GENETIC NON-DISCRIMINATION: IMPLICATIONS FOR EMPLOYER PROVIDED HEALTH CARE PLANS

HEARING

BEFORE THE

SUBCOMMITTEE ON EMPLOYER-EMPLOYEE RELATIONS

OF THE

COMMITTEE ON EDUCATION AND
THE WORKFORCE
HOUSE OF REPRESENTATIVES

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GENETIC NON-DISCRIMINATION:

IMPLICATIONS FOR EMPLOYER PROVIDED HEALTH CARE PLANS

Thursday, September 6, 2001

Subcommittee on Employer Employee Relations

Committee on Education and the Workforce

U.S. House of Representatives

Washington, D.C.

The Subcommittee met, pursuant to call, at 2:01 p.m., in Room 2175, Rayburn House Office Building, Hon. Sam Johnson, Chairman of the Subcommittee, presiding.

Present: Representatives Johnson, Boehner, Fletcher, Andrews, Payne, Rivers, McCarthy, and Tierney.

Staff Present: Kristin Fitzgerald, Professional Staff Member; David Connolly, Professional Staff Member; David Thomas, Legislative Assistant; Jo-Marie St. Martin, General Counsel; Patrick Lyden, Professional Staff Member; Scott Galupo, Communications Specialist; Deborah Samantar, Committee Clerk/Intern Coordinator; Cheryl Johnson, Minority Counsel; Michele Varnhagen, Minority Labor Counsel/Coordinator; Peter Rutledge, Senior Legislative Associate/Labor; and Brian Compagnone, Minority Staff Assistant/Labor.

Chairman Johnson. Good afternoon. A quorum being present, the Subcommittee on Employer-Employee relations will come to order. We are meeting today to hear testimony on genetic non-discrimination and how its implications for employer-provided

health care plans affect us. We have been dealing with this issue for a long time and we are now getting serious about it. So it is time for us to have more hearings, and this is the second in a series.

I am going to limit the opening statements to the Ranking Minority Member and myself. Therefore, other Members statements may be included in the record. With that, I ask unanimous consent for the hearing record to remain open 14 days to allow Members' statements and other extraneous material mentioned during the hearing to be submitted. Without objection, so ordered.

OPENING STATEMENT OF CHAIRMAN SAM JOHNSON, SUBCOMMITTEE ON EMPLOYER EMPLOYEE RELATIONS, COMMITTEE ON EDUCATION AND THE WORKFORCE

Good afternoon. Let me extend a warm welcome to all of to you, and to the Ranking Member, Mr. Andrews. Today's hearing, as I said, focuses on genetic non-discrimination and what it means for employer-sponsored health care plans. This is our second hearing in a series designed to shed light on the topic of genetic non-discrimination.

As I said at the first hearing, the Members of this Committee are strongly opposed to genetic discrimination. And we believe that access to employer-sponsored health care should be available to employees, regardless of health factors, genetic or otherwise. Several existing Federal laws already protect the privacy and use of genetic information and guard against discrimination based on genetic factors. In addition, more than half of the States have enacted laws that further restrict the privacy and use of genetic information by employers and the health insurance industry as a whole. This Subcommittee has jurisdiction over both the employer provided health insurance and employment aspects of the genetic non-discrimination issue.

In our first hearing, the Subcommittee looked at current employment law and practice, and State laws and implications for employers and employees of potential legislation to prevent employment discrimination. Today we are going to look at the employer-provided health care portion of genetic non-discrimination.

We hope to answer many questions on this issue including, one, does the Health Insurance Portability and Accountability Act, HIPAA, already protect employees from discrimination; two, do the HIPAA privacy regulations already restrict the use of genetic information; three, how additional requirements and penalties would work in conjunction with these regulations; four, what are the unintended consequences of overly broad definitions of genetic information and testing; five, how have States addressed this issue through legislation; six, what enforcement measures and penalties are most applicable to this situation?

Following this investigation of genetic non-discrimination, we expect to conduct another hearing to examine the bills that have been introduced in the Congress. Even I look forward to working with my colleagues on the Subcommittee as we move forward,

including Mr. Andrews, who has already agreed that we need to work on this issue.

So I now yield to the distinguished Ranking Minority Member of the Subcommittee, Mr. Andrews, for whatever opening statement he would like to make.

WRITTEN OPENING STATEMENT OF CHAIRMAN SAM JOHNSON, SUBCOMMITEE ON EMPLOYER EMPLOYEE RELATIONS, COMMITTEE ON EDUCATION AND THE WORKFORCE – SEE APPENDIX A

OPENING STATEMENT OF RANKING MEMBER ROBERT ANDREWS, SUBCOMMITTEE ON EMPLOYER EMPLOYEE RELATIONS, COMMITTEE ON EDUCATION AND THE WORKPLACE

Thank you, Mr. Chairman. It is good to be back with you and Members of our Committee, our staff and our guests today. I think there are two major principles on which there is agreement, and our job is to move from those principles to the specifics of what the law ought to be.

The first principle is privacy. Perhaps no item is more private and more sensitive and personal than one's health care records, in particular, one's genetic records. This really is the key that can unlock all sorts of information about one's life, one's health, and therefore it deserves the highest degree of protection the law can afford.

The second principle is non-discrimination. I don't think that anyone should be denied a job, a promotion, an educational opportunity or any other thing of value because of his or her genetic predisposition toward any particular condition. The fact that someone may have a gene map that would incline him or her toward alcoholism or drug abuse should never be, in my judgment, a valid basis for denying that person a job or an opportunity. Actual behavior should govern decisions about employment and economic opportunities, not predisposition toward behavior.

We are about to be handed an enormously powerful predictive tool. That predictive tool will be the gene map of us and our families and our neighbors. This tool has incredible positive potential. It can lead to the control or elimination of all sorts of diseases and conditions that have led to much human suffering. And for this we should be jubilant. But this powerful predictive tool has some other issues attached to it.

It is rather a mixed blessing. The part of the blessing that is mixed is the potential for abuse of one's privacy rights and private information and the potential for abuse of information about one's medical predisposition for decisions that would bar or impede someone's access as far as his or her abilities would take them. These principles do not easily translate themselves into the statute books. The issues that we will explore this afternoon, I believe, have no simple answer nor do they have a partisan tint. Chairman Johnson has approached this issue with fairness and openness. I know that it is his intent

to make sure that the law reflects the principles that I have just outlined. And we look forward to hearing from our panel of expert witnesses today, their ideas and views and suggestions as to how we may make those principles the law of the land.

With that, I would yield back and ask the chairman to begin the witness statements.

Chairman Johnson. Thank you, Mr. Andrews. You know, what Mr. Andrews said that is very important is that this is a very complicated issue, and covers the spectrum of health and law and employer and employee relations. That is why this Committee has an interest in it. We hope we can solve some of those problems. It is now my pleasure to welcome and introduce our panel of witnesses.

Let me introduce them all, and then they will give their testimony. Our first witness on the panel is Ms. Janet Trautwein. She is director of Federal Policy Analysis and State Government Affairs for the National Association of Health Underwriters. Our second witness is Ms. Jane Massey Licata. She is the senior partner of the law firm of Licata & Tyrrell. Ms. Licata is also a Professor at the Rutgers School of Law in Camden, New Jersey, and has a strong background in biology and chemistry. Our final witness today is Ms. Mary Williams. She is an attorney at the law firm of Alston & Bird, Atlanta, Georgia. Ms. Williams has focused most of her career on matters concerning employee health and benefit plans.

I thank all three of you for being here today, and let me remind witnesses that under our Committee rules, you should limit your oral statements to 5 minutes. However,

the entire written statement will appear in the record. There is a light up there in front of you that is red, yellow and green. The green gives you 4 minutes, the yellow gives you 1 minute and when the red one comes on, we would appreciate it if you would wind up your testimony.

I thank you so much, all of you, for being here. Let me just tell you that in about an hour, I think we are going to have another vote, which will be the last on the floor today. So we would like to get as much in before that time if we can. And we will either finish afterward or close then.

Ms. Trautwein, would you begin with your testimony.

STATEMENT OF JANET TRAUTWEIN, DIRECTOR OF FEDERAL POLICY ANALYSIS AND STATE GOVERNMENT AFFAIRS, NATIONAL ASSOCIATION OF HEALTH UNDERWRITERS, ATLINGTON, VA

Thank you. My name is Janet Trautwein. I am Director of Federal Policy for the National Association of Health Underwriters. NAHU is an 18,000-member association

of insurance professionals involved in the sale and service of health insurance and related products. We appreciate very much this opportunity to present information on the health insurance underwriting process as it impacts employers and the effect well-intended genetic discrimination legislation could have on the cost of health insurance.

NAHU believes that health insurance affordability is the most important component of access to health care. To start out, it may be helpful to explain just what underwriting is. Underwriting is a basic evaluation of risk. Applicants for all types of insurance go through a risk evaluation process or underwriting, as do applicants for credit cards, bank loans and mortgages.

Since the business of insurance is regulated primarily at the State level, fully insured employer health insurance plans are subject to State rules regarding underwriting and rates. All 50 States have regulations on health insurance underwriting and portability provisions. Most have patient protection laws, and many have already passed laws on genetic discrimination in insurance underwriting employment, or both.

In addition to State law and underwriting, Federal legislation HIPAA prohibits discrimination against individual members of a group health plan on the basis of current health status or on the basis of some future predisposition to a particular disease based on genetic information. When an employer of any size obtains health coverage, the employer normally requests bids from several different insurance carriers, usually with the assistance of an insurance broker, to determine which plan is willing to offer the best benefits for the money.

The process of obtaining bids for coverage is somewhat different for different size groups. For mid-size groups of 50 to 300 employees, employers that have a current health plan are required to provide 3 years of claims experience. Claims experience is a list of paid premiums versus paid claims. The claims experience will typically also include a list of large claims by amount and diagnosis, not with an individual's name. The bidding carrier will also ask about any known serious illnesses and their prognosis to the best of the employer's knowledge. The underwriter for the insurance carrier evaluates the information provided and issues a proposal with the benefits and rates the carrier is willing to offer the employer.

The process for larger groups over 300 employees works in a manner similar to that described for the medium-size groups, except that less information on large claims and serious illnesses is required. Plans may be fully insured still at this size, but much more likely to be partially or fully self-insured.

In a self-insured plan, the employer often buys stop-loss coverage to protect against excessive losses. In order for an employer to know how much stop-loss coverage is appropriate for their group, the same information asked of fully-insured cases relating to claims experience, large claims and serious illnesses is required. If stop-loss levels are set too high, the employer may have inadequate protection in event of a year of high claims. So this information is extremely important.

Next in size are small employer groups of 2 to 50. HIPAA and State law provide that small employer health insurance coverage must be issued regardless of the health

status of employees and dependents, although many States allow rates to vary for the group based on overall health status.

In States where underwriting based on health status is allowed, each employer is required to complete an individual questionnaire with detailed health information on the employee and all family members to be covered. Each employee application is considered individually, usually using a point system. And the overall points determine whether the group will be issued at the rates quoted or with a rate-up. We have attached a chart showing the rating laws in each State to our written testimony along with a small sample employer health questionnaire, if you would like to look at the actual questions that are asked.

It is important to briefly mention rate stability. It is critical that a plan's initial rates be as accurate as possible. Rates that are set too low initially can result in very large premium increase at renewal. These large fluctuations are very unsettling for employers and employees and can result in some employees dropping coverage when they can't pay their share of premiums.

How does pending genetic discrimination legislation impact this process? Legislation to expand the HIPAA prohibition on the use of genetic information in underwriting, such as H.R. 602, has broadened the definition of genetic information in a way that could include items that go beyond what is normally considered to be a genetic test. Using too broad a definition could disrupt normal underwriting procedures resulting in unaffordable health insurance premiums for employers and consumers.

In conclusion, health insurance underwriting is a complicated process. It is a combination of art and science and it is highly dependent on not only the risk of the applicants, but also other market conditions that may be beyond the applicant's control. The most important component is complete information to allow for a thorough evaluation of risk. It is critical that as lawmakers consider genetic discrimination legislation, they carefully craft the definition so as not to impede the normal underwriting process. I appreciate this opportunity to come today and welcome any questions you may have.

WRITTEN TESTIMONY OF JANET TRAUTWEIN, DIRECTOR OF FEDERAL POLICY NALYSIS AND STATE GOVERNMENT AFFAIRS, NATIONAL ASSOCIATION OF HEALTH UNDERWRITERS, ARLINGTON, VA – SEE APPENDIX B

Chairman Johnson. Thank you so much. We will reserve our questions until we listen to all three of you. But thank you again for your testimony.

Ms. Licata you may begin yours now.

STATEMENT OF JANE MASSEY LICATA, ATTORNEY, LICATA & TYRRELL P.C., MARLTON, NJ

Good afternoon. My name is Jane Massey Licata, and I am a biotechnology patent and FDA lawyer and professor of patent law at Rutgers School of Law, Camden, NJ. In my practice, I represent universities, biotechnology companies and major pharmaceutical companies. I have filed and prosecuted thousands of patent applications concerning diagnostics and therapeutics, which rely upon genetic information and human genes. As I have watched the technology and the law develop, I have come to appreciate the power of this technology and also the responsibilities and risks created by it.

With the completion of the first map of the human genome, we now have a basis for determining our unique genetic makeup and probable medical future to permit personal diagnostics and therapeutics to be created for us. This is no longer the stuff of science fiction. Every day, new genetic markers are identified and correlated with human biology and disease.

The future of medicine lies in Genomics. Worldwide university and pharmaceutical company researchers alike are mining databases of genetic information and rapidly identifying new drug targets, diagnostic markers and creating a basis for novel therapies. Tests designed to determine the presence or versions of genes that cause diseases or conditions carry with them the most intimate details of a biological past and future as well as a devastating potential for discrimination.

Analysis of our genetic material also provides information about our parents, siblings and children which impacts not only on us, but also on family privacy. The potential for misunderstanding or misuse of this information is so great that it is essential that we establish a national policy for the protection of an individual's privacy interest in their genetic information. H.R. 602 is an important and timely legislative initiative to prohibit health insurance and employment discrimination against individuals and their family members on the basis of predictive genetic information or genetic services.

Overall, this bill is a well-drafted, well-considered proposal. There are a number of points that may bear further consideration, however. The term "predictive," in the definition of genetic information, may have been intended to address the concern that many genetic markers are not conclusively diagnostic, but rather may indicate a predisposition to a disease or condition, or may presently be believed to have a correlation with a disease or condition. In such cases, it would be especially troublesome if the information were relied upon to make employment or insurance decisions.

There is also an exception concerning sharing of information between health care providers for treatment. Health care providers, however, are accustomed to dealing with sensitive, confidential information, such as HIV status and accordingly, a blanket exception is not required. The individual's prior written consent to make the information available between health care providers should not be an undue burden and helps to identify the information that is sensitive and confidential.

Further, there is an exception for information for payment of a claim. This provision places individuals in the position of paying for the genetic tests themselves or risking disclosure. Under the proposed scheme, the insured employer who may not have reasonable access to legal representation may not be able to effectively protect their privacy interest.

I would, therefore, suggest that the government take a more proactive role and that there be substantial penalties provided for in event of a violation or disclosure. While some States, like my State, New Jersey, have enacted genetic Privacy Acts, I believe it is essential to establish a consistent national policy to protect against genetic discrimination this employment and insurance, and to protect the privacy of this most sensitive and personal information. These issues cross State boundaries and affect all of our citizens.

New Jersey's Genetic Privacy Act, which was enacted in 1996 declared the genetic information, is personal information that should not be collected, retained or disclosed without the individual's authorization. The Act prohibits discrimination by employers against employees carrying genetic markers of diseases or behavioral traits. It is unlawful for an employer to refuse to hire or employ, or to discharge or require to retire an employee because of the employee's genetic information, or because the employee refused to submit to a genetic test or make available the results of a genetic test to the employer.

It also prohibits the use of genetic information in the fixing of rates or withholding life insurance or health insurance. The penalties for violations include fines and prison terms, and also actual damages for economic bodily or emotional harm approximately caused by the disclosure. I believe H.R. 602 would be a good beginning in addressing a national issue.

While an Act like the New Jersey Act is an important first step in controlling the flow of genetic information, Federal legislation is still needed. H.R. 602 addresses some of the most urgent needs in protecting an individual's privacy and assuring access to genetic testing and services. Until recently, access to this type of testing was limited to those who could afford to pay for it privately. By paying for it themselves, they could also have greater assurance of confidentiality concerning the testing and the results. While wider acceptance of the need and validity of genetic testing has made insurers more comfortable with reimbursement, there is a huge risk to the insured or employee that very sensitive information, which could easily be subject to misinterpretation, may be widely distributed as a part of the insurance information system.

I would suggest erring on the side of making such information as inaccessible as possible to third parties since the risk of misunderstanding or misuse is so great.

Thank you.

WRITTEN STATEMENT OF JANE MASSEY LICATA, ATTORNEY, LICATA & TYRRELL P.C., MARLTON, NJ – SEE APPENDIX C

Chairman Johnson. Thank you ma'am.

Ms. Williams, you may begin your testimony.

STATEMENT OF MARY K. WILLIAMS, ATTORNEY, ALSTON & BIRD, ATLANTA, GA

My name is Mary Williams. I practice law in the Atlanta, Georgia office of Alston & Bird. Primarily, I represent employers who sponsor self-funded plans for their employees and the third party administrators who provide services to those plans.

A self-funded plan is one where the employer assumes the financial risk of providing benefits to their employee. Rather than purchasing medical insurance from a carrier, they absorb the financial burden of providing benefits to their employees.

Today, I wish to make four points about genetic non-discrimination and how it is applicable to benefits provided by employers. But first, let me emphasize that employers are strongly opposed to genetic discrimination. However, it is not necessary to enact additional legislation to protect that information in the group health plan setting because current laws already do so.

First, current Federal law already protects group health plans from genetic discrimination. HIPAA currently prohibits a group health plan from discriminating with regard to enrollment, eligibility, premium, deductibles and co-payments. For example, under current law, an employer may not exclude an otherwise eligible employee from coverage based on any medical information including genetic information. An employer may not impose benefit restrictions upon any employee based on their medical information. And an employer may not increase deductibles, co-payments or contributions for an individual just based on their medical information.

Second, HIPAA protects collection, use and disclosure of health information including genetic information. HIPAA's privacy rules strictly limit the use and disclosure of medical information, including genetic information obtained by a group health plan and prohibits employers from using that information for any employment-related action.

The privacy regulations also impose substantial administrative burdens upon employers and health plans to control access to and to provide physical security for the health information that they obtain. To ensure that, the employer does not share the information with any one except those needing that information for purposes of administrating the health plan.

Third, employer-sponsored health plans are not using employee’s genetic information in a discriminatory manner. Employers agree that their employees' medical information collected through the group health plan setting should be protected and should be used only as absolutely necessary to effectively administer their group health

plan. Employer-sponsored group health plans as a whole are not participating in the fact-finding activities that are the concern of the genetic community. For example, group health plans are not requiring that their participants fill out questionnaires, or participate in physical examinations, and they are not asking for the results of any test results. Rather, self-funded group health plans use medical information for paying claims and for other vital administrative functions necessary to operate their plans.

For example, a group health plan does obtain stop-loss insurance, as Ms. Trautwein has said. And in order to do that, they must disclose specific information about claims incurred over the past year. Without that stop-loss insurance, self-funded health plans cannot exist.

