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PANEL ON LEGAL ISSUES IN GENETIC TESTING

Prof. Bartha Maria Knoppers
Prof. Mark A. Rothstein

DR. MICHAEL KITA: Our second panel this morning is on legal issues in genetic testing. Our first speaker is Professor Bartha Knoppers. Dr. Knoppers received her Doctorate from the Sorbonne in Comparative Medical Law and has pursued three main interests: bioethics, genetics, and reproductive technology. She is currently professing to the law faculty of the University de Montreal, but in her spare time she is President of the Canadian Society of Bioethics, Vice President of the National Council of Bioethics in Human Research, a member of the Canadian Genome Analysis and Technology Programs Central Committee, Royal Commissioner on Reproductive Technologies, a member of the Hugo International Ethics Committee, and member of the LT Subcommittees of the NIH and the DOE. She has also been a voluntary participant in two genetic experiments, and her children have convinced her of two things: the truly random assortment of genes, and the impossibility of informed consent. It is my pleasure to introduce our first panelist, Dr. Bartha Knoppers.

DR. KNOPPERS: Thank you; it's a pleasure to be here.

By way of introduction, it is important to briefly mention that insurers claim that genetic information is no different than other "sensitive" medical information that they require for risk classification and business viability. It cannot be denied that insurers require a sharing of medical information so as to create actuarial classes/pools of risk-sharing and do so in exchange for offering economic security based on projected personal needs. Moreover, to avoid adverse selection, equality and quality of information is essential.

Nevertheless, critics argue that availability of insurance is a matter of socio-economic justice, of risk-sharing and that community raring should apply. They argue against both total individual "exclusion" and prohibitive "special" rating. In the context of genetic information, such differentiation usually results from a misinterpretation and misunderstanding of both carrier status and of probabilistic, predictive genetic information generally. Accordingly, they maintain that unfair discrimination could lead to the emergence of a new social category, the "genetic proletariat" or even worse (and more realistically) the further stigmatization of persons with genetic conditions.

These arguments based on concepts such as unfair discrimination and on equity and social justice require examining the socio-economic questions underlying the provision of insurance (I) in order to understand suggested legislative responses (II). Because the other speakers will speak to the situation in the United States, I will concentrate on the debate as found in other jurisdictions where surprisingly, in spite of the presence of national health insurance and social security programs, the discussion on genetic information and insurance is very heated - an illustration of the global and political nature of the question (and perhaps of issues to come after the Clinton reforms).

I: THE SOCIO-ECONOMIC DEBATE:

As in the controversy surrounding HIV status and insurance, "determining the moral 'rightness' of this debate requires resolving whether insurance is a private business or a social institution." Even though economics has guided insurance industry practices and even though "discrimination" in insurance is not only a business necessity but also legitimate, it can be asked whether "private businesses generally have a responsibility to promote social justice." Considering the potentially stigmatizing nature of genetic information and its intrusion on familial privacy as well as the public health concerns surrounding possible reluctance to find out one's status for fear of losing or not obtaining life, disability, mortgage or health insurance, the socio-eco-

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nomic debate underlying proposed legislation can be summarized as focussing on both concerns for fairness (A) and for privacy (B).

A. Insurance and Fairness:

In modern societies, the acquisition of different types of insurance is not only a basic necessity and socially acceptable but usually also an economic requirement for access to other benefits or employment. The State also has an interest in the economic security of its citizens against misfortune. Lack of insurance or insufficient insurance inevitably leads to dependance on the State for the support necessary for survival. The insurance industry however is not a state welfare agency and a balance must be struck between economic necessity, social solidarity and commerce.

If one accepts the right of every citizen to stable conditions of existence for physical and irreversible misfortunes beyond individual control, then access to a minimum of different types of insurance is a social economic right and not just a privilege. Even so "this is where a political choice must be made." It is clear that insurance "is not a trait but a concept of membership. It expresses the criteria used by a group to decide whom to include and exclude from its redistributive system. Treated as a scientific test about individuals it disguises fundamentally political decisions about membership in a community of mutual responsibility." The fact that perhaps increasing knowledge and refinement of genetic testing will eventually make the actuarial data more sound and thus more equitable in its differentiation can also be disputed in that "actuarial fairness is neither a necessary nor a sufficient condition for moral fairness or justice in insurance...[T]his link presupposes that individuals are entitled to benefit from any of their individual differences, especially their different risks for disease and disability." Moreover, "(i)n many of our other social arrangements we do not ask those who are in greatest need to shoulder their burdens alone." Finally, "(a)t the present time, genetic testing is not accurately informative to render the use of the applicant's genetic profile either economically efficient or risk distributionally fair." Thus, "because the ultimate goal of insurance law is to serve justice, fair risk distribution (should) take precedence over economic efficiency." How then have other jurisdictions responded to this challenge?

A resolution of the Conference of Data commissioners in the Federal Republic of Germany in 1989, maintained that gene analysis in the insurance industry is irreconcilable with the principle of insurance, that is, to cover rather than to exclude risks. Similarly, the 1989 Report of the Dutch Health Council held that, access to basic health and life or disability insurance and the social security system in general must remain open to all. Even though the Dutch national insurance system guarantees a basic standard of living, it is only a minimum and the Council argued that "many other people need to insure themselves against the risk of incapacity or early death to allow themselves or their surviving relatives to maintain approximately the same standard of living..." The Council feared the possibility of social isolation for those genetically at risk. "Instead of liberating people and making them able to shape their lives according to their own philosophy and religion, (genetic) knowledge thus becomes a social force in the distribution of inequality." In addition to these concerns for the equality of its citizens and their quality of life, the other commonly cited ground for State intervention was that of respect for privacy.

B. Insurance and Privacy

As evidenced by the recently proposed Human Genome Privacy Act in the United States, privacy con-
cerns in the collection, management and diffusion of genetic information are seen differently from medical information generally. The confidentially of medical information is internationally recognized but genetic information is seen as more intimate and sensitive, as requiring longer periods of storage and most importantly, due to its inherent familial nature as requiring different norms since it necessarily identifies others. Like the socio-economic concerns, the possible impact on personal and reproductive health and decision-making is unknown though there is much speculation that people will hesitate to go in for testing and for counselling for fear of loss of privacy.

The right to privacy is explicit in the constitutions of many European countries. Moreover, the Convention on Data Protection was adopted in 1981 and article 8 of the European Convention specifically provides for the protection of one’s “private and family life.” It must be remembered that in most European countries the right to privacy is constitutionally protected or a right of personality under civil law. In any event, it is also a liberty interest and is seen as covering the most intimate sphere of one’s personal life, one’s relations and lifestyle choices.

The Council of Europe’s expert committee on bioethics has recently passed several resolutions on genetic testing but has been studying the difficult issue of genetic information since 1990. One of the proposed recommendations under discussion is a prohibition on all insurers in its member countries to perform genetic tests or ask for results of any tests performed elsewhere as a condition of insurance or prior to the modification of a contract. This recommendation, if passed, is extremely important considering the proposed union of certain European states. Closer to our subject today is the fact that the reasons given are based on the protection of private life. The Committee went so far as to ask that no exceptions such as public health or the health of others be allowed.

