Issue Analysis

Genetic Testing and Insurance

Why the Fear of "Genetic Discrimination" Does not Justify Regulation

By Prof. Neil A. Manson and Gregory Conko

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EXECUTIVE SUMMARY

It is common knowledge that many diseases have a genetic basis and that the presence of more and more disease-related genetic mutations can be detected with simple tests. Unfortunately, much of the American public believes that certain diseases are completely determined by one's genes and that a positive genetic test means doom. In turn, they fear that insurers will use information of such seemingly great predictive value to deny coverage to, or make insurance much more expensive for, those with positive genetic tests. Some also believe that employers may use genetic test information to discriminate against employees who are at greater risk of becoming ill. This has led to calls for government to regulate access to such information in order to prevent insurance companies and employers from engaging in what some have called "genetic discrimination."

Fortunately, it is not true that carrying a genetic mutation for a given disease is a guarantee that the disease will eventually arise. Most genetic mutations only increase the probability of developing the disease, and most such diseases can be prevented or treated once the carrier knows about the mutation. Furthermore, it is already illegal for most health insurers to discriminate against potential customers on the basis of genetic test information. Nevertheless, Members of Congress have introduced legislation to expand current laws that forbid health insurance providers from basing coverage or premium decisions on a customer's genetic status, and to forbid group health insurers from charging all members of a group plan higher rates based on the genetics of one or more members. The legislation would also prohibit employers from discriminating against individuals on the basis of genetic information.

Despite public perceptions, however, there is no strong evidence that genetic discrimination is currently a widespread problem, or that it is likely to become so in the future. Numerous investigations into actual underwriting practices show that neither health nor life insurers currently engage in such practices. The few studies that purportedly document genetic discrimination have not been sound methodologically. They rely solely on patient self-reports with no follow-up to confirm that genetic discrimination actually occurred. And most such studies give a misleading impression by defining use of family medical history in underwriting decisions as a form of "genetic discrimination." Ultimately, Dawn Allain, president of the National Society of Genetic Counselors, told *The Wall Street Journal* in 2004: "We haven't seen any real cases of genetic discrimination."[a]

Of course, even though it is not occurring today, one might fear that genetic discrimination could become a genuine problem in the future, as scientists learn more about the genetic basis of many diseases. The economics of health insurance make it unlikely that those insurers will rely on genetic test information—at least for the foreseeable future. Most health insurance is provided by employers, and premiums for those plans are based on the experience of the insured group, not on the characteristics of any one member. In addition, health insurers tend to see a rapid turnover in enrollment, so trying to predict health problems that may or may not actually occur years into the future makes little sense.

Life insurers, on the other hand, could, one day, have an incentive to use genetic test information, because their customers typically buy their policies individually and tend to keep the same insurer their whole lives. When practical, insurers can reduce the uncertainty in expected payouts by gathering better information about

their customers' health risks. That helps policy holders because reducing such uncertainty lets the insurer reduce the financial cushion it needs to account for unknown high-cost customers within the insured group, leading to lower premiums.

Furthermore, even if life or health insurers were to find it practical to base underwriting decisions on genetic test results, the practice is unlikely to produce one class of genetically blessed and another class of genetically cursed individuals. Nearly all diseases with a genetic component can be prevented or treated with early detection, so widespread genetic testing is far more likely to result in improved health outcomes for most genetic diseases.

It is not even correct to assume that those genetically predisposed to some disease will have worse health outcomes when compared to the general population. In many cases, those armed with the knowledge that they are genetically predisposed to a given disease might well change their behaviors and control their environments sufficiently to gain a statistical edge over those not so genetically predisposed but who do not similarly alter their behavior. That could result in lower health or life insurance premiums. On the other hand, forbidding insurers from using genetic test results or other types of relevant information could restrict efficient underwriting and force all consumers to pay higher costs. Ultimately, arguments for increased government regulation of health and life insurers do not make economic or practical sense.

[a] Sharon Begley, "Bill Seeking to Ban DNA Discrimination Isn't Really Necessary," *Wall Street Journal* (Feb 6, 2004), p. B1.

I. The Specter of Genetic Discrimination

It is common knowledge that many diseases have a genetic basis and that the presence of more and more disease-related genetic mutations can be detected with simple tests. Currently, genetic tests exist for about 1,000 diseases, and many more are in development.[1] Unfortunately, the public understands little about genetics, so many have come to believe that certain diseases are completely determined by one's genes and that a positive genetic test means doom.

Fortunately, this is not true. Carrying a genetic mutation for disease is not a guarantee that the disease will eventually arise. Most genetic mutations only increase the probability of developing a given disease, and most such diseases can be prevented or treated once the carrier knows about the mutation.

Nevertheless, the public and policy makers worry that insurers will use information of such seemingly great predictive value to deny coverage to, or make insurance much more expensive for, those with positive genetic tests.[2]   Some also believe that employers may use genetic test information to discriminate against employees who are at greater risk of becoming ill. This has led to calls for government to regulate access to such information in order to prevent insurers and employers from engaging in this kind of "genetic discrimination."

The federal government and many state governments have already enacted legislation that forbids health insurance companies' use of genetic information. At the federal level, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) prohibits employer-based and other commercially issued group health insurance plans from using any health status-related factor, including genetic information, as a basis for denying or limiting eligibility for coverage or for charging certain individuals more for coverage.[3] HIPAA also forbids doctors and other medical service providers from disclosing private health information, including genetic information, without the patient's consent. And HIPAA explicitly forbids a genetic predisposition to one or more illnesses from being considered a preexisting medical condition unless the afflicted individuals already have expressed symptoms of those illnesses. In addition, the Americans with Disabilities Act of 1990 (ADA) prohibits workplace and other discrimination against individuals with disabilities.[4] While the ADA does not explicitly address genetic conditions, it does cover individuals with symptomatic genetic disabilities the same as those with other disabilities.