Fourth, if Congress moves forward with further regulation, care must be given to avoid unintended consequences of overly broad language. Any additional legislation in the medical information area must be drafted very carefully to avoid unintended consequences that could negatively impact the day-to-day administrative needs of an employer-sponsored health plan. As I have mentioned, I think this is virtually impossible to do. Legislation that is drafted without a complete comprehension of the operations of a group health plan inevitably will create burdensome requirements that will frustrate the ability to offer any group health coverage.

Under current Federal law, current health plans are prohibited from discriminating against enrollment, eligibility, contributions or premium rates based on any genetic information an employer receives. Under current Federal law, group health plans are prohibited from using and disclosing any genetic information concerning a plan participant without that participant's authorization.

Under current Federal law, employers are prohibited from using or disclosing health information or genetic information for employment-related purposes. This is the law today. No additional regulation in this area of employee benefit law is needed to accomplish the objective of genetic non-discrimination. Thank you.

STATEMENT OF MARY K. WILLIAMS, ATTORNEY, ALSTON & BIRD, ATLANTA, GA – SEE APPENDIX D

Chairman Johnson. Thank you, ma'am. I thank all the witnesses for their testimony. We appreciate it.

We are tying to establish an understanding of what the current law is, and determine if there are any deficiencies in it that we need to correct. I would like to pursue what you just said if you don't mind. Is there any difference between a group plan and a company that self-insures by themselves?

Ms. Williams. There are two types of plans that a group can offer in general. One is a self-funded plan, where the employer absorbs the primary burden of providing coverage to the employee. The other is for the employer to go out and purchase a fully insured product just as you would do if you were going to purchase.

Chairman Johnson. But does HIPAA protect them under both those situations?

Ms. Williams. HIPAA protects all types of group insurance or group health coverage.

Chairman Johnson. I wonder if you could address the concept of firewalls contained in the HIPAA regulation, and how this practice further protects the privacy of employees?

Ms. Williams. Yes, sir. When people hear HIPAA now, they are thinking of just the HIPAA privacy regulations because that is just the most recent regular legislation we have received. HIPAA has been around for a long time.

Chairman Johnson. But as I understand, it is not fully implemented.

Ms. Williams. The first part of HIPAA is. The non-discrimination rules are fully implemented. They have been around since 1996. And since 1996, you could not discriminate against someone based on his or her health factors.

The new portion of HIPAA is the privacy rules that govern the use and disclosure and collection of medical information. You are correct they will not be implemented until April 14th 2003. But those regulations require that employers put firewalls in place to separate all of the employer activities from the activities of their health plan. So it may mean that just one or two individuals have access to the health information of the employees. There needs to be physical fire walls that actually separate these people by office, put medical records under lock and key, and implement new password systems for computers.

So HIPAA does require it. The people, who do not need the health information in order to administer the plan and pay the claims, do not have access to the information.

Chairman Johnson. But none of that information can get into the employment process.

Ms. Williams. That is exactly right. None of that information that is learned because of the participation in the health plan can be used for any other employment-related activity.

Chairman Johnson. Do you see any weaknesses in HIPAA that need to be corrected?

Ms. Williams. I do not want my statements to be a clear endorsement of HIPAA because the HIPAA privacy rules do have a lot of problems. In fact, other members of my firm have testified at several Committees about some of the problems that the HIPAA privacy rules face. But as far as the disclosure and use and collection of health information by an employer and by the employer's health plan, there is really nothing more you can do and still allow that health plan to administer claims the way it is supposed to.

Through the 2-year comment period, HIPAA started out with just the payment of claims and that is it. Through the over 76,000 comments that HHS has received, they have learned that employers need this information in other legitimate non-discriminatory ways in order to do other things that a health plan must do.

Chairman Johnson. Thank you so much.

Mr. Andrews.

Mr. Andrews. Thank you.

I would like to thank the panelists for the excellent testimony. I especially want to say to Ms. Massey Licata, that I appreciate her contribution to this discipline and her friendship over the years, and I appreciate her making the trip today.

Her 5-year-old son, for the record, is in his third day of kindergarten, and she told me she had to catch a later train because he had a little difficulty on his third day. He was a little bit sad. So for a parent to leave on the third day of kindergarten is an extraordinary effort and I appreciate that.

Ms. Williams, in your statement, you indicate that your interpretation of HIPAA is that group health plans are prohibited from discriminating against enrollment eligibility contributions based on any genetic information. Let me ask you this hypothetical: What if an employer with 20 employees attempts to enroll in a health plan and there is information that one of the employees is highly prone to stroke, given their genetic profile? Does HIPAA prohibit the insurance company from selling to the group?

Ms. Williams. You are talking about a fully insured situation?

Mr. Andrews. Could the plan not take on the whole group because one employee is so inclined?

Ms. Williams. I do not believe so. Again, my expertise is in self-insured plans.

Mr. Andrews. How about a self-insured plan, the same thing?

Ms. Williams. Absolutely not; the employer is the one funding the plan. No one says we will not provide coverage. The employer is paying for the coverage himself or herself. They have to let everybody in. In a group insurance setting, if you have 20 people, HIPAA does govern that health plan.

Mr. Andrews. So it is your position that they could not deny coverage to the entire group on the basis of the one individual?

Ms. Williams. That is correct.

Mr. Andrews. I am not so sure I agree with that interpretation, but I understand it.

Ms. Licata, would you favor an amendment to Title VII of the employment discrimination civil rights laws to include a genetic predisposition such as race as a protected classification?

Ms. Licata. I think that it would be appropriate to consider that because your genetic profile for the genetic background that you are born with is something that you can't

change. It is not necessarily inevitable how those genes will be expressed, but if people judge you on your predispositions as to whether it is alcoholism, depression, heart disease or cancer, it is something that you can't change. People are going to judge you based upon that.

So I think, like yourself, the color of your skin, which is determined genetically could denote your race, and these are characteristics that people are going to judge you on.

Mr. Andrews. What these things have in common is they are immutable characteristics that should not be the basis for the evaluation of your fitness for a job. Is that your position?

Ms. Licata. Yes.

Mr. Andrews. Ms. Trautwein, I appreciate your testimony.

I know that NAHU embraces a definition of genetic information that should be limited to DNA and related gene testing done for the purpose of predicting risk of disease in symptomatic or undiagnosed individuals. What if the genetic test is not given for the purpose of predicting disease but exists anyway? What if an employee is tested for the purpose of having their profile on record and not to predict any given disease, but an employer or insurer uses it for that purpose? Why should we limit the definition to purposeful testing for disease?

Ms. Trautwein. Let me make sure I understand your question. What would an insurer do this test for?

Mr. Andrews. They were collecting data to develop models of health care behavior, health care risk, and they happen to get data in a particular person in a sample study they were doing. It seems to me, under your proposed definition, it would not be illegal to use that information in discriminatory fashion because the purpose for which it was collected wasn't to predict a disease.

Ms. Trautwein. I am not an attorney, so I don't pretend to know every law on the books, but I don't believe that is legal. I am not aware of any of them that are doing that. In fact, we have recently been working with the CBO providing some information on when blood work is requested not in groups, but on the individual process. Occasionally they do blood work, and we have some information that I would be happy to share with you later about what types of tests actually are run.

Mr. Andrews. Is it your position that what I said should be illegal? Do you think genetic information collected for any purpose should be used in a discriminatory fashion?

Ms. Trautwein. I am certainly not in favor of discrimination.

I think the point in my testimony made a different distinction between someone who has a current illness and a genetic test that might be used in conjunction with it as opposed to someone who is getting some genetic tests run to see if they have markers for

any particular disease.

Mr. Andrews. I understand and I agree with that distinction.

Thank you, Mr. Chairman.

Chairman Johnson. Let me follow up on what he said. I know he asked Ms. Williams about whether or not you could stop an employment action under the law currently for genetic reasons. Does that apply to fully insured plans too?

Ms. Trautwein. Yes, it does. I can explain just a little about how that works, because there is one thing I might add. In a group of 20, the example that you gave before, if it is a fully insured plan, one person's health information could impact the rates the group pays whether no matter what kind of health information.

Chairman Johnson. So they can't deny him insurance but they can charge him more.

Ms. Trautwein. The whole group could possibly pay a higher rate because of one person's health information of any kind in some States.

Chairman Johnson. That is within the law?

Ms. Trautwein. Yes.

Chairman Johnson. Thank you.

Mr. Fletcher.

Mr. Fletcher. Thank you, Mr. Chairman. I appreciate you having this hearing. It is really a very complex issue. The more you look at it, the more difficult it gets.

Let me ask you something, Ms. Licata. You will find this place is not as family friendly as we would like for it to be. How do you answer some of the concerns that have been expressed here by others regarding the ability to predict rates, actuarial predictions, and stability of premiums, to make sure that we provide as much access to health care as possible? What experience have you had in New Jersey? What do you think H.R 602_would do regarding cost predictability and premiums in answer to some of the questions that have been brought up?

Ms. Licata. In New Jersey, under the Genetic Privacy Act, genetic information, cannot be used in establishing rates or in a decision to allow a contract or not. That information is absolutely prohibited from use, which is, I think, a really good position.

The danger is how and where you draw the line. The type of information we are talking about under H.R. 602 is predictive genetic information. There are literally thousands of genes, more being discovered every day that correlate with all kinds of conditions and diseases. For lung cancer alone, there are probably over 1,000 markers.

So there is a ton of information to look at in a particular individual, and find this marker, that marker, the other marker, to create a profile for that individual. But all that is going to tell you is what markers that person is carrying. It may also give you the ability to quote some probabilities whether, at some point in their life, 20 or 30 or 40 or 50 years from now, one of those diseases or conditions may occur.

And even if you took identical twins, who, by definition, have an identical genetic makeup because genes must be expressed in context, it is their life experience and their environment which is going to control that expression. You have no way of really knowing what is going to happen based on that profile.

So the New Jersey Act takes the position that information is just probabilities and because it could be misinterpreted and there is such uncertainty, you just can't even take that into account.

H.R. 602 is saying that that particular type of information should not be allowed to be taken into account when you are making these types of decisions, and that information should be protected as opposed to things that are relevant to current health status. If there are some markers that have one change in the genetic code and you are going to have a disease, then you are diagnosed with that disease. That information is current health status under H. R. 602, and it can be factored into your plan.

Mr. Fletcher. So if a patient is diagnosed with, let us say, colon cancer, and subsequently a colon cancer genetic marker is found the screening that is done in the family might change substantially. Would that pre-existing condition still be allowed to be used in computing the group rate predictions and premium rate predictability or not in that situation?

Ms. Licata. I think if the status changes in the way H.R. 602 is written, because once it is diagnostic, it becomes current health status.

Mr. Fletcher. So what you are saying is once a disease is diagnosed, genetic information is either commensurate or subsequent to that, and that health status is still able to be used for predictability of group rates, et cetera, in spite of the fact that genetic information is available.

Ms. Licata. Right. That is one of the concerns I have with H.R. 602 is I don't think it goes far enough. You know, I understand why there has been a distinction made between predictive versus current.

Mr. Fletcher. Let me say this: If you are not able to predict premiums, then obviously you are not going to be able to pay for future health care issues. If there is a subsequent diagnosis, I can understand why H. R. 602 does that. How many actions have been brought under the New Jersey Act for violations of its provisions, do you know?

Ms. Licata. I don't know, but I am not actually aware of any. I can check for you.

Mr. Fletcher. If you can check and bring that back to us, we will enter that into the record.

SUBMITTED FOR THE RECORD, ADDITIONAL ANSWERS TO QUESTIONS POSED DURING QUESTION AND ANSWER PERIOD, JANE MASSEY LICATA, J.D., Ph.D., SEPTEMBER 6, 2001 – SEE APPENDIX E

Chairman Johnson. Thank you.

Mrs. McCarthy.

Mrs. McCarthy. Thank you, Mr. Chairman.

Ms. Williams, in your testimony you basically state that it is virtually impossible to write definitions for this law that are not overly broad, so we should not even try to pass a genetic non-discrimination bill. And yet, you know I sit here as a nurse and I am very comfortable with health care providers and experts in health care policy defining terms for this bill. Since you are obviously not comfortable with these definitions, who do you think should write the definitions?

Ms. Williams. I am sorry if that is how my testimony was construed. What I meant was it is virtually impossible to write these definitions broadly enough to encompass all the administrative tasks that are involved in how that information is needed. I do think HIPAA has gone a long way in doing that in the privacy regulations, because they include payment of claims, which I think most legislation always recognize is a needed task of plan administration, and that medical information must be needed for that.

They go further to include health care operations, which includes providing that information for getting stop-loss coverage, for doing quality assurance, for doing wellness programs, and disease management programs within the plan. H. R. 602 doesn't do that right now, and most legislation coming out of State and Federal areas doesn't do that. It was only after 2 years of commentaries that HHS inserted the broader language to include some of those vital administrative tasks.

So I think the most important thing to employers is that the people that write the legislation understand how a health plan actually operates and make sure that any definition of payment of a health claim or health care operation includes these other tasks that the general public isn't aware of, and certainly the employees aren't aware of that go on.

Mrs. McCarthy. Thank you.

Ms. Trautwein, I am curious especially about life insurance because I just went through it. And basically the questions they asked me were about my family, my mother and my father, certainly my brothers and sisters. There were medical histories of high blood pressure and cholesterol, and I am on cholesterol pills.

So I am curious, would underwriters for life insurance look at those markers, because I consider them markers? If my mother had high cholesterol, and I have high cholesterol, why should they give me life insurance, because obviously even though I am in good health, take care of myself, and eat the right foods, my cholesterol is high. I still have a higher risk down the road of having a heart attack or a stroke. Why would you even want to take a risk on someone like myself?

Ms. Trautwein. Well, I am actually glad that you asked about that. First of all, let me distinguish between health insurance underwriting and life insurance underwriting. It is different for the two. I represent health underwriters, but I know the answer to your question having done that in a previous life.

First, family medical history is never asked for at all during the group process that you just described regarding parents, siblings and so forth for health insurance. It is only occasionally asked for, and we just completed a survey. By occasionally I mean, I found only three insurance companies in the United States that asked these questions on health insurance.

On life insurance it is different. And what is different is that actuaries for life insurance base rates on mortality as opposed to morbidity. It is whether you are going to die because that is when their claim is going to be paid, or if you are going to be sick. The underwriting is completely different for life insurance as opposed to health insurance.

I just want to point out that we are not talking about restrictions on life insurance underwriting. I can't rightfully speak for the life insurance industry who may, at some point, decide as you have stated, that legitimate genetic tests, are in the same category as family medical history.

I can tell you how your family medical history was used on your application. It was not considered on its own. Each ramification is considered on a point system. Your current history is given far greater weight than anything else. They only look at the additional items if they want confirmation of a particular thing. For example, a family medical history might be the third or fourth item if you have three other risk factors, for example. So the weight is small on that compared to the other items that are current.

Mrs. McCarthy. Thank you.

Chairman Johnson. Thank you, Mrs. McCarthy. Good questions.

Mr. Payne.

Mr. Payne. Thank you.

I understand that the Health Insurance Portability and Accountability Act of 1996 does not and would not prohibit group health insurers or health plans from requiring or requesting genetic testing. I have heard your testimony that it is against the law to discriminate, however, there seems to be loopholes and I just wonder, Ms. Williams or Ms. Licata, how you feel about legislation which would prohibit discrimination in

employer-provided health plans based on genetic findings?

Ms. Williams. That is what HIPAA does. It expressly in ERISA, prohibits discrimination based on genetic information. And genetic information is one of the line items in that portion of the statute. I think it is absolutely a good thing, and HIPAA does it now.

Mr. Payne. However, weren't there some cases under ADA where persons sued the insurer for genetic discrimination?

Ms. Williams. The ADA and HIPAA and ERISA do interact, but not that much because HIPAA and ADA are more than employment driven statutes, in that they govern the conduct of the employer in general. ERISA is just really governing the conduct of the health plan and the employer as a plan administrator.

So there may be cases, but I can't speak to whether employers did or did not get health information from the health plan in a discriminatory fashion. The ADA may have spoken to that. But the cases arising out of the ADA are generally not directed at the employer's activities for administering their health plan. I hope I have made the distinction clear.

H. R. 602 and other legislation that has been presented, attempts to amend many different parts of many different laws, and some may be perfectly warranted, including any amendments to the Civil Rights Act or ADA. What I am trying to get across is that the amendments to ERISA, have already met the goal of non-discrimination. The major amendments to ERISA that are broadening this genetic discrimination line item and expanding on the definition, don't add to the fact that employers cannot discriminate in their health plan based on genetic information now. It is prohibited.

What it does do is try to further hinder the employer as administrator of a health plan from disclosing information in ways that it needs to administer the plan. For example, we have been talking about genetic tests and genetic information. But H. R. 602 goes beyond that. It talks about genetic services, that is, treatment for genetic conditions, and H. R. 602 limits the way in which health plans can disclose that.

So any time you start talking about limiting disclosure of actual treatment, that is where a health plan runs into problems because it doesn't care what the treatment is for, but it cares how much it paid because it needs those figures to give to its stop-loss carrier, it needs those figures to figure out what it is going to owe next year. That is where this legislation, even other legislation that is currently on the table right now, has gone further than it needs to accomplish the goal that we have achieved.

Mr. Payne. Ms. Licata?

Ms. Licata. I guess there are a couple of loopholes in HIPAA. One is that they would be free to raise the rates for the group as a whole based on predictive genetic information of a member. Again, we are talking about using information that does not necessarily indicate what is going to happen, but that can affect the whole group. So that is an issue that is a loophole currently in HIPAA.

In addition, I think it is a big issue in terms of how we are going to look at this type of information, because there is going to be a lot of it available very soon. These diagnostic tests are currently available and there is more and more information that is going to become available. We are going to actually be in a situation where we may have more information than people can properly interpret and judge appropriately what is going to happen.

I think the line that is drawn in H.R. 602 is between the here and now. That is somebody is sick and they are being taken care of under a health plan and information, which is going to talk about what might happen in the future and for the counseling and care that, might be attendant to that.

I think the definition of "predictive" or now protected information in H.R. 602 is extremely crafted, and it has evolved where we are saying if you are getting this information, to identify these markers rather than to diagnosis a current health status, that is really a different kind of thing.

I don't really understand why you have to have that information to calculate your rates. I also think that once you open Pandora's box and you make this information available, it is incredibly enticing to take a look at it. I mean, if you knew that you had an employee that had a strong predisposition based upon their genetic profile to violence or to alcoholism or to some kind of physical condition that might be relevant in the workplace, it would be very tempting to factor that information in and probably impossible for the employee to ever prove that it was taken into account.

Therefore, I think we can draw a bright line and take a firm policy that this type of information is so personal, so intimate, and has such a huge impact on both the individual, their family and our society, that we need to be clear that that type of information should be at least as protected as something like HIV status. That would go a long way to make it easier for the employers as well to implement their plans.

Chairman Johnson. Thank you very much.

Mr. Fletcher do you have a follow-up question?

Mr. Fletcher. Thank you.

Ms. Trautwein let me ask you something. You specifically referenced the issue of cholesterol screening in your testimony. How is cholesterol testing addressed in various legislative proposals that have been sponsored on this issue and how would the inclusion of cholesterol in a category of protected information impact current procedures with regard to health care insurance?

Ms. Trautwein. Well, currently, we can talk about two bills, and we can categorize it like that. There is a bill in the Senate, Senator Snowe's bill, S. 382, which has some language that has been used in several other bills. It includes in its exceptions what is not genetic information, information about current physical exams, lab work, so forth, and it specifically names cholesterol screening. H.R. 602 does not do that. It does not name any specific tests. We have a particular concern about cholesterol screening.

