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Health Insurer's Use of Genetic Information: A Missouri Perspective on a Changing Regulatory Landscape

*Robert H. Jerry, II **

At the dawn of the new millennium, the mysteries of the human genome¹ are being revealed: A working draft of ninety percent of the human genome sequence is expected to be completed by mid-2000, five years ahead of schedule.² Few endeavors in human history have promised so much while causing so much concern. Miraculous solutions to dreaded diseases seem within

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1. According to the *Encyclopedia of Human Biology*, the human genome: [C]ontains the hereditary information necessary to specify the human organism. This information is encoded in the sequence of some 3 billion nucleotide subunits composing the DNA in the nuclei of human haploid cells. Over 99% of this sequence is identical in all humans and distinguishes us as a species from other organisms; differences at various points in the other 1% ensure that no two individuals, except identical twins, have exactly the same genetic complement and account for the extensive inherited variation seen in the human population.

Philip Green, *Human Genome*, 4 *ENCYCLOPEDIA OF HUMAN BIOLOGY* 617 (2d ed. 1997). For a recent discussion of a variety of issues associated with advances in genetic technology, see Symposium, *Genetic Technology: Social Values & Personal Autonomy in the 21st Century*, 34 *WAKE FOREST L. REV.* 557 (1999).

2. Charles W. Henderson, *Human Genome Sequence Almost 90 Percent Complete*, *GENE THERAPY WKLY.*, July 26, 1999, available in 1999 WL 11598526 (citing Dr. Francis Collins, Director of the U.S. National Human Genome Research Institute).

reach, but the largely unknown consequences of genetic manipulation of life on this planet cast long shadows on the public's enthusiasm for these remarkable discoveries. When measured against the international turmoil caused by disagreements over genetically engineered agricultural products³ and the widespread fear of the prospect of human cloning,⁴ the implications of the new genetic knowledge for the insurance business seem tame by comparison. Currently, no health insurers are known to use genetic information⁵ in underwriting decisions.⁶ But the implications of genetic information for

3. See, e.g., *EU/US: Washington Recoils from Gene Food Fight*, EUROPEAN REPORT, July 28, 1999 (U.S. Secretary of Agriculture warns that EU's de facto moratorium on genetically modified crops may undermine the launch of the autumn 1999 talks of the World Trade Organization); *Gerber Vows to Stop Using Bioengineered Products*, SAN DIEGO UNION & TRIB., July 31, 1999, at A10 (largest maker of baby food in U.S. announces that it is dropping suppliers who use genetic engineering in corn and soybean products); Jeffrey Kluger, *Atlantic Food Fight: The Battle Heats up between the U.S. and Europe over Genetically Engineered Crops*, TIME, Sept. 13, 1999, at 42 (discussing the continuing trade dispute over genetically modified food products); *US, France Try to Ward Off Biotechnology Dispute*, AM. POL. NETWORK-GREENWIRE, June 30, 1999, at 25 (U.S. Agriculture Secretary, after meeting with French Agriculture Minister, states that closure of EU markets to genetically modified crops could case "train wreck between the US and Europe on biotechnology").

4. In a recent poll of 1,264 adult Americans, 60% said they "dread" the thought of living in the world when human cloning is a reality. See August Gribbin, *40 Percent of Americans Fear Major War*, WASH. TIMES, Jan. 3, 1999, at A4 (reporting on poll conducted by Peter Hart for Shell Oil Company on Americans' thoughts about the future); see also Kevin Coughlin, *The Precautionary Principle: We can Clone Sheep, Create Super Crops and See Your Genetic Future. But should we? Some say it's time to stop and think*, STAR-LEDGER (Newark, N.J.), July 25, 1999, at 1 (reporting on social concerns about cloning and other kinds of genetic engineering).

5. Definitions are important, as the discussion of the regulatory landscape, *infra*, makes clear. See *infra* text accompanying notes 23-25, 50-59. Family history is, of course, a kind of genetic information, and family history has been a routine part of insurance underwriting in the personal lines for decades.

6. See Mark. A. Hall, *Legal Rules and Industry Norms: The Impact of Laws Restricting Health Insurers' Use of Genetic Information*, 40 JURIMETRICS J. (forthcoming Fall, 1999). Based on surveys conducted in seven states of insurance regulators, insurance company officials, insurance agents, genetic counselors, patient advocates, and others, Professor Hall concludes that "genetic discrimination by health insurers is very low or nonexistent, both before these laws were enacted and afterwards, and both in states with and without these laws." *Id.* (manuscript at 8). Although some prior research documented employers and insurers using genetic information to deny or limit coverage or raise insurance rates, *Id.* (manuscript at 2 n.5), Professor Hall's detailed assessment of the data indicates that most of these cases either involved existing symptoms rather than predictive genetic information, did not involve health insurance, or related to the "coverage of genetic services rather than the availability and pricing of health insurance." *Id.* (manuscript at 16). Although Professor Hall's research is the most careful on the subject to date, it is consistent with the sentiments of earlier commentators who have

underwriting practices were recognized early on, and the result has been a voluminous quantity of scholarly and popular literature on the significance of genetic information for both the insurance industry and those who purchase its products.⁷

Given what has already been written about genetic testing and insurance, one might fairly wonder if anything remains to be said about a largely nonexistent business practice. As it turns out, the regulatory landscape for insurers' use of genetic information underwent considerable change during the 1990s at both federal and state levels, making it appropriate to revisit this terrain and describe its new contours. Furthermore, in 1999, Missouri joined a majority

some familiarity with the practices of health insurers. See, e.g., Richard E. Braun, *Keeping Life Insurance Affordable in the Era of Genetic Medicine*, 53 J. FIN. SERV. PROFS. 46 (1999), available in 1999 WL 1131096 (“[I]nsurers are not interested in screening tests for conditions that are rare, that do not affect mortality, or that would not lead to significant anti-selection. For that reason, insurers do not use any of the existing conventional screens for heritable diseases.”); William J. Warfel et al., *Genetic Information and Risk Classification in Individual Life and Health Insurance*, 52 J. AM. SOC’Y CLU & CHFC 44 (1998), available in 1998 WL 27615690 (stating that “it appears that insurers currently do not require genetic testing, do not use it in the underwriting process, and rarely encounter genetic testing information on applications”); *No Insurance Discrimination*, APPLIED GENETIC NEWS, June 1, 1999, available in 1999 WL 12885741 (“Contrary to general concern, a recent study [performed by Myriad Genetics] suggested that insurance companies do not discriminate based on genetic tests that show that a particular patient has a [sic] increased risk of developing cancer.”); Chuck Jones, *Insurers Interested in Gene Testing for Underwriting; Agents Not So Sure*, LIFE ASS’N NEWS, April 1, 1998, at 44 (“There are no insurance companies currently using genetic tests in their underwriting of life or health coverage”); Joanne Denise, *Testimony before the Committee on Labor, U.S. Senate*, 144 Cong. Rec. D545-02, D549 (1998), full transcript available in 1998 WL 11518495 (reporting on survey of members of National Association of Health Underwriters which found no health insurers asking questions about genetic testing on an application for health insurance). For predictions on the availability of genetic testing in the future, see *infra* note 31.

7. See, e.g., THOMAS H. MURRAY ET AL., *THE HUMAN GENOME PROJECT AND THE FUTURE OF HEALTH CARE* (1996) (nine essays examining the Genome Project and how it might affect health care); Roberta M. Berry, *The Human Genome Project and the End of Insurance*, 7 U. FLA. J. L. & PUB. POL’Y 205 (1996); Mark A. Hall, *Insurers’ Use of Genetic Information*, 37 JURIMETRICS J. 13 (1996) (surveying arguments for and against allowing insurers to use genetic information; bibliographic information contained in footnotes); Eric Holmes, *Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project*, 85 KY. L. J. 503 (1997); Mark A. Rothstein, *Genetic Privacy and Confidentiality: Why They Are So Hard to Protect*, 26 J. L. MED. & ETHICS 198 (1998) (discussing health insurance, life insurance, and employment issues); Robert H. Jerry, II, *Genetic Testing and Health Insurance: Regulatory Summary and Bibliography*, June 5, 1999 (paper accompanying presentation at 20th Annual Health Law Teachers Conference in St. Louis, Missouri; contains extensive bibliography of articles, essays, congressional materials, and internet materials; on file with the *Missouri Law Review*).

of states that have placed limitations upon health insurers' use of genetic information. This Article examines these new developments in federal and state statutory law and considers whether the regulatory regime is adequate to achieve its communitarian objectives. Specifically, Part I provides a narrative explanation of the significance of genetic information in health insurance. The hypothetical presented in this part illuminates the rationales for existing regulations and illustrates how the availability of information alters the ways in which individuals respond to risk, which in turn affects what risk transference and distribution opportunities insureds demand from insurers. Part II describes the current array of regulations of health insurers' use of genetic information. This part explores both federal and state regulation and gives special attention to the recent statutory enactment in Missouri. Part III links the regulatory framework described in Part II to the rationales for regulation developed in Part I. It concludes that the current regulatory scheme is both tentative and ambivalent. This conclusion casts doubt on whether, in a hypothetical environment where genetic testing is widely available and widely used, the regulatory objectives could be achieved without further changes in federal and state law.

I. A NARRATIVE ON THE SIGNIFICANCE OF GENETIC INFORMATION FOR THE ORGANIZATION OF RISK DISTRIBUTION POOLS

Fifty men and women, all strangers to each other, sit in a room. The "leader" enters the room and distributes to each of the fifty a one-page sheet with approximately one hundred letters and numbers printed on it.⁸ The meaning of the pattern of seemingly random letters and numbers is not known to anyone in the room.⁹ The leader explains that she, having secured the genetic code for each person in the room, has just distributed it to its respective "owner." At this moment, it is obvious that each person feels profoundly violated and insecure. The violation comes from the leader's demonstration that she could access such intimate and personal information. The insecurity comes from the shared suspicion about what the leader is going to say next. The air is heavy with fear that the leader will reveal disturbing information about their futures, information that many prefer not to know. Indeed, some would rather not know even "good information" about their genetic profiles, preferring instead to live in ignorance of whatever the future holds.