Because nearly all diseases with a genetic component can be prevented or treated with early detection, widespread genetic testing is far more likely to result in improved health outcomes for most genetic diseases, which would likely lead to lower health and life insurance premiums.

Nevertheless, concerned that these laws do not provide sufficient protection against genetic discrimination, Members of Congress have introduced legislation to expand HIPAA's prohibition on the use of genetic test results. The Genetic Information Nondiscrimination Act of 2007 (H.R. 493 and S. 358) would make it illegal for individual health insurance providers to base coverage or premium decisions on a customer's genetic status, and would forbid group health insurers to charge all the members of a group plan higher rates based on the genetics of one or more members. Finally, the legislation would prohibit employers from discriminating against individuals in employment practices on the basis of genetic information, and it would prohibit collection or disclosure by employers of employees' genetic information in nearly all instances.

The Genetic Information Nondiscrimination bills were introduced in the House and Senate in January 2007. A similar bill was passed unanimously in the Senate both in 2003 and in 2005, but was never voted on by the House. This year, however, Congressional Democrats are optimistic about the legislation's prospects,[5] and President Bush has announced his support for the bills.[6]

However, despite public perceptions, there is no strong evidence that genetic discrimination is a widespread problem, or that it is likely to become so in the future. Because nearly all diseases with a genetic component can be prevented or treated with early detection, widespread genetic testing is far more likely to result in improved health outcomes for most genetic diseases, which would likely lead to lower health and life insurance premiums. On the other hand, forbidding insurers' use of genetic test results or other types of relevant information can restrict efficient underwriting and trap all consumers into higher overall costs.

Ultimately, increased government regulation of health and life insurers makes neither economic nor practical sense.

II. Is Genetic Discrimination a Problem?

Advocates for increased government regulation argue that discrimination is already a rampant problem and a looming public health crisis. To support their claims, they cite several published studies that purportedly demonstrate how consumers are already being impacted. But, while some insurers undoubtedly have used genetic test information in underwriting, the evidence of a significant impact is quite weak, and cannot be relied upon to support claims of widespread genetic discrimination. Just three

years ago, Dawn Allain, president of the National Society of Genetic Counselors, told *The Wall Street Journal*: "We haven't seen any real cases of genetic discrimination."[7]

Sharon F. Terry, Executive Director of PXE International (a research advocacy organization for the genetic condition pseudoxanthoma elasticum) and Wendy R. Uhlmann, a genetic counselor at the University of Michigan, reached a similar conclusion after they reviewed various published studies that attempted to document genetic discrimination in life insurance markets.[8] As Terry and Uhlmann note, most of the studies of genetic discrimination have not been sound methodologically. They rely solely on patient self-reports—often collected by advocacy groups from member surveys—and no follow-up with the patients or their insurance providers was conducted to confirm that genetic discrimination actually occurred.

Terry and Uhlmann's results confirm earlier research conducted by Philip R. Reilly, executive director of the Shriver Center for Mental Retardation, who examined several of the biggest studies purporting to show evidence of widespread genetic discrimination.[9] According to Reilly, the results of one of the most influential early studies in the field, published in the journal *Science* in 1996, is typical of this research.[10] This study relied on a biased sample of respondents who were encouraged by advocacy groups to participate, and the researchers based their conclusions on an overly-broad definition of genetic discrimination that included use of family medical history in underwriting decisions. Family medical history can give an insurer insights into a customer's genetic makeup because it can reveal the likely presence of certain hereditary diseases. But use of such information has been a common practice in life insurance markets since long before the discovery of genes, let alone individualized genetic testing. Counting this kind of information gathering as "genetic discrimination" would inevitably overestimate the alleged problem. Nevertheless, what most surprised Reilly was that even such a biased study found so few reported cases of discrimination.[11] Moreover, Reilly's own surveys of state insurance commissioners found that "only a miniscule number of consumers had formally complained to commissioners about life insurers' use of genetic data," and that the commissioners themselves "did not perceive genetic testing to pose a significant problem."[12]

Health insurers also appear not to have engaged in genetic discrimination, probably due in large part to the nature of health insurance markets. The vast majority of Americans who have health insurance

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coverage receive it through an employer-sponsored group plan or from a government entitlement program. In 2004, approximately 174 million Americans were covered by a private group health plan, and 77 million were enrolled in Medicare or Medicaid. Only 24 million Americans were enrolled in a private individual health plan, fewer than the 46 million who, at some time during the year, had no health insurance at all.[13] In employer-sponsored insurance plans, federal and state regulations require that all enrollees in a given plan pay the same premiums, and governments pay the bulk of costs associated with Medicare or Medicaid coverage. Only in the individual health insurance market should one expect genetic test results to play a significant role in setting premiums. Even there, however, health insurance economics suggests discrimination is unlikely to become a substantial problem.

Importantly, health insurers of all types—though especially those in the group health market—rarely engage in conventional risk rating of any kind because they typically find it uneconomical to do so. Instead, most health insurance plans are "experience rated," a practice in which insurers base future premiums on a combination of the insured group's actual recent medical expenses and very rudimentary health information about the insured group. According to Mark A. Hall and Stephen S. Rich of the Wake Forest University School of Medicine, health insurers tend to focus on existing and prior health problems that are likely to result in the near-term payment of benefits, for several important reasons.[14] Compared with life insurers, both individual and group health insurers see a rapid turnover in enrollment—an average length of enrollment of just two to four years— so trying to predict health problems that may only occur many years into the future, or not at all, makes little sense. On the other hand, near-term medical expenses arising from existing and prior health problems that have actually been manifested are more relevant and can be predicted with more certainty.