Cholesterol screening is a metabolite test. There are many genetic tests that we consider legitimate genetic tests that are also metabolite tests, and we are concerned that cholesterol screening not be spelled out. It comes back to this issue of it being predictive genetic information. There are millions of dollars of claims paid every year for cholesterol lowering medications. If cholesterol testing moves from a category of a diagnostic test into that of a genetic test, it no longer would have a diagnostic code, because it is not a diagnosis when your test comes back high.

Every insurance claim has to have a diagnostic code to be paid, and we are concerned that this is one of the big unintended consequences that could occur, not to mention the underwriting process in accomplishing the actual overall health of a person currently. This other unintended consequence could easily happen, because it would lose its diagnostic code if it were no longer a diagnosis and went into another category.

Mr. Fletcher. Let me ask you something. Say there is a true genetic test that shows predictability of coronary artery disease and maybe the effect of a certain cholesterol spectrum that one of the current medications or developed medication could treat. The thing I get concerned about under this scenario I have spelled out is that I do want to predict the genetic information and prevent discrimination, but I also realize that from the provider's side there has to be the ability to access the information. If we are going to start this patient on some preventive medication, we have got a genetic predisposed diagnosis, but we don't have, quote, the diagnosis like hyperlipidemia. Then we use our coding system to bill Medicare or Medicaid, the government, or a group or fully insured product.

How is that going to play into all this? Are we going to be able to say this visit was regarding that particular treatment for this predisposition? I mean that is where we are going. In Medicare right now, we can only order a complete blood count for certain things. Everybody all of a sudden has fatigue; because that is one of the things we can order it for. You are going to push the provider to use other codes to avoid the problems that come from unintended consequences of the things we are trying to protect. I wonder if there are any comments on that?

Ms. Trautwein. Well, the only comment I would make is that this is obviously a changing dynamic. The advances in this science are rapid, but in terms of your specific question about diagnostic codes and how you mark it payable, I think that is going to have to evolve over time.

Mr. Fletcher. Well, would that be a viable diagnosis, especially in a self-administered plan? Now, I know as of April 14th when we institute privacy, there may be these electronic and physical laws, but how is that information given to an employer in that situation for reimbursement?

Maybe Ms. Williams wants to comment?

Ms. Williams. You are correct in that the only way that an employer can reimburse, either through a self-funded or a fully insured plan, is by the diagnostic code. They have got to go above and beyond to make sure that whatever treatment this patient received is covered by the terms of the plan, because some things aren't covered by the terms of the

plan. So if there is not a clear diagnosis they would not be able to pay the treatment claim.

Now, employers are not concerned with the diagnosis code. As far as their claims administrator, they may see that the treatment was medically necessary for the diagnosis and match those up, but as far as getting a diagnosis code, they need it to pay the claim, but they are not that concerned with what it is.

Now, doctors, like you say, in an effort to get their claims paid, are going to have to code these things is a different matter. The health plan would have no way of knowing that that was going on.

Mr. Fletcher. Well, the concern I get is the fact that we are going to see more policies written to avoid the conflict that I have just mentioned, and then you actually reduce the ability to treat patients preventively. And in the future we are moving toward prevention of diseases, so the genetic information is going to be essential for the provider to have. Whether there is going to be a change in reimbursal regarding this, remains to be seen but it is going to have a substantial impact on how policies are written, how reimbursements are done and coding. All that needs to be taken into account when we pass some legislation that tries to protect a right, not understanding the unintended consequences may do just the opposite on the patient's health.

Ms. Williams. You are right. And employers have a legitimately strong interest in preventing health problems. It is good for their financial bottom line to prevent health problems. It increases their productivity. That is why a lot of the preventive maintenance and wellness and the disease management programs are in effect. They don't want those programs to be hurt by the failure to be able to disclose information. So certainly they would have an interest in that.

Chairman Johnson. Thank you, Doctor.

Mr. Andrews do you have a follow-up?

Mr. Andrews. Mr. Chairman. I will be brief. One of the strong concerns that we have is consent and whether it is really informed consent for the use of a test. If I am not mistaken, genetic testing is generally done by drawing someone's blood, and although a skilled student or observer like Mrs. McCarthy, who is a nurse, might know to ask what it is going to be used for, I would trust that most of us don't do that when our blood is drawn for, quote, medical tests. We just have it drawn, and off it goes to the lab, and we sign the printed forms at the lab and go on our way.

How often do people ask what these tests are going to be used for? Is there any data on that? And if they do ask, how might we make sure that the explanation that someone is given truly aides in informed consent, and they don't just thinks they are being tested for cholesterol or some other problem? In other words, how broad is the scope of the consent that someone gives and how can we ensure that people know what they are agreeing to when they go to give the sample?

Do you have any ideas on that?

Ms. Licata. I can address that.

Currently a lot of identification of markers and creating correlations has been done on a research basis. So when people agree to participate in the research, they are very well informed. The protocol has to be reviewed and approved by an institutional review board. They are given a written consent, which explains what the biological material is going to be used for, and certain assurances as to what will happen to the material. In many cases the information will not have identifiers on it, so that you couldn't necessarily match up that data with the individual.

Mr. Andrews. What about the case where it is not a study, and an employee agrees, and signs a consent form to give blood to test for high cholesterol. Should the employer or the health plan be able to use that blood sample to test for other conditions?

Ms. Williams. No. No. The taking of blood or any other treatment that an employee receives is an issue between the health care provider and the employee. The employers wants no part in that process. The employer as an administer of a health plan would have no reason for having a provider do additional testing, and as you are talking about the administration of a health plan, that doesn't occur. Whether employers as employers or for other purposes other than their health plan are doing that, I don't know. But if they are, amendments to ERISA aren't going to change that. As far as group health plans, they are not doing it.

Mr. Andrews. Ms. Trautwein, do you think the consent authorization should spell out the specific use of blood and that any other uses should not be authorized?

Ms. Trautwein. Probably so.

Let me tell you how it is actually done now. Blood draws are not done in the group market at all. It is just not done. They are done in the individual market occasionally. The disclosure that someone signs authorizes a check of the information base and the information provided on the application. So it would be to confirm other things. We have not found anyone that screens for anything genetic. Drug screens are common, quite common, and complete blood counts and those types of things.

But the consent currently does not spell it out. Do we think it should? I am not sure about the answer to that. I think as long as it references information back to the questions that are asked on the application, because it could be quite lengthy.

Mr. Andrews. Aren't the applications so broad and cover so many conditions that you could reference it back to almost anything if you wanted to?

Ms. Trautwein. I don't know the answer to that. I think that insurance carriers should answer that, the ones that actually do the blood work.

Mr. Andrews. With the Chairman's consent, we do have some examples of insurance company questionnaires we would like to put into the record after the hearing, and with that I would yield back.

Chairman Johnson. I don't have an objection. So ordered.

Regarding that question that he just referred to about a broad definition, you indicated that would possibly cause rates to go up, because there would be no idea what would be done and what the cost would be. Is that true?

Ms. Trautwein. First of all, I just want to make clear, we are opposed to genetic discrimination. We are just concerned about what genetic information is, and if it normally includes items that are on an everyday basis regularly included in the underwriting process that have to do with current health status that are not predictive in nature. We are concerned about those items, because when an underwriter does not have the information they need to underwrite that application, they do underwrite more conservatively, which means they add a little in it for errors.

Chairman Johnson. I understand. You also indicated that there are many State laws that regulate the underwriting and privacy aspect of genetic discrimination. How have the States defined genetic tests and protected information?

Ms. Trautwein. Well, they have defined it in a variety of ways. I haven't found any two States actually that define it exactly the same way, and you all probably have done some research in that regard as well.

Chairman Johnson. None of us define it the same way either.

Ms. Trautwein. A number of them actually use the word "predictive" in there. A number of them imply that the information should be predictive in nature. Most of them spell out the types of genetic tests. Some of them use the word "inherited characteristics," which means family medical history. And that is also the main primary categories. None of the States have done it exactly the same way. Some of them extend the prohibition on eligibility only. Most of them extend it to eligibility and discrimination in the underwriting process. Some of them do only health insurance. Some of them extend it to life, long-term disability, and long-term care insurance. So it is different in every State.

Chairman Johnson. You can't define it.

We appreciate all three of you being here. Your time is valuable, and your testimony was great. I appreciate the Members who were here for their participation and their testimony, and if there is no further business, this Subcommittee stands adjourned.

Thank you.

Whereupon, at 3:14 a.m., the Subcommittee was adjourned.

APPENDIX A - WRITTEN OPENING STATEMENT OF CHAIRMAN SAM JOHNSON, SUBCOMMITEE ON EMPLOYER EMPLOYEE RELATIONS, COMMITTEE ON EDUCATION AND THE WORKFORCE

OPENING STATEMENT OF REP. SAM JOHNSON (R-TX),

CHAIRMAN, SUBCOMMITTEE ON EMPLOYER-EMPLOYEE RELATIONS

SEPTEMBER 6, 2001

GOOD AFTERNOON. LET ME EXTEND A WARM WELCOME TO ALL OF YOU, TO THE RANKING MEMBER, MR. ANDREWS, AND TO MY OTHER COLLEAGUES.

TODAY'S HEARING FOCUSES ON GENETIC NON-DISCRIMINATION AND WHAT IT MEANS FOR EMPLOYER SPONSORED HEALTH CARE.

THIS IS OUR SECOND HEARING IN A SERIES, DESIGNED TO SHED LIGHT ON THE TOPIC OF GENETIC NONDISCRIMINATION. AS I SAID AT THE FIRST HEARING – THE MEMBERS OF THE SUBCOMMITTEE ARE STRONGLY OPPOSED TO GENETIC DISCRIMINATION. WE BELIEVE THAT ACCESS TO EMPLOYER-SPONSORED HEALTH CARE SHOULD BE AVAILABLE TO EMPLOYEES, REGARDLESS OF HEALTH FACTORS, GENETIC OR OTHERWISE.

SEVERAL EXISTING FEDERAL LAWS PROTECT THE PRIVACY AND USE OF GENETIC INFORMATION, AND GUARD AGAINST DISCRIMINATION BASED ON GENETIC FACTORS.

IN ADDITION, MORE THAN HALF OF THE STATES HAVE ENACTED LAWS THAT FURTHER RESTRICT THE PRIVACY AND USE OF GENETIC INFORMATION BY EMPLOYERS AND THE HEALTH INSURANCE INDUSTRY.

THIS SUBCOMMITTEE HAS JURISDICTION OVER BOTH THE EMPLOYER-PROVIDED HEALTH INSURANCE AND EMPLOYMENT ASPECTS OF THE GENETIC NON-DISCRIMINATION ISSUE.

IN OUR FIRST HEARING THE SUBCOMMITTEE LOOKED AT CURRENT EMPLOYMENT LAW AND PRACTICE, STATE LAWS, AND IMPLICATIONS FOR EMPLOYERS AND EMPLOYEES OF POTENTIAL LEGISLATION TO PREVENT EMPLOYMENT DISCRIMINATION.

TODAY, WE WILL LOOK AT THE EMPLOYER PROVIDED HEALTH CARE PORTION OF GENETIC NONDISCRIMINATION. WE HOPE TO ANSWER MANY QUESTIONS ON THIS ISSUE INCLUDING:

1) DOES THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA), ALREADY PROTECT EMPLOYEES FROM DISCRIMINATION,

2) DO THE HIPPA PRIVACY REGULATIONS ALREADY RESTRICT THE USE OF GENETIC INFORMATION,

3) HOW ADDITIONAL REQUIREMENTS AND PENALTIES WOULD WORK IN CONJUNCTION WITH THESE REGULATIONS,

4) WHAT ARE THE UNINTENDED CONSEQUENCES OF OVERLY BROAD DEFINITIONS OF GENETIC INFORMATION AND TESTING,

5) HOW HAVE STATES ADDRESSED THIS ISSUE THROUGH LEGISLATION,

6) WHAT ENFORCEMENT MEASURES AND PENALTIES ARE MOST APPLICABLE TO THIS SITUATION?

FOLLOWING THIS THOROUGH INVESTIGATION OF GENETIC NONDISCRIMINATION, WE EXPECT TO CONDUCT ANOTHER HEARING TO EXAMINE BILLS THAT HAVE BEEN INTRODUCED IN THE CONGRESS. I LOOK FORWARD TO WORKING WITH MY COLLEAGUES ON THE SUBCOMMITTEE AS WE MOVE FORWARD.

APPENDIX B - WRITTEN TESTIMONY OF JANET TRAUTWEIN, DIRECTOR OF FEDERAL POLICY ANALYSIS AND STATE GOVERNMENT AFFAIRS, NATIONAL ASSOCIATION OF HEALTH UNDERWRITERS, ARLINGTON, VA

Testimony of Janet Stokes Trautwein
before the
Employer-Employee Relations Subcommittee

September 6, 2001

Good afternoon. My name is Janet Stokes Trautwein. I am Director of Federal Policy Analysis and Director of State Government Affairs for the National Association of Health Underwriters. The National Association of Health Underwriters is an 18,000 member association of insurance professionals involved in the sale and service of health insurance, long-term care insurance, and related products, serving the insurance needs of over 100 million Americans. We appreciate this opportunity to present information on the health insurance underwriting process as it impacts employers and the effect well-intended genetic discrimination legislation could have on the cost of health insurance. NAHU believes health insurance affordability is the most important component of access to health care.

To start out, it may be helpful to explain what underwriting is. Underwriting is a basic evaluation of risk. Applicants for all types of insurance go through a risk evaluation process, or underwriting, as do applicants for credit cards, bank loans and mortgages. A bank would be very reluctant to issue a loan to someone who appears unlikely to be able to repay it, and an insurer would be unlikely to insure a house that was already on fire. If banks were unable to ask the information necessary to ensure the financial stability of applicants, they would either stop issuing loans or increase the interest rate to account for the increased likelihood of losses. Similarly, if an insurer couldn't ask whether a home was already on fire, the insurer would likely not insure homes or dramatically increase the cost to cover the cost of those that waited until their house was on fire to purchase coverage. On the other hand, if the bank and insurer are able to ask the questions needed to accurately assess the risk of an applicant or homeowner, the applicant may enjoy a "preferred" rate based on their good credit history, and the homeowner may be able to receive discounts for certain safety and security features in their homes. Health insurance underwriting works the same way – the more information the underwriter has, the better rates will be for most applicants overall.

Since the business of insurance is regulated primarily at the state level, fully insured employer health insurance plans are subject to state rules regarding underwriting and rates. All 50 states have regulations on health insurance underwriting and portability provisions. Most have patient protection laws and many also have already passed laws on genetic discrimination in insurance underwriting, employment, or both.

Federal legislation, the Health Insurance Portability and Accountability Act of 1996

(HIPAA), prohibits discrimination against individual members of a group health insurance plan on the basis of current health status or on the basis of some future predisposition to a particular disease based on genetic information. For example, if a generally healthy person had some genetic tests run to see if he or she had markers for any particular illnesses, that information would be prohibited from use. The law prohibits denial of benefits or increases in premium to individual members of a group health plan due to health status. HIPAA does not address the issue of genetic information in the individual health insurance underwriting process, nor does it address employment discrimination based on genetic information. In addition, group health plans of all sizes are guaranteed the right to renew policies, and employees may move between group health plans with full credit towards preexisting conditions limitations which have already been satisfied, without regard to health information, including genetic information.

Underwriting of Health Plans

Mid-size Employers of 50-300 Employees

This market is considered to be the "medium" size market. Most employers in this category purchase fully insured health insurance or HMO policies that are regulated by state departments of insurance or another state regulatory body. Many employers of this size offer PPO plans, and a large number offer more than one plan choice for employees.

It is quite common for an employer to "shop" his health insurance plan every year to be sure he is getting the best value for his dollar. This is normally done with the assistance of an insurance broker.

In order to obtain bids for coverage, employers that have a current health plan or plans are required to provide three years of claims experience to the carrier or carriers from which they are soliciting a bid for coverage. Claims experience is a listing of paid premiums vs. paid claims, and also includes a calculation for anticipated claims that have not yet been received by the in-force carrier.[1] The claims experience will typically also include a list of large claims by amount and the diagnosis associated with the claim. If this is not included with the claims experience, the bidding insurance carrier will request the large claim information. The bidding carrier will also ask about any known serious illnesses, to the best of the employer's knowledge, such as cancer, heart problems, AIDS, and the prognosis of each, to the best of the employer's knowledge. Names of the employees with these conditions are not requested, but gender and age for the employee or dependent with the condition may be requested as it may better enable the underwriter to assess the risk.

Sometimes other questions are asked as well. For example, if a person has had recent heart surgery, questions about current blood pressure, weight, smoking status and cholesterol level might be asked. Supplying this information can have a very positive impact on the rates the employer pays for coverage. For example, if an

employee who had a large claim is now deceased or is no longer employed, or if the large claim was due to an accident from which the employee has completely recovered, the amount of the large claim is adjusted out of the overall claims experience. If a person had bypass surgery early in the previous plan year, has recovered well and now has normal lab work and blood pressure readings, the chances of another large claim occurring soon are very low, and the underwriter will take that into consideration in setting the plan rates.

If the employer is not able to supply large claim and serious illness information, the insurance carrier may either underwrite more conservatively[2] to be sure it covers its bases on the risk assessment or, in some instances, may decline to write coverage on the group. Groups over 50 lives are **not** guaranteed issue. Even though a larger group has more employees over which to spread risk, a group of 50-300 is not considered large enough to spread all possible risks it may contain, and it is necessary to identify particularly high risks in order to establish rates that are adequate to sustain the cost of claims and administration. If the employer is unaware of a serious condition, the health plan will not come back mid-year and penalize the employer for not reporting the condition during the bid process, but an adjustment based on the actual risk will be made at the plan's renewal.

In addition to the claims experience, a list of employees including gender, date of birth and the type of family members to be covered[3] is required to calculate an average age for the group and male and female content. Age has an obvious impact on the level of claims since older individuals statistically have higher medical expenses. Females tend to incur higher costs than males until about age 50, and that is the reason for the calculation on gender.

A group of 300 is considered to be 100 % credible for its claims experience by most insurance companies. This means that if an employer has three years of available claims experience, an accurate rate can be calculated even without information on age or gender of the employees, just based on the group's past experience. Statistically, most groups follow a fairly predictable three-year pattern if they are large enough. Of the three years of claims experience, the most weight is given to the most recent year. In addition, insurance carriers have a book rate based on their experience with other groups of employees of similar age, gender and industry. The book rate is used for newer groups who haven't had previous coverage and also for groups that are a little smaller and not fully credible with their own claims experience. For example, a group of 200 might be considered 75 % credible for its claims experience. Therefore, in calculating the rate, claims experience would be given 75 % weight and the "book" rate would be given 25 %. A group of 150 might be considered 50 % credible and a group of 100 might be 25 % credible. A group of 50 would receive a 100 % book rate, modified by any known serious health conditions. This can vary slightly from carrier to carrier, but the general process is the same.

Rate Stability

A number of things can impact a group's rates from year to year. A group may have a large number of maternity cases in a single year, or one or more persons may have large claims that cause the group's claims experience to be abnormally high. New state or federal laws that require payment for specific items and services are not without cost. This cost adds to the total cost of claims paid under the plan, which in turn causes premiums to increase. The cost of prescription drugs is increasing for all employers, as is the cost of medical care in general. Even if nothing unusual happens in a group in a given year, these increasing costs may cause a group's claims experience to go up, and its rates to be increased at the plan's renewal. This is why it is so critical that the rates be as accurate as possible from the start. A plan that's rates are set too low initially will simply recoup its losses at renewal with a very large increase. These large fluctuations in premium are very unsettling for employers and employees and can result in some employees dropping coverage, as they become unable to pay their share of premiums.