As a result of these socio-economic and privacy concerns, the proposed resolution found in the legal debate is one of legislative intervention often hastily prepared and ill-conceived in terms of long term impact or what such legal intervention says about genetic information itself.

II: THE LEGAL DEBATE:

Other authors have documented the range of future legislative options such as outright bans, state regulation, amending or eliminating the ERISA exemption for self-insurers, establishing high risk pools or state mandated coverage, allowing limited testing, providing a minimum no questions asked policy, allowing testing but setting standards, or, finally, creating high risk pools.18 Two current legislative approaches to genetic testing and insurance seem to dominate the debate however, the first is genetic-specific legislation(A) and the second, is anti-discrimination legislation (B).

A. Genetic-Specific Legislation:

Since other speakers are addressing the situation in the United States where to date both Arizona and Wisconsin19 have adopted legislation specifically banning the use of genetic information to determine health insurance eligibility, I will again turn to other countries where, as mentioned before, the presence of national health insurance and social security programs has not stemmed the call for total bans or at the least restrictions on all insurers from testing for, using, or having access to, genetic information for any type of insurance.

In a 1989 resolution on the ethical and legal problems of genetic engineering, the European Parliament maintained that: insurance companies should have no right to demand genetic testing before or after the conclusion of an insurance contract; nor should they have the right to demand to be informed of the results of any such tests which have already been carried out; genetic analysis should not be the requirement for the conclusion of an insurance contract; and furthermore, insurers have no right to be notified by the policy-holder of all the genetic data known to the latter.20

Similarly, France, in a 1992 statement of its national ethics Committee recently incorporated in a bill, asked that legislation be introduced prohibiting access by insurers to genetic information in registries or banks, or even to ask for authorization to access the medical file.21

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19 Ibid., pp. 60-62.


A Conference of Data commissioners in the Federal Republic of Germany in 1989, foresaw the need for a clause in the law covering insurance contracts, specifically prohibiting gene analysis. They suggested that there be no access to medical files for genetic information. Yet, they conceded that if at the time of contract, the applicant had knowledge of a serious genetic disorder, then it must be revealed and the interest of the insurer in such information would be legitimate.22

The Dutch Health Council has recommended a general prohibition on the use of genetic testing in connection with access to life and disability insurance and to personal pension schemes. It urged legislative restrictions on the rights of insurers to require disclosure of known genetic information on themselves or other family members as long as the coverage sought is below the ceiling appropriate to the applicants social and financial circumstances. It asked for legislative intervention.23 In November, 1990, Dutch insurers adopted a self-imposed five year moratorium on the use of genetic information and in August, 1992 a bill was tabled. This bill reiterated this concept of the industry responding at a minimum to the real needs of applicants (i.e. present income and future financial prospects). Thus, "(a)s long as the candidate seeks insurance for amounts not exceeding these real needs, the insurer must abstain from further physical examinations and from questions about genetic information. It is up to insurers and consumers to determine the limits of real needs."24

Finally, in Denmark on April 25, 1991, Parliament resolved to ban the use of genetic testing for the purposes of employment, pensions and insurance. Legislation was adopted and was to have been enacted on July 1, 1992. Surprisingly enough, this legislation was opposed by trade unions who saw some usefulness in the genetic monitoring of workers.25

B. Anti-Discrimination Legislation

Another approach is to incorporate genetic characteristics as a prohibited ground of discrimination under general human rights legislation. In this vein, the 1992 World Medical Assembly stated: "(t)here is a conflict between the increasing potential of new technologies to reveal genetic heterogeneity and the criterion for private insurance and employment. It may be desirable, regarding genetic factors, to adopt the same tacit consensus which prohibits the use of race discrimination in employment and insurance."26

More specifically, this approach is under consideration in the States of New York and California.27 In spite of the attraction of this more general anti-discrimination approach, the governor of California vetoed this proposition in 1991 even though both Houses had passed the bill. Because of the absence at that time of any national health program or insurance - managed or otherwise - the proposal involved the usual trade-off. Insurers in California would have been banned for 8 years from using genetic testing for any health insurance purposes and indefinitely for group life or group disability. Individual policies for life or disability insurance would not have been protected. The governor justified his veto as follows: "I am concerned that we are providing a remedy for a problem whose nature and magnitude are not yet sufficiently defined."28

There may be some truth in this, for, the philosophical difficulty with either the genetic-specific approach or with labelling "characteristics" or "traits" as genetic under human rights legislation is the contribution it makes to the further stigmatization of anything labelled "genetic."

CONCLUSION:

We must wait for public and medical education to accept the concept that genetic information is "normal" though highly sensitive, medical information, that genetic difference is "normal" (and that there is a possibility of recognizing some equivalence between persons based on this difference), in order to avoid both hasty genetic-specific legislation and problematic genetic discrimination statutes. Current negative attitudes towards testing derived from potential loss of socio-economic stability and from fear of unauthorized intrusions into one's personal and intimate family life mandate some response, however.

22 Resolution of the Conference of the Data Protection Commissioners, supra, note 12.
23 Dutch Health Council, supra, note 2, pp.133-141.
27 Council of State Governments. supra, note 18, p.62.
As we wait for this education, for social acceptance and for greater actuarial precision and lower costs in genetic testing, wouldn't a better solution be to recognize a "right to genetic privacy"? This right could be seen as included within the right to personal privacy be it economic, social or medical. Indeed, if genetic information were to be considered as personal risk information within the zone of personal and familial privacy, the larger right of "informational self-determination" would govern relationships with economic third parties.

In our rush to define and protect perhaps we should step back, take a more classical approach based on larger policy considerations, and, treat the personal, economic, medical and genetic, private life of an individual as a whole. It could well be that the insurance industry is but the first to be singled out in what is really a debate about social change in an age of explosion of information. Thank you. (applause)

DR. KITA: Thank you Dr. Knoppers. Our second panelist for legal issues this morning is Law Professor Mark Rothstein. Counsel received his JD from Georgetown and currently directs the Health, Law and Policy Institute at the University of Houston. An expert in employment and occupational health law, he is widely published on the subject. But his own personal ethics and the bounds of good taste preclude him from urging Dr. Rotter to buy his textbook. (laughter) He has lectured on genetic testing, reproductive hazard, the ADA and other topics, and consulted to numerous government, medical and scientific bodies. You might say he has first hand experience with everything from the ADA to the AMA and AHA. And that he knows policy making from OSHA to OTA. Please welcome our second panelist Dr. Mark Rothstein. (applause)

DR. ROTHSTEIN: Thank you and good morning. I'd like to begin by demonstrating the fact that I really am a lawyer by beginning my talk with two caveats. I'd like you all to take notice of the fact that I'm the fourth panelist this morning to address the same topic. Therefore, one possibility would be merely to incorporate by reference everything that was said before and sit down. The other possibility is for me to try to put my own personal spin on some of the topics that were discussed. The second caveat is that, even though this is a panel dealing with legal issues, much of what I'm going to say has to do with ethical and policy implications of genetics and genetic testing. I feel no remorse for doing this because I know that Ray Mosely and Tom Murray have frequently trodden into the area of legal issues. And, therefore, they clearly wouldn't mind my discussing some of the broader ethical and social issues.