Hall and Rich surveyed genetic counselors and patient advocates, as well as state insurance regulators, and found that, while most had read or heard that genetic discrimination occurs to a significant extent, "almost every counselor and every patient advocate said he or she knew of no actual cases of health insurance discrimination."[15] The authors also conducted their own market study in which they posed as a fictitious three-employee firm with two unhealthy employees, one of whom "volunteered that she had tested positive for the breast cancer gene," in order to obtain information on the availability of small group health insurance and rate

quotes. The authors also conducted a content analysis of health insurance application forms from 50 insurers to look for evidence that insurers were requesting information about genetic tests. The study produced a "[s]trong confirmation of health underwriters' lack of interest in presymptomatic, predictive genetic testing." Even information about family medical history appeared to be used only for "important disease categories such as heart disease, cancer, and diabetes, [and insurers used it] only to look for or evaluate other signs of existing or prior disease, not to predict the onset of future health problems."[16]

Of course, even if genetic discrimination is not a significant problem now, it could become so in the future. But is this likely? No. The expectation that widespread genetic discrimination will emerge in an unregulated insurance market rests on a host of misunderstandings both about the nature of genetics and the behavior of insurers, both of which are discussed below.

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III. Genes, Disease, and Genetic Tests

The push for legislation to thwart genetic discrimination rests in part on the widespread misconception that carrying a genetic mutation for disease is a guarantee that the disease will eventually arise in the carrier. In fact, few genetic mutations guarantee that the carrier will develop the associated disease. Most only raise the probability of developing the disease. Geneticists use the term "penetrance" to describe the probability that a person carrying a mutation will develop a disease or condition associated with that mutation. Extraordinarily few known mutations have 100 percent penetrance. One study, for example, concluded that genes account for less than half the risk of developing each of 11 common cancers.[17] Of those 11, prostate cancer and colorectal cancer were found to have the highest genetic component, yet only 42 percent of the risk of prostate cancer and 35 percent of the risk of colorectal cancer can be attributed to a genetic cause.

Among of the few genetic mutations with 100 percent, or near-100 percent, penetrance is the one associated with Huntington's disease—an adult-onset neurological disorder that is essentially guaranteed to occur among those who carry the mutation. Furthermore, while some of the worst symptoms may be controlled with medication, Huntington's disease is currently incurable. Huntington's sufferers can survive for 30 years or more after the onset of symptoms—which usually occurs in the patient's 30s or 40s—but most will die within 15 to 20 years.[18]

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Fortunately, the mutation for Huntington's disease is of a very rare kind. Not only do few mutations have total (100 percent) penetrance, most of the diseases known to be associated with a genetic mutation are treatable or preventable to some degree. For example, Phenylketonuria (PKU) is a genetic condition with 100 percent penetrance, but which can be "treated" with proper diet. PKU is a genetic enzymatic disorder in which individuals are unable to process the amino acid phenylalanine.[19] If left unaddressed, it almost always results in mental retardation or death because phenylalanine is present in most protein-rich foods. Fortunately, if the genetic mutation that causes PKU is detected at birth, afflicted individuals can live a completely normal life by altering their diets in order to avoid certain foods. Indeed, most states now require that all newborns take a blood test to detect PKU.

Because the vast majority of genetics-related diseases and disorders are treatable, genetic testing has great therapeutic promise. Employed broadly, it can enable medical professionals to begin monitoring and treatment long before symptoms arise. Thus, judicious use of genetic testing can reduce the risk of disability and mortality. An excellent illustration is the BRCA set of genes in which certain mutations increase the susceptibility of carriers to developing breast cancer. BRCA is what is known as a multifactorial, or polygenic, mutation. Multifactorial mutations increase the risk of contracting the corresponding disease, but behavioral and environmental factors (such as diet, habits such as smoking, exposure to toxins) also play a significant role. In most cases, as illustrated by the prostate and colorectal cancer examples above, non-genetic factors account for the majority of the risk of developing most genetics-related diseases. Breast cancer is one of these, and the penetrance of the BRCA mutations are far less than 100 percent. Estimates in the scientific literature of

BRCA's penetrance vary from about 25 percent to 75 percent.[20]

Because BRCA is multifactorial, patients who test positive for it are typically subjected to aggressive early screening for breast cancer. More importantly, breast cancer is treatable, especially if detected early. Other examples of treatable multifactorial genetic conditions include coronary artery disease, colon cancer, and type-2 diabetes. In each of these cases, there are things the identified mutation carrier can do to prevent the onset of the disease (such as following a strict diet), to detect the disease early in its onset (such as getting regular colonoscopies), or to manage the disease after onset (such as taking insulin). It is simply

wrong to believe that genetic mutations guarantee fatal disease and that all positive genetic tests are death warrants with no therapeutic value.

Indeed, it is not even correct to assume that those genetically predisposed to some disease will have worse health outcomes than will the general population. If a disease is multifactorial, with a relatively low penetrance, those armed with the information that they are genetically predisposed to it might well change their behaviors and control their environments sufficiently to gain a statistical edge over those not so genetically predisposed who do not similarly alter their behavior. Coronary artery disease is a good example. Those whose genetic tests show a predisposition to coronary artery disease might modify their diets and exercise habits enough to compensate, or more than compensate, for their genetic predisposition to the disease, ultimately lowering their chances of developing coronary illnesses to or below the background rate in the general population.