Self-Insured Plans

Self-funded or self-insured plans are plans where the employer takes the risk for the cost of health claims, rather than purchasing a plan from an insurance company. The employer often buys stop-loss coverage to protect against excessive losses, but retains financial responsibility for the plan. Underwriting in self-funded plans works just like it does for fully insured plans in this market, primarily because of the stop-loss insurance. Although most employers in this category are fully insured, a large number are partially self-funded and are subject to federal rather than state regulation. In a self-funded plan, an employer usually selects an insurance carrier or third-party administrator to administer claims, a PPO or HMO network of physicians, hospitals and other providers for preferred-provider benefits, a pharmacy benefit manager to manage prescription drug benefits, and a utilization review organization if this service is not performed by the preferred provider network. Each of these services is normally purchased on a separate monthly fee per employee basis, although the cost of some services may be combined if purchased from the same vendor.

The self-funded employer also normally purchases what is called specific stop-loss insurance to protect against large claims of any one individual covered by the plan, and aggregate stop-loss insurance to protect against excessive utilization by the group as a whole. Once an individual or group's claims reach the stop-loss level, the reinsurance carrier is responsible for the clams for the individual or the group, depending on the type of loss, for the balance of the contract year. In order for an employer to know how much stop-loss coverage is appropriate for their group, the same information asked of fully insured cases relating to overall claims experience, large claims and serious illnesses is required. Since stop loss levels are established based on expected claims, it is very important to be as accurate as possible in anticipating future claims. Complete information during the underwriting process is extremely important or an employer may be forced to set stop-loss levels too high, resulting in inadequate protection in the event of a year of high claims.

Groups of 300 or More Employees

Larger group underwriting works in a manner similar to that described for medium-size employer groups. The differences are a matter of degree. Claims experience is required during the underwriting process, but for a larger group, a claim may not be considered large until it reaches $25,000, $30,000 or even larger, rather than $10,000 or $15,000.

For this reason, the number of claims that must be reported in the large claim listing may be fewer. Information on serious illnesses will be requested, but detailed information on prognosis is less important. The reason fewer questions are asked is that the larger the group becomes, the more credible its past claims experience is, even with some large claims thrown into the mix. Even large employers, however, have difficulty anticipating and budgeting for cost increases due to new technology and the cost of prescription drugs.

The other thing that changes is that the larger the group is, the more likely it is to be partially self-funded and if really large, fully self-funded. Stop-loss coverage is usually purchased, but with a higher trigger point for claims as the group becomes larger and better able to handle cash flow fluctuations. Third-party administrators, brokers and consultants use formulas to help employers determine the level of stop-loss coverage that is appropriate based on expected claims, group size and the employer's level of risk tolerance.

Large employers also have greater ability due to volume purchasing, to offer variety to employees including multiple plan options. Large employers are also increasing their use of disease management programs, wellness programs and options for alternative medicine.

One thing that should be noted is that not all employers that self-fund use administrators and insurance carriers. Although it is not very common, there are employers who self-administer their benefits plans. Not all of these employers are "jumbo" employers, and some are in the 50-300 size category. Self-administration is done to save money, and many of the employers that employ this method would not be able to afford to offer a plan if they didn't administer it themselves. The smaller employers that self-administer usually offer decent coverage without complicated provisions. These employers take great care to pay claims accurately, and actually understand the stop-loss provisions of

their reinsurance contracts very well. The reinsurance coverage they purchase requires all of the same information gathering required under other arrangements, although it is sometimes more difficult for them to obtain reinsurance without the "official" prior claims documentation provided by a third-party claims administrator or insurance carrier.

Small Employer Groups of 2-50[4]

Although many people refer to employer self-funded health plans as ERISA plans, small employer health insurance plans are also ERISA plans. Small employers can select from a variety of plans in most states, including HMOs, PPOs and indemnity plans. The selection depends largely on the regulatory environment in the state in both the small employer **and** individual market, and can vary dramatically from state to state.[5] Availability of coverage is also impacted by the location of the business. In general, rural businesses have less selection than businesses in metropolitan areas, largely due to the reluctance of rural providers to participate in managed care plans.

Even though HIPAA and state law provide that small employer health insurance coverage must be issued regardless of the health status of employees and dependents, many states allow rates to vary for the group based on overall health status. To determine the health status of the group, each employee is required to complete an individual questionnaire with detailed health information on the employee and all family members to be covered. The underwriter normally uses only information obtained from the application, but sometimes the underwriter will request additional information from an applicant's physician or may telephone the applicant to clarify an item on the application. If an underwriter is unable to obtain information necessary to accurately determine the risk of a particular applicant, he or she will underwrite more conservatively, meaning that the assumption relative to the missing information will be negative rather than positive.

So, for example, if an underwriter sees that a person has a history of high blood pressure that appears to be normal with medication and has a weight within normal limits, but is unable to determine whether or not the individual smokes and has a normal cholesterol level, the underwriter will assume that the missing information is negative.

Each employee application is considered individually, usually using a point system, and the overall negative points determine whether the group will be issued at the rates quoted or with a rate-up. On a very small group, one applicant with a health history that would have resulted in a "decline" prior to guaranteed-issue laws will result in a maximum rate-up for the group in most circumstances. It is very important, therefore, that each employee's application be as complete as possible in order to ensure that initial rates are accurate.

The most common type of state rating law allows groups to be rated 25% above or 25% below an "indexed" rate. The indexed rate is determined by averaging the lowest possible rate and the highest possible rate. Most insurance carriers offer the lowest legal rate on their initial quotes, or 25% below the indexed rate, in states that employ this maximum. If a group's health status is such that they would be rated at the maximum level, this means that their final rate could be 67% higher than the rate initially quoted to them. Most states that have this type of rating system also have a limit on rate increases due to the health status of the group, which is helpful in stabilizing rates over time. Even with these initial rate fluctuations for a new group, small employer rates in these states tend to be lower than in states where

health status rating is not allowed. A group that is rated correctly up front is much less likely to have a very large increase at renewal, and in order to rate the group correctly, the correct information on the initial application is essential. A chart showing the rating laws in each state is attached, along with a sample small employer health questionnaire.

Legislation under Consideration

The issue surrounding prohibition of discrimination by health insurance carriers due to genetic information has evolved over the past few years. Legislation to expand the prohibition on the use of genetic information in underwriting has resulted in a variety of opinions as to how genetic information should be defined. The definition of genetic information has been broadened in HR602 in a way that could include items that go beyond what is normally considered a genetic test. Using too broad a definition could disrupt and prevent normal underwriting procedures, resulting in unaffordable health insurance premiums for employers and consumers.

The first issue regarding the definition of genetic information relates to **when** information should be considered genetic information. HIPAA prohibits discrimination by any

individual within a group based on health status, including genetic information, in the absence of a diagnosis. Genetic information when no diagnosis or symptoms of illness is present is called "predictive" genetic information. In contrast to S382, HR602, removes all reference to predictive genetic information, and replaces it with the term "protected" genetic information. This in effect goes far beyond the HIPAA standard and would prevent genetic information from being used in health insurance underwriting or by employers even when a diagnosis of illness is otherwise present.

Because HIPAA did not adequately define **what** "genetic information" is, it is extremely important that any new legislation clearly specify what should be included in the term "genetic information." NAHU believes the definition of genetic information should be limited to DNA and related gene testing done for the purpose of predicting risk of disease in asymptomatic or undiagnosed individuals, and that it should clearly exclude such items as age, gender, and information from physical exams and lab work including items like cholesterol tests, performed to detect symptoms, clinical signs, or a diagnosis of disease.

Finally, in contrast to the definitions in S382, HR602 does not include specific tests in its exceptions, such as cholesterol screening, but it is specific tests such as these where we have serious concern. Cholesterol screening, for example, is a metabolite test. Other legitimate genetic tests are also metabolite tests. Cholesterol screening is currently used as a diagnostic tool, and as such, a "high" result is considered a diagnosis. Changing the status of an item such as cholesterol screening to be included as a genetic test would remove it from the diagnostic category, along with the diagnostic code which allows millions of Americans to have their cholesterol lowering medications covered by their health insurance.

Conclusion

Health insurance underwriting is a complicated process. It is a combination of art and science, and is highly dependent on not only the risk of the applicant but on other market conditions that may be beyond the applicant's control. The most important component of underwriting is complete information to allow for a thorough evaluation of risk.

There is no question that advances in genetics will increase exponentially in the coming decades. Changes in the accuracy and absolute predictability of the information that will be provided will also improve, and the use of this information to diagnose current illness may become as common as taking a blood pressure reading is today. It is extremely important that lawmakers recognize this changing dynamic, but additionally realize the impact their actions will have on the cost of health insurance today and in the years ahead. Great care should be taken to craft legislation that is very specifically related to a prohibition of the use of legitimate genetic tests. Overly broad definitions will impede the normal underwriting process and increase the cost of coverage.

Good underwriting at the inception of any health insurance policy won't prevent premium increases, but it does result in more stable rates over time. This stability allows families and businesses to plan and budget for their health care expenses and helps keep coverage affordable and accessible.

Additional Information about Rates on Health Plans

Rates are also obviously impacted by plan design and plan type. Rates for PPO plans are usually, but not always, higher than HMOs, partly because the way providers are paid impacts the ultimate claims cost. PPO plans pay preferred providers based on a discounted fee for service, or in some cases, on a previously agreed to per diem rate for things like hospital stays. Sometimes "case" rates are paid for maternity or similar types of common expenses. A case rate is a lump sum paid for a certain types of expenses. For example, an uncomplicated vaginal delivery might have a "case" rate of $1,000. Out-of- network providers are paid based on a percentile of the usual and customary (UCR) cost of a service in the zip code of the provider. Some plans pay out of network providers based on the 80th percentile of UCR, some on the 70th percentile, and some on the 90th percentile. The percentile used is important because on out of network claims, the insured is responsible for all charges the insurance plan doesn't pay for, and because it impacts the dollar amount of total claims paid.

Example: Employee is covered by a plan that pays for services at 90% in network and 70% out of network. Out-of-network charges are paid on the 90th percentile. Employee has surgery by an out-of-network physician who charges $1,000. Ninety percent of physicians in the area charge $900 or less for the procedure, so the physician the employee selected is above the 90% percentile of usual and customary

charges by $100.

Here is how the claim is paid at both the 80th and 90th percentiles:

At 90th At 80th

Percentile Percentile

Surgery $1,000 $1,000

Minus amount over Usual & Customary Charges $ 100 $ 150

Covered fee $ 900 $ 850

Insurance pays 70% $ 630 $ 595

Employee pays 30% plus amount over UCR $ 370 $ 405

If the insured uses an in-network PPO provider, then the insured would not be responsible for charges in excess of the contract rate. Example:

Regular rate for the surgery $1,000

Contract rate for the surgery $ 650

Insurance pays 90% $ 585

Employee pays 10% of contract rate $ 65

As you can see, because of the PPO discount, both the plan and the employee pay less with the PPO provider, even though the plan is paying at 90%. This means claims payments will be less and premiums lower if most employees use preferred providers. It also is an incentive for plans to develop full networks of providers. In this instance, if the plan did not have an adequate network and had to pay the full undiscounted rate to the surgeon at 90%, the plan would have paid $900 for a service that should have cost them $585.[1]

Premiums on PPO plans are also impacted by the ability of the plan to negotiate discounted fees with preferred providers. In rural areas, it is often difficult to negotiate a discounted fee with a physician who may be the only specialist of that type in town, and many physicians in rural areas don't negotiate at all. In those situations, there may be few PPOs available, and for those that are available, it is much more likely that out-of- network claims will be paid at a lower percentile of UCR and that the percentage payable will be less. If you go back to the example above, you will note that the out-of-network claim paid at the 80th percentile

resulted in a payment by the plan similar to the payment made to the PPO provider. The difference in this situation is that for out-of-network claims, the insured takes on all of the responsibility for the amount not paid by the carrier, while with preferred providers, the provider absorbs the cost.

In addition, even though the flexibility of a PPO is attractive, there are few barriers to utilization and, as a result, costs may be higher than they would be under an HMO. All rates are based on claims, whether it is the group's own claims experience or a book rate. Therefore, anything that increases the ultimate cost of claims paid out will impact the rate paid. This includes the cost of prescription drugs; for this reason many employers who want to retain as high a level of benefits as possible for non-pharmaceutical benefits are requiring increasingly larger copays for drugs, especially those not on the formulary.

HMOs pay providers in a variety of ways. Some HMOs actually pay physicians the same way PPOs do, based on a discounted fee for service. This is especially common when an HMO enters a new area and doesn't yet have a significant market share. But more commonly, the HMO pays a primary care physician a fixed rate, called a capitated rate, per member per month regardless of the number of times a person may or may not have seen the physician that month. Some specialists are capitated the same way, and others are paid a discounted fee for service. Certain specialties are very likely to be capitated, such as anesthesia, pathology and radiology. Hospitals are usually paid on a per diem basis, although they may be capitated or paid a "case" rate for some types of admissions.

HMOs usually require a referral from the primary care physician for a patient to see a specialist, and only cover care from network providers. The idea of referrals is to ensure that only patients who actually require specialty care are seen by plan specialists. Because primary care physicians are capitated, the cost of non-hospital care is more predictable and is usually lower than under a PPO where costs are more impacted by the rate of utilization. Most services require authorization from the primary care physician, and this more tightly managed care results in greater cost efficiencies.

In spite of this management of care, a sick person will result in high costs regardless of the type of plan. How high the costs are will vary by degree with the plan type. HMO rates are typically based on the "community" of members in their pool; however, they are permitted to make adjustments based on the demographics of the actual group to be insured. Again, it is essential that the bidding HMO have accurate information on the actual group to be insured in order to establish adequate initial rates.

One other type of common option is a point of service plan (POS). This type of plan option is often confused with a PPO, because it looks similar on the surface. In reality, a POS plan is simply an HMO with an option to use out-of-network providers. Usually the out-of-network option is significantly less attractive that an out-of-network option on a PPO plan, and the in network portion of the plan is an

HMO. This means that in the network, all HMO rules must be followed, including rules on referrals for in-network

specialty care. While not quite as flexible as a PPO plan, a POS plan offers a good value for the dollar, especially if HMO providers will be used most of the time, while still allowing a safety net for people who want to retain the option of using non-network providers.

The Individual Health Insurance Market

Although most people who are insured are covered through employer-sponsored plans, some people do not have access to employer coverage and must buy in the individual health insurance market. The individual health insurance market offers a wide range of policy coverage options in many states, depending on the regulatory environment. Coverage is available in a wide range of deductibles and plan types, and most people can find a policy suitable for their needs, although coverage for maternity and mental health expenses is often limited and prescription drug benefits tend to be more restrictive than those found in the group market.

In most states, individual health insurance is rated based on the age and health status of the applicant and requires the completion of a health questionnaire. Occasionally a paramedical examination and/or a blood and urine sample are required. Questions about genetic tests are not currently asked by any insurance carrier that we have been able to determine, although a small number of insurers ask questions about medical history of the parents and siblings of the applicant.

Applicants are asked a variety of questions about their current and past medical history including height and weight, smoking status and details about recent physical exams, including the results of lab work. Complete information allows the underwriter to evaluate the risk of the applicant accurately and provides for greater rate stability. Any missing information can result in the applicant being turned down for coverage. At best, missing information will result in the underwriter assuming the worst, and the consumer will either pay more for coverage or have coverage excluded.

Depending on the state, an applicant for individual health insurance coverage will have coverage issued as applied for, have coverage issued with a rider for certain conditions or body parts, or have coverage "rated up" or issued at a premium higher than the standard rate. The majority of states don't have limits on rate-ups for individual coverage, but if an applicant's health history is such that a large rate-up is indicated, it is more likely that the person would be declined for coverage.

Applicants who are declined for coverage in many states are eligible for coverage through their state high-risk pool. In other states there is an annual open enrollment period for uninsurable individuals through one insurance carrier in the state. A few states guarantee issue coverage in the individual market, although the cost is high and choices significantly limited. Several states provide coverage through a carrier

of last resort, which means that the designated insurance carrier must accept an individual regardless of health status. Usually there is one month per year when this happens, although in some states applicants are accepted all year. A very small number of states have no option for medically uninsurable individuals. A summary of high-risk pool coverage and other mechanisms for uninsurable individuals across the country is attached.

It may sound attractive to a consumer to have fewer health questions asked during the underwriting process, but in the individual health insurance market where there is not an adequate mechanism to spread risk, a requirement to issue coverage without regard to health status will increase the cost for everyone. This is also the market most sensitive to those cost increases, because individual health insurance consumers do not have employers subsidizing the cost of their health plans. Many individuals and families are faced at some point in their lives with purchasing coverage in the individual health insurance market, and it is critical that the cost be affordable. If it is not, the ranks of the uninsured will rise, and costs in the small group market will also increase as people attempt to game the system to somehow change their status from an individual market buyer to a "group."

Explanation of Terms

Individual Market Reforms

Indicates the reforms each state has adopted concerning their individual health insurance markets. Notes whether or not the state requires guaranteed issue in the individual market. (States marked with an asterisk "*" either have one or more carriers voluntarily offering guaranteed issue or have mandated that there be a carrier of last resort in the state.) Also indicates how many months a pre-existing condition may be excluded from coverage, and what the rating structure in the state. "NRS" means no rating structure, "C" means community rating, "MC" means modified community rating, and "RB" means rate bands are used in the state but the actual indexed rate was not available. If a percentage is indicated, that is the percentage a carrier is allowed to increase rates based on medical underwriting criteria.

Small-Group Market Reforms

Indicates the reforms each state has adopted concerning their small-group health insurance markets. Notes whether or not the state requires guaranteed issue in the small-group market, and also indicates how many months a pre-existing condition may be excluded from coverage, and what the rating structure for small employers with similar characteristics for the same or similar coverage is in the state. "NRS" means no rating structure, "C" means community rating, "MC" means modified community rating, and "RB" means rate bands are used in the state but the actual indexed rate was not available. If a percentage is indicated, that is the percentage a carrier is allowed to increase rates based on medical underwriting criteria. Finally, this section notes how many lives are considered to be a "small-group" in the state.

S-CHIP Approach

Describes the approach the state has taken to insuring children under the State Childrens' Health Insurance Program (S-CHIP). Indicates if the state has chosen to expand coverage under the Medicaid program, develop their own approach, or use a combination of Medicaid expansion and their own alternative method.

Medically Uninsurable

Describes the state's mechanism for providing access to health insurance to people with pre-existing medical conditions so severe they are considered to be uninsurable. Notes if the state has established a high-risk health insurance pool for people with catastrophic medical conditions, or if they offer coverage through either guaranteed issue or open enrollment. Also indicates if the state employs another method (e.g., TennCare or employer mandate).

Medical Savings Accounts

Indicates whether or not medical savings accounts are allowed as a health insurance option in the state.

