FINAL
Signed:

MINUTES

MONTANA SENATE
56th LEGISLATURE - REGULAR SESSION

COMMITTEE ON PUBLIC HEALTH, WELFARE AND SAFETY

Call to Order: By **CHAIRMAN AL BISHOP**, on March 3, 1999 at 3:05 P.M., in Room 410 Capitol.

ROLL CALL

Members Present:
Sen. Al Bishop, Chairman (R)
Sen. Fred Thomas, Vice Chairman (R)
Sen. Sue Bartlett (D)
Sen. Dale Berry (R)
Sen. John C. Bohlinger (R)
Sen. Chris Christiaens (D)
Sen. Bob DePratu (R)
Sen. Dorothy Eck (D)
Sen. Eve Franklin (D)
Sen. Duane Grimes (R)
Sen. Don Hargrove (R)

Members Excused: None.

Members Absent: None.

Staff Present: Susan Fox, Legislative Branch
Martha McGee, Committee Secretary

Please Note: These are summary minutes. Testimony and discussion are paraphrased and condensed.

Committee Business Summary:
Hearing(s) & Date(s) Posted: HB 126, HB 52, HB 111, 2/19/1999
Executive Action: None

HEARING ON HB 126

Sponsor: **REP. ROYAL JOHNSON, HD 10, Billings**

Proponents: **Drew Dawson, Department of Public Health & Human Services**
Doug Kuntzweiler, St. Peter's Hospital
Dr. Warren Bowman, Internist & National Ski Patrol
Paul Laisy, Missoula Rural Fire District
Beda Lovitt, Montana Medical Association
Jim Ahrens, Montana Hospital Association
Sami Butler, Montana Nurses' Association
Pat Clinch, Montana Council of Professional Fire Fighters
Reed Redman, Montana Emergency Medical Association
Jani McCall, City of Billings

Opponents: **Al Smith, Montana Trial Lawyers Association**

Opening Statement by Sponsor:

REP. ROYAL JOHNSON, HD 10, Billings, said **HB 126** allowed for the promulgation of rules for the licensing, etc., of defibrillators (AEDS). He explained fibrillating as the immediate stoppage of the flow of blood to the head. Such a person could last about 10 minutes, under good circumstances. The bill allowed for putting out the rules so people, besides medical and emergency persons, would know how to use the machines. For example, it might be a good thing if there were one or two or three defibrillators in prominent places here in the Capitol, and people who were trained to use them.

Proponents' Testimony:

Drew Dawson, Department of Public Health & Human Services (DPHHS), read his written testimony **EXHIBIT(phs48a01)**.

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Dr. Doug Kuntzweiler, St. Peter's Hospital, said heart disease was still the #1 killer in America, in both men and women. The main cause was disturbance in the rhythm of the heart, which was often otherwise healthy. He stated a high quality of life for these people would remain, if they could be resuscitated enough for a coronary by-pass or some other medical procedure. That was the reason for the development of the defibrillator, which applied an electrical charge to the heart to reset the electrical activity of the heart so it could begin to beat again. However, that had to be done quickly, because the sooner they could get the heart back into the normal rhythm, the greater the chance of survival. He reported currently, people were trained in CPR and the emergency medical technicians (EMTs) would be trained in the defibrillator also; however, it took a long time to get the defibrillator there. The machines were simple and operated themselves; in fact, they could be operated by lay people with minimal training. It should be considered an extension of CPR, and dramatically increased the chances of restarting the heart.

Dr. Warren Bowman, Internist & National Ski Patrol, said the National Ski Patrol supported this legislation and others like it in other states. He said they saw heart attacks and cardiac arrest in ski areas, so he saw many benefits in **HB 126**. He commented residents of Cook City were 100 miles from a hospital, so they had an AED, with three people trained to use it, and four others available for training. He stated it was important for paid ski patrollers to have liability protection, because if they thought they might be sued, they would not be interested.