Finally, it is worth noting that every human being very likely has many genetic mutations, not all of which predispose carriers to developing disease. Some mutations, such as a class of mutations in the genes Caspase 8 and Caspase 10, appear to make women who carry the mutation *less* likely than average to develop breast cancer.[21] Because every person is likely to carry a variety of different genetic mutations—some that increase and some that decrease the propensity to develop various diseases, and all with varying levels of penetrance—knowledge of any one mutation is of limited value to insurers and employers. And knowledge of any given individual's complete set of genetic mutations may raise, lower, or leave unchanged that person's overall propensity to live a long and healthy life.

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IV. The Use of Information in Insurance Markets

Most Americans rightfully place a high value on both health and life insurance, but few truly understand exactly how insurance works. Insurance transfers part or all of the financial risk associated with a specific event (for health insurance, the cost of medical care; for life insurance, the loss of an income earner) from the policy holder to the insurance company. Because covered risks are probabilistic—meaning that there is only a probability, not a certainty, that the event will take place in a given time period—groups of policy holders share the risk that one or more of them could become ill or die during the covered period. Thus, insurance

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is believed to perform a risk-spreading function that causes the more fortunate among us to subsidize the less fortunate. Insurance technically does not spread risk among insured individuals, however, since each policy holder pays a premium that reflects his or her individual probability of experiencing the insured against event.

However, for insurance's risk-shifting function to work properly, it is essential that the insurer understand how likely it is that one or more members will die or need medical care, and thus draw on the group's pooled resources to pay benefits.[22] The insurer must also know how great those expenses are likely to be. When the insurer is uncertain about how much it will have to pay out in the next year, for example, it must charge higher premiums to create a financial "cushion" that compensates for the uncertainty and ensures that covered expenses can actually be paid. This cushion is known as a "risk premium," and it represents the inflated cost of accounting for the risk that an unknown high-cost customer is lurking in the insured group.

Insurers can reduce the uncertainty in expected payouts by gathering better information about the health risks of group members. By considering such characteristics as age, gender, occupation, income, general health status and medical records, family medical history, and a variety of other factors, insurers can better predict the amount of benefits they will have to pay in the coming year. Perhaps more important to policy holders, reducing that uncertainty means the insurer will need a smaller financial cushion, and premiums can be lowered. On the other hand, when a group of policy holders contains certain individuals who develop proportionally more diseases than average, or die earlier than average, the insurer will be forced to raise its rates across the board to account for the added variance, because it has not identified those presenting the higher risk.[23]

For the reasons described in Section II above, most health insurers—especially those in the group health market—do not currently engage in risk pooling (though, it is possible that it could become economical for them to do so in the future). On the other hand, life insurers already engage in true risk rating because most policy holders purchase the insurance directly. Most readers will therefore be more familiar with insurance underwriting from their experience with life insurance.

For an insurer to provide its valuable services, it must evaluate each policy holder's individual characteristics and categorize him or her into

a risk pool along with other policy holders with the same or similar traits (for example, women between the ages of 45 and 55 with a family history of hypertension). Though they may be quite different, the members of each risk pool are very much alike in terms of the probabilities of them dying, getting into accidents, contracting diseases, and so on. And, though insurance does spread risk to some degree, that riskiness is spread only among the members of a given risk pool, each of which poses the same level of risk and pays a premium that reflects the probability that one or more of the members of the risk pool will need to collect benefits during the covered time period.[24]

Furthermore, as better and better information allows insurers to identify additional relevant differences among risk pool members, they will, when practical, split the pools into increasingly discrete groups to take advantage of the reduced uncertainty in expected payouts. If insurers did not do this, people who were in better than average health would be forced to pay a disproportionate share of premiums compared to their expected benefits. Those who *believed* they were in better than average health would begin to question the value of paying such high premiums, and some would drop their coverage. As average payouts for the group increased (because the healthiest members no longer participated), premiums would have to rise to compensate. Still more of the healthiest would drop out, and premiums would rise again as the pool is left with increasingly fewer healthy members—a phenomenon economists call adverse selection.[25]

For example, before the discovery of the link between cigarette smoking and cancer, there was no difference between the life insurance premiums paid by a typical smoker and those paid by a typical nonsmoker. After scientists discovered that smoking greatly increases the risk of developing lung cancer and heart disease, competition in life insurance markets naturally led to what was called "preferred underwriting," the splitting of the old, undifferentiated risk pool into two: smokers and nonsmokers.[26] Any insurance company that failed to split its pool of clients this way quickly saw a loss of business from the nonsmokers in its clientele, since competing insurers were able to offer the nonsmokers a discount for the reduced risk they posed. Where a bit of information reveals only a minor change in risk, the administrative costs of splitting the risk pool may be greater than any anticipated cost savings. But, in many cases, insurers that fail to split risk pools once they learn of relevant risk-

related information will invariably experience adverse selection problems that endanger the ability of the firms to continue paying benefits.

The adverse selection phenomenon occurs less frequently in health insurance markets—in part because the full cost of employer-sponsored group health insurance is not typically apparent to enrollees in those plans, in part because various regulatory and economic factors tend to make individual insurance an unappealing option, and in part because the younger, healthier enrollees who today subsidize their older and less healthy colleagues believe that they too will benefit from the subsidy as they age. Still, adverse selection has been documented even in employer-sponsored group health insurance settings.[27] In the life insurance and individual health insurance markets, low-risk customers can simply choose a different insurance firm. Where adverse selection occurs in group health insurance settings, lower-risk individuals tend to choose the least expensive plan, when more than one is offered, or drop out of the plans altogether. Adverse selection is especially pernicious in group health insurance because those who drop out of an overpriced group health plan will often have no other choice but the expensive and unappealing individual health insurance market. That, in turn, tends to leave them uninsured or severely underinsured. Many fear that insurers' use of genetic information will cause some currently insured individuals to lose coverage. But, even in the absence of genetic testing, forcing low-risk individuals to subsidize higher-risk individuals has already contributed to some insured individuals joining the ranks of the uninsured.

