February 9, 1993

PANEL ON ETHICAL ISSUES IN GENETIC TESTING

Thomas Murray, PhD
Ray Moseley, PhD

DR. MICHAEL KITA, UNUM Mutual: Good morning. Yesterday morning we discussed some of the medical and scientific issues around genetic testing, and this morning we will have two panels on ethical issues and on legal issues around genetic testing. I’ll be introducing each speaker in succession. They will have some prepared remarks and then we will proceed to a panel discussion and some interactive lines of questioning.

Our first speaker this morning is Thomas Murray. Professor Murray is a Bioethicist and Director of the Center for Biomedical Ethics at Case Western Reserve Medical School. He chairs the Task Force on Genetic Testing in Insurance, whose report should be forthcoming in May. His varied interests include consulting to the U.S. Olympic Committee on substance abuse matters. He’s a member of the Hastings Center. He has four children in his F-1 generation, according to the results of HLA matching. Would you please join me in welcoming to our panel, the ethical Dr. Thomas Murray.

DR. MURRAY: Let me caution you about a very big mistake you might make which is to confuse being an ethicist with being ethical. The two don’t necessarily run together at all. Thanks very much. I’m pleased to be meeting with you. We’ll tell you a little bit about the thinking we have done on the moral mission of insurance. I think it is the way to think about insurance if the question that’s being posed is, “Should we be doing anything to reshape the way insurance is provided for people?” The central theme that I want to stress is that any effort at changing either healthcare insurance or other forms of insurance must be mindful of the point of having such a service for people. Let me start with a famous text, which, in its original, was, “All men are created equal.” I presume you remember reading this early in your civics classes. Maybe we should say, “All persons are created equal.” When the founding fathers wrote that line they surely had as great an evidence of human diversity as we have before us in this very room. Some of us are tall, some of us are short, some of us have more hair than others, I note to my own chagrin. Some of us are morning people, some of us are night people. There are many forms of human difference. So when they wrote that, surely, they didn’t mean that all people were created identical. They were created equal, and equality can only have meant to them something political, moral, and legal. That is, before the state and before the laws, all people must be regarded as equal.

The challenge we face in this last part of the twentieth century is to figure out how to maintain our commitment to moral, legal, and political equality in the face of a coming flood of evidence about genetic inequalities. I find it useful to think of genetics as a science of inequality. Human genetics shows us the many ways in which people are different from one another.

Genetics is the science of inequality. The question now is what do we do about inequality, particularly genetic inequality, the kinds of inequality that may be increasingly shown to us by increasingly available and affordable forms of tests? We must look at some old ideas and I’m going to start with a very old one, about 2500 years old. Do you remember Aristotle, the philosopher back in Athens? Aristotle wrote, "Justice consists in treating like cases alike and different cases differently." Think about that for a minute. It’s profound isn’t it? "Like cases alike, different cases differently." If you’ve got two kids and one cupcake what do you do? You give one of them the knife and the other the first choice: that’s called procedural justice. Treating like cases alike and different cases differently is actually a perfectly valid description of distributive justice, which is the problem before us. But the problem with the description is that it’s empty. It’s a purely formal description. What makes cases alike, what makes cases different? That’s the problem we face in all substantive problems of justice, and it’s the problem we face in figuring out what to do about insurance.

I’m going to solicit your help here in figuring out what the appropriate principles are that govern justice in these different spheres. I live in Cleveland, and have for nearly six years. It turns out to be a very nice community to live in. We have a football team. You may have heard of this football team called the Browns, which I gather used to have occasional successes many, many decades, but it has been disappointing lately. The other disadvantage to living in Cleveland is that the winters, as you may have heard, can be a bit gray and cold. I had never seen a community that lived and died as much with any particular sports team as Cleveland does with its Browns. They have Browns’ days at the schools, and all the kids come dressed in sweatshirts. Suppose for a
minute that you are now the committee that will award the Super Bowl Trophy, and I'm here to explain to you why the Browns ought to receive the Super Bowl Trophy. Let me try to persuade you.

I've just described Cleveland. I've just told you how much this city relies on its football team for its own sense of well-being and pleasure in life. We need the Super Bowl Trophy more than anybody else. I mean what does Miami care about this? They've got sunshine. What does any team in Southern California care? Why do they need it? In January it's lovely out there. We deserve it. We need it more than anybody else. Now will you give us the Super Bowl Trophy for that reason? Anybody willing to give it to us? You're a tough, tough jury.

Alright, let me try another approach. I will give you more money than anybody else if you will give us the Super Bowl Trophy. I will pay more than any other owner will pay for the Super Bowl Trophy. Will you give me the trophy?

I see a little more interest out there. But even if you did, you'd know that something was wrong there, wouldn't you? Somehow the point of giving the Super Bowl Championship has been missed if it goes to the team who pays the judges the most. That can't be it. What will it take to get a Super Bowl Trophy from you? What do I have to do?