First, I want to talk about some of the assumptions underlying the controversy. The insurance industry is on record as saying that it has no interest in performing genetic testing. Yet, I think it is clear to everyone that insurers do have an interest in obtaining access to genetic test results obtained by insurance applicants. If the applicants have information available to them that's not available to the companies then the companies, out of self defense, will have to take other measures to obtain their own genetic test results. Another common misconception surrounding genetic testing and insurance is that it is likely to be started by an insurance company as a way of restricting access to insurance by high risk individuals.

Actually, the following scenario is more likely: Insurance company A, perhaps responding to consumer pressure, begins to offer a line of insurance for healthy individuals who do not smoke, do not drink, exercise regularly and, of course, have no genetic or other known risk factors. Applicants who qualify can obtain insurance at rates up to 50 percent below standard rates. Healthy applicants then will flock to company A to take advantage of these reduced rates. What does company B do? Individuals who are unable to qualify for coverage at company A will go to company B. And because the pool of applicants is now further self selecting, company B's applicants will contain a disproportionate number of high risk individuals. Company B then has two choices. It can either raise its own rates for the increased risk, which will have the effect of further segmenting the applicant pool and making a bigger problem when it gets down to company C and D. Or it can also engage in the screening measures used initially by company A. It seems to me that either course of action raises great concerns. In the former, rate increases may make insurance unaffordable to a large portion of the population, which is something that neither the insurance industry nor society would welcome. In the latter, genetic testing has proliferated, thereby raising various ethical and policy issues that we've been talking about this morning.

One of the things that we’ve heard in the context of this morning's presentation is the conflict between actuarial fairness and moral fairness. I think that needs to be explored even further. Insurance is a system of risk sharing, obviously, founded on the principal that policy holders with the same expected risk of loss should be treated equally. The ACLI and HIAA have expressed, "The cornerstone of a private voluntary insurance system is risk classification." Insurers must be able to appraise risks in order to group risks together, to forecast cost and to establish fair and adequate premium rates. This is what has come to be known as the actuarial
fairness argument. At first glance there's a certain appeal to the argument. As Dr. Murray told us this morning, and as he likes to remind us frequently, Aristotle implored us to treat like cases alike and unlike cases differently. We expect our auto insurance rates to be lower if we have an accident-free driving record, and we expect them to be higher if we have a record of accidents. This is both actuarially fair, and also seems to reflect common sense and justice. The argument is seriously flawed however if one considers actuarial fairness not as an end point but merely as a means to the end point or goal of moral fairness. Even the simple example of auto insurance is, on reflection, not so simple after all. No-fault insurance statutes and high risk driver insurance pools operate to insure that individuals who would be excluded from coverage under a system reflecting pure actuarial fairness are not excluded from the auto insurance market. High risk drivers are subsidized by low risk drivers, because, at least in many jurisdictions, there's a public recognition of the desirability of maintaining available auto insurance.

We have to consider the purpose and the effect of health insurance. Under our current healthcare system health insurance has a crucial, allocative social function. To deny an individual health insurance is to deny the individual access to quality healthcare. Actuarially fair practices often operate to deny equality of opportunity and access to healthcare on the basis of one's past, current or future health status. This is a morally dubious proposition. According to philosopher Norman Daniels, "There is a clear mismatch between standard underwriting practices and the social function of health insurance. A purely public insurance system thus leaves no room for the notion of actuarial fairness. It is important to understand, of course, that the criticism of actuarial fairness or medical underwriting in health insurance is not a criticism of insurers." Daniels goes on to say, "The real moral failure is a public or social one, not a failing of individual insurers or a violation of their business ethic. Nevertheless, abdication of social responsibility in the public sector does not make rational, market-based decision-making by the private sector morally fair." One argument used by health insurers to defend actuarial fairness is a practical one. Eighty-five to ninety percent of health insurance is currently purchased through group plans, under which there is little medical underwriting. Yet medical underwriting is performed in some employer groups with fewer than 25 employees, and there is a trend towards increased medical underwriting in both small and large groups. According to the Office of Technology Assessment, each year about 164,000 applicants are denied individual health insurance coverage. It seems that new genetic and computer technologies are likely to make medical underwriting for both individual and group insurance less costly and more common. I need to say a few words about the role of employers in all this, especially for the United States. There are two main reasons why you can't talk about health insurance without focusing on the role of employers. First, as I just mentioned, 85 to 90 percent of Americans covered by health insurance are covered by group health insurance. But 68 percent of these are covered under employer-provided plans. And, second, the topic of my current interest, the percentage of employers who are self-insured has increased dramatically. In 1991 65 percent of all employers were self-insured, and 82 percent of large employers, those with 5000 or more employees, were self-insured. In fact, 22 percent of small employers, those with fewer than 100 employees, were self-insured in 1991, despite serious questions about whether such small groups are able to spread risks adequately.

Unlike commercial health insurance, there are several advantages to self-insurance for employers. Health insurance is regulated by state insurance law, but self-insured health benefits plans are covered under the Federal Employee Retirement Income Security Act (ERISA). The effect of ERISA to preempt the regulation of self-insured plans by the states was most graphically demonstrated by the celebrated case of McGann vs. H & H Music Company. In this case an employee of a chain of music stores in Houston was covered under the employer's group health insurance plan which had a million dollar cap for all illnesses. After Mr. McGann notified H & H that he had AIDS, the company terminated it's commercial health insurance contract, and became self-insured. It hired its previous commercial insurer to administer the new plan, and reduced the maximum lifetime cap, only for AIDS coverage, from one million dollars to five thousand dollars. McGann sued alleging a violation of the anti-discrimination provision of ERISA, section 510. The United States Court of Appeals for the Fifth Circuit affirmed the dismissal of the case on the ground that under ERISA a self-insured employer is free to amend or discontinue any health benefit, even after the submission of claims. The Supreme Court, as many of you know, refused to hear the case.

McGann clearly illustrates, to me at least, both the magnitude and the consequences of ERISA preemption. Self-insured employers are free to modify the terms of their health benefits plans at any time, so long as they satisfy whatever notice provisions are contained in the plan document. Consequently, employees whose health insurance is under an employer's self-insured plan really have no health insurance at all. They merely have an expectation or a hope that their employer will con-
continue to pay health claims in the future. This reality has recently become well understood by many retirees whose health benefits have been reduced or eliminated altogether as part of financial restructuring and cost-savings. When one considers the scope of self-insurance it becomes really quite disturbing. Many employees contribute substantial amounts of money to purchase self-insurance coverage. Many employees and their dependents forego purchasing other insurance products in reliance on this coverage. Few employees understand the precise nature of self-insurance. Given these facts, the entire self-insurance system, it seems to me, verges on fraud.

Fortunately, there are few McGann-type incidents that have been documented so far. But rising health costs, and the increasing ability to predict future claims through genetic testing and other means, provide little assurance that these practices will not become increasingly common. What about the future of health insurance? I think it is evident to everyone in this room that our current, privately-financed healthcare system, at least as we know it, is doomed. Our society no longer can tolerate the unrestrained cost increases, the inequality of access, and the poor aggregate outcomes of the healthcare system in the United States. It would be irresponsible, however, and at odds with my concept of self preservation, to lay the blame for the system solely at the doorstep of health insurance or the health insurance industry or any other single institution. It is a societal problem that will require a societal response.