Information about a genetic predisposition to certain diseases works the same way as information about other risks. When neither the insurer nor the customer knows what the customer's genetic status is, the insurer cannot split high-risk customers into a separate risk pool, and low-risk customers have no reason to flee an overpriced insurance plan. But when a consumer knows he is at a lower than average risk of developing a particular disease, and the insurer does not, the customer has an incentive to flee the risk pool. On the other hand, a high-risk policy holder who has had a positive genetic test has an incentive to conceal that information from the insurer. And, where the insurer is legally barred from inquiring about the customer's genetic status, the net result is adverse selection. In effect, there is little difference between a person who knows he is at a higher than average risk of contracting a particular disease hiding that information from an insurer to obtain a lower premium and a

person who knows he is deathly ill and concealing that from the insurer. As Judge Richard Posner notes, "In either case [the customer who hides information] is shifting his own expected costs (whether reduced longevity or medical expenses) to unconsenting others."[28]

Importantly, splitting risk pools does not inevitably result in one group paying lower premiums and another paying much higher premiums. Efficient risk pooling tends to place downward pressure on premiums across the board by making the payouts from each pool more predictable and thereby reducing the variability in the financial management of those risks. Life insurance analyst Arnold A. Dicke notes that, when preferred underwriting for nonsmokers took hold in the late 1980s, "the premium for preferred risks carved out from the standard class [fell] significantly, while premiums for the rest of the risks that would also have been standard [remained] stable."[29] This happened because the old standard class clustered unequal risks, whereas preferred underwriting segregated those risks and eliminated the risk premium. The extra information resulted in a discount for the members of the newly identified lower-risk pool, but not in a price hike for the remaining members of the higher-risk pool.

Of course, some information will lead to higher premiums. But even when it makes sense to split a risk pool, the financial impacts of the change are not as linear as are often claimed by those who oppose the use of genetic information in insurance underwriting. Increased use of genetic testing is likely to result in the carriers of certain mutations paying higher premiums, while the carriers of others will pay the same or perhaps lower premiums. Therefore, fears that use of test results will inevitably lead to a sizeable genetic underclass that cannot get, or cannot afford, insurance coverage are unfounded.

Increased use of genetic testing is likely to result in the carriers of certain mutations paying higher premiums, while the carriers of others will pay the same or perhaps lower premiums.

V. Will Insurers Inevitably Engage in Genetics-Based Risk Pooling?

Genetic information offers new opportunities for splitting previously undifferentiated risk pools. Does this mean that all people with genetic predispositions to disease can expect insurance market dynamics to place them in a new, high-risk—and therefore higher-premium—risk pool? In other words, is widespread genetic discrimination inevitable in unfettered insurance markets? No. There are several strictly economic factors that indicate that most individuals with positive genetic tests will have their insurance needs met in a market that does not forbid use of genetic information.

Since payouts will not have to increase—indeed, since the better information may actually allow benefits payments to fall, thanks to better treatment—it is inconceivable that all, or even a large portion of, people will become uninsurable.

First, people with genetic predispositions to one disease or another make up a large portion of the insurance market. Indeed, they probably include the entire human population. As genetic tests grow in number, as connections between genes and disease become better known, and as new treatment options develop, the percentage of insurable individuals identified as having a known genetic predisposition to disease will grow and grow. Francis Collins, director of the National Human Genome Research Institute at the National Institutes of Health, has noted: "All of us are at risk for genetic discrimination if protections are not put in place because there are no perfect human specimens."[30] But that is precisely why the availability of genetic information is unlikely to produce one class of genetically blessed and another class of genetically cursed individuals. Insurers will have to cater to the huge market of customers with various propensities for risk, just as insurers already offer coverage to all sorts of policy holders, including those currently placed by conventional information—such as age or family medical history—into higher-risk pools. Any insurance company that fails to accommodate this market will find itself with a vanishing customer base.

Some regulation proponents suggest that in a hypothetical future with a much greater array of genetic tests and vastly better knowledge of gene-disease connections, we will all be uninsurable because we will all be shown to have a genetic predisposition to one disease or another. For example, at a 1998 White House briefing, then-First Lady Hillary Clinton claimed that predicted advances in genetic testing could result in a dystopic world where "most of us will be uninsurable based on our genetic makeup."[31] Such a statement is absurd. In a hypothetical future of such tremendous genetic knowledge, people will not have more disease than today—indeed, people will likely have less—but doctors and insurers will be better able to predict which groups of people are likely to develop which diseases. And the incidence of disease in a population with most disease-linked mutations identified will still be probabilistic, since neither the insurer nor the enrollees will know which individuals will develop the disease or at what point in time.

Furthermore, since payouts will not have to increase—indeed, since the better information may actually allow benefits payments to fall, thanks to better treatment—it is inconceivable that all, or even a large portion of, people will become uninsurable. Nor could an across-the-board hike in premiums be sustained in a competitive insurance market. If an insurance company were to charge its customers more simply for having a positive genetic test, and if all of its customers have a positive genetic test, then

the insurance company would be charging more for the same old coverage product. In a competitive market, another firm could attract those customers by offering policies with accurately priced risk-based premiums.

