C. KALAVRITINOS, JR.
Assistant General Counsel
Director, Professional Liability Programs

1015 Fifteenth Street NW • Washington DC 20005
Phone: 202-347-7474 • Fax: 202-898-0068

To: Member Organization Le

From: ACEC Legal Department

Date: November 27, 1995

Re: Certificate of Merit Laws

The intent of this memorandum is to provide Member Organizations with an introduction to certificate of merit laws, which are currently enforced in Arizona, California, Colorado, Georgia, Hawaii, Kansas and New Jersey. This memorandum begins with a brief explanation of the reasons for certificate of merit legislation, then proceeds to an overview of ACEC's involvement in certificate of merit advocacy (particularly, the ACEC Risk Management Committee),[1] and concludes with a summary of each state's certificate of merit law. This memorandum is supplemented with the following:

1. A comparison chart of state certificate of merit laws.

2. The full texts of the certificate of merit laws of California,[2] Hawaii,[3] and New Jersey (representative of the three categories of certificate of merit laws).

3. The full text of the Proposed Model Act with Regard to Suits or Claims Against Design Professionals (the ACEC model certificate of merit law).

4. "Certificate of Merit and Review Panels: Conditions Precedent to Civil Actions Against Design Professionals," published in Construction Lawyer (April 1995).

5. "Certificates of Merit: A First Step in the Rational Economical Approach to the Resolution of Design Claims," published in Virginia Lawyer (September 1993).

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1 The NSPE-PEPP Professional Liability Committee is also preparing a packet on this topic.

2 The California statute appears in *West's Annotated California Codes, Code of Civil Procedure* and was reprinted with the permission of the West Publishing Company.

3 The statutes reprinted or quoted verbatim in the following pages are taken from the *Hawaii Revised Statutes Annotated* Copyright 1988 and the *Hawaii Revised Statutes Annotated* Copyright 1994, by The Michie Company, a division of Reed Elsevier Inc. and Reed Elsevier Properties Inc. and are reprinted with the permission of The Michie Company. All rights reserved.

The Purpose of Certificate of Merit Laws

The primary goal of certificate of merit laws is to reduce the number of frivolous lawsuits filed, without depriving anyone the right to their day in court. It is especially vital to architects, engineers, and land surveyors that a mechanism exists to screen out frivolous lawsuits which currently require firms to commit valuable resources in needless legal battles. In addition, certificate of merit laws reduce the costs of professional malpractice claims to both plaintiffs and defendants and encourage early and cost effective resolutions of civil cases alleging claims of professional negligence.

The basic premise of the certificate of merit concept is that an attorney filing a lawsuit must receive independent verification of the validity of a client's claim. Failure to obtain a certificate of merit (barring a few exceptions) is grounds to dismiss the plaintiff's claim and may subsequently require the plaintiff to pay the defendant's legal fees.

ACEC Involvement in Certificate of Merit Advocacy

For many years, ACEC and its Member Organizations have been involved in promoting liability reform at the federal and state levels. These efforts have focused on several specific reform initiatives, including efforts to pass certificate of merit laws at the state level. ACEC has established a clearinghouse of certificate of merit materials, which includes state statutes, lists of experts, reports and articles. Member Organizations have drawn upon ACEC's information resources for use in testimony before state legislatures considering certificate of merit proposals. The primary example of ACEC's commitment to future certificate of merit initiatives is reflected in the development of the model certificate of merit law, which is briefly explained below.

Proposed Model Act with Regard to Suits or Claims Against Design Professionals ("The ACEC model law")

The model law was developed by the ACEC Professional Risk Management Committee in 1993 and sent to all Member Organizations. The model law has two main components: a screening panel, which is based in part on Hawaii's law; and an affidavit requirement based on Georgia's certificate of merit law. [To view the model law in its proper perspective, we recommend that the full texts of these state statutes be reviewed beforehand.] The model law was designed for flexibility; it may be adopted in its entirety, or either component (screening panel, affidavit) may be considered individually. The model law is an extremely useful tool for a state legislator who wants to draft a certificate of merit law which deters the filing of frivolous lawsuits, and allows for the orderly processing of claims possessing merit.

The model law applies only to "design professionals," who are defined as licensed professional engineers, architects, surveyors and landscape architects. The model law requires that, prior to filing a formal complaint in court, a plaintiff who alleges

negligence against a design professional must file a claim with a three-person review panel. The panel conducts an informal hearing, during which the panel may review evidence submitted by both parties. Since formal rules of evidence are waived, the panel's findings and verdict are inadmissible in any subsequent legal proceedings. The model law provides a list of four verdicts the panel may render; the panel must select at least one verdict from the list, although it may choose to include more than one. The verdict of the panel is non-binding.

The plaintiff can still reject the panel's verdict and file a formal complaint in court. The complaint must be accompanied by an affidavit from a licensed member of the defendant's profession. The affidavit must state the existence of at least one act of negligence and its factual origins. If obtaining an affidavit would cause the statute of limitations on the claim to expire, the plaintiff is given an additional forty-five days to comply, and the defendant is given thirty days to respond once the affidavit is filed.

Certificate of Merit Laws at the State Level

The certificate of merit laws which are currently in force at the state level share common characteristics and distinct differences, resulting in varying degrees of success in terms of reducing the number of frivolous lawsuits. Despite their unique characteristics, state certificate of merit laws can be divided into three categories: those requiring a certificate drafted by an attorney, those requiring an affidavit from a design professional, and those requiring the resolution of the dispute by a screening panel. The general requirements of the seven states which presently have certificate of merit laws are summarized below.

