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GENETIC DISCRIMINATION BY INSURERS: THE PUBLIC PERCEPTION

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Introduction

NORMA DAVIS: Good morning. Our first speaker this morning is Dr. Paul Billings who is currently at the California Pacific Medical Center, San Francisco.* He studied at Harvard, getting his M.D. and Ph.D degrees there and then went on to the University of Washington where he trained in internal medicine and medical genetics. Following that, he did a post-doctoral fellowship at David Farber Institute and was on the staff at Harvard from 1985 to 1990. He has published widely, both articles and chapters in books. And, in addition to this, has appeared on several of our widely-watched programs (CNN, Nightline, Barbara Walters Special) and has been featured in the *New York Times* and the *San Francisco Chronicle*. He's currently a member of the Joint NIH/DOE Task Force on Insurance and Genetics. And he will be speaking to us on "Genetic Discrimination by Insurers: The Public Perception." Dr. Billings.

DR. BILLINGS: Good morning. I want to thank Dr. Lowden, the HIAA, ACLI, AAIM and the ASHG for inviting me to speak here today. Over the last several years, I have had the opportunity to address many individuals and groups representing various components of the insurance industry. I have a great respect for individuals working in and representatives of this enterprise. I think their quality explains, in part, the great success this business and its products have enjoyed. This includes a long tradition of customer satisfaction, employee loyalty, and significant profits for insurance company stockholders and others.

Given one pundit's definition of an expert as "someone from out-of-town," you will be listening to heady stuff in the following lectures. You will be taught by some of the leading researchers and thinkers on human and medical genetics, its social and legal implications, and its predictable impact on the business of selling insurance policies and providing benefits — which premiums guarantee.

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I will not cover anything about the ethical issues which genetic information and insurance stimulate. With a few exceptions, which certainly include Tom Murray and Ray Moseley, I agree that "if you lined up all the ethicists end to end, that would be a good thing."

The issues reviewed here concern biomedical science, business and the rights and entitlements of citizens of this country as we proceed through the last decade of the 20th century. Though different views about fairness may arise, I think there is substantial agreement about what is *right*. It is true that there is no consensus about how to modify the current insurance system to cope with the literal explosion of human genetic information which is becoming available to individuals and their family members. This data may be of interest to health-care providers and a variety of business, social and political institutions as well. It may exacerbate more general problems in the use of medical information by the insurance industry.

Though the public and academics may be obsessed with the question of "why insurers check genes," the industry (despite people like Dr. Lowden) does not seem fraught with ambivalence. Rather, it favors genetic assessment but is currently not ready to invest in a technology which is expensive. Interest in using genetic information is keen within most businesses and social institutions, as evidenced in several published surveys.

I, thankfully, do not have to explain the miracles of modern genetics: its new techniques; how its novel methods are employed and developed; or to show you the data which demonstrate that molecular genetic analysis is revolutionizing medicine — its diagnostic, prognostic and therapeutic powers. It is clear that a great deal of personal genetic information will be available soon, and storable on your home or office PC.

There are three preliminary points which must be made. Then I will discuss how our research sheds light on our society's view of genetic discrimination and the insurance industry. Finally, I will conclude with some reform and policy suggestions. If adopted, they will allow this country to derive a significant return from its investment in human genetics. They may help insurers

and other members of our citizenry avoid "reaping the whirlwind," which the rise of genetics and the echoes of eugenics could bring.

One last related proviso: I will refer to insurers, the insurance industry and its institutions, as if these terms and entities were relatively homogeneous and monolithic. I am well aware that this is a significant simplification. But, the similarities between life and health insurance products justify my "lumping," rather than "splitting" them. Many insurance agents sell both health and life coverages. Some companies still provide both types of policies. Much of the language and many of the theories and practices are shared between these businesses. In addition, some of the information which is stored in databases about individuals is accessed and used by both branches of the insurance industry. The public does not see the practices underlying health and life insurance as substantially different, although it views the benefits as quite distinct and of differing social value. In the discussion which follows, I will try to make points which are pertinent to both types of coverage. They will surely remain relevant, even if the problems with health or life insurance businesses are miraculously solved tomorrow, by Tinker Bell or Hillary Rodham Clinton.

Principles

Human genetics is a scientific discipline concerned with elucidating the role of genes and their products in observable human differences. Its central subject is human variation: normal, anomalous, and disease-associated. Its methods, whether applied to purely genetic questions or to the analysis of problems in other branches of medicine and biology, tend to emphasize difference and reduce its explanation to the action of genes. It posits genes as inevitably causal in the etiology of the variation being studied.