Indeed, for some diseases, the introduction of genetic information into insurance markets will tend to increase the number of people insured. Take, for example, Huntington's Disease, mentioned in Section III above. Every child of a person with Huntington's Disease has a 50-percent chance of inheriting the gene mutation and developing the disease. But long before the genetic basis of Huntington's was discovered, insurers used information about family medical history in underwriting decisions for *all* children of Huntington's sufferers. Because each child of a person known to have Huntington's had a 50 percent chance of early mortality, such children found it difficult to obtain life insurance. And when they did, premiums were typically quite high.[32] The advent of genetic testing, however, has allowed scientists to identify which children *do not* carry the mutated gene that causes Huntington's. Consequently, testing has made it possible for half the children of Huntington's sufferers to be eligible for insurance at standard rates for the first time.

Another factor to consider is that refinements in risk classification are sometimes what economists call "Pareto efficient"—that is, they leave no one worse off and at least one person better off. A concrete illustration of this is the introduction in the life insurance business of preferred underwriting for nonsmokers, described in Section IV above. In cases of treatable multifactorial diseases, the very same dynamic could act to lower costs for some while not raising them for others. For example, one day there may well be an effective genetic test that can show whether a given individual has an increased risk of developing prostate cancer.[33] Because treatment is less costly and more effective if the cancer is detected early, insurers would have an incentive to subsidize the cost of yearly prostate-specific antigen (PSA) tests, which detect the actual onset of the cancer, for men with a positive test for the prostate cancer mutation, while lower-risk men would be encouraged to get PSA tests only every three or four years after turning 50.

Importantly, the multifactorial nature of the disease also means that overall medical treatment costs are likely to fall substantially because higher-risk males can be targeted with various incentives to make certain behavioral changes—such as eating a better diet or increasing exercise— that will reduce the likelihood that they will develop prostate cancer. And, even though high-risk men might be placed in a separate risk pool because

there will still be treatment costs related to the disease, those men would not be costing the health insurance company any more overall, since they have long been present in the insured population. The splitting of the risk pool into separate high- and low-risk groups will reduce the risk premium associated with the earlier inability to differentiate between the two, resulting in a general downward pressure on premiums for both risk pools. The combination of modified behavior and early treatment could even generate overall savings that could be passed on to the lower-risk men without necessitating a rate increase for those at a higher risk.

Another fact to consider is that insurers are constrained to use genetic tests only when doing so is cost-effective. The saving from splitting the insurance pool must be greater than the costs of conducting the genetic tests, interpreting the results, processing the information, and administering a separate risk pool.[34] Today, genetic tests are quite expensive, ranging from several hundred to several thousand dollars for each specific test. To demand a battery of genetic tests before any policies are issued would make little economic sense, since the savings of excluding a few exceptionally high-risk individuals would not compensate for the very high costs of conducting the battery of tests. Nevertheless, as we discussed above, only life insurers currently seem to have an incentive to use genetic information in underwriting, but the nondiscrimination bills do not forbid that practice in life insurance markets. Further, because almost no medical testing of any kind is currently undertaken for health insurance enrollment, and because HIPAA and various state laws already make it illegal for health insurers to gain access to genetic test results, new genetic nondiscrimination legislation would seem to be pointless.

Of course, genetic tests are likely to become cheaper, and it is possible that the economics and regulation of health insurance might some day make it feasible for health insurers to use genetic test results. But they would have to get much cheaper to warrant insurers demanding a battery of tests as part of the customer application process. Even when customers have voluntarily had certain genetic tests done of their own accord, it may not always make sense for an insurer to demand access to the results.

To justify splitting positive testers into a separate risk pool, in either the health or life insurance industry, the expected difference in claims costs between positive and negative testers would have to be greater than the administrative costs of maintaining separate pools. This is likely to be the case with certain genetic diseases, though how great a proportion is currently unknown. And, where the probability of developing the

disease associated with a genetic mutation is not high enough above the background rate of the disease in the rest of the population, insurers will not find it in their interest to split the high-risk positive testers off as a separate risk pool. Currently, at least, there appears to be little prospect of insurers developing a policy of using genetic information to screen out applicants with genetic predispositions to most diseases. In many cases, doing so would cost too much and would yield too little in the way of prospective financial gain.

VI. Other Flawed Arguments for Regulation

Despite these general factors weighing against the likelihood of genetic discrimination, regulation proponents offer other arguments for controlling insurer access to genetic information. Oftentimes they appeal, not to what insurers can be expected to do, but to *what the general public thinks* insurers can be expected to do. For example, in a 2003 survey of people with a family history of colorectal cancer, roughly half the respondents said they were highly concerned about the possibility of genetic discrimination. And most of them said that apprehension made them reluctant to discuss genetic testing with a health care provider.[35] Consequently, critics say we are justified in regulating against genetic discrimination in the name of reaping the full benefits of genetic technology, which we will not get if patients *fear* genetic discrimination.[36]

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For instance, Dr. Francis Collins said of an earlier incarnation of the Genetic Information Nondiscrimination Act, "If this bill doesn't pass, my concern is that we won't be able to realize the full potential of advances in genetic science, because people will be afraid to participate in clinical trials or obtain genetic tests out of fear of discrimination." He adds later that his own lab found a gene that seems to increase the risk of type 2 diabetes about 30 percent, and said "someone testing positive for this variant could potentially incorporate preventive measures to avoid developing type 2 diabetes. Yet, if such a test is developed, some may be afraid to learn their own risks, for fear their insurance company might deny them insurance or raise their rates."[37]

Of course, this argument begs the question: Why think genetic discrimination is likely in the first place? If the fear is an irrational one, then there is no good reason for governmental action. Regulation in the name of quelling phantom fears is not new, but that does not make it justified, especially since regulations can themselves cause very real

harms. The most that public fear justifies is a public information campaign to explain the nature of genetics and the relationship between genes and disease.

