Political Development In Genetic Testing

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This is an overview of the issue of genetic testing from a government relations perspective, and how it may be, or more likely is, already affecting your job.

Some readers are intimately involved with this issue, and others may be less familiar with the political ramifications of advances in the genetic sciences on the insurance industry. For those of you already following this issue, I hope to give you one or two new insights. For those of you who have not been following the genetic information debate, this is an area in which you or someone from your company needs to be involved.

This issue has the potential of fundamentally changing the way our industry does business. If our industry loses this debate, the risk classification system as we know it will no longer exist.

I will be depicting a broad picture of the battleground on which the genetic testing debate is taking place. I will also attempt to explain why we have seen such a rapid increase in legislation in this area.

**Similarities With The AIDS Issue Of The 1980's**

There are similarities between this issue and the AIDS debate of the late 80's. Both involved privacy and confidentiality issues and the stigmatization of disease, and both force us to reexamine the methods we use to underwrite insurance. Politically, however, the genetic testing debate is far more challenging and presents even greater obstacles than those we have seen with AIDS.

Politically, whether correct or not, AIDS was seen as affecting a relatively small population consisting of gay males and intravenous drug users. Genetic testing, however, is perceived as an issue that can affect anyone, including legislators themselves, their families, their neighbors, and most importantly, most of their constituents.

This issue is gaining public attention, in large part due to the positive strides medical science and the Human Genome Project have made in recent years. In the past year, the popular press has reported that the mutated genes that cause Alzheimer's, leukemia, diabetes, and cancer of the breast, colon, thyroid, skin, and brain, have either been located or soon will be.

Unfortunately, the technology far precedes the response to what we are going to do with the technology, not only in the insurance world but in the medical world as well.

**An Issue Driven By The Media**

Not surprisingly, the public dialogue on this complicated subject is being formed by the media. There has been a tendency in many media reports to leave the impression that insurers are pushing for the development of genetic tests to gain an upper hand over applicants. Here are just a few recent headlines:

  "Genetic testing a double-edge sword."
  "Genetic testing makes an ounce of prediction worth a pound of fear."
  "Tests pose threats of genetic underclass: Insurers likely to seek gene test data."
  "Gene testing raises fears of insurance discrimination."

To give you a sense of the perspective in which most of these articles frame advances in genetic science and their relation to insurance, I would like to quote a brief passage from a March 23, 1994, *Chicago Tribune* article, entitled, "Genetic Testing": It Won't
Insure the Future.” Its author, John Timson, who is described as a “biologist and freelance writer” claims: “The basis of life insurance is that some of those insured will die, but there is no way of knowing who will be the unlucky ones... So it is in the company’s interest to refuse to insure anyone known to have a higher than average chance of dying early.” As more and more genetic tests are developed, the time may come when it will be possible with considerable accuracy to divide the population into those who will reach old age and those who won’t. Those fortunate enough to be in the former group would naturally wish to take out insurance only against accidental death; the rest would soon find there was no life insurance available for them.”

This type of argument is repeated again and again in the media. Rarely, if ever, is it reported that insurers are simply trying to keep up with the rapid pace of medical technology and determine how this technology fits in with our traditional underwriting practices.

Legislators read these articles. They, like the public, generally have observed these advances with a great deal of trepidation.

Aside from the ethical concerns, the perception of having one’s health, and possibility death, “predetermined” raises significant public policy questions as well.

Realizing that there are significant public policy ramifications involved with this new technology (privacy, access to medical records, redisclosure of test results, and implications on future employment, to name just a few) legislators are attempting to protect the public interest as they perceive it.

To further complicate matters, legislators, like many others, are not very familiar with how insurance really works. Risk classification and the basics of an insurance contract are not items legislators ponder in their free time. If they have any familiarity at all with insurance, it stems from complaints they receive from constituents about their insurance coverage, or their own experiences with the insurance industry. Anecdotes abound!