Obviously, there's no shortage of proposals of what to do, although we're going to find out whether there is a shortage of political and public resolve. With regard to the effects of genetics, Deborah Stone has written, "It is too simplistic to say that if we enact laws to prohibit insurers from using the results of genetic testing that the problem will go away." This approach already has been tried in several states. We need to think more carefully about the problem before we leap to the genetic legislation option. Clearly, it's not even necessary to use sophisticated genetic tests to produce genetic discrimination. A simple family health history can often provide more than enough information. New genetic technologies will almost certainly accentuate the problem and underscore the need for fundamental reforms. At a time when the issue of healthcare reform is buzzing around Washington, I think it's important to assess how the possibility of genetic discrimination plays into all this.

A major premise of any new health insurance system in the United States must be the elimination of risk-based health insurance. Community rating, non-cancelable coverage at standard rates, abolishing pre-existing condition clauses or exclusion waivers, and other major reforms seem to be essential just to preserve the viability of private health insurance as the primary source of health insurance coverage.

One problem that must be avoided is simply shifting the incentive to discriminate from the insurance company to employers under a system in which employers are required to offer health benefits in which the additional cost of each health benefit claim is borne directly through self-insurance, or indirectly through experience rating. Employers have tremendous incentives to discriminate against actual or perceived high-cost users of health benefits in employment. The ability to use genetic technologies in the predictive screening process increases the societal risks of such a system. Thus, the evil to be eliminated is not simply risk-based health insurance. It is employer-based risk-based access to health benefits. If employers are to have any role in a healthcare finance system, as they likely will, it must be limited to a flat per capita assessment in the form of a tax or premium contribution for each employee.

Having alienated half of the room with my discussion of health insurance, I'd like to alienate the other half by taking up the issue of life insurance. The conflicts between genetics and life insurance, in my view, are both easier and more difficult to resolve. The rationale and bases for medical underwriting are easier to understand in the life insurance context. An insurance company considers the age, health and risk of the individual, and, using standard mortality tables, calculates the actuarily fair rate to insure the individual's life. Unlike health insurance, life insurance is predominantly individually written and uses medical underwriting of the individual. The difficult part of life insurance is deciding what effect genetic information should play in this process. Health insurance is comparatively simple to analyze because the interests of the individual and society in affording access to healthcare are so fundamental that, in my judgement, they outweigh the commercial interest of the insurers to deny coverage to at-risk individuals. With life insurance, the individual interests are less substantial, and the financial interests of the insurance companies are more demonstrable. There is less divergence between actuarial fairness and moral fairness. Or, simply put, life insurance is a closer case.

What are the interests at stake? With disability or life insurance, the main reason for its existence is to assure income replacement and the peace of mind that comes with having contingent income assured. The need for financial security is important, but it is less essential than the allocative function of health insurance. There
are few alternatives to health insurance. There are various investment alternatives to whole life insurance, and even some alternatives to term life insurance. Although individuals' primary outcome interest in life insurance is financial security, individuals also have substantial, what I call, process interests in life insurance. Two of these interests are the right to have equal access to the insurance product, and the right of medical privacy. An important issue is whether these interests pertain to all forms of medical underwriting. On a purely practical level, I think insurance companies would prefer that there really were no such thing as genetic testing. They could continue to rely on standard mortality tables in assessing risks and setting premiums. As genetic testing becomes more widespread in the clinical setting, however, there is a greater likelihood that an individual will learn that he or she is at risk of a serious genetic disorder and will seek to obtain a substantial amount of life insurance. Unless the insurance company has access to the same information that the applicant has, then the insurer will be at a disadvantage. This obviously is the principal of adverse selection. Now there's some appeal to the argument for this concern. While it would be unethical for a society to deny access to health care to an individual with Huntington's disease, it also may be unethical for an individual identified as pre-symptomatic with Huntington's disease to purchase five million dollars worth of life insurance at standard rates. The insurance companies would either have to go out of business or charge substantially higher rates to all policy holders.

It may be reasonable for a society to require that healthy people subsidize the health insurance or healthcare of those who are ill, but it is unreasonable to require that healthy people subsidize the estate building of people with current or future lethal illnesses. Although industry concerns about adverse selection, I think, are certainly legitimate, the degree to which adverse selection involving genetic disorders would actually occur is not clear. Unlike AIDS, in which it is assumed that all HIV positive individuals will eventually develop and succumb to AIDS, there are few late onset genetic disorders that are invariably fatal, and these are relatively rare disorders. It is simply not known how much adverse selection may be attributable to individuals who are at risk of genetic disorders. Is genetic information different from other types of medical information? I think that few people would be willing to argue that insurers should be required to offer unlimited life insurance to individuals whose extreme hypertension put them at substantial risk of stroke or coronary artery disease, or to offer insurance at standard rates to individuals whose heavy cigarette smoking put them at risk of cancer and heart disease. Thus, it seems to me differentiating between individuals because of their current or likely future health status is not necessarily immoral.

Is there a difference between non-genetic risks and genetic risks that makes exclusionary practices for genetic risks morally questionable when exclusions for non-genetic risks are not? I think there is. I think there are four main reasons why genetic disorders are a special case: First, at least with regard to single gene disorders, there is nothing an individual can do to avoid inheriting the gene. While treatment prospects vary with disorder and are improving for many conditions, one's genotype is immutable and often gene expression is unavoidable. With only a few exceptions, such as PKU, no dietary, environmental, or lifestyle modifications permit an individual to avoid the affects of a purely genetic condition. Undoubtedly medical care and social support should not be based on the moral stigma of a disease. Nevertheless the fact remains that much of society would regard individuals with genetic diseases as powerless to avoid their fate and therefore more deserving of societal support than individuals whose medical conditions are attributable to behavior such as cigarette smoking or substance abuse. Second, there is family stigma that may be associated with genetic disorders. Because genetic conditions are by definition heritable, identifying deleterious genes in one family member automatically means that other family members may be at risk. Without these individuals electing to do anything when a relative is tested, these individuals may become confronted with toxic information that they did not seek and do not want. It also seems unjust that the burden of genetic disease falls so heavily upon particular families. Not only are there physical and psychological burdens of having multiple family members with chronic medical problems, there are the added social and financial costs. If one family member is disqualified from insurance or other opportunities, other family members should not also be subject to the same stigma and the same lack of opportunities and financial burdens.

Third, genetic traits sometimes follow along the lines of race and ethnicity. In contemporary American society, any policies that have the purpose or affect of disqualifying individuals on such bases are both legally and morally suspect. Mandatory genetic testing and disqualification from life insurance on the basis of sickle
cell anemia, thalassemia, or other disorders which primarily affect certain racial or ethnic groups raise troubling policy issues.

Fourth, and finally, given the history of eugenics in the United States in the early part of this century, not to mention Nazi Germany, there is a justifiable reticence to embrace any program of systematic application of genetic criteria. The societal burden would seem to be on the proponents of genetic testing to demonstrate a clear need for the testing, that no other methods of medical underwriting are feasible, and that extraordinary measures to protect confidentiality are in place. Even if we can draw a distinction between genetic and non-genetic medical information, this does not necessarily mean that we ought to. The cost may be too high in making these distinctions, and the distinctions may not be sufficiently determinative of what we ought to do in terms of social policy.