Win? Oh, God, I was afraid you'd say that! All right, that's the moral principle of deserving. We distribute a particular social good to the entity which deserves it. The principle of deserving works in many contexts. Think about who gets the Pulitzer Prize. The person who needs it the most, the person who pays the biggest bribes, or the person who writes the best novel or the best poem for the year? Who should get this position at the company? The person who is related to the owner, the person who pays the biggest bribes, the person whose therapist says they need it the most, or the person who really is the best qualified for it? We think we know what the right principle is there: it's qualification, a form of deserving.

Let's try another kind of good. A lot of males, apparently when they pass their 40th or 45th birthdays, as I have, develop an incredible craving for a red Corvette. It happened to a friend of mine who runs a school system in New York. He's always craved a red Corvette and keeps ending up with things like mini vans for his family. So I come to you, the owners of a Corvette dealership, and I say, "See that red Corvette over there. I need that more than anybody else." What are you going to say? Are you going to give me the keys? What if I've had a rough time with my kids? Do I deserve it more than anybody else? what are you going to say? Tough.

What will it take to get that Corvette out of you? Money. It's the market. The moral principle is free exchange. What makes that transaction just, morally defensible, is that you're willing to give it to me if I give you the right amount of money. Fair enough. Free exchange is a second kind of moral principle. We've talked about deserving and the market or free exchange.

There's a third distribution principle. Suppose you were in a country in sub-Saharan Africa in time of famine, and you happened to have a fairly substantial grain stock on hand at your farm, and your neighbors were starving. You really had plenty, more than you would need until the weather turns and a new crop would be harvested in a few months. You had plenty more than you and family are going to need. And your neighbors come to you and they say, "Will you please give us some of your grain so that we can live?" On what principle should you give it to them? You say, okay, give me money, and they don't have any money. They haven't done anything to "deserve it," short of being human and being hungry. On what principle should we divide that grain up? The answer most of us would give would be compassion for human need. So as philosophers think about it there are typically three kinds of moral principles in comparative justice: Deserving, certain things go to those who deserve them, who earn them in some way; free exchange, where two parties choose to exchange particular goods; and need.

Consider another kind of social good and see where it fits in these three. Say I want to get a VCR. One principle would be deserving. I would say to the store owner that I can actually operate the timed record function of the VCR. Since this makes me an extraordinary person, I deserve one more than the other people. I guess they're getting easier to use, but in our model you still have to press about 43 different buttons to get anything to record. What I do is say, "Peter, would you please arrange to record this for me later tonight?" It's my son that's figured it out. That's not going to persuade anybody. Deserving doesn't seem to be the principle. What if I say, "I really need this VCR?" Now I can imagine an adolescent saying, "I really need that VCR," but it's not really persuasive. So, again, it looks like market or free exchange is the appropriate principle. Most insurance products, the products with which you deal, are governed by free exchange. I presume you all work for mutual companies or some other form of private insurers. You will provide the product, the insurance cover-
age, in exchange for a particular price. And for many social goods, like VCRs or Corvettes, that seems an utterly appropriate and just way of distributing that particular social good. But what about healthcare?

Aristotle said, "Treat like cases alike and different cases differently." What kinds of likenesses and differences are appropriate for distributing healthcare goods? Not a simple or easy question to answer. One approach that the insurance industry has taken has been to stress, through some spokespeople, a particular kind of justice, called actuarial fairness. It's laid out very well in an article in the *Harvard Law Review* by Karen Clifford and Russell Leculono. It's a very thoughtful perspective on justice in insurance. I call it the "Lloyds of London" model. Let me give you an example.

Suppose I'm an oil tanker owner, and Ray Moseley, who will speak to you in a little while, is also an oil tanker owner. During the Gulf War I choose to send some of my tankers through the Arabian Gulf. I can get a great price from my clients if I'm willing to do that. Ray, on the other hand, is shipping oil up from South America through no war zones. You're now Lloyds of London, and I say, "I want to buy insurance against hazard from you." And I say, "I want to pay the same price as Ray Moseley." Is that fair? Do you think that's fair? Is anybody here willing to sell me insurance at the same price as they would sell it to Ray? If not, why not? What's the difference between what I'm proposing to do and what Ray's doing?

Risk. The risk of destruction of my ships and cargo. So I should pay more. That seems fair. It's hard for me to imagine anyone who would think that charging different rates wouldn't be fair in the context of shipping oil from one place to another. That's actuarial fairness. I want to make the premium parallel the risk. That's the concept I assume you're all familiar with. It seems very appropriate in commercial insurance. The question I would raise is this: is it equally appropriate for healthcare coverage? It seems less certain that it's appropriate there.