Arizona (Arizona Revised Statutes, Title 12, Chapter 17)

Arizona's certificate of merit law only applies to "registered professionals," which are defined as engineers, architects, assayers, geologists, landscape artists, land surveyors as well as contractors. The law requires that, in any action by a non-registered professional alleging professional negligence on the part of a registered professional, an affidavit from a licensed member of the defendant's profession must be submitted with the claim.

The affidavit must state "the acts or omissions" and the "factual basis" underlying the claim, as well as "how the acts or omissions" were responsible for causing the plaintiff's injury. If the statute of limitations for the claim would expire while an affidavit is being obtained, the affidavit may be submitted forty-five days after the initial claim is filed. Also, a plaintiff who obtains an affidavit before a claim is filed but fails to submit the affidavit with the claim due to "excusable neglect or mistake" may be given leave by a judge to correct the error without penalty. Otherwise, failure to submit the affidavit with the claim results in automatic dismissal of the claim.

California (California Code of Civil Procedure, Section 411.35)

The certificate of merit law in California requires the plaintiff's attorney to attach a certificate to the complaint in any suit alleging professional negligence by an engineer, architect or surveyor. The certificate must state that legal action was being taken based upon the attorney's prior consultation with a licensed member of the defendant's profession. In the event that a statute of limitations problem would arise while a certificate is being obtained, the law provides the attorney with an additional sixty days to comply. The certificate requirement is waived if an attorney contacts three licensed members of the defendant's profession on separate occasions and they each refuse to consult with the attorney. The certificate requirement is also waived when attorneys base their case on the legal theory of "res ipsa loquitur," which means that the plaintiff's claim would not arise unless there was at least some negligence on the part of the defendant. Failure to comply with the certificate requirement may be grounds for dismissal of the case. California is the only certificate of merit state which contemplates additional sanctions against plaintiffs and their attorneys for failure to obtain a certificate of merit. Non-compliance may result in the plaintiff and/or the plaintiff's attorney being required to pay the defendant's legal costs. In 1995, California strengthened the law by: 1) removing a sunset provision and 2) requiring the consulted professional to express an opinion whether the defendant was negligent in the performance of his duties.

Colorado (Colorado Revised Statutes, Title 13, Section 13-20-602)

In 1987, Colorado expanded the coverage of its certificate of merit law to include all licensed professionals, as well as engineers, architects and land surveyors. In any civil action alleging negligence on the part of a licensed professional, and where expert testimony is required to develop a prima facie case, the plaintiff's attorney must file a certificate of merit (known as a certificate of review) within sixty days of the filing of the original complaint. This period may be extended at the court's discretion. The certificate must state that the attorney has consulted "a person who has expertise in the area of the alleged negligent conduct" and who is qualified to render an opinion concerning the question at issue. The certificate must state that the expert found some substantial justification in support of the plaintiff's claim. Failure to obtain a certificate results in automatic dismissal of a claim.

Georgia (Official Code of Georgia, Title 9, Section 9-11-9.1)

Georgia's certificate of merit law applies to any action where "professional malpractice" is alleged and damages are sought. Although the specific types of professions which are subject to the law are not expressly mentioned, the courts of Georgia have applied the law in cases involving disputes over engineering and architectural services. An attorney must obtain from "an expert competent to testify" an affidavit certifying the presence of at least one act of negligence and its origins. The affidavit must be submitted when a complaint is filed. If obtaining an affidavit would create a statute of limitation problems,

the affidavit may be submitted forty-five days after the complaint is filed. Non-compliance can be grounds for a dismissal only if the defendant's initial responsive pleading mentions the error.

Hawaii (Hawaii Revised Statutes, Volume 13, Chapter 672)

Hawaii's certificate of merit/screening panel law applies to situations where a plaintiff is seeking damages for acts of professional negligence committed by persons who are licensed professional engineers, architects, surveyors and landscape architects. Before filing a formal complaint in court, the plaintiff must file a claim with the Design Professional Conciliation Panel. This requirement is waived under certain circumstances if the judge rules (upon a party's motion) that the subject matter of the claim is not appropriate for the panel's review.

The plaintiff must submit a certificate of merit ("certificate of consultation") at the same time the claim is filed with the panel. If obtaining a certificate would create a statute of limitations problem, the certificate may be submitted within thirty days of filing the claim with the panel. The certificate must state that the attorney has consulted with a licensed member of the defendant's profession, and based upon that consultation, the attorney has found enough merit to the claim to warrant further legal action. A certificate does not have to be obtained when an attorney has made three attempts to obtain a consultation and was refused each time, or when an attorney's case is based upon a claim that the defendant failed to disclose the ramifications of a procedure to the plaintiff.

The screening panel consists of a dispute resolution expert, a trial attorney, and a member of the defendant's profession; the panel's costs are divided equally among the parties. The panel's deliberations are informal, and during a hearing the panel may consider a wide variety of evidence. The panel may also encourage the parties to voluntarily settle the case. Thirty days after the completion of a hearing, the panel renders a non-binding decision which includes assignment of liability and any appropriate award of damages (punitive damages may not be awarded). The statute of limitations begins to run again after the panel has rendered its decision. If a party rejects the panel's decision and pursues the matter in court, the panel's findings, statements, and conclusions are inadmissible as evidence.

Kansas (Kansas Statutes Annotated, Chapter 60, Article 35, Sections 60-3501 - 60-3509)

The Kansas statute provides for the establishment of screening panels, which review the actions of engineers, architects, and other licensed individuals. The law applies in cases where a plaintiff files a "professional liability malpractice action" alleging damages caused by the "rendering or failure to render services" on the part of a licensed professional. A judge presiding over such an action will authorize the convening of a screening panel, but only if one of the parties to the action makes such a request. The four-person screening panel consists of a licensed professional chosen by the plaintiff,

a licensed professional chosen by the defendant, a licensed professional chosen by both parties, and a non-voting attorney selected by the court.