As I think most of us would agree, widespread genetic testing is unlikely to be performed for life insurance in the foreseeable future. It is simply not economically feasible. Few genetic tests now available would pass muster under the industry’s current rule of thumb that medical underwriting costs generally should not exceed one dollar per thousand dollars of coverage. Yet, genetic discrimination in insurance remains a distinct possibility, based on medical and family histories and access to these other genetic tests. Public policies should not deprive individuals of the autonomy to decide whether to undergo genetic testing. The well-founded fear of uninsurability and unemployability has operated to limit the autonomy of many individuals who otherwise would seek genetic testing and genetic information. Regulation by state laws in the realm of life insurance has tended to prohibit the use of genetic information. The Canadian Privacy Commission has recommended that no medical underwriting of life insurance should be permitted for any life insurance policy under $100,000.00. In the Netherlands, as was described earlier, there is a 200,000 guilder point between those medical underwriting decisions that are permissible and medical underwriting that’s not permissible. This general approach of setting maximum levels where there’s no medical underwriting to be performed may be valuable for two reasons: First, it strikes a reasonable balance in protecting access to insurance without creating irresistible pressures for adverse selection. Second, by prohibiting all medical underwriting rather than simply genetic underwriting, it avoids the definitional problem of deciding which medical tests are genetic, although it still must be decided which other inquiries, such as smoking, drinking and family health histories, are medical.

Even under this approach some additional issues need to be resolved. First, individuals should be entitled only to the set amount, for example, $100,000.00 in life insurance, from all insurers which would prevent individuals from stacking a series of small policies. Second, there must be some limitation placed on the timing of insurance applications. It would be unfair to permit individuals near death to submit applications from the intensive care unit of hospitals. One possible solution is to impose a one-year waiting period for life insurance coverage, except for accidental death.

In conclusion, neither wishful thinking nor simplistic legislation can avert the future problem of genetic information being used in the medical underwriting of health and life insurance. Although a strong case can be made that genetic information ought not be used in health insurance, it merely addresses a small subset of the overall problem of a lack of equality of access to healthcare in the United States. The principle of excluding genetic and other health risk assessments in health insurance, therefore, must be a part of a more fundamental reform in our health care system. The issue of life insurance is a closer case, but a reasonable balance might be struck by prohibiting all predictive medical underwriting for insurance policies below a specified amount. Thank you. (applause)

MR. ANDRE CHUFFART, Swiss Reinsurance Company: I’m a little bit confused, and I have three very simple questions. First, what is a genetic test? Second, what is a genetic disorder? Third, what is genetic information? These expressions have been used since yesterday, but I’ve not been able to hear a very clear definition of these three concepts. Could you please say something about this?

DR. ROTHSTEIN: Well, first of all, you raise a very good point. There is no commonly accepted definition of what is genetic testing. Are you talking about simply DNA-based testing? Or cytogenetic testing? Or testing for gene products? I mean, there are various ways that you can define it. And that’s why I’ve suggested that even though there may be a moral difference between some forms of genetic-based testing and other forms of medical testing, it may not be the road to go down, and maybe we shouldn’t differentiate between genetic testing and other forms of medical underwriting. And we should adopt a different approach that has a single set of policies for all medical underwriting.

MR. CHUFFART: I asked three questions.

DR. ROTHSTEIN: I’m not sure that I have a different response to that. I think the answer is the same, depend-
tion on what your definition is, and I think my first answer applies to all three of those.

DR. REILLY: My sense of justice and fairness, which I acquired from Dr. Murray, suggests that people trained in medicine genetics should be asked to respond to this gentleman, rather than people who know a lot about genetics but weren't necessarily trained in it. I don't think really the questions are so hard to answer. You do a disservice to yourself if you ask for rigid definitions. Genetic tests are tests that have been developed in the scientific and medical communities to try to understand something about genetically-based disease. They have evolved over time. They began at a level where we inferred largely Mendelian principles of inheritance governing disease, based on some analysis of a body product. Either a high or a low level of some metabolite, or something like that. Certainly PKU testing is commonly done, and it's not DNA testing, but it says something about genetic disease. Genetic disease has evolved over many decades from the earliest days. Say, Archibald and Gerrad's studies of inborn errors of metabolism, where they were looking at very simple Mendelian concepts, or what came to be thought of as Mendelian concepts, to an era where we learned how to look at chromosomes. We think of Downs syndrome as a genetic disease, although in fact, it has, by and large, no known pattern of inheritance. It's a mitotic event. And now we are entering an era that should be of most concern to you, where we recognize that diseases that we have never thought of as being genetic have a genetic influence. You know that hypertension is, in some families, strongly influenced by family history. You know that there are a growing number of familial cancer syndromes. Two years from now you'll be sitting in a room like this somewhere, and you will hear about how we have a way of ascertaining the 5 or 10 percent of women who are at special risk for breast cancer because of a genetic background. As for genetic information, again to the person who asked the question, I would say it represents our best effort to describe our understanding of a disease process being influenced by specific genetic traits in medical and scientific terms.

DR. LAIRD JACKSON, Thomas Jefferson Medical College: It is evolving over a period of time. At the one end for some disorders, for example Tay-Sachs disease, perhaps one would suggest that is nearly as purely genetic as one can get, since it affects a child in the infant stage of development and the overriding effect comes from the biochemical defect in the protein expression of the gene. And toward the other end perhaps, are cancers which are genetic at the level of the cell and the expression of an altered genome, probably in a single cell to start with, which then evolves within the internal environment of the body, in some relationship to the external environment, and becomes an overriding concern from a single genetic change at the start, which is not heritable. But one can't have rigid definitions for these things if you are going to engage in the kinds of discussion that has been prompted by these two days.

DR. KNOPPERS: I'd like to speak to the third part of your question on the nature of genetic information. Some elements have already been presented by Dr. Rothstein and myself. It's not like saying, "You'll have gangrene in your left leg" to an individual in the privacy of a doctor's office. Genetic information is necessarily, as we said, familial. So you learn something about your brothers, sisters, father, uncle, mother, grandfather, etc. Secondly, in order to be useful it requires storage over longer periods of time, which has all kinds of implications for privacy and confidentiality. Thirdly, on both a personal and a social level, it is extremely sensitive, and this for two reasons. The social level because as we heard it has historical connotations and it also has, in certain cases, racial and ethnic overtones. More important is the current construct of what it means to have a genetic disease. If you believe that the gene is the disease, the disease is the person, then inevitably the person is the gene, you being the sum total of your genetic information. That is very personally stigmatizing and necessarily limiting in terms of how a person interacts with society. Lastly, genetic information is also intergenerational, and it has all kinds of implications for reproductive choices, choices made by previous generations and choices to be made on behalf of future generations. So these four levels, I think, of genetic information distinguish it from ordinary "medical information."