8. The 100 letters and numbers are proxies for the roughly 100,000 genes in the human genome. For more information on the nature of the human genome, see Green, *supra* note 2, at 617.

9. If this exercise is performed in a classroom or other setting, the symbolism of the random distribution of genetic profiles to individuals in the room should be emphasized. Individuals cannot control the genes received at birth; genetic fortune and misfortune are randomly distributed throughout society, just as the hypothetical genetic profiles are distributed to those in the room.

The leader explains that all persons, including everyone in the room, have between five and fifty significant genetic alterations.¹⁰ Some alterations are irrelevant, and others are more serious.¹¹ For about three percent of those in the room, the weak links will be irrelevant; they will perish in an accident¹² before the genetic defect becomes manifest. But for the other ninety-seven percent, the leader explains that one of the weak genetic links eventually will manifest itself and either cause or contribute to their death. The weak link may act by itself or, as is more likely, in conjunction with other factors to produce death. If multiple factors are involved, the genetic weakness is likely to define a range of probabilities within which the individual's fate will be determined by other considerations, including some that he or she can control.¹³ With respect to most genes, however, the leader concedes that science does not yet understand how they function or interact with other elements in the environment to increase or reduce morbidity and mortality. Even so, the leader observes that two of the fifty genetic profiles just distributed convey very bad news: a certainty of early death due to a prolonged, not-yet-manifested, inevitable illness.

At this juncture, the narrative could take one of two turns, each leading to a very different conclusion. In the first scenario, the leader does not reveal who possesses the fateful genetic information, and she observes that each person in the room has the same chance of holding a fateful profile. This equal chance of misfortune creates a shared interest among those in the room. In effect, the randomness of the risk creates a special kind of community. Perhaps without the leader's prompting, someone in the room will speak up and say, "Let's make an agreement among ourselves. No matter who in the room has the unfortunate prognosis, let's agree that each of us will contribute to the cost of taking care of the end-of-life health care needs of that person." The proposal is to form a mutual aid society—to establish a community consisting of all fifty persons in the room. The advantage of membership in this community is the security achieved by belonging to it; the risk of financial loss associated with the probability of holding a poor genetic profile is transferred to the common, to-be-

10. See Monique K. Mansoura & Francis S. Collins, *Medical Implications of the Genetic Revolution*, 1 J. HEALTH CARE L. & POL'Y 329, 334 (1998) ("All of us carry an estimated five to fifty significant genetic alterations.").

11. See also Katrina Allen & Robert Williamson, *Should We Genetically Test Everyone for Haemochromatosis?*, 25 J. MED. ETHICS 209, 212 (1999) ("[W]e all carry a number of recessive genes that are not clinically important unless two persons with the same recessive mutation have children.").

12. In 1997, approximately 3.57 percent of all deaths in the United States resulted from accidents or the adverse effects of accidents. *Table 26: Number of deaths, death rates, and age-adjusted death rates for major causes of death for the United States, 1997*, 47 NAT'L VITAL STATISTICS REPS., June 30, 1999, at 82.

13. For a discussion of the predictive limitations of genetic information, see H. Gilbert Welch & Wylie Burke, *Uncertainties in Genetic Testing for Chronic Disease*, 280 J.A.M.A. 1525 (1998).

created pool. Each person in the room substitutes a certain, small loss—the commitment to absorb one-fiftieth of the cost of caring for the unfortunate persons' health care costs—for the one in twenty-five chance of having to bear one hundred percent of the cost of a life-terminating illness. Each person is asked—and is willing—to pay this certain, small loss in exchange for being freed from the risk of devastating economic misfortune. After all, suffering personal misfortune would be difficult enough; finding a way to avoid compounding the grief with economic devastation is imperative for everyone.

When the leader distributes the uninterpreted genetic information, quick action is needed to form the mutual aid society. Once the manifestation of illness or the interpretation of the genetic information makes it clear who has the fateful genetic profiles, it will become much more difficult, perhaps impossible, to strike the deal. This is the second scenario: Before the multilateral commitments are made, the leader reveals the identities of those who are destined to perish from the genetically ordained illness. Unless the fifty persons in the room are altruists who take pleasure in assuming the expenses of others (and altruists of varied fervor do exist in society), the possibility of forming a mutual aid society fades when the implications of the genetic information are understood. Those forty-eight persons in the room who learn that their genetic profiles are sound will opt to allocate their resources to things other than subsidizing the problem faced by the unfortunate. After all, these forty-eight have learned that they have no risk; consequently, there is nothing to transfer to a risk distribution mechanism. This does not mean that these persons are without empathy for the unfortunate, but their statements to the unlucky ones are predictable: "I feel sorry for you, and I have sympathy for your misfortune. But I have three children at home, college educations ahead, elderly parents confronting uncertain long-term care expenses, and a spouse to think of, not to mention myself, and I regrettably must tell you that I cannot give you the same priority that I give these other people and needs in my life." The revelation of the meaning of the genetic information makes all the difference. If the identities of those who are affected with bad genes remain unknown, the odds are much higher that all fifty persons will enter into a multilateral arrangement to share the expense, certain to occur but uncertain as to whom, of two persons' illnesses.

This exercise, as simple as it is, illustrates several aspects of the dynamics of group formation in insurance markets. First, embedded in the actuarial realities of insurance are communitarian values. When a group is faced with a significant adverse risk that will attach randomly and unpredictably to one or more individuals in the group, the group's members will tend to organize around a shared understanding. Each person in the group will contribute, pursuant to some agreed-upon formula, to a fund that will be used to compensate the unfortunate, yet-to-be-determined member of the group for his or her impending loss. This shared understanding is mutually beneficial. Each person knows that he or she need not save for contingent catastrophes, each person can substitute a smaller, predictable expense for the risk of catastrophic loss, and each person can devote his or her other resources to productive activities, thereby generating

more wealth for others in the community. The shared understanding also has psychological value. Each person gets the benefits associated with the peace of mind that comes with participating in an organization committed to the well-being of its individual members.¹⁴

Second, while individuals desire the benefits of membership in communities, not all individuals are welcomed into membership on equal terms. Under the second scenario above, the forty-eight persons with solid genetic profiles still face equal, random chances of misfortune, some of which is nevertheless related to their genetic compositions. If they begin to think about these risks, they might form a mutual aid society to disperse their remaining risks, but they will not offer the two persons with the weak genetic profiles membership in this more narrowly defined community. Stated otherwise, to the extent that a person desiring membership is known to be "high risk" and therefore more likely to draw upon the resources of the collective, he or she will not be welcome into the membership on the same terms offered to other similarly situated persons, and perhaps not at all. Thus, from the perspective of the forty-eight individuals with common characteristics, it is better if larger communities—the group of fifty in this exercise—are subdivided into differentiated risk pools: one for high-risk and one for low-risk individuals. This segmentation enables those with lower risks to benefit economically by paying lower premiums for the smaller risks they transfer to the pool. One hopes that the two persons excluded from the community of forty-eight will find many other similarly excluded persons and that these high-risk persons will organize their own mutual aid society. Yet if the risk of loss is at or near one hundred percent, the odds of being able to form a community on terms requiring less than a premium equal to the loss are practically nonexistent.

Third, to the extent broader pools of insureds with more extensive risk-sharing among diverse populations based on principles of community rating¹⁵ are

14. The industry promotes peace of mind in its marketing campaigns. Such phrases as "like a good neighbor, State Farm is there," "you're in good hands with Allstate," get a "piece of the rock" (Prudential), "Nationwide is on your side," etc. appeal to the policyholder's desire for security, which underscores the psychological value of insurance. For more discussion, see Tom Baker, *Constructing the Insurance Relationship: Sales Stories, Claims Stories, and Insurance Contract Damages*, 72 TEX. L. REV. 1395 (1994); Deborah A. Stone, *Promises and Public Trust: Rethinking Insurance Law Through Stories*, 72 TEX. L. REV. 1435 (1994).

15. "Community rating" refers to a method of determining the price of health insurance based on the anticipated utilization by the population as a whole, as opposed to anticipated utilization by individuals or specific groups. Premiums, then, average out across the entire community, without regard to whether any particular individual has, or is likely to have (or does not have or is not likely to have) any particular health-related trait or characteristic. Under community rating schemes, low-risk insureds subsidize high-risk insureds. In contrast to community rating is "experience rating," where a premium for health insurance is based on a group's past claims experience. Healthier subgroups of a community pay less for insurance, and those who need more health care

desired, system designers must account for the preferences of insurance consumers, which drive insurers to create smaller, more homogeneous communities. That is, systems which are neither compulsory nor universal must contend with the desire of individuals to organize in mutual aid communities consisting of individuals with similar loss potential. This, in brief, is the practical significance of the foregoing narrative. If members of a large community know about the differences among the members and understand the significance of these differences, and if altruism is not a shared cultural norm, the low-risk members will ask to be segregated from the high-risk members. Products will appear in the market, whether created by the low-risk persons directly or created by others, that will fulfill this demand. The regulatory mechanisms described in Part II can be understood as a social and political response to the inevitable tendency toward market segmentation that arises when information about risk becomes more widely disseminated and understood.

II. REGULATING HEALTH INSURERS' USE OF GENETIC INFORMATION

A. Missouri S.B. 722

In 1998, with relatively little fanfare, the Missouri legislature passed¹⁶ and the Governor signed into law Missouri S.B. 722¹⁷ which, inter alia, restricts Missouri health insurers' use of genetic information in underwriting practices. These provisions comprise one part of a more extensive bill covering two other insurance topics.¹⁸ To the extent the genetic discrimination provisions received

(such as the elderly) pay more for health insurance.

16. There was little controversy about the legislation, Senate Bill 722. S.B. 722, 89th Leg., 2nd Sess. (Mo. 1998). S.B. 722 passed the Senate unanimously (32-0) and passed the House 133-23. S.B. 722 was sponsored by Sen. Betty Sims, *Id.*; a similar but broader House Bill, H.B. 1316, was sponsored by Rep. Patrick Dougherty. *See* H.B. 190, 90th Leg., 1st Sess. (Mo. 1999). The House Bill was reintroduced in the 1999 legislature by Rep. Dougherty as H.B. 190, but was subsequently withdrawn. As proposed, H.B. 190 was more robust than S.B. 722 in that it proposed to make the violator "liable in a civil action for damages and equitable relief" in addition to the \$500 (or less) fine mandated by S.B. 722. *Id.* H.B. 190 also defined "genetic information" so as to include "inherited characteristic . . . information," which presumably referred to information about family history and some data revealed by routine medical tests or exams. *Id.* S.B. 722 has a more limited reach. *See infra* text accompanying notes 23-26.