The panel is charged with determining whether the defendant's conduct went beyond that which is considered acceptable within the profession, and whether the defendant's conduct was the cause of the plaintiff's injury. The panel's hearings are informal, and rules of evidence are not enforced. The panel must release its findings within ninety days of the beginning of its inquiry. The panel's rulings are non-binding, and either party may reject the panel's verdict and continue legal action. During the screening panel's deliberations, the statute of limitations for the plaintiff's claim is temporarily suspended, and does not begin to run again until thirty days after the panel has announced its recommendations. In subsequent litigation, the panel's findings are admissible in court. The cost of the screening panel is the responsibility of the party whom the panel decides in favor of; if the panel's findings are inconclusive, the costs are divided evenly among the parties.

New Jersey (New Jersey Statutes, P.L. 1995, Chapter 139, supplementing Title 2A)

New Jersey's certificate of merit law only applies to six narrowly-defined licensed professions. Engineers and architects are covered by the law, but land surveyors and landscape architects are not. The law requires that, in any tort action alleging negligence on the part of an engineer or architect, the plaintiff must file an affidavit from a licensed member of the defendant's profession. The affidavit must state that there is a "reasonable probability" that the defendant's actions were incompatible with professionally-accepted standards.

The affidavit requirement may be waived only if the plaintiff files a sworn statement explaining that a request was made of the defendant to provide information needed to prepare the affidavit, and that the defendant failed to comply after forty-five days. Failure to submit an affidavit is construed as "a failure to state a cause of action," which might (or might not) lead to the dismissal of the plaintiff's case. The affidavit must be filed within sixty days of the submission of the defendant's answer to the plaintiff's complaint; the time period may be extended another sixty days on a showing of good cause. This is probably the most lenien timing restriction for the filing of the affidavit.

Other State Attempts at Obtaining a Certificate of Merit Law

It is also helpful to examine other states which have attempted to pass certificate of merit laws. Alaska is planning to introduce a certificate of merit bill, similar to the ACEC model bill, in the next legislative session. State tort reform advocates in states such as North Carolina, Missouri and Wyoming have faced mixed success with this legislation. Some states have had difficulty moving the legislation out of committee due in large part to the strength of the trial lawyer lobby. Other states have moved legislation out of committee only to lose on the floor of the state House or Senate. Some state initiatives

have faced even greater difficulty such as Wyoming which had passed a certificate of merit law only to have the Wyoming Supreme Court declare the statute unconstitutional.

Wyoming (Wyoming Statutes § 9-2-1802)

The Wyoming statute had established a screening procedure for professional malpractice claims. In 1990, The Wyoming Supreme Court declared the statute unconstitutional on equal protection grounds. Since the act was very broad and also covered health care professionals, the court found that the statute treated medical malpractice victims differently than persons injured by someone other than a health care professional since the medical malpractice victims had no direct access to the courts, they first had to go through the screening procedure. The court gave great deference to the general public health and did not want an extra hurdle for medical malpractice victims. It is therefore wise to limit the list of professionals covered in a certificate of merit act, although experts do not foresee the Wyoming Supreme Court's holding to affect any of the certificate of merit laws outside of Wyoming.

Political Realities

Rarely, if ever, has there been time when legal reform has been as popular as it is today. From state houses to the halls of Congress, the issue of how to reign in crippling litigation is near the top of the national agenda. However, in spite of the significant public opinion in favor of reform, significant obstacles still exist. The trial lawyer lobbying organizations have been successful in defeating past tort reform efforts -- including certificate of merit legislation. With that in mind, the following questions should be asked before embarking on a legislative initiative to pass a certificate of merit statute in your state:

- Whether current political climate in your state is favorable for passage of tort reform?
- Whether your state has enacted a medical screening panel law which can serve as a model for a law covering design professionals?
- How strong is the trial lawyer lobby in your state?
- How involved is your organization in A/E and state tort reform coalitions?
- Whether the proposed legislation should include all professionals or only design professionals?

Keeping these questions in mind and by reviewing the certificate of merit laws that are currently enforced as well as those that failed, increases the chances of passing a constitutionally sound certificate of merit law.

COMPARISON CHART OF STATE CERTIFICATE OF MERIT LAWS

State	Type	Requirements	Professions Covered	Consequences for Non-Compliance	Miscellaneous
Arizona	Affidavit	Affidavit from a licensed member of the defendant's discipline	Engineers, architects, assayers, geologists, landscape architects, land surveyors (and contractors)	Automatic dismissal	Only applies in actions brought by persons who are not registered professionals nor contractors; the only state that covers contractors
California	Certificate	Certificate from an attorney verifying consultation with a licensed member of the defendant's profession	Engineers, architects and land surveyors	Grounds for dismissal; additional sanctions may be imposed	Only one certificate needed even if multiple defendants and claims
Colorado	Certificate	Certificate from an attorney verifying consultation with a person with expertise in the area	All licensed professionals	Automatic dismissal	
Georgia	Affidavit	Affidavit from a competent expert	All professionals	Grounds for dismissal only if non-compliance raised by defendant	This bill had originally been intended to only cover medical professionals but has been expanded by court decisions
Hawaii	Certificate & Screening Panel	Certificate from an attorney verifying consultation with a licensed member of the defendant's profession	Engineers, architects, surveyors and landscape architects	Sanctions for failing to cooperate with panel	Costs of the panel are shared equally
Kansas	Screening Panel	File a memorandum requesting panel with the court	All licensed professionals (but not health care providers)	None	Costs of the panel are paid by the winning party or split if there is no decision
New Jersey	Affidavit	Affidavit from a licensed member of defendant's profession	Engineers and architects	Grounds for dismissal	Person signing affidavit must have substantially practiced in that area for 5 years
ACEC's Model Act	Conciliation Panel & Affidavit	Affidavit after the panel's decision from competent expert	Engineers, architects, surveyors, and landscape architects	Sanctions for failing to cooperate with panel	Costs of the panel are shared equally