Because genetics is about discriminating differences — some types of genes are more effective in producing observed variations than others — this information is well suited for inclusion in insurance practices. In fact, the insurance industry's central concept of "equity" relies on the ability to discern differences among people, relevant to the payment of benefits, and then charging these groups appropriately differing rates. DNA-based differences can now be reliably assessed and used to differentiate among people for insurance purposes. It would seem to be a natural business practice to discriminate among individuals using genetic tests and then offer these people different policy products.

On the other hand, the focus of social concern is the benefit which is being made more costly to some. When considering access to quality healthcare, or minimal levels of financial security for families, the morality of an equity system which utilizes differences based upon genetic, physical, racial, ethnic or gender distinctions is questionable. Business interests may be superseded by the basic tenet of our society, "all men are created equal." Happily, we are progressing to include women, Afro-Americans, the disabled, and other groups under the umbrella of equal protection and guaranteed access to civil rights in recent years. The extension of protection to "genetic types" should be forthcoming.

Geneticists and insurers see the world differently. I am reminded of a joke about two people watching an evening television news program while coverage of someone jumping off the Golden Gate Bridge is being shown. One of the viewers is a geneticist, the other an insurer. The insurer turns to the geneticist and says, "I'll bet you a \$100 dollars that he does not jump." After a moment's reflection, the geneticist retorts, "I'll take your bet." Seconds later the suicide is accomplished. As the insurer is about to pay the debt, the geneticist hesitates. "I can't take your money. It wouldn't be right. I didn't tell you that I saw a tape of the event on the afternoon news show." "No, that's all right," the insurer retorts. "I saw the same tape and I never thought it could happen twice!!"

Geneticists embrace technologies; insurers are suspicious about their accuracy and costs. Some geneticists believe that their research will explain all illnesses and accurately predict every person who will be diseased. Insurers seem unconvinced of geneticists' clairvoyance with respect to sickness and death. Geneticists believe that the characterization of DNA differences among individuals will explain disease variability, while insurers often do not seem to acknowledge that illness varies among individuals at all. Finally, geneticists know that genetic mutations can be prevented and hope that human DNA-based information leads to new therapies. Insurers have only been interested in prevention they can assess (which is quite limited), and wary of the costs of new therapy. The disparate visions and attitudes of both parties foster misunderstanding and public confusion.

Confusion

Are there other sources for public confusion? Certainly, geneticists over-value and oversell their own work for the usual variety of personal reasons. In addition, individuals and societies grasp for genetic explanations of phenomena which haunt them, seemingly for psycho-

reporters, and the depthlessness of media formats generates confusion and fear rather than insight.

Coverage of our work, as well as interest in the financial problems of insurers and empathy for the growing number of uninsured, has led to an unexpected development. Genetic discrimination has been featured in various periodicals and TV shows. In response, the serious press have done some interesting reporting on insurers' decision processes. Stories about "Why insurance companies say, 'No.'"; "The discriminating use of genetic information by insurers and employers"; on the problems with insurance administration within the industry; and on important phenomena such as, "Social constraints arising from insurance practices," and "Differential access to insurance" have appeared. Privacy violations occurring as a result of normal insurance business practices have been reported. Stories on fraud and adverse selection also exist, though the public's response seems to be sympathetic with those who need healthcare and insurance, getting it in nearly any conceivable way.

The arguably sensationalized reporting on individual tragedies with healthcare financing has led to widespread disaffection with insurers. What has been the insurance industry's response? How have insurers coped with their falling rating in the polls? They seem to have taken a page out of the George Bush campaign book.

The insurance industry has coped with their changing public image by playing hardball via ACLI and HIAA publications. Unfortunately, a 1989 manifesto authored primarily by Dr. Robert Pokorski only enflamed the problem, and, as I understand it, has been withdrawn.* Though the 1991 edition is better, the arguments for equity and adverse selection seem hollow amidst 40 million uninsured and many more at risk. The American public wants no more divisiveness in health matters and is not convinced that anti-selection is not trivial financially — the moral equivalent of shoplifting. No one believes that medical information used and stored by insurers is confidential.

A second industry strategy has been to use advertisements evoking "motherhood and family." Yet, few people trust insurers or HMO's in health matters enough to take this very seriously.