### Insurance Is Insurance Is Insurance

Legislators, again, like the public, do not easily distinguish between types of insurance. To many, insurance is insurance is insurance. The recent national debate revolving around health insurance raises many issues spilling into other lines of insurance: availability of coverage, insurability, portability, community rating, and entitlement.

Legislators are reluctant to acknowledge the differences between life insurance—a lifelong contractual agreement for a financial product—and health insurance—a medical expense reimbursement plan.

### Risk Classification Public Attitudes

To give you a bit more perspective on how the public perceives this issue, I’d like to briefly share with you the findings of many surveys and focus groups the ACLI conducted regarding risk classification last year.

First, while the public seems to understand the business reasons for underwriting, a growing number of people think the practice is unfair. This is particularly true when underwriting is based on a factor over which the applicant has little control or when the results mean insurance could be denied.

Second, there is an increasing belief in a certain amount of insurance as an entitlement. I will address this matter further in a little bit.

Third, there is a growing concern about privacy—an increasing lack of confidence that personal information given during the application process will be used solely for insurance purposes.

While, the public’s views about industry risk classification processes are getting more negative, members of the public also demonstrate an overwhelming lack of knowledge about these practices. Estimates of the number of applicants denied coverage or charged higher than standard rates are grossly exaggerated. Many people believe that life companies can cancel a policy if the policyholder comes down with a serious illness.

### Genetic Testing Public Attitudes

While the public’s views about risk classification are, at best, ambivalent, the issue of genetic testing is even more difficult for the industry.

The use of genetic testing by life insurers in the underwriting process is consistently rejected by the public in surveys. Sixty-seven percent believe that life insurance companies should not be allowed to require applicants to take genetic tests. Sixty-five percent believe that life insurance companies should not have access to results of tests already taken.

If you want some really depressing news, sentiment is as strong among life insurance company employees, with a surprising number feeling we should not have access to test information or be allowed to require tests.

According to ACLI’s research, people don’t even
want testing done to find out about a condition they may have. Only 14 percent say they are very likely to submit to a genetic test for their own information.

As a quick aside, my company has been taking active steps to increase employee understanding of risk classification and genetic testing. We realize that our employees could be chatting with neighbors or relatives, and if these types of issues come up they can be our best advocates. Accordingly, we put out two articles relating to genetic testing, one in our home office publication, the other in our agents' newsletter. At our most recent management meeting, one of our executive vice presidents gave a talk on risk classification and its role in a private insurance system to several hundred of our management level employees. We can no longer take our employees' understanding of this issue for granted.

Now having served in the public sector, I have a great deal of respect for legislators and their motives. But to be reelected, which is the primary concern of almost every elected official, they must keep their constituents happy.

Legislators read these articles, hear these anecdotes, sense this concern, and say, "Something needs to be done." They have constituents who have been denied insurance and suffer from genetic diseases. Many legislators themselves have or suspect they have a genetic disease. They and their constituents are leery of insurers and this mysterious "Medical Information Bureau" which they believe is putting together a database of genetic information for nefarious purposes.

Let me give you an example of the perspective from which some legislators approach this issue. This is a quote from a speech by Wisconsin State Representative, Marlin Schneider. Representative Schneider is the prime advocate of restrictive genetic testing laws in our state. And I quote:

"I would like you to take a moment and imagine a world where your boss knows every time you see the doctor and what you see the doctor for. Where businesses routinely exchange the most personal of all information about you, your medical records. Where insurance companies employ credit bureaus to help them administer health care claims, and where these credit bureaus are given access to all of your health care records, including treatment for alcohol or drug problems, psychiatric care or even treatment for AIDS or some other sexually transmitted disease. Imagine a computer tracking everything you buy from aspirin to birth control pills to prozac. If this sounds like something out of Orwell, think again. The world I asked you to imagine is real! These things are happening every day. You may not realize this, but your medical record, the most personal file ever kept on you, is also the least protected."