Some of the differences between this situation of the two oil tankers and healthcare coverage are, for one thing, the two ships are exposed to vastly different risks and it seems only fair to charge them accordingly. Secondly, those risks were assumed voluntarily by the owners. I didn't have to run my tankers through the Persian Gulf. I chose to. And, thirdly, both Ray's goal and my goal in this case is profit, making more money, and it seems reasonable to ask each of us to bear the expense of a risk that we've assumed voluntarily in order to make money. The individual need for health-care is different from the sending of oil tankers, from the Lloyds of London model. Most ill health is not voluntarily chosen. Despite the great emphasis on prevention, on health promotion, all your doctors' injunctions to eat right, lose weight, don't have too many fats, exercise, etc.; we know that in the end we may become ill quite irrespective of our health-seeking behaviors. So it's not voluntary in the same sense. Also, our goal in trying to maintain our health is not just to make more money, but in some ways health, reasonably good health, is the precondition for the pursuit of all the other things that are good in life. Health has a different status and people regard healthcare as a different sort of good from, say, oil shipping. It's not simply a consumer good. It's not something that ought to be distributed simply according to deserving. It's not just that good people get healthcare. We don't allow the distribution of healthcare to be determined purely by the marketplace. Instead, we treat healthcare as if it were a response to a need, and that ought to be the appropriate principle for distribution.

If you still have doubts about that, consider a case like this. We don't have a market in transplantable organs at this point in the U.S. We forbid the interstate transport of organs for sale by federal law. One fellow a few years ago tried to set up a market, an import business in transplantable organs, and he went so far as to get an import license. But he was rather quickly put out of business when people got wind of it. I'm not sure he ever brought any organs in. We do know that markets in organs flourish in some countries. There is, for instance, a documentable market in India for kidneys where the very rich buy from the very poor.

Let's imagine for a minute that you're now part of an organ procurement agency and somebody comes in and offers you three times as much money for that organ as you would normally get. You ask what they intend to do with it, and they tell you, "Fresh human livers are the best rose fertilizer imaginable, and that's how I intend to use it." Now would you sell it? Would it be morally right to sell it to that person as opposed to giving it to somebody for transplantation, or does that trouble you a little bit somehow? It should trouble you, because, clearly, the market isn't the only principle involved here. The person who needs that liver is the one who ought to get it. The person in whom the liver's most likely to work is the one who should get it. But that's consistent with distributing according to need. Efficiency and need are mutually compatible in many circumstances. They are different sorts of values, but they can be balanced. Healthcare seems to be a response in most of our hearts and minds to need.
The social purpose of healthcare coverage would seem to be to provide, in a reasonably efficient and fair manner, healthcare to those who need it. You have probably heard about the point of absolute nausea all the complaints about the healthcare system in the United States. You've heard about the 30-some million who have no healthcare coverage, etc. In fact, the situation may be even a little worse than that. It is estimated that roughly 63 million people were without health insurance for at least a part of the year. Over the course of a year as much as a quarter of the American population is without health insurance. Put another way, roughly one out of four Americans will go through at least some period without any healthcare coverage, and that means not just private insurance, that means public insurance as well.

In a different survey, 82 percent of the American public identified health care as a major concern. When asked to rank various social issues in order of importance, for the first time in history, healthcare was the number two issue for people. It certainly seems to be the case that American people regard distribution by need as the right way to think about healthcare: not deserving, not free exchange of market, but need. So the question is how to provide healthcare to people according to need, yet consistent with other values like efficiency and with the American preference for the efficiencies fostered by markets. We have a task force set up by the Human Genome Project, called the Task Force on Genetic Information and Insurance. Our original mandate was to look at healthcare coverage, life insurance, and disability income insurance. Now, while I cannot tell you in detail the task force’s findings because we are still in progress, I can tell you a couple of things. We focused on healthcare coverage and have not given extensive treatment to either life insurance or disability income insurance. They are different enough that we didn’t feel it was fair to try to lump them together in a single report. It seemed that healthcare coverage was the issue that concerned people most, and in which genetic testing could have some of the most fearful consequences, at least in the convictions of many people.

We’ve mentioned some of the ways in which healthcare seems to differ from life and disability income insurance. For one thing people seek healthcare. It's not usually a one-time catastrophic event. People want healthcare coverage, not just to guard against the sinking of the entire vessel, but as a kind of continuing maintenance program. It also seems to be the case that the potential impact of adverse selection on life and disability income insurance is much more immediate and graver than it would be in healthcare coverage. It's a matter of degree, but it seemed to be a large enough difference in degree as to almost amount to a difference in kind. For those reasons, we will be focusing our report on healthcare coverage. Our report will be issued in the middle of May.

The task force is an interdisciplinary, interprofessional, interinstitutional group that includes representatives from the HIAA and the ACLI, as well as from Blue Cross/Blue Shield, as well as various healthcare consumers, including people with family members or themselves at risk for suffering from genetic disorders. It has included, as a consultant, your own Sandy Louden, who’s been a very helpful and constructive voice. Ray Moseley is a member. Paul Billings, who has established a reputation as the loudest and most persistent critic of the insurance industry, is a member. We felt it important to get the strong opposing views all together. The good news is that it looks like we have hope of coming up with a solid, substantive report. That may help carve some reasonable path down the middle of the problems we’ve discovered.

DR. KITA: Our second panelist for ethical issues in genetic testing is Ray Moseley. Since receiving his Doctorate in Bioethics from the Kennedy Institute at Georgetown, he has conducted extensive research on various ethical issues of our time, from advance directives in life support withdrawal to animal research issues. As a professor of family medicine and community health, he teaches bioethics at the University of Florida Medical School and directs their Medical Humanities Program. He is also a Director of NIH’s initiative looking at the implications of genetic testing technology for health and life insurance. Please welcome the ethical Ray Moseley, PhD.