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As you can see, because of the PPO discount, both the plan and the employee pay less with the PPO provider, even though the plan is paying at 90%. This means claims payments will be less and premiums lower if most employees use preferred providers. It also is an incentive for plans to develop full networks of providers. In this instance, if the plan did not have an adequate network and had to pay the full undiscounted rate to the surgeon at 90%, the plan would have paid $900 for a service that should have cost them $585.[1]

[1] One of the reasons rural areas have fewer PPO and other managed care plan options is that PPOs and HMOs frequently experience difficulty in getting physicians in rural areas to participate. This results in the problem described above, where the plan is forced to pay for a service at the full undiscounted rate at the highest applicable percentage, while the employee's cost-sharing is not allowed to be more than it would have been with an in-network provider, because of rules on network adequacy. Network adequacy rules require plans to include providers in each specialty that might be required by people insured under the plan, as well as provide for adequate facilities for lab, x-ray and hospital care. In this case, a plan may decide it's not economically feasible to offer coverage in the area, or may attempt to control costs with a "hospital only" PPO, or an indemnity plan where it can have some control over reimbursements by lowering the percentile it uses for usual and customary charges.

Premiums on PPO plans are also impacted by the ability of the plan to negotiate discounted fees with preferred providers. In rural areas, it is often difficult to negotiate a discounted fee with a physician who may be the only specialist of that type in town, and many physicians in rural areas don't negotiate at all. In those situations, there may be few PPOs available, and for those that are available, it is much more likely that out-of-network claims will be paid at a lower percentile of UCR and that the percentage payable will be less. If you go back to the example above, you will note that the out-of-network claim paid at the 80th percentile resulted in a payment by the plan similar to the payment made to the PPO provider. The difference in this situation is that for out-of-network claims, the insured takes on all of the responsibility for the amount not paid by the carrier, while with preferred providers, the provider absorbs the cost.

In addition, even though the flexibility of a PPO is attractive, there are few barriers to utilization and, as a result, costs may be higher than they would be under an HMO. All rates are based on claims, whether it is the group's own claims experience or a book rate. Therefore, anything that increases the ultimate cost of claims paid out will impact the rate paid. This includes the cost of prescription drugs; for this reason many employers who want to retain as high a level of benefits as possible for non-pharmaceutical benefits are requiring increasingly larger copays for drugs, especially those not on the formulary.

HMOs pay providers in a variety of ways. Some HMOs actually pay physicians the same way PPOs do, based on a discounted fee for service. This is especially common when an HMO enters a new area and doesn't yet have a significant market share. But more commonly, the HMO pays a primary care physician a fixed rate, called a capitated rate, per member per month regardless of the number of times a person may or may not have seen the physician that month. Some specialists are capitated the same way, and others are paid a discounted fee for service. Certain specialties are very likely to be capitated, such as anesthesia, pathology and radiology. Hospitals are usually paid on a per diem basis, although they may be capitated or paid a "case" rate for some types of admissions.

HMOs usually require a referral from the primary care physician for a patient to see a specialist, and only cover care from network providers. The idea of referrals is to ensure that only patients who actually require specialty care are seen by plan specialists. Because primary care physicians are capitated, the cost of non-hospital care is more predictable and is usually lower than under a PPO where costs are more impacted by the rate of utilization. Most services require authorization from the primary care physician, and this more tightly managed care results in greater cost efficiencies.

In spite of this management of care, a sick person will result in high costs regardless of the type of plan. How high the costs are will vary by degree with the plan type. HMO rates are typically based on the "community" of members in their pool; however, they are permitted to make adjustments based on the demographics of the actual group to be insured. Again, it is essential that the bidding HMO have accurate information on the actual group to be insured in order to establish adequate initial rates.

One other type of common option is a point of service plan (POS). This type of plan option is often confused with a PPO, because it looks similar on the surface. In reality, a POS plan is simply an HMO with an option to use out-of-network providers. Usually the out-of-network option is significantly less attractive that an out-of-network option on a PPO plan, and the in network portion of the plan is an HMO. This means that in the network, all HMO rules must be followed, including rules on referrals for in-network specialty care. While not quite as flexible as a PPO plan, a POS plan offers a good value for the dollar, especially if HMO providers will be used most of the time, while still allowing a safety net for people who want to retain the option of using non-network providers.

The Individual Health Insurance Market

Although most people who are insured are covered through employer-sponsored plans, some people do not have access to employer coverage and must buy in the individual health insurance market. The individual health insurance market offers a wide range of policy coverage options in many states, depending on the regulatory environment. Coverage is available in a wide range of deductibles and plan types, and most people can find a policy suitable for their needs, although coverage for maternity and mental health expenses is often limited and prescription drug benefits tend to be more restrictive than those found in the group market.

In most states, individual health insurance is rated based on the age and health status of the applicant and requires the completion of a health questionnaire. Occasionally a paramedical examination and/or a blood and urine sample are required. Questions about genetic tests are not currently asked by any insurance carrier that we have been able to determine, although a small number of insurers ask questions about medical history of the parents and siblings of the applicant.

Applicants are asked a variety of questions about their current and past medical history including height and weight, smoking status and details about recent physical exams, including the results of lab work. Complete information allows the underwriter to evaluate the risk of the applicant accurately and provides for greater rate stability. Any missing information can result in the applicant being turned down for coverage. At best, missing information will result in the underwriter assuming the worst, and the consumer will either pay more for coverage or have coverage excluded.

Depending on the state, an applicant for individual health insurance coverage will have coverage issued as applied for, have coverage issued with a rider for certain conditions or body parts, or have coverage "rated up" or issued at a premium higher than the standard

rate. The majority of states don't have limits on rate-ups for individual coverage, but if an applicant's health history is such that a large rate-up is indicated, it is more likely that the person would be declined for coverage.

Applicants who are declined for coverage in many states are eligible for coverage through their state high-risk pool. In other states there is an annual open enrollment period for uninsurable individuals through one insurance carrier in the state. A few states guarantee issue coverage in the individual market, although the cost is high and choices significantly limited. Several states provide coverage through a carrier of last resort, which means that the designated insurance carrier must accept an individual regardless of health status. Usually there is one month per year when this happens, although in some states applicants are accepted all year. A very small number of states have no option for medically uninsurable individuals. A summary of high-risk pool coverage and other mechanisms for uninsurable individuals across the country is attached.

It may sound attractive to a consumer to have fewer health questions asked during the underwriting process, but in the individual health insurance market where there is not an adequate mechanism to spread risk, a requirement to issue coverage without regard to health status will increase the cost for everyone. This is also the market most sensitive to those cost increases, because individual health insurance consumers do not have employers subsidizing the cost of their health plans. Many individuals and families are faced at some point in their lives with purchasing coverage in the individual health insurance market, and it is critical that the cost be affordable. If it is not, the ranks of the uninsured will rise, and costs in the small group market will also increase as people attempt to game the system to somehow change their status from an individual market buyer to a "group."

National Association of Health Underwriters
State-Level Health Insurance Reforms
As of August 1, 2001

State	Individual Market Reforms			Small-Group Market Reforms				S-CHIP Approach			Medically Uninsurable				MSA
	Guaranteed Issue	Pre- Ex Conditions (look back/ exclusion period)	Rating Structure	Guaranteed Issue	Pre-Ex Conditions (look back/ exclusion period)	Rating Structure	Group Size	Medicaid	Combination	Other	Risk-Pool	Guaranteed Issue	Open Enrollment	Other	
Alabama		none	NRS	•	6/12	RB	2-50		•		•				
Alaska		none	NRS	•	6/12	35%	2-50	•			•				
Arizona		none	NRS	•	6/12	RB/MC	2-50			•	None				•
Arkansas		none	NRS	•	6/6	25%	2-50	•			•				•
California		12/12	NRS	•	6/12	10%	2-50		•		•		•		•
Colorado		none	NRS	•	6/12	MC	1-50			•	•				•
Connecticut		12/12	NRS	•	6/12	MC	1-50		•		•				
Delaware		none	NRS	•	6/12	35%	1-50			•	None				
District	•*	none	NRS	•	6/12	NRS	2-50	•					•		•
Florida		6/12	NRS	•	6/12	MC	1-50		•		•				•
Georgia		none	NRS	•	6/12	25%	2-50			•	None				
Hawaii	•*	none	NRS/C	•	0	NRS/C	1-50	•						•	
Idaho	•*	6/12	25%	•	6/12	50%	2-50	•			•				•
Illinois		none	NRS	•	6/12	25%	2-50		•		•				•
Indiana		12/12	35%	•	6/9	35%	2-50		•		•				•
Iowa	•*	12/12	20%	•	6/12	25%	2-50		•		•	•			
Kansas		none	NRS	•	6/3	25%	2-50			•	•				•
Kentucky	•*	12/12	35%	•	6/12	35%	2-50		•		•				
Louisiana		12/12	20%	•	6/12	20%	2-50	•			•				•
Maine	•	12/12	MC	•	6/12	MC	1-50		•			•			•
Maryland	•*	6/12	NRS	•	0	MC	1-50		•				•		•
Massachusetts	•*	6/6	MC	•	6/12	MC	1-50		•			•			
Michigan	•*	6/6	NRS	•	6/12	NRS/C	2-50		•				•		•
Minnesota	•*	6/12	25%	•	6/12	25%	2-50		•		•				•
Mississippi		12/12	NRS	•	6/12	25%	1-50		•		•				•
Missouri		none	NRS	•	6/12	25%	3-25	•			•				•
Montana		36/12	NRS	•	6/12	RB	2-50			•	•				•
Nebraska		none	NRS	•	6/12	RB	2-50	•			•				•
Nevada		none	RB	•	6/12	30%	2-50			•	None				•
New Hampshire		3/9	RB	•	3/9	MC	1-100		•		•				
New Jersey	•	6/12	C	•	6/6	MC	2-50		•			•			•
New Mexico		6/6	MC	•	6/6	20%/ MC	2-50	•			•				•
New York	•	6/12	C	•	6/12	C	1-50		•			•			
North Carolina		none	NRS	•	6/12	RB	1-50			•			•		
North Dakota		6/12	MC	•	6/12	20%	2-50		•		•				
Ohio	•*	6/12	NRS	•	6/12	35%	2-50	•				•			•
Oklahoma		none	NRS	•	6/12	25%	2-50	•			•				•
Oregon	•*	6/6	MC	•	6/6	MC	2-50			•	•				•
Pennsylvania	•*	none	NRS/C	•	6/12	NRS/C	2-50			•			•		•

State	Individual Market Reforms			Small-Group Market Reforms				S-CHIP Approach			Medically Uninsurable				MSA
	Guaranteed Issue	Pre- Ex Conditions (look back/ exclusion period)	Rating Structure	Guaranteed Issue	Pre-Ex Conditions (look back/ exclusion period)	Rating Structure	Group Size	Medicaid	Combination	Other	Risk-Pool	Guaranteed Issue	Open Enrollment	Other	
Rhode Island	•*	0	NRS	•	0	10%	1-50	•					•		
South Carolina		none	NRS	•	6/12	25%	2-50	•			•				
South Dakota	•*	12/12	RB	•	6/12	25%	2-50	•			None				
Tennessee		none	NRS	•	6/12	25%-35%	2-50	•						•	
Texas		none	NRS	•	6/12	25%	2-50		•		•				•
Utah		6/12	RB	•	6/12	30%	2-50			•	•	•			•
Vermont	•	12/12	C	•	6/12	C	1-50			•		•			
Virginia	•*	12/12	NRS	•	6/12	NRS/ 20%	2-50			•			•		•
Washington		3/9	MC	•	3/9	MC	1-50			•	•	•			•
West Virginia	•*	none	RB	•	6/12	30%	2-50		•		None				•
Wisconsin		none	NRS	•	6/12	35%	2-50		•		•				•
Wyoming		6/12	NRS	•	6/12	25%	2-50			•	•				•

Explanation of Terms

Individual Market Reforms
Indicates the reforms each state has adopted concerning their individual health insurance markets. Notes whether or not the state requires guaranteed issue in the individual market. (States marked with an asterisk "*" either have one or more carriers voluntarily offering guaranteed issue or have mandated that there be a carrier of last resort in the state.) Also indicates how many months a pre-existing condition may be excluded from coverage, and what the rating structure in the state. "NRS" means no rating structure, "C" means community rating, "MC" means modified community rating, and "RB" means rate bands are used in the state but the actual indexed rate was not available. If a percentage is indicated, that is the percentage a carrier is allowed to increase rates based on medical underwriting criteria.

Small-Group Market Reforms
Indicates the reforms each state has adopted concerning their small-group health insurance markets. Notes whether or not the state requires guaranteed issue in the small-group market, and also indicates how many months a pre-existing condition may be excluded from coverage, and what the rating structure for small employers with similar characteristics for the same or similar coverage is in the state. "NRS" means no rating structure, "C" means community rating, "MC" means modified community rating, and "RB" means rate bands are used in the state but the actual indexed rate was not available. If a percentage is indicated, that is the percentage a carrier is allowed to increase rates based on medical underwriting criteria. Finally, this section notes how many lives are considered to be a "small-group" in the state.

S-CHIP Approach
Describes the approach the state has taken to insuring children under the State Childrens' Health Insurance Program (S-CHIP). Indicates if the state has chosen to expand coverage under the Medicaid program, develop their own approach, or use a combination of Medicaid expansion and their own alternative method.

Medically Uninsurable
Describes the state's mechanism for providing access to health insurance to people with pre-existing medical conditions so severe they are considered to be uninsurable. Notes if the state has established a high-risk health insurance pool for people with catastrophic medical conditions, or if they offer coverage through either guaranteed issue or open enrollment. Also indicates if the state employs another method (e.g., TennCare or employer mandate).

Medical Savings Accounts
Indicates whether or not medical savings accounts are allowed as a health insurance option in the state.

National Association of Health Underwriters

Comparison of State-Level High Risk Pools
(as of June 15 2001)

Twenty-eight states currently operate high-risk health insurance pools as a means of providing high-quality comprehensive health insurance coverage to individuals with catastrophic medical conditions. In this study, the National Association of Health Underwriters (NAHU) compared the maximum benefits, premium caps, financing mechanisms, rates, benefits and cost-sharing requirements for all state-level high-risk insurance pools around the country. For each state, NAHU sought price and benefit information for a PPO product with a $500 deductible and a 80% coinsurance rate. In several states, such plans were not available, so for those states NAHU gathered data for the plan with the lowest annual deductible available. Some states offer different rates based on smoker status, so in those cases, NAHU assumed that both participants were non-smokers. In addition, some states offer different rates if the applicant is enrolling as a HIPAA-eligible rather than as a medically uninsurable individual. Unless otherwise noted, NAHU assumes that the applicant is a medically uninsurable individual.

State	Maximum Benefit	Premium cap (of an average comparable plan)	Financing Mechanism	35 Year-Old Female	53 Year-Old Male
Alabama (Pool is only available for HIPAA eligible)	*Lifetime:* $1 million	200%	Financed through member premiums and assessments to the insurance industry based premium volume in the state. Insurance carriers will be provided an offset of the assessment against any premium taxes they pay to the state.	*Monthly Premium Rate:* $300 *Summary of Benefits and Cost-sharing:* $500 deductible with $1000 plus deductible in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical and specific disease care.	*Monthly Premium Rate:* $400 *Summary of Benefits and Cost-sharing:* $500 deductible with $1000 plus deductible in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical and specific disease care.
Alaska	*Lifetime:* $1 million	200%	Funded through subscriber premiums and assessments to association members in proportion to the percentage of total health insurance premiums each member writes in the state.	*Monthly Premium Rate:* $360.03 *Summary of Benefits and Cost-sharing:* $500 deductible with $2000 in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, preventive care, major medical and specific disease care.	*Monthly Premium Rate:* $611.25 *Summary of Benefits and Cost-Sharing:* $500 deductible with $2000 in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, preventive care, major medical and specific disease care.
Arkansas	*Lifetime:* $1 million	150%	Association members are assessed for net losses in proportion to their share of total health insurance premiums received in the state	*Monthly Premium Rate:* $199.76 *Summary of Benefits and Cost-sharing:* $1000 deductible with $2000 in stop-loss coverage. 80% coinsurance in-network and 60%	*Monthly Premium Rate:* $347.80 *Summary of Benefits and Cost-sharing:* $1000 deductible with $2000 in stop-loss coverage. 80% coinsurance in-network and 60%

State	Maximum Benefit	Premium cap (of an average comparable plan)	Financing Mechanism	35 Year-Old Female	53 Year-Old Male
			during the year.	out-of network. Comprehensive coverage includes RX, major medical, preventive and specific disease care.	out-of network. Comprehensive coverage includes RX, major medical, preventive and specific disease care.
California*	*Lifetime:* $750,000 *Annual:* $75,000	125%	The plan is funded through subscriber contributions and the Major Risk Medical Insurance Fund directed by the state. $45 million is deposited annually in the fund from the State Cigarette and Tobacco Products Surtax Fund. Enrollment will be curtailed to assure the program operates within its budget. One of the participating carriers, Blue Cross, offers a non-subsidized look-alike product to persons on the waiting list.	*Monthly Premium Rate:* $181 *Summary of Benefits and Cost-Sharing:* No deductible with $2500 in stop-loss coverage. 25% coinsurance in-network and $25 office visit. Coverage includes RX, major medical, preventive and specific disease care.	*Monthly Premium Rate:* $365 *Summary of Benefits and Cost-Sharing:* No deductible with $2500 in stop-loss coverage. 25% coinsurance in-network and $25 office visit. Coverage includes RX, major medical, preventive and specific disease care.
Colorado*	Lifetime: $500,000	150%	As of December 1993, CUHIP began receiving $2.5 million a year from the Business Association Unclaimed Property Fund. Items making up this fund include unclaimed wages, gift certificates and public utility deposits. As of 1995, Colorado has also received approximately $1.5 million annually from unclaimed insurance funds.	*Monthly Premium Rate:* $380.17 *Summary of Benefits and Cost-Sharing:* $500 deductible. Comprehensive coverage includes RX, major medical, preventive care, specific disease care.	*Monthly Premium Rate:* $354.69 *Summary of Benefits and Cost-Sharing:* $500 deductible. Comprehensive coverage includes RX, major medical, preventive care, specific disease care.
Connecticut	Lifetime: $1 million	125% initial, 150% maximum	Association members are assessed for plan losses based on their share of health insurance direct claim volume in the state.	*Monthly Premium Rate:* $430.15 *Summary of Benefits and Cost-sharing:* $550 in-network/$1000 out-of-network deductible with $2500 individual/$5000 family in stop-loss coverage. 80% in-network/60% out-of-network coinsurance.	*Monthly Premium Rate:* $555.23 *Summary of Benefits and Cost-sharing:* $550 in-network/$1000 out-of-network deductible with $2500 individual/$5000 family in stop-loss coverage. 80% in-network/60% out-of-network coinsurance.