Finally, some insurers are telling the ugly truth (previously denied) and promising to make amends. There

have been advertisements discussing problems in the small group insurance market, and a very expensive advertising campaign in California which admitted practices of "gouging" and "redlining." This is a good strategy, in general, and if followed by consistent action and cooperation, could yield some rehabilitation of public image. A cut in the lobbying budget for Washington and the state capitols may be also be in order.

What has been the public response to this media campaign? First, there has been organization. One example is a lobbying group called Victims of Insurance Company Errors (VOICE). There has also developed the general feeling amongst the public that you "live right," or else!

Despite its diminished power, the recent position of the HIAA calling for mandatory universal health coverage, and the cooperation of various industry representatives in state and federal policy deliberations, is hopeful. Unfortunately, insurance industry representatives continue to assert the right to discriminate on TV, while the results of their actions are portrayed as increasing the likelihood that children will suffer from illness and mental retardation. The end result? One step forward and two back.

Genetic Discrimination Today

We have completed a review of 93 cases of self-reported genetic discrimination. Many respondents have provided documentation of their claims, and most involve insurance matters. We are currently analyzing over a thousand responses to a questionnaire mailed to 30,000 individuals connected to single gene disorder support groups. Even among individuals who do not report genetic discrimination, there is evidence of adaptations and behaviors reflecting perceptions of a hostile healthcare access system and insurance environment. Within the original pilot survey, there are examples of insurance practices including underwriting based exclusions for asymptomatic individuals who never became ill. This happens to be quite common in disorders of the neuro-muscular system and there are even some examples of carriers of recessive disorders experiencing problems.

There are examples of limitations of coverage justified by "pre-existing condition" clauses invoked at the time of initial contracts or after claims for later unforeseen symptoms are submitted. One amazing case involved an individual who was at risk for Marfan's syndrome, but had no symptoms of this disorder. He signed an insurance contract, after underwriting, and then some months later developed a complication of the underlying

* *The Potential Role of Genetic Testing in Risk Classification*. Published by the ACLI, 1989.

ing genetic disorder. After a long legal case claiming that this was a pre-existing condition, there was a settlement.

Also, caps are placed on coverages after claims have been submitted. This is actually quite common among HMOs and some insurers for several clinically variable disorders.

We have found evidence of coercion to treatment pathways by threat of withholding financing. Particularly in cystic fibrosis, the birth of one affected child can be followed by economic pressure influencing the management of second pregnancies.

Finally, we have evidence of cancellations, payment delays, and administrative unresponsiveness after claims. These practices are illegal, unethical, and discriminatory.

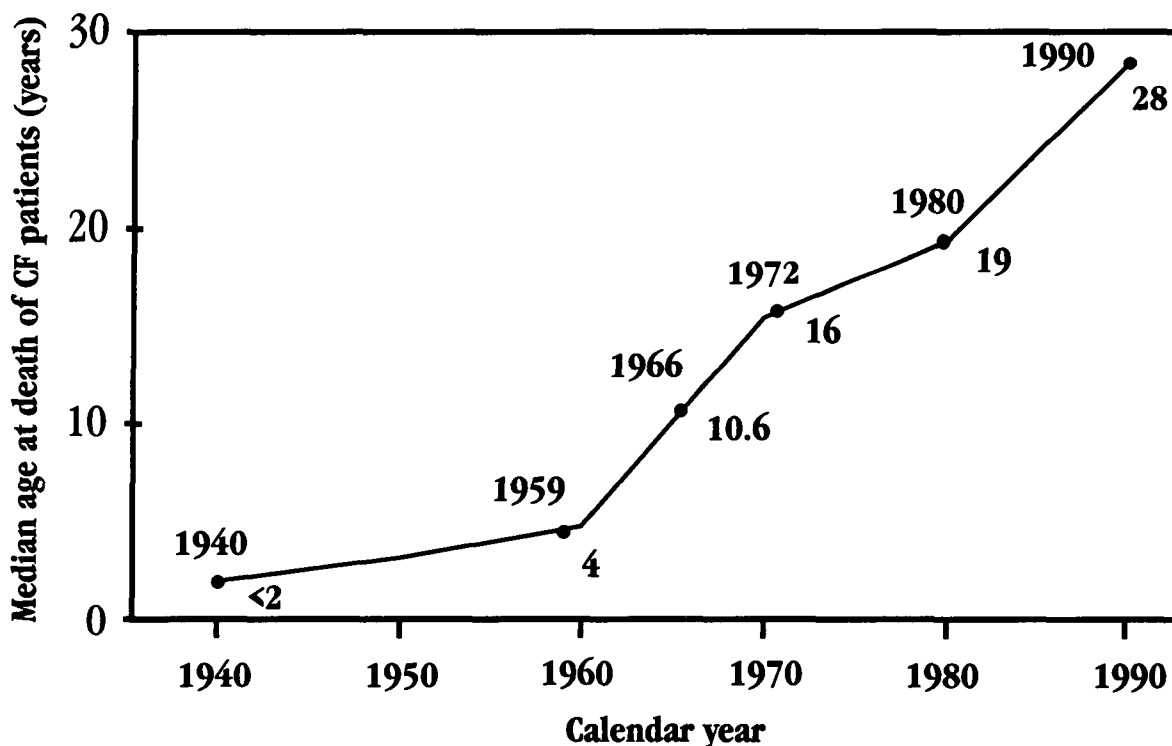
We conclude that, in matters related to genetic information, the insurance industry has been particularly slow to perceive the changes the field of human genetics has undergone. Though attracted to its technology, discriminatory power and claims of predictiveness, insurers' practices reflect notions that disease genes are rare,