DR. MOSELEY: Thank you. I am pleased to speak with this group today. Presently, I am director of an interdisciplinary research group at the University of Florida. We are in the middle of a three-year project that is aiming to generate some policy recommendations, and, hopefully, some model legislation, if needed. The following will illustrate some of the problems that have arisen for our research group, and point out some of the ethical issues that the health insurance industry needs to resolve.

The first problem for our research group was communication. Since our group is interdisciplinary - it includes insurers, scientists, geneticists, policy-makers, members of public advocacy groups, members of the general public, philosophers, ethicists, and some genetic counselors - we quickly discovered that we could not effectively talk to each other. The central reason for this communication problem was that each member...
I think part of the controversy over rights to healthcare arises from the public's changing views of medical availability and effectiveness. A hundred years ago the general population certainly did not consider healthcare delivery a right. Healthcare services were absent in most places people lived; one could not easily get to a physician, nor to a hospital. Moreover, healthcare services were not terribly effective. Today, physicians, hospitals, and their medical technology are not only effective in preventing, managing, and curing illnesses, but they are accessible (e.g., available) to most Americans. Given their effectiveness and availability, the question becomes, "Is accessing them a matter of right, of desert, or of free market exchange?"

Today Social Security benefits are seen as a right and not just as a safety net, or additional protection. It is considered a right (an entitlement) and we will fight for it. Healthcare benefits are viewed similarly. At our hospital, we take all the individuals that are rejected by emergency rooms in the other hospitals in our community. Individuals who come to our hospital feel like they have a right to see a physician, a right to healthcare and can be very dissatisfied if they do not get what they think they are entitled to.

I think that the view that healthcare benefits are a right comes from many different sources. It comes from the insurance industry itself. Recently, while watching insurance commercials on television, I have noticed that these commercials portray insurance, not as a service that it would be nice to purchase, but as a service you must have — a necessary service. For example, one life insurance commercial shows a group of children and then asks, "What would happen to these children if you die and do not buy insurance?" And in healthcare commercials the question is, "What would happen if you do not have healthcare insurance?" The message to the public is that you must have this insurance, and items one must have — necessities — are rights. So, in essence, these commercials tell the public that having healthcare insurance is a right. Admittedly, different healthcare insurance options exist, but the message is that some kind of healthcare insurance is essential; it is an absolute necessity. Since healthcare insurance is discussed in terms of absolute necessity, like other items of necessity, society begins to ask, "Who is going to provide that necessity?" That is how healthcare insurance becomes translated in terms of a right. So I think that insurance commercials have played a role in creating the image of healthcare as a right.

Whether healthcare is a right, and at what level, is an ethical question, of course, and a debatable one. This is a terribly complex issue. But, since there is a strong perception by the public that healthcare is a right, our research group must take that into consideration. Future proposals for universal access will not only strengthen the arguments for it being a moral right, but it will eventually make some basic level of healthcare a legal right.

I want to return to the issue of insurance and its relationship to genetic testing. As I mentioned above, "insurance" is a difficult term to discuss among individuals from different professional backgrounds. For example, if one talks to insurers, by "insurance" they do not mean "self-insured employee plans" or "Medicare and Medicaid." If one talks to individuals outside the insurance industry, by "insurance" they do not just mean "private commercial insurance" rather they include Medicare, etc. So when we first got together in our interdisciplinary groups, we spent a long time just agreeing on what we meant by "insurance," the very basic terms. Another term that has the same sort of problem is "discrimination." For insurers that term does not necessarily have a negative connotation — if you discriminate between risks. For the general public, however, "discrimination" is always viewed negatively. For philosophers the context will determine whether "discrimination" has a negative connotation. Finally, a scientist may use "dis-
crimination" in another sense altogether. So using certain terms in our research group generated communication problems; these kinds of problems must be resolved.

But why is insurance an issue? The reason centers on the prospect that many new genetic testing technologies are coming on-line. Soon, much more genetic information may be available to insurers, to physicians, to the general public, and this is causing some concern. This new information could be misused. It brings up the specter of eugenics; it raises many privacy issues as well as issues regarding the essence of being human. But when we start asking the precise questions needed to formulate public policy, e.g., "What counts as genetic information? What counts as genetic diseases?" The notion that "genetic information" somehow needs special protection is a problem, because we know, for example, that genetic information has been used for years by insurers for determining risk, e.g., a family history is "genetic information." So when you start thinking about formulating some public policy that uses terms like "genetic information," you get into all sorts of quandaries about where to draw the line. It is difficult to know what kind of "genetic information" should be used. The same problems arise for "genetic diseases." What counts as a "genetic disease"? And how much of the disease has to be genetic before it is a "genetic disease"? Using these terms in public policy language raises controversial ethical and legal interpretation problems.