17. S.B. 722 is codified at MO. REV. STAT. §§ 375.1300-.1309 (Supp. 1999). It was signed into law by Governor Carnahan on July 10, 1998, and became effective on January 1, 1999. *See* MO. REV. STAT. §§ 375.1300-.1309 (Supp. 1999).

18. S.B. 722, Section 3 prohibits Missouri insurers from discriminating against victims of domestic violence. This subject is one which has recently received attention in many other state legislatures. *See, e.g.,* ALASKA STAT. § 21.36.430 (Michie 1997) (insurer may not refuse to issue or renew coverage, etc. if the refusal, etc. is based strictly on the fact that insured is a victim of domestic violence); ARIZ. REV. STAT. ANN. § 20-

any attention, the debate closely tracked the debate in other jurisdictions in which the merit of similar regulations has been considered.¹⁹

1. Scope

Most of the statute's scope-defining provisions are drafted narrowly; the cumulative impact is to limit the statute's overall regulatory effect. Like most other state laws regulating the use of genetic information in insurance, the Missouri statute applies only to health insurance. Life insurance, disability insurance, long-term care insurance, and reinsurance are specifically exempted.²⁰ This underscores the uniqueness of health insurance and the special status that access to health care enjoys in the United States, at least relative to the importance placed on the economic welfare of the survivors of decedents, on replacing income when one cannot work due to illness or accident, and on the affordability of housing and personal care services for the elderly. Although the

448 (West 1998); 1999 N.D. LAWS 272. It has also been featured in the popular media. See, e.g., *Cover Domestic Victims*, DENVER POST, May 28, 1998, at B10; Andrea Glen, *States Adopt Measures to Protect Abuse Victims from Insurers' Bias*, WALL ST. J., Feb. 8, 1996, at B11. The abuse status of applicants and policyholders is now the subject of several NAIC model acts. See NATIONAL ASSOCIATION OF INSURANCE COMMISSIONERS, MODEL LAWS, REGULATIONS, AND GUIDELINES 895-1 (1999) (*Unfair Discrimination Against Subject of Abuse in Health Benefit Plans Model Act*); *Id.* at 896-1 (*Unfair Discrimination Against Subjects of Abuse in Life Insurance Model Act*); *Id.* at 897-1 (*Unfair Discrimination Against Subjects of Abuse in Disability Income Insurance Model Act*); *Id.* at 898-1 (*Unfair Discrimination Against Subjects of Abuse in Property and Casualty Insurance Model Act*).

The remaining Sections of S.B. 722 regulate the illustrations that insurers might use to explain certain kinds of life insurance products. See S.B. 722 §§ 6-15 (codified at MO. REV. STAT. §§ 375.1500-.1530 (Supp. 1999)).

19. Supporters of the bill claimed that regulation was needed to prevent discriminatory practices by health insurers. The director of cancer screening services at Ellis Fischel Cancer Center in Columbia, Missouri said that all 50 women in the Center's risk-assessment program had declined to take an available genetic test for fear that the privacy of the test results could not be maintained. Data compiled by the Council for Responsible Genetics, claiming that 200 cases of discrimination had existed through the country, was presented. Some insurers opposed the bill on account of its alleged ambiguity and potential effects on life insurance. Alliance Blue Cross/Blue Shield said it does not require genetic tests and had no plans to start doing so. No evidence was presented showing that any resident of Missouri suffered an adverse insurance result on account of genetic testing. See Kim Bell, *Missouri Bill Would Separate Genetic Testing, Insurers' Action*, ST. LOUIS POST-DISPATCH, Feb. 10, 1998, at A1 (reporting on bill and recent hearing before House Insurance Committee); see also Bill Bell Jr., *Insurance Discrimination Measure is Backed; Panel Oks Bill to Help Domestic Violence Victims*, ST. LOUIS POST-DISPATCH, April 22, 1998, at B4; Bill Bell Jr., *Senate Passes Bill to Prevent Bias After Genetic Testing*, ST. LOUIS POST-DISPATCH, May 9, 1998, at A20.

20. S.B. 722, § 2(3), 89th Leg., 2nd Sess. (Mo. 1998).

statute's scope is confined to health insurance, "insurer" is defined broadly to include any entity engaged in the business of insurance as well as health maintenance organizations and "other similar health service plans."²¹

"Genetic information" and "genetic test" are defined narrowly, thereby further limiting the statute's reach. Section 1(3) defines "genetic information" as "the results of a genetic test," but expressly excludes from this definition information obtained from "family history, the results of routine physical measurements, or the results of chemical, blood, urine analysis, or from results of tests for drugs or the presence of human immunodeficiency virus, or the results of any other tests commonly accepted in clinical practice at the time."²² Further, "genetic test" is defined as "a laboratory test of human deoxyribonucleic acid (DNA) or ribonucleic acid (RNA) used to identify the presence or absence of inherited alterations in the DNA or RNA which cause predisposition to disease or illness." This definition explicitly excludes information obtained from "routine physical measurements and examinations, routine tests performed as a part of a physical examination, chemical blood or urine analysis, cholesterol tests, tests for the presence of the human immunodeficiency virus, a test for drugs, or tests commonly accepted in clinical practice at the time."²³ The upshot of these definitions is that health insurers are authorized to conduct traditional medical tests as part of the underwriting process, even if such tests reveal genetic disorders or other kinds of information that would be revealed by a genetic test. Similarly, if the insurer (or its agent) directly examines the applicant and detects a genetic disorder by merely observing a physical symptom of that disorder, the insurer can lawfully use the information in underwriting. Moreover, the insurer is allowed to use the information with respect to not only the insured or prospective applicant but also the relatives of that individual, which may be important if the information concerns an inheritable genetic disorder.

The statute's narrow definitions of "genetic information" and "genetic test" are ironic in that they forbid use of the "best evidence" of a genetic condition—the results of a genetic test—but allow insurers to use "second-best evidence," such as inquiries about family history and other non-genetic medical tests which nevertheless discover genetic information. To the extent second-best evidence is used as a proxy for the best evidence (*i.e.*, to the extent second-best evidence is used to make a distinction that could be made more accurately through some other means), some persons will be disadvantaged. Yet if genetic tests are too expensive relative to the gains in accuracy to be achieved by administering them, no one should favor their use, because no one would benefit economically from such testing. This appears to be the situation in Missouri and

21. *Id.* § 1(5).

22. *Id.* § 1(3). For the argument that DNA-based information is distinct from information garnered from non-genetic tests and therefore should be regulated differently, see Ronald M. Green & A. Mathew Thomas, *DNA: Five Distinguishing Features for Policy Analysis*, 11 HARV. J. L. & TECH. 571 (1998).

23. S.B. 722, § 1(4).

elsewhere, at least for the present. Essentially, the statute forbids a method of inquiry into risk that no insurer in Missouri apparently now uses or desires to use. At the same time, the statute authorizes insurers to use other types of inquiry that can reveal, albeit less accurately, the same kind of information as genetic tests, thereby producing similar trends toward genetic segregation. If a more durable stand against genetic discrimination were desired, one would not authorize the use of less exact proxies (such as family history) as a substitute for the information that would have been garnered from genetic tests and would instead prohibit insurers from using genetic information acquired from *any* source, including family history, medical history, and routine physical tests.

In contrast to the provisions defining “genetic test” and “genetic information” and confining the statute’s reach to health insurance, the types of insurer activities subject to the statute’s reach are articulated broadly. The underwriting practices that must comply with the statute’s substantive provisions include “determining eligibility for coverage, establishing premiums, limiting coverage, renewing coverage or any other underwriting decision.”²⁴ Furthermore, these practices are to be scrutinized with respect to the “offer, sale, or renewal of a health plan,”²⁵ which covers all ways in which a health plan is marketed.

2. Prohibitions

The statute’s substantive provisions identify four specific practices in which insurers may not engage: (1) “requir[ing] or request[ing] a person or blood relative of such person to provide genetic information or take a genetic test”; (2) “inquir[ing] to determine whether a person or blood relative of such person has taken or refused a genetic test or what the results of any such test were[,]” unless approved by the applicant or insured; (3) “consider[ing] . . . the fact that genetic information or a genetic test was taken or refused by a person or blood relative of such person[,]” unless approved by the applicant or insured; and (4) “consider[ing] . . . genetic information or the results of any genetic test taken by a person or blood relative of such person[,]” unless approved by the applicant or insured.²⁶ Taken cumulatively, these provisions prohibit an insurer from requiring an individual (or blood relative) to undergo a genetic test (or ask about the results of any such test) as a condition to obtaining or renewing insurance coverage. Furthermore, they prohibit an insurer from using, unless approved by the applicant or insured, already existing genetic test results and genetic information (or the fact of whether such a test was ever taken or refused) about an applicant, insured, or any of his or her blood relatives to deny or cancel, or to increase the premiums for, such coverage. If the insurer violates this section, it

24. *Id.* § 2.

25. S.B. 722, § 2, 89th Leg., 2nd Sess. (Mo. 1998).

26. *Id.*

commits an "unfair trade practice" within the meaning of the Missouri Unfair Trade Practice Act.²⁷

Because the statute prohibits insurers from inquiring about genetic tests or genetic test results or otherwise requesting that a test be taken, the question arises as to how an insured's or applicant's approval to use existing genetic information can ever be obtained. By the statute's plain terms, the approval cannot be requested by an insurer or otherwise obtained at the insurer's behest. But if an insured voluntarily discloses or announces a willingness to disclose the results of genetic tests, including those tests taken by blood relatives, the insurer can accept the information without contravening the statute's prohibitions. Thus, an insured or applicant can offer results of genetic tests in order to clarify what might otherwise appear to be a problematic symptom or trait for underwriting purposes. The critical point is that the insurer can accept information offered to it, but the insurer must be careful not to request it.