California

Certificate of Merit Law

As of June 1995

West's
ANNOTATED
CALIFORNIA CODES

CODE OF CIVIL PROCEDURE

Sections 367 to 419

Volume 14

1995
Cumulative Pocket Part

Replacing 1994 Pocket Part supplementing 1973 main volume

Includes laws through the 1993–1994 Regular and First Extraordinary Sessions and the November 8, 1994, Election

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establishes a rebuttable presumption that the fees were not paid. This presumption is a presumption affecting the burden of producing evidence.

(Added by Stats.1982, c. 1543, p. 6007, § 3. Amended by Stats.1994, c. 587 (A.B.3600), § 3.7.)

Historical and Statutory Notes

1982 Legislation.

Former § 411.20 was repealed by Stats.1982, c. 1543, p. 6007, § 2.

1994 Legislation

The 1994 amendment, in subd. (a), inserted "except as provided in subdivision (d)," following "fee,"; and added subds. (d) and (e), relating to payment of the fee when a hearing is scheduled before the expiration of the 20-day period and the suspension of proceedings if the clerk performs a service and payment is made by check which is returned without payment.

Derivation: Former § 411.20, added by Stats.1969, c. 1610, p. 3363, § 3, amended by Stats.1970, c. 480, p. 952, § 7.

Library References

California Practice Guide: Civil Procedure Before Trial, Weil & Brown, see Guide's Table of Statutes for chapter paragraph number references to paragraphs discussing this section.

Notes of Decisions

1. In general

Where the husband and wife intend that a property-settlement agreement be incorporated into a court judgment to dissolve their marriage, the clerk should not file the agreement without the fee required for a "first paper" on behalf of a defendant. 61 Ops.Atty.Gen. 80, 2-28-78.

§ 411.30. Repealed by Stats.1986, c. 247, § 1, operative Jan. 1, 1989

Historical and Statutory Notes

The repealed section, added by Stats.1978, c. 1165, § 1, amended by Stats.1979, c. 988, § 1; Stats.1982, c. 1040, § 2; Stats.1983, c. 429, § 1; Stats.1984, c. 1705, § 1; Stats.1986, c. 247, § 1, relating to malpractice action, was repealed by its own terms on Jan. 1, 1989.

Notes of Decisions

In general 1
Certificate of merit 2
Validity ½

½. Validity

Requirement of filing of certificate of merit in medical malpractice suit, which did not toll § 583, was not equal protection violation, as requirement was rationally related to legitimate legislative purpose of ameliorating malpractice insurance crisis. Adams v. Roses (App. 2 Dist.1986) 228 Cal.Rptr. 339, 183 C.A.3d 498.

1. In general

Amendment to this section, effective in 1980, that operated to authorize filing of certificate of merit after filing of medical malpractice complaint, rather than requiring, as before, that complaint be accompanied by certificate of merit, was procedural, since new cause of action was not created, malpractice defendant was not deprived of any defense on merits and no vested rights were affected; thus, although plaintiff did not accompany complaint with certificate of merit as required when complaint was filed and when trial court in 1979, granted plaintiff's motion for relief from late filing, the failure was demurrable only and curable by filing of certificate as allowed by intervening amendment effective in 1980. Strauch v. Superior Court of Sacramento County (1980) 165 Cal.Rptr. 552, 107 C.A.3d 45.

2. Certificate of merit

Requirement that attorney's certificate of merit filed in medical malpractice action must indicate that plaintiff's counsel has consulted with licensed professional does not require that plaintiff's counsel consult with professional licensed in same discipline as defendant; rather, if after consultation with expert and review of facts, attorney concludes that there is reasonable and meritorious cause for filing action, objective of subd. (b)(1) of this section has been satisfied. Ammon v. Superior Court (Carpenter) (App. 1 Dist.1988) 252 Cal.Rptr. 748, 205 Cal.App.3d 783.

Counsel for patient bringing medical malpractice action against chiropractor satisfied requirement of certificate of merit, indicating that attorney has consulted with licensed physician and surgeon, dentist, podiatrist, or chiropractor, by submitting certificate of merit with complaint indicating that attorney consulted with licensed physician. Ammon v. Superior Court (Carpenter) (App. 1 Dist.1988) 252 Cal.Rptr. 748, 205 Cal.App.3d 783.

§ 411.35. Malpractice actions; architects, engineers, surveyors

(a) In every action, including a cross-complaint for damages or indemnity, arising out of the professional negligence of a person holding a valid architect's certificate issued pursuant to Chapter 3 (commencing with Section 5500) of Division 3 of the Business and Professions Code, or of a person holding a valid registration as a professional engineer issued pursuant to Chapter 7 (commencing with Section 6700) of Division 3 of the Business and Professions Code, or a person holding a valid land

surveyor's license issued pursuant to Chapter 15 (commencing with Section 8700) of Division 3 of the Business and Professions Code on or before the date of service of the complaint on any defendant, the plaintiff's attorney shall file the certificate specified by subdivision (b).