State	Maximum Benefit	Premium cap (of an average comparable plan)	Financing Mechanism	35 Year-Old Female	53 Year-Old Male
			the federal government, or one covered by an insolvent insurer) admitted to the hospital for treatment other than for mental health or substance abuse, shall be assessed a risk-pool service charge of $2 per day for inpatient admissions and $1 for outpatient procedures. If the insurance arrangement does not pay the service charge, it may be collected from the patient.		
Minnesota	Lifetime: $2.8 million	125%	Health insurers are assessed for net losses in proportion to the share of total health insurance premiums received in the state during the year. In FY 2000, the legislature also appropriated $15 million to help offset MCHA's 2001 losses. The funding will come from surplus funds in Minnesota's Workers Compensation Assigned Risk Plan.	*Monthly Premium Rate:* $136.91 *Summary of Benefits and Cost-sharing:* $500 deductible with a $3000 stop-loss coverage. 20% in-network co-insurance. Comprehensive coverage includes RX, preventive care, mental health and chemical dependency.	*Monthly Premium Rate:* $237.37 *Summary of Benefits and Cost-sharing:* $500 deductible with a $3000 stop-loss coverage. 20% in-network co-insurance. Comprehensive coverage includes RX, preventive care, mental health and chemical dependency.
Mississippi	Lifetime: $500,000	150% initial 175% maximum	The plan mandates that each insurer shall be assessed an amount not to exceed $1 per policy per month for the individual market and $1 per covered employee per month for the group market. Excluded are policies insuring federal or state employees.	*Monthly Premium Rate:* $258.00 *Summary of Benefits and Cost-sharing:* $1000 deductible with limited stop-loss coverage. 80% coinsurance. Comprehensive coverage includes RX, major medical and specific disease care.	*Monthly Premium Rate:* $378.00 *Summary of Benefits and Cost-sharing:* $1000 deductible with limited stop-loss coverage. 80% coinsurance. Comprehensive coverage includes RX, major medical and specific disease care.
Missouri	Lifetime: $1 million	150% initial 200% maximum	Association members are assessed for net losses in	*Monthly Premium Rate: Summary of Benefits and Cost-*	*Monthly Premium Rate: Summary of Benefits and Cost-*

State	Maximum Benefit	Premium cap (of an average comparable plan)	Financing Mechanism	35 Year-Old Female	53 Year-Old Male
Iowa	*Lifetime:* $1 million	150%	Association members are assessed for losses in excess of those covered through premiums and the Health Insurance Trust Fund. Assessments are allowed as offset against premium taxes or other forms of taxes payable to the state. These offsets are granted at the rate of 20% per year over a five-year period.	*Monthly Premium Rate:* $513.36 *Summary of Benefits and Cost-sharing:* $500 deductible with $1500 individual/$3000 family stop-loss coverage. 80% coinsurance. Comprehensive coverage includes RX, major medical, and specific disease care.	*Monthly Premium Rate:* $859.88 *Summary of Benefits and Cost-sharing:* $500 deductible with $1500 individual/$3000 family stop-loss coverage. 80% coinsurance. Comprehensive coverage includes RX, major medical, and specific disease care.
Kansas	Lifetime: $1 million	Rates will be reasonable in terms of the benefits provided, risk experience and the expenses of providing coverage.	Premium rates are to be nearly self-sustaining. Insurers may be assessed to recoup net losses. Eighty percent of such assessments may be offset against premium taxes. Also, the commissioner was authorized, upon request by the Kansas Health Insurance Association to borrow up to $500,000 per year for the first four years to fund the plan's implementation and initial operations.	*Monthly Premium Rate:* $422.58 *Summary of benefits and Cost-sharing:* $500 deductible with 70% co-insurance for the first $5000 then 90% thereafter. Comprehensive coverage that includes RX, preventive care, mental health and substance abuse.	*Monthly Premium Rate:* $533.47 *Summary of benefits and Cost-sharing:* $500 deductible with 70% co-insurance for the first $5000 then 90% thereafter. Comprehensive coverage that includes RX, preventive care, mental health and substance abuse.
Kentucky	None	150%	Funded through three sources, assessments on insurers, Tobacco Settlement Funds and premiums from enrollees.	*Monthly Premium Rate:* $389.18 *Summary of Benefits and Cost-sharing:* $400 in-netwrok/$700 out-of-network deduction with $1500 stop-loss coverage.	*Monthly Premium Rate:* $425.59 *Summary of Benefits and Cost-sharing:* $400 in-netwrok/$700 out-of-network deduction with $1500 stop-loss coverage.
Louisiana*	Lifetime: $500,000 Annual: $100,000	125% initial, 200% maximum	Louisiana received $2 million in 1999 and requested an additional $2 million in 2000. In addition, each patient (except those covered by either the State Employees Group Benefit program, a program directly subsidized by	*Monthly Premium Rate:* $268.50 *Summary of Benefits and Cost-sharing:* $1000 deductible with $3500 in stop-loss coverage. Comprehensive coverage includes RX, major medical, preventive and specific disease care.	*Monthly Premium Rate:* $405.95 *Summary of Benefits and Cost-sharing:* $1000 deductible with $3500 in stop-loss coverage. Comprehensive coverage includes RX, major medical, preventive and specific disease care.

State	Maximum Benefit	Premium cap (of an average comparable plan)	Financing Mechanism	35 Year-Old Female	53 Year-Old Male
			the federal government, or one covered by an insolvent insurer) admitted to the hospital for treatment other than for mental health or substance abuse, shall be assessed a risk-pool service charge of $2 per day for inpatient admissions and $1 for outpatient procedures. If the insurance arrangement does not pay the service charge, it may be collected from the patient.		
Minnesota	Lifetime: $2.8 million	125%	Health insurers are assessed for net losses in proportion to the share of total health insurance premiums received in the state during the year. In FY 2000, the legislature also appropriated $15 million to help offset MCHA's 2001 losses. The funding will come from surplus funds in Minnesota's Workers Compensation Assigned Risk Plan.	*Monthly Premium Rate:* $136.91 *Summary of Benefits and Cost-sharing:* $500 deductible with a $3000 stop-loss coverage. 20% in-network co-insurance. Comprehensive coverage includes RX, preventive care, mental health and chemical dependency.	*Monthly Premium Rate:* $237.37 *Summary of Benefits and Cost-sharing:* $500 deductible with a $3000 stop-loss coverage. 20% in-network co-insurance. Comprehensive coverage includes RX, preventive care, mental health and chemical dependency.
Mississippi	Lifetime: $500,000	150% initial 175% maximum	The plan mandates that each insurer shall be assessed an amount not to exceed $1 per policy per month for the individual market and $1 per covered employee per month for the group market. Excluded are policies insuring federal or state employees.	*Monthly Premium Rate:* $258.00 *Summary of Benefits and Cost-sharing:* $1000 deductible with limited stop-loss coverage. 80% coinsurance. Comprehensive coverage includes RX, major medical and specific disease care.	*Monthly Premium Rate:* $378.00 *Summary of Benefits and Cost-sharing:* $1000 deductible with limited stop-loss coverage. 80% coinsurance. Comprehensive coverage includes RX, major medical and specific disease care.
Missouri	Lifetime: $1 million	150% initial 200% maximum	Association members are assessed for net losses in	*Monthly Premium Rate: Summary of Benefits and Cost-*	*Monthly Premium Rate: Summary of Benefits and Cost-*

State	Maximum Benefit	Premium cap (of an average comparable plan)	Financing Mechanism	35 Year-Old Female	53 Year-Old Male
			proportion to share of total health insurance premiums received in the state during the year. Assessments are offset against premium taxes in the year of assessment.	*sharing:* $500 deductible with $2500 in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical and specific disease care.	*sharing:* $500 deductible with $2500 in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical and specific disease care.
Montana	Lifetime: $1 million	200%	Association members are assessed for net losses in proportion to share of total health insurance premiums received in the state during the year. Assessments are offset against premium taxes in the year of assessment.	*Monthly Premium Rate:* $233.38 *Summary of Benefits and Cost-sharing:* $1000 deductible with $5000 in stop-loss coverage. 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive care and specific disease care.	*Monthly Premium Rate:* $357.30 *Summary of Benefits and Cost-Sharing:* $1000 deductible with $5000 in stop-loss coverage. 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive care and specific disease care
Nebraska*	Lifetime: $1 million	135%	Association members are assessed for net losses in proportion to share of total health insurance premiums received in the state during the year. Assessments are offset against taxes in year of assessment or following years.	*Monthly Premium Rate:* $316.25 *Summary of Benefits and Cost-sharing:* $500 deductible with $2000 in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive care and specific disease care.	*Monthly Premium Rate:* $409.60 *Summary of Benefits and Cost-sharing:* $500 deductible with $2000 in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive care and specific disease care.
New Mexico	Lifetime: $1.5 million	150%	Any deficit incurred by the pool shall be recouped by assessments apportioned among the members of the pool pursuant to the assessment formula, provided that the assessment for any pool member shall be allowed as a 30 percent credit on the premium tax return for that member.	*Monthly Premium Rate:* $284.00 *Summary of Benefits and Cost-sharing:* $500 deductible with $2000 individual/$4000 family in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive care and specific disease care.	*Monthly Premium Rate:* $436.00 *Summary of Benefits and Cost-sharing:* $500 deductible with $2000 individual/$4000 family in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive care and specific disease care.
North Dakota	Lifetime: $1 million	135%	Association members doing more than $100,000 in accident and health insurance business within the state are assessed for net losses of the	*Monthly Premium Rate:* $216.90 *Summary of Benefits and Cost-Sharing:* $500 deductible with $3000 in stop-loss coverage. Comprehensive coverage includes	*Monthly Premium Rate:* $299.80 *Summary of Benefits and Cost-sharing: $500 deductible with $3000 in stop-loss coverage. Comprehensive coverage includes*

State	Maximum Benefit	Premium cap (of an average comparable plan)	Financing Mechanism	35 Year-Old Female	53 Year-Old Male
			pool. These members are allowed a direct offset against premium taxes in year of assessment.	RX, major medical, preventive care and specific disease care.	*RX, major medical, preventive care and specific disease care.*
Oklahoma	Lifetime: $500,000	150%	Association members are assessed for net losses in proportion to their share of the total health insurance premiums received in the state during the year. Assessments are offset against premium taxes in the year of assessment or following years.	*Monthly Premium Rate:* $330.09 *Summary of Benefits and Cost-sharing:* $500 deductible with $10,000 in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical and specific disease care.	*Monthly Premium Rate:* $427.42 *Summary of Benefits and Cost-sharing:* $500 deductible with $10,000 in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical and specific disease care
Oregon*	Lifetime: $1 million	125%	The pool is currently funded through a combination of member premiums, assessments to insurers and reinsurers and interest earned on money held in reserve. The pool operates under expenditure limitations.	*Monthly Premium Rate:* $196.00 Summary of Benefits and Cost-sharing: $300 deductible with $1300 in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive and specific disease care.	*Monthly Premium Rate:* $299.00 *Summary of Benefits and Cost-sharing:* $300 deductible with $1300 in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive and specific disease care.
South Carolina	Lifetime: $1 million	200%	Insurers are assessed for net losses in proportion to share of total health insurance premiums written in the state during the preceding year. Assessments are offset against premium or income taxes in year of assessment or following years. If the offset exceeds $5 million in one year, premiums of the plan must be raised to assure that the offset does not exceed $5 million in the following years.	*Monthly Premium Rate:*$326.85 *Summary of Benefits and Cost-sharing:* $500 deductible with $2000 in-network/ $7000 out-of-network stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX and major medical.	*Monthly Premium Rate:* $409.63 *Summary of Benefits and Cost-sharing:* $500 deductible with $2000 in-network/ $7000 out-of-network stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX and major medical.
Texas*	Lifetime: $ 1 million	150%	Health insurers are assessed for net losses in proportion to their share of total assessable	*Monthly Premium Rate:* $227.00 *Summary of Benefits and Cost-Sharing:* $500 deductible with $2500	*Monthly Premium Rate:* $283.00 *Summary of Benefits and Cost-sharing:* $500 deductible with $2500

State	Maximum Benefit	Premium cap (of an average comparable plan)	Financing Mechanism	35 Year-Old Female	53 Year-Old Male
			health insurance premiums received in the state during the year.	in net-work/$4500 out-of-network stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive and specific disease care.	in net-work/$4500 out-of-network stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive and specific disease care.
Utah	Lifetime: $1 million Annual: $200,000	Adjusted annually	The plan is funded by the Comprehensive Health Insurance Pool Enterprise Fund. The state Legislature appropriated addition funds in 1992-1995 and 1998-2000. In 2000 the legislature appropriated $4.1 million.	*Monthly Premium Rate:* $238.00 *Summary of Benefits and Cost-sharing:* $500 deductible with $2000 in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive and specific disease care.	*Monthly Premium Rate:* $330.00 *Summary of Benefits and Cost-sharing: $500 deductible with $2000 in stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive and specific disease care.*
Washington*	Lifetime: $500,000	150%	Association members are assessed for net losses in proportion to their share of total health insured population in the state during the year. Assessments offset against premium taxes in year of assessment or following years.	*Monthly Premium Rate:*$296.21 *Summary of Benefits and Cost-sharing:* $500 deductible with $1500 stop-loss coverage and 20% coinsurance. Comprehensive coverage includes RX and major medical.	*Monthly Premium Rate:* $456.93 *Summary of Benefits and Cost-sharing:* $500 deductible with $1500 stop-loss coverage and 20% coinsurance. Comprehensive coverage includes RX and major medical.
Wisconsin*	Lifetime: $1 million	200%	HIRSP is funded by four sources, state general purpose revenues, policyholder premiums, insurer assessments and a reduction in the payments to health care providers.	*Monthly Premium Rate:* $690 *Summary of Benefits and Cost-sharing:* $1000 deductible with $2000 stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive and specific disease care.	*Monthly Premium Rate:* $1044 *Summary of Benefits and Cost-sharing:* $1000 deductible with $2000 stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX, major medical, preventive and specific disease care.
Wyoming	Lifetime: $350,000	125-150%	Association members are assessed for plan losses based on their share of health insurance premium volume in the state. Also assessed are any self-insurers not governed by ERISA law. The state will grant a partial credit against	*Monthly Premium Rate:* $267.00 *Summary of Benefits and Cost-sharing:* $500 deductible with $4000 stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX and major medical.	*Monthly Premium Rate:* $337.00 *Summary of Benefits and Cost-sharing:* $500 deductible with $4000 stop-loss coverage and 80% coinsurance. Comprehensive coverage includes RX and major medical.

State	Maximum Benefit	Premium cap (of an average comparable plan)	Financing Mechanism	35 Year-Old Female	53 Year-Old Male
			any premium tax owed to the state toward assessment paid. However, the total credit allowed by all members cannot exceed $1,625,000 in any one year.		

*The high-risk insurance pools in California, Colorado, Florida, Illinois, Indiana, Louisiana, Oregon, Nebraska, Texas, Washington and Wisconsin charge different premium rates according to the participant's city/county of residence. For all eleven of these states, we sought premium rates for individuals who lived in the state capitals, which would be Sacramento, Denver, Tallahassee, Springfield, Indianapolis, Baton Rouge, Salem, Lincoln, Austin, Olympia and Madison, respectively.

‡ Enrollment in the Florida Comprehensive Health Association was closed on June 30, 1991. Legislation has been introduced this session that would open pool enrollment for 2002, but that legislation has not yet been enacted. Therefore, the rate data listed on this chart represents the rates that would be charged to current pool participants who meet the specified age/gender criterion.

States with programs for the medically uninsurable, excluding risk pools.

California	Open Enrollment
District of Columbia	Open Enrollment
Hawaii	State Comprehensive employer program
Iowa	Guaranteed Issue
Kentucky	Guaranteed Issue
Maine	Guaranteed Issue
Maryland	Open Enrollment
Massachusetts	Guaranteed Issue
Michigan	Open Enrollment
New Hampshire	Guaranteed Issue
New Jersey	Guaranteed Issue
New York	Guaranteed Issue
North Carolina	Open Enrollment
Ohio	Guaranteed Issue
Pennsylvania	Open Enrollment

Rhode Island	Open Enrollment
Tennessee	TennCare
Utah	Guaranteed Issue
Vermont	Guaranteed Issue
Virginia	Open Enrollment
Washington	Guaranteed Issue

PLEASE NOTE: The information presented in this analysis is the exclusive property of the National Association of Health Underwriters (NAHU). It was prepared as an informational resource for NAHU members, state and federal policymakers and other interested parties. It is not to be duplicated, copied, or taken out of context. Any omission or the inclusion of incorrect data is unintentional. If you have any questions about the information presented in this document, please contact either Janet Trautwein, NAHU's Director of Federal Policy Analysis, at (703) 276-3806 or jtrautwein@nahu.org, or Jessica Waltman, NAHU's Manager of Health Policy at either (703) 276-3817 or jwaltman@nahu.org.

UnitedHealthcare

A UnitedHealth Group Company

UnitedHealthcare Choice
Offered by UnitedHealthcare of the Midwest, Inc.

UnitedHealthcare Choice Plus
Offered by UnitedHealthcare of the Midwest, Inc.
and UnitedHealthcare Insurance Company

SMALL GROUP ENROLLMENT APPLICATION FORM

A. EMPLOYEE INFORMATION

First Name | M.I. | Last Name | Social Security Number

Street Address | City | State | Zip Code | County

Home Phone ( ) | Work Phone ( ) | Sex M F | Birthdate | Marital Status ☐ Widowed ☐ Married ☐ Single

Company Name | Date of Employment | Position | ☐ Full Time ☐ Part Time | ☐ Union ☐ Non-Union | ☐ Salaried ☐ Hourly

B. PRODUCT SELECTION *(CHECK ALL THAT APPLY)*

MEDICAL BENEFITS:

☐ Employee Only Medical Coverage ☐ No Medical Coverage*
☐ Employee/Spouse Medical Coverage
☐ Employee/Children Medical Coverage
☐ Employee/Spouse/Children Medical Coverage

DENTAL BENEFITS:

☐ Employee Only Dental Coverage ☐ No Dental Coverage*
☐ Employee/Spouse Dental Coverage
☐ Employee/Children Dental Coverage
☐ Employee/Spouse/Children Dental Coverage

Salary $ ☐ Wk ☐ Mo ☐ Yr

☐ Life Benefit | ☐ Accidental Death and Dismemberment

☐ Dependent Life – List applicable dependents: | Date of Birth / Social Security #

Your Beneficiary's Full Name (if applicable) | Relationship

Your Beneficiary's Full Address

NON-MEDICAL PRODUCTS PROVIDED BY UNITEDHEALTHCARE INSURANCE COMPANY

***WAIVER OF COVERAGE SECTION (Must be completed if waiving either MEDICAL or DENTAL coverage)**

☐ Covered by spouse's group (medical) (dental) plan _____ (name of carrier)
☐ Covered by another group (medical) (dental) plan _____ (name of carrier)

NOTE: If you are declining coverage for yourself or your dependents, because of other health coverage, you are required to complete this section. You will not be eligible to enroll until the next open enrollment period or a special enrollment period as defined in the Certificate of Coverage.