Missouri is not the only state that allows insureds to volunteer the results of genetic tests and other genetic information.²⁸ Obviously, in these states, no insured will freely submit adverse information to an insurer. Consequently, insurers will receive permission to use information only when it is favorable to the insured or the applicant. Under the Missouri statute, nothing prohibits an insurer from giving *favorable* treatment, in terms of coverage or price, to a person who volunteers good genetic information. As a result, insurers might offer premium reductions to someone who submits a test showing a good genetic profile. In a hypothetical market in which many genetic tests have been given and most persons are able to produce the favorable results of their tests, one should expect a large number of insureds to voluntarily convey their good information in order to secure premium reductions, leaving those with either no tests or poor results to pay higher premiums.

This phenomenon is appropriately labeled proverse selection, which can be understood as a corollary to adverse selection. Adverse selection refers to the tendency in any risk classification for a higher proportion of riskier insureds to self-select into the pool, given that more high-risk insureds will perceive any given classification as a better bargain than lower-risk insureds who fall within the parameters of the classification.²⁹ In contrast, proverse selection refers to the tendency of low-risk insureds to depopulate risk pools when given an opportunity to opt into classifications that offer more coverage or a reduced

27. *Id.* § 2(1) (incorporating the provisions of MO. REV. STAT. §§ 375.930 -.948 (1998)).

28. *See, e.g.*, 410 ILL. COMP. STAT. ANN. 513/20 (West 1997) (insurer may consider results of genetic test if voluntarily submitted by insured and results are favorable); IND. CODE ANN. § 27-8-26-9 (Michie 1994 & Supp. 1999); Genetic Information Nondiscrimination in Health Insurance Act of 1999, 1999 MD. LAWS ch. 50 (disclosure of genetic information allowed only upon consent from the individual tested).

29. *See* ROBERT H. JERRY, II, UNDERSTANDING INSURANCE LAW § 10[c], at 16 (2d ed. 1996).

premium, or both. When a process of proverse selection has run its course, a disproportionate number of high-risk insureds will remain in the former classification, which will prompt an increase in the premiums charged in order to cover the higher losses. The Missouri statute, by authorizing insureds to voluntarily submit genetic information in order to acquire a preferred rate, leaves open the possibility that, notwithstanding the statutory prohibitions, those with adverse genetic information might be charged more for insurance or receive less coverage than those without problematic genetic profiles. This, of course, is precisely the situation the legislature sought to foreclose through the enactment of S.B. 722. For the present, this unintended outcome is unlikely because genetic testing is not widespread. If, however, genetic testing becomes less expensive and more prevalent, as many observers expect,³⁰ the market segmentation which S.B. 722 seeks to foreclose could develop through the process of proverse selection.

3. Other Provisions

Two other aspects of the Missouri statute's genetic information provisions deserve mention. First, a separate section of the statute applies to employers. This section states that "[a]n employer shall not use any genetic information or genetic test results [as defined in the provisions discussed above] . . . of an employee or prospective employee to distinguish between, discriminate against, or restrict any right or benefit otherwise due or available to such employee or prospective employee."³¹ By its terms, this prohibition applies to self-funded

30. See *Genetic Tests Remain Unregulated and Inaccurate*, 6 AM. POL. NETWORK-AM. HEALTH LINE 14 (quoting Francis Collins, Director of the U.S. National Human Genome Research Institute at the NIH, who observes that of the 600 genetic tests already available, "[the] majority are now for very rare diseases in families plagued by certain illnesses," but "more routine testing of now-healthy people to predict their future risks of cancer or other killers is poised to explode"); Braun, *supra* note 7 (observing that although genetic tests will remain expensive for the "near future," "silicon chip-based tests for multiple genetic mutations will be available early in the next century"); Steve Connor, *Firms' Genetic Tests on Staff Should be Illegal, Say Experts*, THE INDEPENDENT (London), July 15, 1999, at 10 (reporting study by UK Human Genetics Advisory Commission finding only one employer using genetic tests now, but observing that the practice could become more widespread as the tests become less expensive).

31. S.B. 722, § 4(1), 89th Leg., 2nd Sess. (Mo. 1998). This Section enumerates four safe harbors for the employer. The prohibition does not apply to (1) underwriting in connection with individual or group life, disability, or long-term care insurance; (2) "[a]ny action required or permissible by law or regulation"; (3) "[a]ction taken with the written permission of an employee or prospective employee or such person's authorized representation"; (4) "[t]he use of genetic information when such information is directly related to a person's ability to perform assigned job responsibilities." *Id.* An employer can be fined for violating the provision, but the fine is small—\$500 for each violation. *Id.* § 4(2). For a concise discussion of the employer provisions, see Armstrong, Teasdale,

health insurance plans. In other contexts an employer operating a self-funded plan can disregard a state regulatory statute because state regulation of self-funded plans is preempted by ERISA.³² In this context, however, state law is in accord with federal prohibitions which, as discussed below, apply to self-funded plans and prohibit the use of genetic information in the underwriting of self-funded plans.³³

Second, a separate section of the statute pertains to confidentiality of genetic information. In essence, any person who handles genetic information in the course of business, the practice of a profession, or the rendering of a service "shall hold such information as confidential medical records and shall not disclose such genetic information" without the written authorization of the person (or his or her authorized representative) to which such information pertains.³⁴ The confidentiality provision applies to any health insurer that happens to acquire access to genetic information. It also applies to any other insurance entity, such as a life, disability, or long-term care insurer, that acquires such information.

B. The Missouri Statute in a Broader Context

The Missouri statute is only one aspect of a much broader regulatory framework. First, federal law places some limits on the use of genetic information by insurers and group health plans.³⁵ Second, thirty-four other states have enacted statutes limiting health insurers' use of genetic information.³⁶ Although these statutes vary in their scope and effect,³⁷ most of them regulate insurers' use of genetic information with respect to both group and individual

Schafly & Davis, *Missouri Law to Prohibit Genetic Discrimination in the Workplace*, 8 MO. EMP. L. LETTER 1 (1998).

32. The Employee Income Retirement Security Act of 1974, 29 U.S.C. § 1001-1461 (1994) (hereinafter ERISA), is a comprehensive federal regulatory scheme for employee benefit plans. As interpreted, ERISA prevents states from regulating self-funded health insurance plans provided to employees as fringe benefits. *See, e.g., American Med. Sec., Inc. v. Bartlett*, 111 F.3d 358 (4th Cir. 1997).

33. *See infra* text accompanying notes 41-63.

34. S.B. 722, § 5(1), 89th Leg., 2nd Sess. (Mo. 1998). This Section has four safe harbors. The prohibition does not apply to (1) anonymous statistical data; (2) data associated with certain kinds of health research; (3) "release of such information pursuant to legal or regulatory process"; or (4) "release of such information for body identification." *Id.* A person can be fined for violating the provision, but the fine is only \$500. *Id.* § 5(2).

35. *See infra* text accompanying notes 41-84.

36. *See infra* text accompanying notes 85-103.

37. For a recent discussion of some of these differences, see Helen R. Davis & Janice V. Mitrius, Note, *Recent Legislation on Genetics and Insurance*, 37 JURIMETRICS J. 69 (1996); Meredith A. Jagutis, Comment, *Insurer's Access to Genetic Information: The Call for Comprehensive Federal Legislation*, 82 MARQ. L. REV. 429 (1999).

plans, and some have freestanding privacy provisions. By virtue of ERISA preemption,³⁸ these statutes do not reach (or, at least, should be understood not to reach³⁹) self-funded plans. Consequently, federal law provides the outer bounds of regulation on insurers' use of genetic information for self-funded plans.

1. Federal Regulation: HIPAA

The Health Insurance Portability and Accountability Act of 1996 ("HIPAA")⁴⁰ regulates the use of genetic information in health insurance in two ways. Because HIPAA does not regulate individual insurance plans, neither set of restrictions extends to the underwriting process for individual insurance plans.

a. Preexisting Conditions and Genetic Information

HIPAA's first restriction on insurers' use of genetic information is related to HIPAA's goal of increasing the portability of group health insurance plans by limiting the effectiveness of preexisting condition exclusions. In essence, this restriction provides that genetic information cannot, in and of itself, constitute a preexisting condition, which means that a covered employee cannot face a denial of coverage based on genetic information alone. Although the principle is easily stated, the statutory structure that produces this outcome is complicated.

HIPAA's portability requirements extend to two categories of entities. First, they extend to any "group health plan," which is defined as "an employee welfare benefit plan to the extent that the plan provides medical care . . . to employees or their dependents . . . directly or through insurance, reimbursement, or otherwise."⁴¹ Thus, this part of HIPAA extends to ERISA-type plans,

38. *See supra* note 33.

39. A few state statutes regulating genetic information purport to reach self-funded plans. *See, e.g.*, ALA. CODE § 27-53-1(3) (Supp. 1999) (defining "health benefit plan" subject to statute as, *inter alia*, "self-insured health plan"); FLA. STAT. ANN. § 627.4301(2) (Supp. 1999) (defining "health insurer" to include self-insured plan). *Compare* GA. STAT. ANN. § 33-54-2(2) (Michie 1996) (defining "insurer" to include, *inter alia*, self-insured plans not subject to exclusive jurisdiction of ERISA). Whatever the intentions of the legislatures in these states, if such regulation occurred and if it were subsequently challenged, existing judicial interpretations of ERISA's preemptive reach would, if consistently applied, invalidate the regulation.

40. Pub. L. No. 104-191, 110 Stat. 1936 (1996) (codified in scattered sections of 29 & 42 U.S.C.).

41. 29 U.S.C. § 1191b(a)(1) (1994). In the corollary provisions in the Internal Revenue Code, "group health plan" is defined by reference to 26 U.S.C. § 5000(b)(1) (1994), which defines the term as "a plan (including a self-insured plan) of, or contributed to by, an employer (including a self-employed person) or employee organization to provide health care (directly or otherwise) to the employee, former employees, the employer, others associated or formerly associated with the employer in

including self-funded plans. Second, the portability requirements extend to “health insurance issuer[s] offering group health insurance coverage.”⁴² A “health insurance issuer” is defined as “an insurance company, insurance service, or insurance organization (including a health maintenance organization . . .) which is licensed to engage in the business of insurance in a State and which is subject to State law which regulates insurance (within the meaning of section 514(b)(2).”⁴³ Thus, with respect to both health plans and health insurers, HIPAA restricts the use of preexisting condition exclusions.