At any rate, it is difficult to know what tests will be developed, when they will be ready for use, how good they will be, and how much they will cost. In our research we have heard a number of insurers say, "We don't want to use these tests; they're probably going to be too expensive to use, and the only way we would use them is in very isolated circumstances." On the other hand, other people say that these tests are going to be inexpensive in a few years; there is going to be a battery of tests you will be able to run, and it will be the family physician, the primary care physician, doing these tests routinely. So this information might be readily available soon. This uncertainty with regard to whether this information will be readily available and readily used in the near future creates difficulties for deciding what kind of legislation is necessary, and for determining how serious a problem this whole issue might be. If it turns out that the genetic tests are going to come on-line very slowly, that they are going to be very expensive, and that it is going to take years to assess the clinical validity and predictive value of that information, then genetic testing is not a major issue right now. We can debate the issues over a longer period of time. On the other hand, if the range of tests and identification of diseases continues to increase at the same rate it has been increasing over the last few years, then we may have some real problems to think about in the next one, two, or three years. The seriousness of the issue depends on our assessment of genetic technology companies. There is a huge potential market out there. That is one reason those companies are doing so well in the stock market. They are in the process of developing tests, and we know from the pharmaceutical industry, once those tests are ready, they will try to sell them. In particular, they will try to sell them to the insurance industry and the medical industry and they will begin to use those tests extensively. We have no idea what kind of advertisement might ask, "Have you got your colon cancer tests, your breast cancer tests?" These advertisements might create a demand for a whole package of tests. If such tests become reality, then problems like adverse selection may become serious.

The difficulties in deciding on the appropriate legislation for genetic testing is compounded by the fact that we ave no idea what kind of healthcare system we might have next year — predictions depend on who you talk to and how optimistic he or she is. Of course, we have been hearing for the last 25 years that next year we are going to have a new healthcare system. I have reasons to hope that we might solve some of the problems in the healthcare system in the next few years, although I am somewhat of a cynic on that issue. Nevertheless, it is very difficult to predict what kind of policies we are going to need in this area if we have no idea exactly what form the healthcare system might take: there may be radical changes, or there may be a long phase-in period. It is possible that each state will enact different kinds of reform. Thus not knowing what kind of policies that are needed for genetic testing. To deal with this uncertainty, our research group is considering the kinds of policies that would be needed if no changes were made, if a few changes were made, or if a great deal of change was made. By anticipating a range of options, we hope to be ready no matter what changes are made.
Finally, we need to consider who needs to be educated about these genetic testing issues. That is quite a difficult problem, in itself. You do not get good policy, and it does not get followed, unless you build some understanding about the need for it. Certainly, the public has to be educated. The public has quite a way to go to understand the implications of genetic screening technologies. Eventually, we will undoubtedly witness a backlash as the frequency of genetic tests increases. Some individuals will claim that genetic testing is immoral since such tests will inevitably lead to more abortions. Or, some might claim that the tests reveal information we were not intended to know. On the other hand, others will argue that we should use the genetic test technologies for routine screening — mandatory screening of the population — because such screening is good public health practice. So we need to educate the public about the potential benefits and risks of these new technologies.

We also need to educate the insurance industry. We have discovered in our conversations with medical directors at insurance companies that there is a wide range of knowledge and expertise about genetic technologies, genetic tests and the role of genetic testing — from the extremely naive to the extremely sophisticated. That is one place where an educational program is needed.

Beside the public and the insurance industry, we need to educate our elected officials. We have been cautioned that we should write our policies ranging from eighth grade level of a sophomore college level of effectively communicate policy goals. This need to educate our public officials is especially a concern when we start discussing ethical and social implications of genetic testing, and the kinds of policies that might need to be developed. Our research group is at a draft stage now, and our report is upwards of 50 pages! I cannot even get the table of contents on one page! I have a great deal of understandable about the public policy necessary for genetic testing. Do patients have a right to informed consent with regard to being tested? Moreover, can a patient really make an informed and voluntary, uncoerced consent regarding such a test? Or is healthcare or insurance perceived as such a need that they will say anything in order to get it? In order to have voluntary informed consent, the patient has to be able to freely say, "No," and it is very difficult to do that when he or she may be denied health insurance coverage.

A number of privacy and confidentiality issues arise. One of the major concerns is that genetic testing will reveal very private information about the essence of who we are. We do not like people to know how much money we make, our intimate sex lives, what we do in our living rooms or in our kitchen. Will we want people to have access to our very essence? At any rate, we need to think seriously about those privacy and confidentiality issues, as well as the many other issues I have tried to bring to your attention today. Thank you.

DR. JEFF SULLIVAN, IDS Life Insurance Company: I would encourage that we set health insurance aside for the rest of the morning. It is an enormous and complicated topic that I suspect most of the people in this room will pass off to Hillary and others, and focus on life insurance. And I would like to focus the discussion and sort of set it up by making a provocative statement, that individually underwritten life insurance is the red Corvette.