(b) A certificate shall be executed by the attorney for the plaintiff or cross-complainant declaring one of the following:

(1) That the attorney has reviewed the facts of the case, that the attorney has consulted with at least one architect, professional engineer, or land surveyor who is licensed to practice and practices in this state or any other state, or who teaches at an accredited college or university and is licensed to practice in this state or any other state, in the same discipline as the defendant or cross-defendant and who the attorney reasonably believes is knowledgeable in the relevant issues involved in the particular action, and that the attorney has concluded on the basis of such review and consultation that there is reasonable and meritorious cause for the filing of such action. The person consulted may not be a party to the litigation.

(2) That the attorney was unable to obtain the consultation required by paragraph (1) because a statute of limitations would impair the action and that the certificate required by paragraph (1) could not be obtained before the impairment of the action. If a certificate is executed pursuant to this paragraph, the certificate required by paragraph (1) shall be filed within 60 days after filing the complaint.

(3) That the attorney was unable to obtain the consultation required by paragraph (1) because the attorney had made three separate, good faith attempts with three separate architects, professional engineers, or land surveyors to obtain such consultation and none of those contacted would agree to such a consultation.

(c) Where a certificate is required pursuant to this section, only one certificate shall be filed, notwithstanding that multiple defendants have been named in the complaint or may be named at a later time.

(d) Where the attorney intends to rely solely on the doctrine of "res ipsa loquitur," as defined in Section 646 of the Evidence Code, or exclusively on a failure to inform of the consequences of a procedure, or both, this section shall be inapplicable. The attorney shall certify upon filing of the complaint that the attorney is solely relying on the doctrines of "res ipsa loquitur" or failure to inform of the consequences of a procedure or both, and for that reason is not filing a certificate required by this section.

(e) For purposes of this section, and subject to Section 912 of the Evidence Code, an attorney who submits a certificate as required by paragraph (1) or (2) of subdivision (b) has a privilege to refuse to disclose the identity of the architect, professional engineer, or land surveyor consulted and the contents of the consultation. The privilege shall also be held by the architect, professional engineer, or land surveyor so consulted. If, however, the attorney makes a claim under paragraph (3) of subdivision (b) that he or she was unable to obtain the required consultation with the architect, professional engineer, or land surveyor, the court may require the attorney to divulge the names of architects, professional engineers, or land surveyors refusing the consultation.

(f) A violation of this section may constitute unprofessional conduct and be grounds for discipline against the attorney, except that the failure to file the certificate required by paragraph (1) of subdivision (b), within 60 days after filing the complaint and certificate provided for by paragraph (2) of subdivision (b), shall not be grounds for discipline against the attorney.

(g) The failure to file a certificate in accordance with this section shall be grounds for a demurrer pursuant to Section 430.10 or a motion to strike pursuant to Section 435.

(h) Upon the favorable conclusion of the litigation with respect to any party for whom a certificate of merit was filed or for whom a certificate of merit should have been filed pursuant to this section, the trial court may, upon the motion of a party or upon the court's own motion, verify compliance with this section, by requiring the attorney for the plaintiff or cross-complainant who was required by subdivision (b) to execute the certificate to reveal the name, address, and telephone number of the person or persons consulted with pursuant to subdivision (b) that were relied upon by the attorney in preparation of the certificate of merit. The name, address, and telephone number shall be disclosed to the trial judge in an in-camera proceeding at which the moving party shall not be present. If the trial judge finds there has been a failure to comply with this section, the court may order a party, a party's attorney, or both, to pay any reasonable expenses, including attorney's fees, incurred by another party as a result of the failure to comply with this section.

This section shall remain in effect only until January 1, 1997, and as of that date is repealed.

(f) For purposes of this section, "action" includes a complaint or cross-complaint for equitable indemnity arising out of the rendition of professional services whether or not the complaint or cross-complaint specifically asserts or utilizes the terms "professional negligence" or "negligence."

(Added by Stats.1979, c. 973, p. 3334, § 1. Amended by Stats.1983, c. 414, § 1; Stats.1985, c. 1231, § 1; Stats.1988, c. 1070, § 1; Stats.1990, c. 204 (S.B.2089), § 1; Stats.1991, c. 272 (S.B.527), § 1.)

Repeal

Section 411.35 is repealed by its own terms on Jan. 1, 1997.

Historical and Statutory Notes

1983 Amendment. In subd. (a), substituted "every" for "any" preceding "action", inserted "including a cross-complaint", and inserted "or indemnity", and substituted "by" for "in" preceding "subdivision"; in subd. (b), inserted "or cross-complainant" in the first sentence; in subd. (b)(1), inserted a comma following "state", inserted "who" preceding "teaches", inserted "is licensed to practice in the state or any other state, in the same discipline as the defendant or cross-defendant and", and added the second sentence; in subd. (c), deleted "such" preceding "certificate", and added a comma following "filed"; in subd. (e), substituted "The" for "Such" preceding "privilege"; in subd. (g), inserted "in accordance with" and "or a motion to strike pursuant to Section 435"; and, in subd. (h), substituted "1987" for "1984", and substituted "that" for "such" preceding "date".

1986 Legislation

The 1986 amendment, in subd. (h), substituted "1989" for "1987".

1988 Legislation

The 1988 amendment rewrote subd. (h) which read: "This section shall remain in effect only until January 1, 1989, and as of that date is repealed."

1990 Legislation

The 1990 amendment added subd. (f) defining action; and made nonsubstantive changes in subd. (a).

1991 Legislation

The 1991 amendment in subd. (h), in the second paragraph, substituted "January 1, 1997" for "January 1, 1992" as the repeal date of the section.

Law Review Commentaries

Review of selected 1990 California legislation. 22 Pac. L.J. 437 (1991).

Library References

Negligence ⇐104.
C.J.S. Negligence §§ 178 to 180.
California Practice Guide: Civil Procedure Before Trial, Weil & Brown, see Guide's Table of Statutes for chapter paragraph number references to paragraphs discussing this section.