Consider Dr. Collins' own example: The incidence of type 2 diabetes in the U.S. is about 6 percent. A gene that increases the risk by 30 percent over that background rate thus increases the probability that any given individual carrying the mutation will develop type 2 diabetes to about 8 percent. If an insurer wished to act rationally and were not prevented by regulation from doing so, how would that insurer react to the news that someone it covered tested positive for the gene Dr. Collins mentions? Canceling the policy makes little sense economically. Instead, customers and policy makers should expect insurers to behave rationally in order to maximize profits. A life insurance firm might theoretically carve out a new risk pool that includes those with type 2 diabetes, and it may be forced to increase the premiums paid by policy holders in that risk pool. But health insurers, on the other hand, are unlikely to have sufficient economic incentive to change their current practices.

Perhaps more importantly, a fear that one's insurance premiums may rise slightly due to genetic information hardly seems to warrant refusing to be tested, especially given the significant medical value of the information. Knowing that you are genetically predisposed to type 2 diabetes provides important information that you could use to take action to prevent or at least manage the disease. Indeed, armed with the knowledge that one or more policy holders are at a greater risk of developing type 2 diabetes—a multifactorial disease that appears to be affected as much, if not more, by diet and exercise—the insurer may well offer financial incentives, in the form of lower premiums, to encourage risk-reducing behavior among those customers. If the incentives do, indeed, cause the customers to eat a better diet and to exercise more, they may actually reduce the overall risk of illness to a point as low as or lower than those who test negative for the same mutation and who therefore continue to eat poorly and get little exercise.

Even if there were a reasonable fear of substantial insurance repercussions from a positive test, this does not show that the rational customer would forgo genetic testing, and it therefore does not indicate that the rational customer will fail to reap the full benefits of genetic testing. Consider the COLARIS test for the genetic predisposition to colon cancer.[38] If you know that early detection and removal are crucial

to the effective treatment of colon cancer, then you know that you would be better off having the COLARIS test, even at the risk of a rise in your rates on news of a positive test. Putting the matter in terms of fears—as regulation's proponents so often do—the fear of colon cancer spreading undetected in your body surely rates higher than the fear of losing insurance or, more likely, paying somewhat more for insurance.

Other arguments for controlling insurer access to genetic information rest on "genetic exceptionalism"—the idea that there is something special about genetic information that makes it different from all other medical information. This idea probably stems from the public's misunderstanding of what a positive genetic test actually indicates. Regulation proponents often point out that one's genes are unchosen and immutable, and thus argue that it is unfair to penalize anyone for such attributes. Yet there is no practical distinction between genetic information and other information in one's medical records—information such as family history, history of disease, blood test results, and so on. Many of the attributes revealed by this information (e.g. parentage) are also unchosen, but insurers are permitted access to this information because it allows them to provide the services that most of us have come to rely upon. Similarly, neither family medical history nor a positive result on most genetic tests guarantee that a person will develop a particular disease. The latter may have somewhat greater predictive value than the former, but both merely provide information to insurers and consumers that indicate a greater propensity. Why should genetic information be treated differently?

Because nearly all diseases with a genetic component can be prevented or treated with early detection, widespread genetic testing is far more likely to result in improved health outcomes, which could yield lower health and life insurance premiums.

VII. Conclusion

Arguments in favor of bans on using genetic test information simply cannot be sustained. There is no strong evidence that genetic discrimination is currently a widespread problem, or that it is likely to become one in the future. Indeed, since the passage of HIPAA in 1996, the use by health insurers of such genetic information has been forbidden by law. Even in the absence of such legislation—such as in the life insurance market—there is little reason to believe that most genetic information would result in a genetic discrimination crisis. Because nearly all diseases with a genetic component can be prevented or treated with early detection, widespread genetic testing is far more likely to result in improved health outcomes, which could yield lower health and life insurance premiums.

On the other hand, forbidding insurers to use genetic test results or other types of relevant information can restrict efficient underwriting and trap all consumers into higher overall costs. Ultimately, arguments for increased regulation of health and life insurers make neither economic nor practical sense.

Notes

1   Shawna Williams, "The impact of genetic discrimination," Genetics & Public Policy Center Issue Brief (October 24, 2006).

2   With regard to life insurance in particular: "In general, the public believes that genetic information would result in life insurance companies refusing to issue policies (85.1 percent) or charging higher premiums (85.1 percent)." *See* Mark A. Rothstein and Carlton A. Hornung, "Public Attitudes," *in* Mark A. Rothstein (ed.), *Genetics and Life Insurance: Medical Underwriting and Social Policy* (MIT Press: Cambridge, MA, 2004), p. 8.

3   Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified in various sections of 26, 29, and 42 U.S.C.).

4   Americans With Disabilities Act, Pub. L. No. 101-336, 104 Stat 327 (codified in 42 U.S.C. §§12101-12213).

5   Will Dunham, "Backers push for genetic nondiscrimination bill," *Science News* (January 31, 2007).

6   Sheryl Gay Stolberg, "President Calls for Genetic Privacy Bill," *New York Times* (Jan. 18, 2007) p. A14.

7   Sharon Begley, "Bill Seeking to Ban DNA Discrimination Isn't Really Necessary," *Wall Street Journal* (Feb 6, 2004), p. B1.

8   Wendy R. Uhlmann and Sharon F. Terry, "Perspectives of Consumers and Genetics Professionals," *in* Mark A. Rothstein (ed.), *Genetics and Life Insurance: Medical Underwriting and Social Policy* (The MIT Press: Cambridge, MA, 2004), especially pp. 151-6.

9   Philip R. Reilly, "Genetic Discrimination," *in* Clarisa Long (ed.), *Genetic Testing and the Use of Information* (AEI Press: Washington, 1999), pp. 106-33.