DR. MICHAEL KABACK, University of California, San Diego: I think Dr. Rothstein's response was exactly on the mark in the context of this meeting. I would suggest that genetic tests are very difficult to define. When you do a hemoglobin on someone, are you doing a genetic test? Or are you doing a simple health screening test? When you do a blood smear are you just assessing their nutritional status vis-a-vis the iron intake in their diet? Or, in fact, are you looking for thalassemia or sickle cell disease? I would suggest to you that there is a very difficult definition. From the point of view of underwriting, what is a genetic test? What is a genetic disease? Because of the spectrum of environment and genotype that we've alluded to for several days, I think Dr. Rothstein's response is exactly correct. I think that this notion should probably be dropped from the underwriting issue, at least to some level of minimum insurance qualification, because these definitions are, in fact, im-
It's called financial underwriting, and it is done.

DR. JOHN PHILLIPS, Vanderbilt University School of Medicine: I'd like to comment on what my perception of genetic testing is. I think Dr. Knoppers came very close. I'd like to simplify it just a little bit. I think genetic tests focus on a predictive value, something that will happen in the future. An example of that is an EKG can be a genetic test if you see a prolonged QT interval and sudden death in the family. That is very important for the person that has such an EKG, because it predicts an event that may well happen in the future. The second aspect of genetic tests is the confidentiality issue that arises because of the implications it has for relatives. So that the need for confidentiality extends beyond the person who you did the EKG on, to anyone in their family. That is very important. I think genetic tests focus on a predictive value, something that will happen in the future. An example of that is an EKG can be a genetic test if you see a prolonged QT interval and sudden death in the family. That is very important for the person that has such an EKG, because it predicts an event that may well happen in the future. The second aspect of genetic tests is the confidentiality issue that arises because of the implications it has for relatives. So that the need for confidentiality extends beyond the person who you did the EKG on, to anyone in their family. That is very important for the person that has such an EKG, because it predicts an event that may well happen in the future.
writing itself, and that is something else. If you consider an EEG or the family history as being a genetic test, then I think we have serious questions to ask and to be answered there. We have been living with this information for the last 50 or 70 years. Now, because of the advent of these kinds of tests, we will no longer be able to underwrite cases.

DR. KNOPPERS: Well, how actuarially sound are the current tables and information provided to actuaries as concerns genetic conditions? Will they, or can they, or have they been incorporated into them. Or, how far behind are the tables in terms of incorporating this predictive probabilistic type of information? I think if you look at an area where it is being used, not in insurance but in the courts, for DNA forensic type of evidence, increasingly what was thought to be the end all of tests, to either prove innocence or guilt, is being questioned, even the DNA profiling and matching between a victim and a perpetrator on the basis of reference populations. How are actuaries going to fit in the fact that you can’t take a reference base, a bank which covers the heterogeneity of a society that is made up of many different immigrants from different cultures, from different racial and ethnic lines? So, in addition to the problem that genetic information itself will be more and more probabilistic, we also have the problem of actuaries trying to work in reference populations when they’re doing actuarially sound "underwriting." They don’t do the underwriting, but in terms of setting the limits of their tables. In the life insurance area, I would agree that a minimum "no questions asked" is probably the best way to go.

DR. DAVID MALKIN, University of Toronto: I just have a follow-up to Dr. Knoppers’ last statement. On this day in February we have a certain number of tests, perhaps 30 or 40 so-called genetic diseases that we can screen for with some degree of certainty and accuracy. Any policies that may be made today may be completely irrelevant a year from now, when a whole number of other disease become apparent, with perhaps just as devastating eventual effects. So my question is, will there ever be a time where we can actually design any sort of policy that would be all encompassing?

DR. KNOPPERS: I’m not sure, and I’m not a geneticist so as lawyers working in this area, we dabble in the minimum amount of knowledge necessary so as not to make fools of ourselves.

Just take cystic fibrosis, for example, and herald it as the great discovery. We started off with the Delta 508 covering 70 percent of the affected population. You add on a few more markers, you might make it up to about 80 percent. But if you really want to do all the mutations (180 mutations or 200), the cost of incorporating this kind of testing into underwriting is totally prohibitive at this time. If you want to be actuarially sound and scientifically accurate, which for me is the basis of good science, good ethics and good business practice, I can’t see any way of integrating anything other than the single gene disorders in the immediate future. We have the greatest challenge in terms of social policy for those rare identifiable disorders where we’re either going to have to create high risk pools for these individuals or simply go the other route just mentioned, offering a minimum policy. After that, every one goes back to traditional underwriting based on family history and whatever tests are available, incorporated in the practice, and not too costly. So, I can’t see an immediate future for genetic testing, based on the science and based on the cost.

DR. JUDY BEAMISH, Munich Reinsurance Company: I’d like to make a couple of comments on this minimum policy. Somebody has to pay for all these minimum policies if there’s no underwriting. This can either be done by the entire population, in which case it’s really a tax, and it’s a form of social security, whether you make it mandatory insurance or strictly income tax. If you do it on the basis of people who have the option of buying insurance, policyholders subsidize those people who are poor risks. Eventually, rates go up to the point where those people who know they’re good risks will now become self-insured and put their money in the bank instead of paying premiums to subsidize the bad risks. Which means, really, that people are going to stop buying insurance, except for the people who are poor risks, and for them it will be prohibitively expensive. So I don’t understand really how this would work unless it’s really a tax, a form of Social Security.

DR. ROTHSTEIN: Well, I think you make some very good points, but we just don’t have the data at the moment to quantify any of those concerns. I think one of the things that should precede any kind of legislation is an attempt to find out what is likely to occur at what different benefit levels. I mean, you can’t generalize what people are going to do at 20,000, 50,000 and 100,000 and a million in terms of coverage, versus six-month waiting period, one-year waiting period, two-year waiting period, and so on. All these variables play into it. Low risk people may well be subsidizing high risk people to some extent. But I think the benefit to low risk people is the application for life insurance at some stated value without having to go through any kind of medical examination, medical records checks, testing that you don’t want, disclosures that you don’t want. There are all sorts of risks to people that may not be
quantifiable. Your point is an excellent one, but this would be a good area for research done by economists, actuaries and so on, before we decide on something like that.

DR. LOWDEN: It's done today, but very expensive.

DR. ROTHSTEIN: Well, the reason they're so expensive now is we have the regular insurance market, for which there is medical underwriting, and the special insurance market for people who are basically uninsurable. So, you've got the worst of adverse selection. For the people who buy, the benefits won't go down, and the cost won't go up. It's only $90.00 a week for a $1000.00 of insurance, or whatever the rate is. If we cut out the other side of this, then there wouldn't be that adverse selection if there was this one approach across the board. The problem is, as you say, because we have two systems now.

DR. GERALD FOLEY, CNA Insurance Companies: I'd like you to back up for just a minute to a question that was asked previously, having to do with underwriting. If we accept, as we must accept, the premise that all chronic disease and just about every disorder has some genetic association with it, and if we admit that for the last 50 to 75 years the underwriting process, having to do with predictability of disease, and actuarial projections of life expectancies that we've been utilizing are legitimate, any current mandate having to do with restriction of genetic testing is necessarily going to impact traditional underwriting or restrict it in some sense. So, are we biting off more than we can chew? Or should we be aware of that when we put restrictions on genetic testing?