Legal Secretary's Handbook, Legal Secretaries, Inc., see Handbook's Table of Codes for paragraph number references to paragraphs discussing this section.

Notes of Decisions

1. Purpose

Purpose of statute requiring filing of certificate of merit in action against engineer for professional negligence is to discourage frivolous professional negligence suits against registered civil engineers. Guinn v. Dotson (App. 4 Dist. 1994) 28 Cal.Rptr.2d 409, 23 Cal.App.4th 262.

2. Reasonable expenses

Statute, stating that trial court may order payment of any reasonable expenses, including attorney fees, incurred by another party as result of failure to comply with statute requiring filing of certificate of merit in action against engineer for professional negligence, allows court to award as reasonable expenses, including attorney fees, expenses incurred in successful pursuit of fee award. Guinn v. Dotson (App. 4 Dist. 1994) 28 Cal.Rptr.2d 409, 23 Cal.App.4th 262.

3. Attorney fees

Reasonable paralegal fees, billed to prevailing civil engineer in property owners' negligence action against engineer arising from construction of street, were included as compensable element in term "attorney's fees" in statute stating that trial court may order payment of any reasonable expenses, including attorney fees, incurred by another party as result of failure to comply with statute requiring filing of certificate of merit in action against engineer for professional negligence. Guinn v. Dotson (App. 4 Dist. 1994) 28 Cal.Rptr.2d 409, 23 Cal.App.4th 262.

Court of Appeal could look to judicial construction of similar language in analogous statute to determine whether legislature intended term "attorney's fees," as used in statute stating that trial court may order payment of any reasonable expenses, including attorney fees, incurred by another party as result of failure to comply with statute requiring filing of certificate of merit in action against engineer for professional negligence, to include paralegal fees as element. Guinn v. Dotson (App. 4 Dist. 1994) 28 Cal.Rptr.2d 409, 23 Cal.App.4th 262.

4. Failure to file

Civil engineer was entitled to award of reasonable attorney fees for reasonable services of attorney and paralegals in obtaining order awarding to engineer reasonable expenses in property owners' negligence action against engineer due to owners' failure to comply with statute requiring filing of certificate of merit in an action

against an engineer for professional negligence. Guinn v. Dotson (App. 4 Dist. 1994) 28 Cal.Rptr.2d 409, 23 Cal. App.4th 262.

5. Favorable conclusion

Dismissal of professional negligence suit against engineer, which was condition precedent to settlement, was not "favorable conclusion," within meaning of attorney fee statute providing that, upon favorable conclusion of litigation as to any party for whom certificate of merit was filed, plaintiff's attorney may be required to identify person or persons consulted with and relied upon in preparation of certificate; dismissal did not reflect plaintiff purchaser's opinion that his suit would be unsuccessful, and while engineer made no monetary contribution toward settlement, his waiver of fees and costs in return for dismissal conferred valuable consideration upon plaintiff. Korbel v. Chou (App. 4 Dist. 1994) 33 Cal.Rptr.2d 190, 27 Cal.App.4th 1427.

"Favorable conclusion," within meaning of attorney fee statute providing that, upon favorable conclusion of litigation with respect to any party for whom certificate of merit was filed, attorney for plaintiff may be required to reveal identity of person or persons consulted with and relied upon by attorney in preparation of certificate, is same as "favorable termination" in context of malicious prosecution action. Korbel v. Chou (App. 4 Dist. 1994) 33 Cal.Rptr.2d 190, 27 Cal.App.4th 1427.

§ 411.36. Common interest development associations; occupational negligence of contractors; certificate of merit; filing; disclosure of consultant

(a) In every action brought by a common interest development association pursuant to Section 383, or cross-actions or separate actions arising therefrom for indemnity or contribution, arising out of the occupational negligence of a person holding a valid contractor's license pursuant to Chapter 9 (commencing with Section 7000) of Division 3 of the Business and Professions Code, on or before the date of service of the complaint on any defendant, the plaintiff's attorney shall file the certificate specified by subdivision (b). "Occupational negligence," as used in this section, means a negligent act or omission in the construction, reconstruction, repair, or improvement of a structure or other work of improvement which is the proximate cause of a construction defect or of damage to property resulting from such a construction defect. This section does not apply to causes of action based on strict liability in tort or express contractual indemnity.

(b) A certificate shall be executed by the attorney for the plaintiff or cross-complainant declaring one of the following:

(1) That the attorney has reviewed the facts of the case, that the attorney has consulted with at least one contractor who is licensed and does business in this state or who teaches at an accredited college or university and who is licensed in this state or any other state and who the attorney reasonably believes is knowledgeable in the relevant issues involved in the particular action, and that the attorney has concluded on the basis of that review and consultation that the named defendant or cross-defendant participated in the construction, installation, grading, or landscaping of those building elements or grounds alleged in the complaint or cross-complaint to have been negligently constructed, installed, graded, or landscaped. The person consulted may not be a party to the litigation.

(2) That the attorney was unable to obtain the consultation required by paragraph (1) because a statute of limitations would impair the action and that the certificate required by paragraph (1) could not be obtained before the impairment of the action. If a certificate is executed pursuant to this paragraph, the certificate required by paragraph (1) shall be filed within 60 days after filing the complaint.

(3) That the attorney was unable to obtain the consultation required by paragraph (1) because the attorney had made three separate good faith attempts with three separate contractors to obtain such a consultation and none of those contacted would agree to the consultation.

(c) Where a certificate is required pursuant to this section, only one certificate shall be filed, notwithstanding that multiple defendants have been named in the complaint or may be named at a later time.