HIPAA broadly defines “preexisting condition exclusion” as “a limitation or exclusion of benefits relating to a condition based on the fact that the condition was present before the date of enrollment for such coverage, whether or not any medical advice, diagnosis, care, or treatment was recommended or received before such date.”⁴⁴ With respect to this definition, HIPAA states further that “[g]enetic information shall not be treated as a condition described in (a)(1) of this section in the absence of a diagnosis of the condition related to such information.”⁴⁵ Under Section (a)(1), plans and insurers can impose a preexisting condition exclusion only if it meets the requirements of that Section.⁴⁶ Thus, genetic information, in and of itself, cannot constitute a preexisting condition, and a covered employee cannot be denied coverage on that account. If, however, a physician diagnoses the individual as having a health condition that is related to the person’s genetic profile, the condition could be the subject of a valid preexisting condition exclusion, assuming the other requirements of Section (a)(1) are met.

There is room to argue about the scope of the “physician diagnosis” exception. The statutory language plainly contemplates that a diagnosis of a symptomatic illness related to genetic information can be a preexisting condition. But it is unclear whether a diagnosis of a predisposition to a health condition related to the genetic information in circumstances where the person is asymptomatic at the time of the diagnosis falls within the exception.⁴⁷ If it is agreed that genetic information unaccompanied by any medical interpretation of the information is not a “condition” and therefore cannot possibly be a

a business relationship, or their families.”

43. 29 U.S.C. § 1181(a) (Supp. III 1997).

44. 26 U.S.C. § 9832(b)(2) (Supp. III 1997); 29 U.S.C. § 1191(b)(2) (Supp. III 1997).

44. 26 U.S.C. § 9801(b)(1)(A) (Supp. III 1997); 29 U.S.C. § 1181(b)(1)(A) (Supp. III 1997).

45. 26 U.S.C. § 9801(b)(1)(B) (Supp. III 1997); 29 U.S.C. § 1181(b)(1)(B) (Supp. III 1997).

46. *See* 26 U.S.C. § 9801(a)(1) (Supp. III 1997); 29 U.S.C. § 1181(a)(1) (Supp. III 1997).

47. *See* Alexandra K. Glazier, *Genetic Predispositions, Prophylactic Treatments and Private Health Insurance: Nothing is Better than a Good Pair of Genes*, 23 AM. J. L. & MED. 45, 65-66 (1997).

“diagnosis of a condition,” Congress must have meant that a diagnosis, based on genetic information, that a person is susceptible to developing symptoms (*i.e.*, a condition) sometime in the future should not be understood to fall within the preexisting condition exclusion. In other words, to be a condition for which coverage might be excluded under the preexisting condition exclusion, the condition related to the genetic information must be manifest or, at a minimum, symptomatic.⁴⁸

b. Defining “Genetic Information”

The term “genetic information,” as used in the above-quoted sections (and elsewhere in HIPAA), is not statutorily defined. At a minimum, the term must be understood to include the results of DNA, RNA, and related gene testing. Family medical history would seem to fit squarely within the ambit of “genetic information”; indeed, the reason insurers have long asked family medical history questions on applications for personal insurance is because of what is known about inheritable characteristics and the implications of such information for the mortality and morbidity of applicants and insureds. This commonsense understanding of “genetic information” is, however, undercut by the text and structure of the statute. In the separate antidiscrimination provisions of HIPAA,⁴⁹ “genetic information” is listed as one item in a series and as one alternative to “medical history,” as well as other factors.⁵⁰ If “genetic information” subsumes “medical history,” one would expect the antidiscrimination provision to have read “genetic information (including medical history),” but this is not how Congress structured the statute. Congress was aware of the role a parenthetical construction might play in the itemized list of health factors because this construction was used in the item “evidence of insurability (including conditions arising out of acts of domestic violence).”⁵¹

48. For the argument that diagnosis of a genetic predisposition is a preexisting condition and that subsequent treatment for that condition may be excluded from coverage, see Glazier, *supra* note 48, at 64-66.

49. See *infra* text accompanying notes 60-63.

50. 42 U.S.C. § 1182 (1994) lists “genetic information” as a health factor, along with “health status,” “medical condition (including both physical and mental illnesses),” “claims experience,” “receipt of health care,” “medical history,” “evidence of insurability (including conditions arising out of acts of domestic violence),” and “disability.”

51. 42 U.S.C. § 300gg-1(a)(1)(G) (Supp. III 1997). Text and its organization are, of course, highly relevant to discerning congressional intent. See, e.g., *Jones v. United States*, 119 S. Ct. 2090, 2102 (1999) (“Statutory language must be read in context and a phrase ‘gathers meaning from the words around it.’”) (quoting *Jarecki v. G.D. Searle & Co.*, 367 U.S. 303, 307 (1961)); *Holloway v. United States*, 119 S. Ct. 966, 969 (1999) (stating that “the language of the statutes that Congress enacts provides ‘the most reliable evidence of its intent’”) (quoting *United States v. Turkette*, 452 U.S. 576, 593 (1981)); *Securities Indus. Ass’n v. Board of Governors*, 468 U.S. 207, 218 (1984) (stating that it is a “familiar principle of statutory construction that words grouped in a list should be

Because Congress did not use the phrase “genetic information (including medical history),” the logical conclusion to draw is that “genetic information,” as that term appears in HIPAA’s portability regulation provisions, should be given a reading that does not include medical history,⁵² notwithstanding the irony that such a conclusion entails.⁵³

To defend a reading of “genetic information” that extends to family medical history and personal medical history, including the results of routine laboratory tests, one must reason that the use of the phrase in the antidiscrimination sections is irrelevant to the portability regulation provisions.⁵⁴ Without acknowledging the nuances of the statutory text, the Pension and Welfare Benefits Administration of the Department of Labor in its 1997 regulations implementing HIPAA gave the term “genetic information” an expansive reading: “Genetic information means information about genes, gene products, and inherited characteristics that may derive from the individual or a family member. This includes information regarding carrier status and information derived from laboratory tests that identify mutations in specific genes or chromosomes, physical medical examinations, family histories, and direct analysis of genes or chromosomes.”⁵⁵ These regulations have not been subjected to judicial review.

given related meaning”).

52. Note that for purposes of the antidiscrimination provisions, the separate itemization of “genetic information” and “medical history” has no significance, because all items on the list are proscribed. For more discussion, see *infra* text accompanying notes 60-63.

53. See *supra* text following note 24; see also Cedar Rapids Community Sch. Dist. v. Garret F., 119 S. Ct. 992, 997 (1999) (“The phrase ‘medical science’ in [Individuals with Disabilities Education Act] does not embrace all forms of care that might loosely be described as ‘medical’ in other contexts . . .”).

54. The standard to be used to assess whether the agency has departed from the statutory text has been described by the Supreme Court on numerous occasions. See, e.g., United States v. Haggar Apparel Co., 119 S. Ct. 1392 (1999); National Credit Union Admin. v. First Nat’l Bank & Trust Co., 522 U.S. 479 (1998). In *Haggar Apparel*, the Court explained:

In the process of considering a regulation in relation to specific factual situations, a court may conclude the regulation is inconsistent with the statutory language or is an unreasonable implementation of it. In those instances, the regulation will not control. Under *Chevron* [U.S.A. v. Natural Resources Defense Council, 467 U.S. 837 (1984)], if a court determines that ‘Congress has directly spoken to the precise question at issue,’ then ‘that is the end of the matter; for the court, as well as the agency, must give effect to the unambiguously expressed intent of Congress.’ If, however, the agency’s statutory interpretation ‘fills a gap or defines a term in a way that is reasonable in light of the legislature’s revealed design, we give [that] judgment ‘controlling weight.’”

119 S. Ct. at 1399 (quoting *Nations bank, N.A. v. Variable Annuity Life Ins. Co.*, 513 U.S. 251, 257 (1995)) (second alteration in original) (internal citations omitted).

55. 29 C.F.R. § 2590.701-2 (1999).

As of late 1999, legislation was pending in Congress that, if enacted, would supersede the PWBA interpretation.⁵⁶ Under the proposed legislation, a distinction is drawn between "genetic information," which includes not only information about genes but also "inherited characteristics that may derive from an individual or family member," and "predictive genetic information," which includes genetic test information and "information about the occurrence of a disease or disorder in family members" but not information acquired from medical tests, physical exams, or information about a person's sex or age.⁵⁷ In the proposed legislation, insurers are prohibited from premium discrimination based on "predictive genetic information," which has the effect of allowing insurers to consider some genetic information, *i.e.*, that obtained through "physical" medical tests and exams.

If one gives a broad interpretation to the term "genetic information," such as that provided by the PWBA, then the regulatory sweep of HIPAA becomes much wider than that of the Missouri statute. In that event, the narrower definition in the Missouri statute is irrelevant for plans within the reach of HIPAA. If, however, "genetic information" is given a narrower reading, the possibility exists that a state might define "genetic information" more broadly and thereby impose more aggressive regulation on the use of the information. Because the Missouri definition of "genetic information" is already quite narrow,⁵⁸ it is doubtful, given the pending federal legislative proposals, that this latter circumstance will arise, at least in Missouri.

c. HIPAA's Antidiscrimination Provisions and Genetic Testing

The second way in which HIPAA regulates health insurers' use of genetic information arises out of the statute's antidiscrimination provisions. This part of HIPAA prohibits group health plans and health insurance issuers⁵⁹ from using genetic information, medical history, or other specified health factors to discriminate against individual participants and beneficiaries (*i.e.*, either

56. *See infra* notes 84-89.

58. *See* S.B. 1344, § 301(c), 106th Cong., 1st Sess. (1999). In the proposed statutory text, the medical tests are described as "physical tests, such as the chemical, blood, or urine analyses of the individual including cholesterol tests." *Id.* Under this proposed statutory language, an insurer could not use information from a urine test that revealed a kidney disorder, but the insurer could use the insured's answers that he or she had been treated in the past for a kidney disorder, assuming the information was used in connection with the premium charged all members of the group and not just the individual with the disorder.