DR. ROTHSTEIN: I think we clearly have to be aware of that. That's why I was critical of the trend toward state-by-state laws that restrict certain kinds of genetic testing. I think that is the wrong way to go. I think it would be a mistake. I think the industry needs to be a little more flexible, because if you don't get together and figure out the best system that will work for you, somebody's going to impose it on you because of this technological imperative. What's imposed on you may not be nearly as good a system as you can come up with yourself to try to deal with all the issues that were raised. I would just urge you to think about ways to improve the current system, because it's going to change. It's going to have to.

DR. PHILLIPS: I'd like to add a word of caution to that also. I made a list at the end of this handout that has 154 diseases that can be diagnosed by DNA analysis. I wrote the list for a chapter in a book, and in the three months between the time I submitted the first draft and had the page proofs, I had to add 34 more diseases. Some of these diseases have 200 different mutations that cause them. It's a hopeless task to keep up with, and these are just DNA tests; these aren't biochemical tests or chromosome tests. So, I think you're going up a very steep hill if you're trying to say that you can keep up with us and figure out which ones are practical and which aren't.

DR. KNOPPERS: I agree with Dr. Rothstein. I think legislative intervention is premature at this state of knowledge and also considering consumer attitudes toward a profit-making industry and their fear of genetics generally. I think the industry should establish their own internal policies on a nationwide basis, rather than waiting for a state-by-state. Who knows what kind of hodge-podge we'll be getting from the states themselves.

DR. THORNE SPARKMAN, Covenant Life: I think we're here because we're trying to do that. We are trying to get a sense of what it is about this funny thing that has been called genetic testing that is so inflammatory. Why is it that a person has the right to withhold information about himself? Why is it that the person doesn't want to know the facts about his life? Why is it that we're trying to hold back science, here telling these geneticists that they should not be doing this testing? We don't like this testing to come up. People don't want to know it. It is very difficult for me to understand that. It's difficult to understand when a person has an infection like HIV and doesn't want to be tested. From my fair city, Philadelphia, someone can go around and expose hundreds of people to his disease because he has a right not to know. Somewhere the inflammatory aspect of this has to be looked at. What we want you to help us with is understanding why they don't want to know, and where the benefit from that comes? We want to make a better product for better people. Many people want to come to us with genetic testing and say, "See, I'm clean." Now do they have the right to do that? — What's the inflammatory part about this essence of human nature that we think we are evolving here, when, in fact, we're just talking about chromosomes.

DR. KNOPPERS: Right. I think that's the question. And I mentioned some of the characteristics of genetic information that are different, and perceived as being different. People still see themselves as being their genes. Even if the information is probabilistic and predictive, and doesn't really change their immediate lifestyle or their future prospects in any way, they see it in a deterministic, Calvinist sort of predestination sense. How is genetic information understood? It's understood differently from other medical information. They interpret
genetic information as being a handicap, a disability. In a research project at the University of Montreal we’re looking at the social construction of genetic disease. How are diseases described and understood by the producers, the molecular biologists in the labs, the providers, the physicians in the physician-patient relationship or the clinical geneticists, and by the users, the population? We’re looking at the literature, starting with the very scientific long titles when something is found. How that is translated, one level down, in the information provided to physicians in their ordinary physician literature. Slightly less academic and scientific, and slightly more user friendly. But, again, very neutral, very objective, no interpretation as to how their own patients might see or use this information. Go down another level to the newspapers. From what was an extremely difficult incomprehensible title, you get to “Gene for cystic fibrosis found.” Go down one level further, to very popular tabloid: “Cure for cystic fibrosis found.” You get this equation, going from the scientific all the way down to the popular, where the same information is interpreted differently at four different levels. Then you get pictures, again, the type of illustrations from scientific tables all the way down to children that are obviously very handicapped or having their backs and chests pounded every day by their parents. The images that accompany the same kind of literature vary at the four levels. There is no doubt that at the popular level, at the voters’ level, at the consumers, who don’t see themselves right away as being genetically handicapped, there is a great fear of genetic information. Maybe even cancer used to have this stigma, many years ago. We’ve forgotten about the stigma that cancer had. But genetic information still holds that equation between “I’m diseased, I’m handicapped,” instead of saying, “I’m normal, because everybody is genetically at risk and we’re equivalent in our difference.” It’s not seen that way at all yet. You’re in an industry where you have to deal with this “at risk” information, and yet people don’t see it as normal “at risk” information. The immediate question is how to respond in the short term, while the public and medical education catch up with the times in terms of what you offer your consumers who are thinking about it much differently than you are.

DR. RON FELDMAN, William Penn Life Insurance Company of New York: The argument about what is genetic, I think, is a straw man that’s being set up here, because it’s been pointed out clearly that all of our illnesses are genetic. I think the difference should be that we talk here about testing of genes, or testing of DNA, and get rid of this notion that we’re talking about genetic testing. Maybe that simplification will make it easier for people to accept and understand that we’re debating now, not about genetic testing, but we’re debating now about whether or not to use gene analysis or DNA analysis in our underwriting process. That simplification might help diffuse some of this heat about what is genetic.

DR. MICHAEL KABACK: I think the comment and question that you raised are extremely important. I hope everybody in this room understands that identifying the gene does not equal an effective intervention therapy, treatment or cure for the disease which that gene predicts. And therein lies the difficulty. I like to remind my geneticist colleagues about this, about almost every year. The beta globin gene was identified in sequence, I believe, in 1976. That’s the gene where sickle cell anemia is caused. There were newspaper articles, "The genetic defect in sickle cell anemia identified, cure immediate." Geneticists throughout this country and others stood up at meetings of geneticists and talked about gene therapy for sickle cell anemia. We’re nearly 20 years since the gene was isolated, sequenced, the specific nucleotide that was missing identified, and yet there has been no cure or intervention for sickle cell anemia, no genetic cure or even effective therapy. There’s some ameliorative, prophylactic kind of interventions. The issue, that comes back to your question, is all of these wonderful tests that have been alluded to, that are available for genetic defects, do not define interventions. They only define predictions of what’s going to happen to you. How many patients who are at risk for the Huntington’s gene because of family history opted not to be tested? A sizeable number. That seems anti-intellectual. Why, in God’s name, would someone not want to know that their brain and spinal cord were going to deteriorate within the next 10 to 30 years and they would become a basket case? I mean doesn’t everyone want to know that? Well, not everyone does, and I think for understandable reasons. I think the humanity aspect of it would dictate that a lot of people might not want certain information about themselves, particularly if there’s nothing that can be done about it. Some would argue, “Well, they can make better family plans.” That’s true. Or they can decide to take the trip to Tahiti this year, rather than putting it off for five years. Of course, Lord knows, they may not be here five years from now. But there are a lot of people who would, in fact, find it so oppressive to have that information, in a personal sense, that they would prefer not to have it. So here comes an insurance policy that they’re applying for, and the insurance company says, "We want you to have this test." Well, not only do they find out, but now they’ve got brothers and sisters and aunts and uncles and cousins who also, not by choice, suddenly become part of that information stream. And when they apply for their insurance company, if the big brother computer’s got my name in it, then my cousins and my
brother and my sister and so forth are going to come out of that computer as being related to me and therefore, at risk, and therefore should pay higher premium, unless they're tested and prove not to have it. The most important reason for my point of view is that, in fact, we can identify genes that are abnormal, but we can't do a lot about most of them yet. That's what the research of the next 5, 10, 20 years will hopefully give us a handle on. Diabetes is an example. We screen for diabetes now when you do an insurance physical. You take a blood sample; you check for glucose. Or you do a blood pressure. I don't think there's a great stigma in being hypertensive in America, or Western society. Hypertension, in a large part, may be due to genetic factors, but there are interventions available. We can control or manage hypertension much better than we could years ago. So, there is an evolution of information and education that has to occur. But I would agree with the notion that there differences between genetic and (?) issues. And it isn't a we/you guys. It's really I hope that is not the feeling here. Because I bring much (?) not only to share my views but to hear the views that you people are expressing as well. Because we've got to work this out together some how. It's not going to happen one versus the other clearly.