I decline to enroll for coverage for myself, my spouse, and my dependent child(ren) due to:
(1) Existence of other health coverage _____
(2) Other reason (Explain) _____
(see signature section)

C. FAMILY INFORMATION

Employee and dependents to be enrolled, cancelled, changed: (Attach sheet if necessary)

Check appropriate box	Employee/Dependent Social Sec. No.	Last Name	First Name	M.I.	Birthdate	Relationship	Sex	Full-Time College Student	Height/ Weight
Enroll / Cancel / Change						SELF	M F		
Enroll / Cancel / Change						SPOUSE	M F		
Enroll / Cancel / Change		Address (if different)					M F	☐ YES ☐ NO School Name:	
Enroll / Cancel / Change		Address (if different)					M F	☐ YES ☐ NO School Name:	

D. OTHER HEALTH INSURANCE INFORMATION *(THIS SECTION MUST BE COMPLETED)*

On the day your coverage begins will any family members be covered by other health or dental insurance or Medicare?
☐ YES ☐ NO **If yes, fill out this section. Use extra paper if more than one additional policy will be in force.**

Coverage type: ☐ Medical Insurance ☐ Dental Insurance ☐ Medicare (see below) | Insurance Company Name and (Area Code) Phone Number

Policy Coverage Dates ____ to ____ | Name of Insured | Insured's Birthdate / / | Family Members Covered

Insured's Employer Name | Policy Number

Names of family members covered by Medicare | Medicare Claim Number | Part A Effective Date / / | Part B Effective Date / / | Is Medicare eligibility due to: ☐ Kidney failure ☐ Disability

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Continued on other side

E. HEALTH INFORMATION – Explain only "YES" answers below – If not applying for medical coverage

1. Have you or your dependents had or been treated during the past ten years for:	YES	NO
A. diabetes or sugar, albumin or blood in the urine. If yes, when first diagnosed? _____	☐	☐
B. high blood pressure, chest pain, heart murmur, shortness of breath, angina, or other heart or circulatory disorder?	☐	☐
C. stroke, epilepsy, fainting, dizziness, headaches or any disorder of the brain or nervous system?	☐	☐
D. tuberculosis, asthma, hay fever, lung or respiratory disorder?	☐	☐
E. stomach or duodenal ulcer, other ulcer, colitis, disorder of gall bladder, liver, stomach or intestines?	☐	☐
F. varicose veins, varicose ulcers, or phlebitis or hernia of any kind?	☐	☐
G. kidney, bladder or prostate disorder or other urinary disorder?	☐	☐
H. tumor or disease or dysfunction of the breast, reproductive organs or abnormal menstrual period?	☐	☐
I. arthritis, rheumatism or any pain/disorder of the joints, muscles, back or bones?	☐	☐
J. cancer or tumor or ulcer of any kind, growth or cyst?	☐	☐
K. any disorder of the eyes, ears, nose or throat?	☐	☐
L. alcoholism, drug habit (or have you or your dependents joined any organization for alcohol or drug abuse)?	☐	☐
M. nervous, mental or sleep disorder (including professional counseling)?	☐	☐
N. positively diagnosed or treated for a disease of the immune system including AIDS or ARC?	☐	☐

2. Have you or your dependents:	YES	NO
A. been released from the military for medical reasons?	☐	☐
B. received payment for disability, illness or injury?	☐	☐
C. had a weight change of more than 10 pounds in the last 12 months?	☐	☐

3. Within the past 5 years, have you or your dependents:	YES	NO
A. had a physical examination, electrocardiogram, X-ray, blood test or diagnostic test, or seen a physician for any medical reason?	☐	☐
B. had inpatient or outpatient surgery?	☐	☐
C. been advised to have surgery not yet done?	☐	☐
D. had any medical treatment, mental or physical impairment, condition or congenital anomaly not mentioned above?	☐	☐

4. Have medications been prescribed for you or your dependents in the last 12 months for any reason? If yes, please list name, dose, and condition used for: _____	YES	NO
	☐	☐

5. Are any family members pregnant (including spouse not applying for coverage)?	YES	NO
A. If YES, when is delivery expected? _____	☐	☐
B. If NO, date of last menstrual cycle? _____		

Explain "YES" answers to any part of questions 1, 2, 3. Give complete details. Use extra paper if necessary.

Question No.	Name	Diagnosis, Treatment or Reason for Physical Checkup	Date of Treatment, Length of Hospital Stay and Degree of Recovery	Doctor's Name, Address and Phone Number

F. IMPORTANT INFORMATION – PLEASE READ CAREFULLY

The information provided on this application is accurate and complete. I understand and agree that any omissions or incorrect statements made by Us on this application may invalidate my and/or my dependents' coverage. I understand that coverage will become effective only on the date specified by the Insurer after the application has been approved by the Insurer and after the first full premium has been paid. By signing this enrollment form, I hereby represent that all the information provided is true and correct.

G. SIGNATURE *(FORM MUST BE SIGNED)*

AUTHORIZATION TO OBTAIN OR RELEASE MEDICAL INFORMATION: On behalf of myself and anyone enrolled on or added to this application ("Us"), I authorize any health care professional or entity to give UnitedHealthcare of the Midwest, Inc. any and all records or information pertaining to medical history or services rendered to Us for any purpose related to my UHC coverage. I also authorize UHC to provide records or information relating to my medical history or services rendered to me to my primary care physician, or any other person(s) designated by the organization, for the purpose of coordinating my medical care. I understand all information will be kept confidential. Any information gathered will be reported in aggregate and will contain no identifying/identifiable information. I also authorize on behalf of Us the use of a Social Security Number for purpose of identification. The information provided on this application is accurate and complete. I understand and agree that any omissions or incorrect statements knowingly made by Us on this application may invalidate my and/or my dependents coverage.

NOTICE OF ENROLLMENT RIGHTS: I understand that if I and/or my dependents, if any, waive coverage and desire to participate in the plan at a later date, I (we) will not be eligible to enroll until the next open enrollment period or a special enrollment period as defined in my Certificate of Coverage. I further understand that if I decline enrollment for myself or my dependents (including my spouse) because of other health coverage, I may in the future be able to enroll myself or my dependents in this plan, provided that I request enrollment within 30 days after such coverage ends. In addition, if a new dependent relationship forms as a result of marriage, birth, adoption, or placement for adoption, I may be able to enroll myself and my dependents provided that I request enrollment within 30 days after such marriage, birth, adoption, or placement for adoption.

X

Employee Signature _____ Date Signed _____

H. EMPLOYER AUTHORIZATION

Company Name	Branch/Division	Group Number	Dept Number

Approved by	Date

FOR HEALTH PLAN USE ONLY

Group Number	Effective Date(s)	County	Rate Class	Department

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MEDICAL HISTORY -- FOR ALL APPLICANTS

IMPORTANT! PLEASE PROVIDE DETAILS OF EACH YES ANSWER IN "MEDICAL HISTORY DETAILS."

	Yes	No
14. Is any family member (whether or not named in this application) pregnant or an expectant mother or father?	❑	❑
15. Do any applicants, other than dependent children, **not** read, write, speak, and understand the English language?	❑	❑
16. Do you have an adoption pending?	❑	❑
17. In the last 6 months, has any applicant taken, or been advised to take, medication or received medical advice or treatment of any kind?	❑	❑
18. **Within the last 10 years, has any applicant had any indication, signs, symptoms, diagnosis, or treatment of any disease or disorder of the:**		
a. gallbladder?	❑	❑
b. pancreas or liver?	❑	❑
c. joints or spine?	❑	❑
d. kidney?	❑	❑
e. eyes, ears, or nose?	❑	❑
f. mouth, throat, or jaw?	❑	❑
19. **In the last 10 years, has any applicant had any indication, signs, symptoms, diagnosis, or treatment of:**		
a. high blood pressure?	❑	❑
b. chest pain?	❑	❑
c. headaches?	❑	❑
d. paralysis?	❑	❑
e. arthritis?	❑	❑
f. convulsions or epilepsy?	❑	❑
g. elevated cholesterol?	❑	❑
h. sexually transmitted disease (excluding AIDS or HIV)?	❑	❑
i. cancer?	❑	❑
j. diabetes or sugar in the blood or urine?	❑	❑
k. stroke?	❑	❑
l. tumor, cyst, polyp, lump, or growth of any kind?	❑	❑
m. mental, emotional, or behavioral disorder?	❑	❑
20. **In the last 10 years, has any applicant:**		
a. had a complicated pregnancy or delivery?	❑	❑
b. been hospital confined, had surgery, or discussed surgery?	❑	❑

	Yes	No
21. **In the last 10 years, has any applicant had any indication, signs, symptoms, diagnosis, or treatment of any disease, disorder, or abnormality of the:**		
a. heart or circulatory system?	❑	❑
b. nervous system?	❑	❑
c. digestive system?	❑	❑
d. muscular or skeletal system?	❑	❑
e. respiratory system?	❑	❑
f. male or female reproductive system, including infertility?	❑	❑
g. urinary system?	❑	❑
h. thyroid, breast, or other glands?	❑	❑
22. In the last 10 years, has any applicant had, been diagnosed as having, or been treated for, Acquired Immune Deficiency Syndrome (AIDS) or any HIV-related disease or illness?	❑	❑
23. In the last 10 years, has any applicant had any indication, signs, symptoms, diagnosis, or treatment of any other disease, disorder, injury, or adverse finding, or had any adverse or abnormal test results?	❑	❑
24. In the last 12 months, has any applicant experienced a weight gain or loss of 15 pounds or more?	❑	❑
25. In the last 5 years, has any applicant had any indication, diagnosis, or treatment of an alcohol or drug dependency, problem, or abuse; or any alcohol- or drug-related conviction or driver's license suspension?	❑	❑
26. Is any applicant currently, or in the last 5 years been, a user of alcoholic beverages in excess of 14 drinks per week? If yes, show who and how many drinks per week in "Medical History Details" (one drink equals: 12 oz. of beer, 4 oz. of wine; 1 oz. of hard liquor)	❑	❑
27. Has any applicant smoked cigarettes or used tobacco in any form (including smokeless tobacco) or nicotine substitute within the past 12 months?	❑	❑
28. List in "Medical History Details" any additional doctors or other health care professionals that any applicant has consulted with or been treated by in the last 5 years, and give full details below.		

MEDICAL HISTORY DETAILS -- FOR ALL APPLICANTS

Question Number	Person	Symptoms or Condition	Dates	Treatment, Advice Given, Results, and Other Details	Name, Address, and Phone # of Doctors, Hospitals, etc.

Committee on Education and the Workforce

Witness Disclosure Requirement – "Truth in Testimony"
Required by House Rule XI, Clause 2(g)

Your Name: Janet Stokes Trautwein		
1. Will you be representing a federal, State, or local government entity? (If the answer is yes please contact the Committee).	Yes	No X
2. Please list any federal grants or contracts (including subgrants or subcontracts) which you have received since October 1, 1998: None		
3. Will you be representing an entity other than a government entity?	Yes X	No
4. Other than yourself, please list what entity or entities you will be representing: The National Association of Health Underwriters		
5. Please list any offices or elected positions held and/or briefly describe your representational capacity with each of the entities you listed in response to question 4: I am employed by the National Association of Health Underwriters as Director of Federal Policy and Director of State Government Affairs.		
6. Please list any federal grants or contracts (including subgrants or subcontracts) received by the entities you listed in response to question 4 since October 1, 1998, including the source and amount of each grant or contract: None		
7. Are there parent organizations, subsidiaries, or partnerships to the entities you disclosed in response to question number 4 that you will not be representing? If so, please list:	Yes	No X

Signature: Janet Stokes Trautwein Date: 9/4/01

Please attach this sheet to your written testimony.

PERSONAL INFORMATION: Please provide the committee with a copy of your resume (or a curriculum vitae). If none is available, please answer the following questions:

a. Please list any employment, occupation, or work related experiences, and education or training which relate to your qualifications to testify on or knowledge of the subject matter of the hearing:

See attached.

b. Please provide any other information you wish to convey to the Committee which might aid the members of the Committee to understand better the context of your testimony:

Please attach to your written testimony.

APPENDIX C - WRITTEN STATEMENT OF JANE MASSEY LICATA, ATTORNEY, LICATA & TYRRELL P.C., MARLTON, NJ

Testimony of Jane Massey Licata, J.D., Ph.D.
before the
Employer-Employee Relations Subcommittee

September 6, 2001

With the completion of the first map of the human genome, we now have a basis for determining our unique genetic makeup and probable medical future and to permit personal diagnostics and therapeutics to be created for us. This is no longer the stuff of science fiction. Everyday new genetic markers are identified and correlated with human biology and disease. The future of medicine lies in genomics. Worldwide, university and pharmaceutical company researchers alike are mining databases of genetic information and rapidly identifying new drug targets, diagnostic markers and creating a basis for novel therapies. Tests designed to determine the presence or version of genes that cause diseases or conditions carry with them the most intimate details of our biological past and future as well as a devastating potential for discrimination. Analysis of our genetic material also provides information about our parents, siblings and children which impacts not only on ourselves but on family privacy. The potential for misunderstanding or misuse of this information is so great, however, that it is essential that we establish a national policy for the protection of an individual's privacy interest in their genetic information.

H.R. 602 is an important and timely legislative initiative to prohibit health insurance and employment discrimination against individuals and their family members on the basis of *predictive* genetic information or genetic services. "Predictive genetic information" is defined as information about an individual's genetic tests (i.e., the analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect genotypes, mutations, or chromosomal changes); information about genetic tests of family members; or information about the occurrence of a disease or disorder in family members. Information about the sex or age of the individual, information about chemical, blood, or urine analysis of the individual, unless these analysis are genetic tests, and information about physical exams and other information relevant to determining the current health status of the individual are specifically excluded from the definition of predictive genetic information. "Genetic services" are defined as health services, including genetic tests, provided to obtain, assess, or interpret genetic information for diagnostic and therapeutic purposes, and for genetic education and counseling.

An insurer may not deny eligibility or adjust premium or contribution rates for a group on the basis of predictive genetic information or information about a request for or receipt of genetic services. An insurer may also not request or require genetic testing. Further, the insurer may not request, require, collect or purchase such predictive genetic information. The insurer may also not disclose predictive genetic information or a request for genetic services; disclosures to the Medical Information

Bureau and the individual's employer or plan sponsor are specifically prohibited. However, with respect to payments for genetic services, the insurer may request evidence that such services were performed (but not the results) and if the evidence is not provided, may deny payment. An insurer may also request that an individual provide predictive genetic information so long as such information is used solely for the payment of a claim and limited to information that is directly related to and necessary for the payment of the claim (i.e. the claim would otherwise be denied). Disclosure is limited to individuals within the plan who need access to the information for payment of the claim.

Prior, knowing, voluntary, written authorization for the collection or disclosure of predictive genetic information is provided for. Disclosures between health care providers for the purpose of providing treatment are exempted.

Civil actions for legal and equitable relief including civil attorney fees and the costs of expert witnesses are provided for. Civil penalties, payable to the United States Treasury, are also provided for. Further, it is provided that these provisions shall not be construed to supersede any State law provision that more completely protects confidentiality or privacy or protects against discrimination with respect to such information.

Further, employers, employment agencies and labor organizations are prohibited to fail or refuse to hire, discharge or otherwise discriminate on the basis of predictive genetic information. Employees may also not be classified on the basis of predictive genetic information or a request for genetic services. Employers may not request, require, collect or purchase predictive genetic information about employees for genetic monitoring without prior, knowing, voluntary and written authorization by the employee and without informing the employee of the monitoring results. "Genetic monitoring" is defined as the periodic examination of employees to evaluate changes in their genetic material (e.g. chromosomal damage or evidence of increased occurrence of mutations) that may have developed during the course of employment due to exposure to toxic substances in the workplace in order to deal with adverse environmental exposures in the workplace. Any monitoring must conform to OSHA or FMSHA requirements. Further, the results of the monitoring may not disclose the identity of an employee. Any predictive information about an employee must be treated or maintained as part of the employee's confidential medical records. A Federal or State court may award any appropriate legal or equitable remedy which may include payment of attorney's fees and costs, including the costs of experts. The EEOC may also enforce.

Overall, this bill is a well drafted, well considered proposal. There are a number of points that may bear further consideration, however.

The use of the term "predictive" in the definition of genetic information may have been intended to address the concern that many genetic markers are not conclusively diagnostic but rather may indicate a predisposition to a disease or condition or may presently be believed to have a correlation with a disease or

condition. In such cases it would be especially troublesome if the information were relied upon to make employment or insurance decisions. However, there are well established genetic markers which can be diagnostic. I am concerned that the exception in the definition of "predictive genetic information" for "other information relevant to determining the current health status of the individual" could allow inadvertent access to some genetic information or test results. I would therefore suggest that this exception be removed or qualified to not include genetic tests. There is also an exception concerning sharing of information between health care providers for treatment. Again, I would suggest that health care providers are accustomed to dealing with sensitive, confidential information, for example HIV status, and accordingly a blanket exception is not required. The individual's prior written consent to make the information available between health care providers should not be an undue burden and helps identify the information as sensitive and confidential. Further, there is an exception for information for payment of a claim. This provision places individuals in the position of paying for the genetic test themselves or risking the disclosure. While there are provisions that restrict the scope of the disclosure and to whom the information would be disclosed, I would suggest that the results never be disclosed an insurer or employer. I would also suggest that there be clarification as to what would be "sufficient evidence" that the services were performed, i.e. a receipt from a licensed laboratory or health care professional that a genetic test was performed should be sufficient.

I would also suggest that while the proposed legislation goes a long way to protect the interests of employees and insurers, that there are several areas where it could be improved. Unfortunately it is those seeking individual health insurance protection who may be at the greatest risk for discrimination. While there are provisions that cover individual policies in some instances, I would suggest that it be investigated whether there is any way to expand the coverage as fully as possible into the individual market. Also, while there are provisions for civil suits and administrative actions, I would suggest that there should be significant penalties for any knowing violation by an insurer or employer. Under the current scheme, the employee or insured, who may not have reasonable access to legal representation, may not be able to effectively protect their privacy interests. I would therefore suggest the Government take a more proactive role and that there be substantial civil penalties provided for in the event there is any violation. Clearly, this is provided for to some extent under the proposed legislation, however, strengthening the role for government enforcement could be helpful.

While some states, like my state, New Jersey, have enacted genetic privacy acts, I believe it is essential to establish a consistent, national policy to protect against genetic discrimination in employment and insurance and to protect the privacy of this most sensitive and personal information. These issues cross state boundaries and affect all of our citizens. New Jersey's Genetic Privacy Act which was enacted in 1996 declared that genetic information is personal information that should not be collected, retained or disclosed without the individual's authorization. The Act prohibits discrimination by employers against employees carrying genetic markers of diseases or behavioral traits. It is unlawful for an employer to refuse to hire or

employ, or to discharge or require to retire, an employee because of the employee's genetic information, or atypical hereditary cellular or blood trait, or because the employee refused to submit to a genetic test or make available the results of a genetic test to the employer. It also prohibits the use of genetic information in the fixing of rates or withholding of life insurance and bans the use of genetic information to establish the amount of insurance premiums, policy fees, or rates charged for a health insurance contract. The penalties for violation of the provisions of the Act include fines and prison terms. Actual damages, including economic, bodily or emotional harm proximately caused, may also be recovered for wanton disclosure of genetic information. The New Jersey Act is an important first step in controlling the flow of genetic information, however, Federal legislation is still needed.

I believe H.R. 602 would be a good beginning. It addresses some of the most urgent needs in protecting an individual's privacy and in assuring access to genetic testing and services. Until recently, access to this type of testing was limited to those who could afford to pay for it privately. By paying it for it themselves, they could also have greater assurance of confidentiality concerning the testing and the results. While wider acceptance of the need and validity of genetic testing has made insurers more comfortable with reimbursement for this type of service, there is a huge risk to the insured or employee that very sensitive information, which could easily be subject to misinterpretation may be widely distributed as a part of the insurance information system. I would suggest erring on the side of making such information as inaccessible as possible to third parties since the risk of misunderstanding or misuse is so great.

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EDUCATION/PROFESSIONAL

Strong background in biology and chemistry. Academic honors. Member Sigma Xi, Phi Kappa Phi, Beta Beta Beta. Registered Patent Attorney. Also licensed to practice law in Pennsylvania, New Jersey and Florida.

J.D., 1984, Rutgers School of Law, Camden, New Jersey.

Ph.D., 1978, University of Hawaii, Honolulu, Hawaii.

B.A., 1975, Western Maryland College, Westminster, Maryland.

EXPERIENCE

September 1999 to present Professor of Patent Law, Rutgers School of Law, Camden, NJ

Teaching Patent Law I and II and Patent Prosecution Seminar

April 1993 to present Partner, Licata & Tyrrell, P.C., Marlton, NJ

Biotechnology patent prosecution and litigation practice; also health law including research, regulatory compliance and ethics.