DR. MURRAY: You’re probably right about that. If I may, I was going to make a couple of comments before the first question was asked. Let me make them quickly and then try to respond to that. The first has to with your image of ethicists. God knows what your image of ethicists. Whatever it was, it’s probably less favorable now that Ray and I have spoken. Nonetheless, if you think of our relationship with the biomedical sciences like genetics, I think for most of the history of bioethics, which extends now about 25 years, we have been roughly in the position of the fellow with the shovel who follows the elephant down Main Street in the parade. We try to clean up the big messes once they appear. This ethical, legal, and social issues program that’s part of the genome project, is, as far as I know, the first systematic effort to at least allow us to walk alongside the elephant.

The second thing is, Ray made a comment about state legislators and their sophistication. That was brought home to me most graphically by an individual who works closely with state legislators, who in trying to emphasize to us how to think about making an impact on legislators, told us what he claims is a true story about a legislator in Texas. The debate was over whether English should be declared the official language of Texas, which could also be read as whether Spanish should be downgraded. And the legislator’s argument was, "If English was good enough for the Lord Jesus Christ, it's good enough for us."
To get serious about whether individually underwritten life insurance is the red Corvette, in some ways it clearly is, and in other ways it clearly is not. What's the point of life insurance? Why do people buy life insurance? The point, I presume, is to provide financially for those who are dependent on that individual. That's why I buy life insurance. I buy for my kids and my spouse. It's not like the lottery. We all hope to lose, at least for a long time. We buy it to provide so that our family, those who are dependent on us, don't fall into dire poverty; so that the expectations and hopes we've had for the people we love can be realized. That's the point of life insurance, I think. To the extent that our current mix of policies, which include private life insurance, individually negotiated, various kinds of group policies through employers, and the rest of the social welfare system, social security or whatever one can fall back on can meet that need, then it seems quite morally acceptable. To the extent that it fails to meet the need, we have a problem. I can't speak about the task force's conclusions here. One proposal that was floated was that there should be a modest-to-low level of life insurance that should be made available to everybody to buy without having to go through any genetic testing at that modest or low level. I don't know what it would be: $100,000 or $50,000, perhaps. That's been the kind of proposal that's been floated, and you see its aim is not to bankrupt companies. It's not to allow people to buy 50 such policies. Presumably we would try to eliminate that route. The idea is to allow people to make some provision for the welfare of those who depend on them even if they, themselves, are at particular risk.

DR. BOB GLEESON, Northwestern Mutual Life Insurance Company: We have that. It's what's called social security.

DR. MURRAY: Yes, but if I croaked today how much would my family get in social security? I don't know, but I presume not much.

DR. PAUL MAHONEY, Prudential Life Insurance Company: I wanted to add to Dr. Sullivan's question about the red Corvette and, I guess, whether you get it with wheels or not, or you get it with automatic or not, and it relates to your question, or the outline in your handout: actuarial fairness versus moral fairness. Are you implying they're mutually exclusive, or are we deciding whether they are the same, or is there some difference that you're trying to suggest?

DR. MURRAY: They're two different concepts. Actuarial fairness is, I think, a good description of justice in certain kinds of settings. In the case of oil tankers, it seems to me actuarial fairness is a very good description of what true justice does in those circumstances. We ought to charge people according to risk of losing their cargo. With healthcare coverage, I think the situation is different. People regard health care as something that should be distributed according to need, not according to who can pay for it. Now that doesn't mean there's no role for a private insurance market in healthcare. What it means, again, is that the system in total must insure that those people who genuinely need healthcare get it without it being at a cost that is prohibitive to them. To the extent that private insurance, in whatever form it may take in the future, is a component of that overall system, that's fine. I don't just favor a move to a kind of entirely government-run insurance system. I'm as worried about the inefficiencies of mass bureaucracies as any of you. To the extent that we can put into practice competitive principles that encourage efficiency, that encourage health promotion behaviors and responsible use of healthcare by individuals, I'm entirely in favor of that. But a system that leaves some 60 million people out of it for a significant part of each year, is not a good system.

DR. BOB POKORSKI, North American Reassurance Company: I have a question for either of the two panelists. I might add that Tom and I have been on the same panel before, and usually I'm speaking to a group of people very friendly to him. So, Tom, it's very, very nice to have you up in front for a change talking to us. I often make the point that we are criticized because we do underwriting and we look at criteria that are beyond an individual's control when we work in life insurance. I'd like you to confine your remarks to life, please, and I'd like to give some examples and would ask you to respond to the equality or inequality of underwriting these individuals the same. I have four cases here. First, you have two epileptics, and one was born with a hereditary disorder, and one had a hypoxic episode caused by a drug overdose, lost consciousness and became epileptic after that, and they're both heading towards the same early mortality. They both have epilepsy that's not well controlled.

Second, you have two quadriplegics. One is because of a meningomyelocele and one individual was driving drunk and ran his car into a tree.

Third, you have a familial Parkinson's individual applying for life insurance, and you have a prize fighter that becomes Parkinsonian because he was hit in the head a few too many times, and they're both heading for the same extra early mortality.

Last, you have two people that have a likelihood of getting lung cancer. One because it's genetic, and one
because because of smoking. I would like you to address why we should treat them differently when they’re going to the same early mortality.