Paul Laisy, Missoula Rural Fire District, said he was selected to train the trainers across the state to use the defibrillator. He shared the story of a man who was brought back to life by a defibrillator, and two weeks later the man walked into the fire station to thank them. He stated the training program was comprehensive; in fact, they called it training in context. At the end of the training session, they had to successfully complete a practical scenario where they had to actually use the defibrillator and do CPR. They also had to complete a written test on the knowledge. The Montana State Fire Chiefs' Association also supported the bill.

Beda Lovitt, Montana Medical Association (MMA), said they supported **HB 126** in the House, and the amendments as well. The bill was well-crafted and had safeguards. She urged its support.

Jim Ahrens, Montana Hospital Association, said he urged support for the bill.

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Sami Butler, Montana Nurses' Association, said she had defibrillated hundreds of hearts, so she had first-hand knowledge of what a life-saving device the defibrillator was. She encouraged support for **HB 126.**

Pat Clinch, Montana State Council of Professional Fire Fighters (MSCPFF), said they were in favor of the bill, because time was the most important critical factor in saving someone's life. He explained in Helena, someone from the fire department could be at the Capitol in about three minutes; however, it could take another three or four minutes to find the scene of the need. Therefore, it was important to have these machines in large buildings. He said he was one of the first EMTs in Montana who was trained to use this machine. He stressed the machines were almost foolproof. He urged support for the bill.

Reed Redman, Montana Emergency Medical Association, said the Association supported **HB 126** because it was well-integrated with the current emergency system. He urged its consideration.

Jani McCall, City of Billings, expressed support for **HB 126**.

Opponents' Testimony:

Al Smith, Montana Trial Lawyers' Association, said they were in favor of the purpose and intention of the bill; however, "gross negligence" was not in the bill. The language on Page 7, Lines 6-7, was "willful or with wanton disregard". He said the machines were not made for use on infants or small children, and a trained person would learn that as part of his or her training. If someone in the field went ahead and used the defibrillator on those infants or small children, that would be gross negligence, but not willful or wanton disregard. The language in the bill provided they would bear no "gross negligence" responsibility for their actions; in fact, their responsibility would be "willful and wanton disregard". He reiterated the machines were almost 100% foolproof, but mistakes could be made. Other states went to their "Good Samaritan" statutes and inserted the pertinent language, or they used the language in **EXHIBIT(phs48a02)**, which was based on **EXHIBIT(phs48a03)**. He again stated they were in favor of the bill, except for the negligence standard.

{Tape : 1; Side : A; Approx. Time Counter : 23.5}

Questions from Committee Members and Responses:

SEN. JOHN BOHLINGER asked for comment on the amendments by Al Smith **(EXHIBIT 2)**. **REP. ROYAL JOHNSON** said if tightening the language was necessary, neither he nor the sponsors had a problem.

SEN. BOHLINGER asked the same question to **Drew Dawson**, who said portions of the "Good Samaritan" law were appropriate; however, parts of it were confusing. "Without compensation" was included in the bill, because paid security persons, professional ski patrols, etc., would not be included in the realm of the "Good Samaritan" law. He said it was important the training program, the physician and entity offering the AED had exemption from "up to gross negligence." Whatever amendments were made, it was important to maintain those basic principles.

SEN. BOHLINGER commented testimony revealed one defibrillator cost $3,000; however, the Fiscal Note showed no impact. He wondered if DPHHS had plans for acquiring these machines. **REP. JOHNSON** said they did not, because they were not dictating who needed to use them, who should buy them, etc. This was strictly pay-as-you go, i.e., if a business wanted the machine, it would buy the machine.

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SEN. B.F."CHRIS" CHRISTIAENS asked for elaboration on each area used and having a control physician. **Drew Dawson** said the position would be contemplated in administrative rule, and it would be addressed in Section 1(D) or Section 3, Subsection 5.

SEN. CHRISTIAENS asked for further clarification, using the example of the Capitol having a program, and wondered if the control physician would be from St. Peter's Hospital. **Mr. Dawson** said that probably would be the case, provided they were given the immunity protection, so they would not have to worry about the compensation or liability. He said the physician could also be one from another area of Helena who would choose to work with them. The important thing would be to make it fairly easy to provide the medical oversight, and it was also important to remember it was a medical device which needed medical direction and control.