DR. BILLINGS: I wanted to address the question of why individuals don't want to know about their risk information. My work with patients and clients would suggest it's not homogeneous. We're a multi-cultural society and different cultures, different kinds of people, have different reasons for why they don't want to know. But, I feel there are three important reasons. One is simply personal. You might call it a rugged individualism. There are people who just simply don't want to know this kind of stuff, for their own reasons. And, we'll never understand them. The second, an important one, is familial. There are individuals in our culture who believe that hereditary information, genetic information, is damming to the family. It shames their ancestors. It provides guilt that you've passed on certain traits to your children by genetic mechanism. So, some families choose to keep that information secret, for their own reason. But I think the most important one, the one that's most relevant to the discussions here, is what you've got to lose by knowing. If you lose access to healthcare, lose financial security for your family, lose, let's say, the possibility of certain kinds of jobs, you can't get into the military because you have a certain hereditary predisposition to one thing or another that the military has decided is not appropriate for military service, that might be a substantial reason not to want to know whether you have that hereditary predisposition or not. And I would like people to feel safe enough so that they would want to know about their genetic risk. Particularly genetic risk where there's prevention, or where one can modify that risk by behavior. But we don't live in that kind of society, and until we do, there are going to be a substantial number of people who don't want to know. I would be in favor of preserving their right not to know.

We've been talking about genetic disease, and about the concept of genetic disease and how it fits into the insurance business. One good example that's often brought up is breast cancer, and this evolving notion of the genetic nature of breast cancer. Another one is infectious diseases, and I thought I might bring it up. Leprosy is a good example. Leprosy is a classic infectious illness. We know what the mycobacterium which produces leprosy is, yet there are some people who are more susceptible to leprosy, and some people who are less susceptible to leprosy. If you look in the literature of the Human Genome Project, leprosy is one of those disorders which the genome project hopes to elucidate why some groups are at higher risk and why some groups are at lower risk. The wildfire that's sweeping medical research, and which is being fueled by investment in genetic technology, is going to make all sorts of disorders, including infectious illnesses, genetically analyzable conditions. Through DNA analysis you're going to be able to fairly precisely define genetic risk. That's not going to be all the risk from a life insurance point of view or even a health insurance point of view. There will still be non-genetic events. Accidents will still be the most common cause of morbidity and mortality in children. But you will be able to say precisely what the genetic component of health risk and mortality risk will be.

DR. BOB POKORSKI: I have two comments and one question. First, I would ask the members of the group that are not in the insurance industry to understand our reticence to accept a proposal to not underwrite under some certain amount, no matter what amount it may turn out to be. This is a very dramatic departure from the way we do business. It's not like making a book, keeping adjustment, and tomorrow you start taking everyone that applies under $25,000.00 at standard rates. It's a dramatic change in the way we do business. To give you a practical example, most companies that write life insurance in the United States and probably Canada too are small companies. They're not the household names that you think of. They may not see a $100,000.00 policy in a year. Their average policy may be $25,000.00. To ask them to suddenly take all of those people at standard rates probably would put them out of business because they couldn't compete. They have no one to subsidize; that's their entire market. So those small companies would logically say, "We just couldn't live with this kind of a proposal." Secondly, regarding
the idea of subsidization, I don’t think we have to look any farther to see how this would work in the American society, then to look at the catastrophic healthcare bill of a couple of years ago, when we were going to offer our elderly Americans the chance to purchase insurance so that if there’s a catastrophic healthcare problem they wouldn’t be faced with monumental health bills. Wealthy Americans immediately called their Congressman and Senators and said, "We have this coverage already. There’s no way we want to pay extra to subsidize someone else." That’s a very pertinent example of what happens when you ask people in our country to subsidize others in private insurance. It doesn’t work well. Finally, to get to my question, I had read a report about a psychologist in Australia. He was talking about what’s going to evolve in the next century with the use of genetic information, and he was talking about using it to set up separate classes for individuals that were genetically smarter, or perhaps genetically more gifted in music. I would bet in your genetics community there must be a lot of people that think that we are not all created equal. That belief may grow, and there’ll be problems because it will be very apparent that the Bill of Rights really doesn’t apply. We’re not created equal. If you could just comment upon repercussions in that regard?

DR. KNAPPERS: I think Dr. Murray did say this morning that, contrary to all persons being created equal, genetics will show inequality between persons. I think the only equalizing factor in the inequality to be shown by the eventual revelation, if you want to use biblical terms, will be equivalence in difference. The sum total of all the differences between genetic risks of various individuals in a society will be that we will be equivalent in difference. But you’re right. If you accept genetics as being you, you’re limited by it. There are many other theories out there, even by geneticists that it’s not just the gene, and it’s not just the environment, the old nature/nurture stuff. It’s also the interaction in a given culture, and it’s how society receives and perceives and treats not only disease but the potential for disease. Most of it’s predictive, and there’s no treatment, which will influence how the person interacts with the given culture and how difference then becomes the basis for equivalence, though not necessarily equality.

DR. ROTHSTEIN: I’d just like to respond to that briefly. I think Dr. Pokorski puts his finger on a very interesting and important point that we should keep in mind. Although we’ve been talking about the use of genetic information in insurance, genetic information has the potential to be used across society. To a large extent what we really need to be doing is think about how we want to use genetic information more broadly. Insurance is only one part of that problem. Just take his example, the use of genetic information by schools. I think that it’s not unlikely that in the next few years we will have identified the genetic factors in various learning disorders. I am troubled by the prospect of schools doing genetic testing on second graders and putting them in various tracks based on whether they think they’re going to develop a learning disorder, or maybe even their potential to understand information. We also can’t think about the potential discrimination in insurance in a vacuum. We’ve got the potential for discrimination in education, in employment, in financial interests and other opportunities. What we need to be doing as a society is think about what does genetic information mean? Why should or shouldn’t this information be available? And what are the dangers in using genetic information to classify and identify people?

DR. KITA: Thank you. Each of us is the cumulative expression of multiple phenotypes. Partly the genetic endowment we have at birth, and partly the cumulative assault on genome through aging and environmental influences, as we’ve learned over the last couple of days. Those phenotypes have been brought to insurers for different types of insurance for many years. Genetic testing is not new, it’s just the level of scrutiny we have these days, by way of DNA tests. Now, we’re in the midst of a transition, on the cusp of the change, in some of the initiatives in the direction of education and some in the direction of regulation. Some of the motivation comes from fear, and some from anger, and some from appreciation of moral imperatives, and some from risk, and some from combinations of all of the above. Out of the various dialogues this morning, we’ve explored those points a little more deeply.