(d) Where the attorney intends to rely solely on the doctrine of "res ipsa loquitur," as defined in Section 646 of the Evidence Code, or exclusively on a failure to inform of the consequences of a procedure, or both, this section shall be inapplicable. The attorney shall certify upon filing of the complaint that the attorney is solely relying on the doctrines of "res ipsa loquitur" or failure to inform of the consequences of a procedure or both, and for that reason is not filing a certificate required by this section.

(e) For purposes of this section, and subject to Section 912 of the Evidence Code, an attorney who submits a certificate as required by paragraph (1) or (2) of subdivision (b) has a privilege to refuse to disclose the identity of the contractor consulted and the contents of the consultation. The privilege shall also be held by the contractor so consulted. If, however, the attorney makes a claim under paragraph (3) of subdivision (b) that he or she was unable to obtain the required consultation with the contractor, the court may require the attorney to divulge the names of contractors refusing the consultation.

(f) A violation of this section may constitute unprofessional conduct and be grounds for discipline against the attorney, except that the failure to file the certificate required by paragraph (1) of subdivision

Hawaii

Certificate of Merit / Screening Panel Law

As of June 1995

HAWAII
REVISED STATUTES
ANNOTATED

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CHAPTER 672

DESIGN PROFESSIONAL CONCILIATION PANEL

Cross references. — As to professional engineers, architects, surveyors and landscape architects, see Chapter 464.

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§ 672-1. Definitions.

For the purposes of this chapter:

"Design professional" means a professional engineer, architect, surveyor, or landscape architect.

"Entities employing design professionals" means professional corporations or other business structures under which design professionals may practice and does not include nondesign professional entities. [L 1981, c 228, pt of § 1; am L 1985, c 36, § 2]

§ 672-2. Actions against architects, professional engineers, surveyors, and landscape architects.

In any action for damages arising out of the alleged professional negligence of actions performed in the professional practice of a person holding a license as a professional engineer, architect, surveyor, or landscape architect under chapter 464, before the time of filing the complaint, the aggrieved person shall file a claim with the design professional conciliation panel. [L 1981, c 228, pt of § 1; am L 1985, c 36, § 3]

[§ 672-2.1]. Determination of unsuitability.

Any party or any person served with notice of a claim may file a motion with the circuit court in the judicial circuit in which the claim arose for a determination that the subject matter of the dispute is unsuitable for review by a panel under this chapter; provided that no such application may be filed

within ten days of the date on which the claim is scheduled to be heard by a panel or after such a hearing has taken place.

In determining whether the subject matter of a dispute is unsuitable for disposition pursuant to this chapter, a court may consider:

(1) The magnitude of the potential award, or any issue of broad public concern raised by the subject matter underlying the dispute;

(2) Problems referred to the court where court regulated discovery is necessary;

(3) The fact that the matter in dispute is a reasonable or necessary issue to be resolved in pending litigation and involves other matters not covered by or related to this chapter;

(4) The fact that the design professional's involvement in the matter is distinctly secondary in importance to the involvement of parties not covered by this chapter;

(5) The potential for unreasonable delays in reaching any resolution of the matter by its referral to a panel pursuant to this chapter; or

(6) The fact that there are too many parties or issues involved to be effectively handled by the informal processes of this chapter.

Any such application to the circuit court shall be made and heard in a summary manner and in accordance with procedures for the making and hearing of motions. [L 1985, c 36, pt of § 1]

[§ 672-2.5]. Certificate of consultation.

(a) Any claim filed under this chapter shall be accompanied by a certificate which declares one of the following:

(1) That the attorney has reviewed the facts of the case, that the attorney has consulted with at least one design professional who is licensed to practice and practices in this State or any other state, or who teaches at an accredited college or university and is licensed to practice in this State or any other state, in the same discipline as the design professional against whom the claim is made and who the attorney reasonably believes is knowledgeable in the relevant issues involved in the particular action, and that the attorney has concluded on the basis of such review and consultation that there is a reasonable and meritorious cause for the filing of the claim. The persons consulted may not be a party to the case;

(2) That the attorney was unable to obtain the consultation required by paragraph (1) because a statute of limitations would impair the action and that the certificate required by paragraph (1) could not be obtained before the impairment of the action. If a certificate is executed pursuant to this paragraph, the certificate required by paragraph (1) shall be filed within thirty days after filing the claim; or

(3) That the attorney was unable to obtain the consultation required by paragraph (1) because the attorney has made three separate good faith attempts with three separate design professionals to obtain such consultation and none of those contacted would agree to such a consultation.

(b) Where an attorney intends to rely solely on a failure to inform of the consequences of a procedure, this section shall be inapplicable. The attorney shall certify upon filing of the claim that the attorney is relying solely on the failure to inform of the consequences of a procedure and for that reason is not filing a certificate as required by this section.

(c) For the purposes of this section, the attorney shall not be required to disclose the names of design professionals consulted to fulfill the requirements of subsection (a).

(d) Unless a certificate is filed pursuant to subsection (a) or (b), the claim shall not be received for filing by the department. [L 1985, c 36, pt of § 1]

§ 672-3. Design professional conciliation panel; composition, selection, compensation.

(a) There are established conciliation panels which shall review and render findings and advisory opinions on the issues of liability and damages in tort claims against professional architects, engineers, surveyors, and landscape architects.

(b) A design professional conciliation panel, hereafter called "the panel", shall be formed for each claim filed pursuant to section 672-4 and after each panel renders its decision or the claim is otherwise disposed of it shall be disbanded. Each design professional conciliation panel shall consist of one chairperson selected from among persons who are familiar with and experienced in the tort claims settlement process, one attorney licensed to practice in the courts of the State and experienced in trial practice, and one architect, engineer, surveyor, or landscape architect licensed to practice under chapter 464. The chairperson shall be appointed by the chief justice of the supreme court of Hawaii. The attorney shall be appointed by the chairperson from a list of not less than thirty-five attorneys experienced in trial practice submitted annually by the supreme court. The architect, engineer, surveyor, or landscape architect shall be appointed by the chairperson from a list of not less than thirty-five design professionals submitted annually by the board of registration of professional engineers, architects, surveyors, and landscape architects.