10   Virginia E. Lapham, Chahira Kozma, and Joan O. Weiss, "Genetic Discrimination: Perspectives of Consumers," *Science* Vol. 274 (October 25, 1996), pp. 621-24.

11   Reilly, "Genetic Discrimination." p. 116.

12   *Id.*, p. 112.

13   Approximately 66 percent of full time workers participated in an employment-based health care benefits program in 2005. U.S. Census Bureau, *Statistical Abstract of the United States: 2007* (Government Printing Office, Washington, 2007) Tables 144, 147.

14   Mark A. Hall and Stephen S. Rich, "Laws Restricting Health Insurers' Use of Genetic Information: Impact on Genetic Discrimination," *American Journal of Human Genetics*, Vol. 66 (2000), pp. 293-307.

15   Ibid., p. 296.

16   Ibid., p. 299.

17   P. Lichtenstein, N.V. Holm, P.K. Verkasalo, et al., "Environmental and heritable factors in the causation of cancer—analyses of cohorts of twins from Sweden, Denmark, and Finland," *New England Journal of Medicine*, Vol. 343, No. 2 (July 13, 2000), pp. 78-85.

18   Cristina Gutierrez and Angus MacDonald, "Huntington's Disease and Insurance I: A Model of Huntington's Disease," Department of Actuarial Mathematics and Statistics Research Report No. 02/3 (Heriot-Watt University: Edinburgh, 2002).

19   Darryl R. J. Macer, "Ethics and Prenatal Diagnosis," *in* A. Milunsky (ed.) *Genetic Disorders and the Fetus: Diagnosis, Prevention and Treatment* (John Hopkins University Press 1998), pp. 999-1024; James P. Collman, *Naturally Dangerous: Suprising Facts About Food, Health, and the Environment* (University Science Books: Sausalito, Calif., 2001).

20   C.B. Begg, "On the use of Familial Aggregation in Population-based Case Probands for Calculating Penetrance," *Journal of the National Cancer Institute*, Vol. 94 (2002), pp. 1221-1226.

21   Bernd Frank, Kari Hemminki, Barbara Wappenschmidt, et al., "Association of the CASP10 V410I variant with reduced familial breast cancer risk and interaction with the CASP8 D302H v," *Carcinogenesis* Vol. 27, No. 3 (2006), pp. 606-609; National Cancer Institute, "Variation in gene caspase-8 may help protect against breast cancer," National Cancer Institute press release (Feb. 12, 2007), http://www.cancer.gov/newscenter/pressreleases/CASP8.

22   *See*, *generally*, Catherine England, *The Business and Regulation of Insurance: A Primer* (Competitive Enterprise Institute: Washington, 1996).

23   Mark A. Hall and Stephen S. Rich, "Laws Restricting Health Insurers' Use of Genetic Information: Impact on Genetic Discrimination," *American Journal of Human Genetics*, Vol. 66 (2000), pp. 293-307.

24   England, *The Business and Regulation of Insurance*.

25   Hall and Rich, "Laws Restricting Health Insurers' Use of Genetic Information."

26   Arnold A. Dicke, "The Economics of Risk Selection," *in* Mark A. Rothstein (ed.), *Genetics and Life Insurance: Medical Underwriting and Social Policy* (MIT Press: Cambridge, MA, 2004), especially pp. 64-6.

27   Mark A. Hall, "Restricting Insurers' Use of Genetic Information: A Guide to Public Policy," *North American Actuarial Journal*, Vol. 3, No. 1 (Jan. 1999), pp. 34-46.

[28] Richard A. Posner, "Should Genetic Testing Be Forbidden?" *Becker-Posner Blog* (Feb. 19, 2007), http://www.becker-posner-blog.com/archives/2007/02/should_genetic.html#trackbacks.

[29] Dicke, "The Economics of Risk Selection."

[30] Jane Zhang, "Genetic-Discrimination Ban Nears Congressional Approval," *Wall Street Journal* (Feb. 15, 2007), p. A11.

[31] Caren Bohan, "Mrs. Clinton: Universal Healthcare Needed," Reuters (June 3, 1998), http://www.netlink.de/gen/Zeitung/1998/980306.htm.

[32] Gutierrez and MacDonald, "Huntington's Disease and Insurance"; *see also* Phil Hardt, Testimony before the Secretary's Advisory Committee on Genetics, Health, and Society, National Institute of Health (October 18-19, 2004), http://www.hdac.org/features/article.php?p_articleNumber=303.

[33] Currently, a chemical test that detects antigens associated with the actual presence of prostate cancer exists, as does a genetic test that can predict the recurrence of the disease in a patient who has already had a cancerous prostate gland removed. But no predictive genetic test for individuals who have not previously been afflicted with prostate cancer is known to exist.

[34] For development of this point, *see* J. Alexander Lowden, "Genetic Risks and Mortality Rates," *in* Mark A. Rothstein (ed.), *Genetics and Life Insurance: Medical Underwriting and Social Policy* (The MIT Press: Cambridge, MA, 2004), especially pp. 98-99.

[35] Williams, "The impact of genetic discrimination."

[36] Precisely this claim is made in section 2.5 ("Findings") of The Genetic Information Nondiscrimination Act of 2007: "Federal legislation establishing a national and uniform basic standard is necessary to fully protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies."

[37] Francis Collins, "Comments by Francis Collins, M.D., Ph.D., Director, National Human Genome Research Institute, Regarding Genetic Nondiscrimination Legislation," National Human Genome Research Institute (April 1, 2004), http://www.genome.gov/11511396.

[38] See "COLARIS: genetic test for hereditary nonpolyposis colorectal cancer (HNPCC)," Myriad pharmaceutical company website, http://www.myriad.com/products/colaris.php.

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