SEN. CHRISTIAENS asked if the bill was based on a model from another state. **Drew Dawson** said it was based on an initial draft by the American Heart Association, which the Association wanted to use as national model legislation.

SEN. CHRISTIAENS asked about the liability for ski patrolmen and how they were currently covered. **Dr. Warren Bowman** said volunteer ski patrolmen had liability insurance for mistakes in training, which was covered by the National Ski Patrol. Mistakes in actual giving of first aid or accidents were covered by the area of work. A ski patrolman had to be trained in the same way as any other person, which was through a physician taking responsibility for training and oversight. Most ski patrols had a medical advisor who assumed this responsibility.

SEN. CHRISTIAENS asked who paid that physician's liability coverage. **Dr. Bowman** said many insurers would allow the insurees to do certain types of uncompensated, volunteer work, which would be covered by the company.

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Closing by Sponsor:

REP. ROYAL JOHNSON reminded the Committee only trained personnel would be using the fibrillator, and if it had concerns about the liability limitations, he would consider amendments to clarify the language, as being friendly. Also, the bill needed a two-thirds vote in the Senate, which was something it already got in the House.

HEARING ON HB 52

Sponsor: **REP. WILLIAM "RED" MENAHAN, HD 57, Butte**

Proponents: **None**

Opponents: **None**

Informational: **Major James Moran, Department of Military Affairs**

Opening Statement by Sponsor:

REP. WILLIAM "RED" MENAHAN, HD 57, Butte, said the bill extended the power of attorney, for family reasons, when National Guard members were called to duty for an extended period of time.

Proponents' Testimony: None.

Opponents' Testimony: None.

Informational Testimony:

Major James Moran, Department of Military Affairs, read his testimony **EXHIBIT(phs48a04)**.

{Tape : 1; Side : B; Approx. Time Counter : 12}

Questions from Committee Members and Responses:

SEN. B.F."CHRIS" CHRISTIAENS asked if the intent was to ask for durable power of attorney. **Major James Moran** said the definition of "durable power of attorney" was power of attorney continued to act in case of mental incapacity or inability to be in charge of one's own affairs.

SEN. CHRISTIAENS asked if the code specifically stated the family-care power of attorney expired upon completion of the extended tour of duty. **Major Moran** said it was geared more toward peace-time extended periods of duty, such as temporary tours of duty, continuous schooling, etc.

SEN. CHRISTIAENS asked if he completed a temporary tour of duty and returned, would he need to enter into another family-care power of attorney. **Major Moran** said he would most likely be back in-state, so the process would not be as arduous as if he were at Ft. Benning, Georgia, trying to execute the process from there. He said the military society, as in the civilian, was experiencing more and more single parent families, and whatever could be done to ease those challenges would be helpful.

SEN. SUE BARTLETT said she did not see the power of attorney automatically lapsing, according to the statute, in the bill. She wondered if that was in another part of the law. **Major Moran** said it would be as long as the 180 days were continuous, pursuant to Title 32. In other words, once the continuous service had been completed, the family-care power of attorney would lapse automatically, and a new one would need to be executed.

SEN. AL BISHOP commented the guardian would have to be court-appointed, or was there another kind of guardian. **Major James Moran** said he was correct, but there would be a problem if, for example, he was the court-appointed guardian of his niece and was also a Guardsman who was called away to duty. In that case, he would need some mechanism to be able to provide for her, i.e., delegate duties to someone else.

SEN. BISHOP was of the opinion that could not be done under the probate section because there was no provision there. **Major Moran** said it was his opinion the proposition of the Department of Military Affairs, in **HB 52**, did not get into that argument.

Closing by Sponsor:

REP. WILLIAM "RED" MENAHAN said he closed.