DR. MURRAY: Ray’s the one who actually owns a sports car, so I’m going to let him answer this question.

DR. MOSELEY: I’m in a great deal of sympathy with that, and I don’t think I can completely disagree by any means. In fact, I’ve argued that we ought to think seriously about looking at people who are responsible for their illnesses and the kinds of treatment that they get and make some distinctions there. But the problem with that kind of system lies in making clear distinctions between when one is responsible and when one is not responsible for their current situation. It turns out that that’s a very difficult thing to do. You take someone that drives a lot versus someone that drives just a little bit. Now the person that drives a lot is at a higher risk of all sorts of things. You say, well, that person that drives a lot, but drives very slowly, very safely, and the person that doesn’t drive very much at all but drives very fast and doesn’t wear a seat belt, or they may or may not both have air bags in their cars. They may or may not have the same drivers’ training, and all those facts bear on the actual risk. The same goes with any of your examples. For the drunk person, it depends on what state you’re in, what levels count as being drunk or impaired. We can think of certain circumstances where if you live out in the middle of a country and you’re driving down a dirt road a half block to your house, and you may be relatively impaired, but if the worst thing that happens is you run off the road into a cornfield, and that’s the only place you drive, especially if it’s the only place you drive impaired, then the risks there are different. So I guess the difficulty I have is drawing the line there and using those as the appropriate discriminators. I think it becomes difficult to actually do that in practice. I can think of some cases where it is relatively clear, and one is responsibility.

Dr. MURRAY: What seems to me to be an undeniable truth is that what we decide to use or not use in actuarial underwriting is not determined by some irrevocable natural law. In the United States the life tables for people of different ethnic backgrounds are different. Yet, as far as I know, life insurers do not use race in underwriting. It’s against the law. That’s a matter of social policy. Do you think it’s a bad law that forbids you from using race, or do you think that was basically a good idea to forbid the use of race? It’s not actuarially "sound." We can make social policy choices for reasons other than just actuarial fairness or soundness. Our insurance system has, again, a social purpose. You are, in fact, a business and there’s nothing wrong with that. The rules under which your business serves are determined by public policy and by general decency, and you serve a social purpose. The point is to keep that social purpose in mind, and when actuarial factors push you in a way that is contrary to the social purposes of life insurance, then it makes sense to have a public policy that doesn’t permit it. Now, in your cases, Bob, as long as we think life expectancies of people with Parkinson’s, or quadriplegia, or lung cancer, or epilepsy are different, I don’t see any good reason for distinguishing between the cases that were genetic and congenital and the cases that were by accident of birth, or by accident or choice of lifestyle after birth. So I couldn’t give you a principle that would say that we should treat the two lung cancer patients or the two Parkinson’s cases differently for life insurance. Really, we ought to treat them the same, I think.

DR. KITA: We have four more questions. We’ll try to get them in before the break.

DR. WARREN KLEINSASER, Osborn Laboratories: I heard Tom Murray say that he doesn’t necessarily support a mandatory healthcare system for all. I think I heard that.

DR. MURRAY: No, but go ahead and ask your question.

DR. KLEINSASER: Well, if that’s the case, and if you’re still going to base accessibility on the basis of need, what’s to prevent people from waiting until a catastrophe occurs and they’re in the hospital and then they can get their insurance. This seems to me to be an unethical burden on those who have been paying and have been prudent enough to have had their insurance all along.

DR. MURRAY: I’m glad you asked that question. I, obviously, left something ambiguous out there. The answer is I do support a mandatory program. I don’t just want a large, sort of single, government bureaucracy running the program. I do favor something like a managed competition program with mandatory participation by all with no underwriting by the providers and financiers, but everyone must participate. People couldn’t hold out until they were sick and then decided to play. Does that answer your question clearly?

DR. PHILLIP REILLY, Shriver Center: I’d like to make a comment about red Corvettes, and then I would like to respond to Bob Pokorski with a comment. I guess most people in this room do not own red Corvettes, but virtually everybody has life insurance. It seems to me that the analogy of life insurance to a red Corvette is strained. I see why it was offered and the way it was offered, but it seems to me one can make an equal
argument that from the point of view of someone like myself who has four young children, when I spend that money on those premiums, it's more in the nature of an equivalent to an HMO or something like that. I am buying prevention or protection for my family. It is not a luxury, in that if I died today my family's lifestyle would fall apart virtually overnight if I didn't have life insurance. So I think the analogy is oversimplified.

I'll take the option of responding to Bob Pokorski now. I think that we give away everything to the debate if we give you your assumption, which is that in each case the two people have an equal life expectancy. I submit that we don't necessarily know that about a lot of genetically predisposed conditions. If you do know it, it's fine. Does the industry have the actuarial data to say flatly that these people belong in the same risk group?