59. *See supra* text accompanying notes 23-24.

59. 29 U.S.C. § 1182(a)(1) (Supp. III 1997) applies to group health plans and to health insurance issuers offering group health insurance coverage in connection with a group health plan. The corollary provision, 26 U.S.C. § 9802 (Supp. III 1997), applies only to group health plans.

employees or their dependents).⁶⁰ In other words, plans cannot adopt eligibility criteria or enrollment rules that discriminate against individuals based on any of the enumerated factors.⁶¹ HIPAA also prohibits plans from charging an individual a premium that exceeds the premium charged to other similarly situated individuals in the group based on genetic information or any of the other enumerated health factors.⁶²

d. What HIPAA Does Not Do

By HIPAA's express terms, the antidiscrimination provisions do not require plans to provide particular benefits or to restrict the "amount, level, extent, or nature of the benefits or coverage for similarly situated individuals enrolled in the plan or coverage."⁶³ Thus, plans and health insurers are free to determine what coverage they wish to offer and what premiums they wish to charge, subject to state insurance laws that may regulate coverage and premiums, at least to the extent the plans are not self-funded.⁶⁴ This means that a plan may decide to exclude coverage for a particular medical condition, but it must apply the exclusion to all enrollees on a nondiscriminatory basis. In other words, the plan could not refuse to enroll (or fail to renew) a particular individual with the medical condition when its policies provide coverage for that condition. Thus, if a group contains one or more persons with a known or suspected genetic disorder, the insurer could, without running afoul of HIPAA, raise the premium for that group (subject only to the proscriptions of a particular state's regulations) as long as everyone in the group is required to pay an identical, higher premium.

HIPAA does not regulate individual policies of health insurance.⁶⁵ Insurers remain free, subject to whatever state regulations might exist, to utilize genetic information in determining eligibility to enroll, continued eligibility, price, and coverage for individual policies of health insurance. Because most health insurance is obtained through employer-created groups,⁶⁶ this regulatory gap is

60. For a list of the specified health factors, see *supra* note 51.

61. 26 U.S.C. § 9802(a)(1) (Supp. III 1997); 29 U.S.C. § 1182(a)(1) (Supp. III 1997).

63. 26 U.S.C. § 9802(b) (Supp. III 1997); 29 U.S.C. § 1182(b) (Supp. III 1997).

64. 26 U.S.C. § 9802(a)(2) (Supp. III 1997); 29 U.S.C. § 1182(a)(2) (Supp. III 1997).

65. In that event, the plan is free from state regulation by virtue of ERISA preemption. See *supra* note 33.

65. 26 U.S.C. § 9831(a)(2) (Supp. III 1997); 29 U.S.C. § 1191(a)(1) (Supp. III 1997).

66. In 1996, 71.1% of the U.S. population under age 65 had private health insurance, and 91% of these persons obtained their insurance through a present or former employer or labor union. See UNITED STATES DEP'T OF HEALTH & HUMAN SERVS., HEALTH, UNITED STATES, 1998, at 361, tbl. 133 (1998).

not huge, but it is significant: Approximately 23.5 million Americans obtain their health insurance through individual plans.⁶⁷

HIPAA does not regulate genetic privacy. Thus, it does not prohibit insurers from requiring applicants to undergo genetic testing or to disclose the results of past tests. Nor does it affect the extent to which genetic information might be transmitted to insurers from third parties holding that information and then used by insurers for purposes not affected by the Act, such as setting rates or limiting coverage for an entire group. Because HIPAA does not prohibit insurers from requiring or requesting individuals to undergo genetic tests or to provide the results of any such tests, the insured carries the burden of establishing that an insurer used information against a member of a group in violation of HIPAA's antidiscrimination provisions.

HIPAA does address the issue of genetic privacy in one respect. It requires the Secretary of Health and Human Services to study the privacy issues relating to electronically transmittable individually identifiable health information and make recommendations to Congress.⁶⁸ These recommendations were forwarded to Congress on September 11, 1997.⁶⁹ HIPAA contemplated that Congress would enact privacy legislation; but if Congress failed to enact such legislation by August 21, 1999—a self-imposed deadline Congress failed to meet⁷⁰—the Secretary of HHS is required to promulgate final regulations on such standards by February 21, 2000.⁷¹ This, of course, does not prevent Congress from enacting superseding legislation before or after the Secretary acts. One way or another, however, federal confidentiality standards for individually identifiable medical information will be in place by February 21, 2000, unless Congress repeals its own deadline.

67. This accounts for roughly 10% of insured Americans. *Id.*

68. 42 U.S.C. § 1320d-2, 1320d-3 (Supp. III 1997) (requiring Secretary to make recommendations no later than 18 months after August 21, 1996). For more discussion, see Bartley L. Barefoot, Comment, *Enacting a Health Information Confidentiality Law: Can Congress Beat the Deadline?*, 77 N.C. L. REV. 283 (1998).

69. See Secretary of Health and Human Services, *Confidentiality of Individually-Identifiable Health Information* (visited Oct. 28, 1998) <<http://aspe.os.dhhs.gov/admsimp/pvcrec0.htm>>.

70. See Meg Fletcher, *Deadline Missed on Privacy Rules: Congress May Still Act Before HHS Issues Rules*, BUS. INS., Aug. 16, 1999, at 56 (discussing Congress's failure to meet August 21, 1999 deadline and its implications).

71. Section 264 of Public Law 104-191 provided that "[i]f legislation governing standards with respect to the privacy of individually identifiable health information . . . is not enacted by the date that is 36 months after the date of the enactment of this Act [August 21, 1996], the Secretary of Health and Human Services shall promulgate final regulations containing such standards not later than the date that is 42 months after the date of the enactment of this Act." Pub. L. 104-191, 110 Stat. 2033-34 (1996). On November 1, 1999, President Clinton and Health & Human Services Secretary Shalala announced proposed regulations on the privacy of medical information. See *The White House*, M2 PRESSWIRE, Nov. 1, 1999, available in 1999 WL 24365493.

2. Federal Regulation: The ADA

The Americans with Disabilities Act (“ADA”)⁷² is pertinent to genetic screening in the context of employment-based health insurance, even if much is unclear about this relationship. Title I of the ADA prohibits disability discrimination in the “terms, conditions, and privileges” of employment,⁷³ and the EEOC has interpreted this language as extending to employer-provided fringe benefits, which necessarily includes health insurance.⁷⁴ In March 1995, the EEOC issued a compliance manual that took the position that individuals who experience discrimination due to their genetic profiles are protected under the ADA:

This part [the third part] of the definition of disability [referencing individuals who are regarded as having impairments that substantially limit one or more major life activities] applies to individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders. Covered entities that discriminate against individuals on the basis of such genetic information are regarding the individuals as having impairments that substantially limit a major life activity.⁷⁵

The manual offered the following example:

CP’s genetic profile reveals an increased susceptibility to colon cancer. CP is currently asymptomatic and may never in fact develop colon cancer. After making CP a conditional offer of employment, R learns about CP’s increased susceptibility to colon cancer. R then withdraws the job offer because of concerns about matters such as CP’s productivity, insurance costs, and attendance. R is treating CP as having an impairment that substantially limits a major life activity. Accordingly, CP is covered by the third part of the definition of “disability.”⁷⁶

The EEOC’s position—that the ADA protects persons with asymptomatic genetic conditions from workplace discrimination—deserves deference as an agency effort to interpret the statute it is required to administer, but the agency guidance in the manual is necessarily less authoritative than a statute. Moreover,

72. 42 U.S.C. § 12101-13 (1994).

73. 42 U.S.C. § 12112(a) (1994).

74. 29 C.F.R. § 1630.4(f) (1999).

75. EEOC COMPLIANCE MANUAL 902.8 (1995).

76. *Id.*

commentators disagree on whether the EEOC's interpretation is correct, and the EEOC's interpretation of "disability" has not been subjected to judicial review.⁷⁷

Even if the EEOC's interpretation of "disability" is correct with respect to asymptomatic genetic predispositions, exactly where the interpretation leads is uncertain because the ADA also permits insurers and employers (whether the plan is self-funded or issued by an insurer) to engage in traditional risk classification and underwriting as long as there is no "subterfuge" of the purposes of the ADA.⁷⁸ The correct meaning of "subterfuge" in this context has been much debated,⁷⁹ but a fair reading of the ADA is that Congress intended that "plans remain free to consider how various disabilities influence a person's risk of death or illness. This exclusion permits risk-bearing health plans . . . to consider the anticipated cost of treating various disabilities."⁸⁰ Thus, it would seem that the ADA, although having considerable importance when genetic information is used for non-underwriting purposes, was not intended to prevent insurers and health plans from making coverage distinctions based on genetic information if such distinctions have cost-based, actuarial justifications. Yet if a particular coverage provision or exclusion that adversely affects a person with a particular genetic profile is viewed as a "subterfuge" to discriminate against that person (*e.g.*, to make the job unattractive for disabled workers), the ADA would appear to foreclose use of the genetic information by the insurer or health plan. Absent further guidance from the regulators or Congress, this issue must await clarification by the courts.⁸¹

3. Proposed Extensions of Federal Regulation

As of 1999, various proposals were pending in Congress that, if enacted, would regulate insurers' use of genetic information in the individual health

77. See Paul Steven Miller, *Genetic Discrimination in the Workplace*, 26 J. L. MED. & ETHICS 189, 191 (1998) (discussing Title I of the ADA, the EEOC interpretation, and the attendant controversy). For additional discussion, see William M. Tarnow, *Genetic and Mental Disorders Under the ADA*, 2 DEPAUL J. HEALTH CARE L. 291 (1998). The EEOC's interpretation of "disability" has not yet been subjected to judicial review.

78. 42 U.S.C. § 12201(c) (1994).