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HEARING ON HB 111

Sponsor: **REP. MARY ANNE GUGGENHEIM, HD 55, Helena**

Proponents: **John Johnson, Shodair Hospital**
Kathryn Berry, Shodair Hospital

Claudia Clifford, State Auditor's Office
Beda Lovitt, Montana Medical Association
Jim Ahrens, Montana Hospital Association
Kip Smith, Montan Primary Care
Susan Witte, Blue Cross/Blue Shield
Betty Beverly, Montana Senior Citizens' Association
Chris Jankowski, American Council of Life Insurance
Greg Van Horssen, State Farm Insurance
Page Dringman, Health Insurance Association of America
Mona Jamison, Shodair Hospital
Sandy Lowden, State Farm Insurance

Opponents: **None**

Opening Statement by Sponsor:

REP. MARY ANNE GUGGENHEIM, HD 55, Helena, drew her opening remarks from **EXHIBIT(phs48a05)**. She also offered the amendments in **EXHIBIT(phs48a06)**.

{Tape : 2; Side : A; Approx. Time Counter : 12.7}

Proponents' Testimony:

Dr. John Johnson, Shodair Hospital, said genetic discrimination by health insurances was currently more a potential than a reality, but consumers were concerned about taking genetic testing because of its impact on their health insurance, life insurance and their jobs. He said they told people before they had genetic testing, they should line up all those things so they would not suffer adverse consequences. He related how genetic testing could reveal a risk of a clotting disorder in a person, which would be helpful in preventing complications during that person's lifetime. It would be useful in taking proactive steps to prevent those complications. He stressed this legislation would protect only those who had exhibited no manifestations of genetic disorders. **Dr. Johnson** said some disorders were rare, while others were more common, such as a clotting disorder, which affected about 36,000 Montanans. He also commented everyone carried about five or six genes which were not the correct version of the gene; however, sometimes people were not aware of that during their lifetime. He shared the true story of a man whose genetic testing revealed a propensity toward breast cancer, but through awareness, he was able to take steps to stay as healthy as possible. This man urged passage of **HB 111** to prohibit discrimination by insurance companies toward those who opted for genetic testing. **Dr. Johnson** also urged favorable consideration of **HB 111**.

{Tape : 2; Side : A; Approx. Time Counter : 19.7}

Katherine Berry, **Shodair Hospital**, said a genetic counselor's job was to provide information and support to couples and families regarding genetic and potentially genetic conditions. She said during her tenure at Shodair, she worked with approximately 2,000 families, and she was in favor of **HB 111** for several serious life-planning reasons, including marriage, whether to have children, deciding on a career path or planning for the future regarding physical decline. She said more effective health surveillance strategies could result from knowing one's gene status, such as breast cancer. If a person had testing and was found she did not carry the gene, costly mammograms or preventive mastectomies could be avoided. On the other hand, if a female were found to carry the breast cancer gene, early detection measures could begin, which would also result in cost savings. She stated when a family dealt with a member's chronic illness, there was a great deal of stress, depression, decreased productivity and problems in family dynamics. Some people felt more in control if they had a knowledge of their gene status.

She explained people were reluctant to have gene testing because they were concerned with discrimination issues. She related the story of Bill, whose mother contracted Huntington's Disease in her mid-life, and eventually died from it. Bill came to Shodair with his fiancee for counseling in order to learn more about genetic testing, because he had a 50% risk of having the gene and developing the condition. He also was concerned about having children to whom he could pass the gene. They met a couple of times and eventually he had a blood draw, so the testing could be done. The result of the testing was Bill did not carry the gene; therefore, their having children would be safe in that regard. She said all people carried genes which could eventually cause trouble. She urged the Committee to pass **HB 111**, which would make the genetic testing available to all.

Claudia Clifford, **State Auditor's Office**, said the bill was a public policy issue which many states were considering; in fact, about 30 states already had similar laws. There already was some protection in group insurance, but the bill was getting at individual policies, as well as expanding the protections under group coverage. However, consumers had a major fear if they took advantage of this fast-paced, developing technology, they could be denied insurance. **Ms. Clifford** summarized the story in **EXHIBIT(phs48a07)** and stressed the lady chose to pay for the genetic testing herself, so there would not be a chance she would be denied insurance. This bill dealt with treating healthy people when they applied for insurance; therefore, they should be underwritten. There was no guarantee these genetic conditions would manifest themselves; in fact, it just showed a propensity toward a particular problem. She asked for support of **HB 111.**

Beda Lovitt, Montana Medical Association, urged support for the bill.