The chairperson shall preside at the meetings of the panel. The chairperson and all panel members shall be compensated at the rate of $300 per claim handled which will become payable when the decision of the panel is submitted and shall be paid allowances for travel and living expenses which may be incurred as a result of the performance of their duties and they shall be paid by the department of commerce and consumer affairs from funds collected from the claimant and defendant, to be shared equally. The claimant shall deposit $450 with the department upon the filing of the claim and the failure to do so shall result in the claim being rejected for filing. The design professional shall deposit $450 with the department within twenty days of being served with the claim and the failure to do so shall result in termination of proceedings under this chapter allowing the claimant to proceed in accordance

with section 672-8. If the claim is withdrawn, determined to be unsuitable for proceedings under this chapter, or otherwise terminated without participation by a panel, the department shall return all moneys collected to the respective parties.

The office and meeting space, secretarial and clerical assistance, office equipment and office supplies for the board shall be furnished by the department of commerce and consumer affairs.

The board of registration shall prepare a list of architects, engineers, surveyors, and landscape architects along with their respective specialties who shall then be considered consultants to the panel in their respective fields. Panel members may consult with other legal, technical, and insurance specialists. Any consultant called by the panel to appear before the panel shall be paid an allowance for travel and living expenses which may be incurred as a result of such person's appearance before the panel. Such costs shall be paid by the department of commerce and consumer affairs. [L 1981, c 228, pt of § 1; am L 1982, c 204, § 8; am L 1985, c 36, § 4]

§ 672-4. Review by panel required; notice; presentation of claims; termination.

(a) Any person or the person's representative claiming that a tort has been committed by the design professional or entities employing such design professionals shall file a claim with the department of commerce and consumer affairs before a suit based on the claim may be commenced in any court of the State. All claims shall be submitted to the department of commerce and consumer affairs in writing on forms provided by the department. If the claim is presented orally, the department of commerce and consumer affairs shall reduce the claim to writing. The claimant shall set forth facts upon which the claim is or may be based and shall include the names of all parties against whom the claim is or may be made who are known to the claimant. Within five business days thereafter, the panel shall give notice of the claim, by certified mail, to all architects, engineers, surveyors, or landscape architects and others who are or may be parties to the claim and shall furnish copies of written claims to such persons. Such notice shall set forth a date, not more than twenty days after mailing the notice, within which any design professional against whom a claim is made may file a written response to the claim, and a date and time, not less than five days following the date for filing a response, for a hearing of the panel. Such notice shall describe the nature and purpose of the panel's proceedings and shall designate the place of the hearing. The times originally set forth in the notice may be changed by the chairperson, on due notice to all parties, for good cause; provided that a party requesting the rescheduling of the hearing within seven days of the scheduled date shall be required in the sole discretion of the panel chairperson to additionally compensate the panel in an amount equal to the fee panel members receive pursuant to section 672-3.

(b) At any time, by mutual consent of the parties involved, the department of commerce and consumer affairs, prior to the appointment of the chairperson, or the chairperson after the chairperson's appointment, may terminate the proceedings and the claimant may proceed in accordance with section 672-8. [L 1981, c 228, pt of § 1; am L 1982, c 204, § 8; am L 1983, c 138, § 1; am imp L 1984, c 90, § 1; am L 1985, c 36, § 5]

§ 672-5. Design professional conciliation panel hearing; fact-finding; evidence; voluntary settlement.

Every claim of a tort shall be heard by the design professional conciliation panel within thirty days after the date for filing a response. No persons other than the panel, witnesses, and consultants called by the panel, and the persons listed in section 672-6 shall be present except with the permission of the chairperson. The panel may, in its discretion, conduct an inquiry of a party, witness, or consultant without the presence of any or all parties.

The hearing shall be informal. The panel may require a stenographic record of all or part of its proceedings for the use of the panel, but such record shall not be made available to the parties. The panel may receive any oral or documentary evidence. Questioning of parties, witnesses, and consultants may be conducted by the panel, and the panel may, in its discretion, permit any party, or any counsel for a party to question other parties, witnesses, or consultants. The panel may designate who, among the parties, shall have the burden of going forward with the evidence with respect to such issues as it may consider, and unless otherwise designated by the panel, when design professional's records have been provided for the claimant's proper review, such burden shall initially rest with the claimant at the commencement of the hearing.

The panel shall have the power to require by subpoena the appearance and testimony of witnesses and the production of documentary evidence. When such subpoena power is utilized, notice shall be given to all parties. The testimony of witnesses may be taken either orally before the panel or by deposition. In cases of refusal to obey a subpoena issued by the panel, the panel may invoke the aid of any circuit court in the State, which may issue an order requiring compliance with the subpoena. Failure to obey such order may be punished by the court as a contempt thereof. Any member of the panel, the director of the department, or any person designated by the director of the department may sign subpoenas. Any member of the panel may administer oaths and affirmations, examine witnesses, and receive evidence. Notwithstanding such powers, the panel shall attempt to secure the voluntary appearance, testimony, and cooperation of parties, witnesses, and consultants without coercion.

At the hearing of the panel and in arriving at its opinion the panel shall consider, but not be limited to, statements or testimony of witnesses, construction documents, inspection reports, calculations, and other records kept in the usual course of the practice of the design professional without the necessity for