79. See John V. Jacobi, *The Ends of Health Insurance*, 30 U.C. DAVIS L. REV. 311, 354 (1997).

80. Philip G. Peters, Jr., *Health Care Rationing and Disability Rights*, 70 IND. L.J. 491, 511 (1995).

81. For more discussion of the intersection between the ADA and health insurance generally, see John K. DiMugno, *The Americans with Disabilities Act and Insurance*, INSURANCE LITIGATION REPORTER, Aug. 15, 1998, at 641; Jacobi, *supra* note 80, at 345-66; Chrys A. Martin & Linda M. Bolduan, *The Impact of the ADA on Life, Health, and Disability Insurance*, 27 THE BRIEF, Summer 1998, at 14.

insurance market and in Medigap plans,⁸² and employers' use of such information in self-funded plans. Moreover, some of these proposals would restrict the adjustment of rates on the basis of genetic information, including prohibiting the adjustment of rates of entire groups based on a group member's genetic information.⁸³

82. The term "Medigap" insurance refers to supplemental health insurance plans sold to the elderly by private carriers. These policies are intended to fill coverage gaps in the Medicare program. For more discussion of these plans and the federal regulations to which they are subject, see Peter Fox et al., *Medigap Regulation: Lessons for Health Care Reform*, 20 J. HEALTH POL. POL'Y & L. 31 (1995).

83. As of September 1999, over twenty bills were pending in the 106th Congress which would affect the use of or access to genetic information by health insurers. On July 15, 1999, the Senate passed S. 1344 (the "Patients' Bill of Rights Plus Act"), which contained among its titles a proposed "Genetic Information Nondiscrimination in Health Insurance Act of 1999." S. 1344, 106th Cong. (1999). This legislation would prohibit a group health plan from adjusting "premiums or contribution amounts for a group on the basis of predictive genetic information concerning any individual (including a dependent) or family member of the individual (including information about a request for or receipt of genetic services)." See Comm. Print, § 302(a) (July 15, 1999). In addition, plans would be prohibited from requesting or requiring such "predictive genetic information." *Id.* A proposed exception from this prohibition, as drafted, read as follows:

[A] plan that provides health care items and services to an individual or dependent may request (but may not require) that such individual or dependent disclose, or authorize the collection or disclosure of, predictive genetic information for purposes of diagnosis, treatment, or payment relating to the provision of health care items and services to such individual or dependent.

Id. § 302(b). S. 1344 would also amend the provisions of HIPAA to include definitions of "genetic information" and "predictive genetic information." *Id.* § 302(a). In the bill, "genetic information" is defined as "information about genes, gene products, or inherited characteristics that may derive from an individual or a family member (including information about a request for a receipt of genetic services)." *Id.* § 302(c). "Predictive genetic information" is defined as:

[I]n the absence of symptoms, clinical signs, or a diagnosis of the condition related to such information—(i) information about an individual's genetic tests; (ii) information about genetic tests of family members of the individual; or (iii) information about the occurrence of a disease or disorder in family members.

Id. This text reaches more information than early drafts of the bill, which qualified the foregoing definition to limit its reach to information "associated with a statistically significant increased risk of a disease or disorder in the individual." See S. 326, 106th Cong. (1999). Specifically excepted from the definition of "predictive genetic information" are information about the individual's age or sex, information "derived from physical tests, such as the chemical, blood, or urine analyses of the individual, including cholesterol tests; and information about physical exams of the individual." Comm. Print, § 302(c) (July 15, 1999).

4. State Regulation

The first state statutes regulating insurers' use of genetic information were enacted in the 1970s.⁸⁴ These statutes tended to focus on specific genetically related conditions, such as sickle-cell, hemoglobin C, and Tay-Sachs traits, and prohibited insurers from basing premium or coverage determinations on them.⁸⁵ In the 1990s, state statutes went beyond specific conditions to broader regulation of insurer practices with respect to genetic testing and underwriting on the basis of such tests. Frequently, these statutes were combined with some measure of privacy protection for the individual applicant and his or her family.⁸⁶

By the end of the 1999 legislative sessions, thirty-five states had enacted statutes regulating the use of genetic information by insurance companies.⁸⁷ The

84. See Karen H. Rothenberg, *Genetic Information and Health Insurance: State Legislative Approaches*, 23 J. L. MED. & ETHICS 312, 313 (1995).

85. *Id.*

86. The enactment of a statute in Wisconsin in 1991 arguably marks the beginning of the era of broader state regulation. *Id.* at 313 (referring to WIS. STAT. ANN. § 631.89 (Supp. 1999)).

87. The statutes of 32 of these states are summarized in *State Positions on the Issue of Genetic Testing for Insurance Coverage*, in 1 NAIC COMPENDIUM OF STATE LAWS ON INSURANCE TOPICS, HE-43-1 through HE-43-7 (1999). For a collection, current as of 1996, of relevant excerpts of many of these statutes, see *Report of the NAIC Genetic Testing Working Group*, 15 J. INS. REG. 7, 21-63 app. (1996). For another detailed compilation of state statutes, see William F. Mulholland & Ami S. Jaeger, *Genetic Privacy and Discrimination: A Survey of State Legislation*, 39 JURIMETRICS J. 317 (1999). Three states—Kansas, Nebraska, and North Dakota—enacted statutes after January 1, 1999, and for that reason are not yet included in the NAIC compendium. See Act of Mar. 19, 1999, 1999 Kan. Sess. Laws ch. 15 (amending KAN. STAT. ANN. § 40-2209 (Supp. 1998)) (in group sickness and accident insurance, “genetic information shall not be treated as a preexisting condition in the absence of a diagnosis of the condition related to such information,” and insurer may not condition eligibility based on genetic information); Act of Feb. 24, 1999, 1999 Neb. Laws L.B. 259 (any entity which issues a health insurance contract subject to state regulation through a “network plan” may decline to cover certain described persons, but only if coverage is terminated without regard to, inter alia, genetic information); Act of Apr. 1, 1999, 1999 N.D. Laws ch. 232 (to be codified at N.D. CENT. CODE § 21-01.3-01 to -09) (defining “genetic information” as “protected health information” which “is created or received by a . . . health plan . . . health or life insurer”; and limiting the extent to which public health authority may disclose information, and the extent to which those who possess genetic information may disclose the information to public health and law enforcement authorities). Two additional states had activity in 1999 relating to prior statutory enactments. New Mexico enacted a technical amendment of its prior statute, which had become effective in 1998. See Act of Mar. 19, 1999, 1999 N.M. Laws ch. 82 (amending N.M. STAT. ANN. § 24-21-7 (Michie Supp. 1998)) (stating that proceedings brought alleging violation of the Genetic Information Privacy Act shall apply to genetic analysis whenever performed and genetic information and gene products whenever obtained). Virginia reenacted, with

content and scope of these statutes vary widely. Some statutes still apply only to specific diseases,⁸⁸ while most apply to genetic information more generally.⁸⁹ Some statutes regulate the use of genetic information only in insurance⁹⁰ or in both insurance and employment.⁹¹ Most statutes pertain only to health insurance,⁹² but a few also apply to health and life insurance,⁹³ and sometimes also to disability insurance.⁹⁴ It is common for the term “genetic information” or “genetic test” to be defined as excluding routine physical tests and other measurements, and many statutes by their terms do not regulate insurers’ use of family or personal medical history.⁹⁵ A few more recent legislative enactments

some amendments, a statute which had expired in 1998. *See* VA. CODE ANN. § 38.2-508.4 (Michie 1999); Act of Mar. 28, 1999, Va. Acts ch.789 (amending VA. CODE ANN. § 38.2-3431 (Michie 1999)); Act of April 7, 1999, 1999 Va. Acts ch.1004 (amending VA. CODE ANN. §§ 38.2-3430.2, -3430.3, -3430.8, -3431, -3432.3, -3514.1 (Michie 1999)); Act of Mar. 29, 1999, 1999 Va. Acts ch. 815 (amending VA. CODE ANN. § 38.2-3431 (Michie 1999)).

88. *See, e.g.*, FLA. STAT. ANN. §§ 626.9706, .9707 (West 1996) (no insurer may discriminate on the basis of applicant having sickle cell trait); LA. REV. STAT. ANN. § 22:652.1 (West 1995) (same); N.C. GEN. STAT. § 58-58-25 (1994) (same plus hemoglobin C); TENN. CODE ANN. § 56-7-207 (Supp. 1997) (same as North Carolina).

89. *See, e.g.*, ARIZ. REV. STAT. ANN. § 20-448 (West Supp. 1999) (insurers not to consider “genetic condition”); CAL. INS. CODE § 10140 (West Supp. 1999) (insurer not to discriminate against person carrying a gene which may be associated with a disability); Va. Code Ann. § 38.2-508.4 (Michie 1999) (insurer not to consider “genetic information”).

90. *See, e.g.*, COLO. REV. STAT. ANN. § 10-3-1104.7 (West 1999); GA. CODE ANN. §§ 33-54-1 to 33-54-8 (1996); MD. CODE ANN., INS. § 27-909 (Supp. 1999).

91. *See, e.g.*, ARIZ. REV. STAT. ANN. § 20-448 (West Supp. 1999) (insurance); ARIZ. REV. STAT. ANN. § 41-1463 (West Supp. 1999) (employment); CONN. GEN. STAT. ANN. § 38a-816 (West Supp. 1999) (insurance); CONN. GEN. STAT. ANN. § 46a-60 (West Supp. 1999) (employment); DEL. CODE ANN. tit. 18, § 2317 (Supp. 1998) (insurance); DEL. CODE ANN. tit. 19, § 711 (Supp. 1998) (employment).

92. *See, e.g.*, GA. CODE ANN. §§ 33-54-1, -8 (1996) (prohibiting genetic information to be used in health insurance); N.H. REV. STAT. ANN. §§ 141-H:1 to -H:6 (Supp. 1999) (health insurer may not require genetic testing or make issuance of policy dependent on result of genetic test); MD. CODE ANN., INS. § 27-909 (Supp. 1999) (same).

93. *See, e.g.*, ARIZ. REV. STAT. ANN. §§ 20-448, -1051 (West Supp. 1999) (unfair trade practice to consider genetic condition in issuing a life and/or health insurance policy); N.Y. INS. LAW § 2612 (McKinney 1999) (genetics not to be considered by insurer of any type of insurance policy); VT. STAT. ANN. tit. 8, § 4724 (1999) (same).