Jim Ahrens, Montana Hospital Association, said they supported the bill and urged the Committee's support also.

Kip Smith, Montana Primary Care, said they supported the bill, but not the amendment.

Susan Witte, Blue Cross/Blue Shield (BC/BS), said they supported the bill.

Betty Beverly, Montana Senior Citizens' Association (MSCA), said they were in support of **HB 111.**

Chris Jankowski, American Council of Life Insurance (ACLI), said they supported the bill if it was amended.

Greg Van Horssen, State Farm Insurance, said they supported the bill, with the sponsor's amendments. However, they had some concerns with the bill's existing definitions, so he distributed copies of **EXHIBIT(phs48a08).** He said State Farm could support the definitions in the exhibit.

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Page Dringman, Health Insurance Association of America (HIAA), said they would support the bill with the amendments offered by both the sponsor and State Farm. She referred to Section 7 and said she was concerned with the definition of "genetic information", because it could include family history. If this genetic information was prohibited for anything other than therapeutic purposes, an insurance company may not be able to set reserves, set losses, consider utilization review analysis, etc. The company might want to use genetic information in setting the reserves, not discrimination, and that would not be a therapeutic purpose.

Mona Jamison, Shodair Children's Hospital, said they supported the bill, as well as the amendments by the sponsor. However, they opposed the definitions presented by State Farm; in fact, no other state or Canadian province had adopted their amendment. She stressed the group, Ethical and Legal Social Issues (ELSI), that developed the definitions submitted by State Farm, did not mean it for anti-discrimination legislation. Rather, the proposed definition was developed as part of the document designed to promote awareness of crucial, genetic issues. She reiterated their opposition to the State Farm amendments was because it was a 13th-hour proposal and it was never developed for the purposes of this type of legislation. She asked the Committee to favor the bill with the sponsor's amendments, but resist the amendments by State Farm.

Dr. Sandy Lowden, State Farm Insurance, said they supported the bill. He said he was the one who brought the (ELSI) definition. This working group was formed to look at the impact of genetic testing, how it would be controlled, who would do it, etc. He stressed the Committee should look at the definition and consider stopping using the genetic testing inappropriately. It would be reasonable that genetic testing not be used to be prohibited from having insurance, and should not be ordered by them; in fact, the test should be ordered by genetic counselors. He stated there were serious problems in the current definition of genetic testing, because the way it was written had potential for a great court case. The definition should be specific, rather than all-encompassing.

Opponents' Testimony: None.

{Tape : 2; Side : B; Approx. Time Counter : 7.4}

Questions from Committee Members and Responses:

SEN. FRED THOMAS asked for further explanation of the definition proposed by State Farm. **Greg Van Horssen** said the concerns regarding the current definitions in the bill, were discussed in the House hearing. He said the concern should be what exactly was a genetic test and genetic information, as stated by the bill and its potentially becoming law. The bill defined "genetic information" as information derived from genetic testing or a medical evaluation. He suggested it seemed appropriate, on the surface; however, the concern should cover the definition of a medical evaluation and what type of information could come from that evaluation. Also, under this definition, was all such information genetic information. Another concern was a series of standardized tests, normally identified as routine tests, could become, under this definition, a test for genetic information. He said they had the same concerns in the exclusions to the definition of "genetic tests", because "including but not limited to" left it wide open.

Also, according to the language, many routine tests were arguably designed with dual purposes. They felt that language would be difficult from a litigation perspective. When important issues, such as this, were being legislated, the attempt should be made to carefully define the information they intended to limit. State Farm felt the bill could benefit from clarification of the discussed definitions.

SEN. THOMAS asked the sponsor who wrote the definition in the bill. **REP. MARY ANNE GUGGENHEIM** said it was a process, not a person. She felt they were very clear in their intent to exclude genetic trait information from discriminatory insurance practices, when there was no manifestation of the condition.