To many, this is persuasive political rhetoric. While we may have the facts on our side, using terminology like "pooling of risks," "mortality rates," and "adverse selection," and attempting to explain the risk classification system pales in comparison to the fiery and populist talk of "big brother" and the emotional stories of individuals who cannot receive insurance coverage because they suffer from X, Y, or Z disease and how this lack of insurance severely affects their ability to provide for loved ones.

In response to these concerns, legislators draft bills, often with the best of intentions, to stop this "discrimination" and stop these insurance companies from taking advantage of their constituents.

**States With Genetic Testing Laws**

Genetic testing legislation began to be introduced in the state legislatures in 1989. In the past three years, at least ten states have enacted into law genetic testing measures. Midwestern states, particularly Wisconsin, have been in the forefront of this effort.

Wisconsin law prohibits health insurers from requiring or gaining access to the results of genetic tests and forbids employers from demanding that job applicants undergo such screening. Iowa, Oregon and Rhode Island passed similar rules covering only employers.

California and Ohio have enacted new laws which prohibit compulsory genetic tests or access to genetic test results for health insurance.

A 1994 Colorado statute prohibits health insurers, group DI insurers, and long-term care insurers from underwriting based on genetic tests.

Arizona, Georgia, Minnesota, Montana, New Hampshire, and Oregon also have genetic testing laws on the books.

Fortunately, with some minor exceptions, we have been able to exempt life and individual disability income insurance from the provisions of these laws.

In 1995, however, 30 bills were introduced in 17 states which would, in some fashion, prohibit the use of genetic tests in underwriting. These numbers keep growing each year. Already, in 1996, we have seen nine bills introduced.
Four Categories Of Genetic Testing Legislation

These genetic testing bills typically fall into one of four categories:

1. Bills which would prohibit underwriting based on broadly-defined genetic tests, which would prohibit most traditional underwriting.
2. Bills which would prohibit all or only health insurers from underwriting based on narrowly-defined genetic tests.
3. Bills which would prohibit underwriting based on carrier status.
4. Bills which would impose a variety of requirements to address confidentiality concerns.

The most troublesome bills are those that fall in category one, since they would impede traditional medical underwriting. Using Wisconsin as an example, legislation introduced last year would change the definition of a genetic test from “a test using DNA extracted from an individual’s cell to determine the presence of a genetic disease or disorder, or the individual’s predisposition for a particular genetic disease or disorder” to “a test, including a physical examination of an individual or an examination of the family history of an individual, used to determine the presence of a genetic disease or disorder or the individual’s predisposition for a particular genetic disease or disorder.”

As you know, phrases like “a physical examination of an individual” or “family history of an individual” greatly expand the definition of a genetic test. We also see the term “gene products” in many definitions. These definitions would expand these bills so that many, if not most, medical tests routinely used as part of the traditional medical underwriting process would be prohibited.

Category two bills are those which would prohibit life, disability income, and health insurers, or occasionally, only health insurers, from underwriting based on genetic tests.

In category two bills, “genetic tests” are narrowly defined to include only those tests looking directly at genes and/or chromosomes. The majority of bills introduced fall into this category. Even with the narrower definitions these bills are troubling due to the anti-selection which may occur if applicants have information, particularly about a serious genetic disorder, and insurers are prohibited from evaluating this information.

Category three bills included those containing prohibitions against underwriting on the basis of carrier status. As with the definition of “genetic testing,” the definition of “carrier status” varies and has been a source of concern.

Category four bills address a number of issues generally related to confidentiality concerns. For example, many of these bills require special disclosure and informed consent forms, limits on re-disclosure to reinsurers or the MIB, counseling requirements and severe penalties for mishandling medical records.