but important, powerful, determining, morbid, without variability and without effective antidotes.

The great lessons of progress in disorders like cystic fibrosis, only partly elucidated by Drs. Collins and Tsu, seem not to be appreciated. The data shown in *Figure 2* illustrates the average life expectancy of people with cystic fibrosis from 1940 to 1990. In 1940, the average life expectancy was 2 years or less. By 1990, people born 20 or 30 years earlier had an average life expectancy of 28 years. Children affected today with cystic fibrosis probably will live into their 40's or 50's. The point is that this information is quite relevant to issues of life or health insurance. For instance, does cystic fibrosis remain a severe, genetic disorder when average life expectancy is 50 years or longer? And is this still an uninsurable condition from a life insurance standpoint, given the relatively long life span?

In addition, the public and insurers do not understand how genetic testing is done. Most DNA tests require material from many family members, which may violate privacy, and certainly threatens old notions of insurers' contractual obligation only to an individual. Also, genetic testing is not just a laboratory assay. It requires family history analysis, physical examination,

Figure 2



SOURCE: Office of Technology Assessment, 1992, based on S.C. Fitzsimmons, "Cystic Fibrosis Patient Registry, 1990: Annual Data Report," Cystic Fibrosis Foundation, Bethesda, MD, January 1992; and S.C. Fitzsimmons, Cystic Fibrosis Foundation, Bethesda, MD, personal communication, February 1992.

laboratory testing, counseling and follow-up to be accurate, predictive, useful and compassionate. Fundamentally, phenotypes should be the business of insurers. Only a broad definition of genetic testing and payment for its services will successfully untangle the complicated relationship of gene to trait in an individual, which might be a useful goal for the insurance industry.

Recommendations

Public perceptions of genetics and insurance, and the existence of genetic discrimination, need further study. The following are specific recommendations which the insurance industry should support:

(1) Cost control is in everyone's interest. Genetic tests, cloned gene products, and new gene therapies are expensive. They are now only accessible to the rich. By reducing the cost of caring for those with genetically-based illness, coercion to undergo genetic testing and action in the public's benefit rather than personal interest is lessened. The benefits and freedoms associated with genetic information may then be realized.

(2) Healthcare access via insurance is an entitlement. Insurers should immediately and voluntarily institute an end to the use of genetic information in underwriting, rating, and benefit determinations for health insurance products. Many disability, life, mortgage, and other insurance products should also be exempt from genetic underwriting.

(3) Insurers should consider novel ways for incorporating new technologies into their practices and preventive mandates. Offer underwritten and non-underwritten options with projected cost comparisons. Pay for tests and treatments which effectively improve and prolong life. Continually reassess if prevention and compliance are popular. Invest in technology which monitors compliance to treatment or prevention regimes. Reward asymptomatic people with lower rates.

(4) Support research on the predictive value of tests. Public understanding of risk information and preventive approaches needs to be promoted.

(5) Business practices and trade secret restraints should not interfere with insurers improving their public image and collaborating to promote the understanding of genetic information and technology transfer.

Conclusions

This essay represents a discursive and incomplete analysis of the complicated interactions among knowl-

edge in human genetics, insurers and the public. I have tried to illustrate the confusion and misconceptions which affect notions of what is genetic; what a genetic test is; and how genetic information is being used by insurers.