SEN. THOMAS asked for comment on the bill from **Dr. Dan Scott, Internist, State Farm Life & Health**, said the intent of the bill was clear and they supported it through the ELSI amendment presented by State Farm. They were concerned this definition could mean in the future, as testing became more prevalent, even a normal blood sugar test, for example, could be construed as a genetic test. He reported **Dr. Sandy Lowden** was an internationally, recognized geneticist, a pediatrician who practiced biogenetics in Toronto for 25 years and served seven or eight years as a medical director. He was now retired and involved in genetic consulting, primarily with insurance carriers, mainly to raise the level of knowledge and understanding of this complex subject. It was his opinion clarifying and simplifying the language would demonstrate leadership in this arena.

{Tape : 2; Side : B; Approx. Time Counter : 17.2}

SEN. THOMAS asked for more discussion on the definition. **Dr. John Johnson** said the controversial language came from the Florida law. He said many other tests were used every day in clinical genetics, in order to make a diagnosis in someone with a manifestation. However, there were situations where things were discovered incidentally, through a routine test. The question was what would be done with that information, and they wanted to ensure that information was not a cause for that otherwise-healthy person to suffer discrimination. He reported elements of the ELSI definition were spread throughout the language. They were concerned about the identification of a genetic trait, which could be gotten through genetic testing or genetic information.

SEN. EVE FRANKLIN asked about the relationship between karyotypes and phenotypes. **Dr. Johnson** said karyotypes was a chromosome test, which was not a problem. The ELSI definition of phenotypes would open up a huge "can of worms" because it was a manifestation. In other words, if genetic testing for a phenotype was not allowed, there would be no testing for any genetic disorder. That was the reason this definition was not proposed.

SEN. FRANKLIN asked for restatement of the potential difficulty with "phenotype." **Dr. Johnson** said for example, if someone was tested for "Guthrie Disease", they wanted to protect the person who was 20 years old, whose father was 50 and had the disorder. The young person tested positive, but currently, was perfectly healthy; however, if he was a bit shaky, he was showing a phenotype. This would mean genetic testing included phenotype, but it could not be used for discrimination; therefore, the disorder could not be diagnosed.

{Tape : 3; Side : A; Approx. Time Counter : 0}

SEN. FRANKLIN asked the same question of **Dr. Sandy Lowden**, who said it was the perfect description of a phenotype; however, ELSI definition said a genetic test was the analysis of the DNA, RNA, chromosomes, proteins and certain metabolites in order to detect heritable disease-related genotypes, mutations, phenotypes or karyotypes for clinical purposes. In other words, the test was an analysis of all these things, in order to detect a person had the disease, or was predisposed to it. The phenotype was not used as part of the analysis. He had no problem with leaving that word in there. The committee which developed this definition included geneticists, people from consumer support groups, lawyers, bioethicists and regulatory agencies.

SEN. DUANE GRIMES commented he understood it was the sponsor's intention not to exclude routine tests or utilization analysis. **REP. GUGGENHEIM** said it was not her intent to alter current practices of insurance underwriting, other than to specifically exclude these genetic tests relative to genes or DNA in a person who had no manifestation of the condition.

SEN. GRIMES asked if the threshold would be if the condition had been manifested. **REP. GUGGENHEIM** affirmed. **SEN. GRIMES** stated it another way: A genetic test was for something which had not been manifested, either in the person or family history, and that was the threshold. **REP. GUGGENHEIM** affirmed, explaining they tried to state that on Lines 17-18. They tried diligently, over the course of many months, to refine it so they as a group could understand what they were talking about. She reiterated they were not trying to alter current practices, but were trying to anticipate new technology.

SEN. GRIMES asked for a copy of the Florida law and the sponsor said she would get it.

SEN. GRIMES asked if "genetic trait" was defined identically in the Florida law. **Dr. John Johnson** said Florida used "genetic information".