Overall, it is becoming more difficult to obtain exemptions for life and disability income insurance and to distinguish life and DI from health insurance. In the states where life and DI have been targeted, it has been difficult to effectively defend life and DI insurers’ essential need to require narrowly defined DNA tests not currently in use. It also has been difficult to persuade legislators of the veracity of industry claims to the effect that prohibitions of broadly defined genetic information would effectively eliminate the process of risk classification.

Even more troubling, we are seeing more and more proposals which would require provision of life insurance policies under prescribed face amounts without underwriting. In other words, for the first time, we are seeing actual evidence of what ACLI research has been showing for several years—that there is beginning to be a public perception of an entitlement to a minimum amount of life insurance.

I find this debate particularly interesting. How many times have you heard the phrase life insurance is sold not bought. Our companies hire an army of agents and spend millions on advertising to persuade people to buy life insurance.

But let a legislator hear of someone who was declined coverage and suddenly these big wealthy insurance companies are preventing them from purchasing a necessity of life. Something they are entitled to. How often do you think an agent’s call is met with the response: “It’s about time you called, I’ve been waiting to hear from you.” Unfortunately, all too often those that truly understand it is a necessity of life have discovered they are seriously ill.

In the days of the New Deal or the Great Society, if government felt the private sector wasn’t fulfilling a need they would rush in to fill it. In fact, they did to some degree with respect to insurance. Social Security provides a small death benefit and some states have state run life insurance programs. In Wisconsin, the State Life Fund can issue policies up to $10,000.

But given the political climate today, coupled with most governments’ budget situations, there would be very little support to get states or the federal government into the life insurance business. Instead, we are starting to see efforts, still at the outer fringes, to regu-
late private life insurers into providing a publicly mandated product.

Don’t be surprised if you start seeing proposals for life insurance risk sharing pools similar to those developed in the health insurance area; medically uninsurable individuals being provided a certain amount of insurance for a set premium, with any shortfall being made up by assessments on insurers, to be ultimately passed on to healthier premium payers.

In addition to state legislatures, numerous other forums are examining this issue.

The National Association of Insurance Commissioners (NAIC) has formed a genetic testing working group which has developed a white paper making recommendations to their parent committee on how insurance commissioners should deal with this topic.

This working group has held two hearings, one in Minneapolis, where Dr. Chambers and Dr. Gleeson gave testimony for the industry, the other in Miami, where Dr. Moore and Dr. Gleeson testified.

At these hearings we have also seen the first signs of an organized effort by advocates supporting restrictive genetic testing legislation.

The most noticeable group is the Council for Responsible Genetics, whose executive director, Wendy McGoodwin, has appeared at these two hearings, as well as two individuals, Phil Bereano, University of Washington, and Dr. Paul Billings, Stanford University.

They argue that insurers want to stratify our society into “haves” and “have nots” and believe that using genetic information in risk classification is actuarily insignificant and immoral.

After several false starts and changes in leadership, the NAIC working group is now being lead by Dr. Dixon Larkin of Utah, who has conveyed a good understanding of the impact of genetic testing on risk classification. We are now making good progress with this group, and I believe many of the participants understand that this is not merely a discussion about genetic tests but about the entire risk classification system.

The federal government is also involved with this issue. In early April, the Equal Employment Opportunity Commission (EEOC) put out regulations stating that anyone who has inherited a genetic defect will be considered disabled. This change would allow workers under the Americans with Disabilities Act to sue an employer who discriminates against them because of their genetic makeup. The impact of this ruling on insurers is still being researched.

In addition, the American Academy of Actuaries, at the request of the NAIC, is planning a full day conference on this topic to gather more information and to discuss the issues at greater length with interested parties.

We are also monitoring the European Community’s dealings with this issue, as they could impact U.S. policy. In 1993, an EC report advised adopting a rule banning the use of genetic information by any party not directly involved with providing health care. A 1994 draft EC document would ban insurers from doing their own DNA-based testing and from accessing the medical record and using genetic information that already exists at the time of application.