When the Human Genome Project has met its goals, DNA-based tests for all important genes related to longevity and disease may be available and affordable. Disease prevention strategies and some new effective gene-based treatments may also ameliorate illnesses which have been afflicting us without respite for centuries. The impact on life insurers will be, longer lives for clients and the insurability of previously uninsurable conditions. Many people who are now denied insurance should be able to purchase it.

For health insurers, recognition of asymptomatic forms of high genetic predisposition, longer pre-symptomatic phases and better illness prediction should ensue. Cost control will be essential to insure the fair and equitable development and use of genetic information.

What if we do not correct the current problems which complicate the use of genetic information? What happens if the science does not meet expectations and adverse discrimination continues? The likely answer is eugenics. Not the state-sponsored programs of genetic improvement, like the Racial Hygiene Program of the German Third Reich or the Eugenic Human Improvement Movement which was so popular in the 20's and 30's in this country. Similar programs exist in other countries today. But rather, what has been described as "homemade" eugenics; decisions made by individuals which are significantly influenced by social and political conditions, and market forces; which result in choices and the enactment of norms of health and "acceptable" life. People will "choose" the kinds of children they raise and these choices will reflect social and economic influences they experience.

There will also be a continuance of the current "eugenics of neglect" — reflected in the high death rates of the increasingly burgeoning uninsurable underclass. The fact that there are higher mortality rates for those who are uninsured, as well as higher morbidity rates, is a classically eugenic outcome. Without reform, the uninsured will be increasingly genetically defined, and without rights or entitlements, they will suffer and die.

MR. RICHARD SCHWEIKER, ACLI: How long do you think it's going to take the public to get up to speed about what's going on in genetics?

DR. BILLINGS: A very long time unless we have a major overhaul of our public education process, and that's not very likely. Historically, the public has always lagged far behind scientists and business in terms of appreciating new developments in science and technology. But with a science as personal as genetics is, and where its use touches on such personal themes, I think it's particularly important for scientists and business representatives to get together and indicate what is true and not true about the use of this technology. Blind acceptance of genetic explanations as well as ignorance of DNA-based advances reflect both poor public education and promote misuse.

DR. RONALD FELDMAN, William Penn Life Insurance Company of New York: You said the uninsured have a greater propensity to die. The implication is if you're uninsured that you don't get the proper medical care which may, in fact, be true. However, it may also be true that people who are uninsured are drug addicts or who practice terrible lifestyles and who die in automobile accidents or homicides or the many other causes that have nothing to do with the fact that they are or are not insured. So I think we have to be careful not to jump from one fact to a conclusion that may not be supported.

DR. BILLINGS: There is no doubt that the uninsured are a heterogeneous group of individuals. But this is not an isolated finding. There have been many studies which have shown that this group in general lacks access to routine primary care services and thus has higher morbidity and mortality rates.

DR. ROBERT POKORSKI, North American Reassurance Company: As you were talking, I had confusion in my own mind about several of the issues which I would like you to clarify. We talk about discrimination based on genetic diseases, and we talk about discrimination based on genetic tests. And as we were looking at the video, I was thinking about the PKU test, and I've been away from basic science for so long, that I was saying to myself, I don't really know if that's what you'd call a genetic test based on DNA analysis, or is that a downstream test based on a gene product and therefore, maybe not a genetic test. So could you just address these issues, please?

DR. BILLINGS: In my comments, I tried to define genetic testing quite broadly. And I think for the purposes of the insurance industry, and really for the purposes of public policy, the broadest definition of genetic testing is necessary. Genetic testing involves taking a family history and analyzing family information. Examining the subject and sometimes family members, and then doing a variety of different kinds of laboratory tests.

This might include a karyotype, a biochemical test, like a cholesterol assay, or an assay for phenylalanine in the blood. It might also involve a DNA analysis. There is then required counseling to explain these results and their impacts to the people from which the information was derived. And finally, there needs to be genetic and medical follow-up. Some of the most horrendous cases that I have been involved with, from a legal point of view, have involved the fact that different components of that definition of genetic testing have been forgotten. One particularly important case was a child who was told he had a very severe genetic disorder, and no follow-up ensued. And the child did not die and the family seemed a little upset by the misdiagnosis. If follow-up had been included, less damage would have been experienced.

PKU is a good example for many reasons. In most states that offer state-sponsored genetic screening, a biochemical test is initially done, though it can be confirmed by DNA analysis. In PKU, the genotype which, if left unaltered or unmodified, leads to severe mental retardation and other health problems, when inherited by children who are appropriately treated with dietary modification, results in less morbidity and IQ's that are difficult to differentiate from normal. Insurers should always help create that disease retarding environment for business reasons.