SEN. GRIMES said his concern with "genetic information" and "genetic testing" both seemed to be tied to the definition of "genetic trait." He wondered if the definition of "genetic trait" was unduly broad and included routine tests which the sponsor wanted excluded. **Dr. John Johnson** said they could devise a very strict and narrow definition of "genetic testing"; however, as a clinical geneticist, he knew that was not the correct definition of "genetic testing", because they used all the information they could get in order to make a diagnosis. He said in the case of a known genetic blood disorder, a routine blood test could be a genetic test; therefore, they wanted to reserve some protection in this law for those people. In other words, they did not want to exclude tests which contained genetic information, which were used to re-rate a person.

SEN. GRIMES said pre-manifestation and post-manifestation did not seem to be in the bill. He wondered if it would hurt the bill to include them. **Dr. Johnson** said that was already included on Line 20.

{Tape : 3; Side : A; Approx. Time Counter : 8.8}

SEN. B.F. "CHRIS" CHRISTIAENS asked several people which amendments they meant. **Chris Jankowski** said the amendments by the sponsor, **Page Dringman** supported both sets and **Greg Van Horssen** said State Farm supported the sponsor's amendments, but they had grave concerns over the issues in their amendments and hoped the Committee would consider them.

SEN. CHRISTIAENS asked if the ELSI definition was in any of the 30 states which already had this in place. **Dr. Sandy Lowden** said it was not, because most of their laws were developed before the definition was published.

Dr. Lowden said the business of whether or not someone had a disease differed from proponents suggesting if DNA was measured and a bit of DNA mutation was found, but nothing was wrong, they did not have the disease, though they could be predisposed to it. Sometimes it was difficult to draw the line between having the disease and a predisposition to it. Therefore, it was hard to use the definition they developed.

SEN. CHRISTIAENS asked if both his parents had contracted cancer and died, he would have a predisposition greater than average toward it. He wondered if that was used in rating. **Dr. Lowden** said it was not, because even though he had a predisposition, the rating would not be very high, because older age made a difference. Also, this was a competitive industry, and if his company rated him because both his parents had cancer, another company would sell him a policy. It was important for insurance companies to sell policies, i.e. they could not afford not to sell them. In Montana, State Farm sold 97% of the policies for which application was made, and in most of the policies declined, the people were older and had serious things wrong with them.

SEN. CHRISTIAENS said he did not argue with the selling; however, those people would pay higher premiums. **Dr. Lowden** said it depended on the disease and how long ago they had it. However, if a woman had a predisposition toward cancer, but had not contracted it, their company would consider her a standard risk, because she would tend to watch very closely for the symptoms. Therefore, her chance for survival was very high.

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SEN. DOROTHY ECK commented the bill had been available for review since August, and wondered if **Greg Van Horssen** had done so. He said he was advised some of State Farm's comments on the bill were made in September or October. Once the bill was introduced, it received more scrutiny, which resulted in an awareness of raising these concerns. They raised them in the House and changes were made there and were in the present bill; however, the geneticists said the changes did not address the problem.

SEN. ECK commented she was surprised the definition from State Farm had not been made into an amendment between the time **HB 111** left the House and arrived in Senate Public Health. **Greg Van Horssen** said the definition came to him about 96 hours before the meeting, and was based on the concerns the doctors had. As soon as possible, a meeting was set up with the sponsor of the bill and the commissioner's office. Mona Jamison was also there and part of the discussion.

SEN. GRIMES referred to Page 4, Lines 19-21, and said if the text between the commas was removed, major changes would be made in the way insurance companies did their business and utilization analysis. **Dr. John Johnson** said there was no good word for this; in fact, there had even been problems in the genetic in coming up with names for genes. Other laws used the term "trait" or "characteristic", and they used "trait" because it had been around longer. He said if a person was not currently affected, he or she should be rated thus.

SEN. SUE BARTLETT asked why the bill should not include life, disability and long-term care coverages. **Chris Jankowski** said they supported the amendments to exclude life, disability and long-term care coverage because they were financial security products. They did not provide benefits to help people get health care, as health insurance did. The reason the bill should apply to health insurance only, was insurance was fundamental and let people get better. A balancing act was in effect, in that the chief availability of financial service and security products was balanced with an attempt to help people get better. Also, 39 states had passed laws, and 38 of them had laws applying only to health insurance, which was a good policy decision.