The insurance industry is taking strong steps to ensure its voice will be heard in this debate. Insurers, led by the ACLI, are responding quickly and aggressively to defend our ability to underwrite. The ACLI’s medical section, working with the ACLI’s state government relations professionals, has been extremely involved in helping establish policy objectives, and, implementing these objectives.

I chair the ACLI state legislative advisory group which is monitoring the activity of genetic testing and other risk classification bills throughout the country and coordinating the industry’s response. Most of you here today participate in our weekly conference calls, where we discuss the previous week’s developments and future strategy.

Charged with ensuring that the industry has the resources necessary to adequately respond to this issue, this group makes sure that experts like yourselves are available to testify at public hearings and meet with legislators and regulators in our continuing effort to educate policy makers on this subject. This group also coordinates grassroots efforts so that insurers, agents, and other allies are acting in concert.

One main tenet of this group’s activities is that we should oppose even what some may categorize as small, incremental steps toward restricting the use of genetic information. We have learned from experience that state legislators are constantly trying to push the envelope. Once any bill is passed, that sets the mark for all future legislation in the area. We are trying to prevent this “slippery-slope” by asserting that insurers must have full access to any relevant medical test results and retain the right to conduct any relevant tests they may deem necessary.

THE MESSAGE

Educating legislators and the public about risk classification is not an easy task. The basic message
we are trying to get out is that insurers stay in business by selling a product, not by declining many people. Life insurers decline less than 3 percent of applicants, and they have every reason to issue a policy if they can price it appropriately.

Additionally, insurers are obligated to charge fair prices to policyholders so that individuals with significantly better risk characteristics are not subsidizing those with fewer favorable ones.

The new technology is not something sought by the insurance industry, but something we must confront if the private insurance system is to survive. Technological advances need not be feared. These advances may actually expand, not restrict, whom insurers cover. New medical tests can indicate that a person is actually free of a predisposition that their family history would otherwise indicate. These individuals might secure coverage or a reduced premium for their coverage.

We also stress that no insurer requires narrowly defined, DNA-based, genetic testing today. However, insurers already use a variety of information that relates to an individual’s genetic makeup.

Most importantly, we try to convince legislators that all we want is a level playing field of knowledge. We can live in the current environment or we can live in an environment with genetic testing if we have the same knowledge as the applicant and the ability to obtain all information about the risk.

I hope I have shed a little light on why we are seeing an increase in genetic testing legislation, the media’s take on this issue, what these bills actually would do, and how our industry is trying to respond.

WHAT YOU CAN DO

I would simply like to reiterate the importance of genetic testing legislation to the future of our industry. It is not rhetoric or hyperbole when we state that this legislation, if enacted widely, would fundamentally change the insurance industry in the United States.

Though life insurance might be more accessible for those who are denied coverage today, it likely would come at the cost of substantially higher premiums for all other applicants. Availability could become a problem if individual insurers reacted to the loss of effective underwriting by dropping out of certain markets.

This is not a debate that will be won solely in the legislative chambers. Rather, it involves changing public perceptions about the industry and how it operates.

We must let people know that risk classification is the foundation of a private, affordable life insurance system.

We must let people know that life insurance is a positive force in society, giving families financial security and supplying the economy with much need capital.

We must let people know that the insurance industry takes confidentiality very seriously and has an excellent record in protecting individuals’ health information.

We are lucky in this debate that we irrefutably have the facts on our side. We are not asking for regulations to be loosened or looking for special privileges. We are trying to provide life insurance at the lowest possible cost.

Getting these messages out will take a lot more work than lobbyists like me trying to convince legislators. It will require the energy and skills of our company’s public relations practitioners. CEOs and yes, medical directors. Start monitoring this issue if you are not already. Determine whether your state is considering a genetic testing bill and how you can get involved in the legislative process. Encourage an educational effort at your company to make all employees aware of risk classification and the important role it plays in our industry.