April 1989 to April 1993 Senior Associate, Woodcock Washburn Kurtz Mackiewicz and Norris
Philadelphia, PA

Biotechnology patent prosecution and litigation practice with a regional intellectual property law firm; also health law including research, regulatory compliance and ethics.

April 1987 to April 1989 Director, Office of Technology Transfer, Thomas Jefferson University
Philadelphia, PA

Responsible for arranging, negotiating, preparing and administering research/development and licensing agreements for University developed technology. Administrated the University's patent, trademark and copyright policies, reviewed and evaluated technical disclosures, assessed patentability and commercial potential, monitored patent prosecutions. Developed innovative technology transfer mechanisms including joint ventures, incubation facilities and partnership grants with state and federal initiatives. Monitored regulatory requirements for investigational drugs and devices. Member Institutional Review Board.

March 1985 to April 1987 Associate Director, Office of Legal Management, University of Medicine and Dentistry of New Jersey, Newark, NJ

Developed technology transfer program for New Jersey's medical university which includes three medical schools and a dental school.

Oct. 1983 to Feb. 1985	Associate, Cohen, Shapiro, Polisher, Shiekman and Cohen Philadelphia, PA
Sept. 1980 to Oct. 1983	Scientist, U.S. Environmental Protection Agency, Region III Philadelphia, PA
Oct. 1979 to Sept. 1980	Biologist (Post-doctoral), Academy of Natural Sciences of Philadelphia Philadelphia, PA
August 1975 to June 1978	Graduate research and teaching assistant, University of Hawaii Honolulu, Hawaii

MEMBERSHIPS

Member: Health and Hospital Law Section of the New Jersey State Bar Association; New Jersey, Pennsylvania, Florida and Philadelphia Bar Associations; American Intellectual Property Law Association; New Jersey Intellectual Property Law Association; Philadelphia Intellectual Property Law Association; Board of Directors, Pine Cabin Run Ecological Laboratory; Institutional Review Board, Thomas Jefferson University; legal advisor, New Jersey Corporation for Advanced Technology, Association of University Technology Managers.

Committee on Education and the Workforce

Witness Disclosure Requirement – "Truth in Testimony"
Required by House Rule XI, Clause 2(g)

Your Name: Jane Massey Licata		
1. Will you be representing a federal, State, or local government entity? (If the answer is yes please contact the Committee).	Yes	No x
2. Please list any federal grants or contracts (including subgrants or subcontracts) which you have received since October 1, 1998: None		
3. Will you be representing an entity other than a government entity?	Yes	No x
4. Other than yourself, please list what entity or entities you will be representing: None		
5. Please list any offices or elected positions held and/or briefly describe your representational capacity with each of the entities you listed in response to question 4: N/A		
6. Please list any federal grants or contracts (including subgrants or subcontracts) received by the entities you listed in response to question 4 since October 1, 1998, including the source and amount of each grant or contract: N/A		
7. Are there parent organizations, subsidiaries, or partnerships to the entities you disclosed in response to question number 4 that you will not be representing? If so, please list:	Yes	No x

Signature: [illegible] Date: September 5, 2001

Please attach this sheet to your written testimony.

PERSONAL INFORMATION: Please provide the committee with a copy of your resume (or a curriculum vitae). If none is available, please answer the following questions:

a. Please list any employment, occupation, or work related experiences, and education or training which relate to your qualifications to testify on or knowledge of the subject matter of the hearing:

I have been a biotechnology patent and FDA lawyer for over 16 years and am also Professor of Patent Law at Rutgers School of Law, Camden. In my practice I represent universities, biotechnology companies and major pharmaceutical companies. I have filed and prosecuted thousands of patent applications concerning diagnostics and therapeutics which rely upon genetic information and human genes. As I have watched the technology and the law develop, I have come to appreciate the power of this technology and also the responsibilities and risks created by it.

b. Please provide any other information you wish to convey to the Committee which might aid the members of the Committee to understand better the context of your testimony:

Please attach to your written testimony.

APPENDIX D - STATEMENT OF MARY K. WILLIAMS, ATTORNEY, ALSTON & BIRD, ATLANTA, GA

Testimony of Mary K. Williams, Esq.
before the
Employer-Employee Relations Subcommittee

September 6, 2001

My name is Mary Williams. I practice law in the Atlanta, Georgia office of the firm of Alston & Bird. Primarily, I represent employers who sponsor self-funded employee benefit plans and third-party administrators who provide services to those plans. I spend much of my time counseling employers about privacy issues that affect the health plans they sponsor.

Let me start by describing how self-funded health plans operate. A self-funded health plan is one in which the employer assumes the financial risk for providing health care benefits to its employees. Rather than obtaining medical coverage from an insurance carrier, an employer elects to fund the risk directly, from contributions from the employer, the employee or both. The employer becomes financially liable for benefits covered under the plan. The employer typically contracts with a third party administrator to assist in the administration of the plan. The third party administrator's duties typically involve adjudicating and paying claims, preparing claim reports, and arranging for managed care services such as network access and case management. Self-funded plans are an important part of the health coverage sector because the administrative costs for a self-funded plan are typically lower than those charged by a full-service insurance carrier. This cost savings often is passed on to the employee.

Today, I wish to make four points about Genetic Non-Discrimination laws and their effect on employer-provided health plans; but first let me emphasize that employers strongly oppose genetic discrimination, particularly with regard to benefits provided by group health plans. However, new legislation is not necessary to achieve the goal of genetic non-discrimination by group health plans because current federal law already accomplishes this objective.

First, current federal law already protects group health plan participants from genetic discrimination.

By enacting the Health Insurance Portability and Accountability Act of 1996 (HIPAA), Congress recognized that the only way to establish clearly understood, workable and effective requirements for privacy and non-discrimination in a health plan was to establish a nationally uniform standard with a single enforcement scheme. Consistent with that purpose, HIPAA protects group health plan participants from discrimination based on genetic information. In my view, any new proposals which would impose new or similar obligations on the sponsors of group health plans for the purpose of protecting individuals from discrimination in

enrollment, eligibility, contributions or premium rates based on genetic information are therefore unnecessary.

HIPAA is far-reaching legislation designed to improve the portability of health coverage and to provide other protections to recipients of health coverage. In its current form, HIPAA already prohibits group health plans and health insurers offering group health coverage from discriminating with regard to enrollment, eligibility, premiums or contributions based on specified health status-related factors, including genetic information.

For example, under current law an employer may not exclude an otherwise-eligible employee or dependent from health plan coverage based on any aspect of the employee's medical history, including a genetic condition, predisposition to a genetic condition, family history of a genetic condition, predictive genetic test results or any other actual or potential medical condition. Likewise, an employer may not impose any benefit restrictions upon such an individual based on the individual's medical history. A plan cannot exclude from coverage a specific condition if the exclusion is directed at a specific employee. In addition, an employer may not increase the required employee premium or contribution, co-payment or deductible for such an individual. In short, a plan participant's genetic information will not adversely affect his ability to acquire and maintain coverage under a group health plan.

Second, HIPAA protects the collection, use and disclosure of group health plan participants' genetic information.

HIPAA's privacy rules strictly limit the use and disclosure of medical information, including genetic information, obtained by a group health plan. Any use or disclosure of genetic information for purposes other than treatment, payment of a claim, or health care operations without written authorization of the plan participant is illegal. HIPAA also prohibits employers from using health information received through the group health plan for any employment-related action.

I want to emphasize that my comments regarding the HIPAA Privacy Regulations are aimed only at genetic non-discrimination issues and the protection of genetic information. My comments should not be interpreted as an endorsement of the Privacy Regulations in their totality. Employers and group health plans have many concerns with the limitations imposed by the Privacy Regulations, and further revisions are needed before employers can practicably comply with the regulations. Earlier this year, my colleague Robert Lower testified before the Energy and Commerce Committee regarding certain fundamental flaws that exist with respect to the HIPAA Privacy Regulations and Mr. Lower's testimony would be helpful in understanding the concerns that employers have regarding the HIPAA Privacy Regulations.

It is important to recognize that in enacting the Privacy Rules, HHS considered the unique and specific issues faced by employers who sponsor group health plans.

HHS took considerable time to understand how group health plans actually use medical information. In November 1999, HHS issued proposed privacy regulations to govern the use and disclosure of individually identifiable health information. Thereafter, HHS considered 52,000 comments before issuing the final regulations in December 2000 (Privacy Regulations), which included significant changes from the 1999 proposed regulations. After issuing the final Privacy Regulations, HHS received over 1,000 inquiries about the impact and operations of the Privacy Regulations. In an effort to better understand the Privacy Regulations' impact on various sectors of the economy, including employer-sponsored health plans, HHS solicited and received 24,000 additional public comments during March 2001. On July 6, 2001, HHS issued the first guidance in a series to clarify certain aspects of the Privacy Regulations. The changes to the Privacy Regulations over the last two years as well as the clarifications issued since the final regulations were issued demonstrate that, through the comments received, HHS has increased substantially their understanding of the administration of employer-sponsored health plans. As result, HHS has taken regulatory steps to ensure that employee medical information is protected without unnecessarily inhibiting the required operations of plan administration. As a consequence, any further regulations impacting a group health plan's handling of any type of medical information are unnecessary.

The Privacy Regulations present a comprehensive and sweeping set of legal requirements applicable to the use and disclosure of individual health information in any form. With regard to employer-sponsored health plans, the regulations protect each plan participant's individually identifiable health information from being used or disclosed by the health plan without express consent or authorization unless the use or disclosure is for payment of a health claim, conducting health care operations or certain narrowly-tailored public policy exceptions such as public health activities or law enforcement. Any uses or disclosures of health information beyond payment or health care operations require an explicit written authorization that can be revoked at any time. Moreover, a health plan cannot condition enrollment or participation upon receiving an authorization.

In addition to protecting the use and disclosure of health information, the Privacy Regulations impose substantial administrative burdens on group health plans to control access to and to provide physical security for employee health information. This involves such measures as employee training to educate employees with regard to privacy protection policies and procedures, locking rooms that contain medical records, limiting access to computer files, and document retention and destruction policies.

In addition, employers who sponsor group health plans must provide adequate firewalls to ensure that employee health information is not shared with persons not directly involved with the administration of the heath plan. The employer must identify the class of employees who may be given access to health information and restrict access to and use by such employees to plan administration functions that the employer performs for the health plan. Finally, employers are prohibited from using or disclosing health information received through the group health plan for

employment-related actions.

In the two years since HHS first issued the proposed HIPAA Privacy Regulations, HHS has considered, worked through and addressed the comments and concerns of group health plans with regard to the use and disclosure of medical information. For example, the Privacy Regulations now permit health plans to use and disclose health information for payment of claims without the burden of obtaining individual consent for each use or disclosure. Equally important, the Privacy Regulations permit health plans to use and disclose health information for other administrative tasks vital to the operation of the plan, but which are not covered under most legislative definitions of "payment of claims," such as internal quality review, activities relating to creation, renewal, or replacement of a contract of health insurance or excess loss insurance, legal services, auditing functions and business planning.

Because of the sweeping and comprehensive nature of HIPAA's Privacy Regulations, it would be virtually impossible to draft additional legislation governing health plans' use and disclosure of medical information without including issues already regulated by those Privacy Regulations. A multiplicity of federal laws governing the same subject matter leads to a complex and conflicting regulatory scheme creating confusion for both regulated entities and consumers alike. Moreover, HIPAA's Privacy Regulations are enforced by the Office of Civil Rights, while the Employee Retirement Income Security Act of 1974 (ERISA) is within the enforcement jurisdiction of the Department of Labor. Accordingly, not only would additional legislation subject health plans to conflicting federal laws, it would subject group health plans to multiple and conflicting penalties imposed by multiple regulatory agencies.

ERISA's statutory mandate is to impose uniformity and predictability for the administration of self-insured plans. Allowing two regulatory agencies to enforce conflicting rules concerning the same subject matter will result in exactly the situation that ERISA was meant to correct. Employers that sponsor group health plans should have a single, uniform framework where the penalties for wrongful use or disclosure of any medical information, including genetic information, are clearly understood and fairly applied. The HIPAA Privacy Regulations attempt to serve this purpose.

Third, employer-sponsored health plans are not using employees' genetic information in a discriminatory manner.

We at Alston & Bird work with some of the largest employers in the United States. In our experience, these employers are dedicated to ensuring that their employees have access to quality medical care at an affordable cost. These employers agree that their employees' medical information collected through group health plan activities should be protected and should be used only as absolutely necessary to effectively administer the health plan. Employer-sponsored group health plans as a whole are not participating in the fact-finding activities that are the subject of the

genetic community's concern. For example, group health plans are not requiring participants or eligible employees to complete health questionnaires, participate in physical examinations or to disclose the results of any type of medical test.

Rather, an employer-sponsored health plan typically receives employee medical information only when a claim for medical expenses is submitted by or on behalf of a plan participant. The group health plan primarily uses this information to pay eligible claims. However, self-funded group health plans also must use this information for other administrative purposes. For example, most self-funded plans secure excess loss insurance, which is designed to limit the employer's loss to a specified amount, to ensure that catastrophic claims, or a multitude of unanticipated claims, do not destroy the financial integrity of the plan. A group health plan cannot obtain excess loss coverage without disclosing to the carrier specific information regarding claims paid by the health plan over the past year – and most self-funded health plans cannot operate without excess loss insurance.

A group health plan may also use medical information to audit the activities of its service providers and to administer wellness and disease management programs. The information is used only for the legitimate purpose of administering the group health plan on behalf of the employees.

Fourth, if Congress moves forward with further regulation, care must be given to avoid unintended consequences of overly broad language.

Any additional legislation in the medical information area, especially if it includes language directed at genetic non-discrimination, must be drafted very carefully to avoid unintended consequences that could negatively impact the broader (and non-discriminatory) use of information for purposes that benefit group health plan participants. As I have mentioned, I think this would be virtually impossible to do. Legislation that is drafted without a complete comprehension of the operations of a group health plan inevitably will create burdensome requirements that will frustrate the ability to offer cost-effective health coverage -- such legislation will have the counterproductive effect of precluding the vast majority of employers from even offering self-funded health plans to their employees.

Employer-provided health plans help protect employees from the financial loss associated with illnesses and accidents. Group health plans also enhance workforce productivity by providing the employees with access to preventive medicine and wellness and disease management programs. Employers and employees have a mutual and equally strong interest in maintaining a high quality and affordable set of benefits.

The most obvious function of a health plan is to pay for medical expenses incurred by plan participants. To accomplish this function, a health plan needs access to certain medical information regarding its employee-participants. Most rules and regulations governing health plans recognize this need. However, a health plan also needs medical information for other plan administration functions such as obtaining

and renewing excess loss insurance policies, coordinating benefits with other health plans, enforcing subrogation rights, and conducting wellness, disease management and quality assurance programs. Nevertheless, legislation directed at the privacy of medical information rarely is drafted to allow health plans to effectively use medical information for these purposes.

HIPAA's Privacy Regulations recognize that a health plan must have access to participant medical information for a variety of legitimate purposes and do not require a health plan to obtain individual consent before using and disclosing personally identifiable medical information for payment or health care operation purposes. The term "health care operations" includes activities compatible with and directly related to payment, but not covered by the standard definition of "payment," such as quality reviews, audits, and obtaining excess loss insurance. Any additional privacy legislation must recognize these vital plan administration activities and permit group health plans to use medical information as necessary to effectively administer the benefits provided under the plan. Additional privacy laws enacted without protections reflected in HIPAA's Privacy Regulations will, as a consequence, undo all that has been accomplished in this area over the past two years.

Conclusion

Under current federal law, group health plans are prohibited from discriminating in enrollment, eligibility, contributions or premium rates based on any genetic information in any form. Under current federal law, group health plans are prohibited from using and disclosing any genetic information concerning a plan participant without that participant's written authorization except as required for payment of claims and health care operations. Under current federal law, employers are prohibited from using or disclosing health information for employment-related actions. This is the law today. No additional regulation in this area of employee benefit law is needed to accomplish the objective of genetic non-discrimination.

Personal Information:
Mary K. Williams

Name: Mary K. Williams

Business Address: Alston & Bird, 601 Pennsylvania Avenue NW 11th Floor North Tower, Washington D.C. 20004; 1201 W. Peachtree Street, Atlanta, Georgia 30309.

Business Phone Number: (404) 881-7000

Any training or educational certificates: B.A. Clemson University, 1986; J.D. University of Georgia School of Law, 1993

Any professional licenses or certifications: Member of Georgia Bar, 1994

Any employment, occupation in firm of business, or work related experiences which relate to your qualifications to testify on or knowledge of the subject matter of the hearing:

1986-1989	Baxter Healthcare, Project Manager
1989-1990	Revlon Corporation, Project Manager
1993-Present	Legal career primarily has focused on employee health and welfare benefit plan matters and the tax, ERISA, compliance and litigation issues that arise in connection with such arrangements.

Any other information you wish to convey to the Committee? No.

Committee on Education and the Workforce

Witness Disclosure Requirement – "Truth in Testimony"
Required by House Rule XI, Clause 2(g)

Your Name: Mary K. Williams		
1. Will you be representing a federal, State, or local government entity? (If the answer is yes please contact the Committee).	Yes	No X
2. Please list any federal grants or contracts (including subgrants or subcontracts) which you have received since October 1, 1998: None		
3. Will you be representing an entity other than a government entity?	Yes	No X
4. Other than yourself, please list what entity or entities you will be representing: N/A		
5. Please list any offices or elected positions held and/or briefly describe your representational capacity with each of the entities you listed in response to question 4: N/A		
6. Please list any federal grants or contracts (including subgrants or subcontracts) received by the entities you listed in response to question 4 since October 1, 1998, including the source and amount of each grant or contract: N/A		
7. Are there parent organizations, subsidiaries, or partnerships to the entities you disclosed in response to question number 4 that you will not be representing? If so, please list:	Yes	No x

Signature: Mary K. Williams Date: 9/4/01

Please attach this sheet to your written testimony.

APPENDIX E - SUBMITTED FOR THE RECORD, ADDITIONAL ANSWERS TO QUESTIONS POSED DURING QUESTION AND ANSWER PERIOD, JANE MASSEY LICATA, J.D., Ph.D., SEPTEMBER 6, 2001

Testimony of Jane Massey Licata, J.D., Ph.D.
before the Committee on Education and the Workforce,
U.S. House of Representatives concerning "Genetic Non-Discrimination: Implications for Employer Sponsored Health Care Plans"
September 6, 2001

In follow up to questions raised during my oral testimony before the Committee on September 6, 2001, I am providing this supplemental testimony. As promised, I have confirmed that there are no reported cases decided under the New Jersey Genetic Privacy Act. There are a number of possible reasons for this. First, the New Jersey Act has the toughest privacy standards to date and the penalties for violations include prison terms, substantial fines and actual damages in some cases, all of which should provide a high level of deterrence. Further, to avoid genetic discrimination, many individuals purchase insurance policies prior to obtaining a genetic test or pay for the tests themselves. It may also be very difficult for an employee or insured to identify and/or prove such genetic discrimination.

In response to another question, I believe that Title VII should also be amended to explicitly prohibit genetic discrimination. A direct correlation between a genetic trait and a protected class recognized by Title VII may be difficult or impossible to demonstrate. Further, the courts have been very reluctant to find a violation based on statistics alone.

Finally, I also believe that the ADA should be amended to explicitly prohibit discrimination based on genetic conditions. I do not believe that it is clear that genetic conditions are covered by the ADA's three prong definition of disability. At best, its protection may be limited to genetic problems which have already manifested themselves or are known to cause a recognized disability.

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