{Tape : 3; Side : A; Approx. Time Counter : 26.7}

SEN. BARTLETT asked what would be different for a life insurance company. **Chris Jankowski** said life insurance companies did not have plans to require genetic testing; however, if the consumer knew about existing genetic information and wanted to purchase a $500,000 life insurance policy, under this bill, the insurance company could do nothing about it. They were not required to disclose the information; therefore, the opportunity for fraud was huge. The result would be the costs being passed on to healthy people. He said they used some genetic information because it was already in the medical file, which the person sent over for individual underwriting. Once a life insurance policy was issued and premiums paid, it could not be canceled; however, health insurance could.

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SEN. BARTLETT said life insurance was sold for years without knowledge of genetic testing. She wondered why it was different now, because it was still the same pool of human beings. **Mr. Jankowski** said if there could be a guarantee that nobody currently knew anymore than they did 50 years ago, they could keep the same rates and underwriting; however, there was more and more information which was helping people. In fact, the playing field was shifting toward the consumer; however, the fact was healthy people were paying more, because the companies were not planning on going out of business.

SEN. FRED THOMAS asked if the ELSI language defined genetic testing. **Dr. John Johnson** said it was one they actually used to develop their own language; however, he wanted to continue to use theirs, because those incidental situations were excluded. He referred to "heritable", which usually meant inherited through the family; however, some genetic disorders were not inherited from the parents, but occurred for the first time in the individual. He said some of the laws were developed since the definitions came out, and they used the best of everything they could find.

SEN. THOMAS said if the bill was passed, it would be the only state law where the definition could be found. **Dr. Johnson** said the language in Florida would be close.

SEN. THOMAS asked for follow-up. **Dr. Sandy Lowden** said there was value in using a common definition which was used across the continent, because it made it easier in the court room and did not exclude the same test done on someone with the disease. He preferred definitions that could be used with different issues. If the definition was changed, there was "word smithing" to do. He was concerned the current definition would end up in court rooms with people not knowing how to interpret it, on the basis of different metabolites, even though the intentions in the Committee room were clear.

SEN. BOB DEPRATU asked for another opinion on why life, long-term disability, etc., should not be included. **Dr. Dan Scott** said the ACI definition was about as good as it could get, in that it was a financial product, it was something they all desired and the desire was to get the product based on the best price and on their present health. It was not a group product, but was underwritten on an individual basis. The individual would not be rated but considered on his or her medical record. The named kinds of insurance were based on the person's condition at the time of sale.

SEN. DUANE GRIMES suggested substituting the Florida law for "information", "testing" and "trait". He wondered if **Dr. Lowden** and **Dr. Johnson** would consider that.

SEN. EVE FRANKLIN asked **Dr. Sandy's Lowden's** role and was told he was a consultant to State Farm Insurance.

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Closing by Sponsor:

REP. MARY ANNE GUGGENHEIM said 24 hours earlier, there had been a meeting with these people, and she understood that as long as life insurance was excluded, they would be comfortable with the bill as presented. She said there was a difference between when it was and was not termed a disease. She referred to the blood disorder, and said it related to how the blood cells looked under a microscope. She said sometimes when that was found, the person could eventually end up with an enlarged spleen or tendency to trap some blood cells; however, sometimes the cells under the microscope just looked different. In that case, it was a test. This was very complicated, but she wanted to bring the focus back to the intention, which was to allow the beneficial use of these new genetic tests. When tests were available which would reduce health care costs, improve health, prolong life and increase work productivity, she did not see how it could be bad business. She expressed thanks to BC/BS for their support of the bill, explaining at first they were cautious, but after meeting together, they came to a common understanding this was a win-win situation. Their support was unequivocal. **REP. GUGGENHEIM** said these newly developed tests could be extremely helpful, and she hoped that through the purposes of **HB 111**, both people and insurance companies would benefit.

ADJOURNMENT

Adjournment: 5:45 P.M.

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SEN. AL BISHOP, Chairman

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MARTHA MCGEE, Secretary

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JANICE SOFT, Transcriber

AB/MM

EXHIBIT(phs48aad)