DR. A. C. FAVORS, General American Life Insurance Company: I'd like to ask the panelists to respond. Two things: One, it seems to me that life insurance is not just protection, it's an investment. Many life insurance products have it built into them to make money on the product: the universal policies, whole life, variable life — those policies are meant to make money. Secondly, even though there's an actuarial basis for the mortality for certain diseases, underwriting is not really a hard science. Many insurers really stray from those mortality figures in the name of competition, in the name of business. There's also nothing for what I call comparative underwriting. If you take two diseases that may be rated equally, I wonder how they got that way when their mortalities are not really equal. So I'd like a response from the panelists, please.

DR. MOSELEY: I don't know how to respond, except I guess I agree with you. Can you add anything else?

DR. MURRAY: Your point about life insurance often being actually an investment vehicle for people is certainly pertinent, since many of your products are of that sort. It's hard for me to think of any good moral argument why everybody has a right to sound investments. I mean, that's not the way it works, it seems to me.

To clarify, I don't really think some decent minimum of social provision for one's survivors is like a red Corvette. I tried to make the opposite claim. It's a need very similar to the sort of needs served by healthcare. So we agree there. I don't think that we all have an inalienable right to a million dollar life insurance policy irrespective of our expected mortality. But to be able to insure that our family is decently provided for should we be unable to do it for them, that seems to me something all of us would deeply wish. What we need is a system, of which private life insurance is a part, that provides that. To the extent that the system leaves some people out in the cold because of genetic or non-genetic causes, that they can't get life insurance or disability income insurance, and to the extent that the remaining safety net is really inadequate to provide for decent life, then we have a problem, and we're all a part of the problem.

DR. KITA: One observation from Sandy, and then one last question, and I think we'll have to save the case of the red Corvette for next to the coffee urns. Sandy?

DR. LOWDEN: The problem of making public policy in a vacuum is a really terrifying one for me. I'm very concerned about legislation that's being written today prohibiting things, when we don't even know what those things are. I wonder if you'd comment on that, because you are suggesting that policies should be established.

DR. MOSELEY: I'm surely concerned, Sandy. The usual response I give to a legislator who calls wanting to draft some policy, or a staff person who wants to draft some policy, is that it's too soon to be doing this, especially the kind of policy where they're anticipating naming specific diseases. I make a real effort to talk them out of that, or to at least say, "Listen, we're in the process of studying this issue. Why don't you just hold off for a little while until we are better able to look ahead and see exactly where we're going?" I wouldn't agree that we can't have any sense of where we're heading.

DR. MURRAY: There's a maxim in our field of ethics which is that good ethics begin with good facts. I should mention that the task force has spent a great deal of its time, probably the majority of its time, listening rather than talking, listening to people like Sandy Lowden help explain how insurance works, and listening to scientists who are doing the basic research that will develop the tests and the predictive vehicles for the future. Listening to people working in biotech labs who are developing the test technology themselves, and also listening to people at risk of genetic diseases and their concerns. We've tried to be responsible, collect all the relevant facts that we can possibly imagine, and not make premature judgements about what sorts of policies will be required. I'm not always popular on Capitol Hill, because I've been called by Congressional staffers who want to draft a law for something, and I'll say it seems premature to me since you really don't know what the shape of the problem is yet. We know something about it, but we don't really know how it will manifest itself.
DR. GERALD FOLEY, CNA Insurance Companies: I didn’t get a clear sense of where the task force is going beyond what you’re describing as your philosophic and ethical considerations, which are entirely appropriate. Can you give me some idea of whether the task force or your group has defined any intention to make specific recommendations in the areas of advice to the insurance associations, both health and life, to the NAL, to state legislatures, or to agencies that regulate the laboratories that are going to be doing these tests?

DR. MURRAY: Yes, we will be making very specific recommendations. I’m not trying to be coy, but I think it would be inappropriate for me to discuss the content of those recommendations right now. They won’t be at the level of the regulation of laboratories and the like, but they will be directly relevant to public policy considerations, to legislators, and indirectly to the industry.

DR. MOSELEY: I agree. The task force will come up with some recommendations. I think they’ll be relatively general recommendations. In the next few months, our project, at the University of Florida, will be publishing a draft for comment on our proposed recommendations.

DR. KITA: I heard Dr. Murray describe how social evolution has occurred here in the United States over the last couple hundred years during which time many hundreds of insurance companies have constituted themselves and sold business as these social changes occurred beneath them. There has been an evolution from access to healthcare as a right, to healthcare as a right, to health as a right, which causes considerable confusion, I think, in assessing the issues. We’ve heard the heterogeneity of the insurance industry acknowledged insofar as life, health, and disability, group and individual. But it’s more broadly heterogenous than that if you consider those companies that do and don’t have medical departments, those companies that take business on a "take vs. no take" basis and others which have provisions for different kinds of substandard offerings. It’s much more complicated than many imagine. Having heard choices between bartering, deserving, and need, it made me wonder about basic human necessities, if your list would include things like food, clothing, shelter, and perhaps health, how do we arrange for those in our own country? Much of it’s for purchase and sale, and yet there’s provision for emergency. Does this suggest that there’s a hierarchy of needs and a need to integrate social and private mechanisms? On that note I’d like to thank our panelists, and we’ll adjourn.