DR. JOHN PHILLIPS, Vanderbilt University: I have a little trouble with one of the points I understood you made; which was that insurers should decrease the use of genetic information? Did I understand that correctly?

DR. BILLINGS: Yes. And I think that this is primarily true for provision of basic benefits in health insurance, and one might argue in life insurance, as well, for basic policies. Simply, this is necessary because currently and for the foreseeable future, genetics will divide the human population. Healthcare financing and some basic level of financial security for families should be an affordable and available option for everyone. Genetics now tends to make it unaffordable for some. Its benefits are only available to a small group. This is misuse of a hopeful scientific enterprise.

DR. ROBERT GLEESON, Northwestern Mutual Life Insurance Company: Two questions: The first question is that your article which appeared recently in the *American Journal of Human Genetics* referred to insurance issues and then lumped together such things as the person who couldn't get a drivers license and the family that could not adopt a baby. I think that we ought to decide whether those are social issues or whether those

are insurance issues. I don't think those are insurance issues.

DR. BILLINGS: The individual you refer to could not get a driver's license, because he could not buy auto insurance.

DR. GLEESON: Okay. But that's a long way from where we are today in terms of insurance and it's a big "lump." The second thing is, I want your opinion on the difference between health insurance and life insurance. Health insurance or disability insurance are things that are today viewed more as a right. You need them to live well. And we have a system which has problems. And everybody admits it and we now have HCFA (Hillary Can Fix Anything). On the other side we have life and disability insurance which are really money in your pocket. If you're disabled, you yourself get the money. If you're buying insurance on a child that you're expecting to die, has a greater likelihood of dying, you may not be spending money for their long term protection. You may be putting money in your own pocket. How do you separate these two? Because one of them is a way of intentional self gain, and the other is self protection.

DR. BILLINGS: Ultimately the question comes down to, "Is the trend to eliminate underwriting?" The most common use of genetic information is in the underwriting process, and if this is eliminated as part of healthcare financing process, that may very well meet with social and public approval. I do not think that there is much public disapproval of the underwriting process vis-a-vis life insurance. Particularly if those policies and benefits remain generally accessible to a large public, which, of course, is in your interest as well, since you want to sell life insurance policies. So, I think that as long as the underwriting practices do not eliminate larger and larger groups of people, and each citizen can have some security, that's fine.

Now you just saw a discussion on TV about genetic testing in breast cancer. Conceivably, all those women who are at high risk for breast cancer and who are thus at high risk for premature mortality, are going to find it increasingly difficult to get life insurance at affordable rates. And to some extent, that makes "sense" as a business practice, in the insurance industry. But I worry about that large a group not being able to buy a life insurance policy.

DR. JUDY BEAMISH, Munich Reinsurance Company: If you eliminate underwriting for health insurance, what's to stop people from waiting until they get sick before they take it out? And how would the insurance be financed, if in fact, nobody takes it out until they're sick?

DR. BILLINGS: I am not qualified to debate about what the mechanism for healthcare financing should be. I like the proposal that health insurance should be like automobile insurance in California — you must have it or you can't drive. It should be mandatory for everybody. We should all contribute to it by a percentage of our incomes and receive comprehensive care. Supplemental policies could be sold, if necessary, by more conventional mechanisms.

MR. RICHARD MINCK, ACLI: Can you tell us something about the 37 million people without health insurance; how many are without it because of genetic testing or underwriting?

DR. BILLINGS: Well, that is a very important question in my field. It is impossible to know now and is another research project which I would be happy to conduct with the help of the insurance industry. It would entail reviewing all the rejections from a company or several companies, and seeing how many could be interpreted as being on a basis of genetic information, testing or perceptions. That information is simply unavailable currently. In our mailing to 30,000 people connected with single gene disorder groups, we got a response of about 500 people who said that they had experienced genetic discrimination. That is a rate of about 1 in 60. If you assume that about 1 in a 100 is, in fact, the true rate — where the cases are relatively clear cut — that means that there could be 10,000 individuals in the United States who would identify themselves as having experienced genetic discrimination. This may be an underestimate. Most of these people have experienced problems with the insurance industry.

DR. PAUL MAHONEY, Prudential Insurance Company: What happens to PKU children that become adults and go back to a normal diet? Do we have any knowledge on that?

DR. BILLINGS: In general, adults with PKU who were appropriately treated in childhood have normal intelligence irrespective of their dietary preferences now. Thank you.