94. *See, e.g.*, COLO. REV. STAT. ANN. § 10-3-1104.7 (West 1999) (prohibiting health and disability income underwriters from either seeking genetic information or using it to deny health or disability income insurance); ME. REV. STAT. ANN. tit. 24-A, § 2159-C (West Supp. 1999) (disability insurers may not discriminate based on results of genetic test); N.J. STAT. ANN. § 17B:30-12 (West Supp. 1998) (insurer may not discriminate based on genetic information in issuing disability policy).

95. *See, e.g.*, COLO. REV. STAT. ANN. § 58-3-215 (West 1999) (defining genetic test

define "genetic information" more broadly to include information from any source relating to genetic characteristics, which embraces medical histories and, presumably, some results of routine medical examinations.⁹⁶ Most statutes are designed to limit the use of genetic tests and information,⁹⁷ but others also include some general genetic privacy provisions with applicability beyond insurance.⁹⁸ Most prohibit the use of genetic information to discriminate *against* an individual or group.⁹⁹ This more common formulation does not expressly prohibit an individual voluntarily providing the insurer with the good results of genetic tests so that the insurer may discriminate in *favor* of the applicant or insured.¹⁰⁰ Some statutes give the greatest attention to preserving the privacy of

in terms of "laboratory test of human DNA, RNA, or chromosomes that is used to identify the presence or absence of alterations in genetic material"); FLA. STAT. ANN. § 627.4301 (West Supp. 1999) (defining "genetic information" as excluding routine physical examinations and chemical, blood, or urine tests; also as excluding questions about family history); GA. CODE ANN. § 33-54-2 (Michie 1996) (excluding "routine physical measurements; chemical, blood, and urine analysis; tests for abuse of drugs; and tests for [HIV]" from scope of "genetic testing"); MD. CODE ANN., INS. § 27-909 (Supp. 1999) (defining "genetic test" as "laboratory test of human chromosomes or DNA"); MINN. STAT. ANN. § 72A.139 (West 1999) (defining "genetic test" as "presymptomatic test of a person's genes, gene products or chromosomes," and excluding "cholesterol test or other test not conducted for the purpose of determining the presence or absence of a person's gene or genes"); NEV. REV. STAT. § 689C.198 (1997) (defining "genetic test" in terms of diagnostic test for DNA); N.C. GEN. STAT. § 58-3-215 (Supp. 1999) (accord with Georgia).

97. *See, e.g.*, S.B. 1165, 44th Leg., 1st Sess. (Ariz. 1999) (genetic information includes information obtained from laboratory tests, physical medical exams, family histories, and direct analysis of genes); H.B. 1685, 82nd Leg., Reg. Sess. (Ark. 1999) (genetic information to include information derived from laboratory tests, physical medical exams, family histories, requests for genetic testing).

97. *See, e.g.*, COLO. REV. STAT. ANN. § 10-3-1104.7 (West 1999) (also limits use of information in research); GA. CODE ANN. § 33-54-3 (1996) (genetic testing may only be conducted to obtain information for therapeutic or diagnosed purposes); 410 ILL. COMP. STAT. ANN. 513/20 (West 1997) (genetic information must be used for therapeutic purpose as it relates to accident and health insurance).

98. *See, e.g.*, CAL. INS. CODE §10148 (West Supp. 1999) (genetic tests must comply with both informed consent and privacy provisions); GA. CODE ANN. § 33-54-3 (Michie 1996) (same); 410 ILL. COMP. STAT. ANN. 513/15 (West 1997) (Genetic Information Privacy Act); N.M. STAT. ANN. § 24-21-5 (Michie Supp. 1999) (Genetic Information Privacy Act).

99. *See, e.g.*, ALA. CODE § 27-53-2(b) (Supp. 1999) (health plan may not use genetic information showing predisposition for cancer "to otherwise discriminate against" a person); ME. REV. STAT. ANN. tit. 24-A, § 2159-C (West Supp. 1998) (insurer "may not discriminate against an individual or eligible dependent" on the basis of genetic information); N.J. STAT. ANN. § 17B:30-12(e)(1) (West 1996) ("No person shall discriminate against any individual on the basis of genetic information . . .").

100. In addition, some states, including Missouri, explicitly authorize the insurer

genetic information,¹⁰¹ but some statutes contain considerable detail on the consequences of misuse of genetic information.¹⁰²

III. THE NARRATIVE REVISITED: IMPLICATIONS FOR THE REGULATORY FRAMEWORK

As the narrative in Part I demonstrated, the extent to which genetic information is known and its implications understood is highly relevant to the terms on which individuals will demand insurance. If particular persons are identified as genetically risky, they will be excluded from health (and life and disability) insurance pools, and this result will be favored by those who are or believe themselves to be genetically advantaged. If, however, the genetic information and its significance is not revealed or understood, individuals will support an arrangement under which everyone substitutes a smaller, predictable commitment in exchange for the ability to draw upon the collective for the expense of genetic illnesses.

This juncture in the narrative symbolizes where America now finds itself with respect to genetic information about health conditions. It is known that all people have genetic defects and that some are serious.¹⁰³ But, at least for now, genetic testing is both novel and expensive; relatively few people have had genetic tests, and few applicants for insurance have genetic test results to report.¹⁰⁴ But this environment could change. As the cost of genetic testing technology declines and such examinations become both more widely available and more frequently administered, society may find itself in a situation where such information is widely accessible.¹⁰⁵ In these circumstances, it will be more difficult to strike a deal under which all persons share in the costs of caring for those whose genetic defects lead to illness. The regulatory response at both the federal and state levels of government described in Part II can be understood as an effort to prevent the realization of the circumstances that will impede the formation of broad health care communities.¹⁰⁶ Through the maintenance of the

to consider information voluntarily submitted by the insured. *See supra* note 29.

101. *See, e.g.*, COLO. REV. STAT. ANN. § 10-3-1104.7 (West 1999) (information gathered via genetic testing is confidential and privileged); GA. CODE ANN. § 33-54-3 (1996) (information derived from genetic testing shall be confidential and privileged); HAW. REV. STAT. § 431:10A-118 (1998) (no insurer may disclose an individual's or a family member's genetic information without the written consent of the person affected).

102. *See, e.g.*, CAL. CIV. CODE § 56.17 (West Supp. 1999); N.Y. CIV. RIGHTS LAW § 79-1 (McKinney Supp. 1999).

103. *See supra* notes 11-12.

104. *See Hall, supra* note 7, manuscript at 37 (noting that genetic tests have only "recently come into clinical use").

105. *See supra* note 31.

106. "[T]his treatment of genetic conditions by insurance law . . . is illustrative of a modern resolution of the historical insurance debate between individual responsibility

confidentiality of genetic information and prohibitions on the use of such information by insurers, low-risk insureds are foreclosed from demanding favorable treatment in low-risk, homogeneous pools.

Missouri's approach to creating the conditions necessary for an optimal deal is imperfect; it allows those with favorable genetic profiles to seek favorable treatment from insurers.¹⁰⁷ To that extent, then, Missouri's legislature has not fully embraced communitarian logic and has endorsed, by allowing the forces of proverse selection to operate, the creation of homogeneous communities that include low-risk individuals and exclude those with higher risks. Whether such segmentation will ever occur, however, is doubtful. Until genetic testing becomes less expensive and more widespread, low-risk persons cannot avail themselves of the consensual disclosure option and thereby achieve more favorable insurance terms. Furthermore, it is possible that more expansive federal regulation will subsume this entire issue, or that efforts to preserve underwriting practices that depend on the identification of individual health characteristics will succumb to an incremental, evolutionary process eventually culminating in universal, comprehensive coverage. Thus, the problem of proverse selection may be more theoretical than real; of course, given that insurers do not presently use genetic tests to segment risk pools, it might also be that the problem of genetic discrimination in insurance is itself more theoretical than real.

The fact remains, however, that Missouri, a substantial majority of other states, and Congress have articulated compelling, if largely symbolic, statements opposing genetic discrimination and favoring broad-based pooling of risks in which neither coverage nor price shall turn on a person's genetic predisposition to adverse health outcomes and their associated costs. These pronouncements should caution any insurer or health plan contemplating increased use of individual characteristics of any sort in underwriting decisions.¹⁰⁸ At the same

and autonomy on the one hand, and social solidarity on the other. . . . [L]egislatures are opting to apply principles of social solidarity. It is inescapable that the genetic underwriting statutes are motivated by an impulse to socialize risk." Jacobi, *supra* note 80, at 336; *see also* Hall, *supra* note 7, manuscript at 32-37 (documenting that some health insurers would be interested in using genetic information in underwriting if the legal climate allowed it).

107. *See supra* text accompanying notes 29-31; *see also* Hall, *supra* note 7, manuscript at 44-46 (reporting examples of individuals using genetic information to negate inferences from adverse family history).

108. Professor Hall suggests that the statutes may have already had this effect. "Even though insurers and agents do not have widespread and accurate knowledge of these laws, these laws have fortified their impression and social disapproval by creating a general climate of legal condemnation. . . . To this extent, they have been effective." Hall, *supra* note 7, manuscript at 50. On the other hand, Professor Hall allows that the statutes may have increased unfounded fears of genetic discrimination and thereby induced more people to forego beneficial genetic testing, thereby creating a difficult public policy dilemma. *See* Hall, *supra* note 7, manuscript at 50-51.

time, the regulatory array represents an additional step in America's slow, incremental trek toward compulsory, community-based rating practices in health insurance.¹⁰⁹

109. See Jacobi, *supra* note 80, at 404 (recognizing that the “trend of regulatory involvement in the market of health coverage has shifted toward favoring a social pooling of risk . . . to reach gradually and economically the goal of universal health coverage”); M. Susan Ridgely & Howard H. Goldman, *Putting the “Failure” of National Health Care Reform in Perspective: Mental Health Benefits and the “Benefit” of Incrementalism*, 40 ST. LOUIS U. L.J. 407, 420 (1996) (“[M]any of those who favored national universal health insurance believe the last opportunity to achieve it may have been squandered. . . . [But] [i]ncremental steps in their own right can achieve significant changes”); Flint J. Wainess, *The Ways and Means of National Health Care Reform, 1974 and Beyond*, 24 J. HEALTH POL. POL’Y & LAW 305, 329 (1999) (stating that “incremental expansions of Medicare could prove politically popular, and could open up a back door to universal national health insurance”).