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Genetic Confidentiality: What's the Big Secret?

PAUL A. LOMBARDO[†]

I. Introduction

The explosion of information generated by the Human Genome Project and related advances in molecular biology come at a propitious time. Never before have Americans been so sensitive to their rights—real and imagined—in the realm of privacy, nor so aware of the potential for abuse of private information. As information that describes some of the most personal features of an individual's identity becomes available via genetic analysis—information linked to conditions that have been characterized as “immutable, heritable traits that intrinsically implicate the bearer's identity”¹—the chorus of support for legislation to prohibit genetic discrimination grows louder. Demands for restriction on the use of information derived from DNA testing have increased, and legal remedies are proposed to avoid the danger of creating a “genetic underclass,” particularly vulnerable to the whimsy of health care insurance markets.

Yet in focusing on this newest kind of medical information, we often fail to realize that the potential misuse of genetic information is only another example of how other types of health-related information may be misused. We overlook the state of the law ostensibly written to protect medical information. Such law varies widely from state to state and contains numerous exceptions. We know relatively little about how effectively or how poorly that law protects the more prosaic brands of medical information—such as diagnostic history or family background reports—which themselves may provide ample basis upon which to found discriminatory decisions, particularly in regard to insurance coverage.

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1. Eric T. Juengst, *Priorities in Professional Ethics and Social Policy for Human Genetics*, 266 J Am Med Ass 1835, 1836 (1991).

Straining to establish a new air-tight standard for uses of genetic data, we overlook the data readily available from blood and tissue samples regularly provided by medical patients, employees, candidates for insurance or the millions of people who flow through the military or our systems of criminal adjudication. Nor do we have a thorough understanding of the numerous well established and legally sanctioned means to conduct DNA testing that already are in place. Before we push through specialized laws to protect genetic confidentiality we should also be asking: how easy is it to collect or access genetic information? And do we have an adequate understanding of existing legal provisions that purport to protect genetic privacy?

It is also worth asking whether too much is being made, in the academic as well as the popular literature, of the dangers inherent in the widespread availability of genetic information, and whether too little is made of the danger to individual privacy that exists in the face of a generally porous medical information system in which the traditional norm of confidentiality has all but deteriorated.

This article is meant to provide some perspective on the recent attention to genetic privacy law. It includes a survey of current practices for collecting genetic data, and a compilation of existing state laws that attempt to regulate the use of genetic information to prevent insurance discrimination.

State insurance law is permeated with contradictory statutes that often fail to make the necessary distinctions between health, disability and life insurance. A hypothetical case is presented to demonstrate the shortcomings in those state laws, and to explain the use of arguments for genetic confidentiality as proxy arguments for the need for health care reform. I argue that however well intentioned our attention to genetic confidentiality is, it will not cure the health care access crisis.

Finally, I wish to call attention to the "genophobic" rhetoric that is imbedded in several recent proposals for an overhaul of genetic privacy. The reductionism of some of the language being used by prominent commentators threatens to push public understanding of genetic conditions further toward an embrace of genetic determinism—to the detriment of those very people whose interests new law is meant to protect. The rhetoric of fear surrounding the impending revolution in genetic information may have the unintended consequence of further stigmatizing precisely those people whose genetic conditions mark them as vulnerable to discriminatory treatment.

II. Why an Examination of Genetic Confidentiality is Timely

Several developments have combined to raise new issues about the claims potential patients and others may have on the developing genetic database. On the scientific front, the Human Genome Project has fueled an expansion of the technology to analyze genetic material. The Project is a systematic attempt to locate, map and sequence the totality of human DNA, thus "defin[ing] all the

genes that make up a human being.”² The Project has already lead to the isolation of 4,000 single gene diseases, and the location of numerous genetic conditions.³ Theoretically, every sample of human blood or tissue can be tested for these conditions. Though economic means for broad scale testing are not yet widely available, no one disputes the likelihood that such tests will appear and be used in the foreseeable future. The tests will yield a bounty of information about current medical conditions, risk factors for numerous other inchoate conditions,⁴ and perhaps—though much less certainly—even portions of a behavioral profile.⁵

The potential for an ever-expanding genetic database emerges in coincidence with high public expectations of rights to privacy. The widespread confidence in the right to privacy is well placed. Federal statutes and numerous court decisions have guaranteed protection for information as seemingly commonplace and unthreatening as a Social Security number.⁶ Governments must surmount such barriers before using personal identifiers even for traditionally favored activities such as compiling lists of voters.⁷

Additionally, a new jurisprudence of privacy has developed as a result of the reproductive rights decisions, most notably *Griswold v Connecticut*⁸ and *Roe v Wade*.⁹ This “constitutionalization” of medical privacy as part of the First Amendment is one source of public expectations. The suggestion that

2. Walter Gilbert, *A Vision of the Grail* in Daniel J. Kevles and Leroy Hood, eds, *The Code of Codes: Scientific and Social Issues in the Human Genome Project* 83 (Harvard 1992).

3. See Ronald G. Crystal, *Transfer of Genes to Humans: Early Lessons and Obstacles to Success*, 270 Science 404 (1995).

4. A number of DNA-based tests have been developed that will allow specific gene mutations to be identified in individuals. Positive test results will signal the heightened probability that a genetic disorder will manifest itself in an individual at some point in life. See Victor A. McKusick, *Genomic Mapping and How It Has Progressed*, 26 Hospital Practice 74, 89 (Oct 1991). Current research suggests that tests for adult onset diseases such as cancer, diabetes or Alzheimer disease may become widely available over the next ten years. *Id.* at 89-90. See also Mary E. D’Alton and Alan H. DeCherney, *Prenatal Diagnosis*, 328 New Engl J Med 114, 118 (1993) (“The mapping of the human genome is expected to be completed in the next 10 to 15 years, and, as a result, molecular genetic techniques are likely to be available for the detection of all common monogenic disorders.”).

5. The controversy over the use of genetic information to predict behavior continues. See Tabitha M. Powledge, *Genetics and the Control of Crime*, 46 BioScience 7 (Jan 1996).

6. Privacy Act of 1974, Pub L No 93-579, 88 Stat 1897 (1974), codified at 5 USC § 552A (1994). See also *Greidinger v Davis*, 988 F2d 1344, 1353 (4th Cir 1993) (“At the time of its enactment, Congress recognized the dangers of widespread use of SSN’s as universal identifiers. . . . [A Senate Report stated that SSN use is] ‘one of the most serious manifestations of privacy concerns in the Nation.’ . . . Since the passage of the Privacy Act, an individual’s concern over his SSN’s confidentiality and misuse has become significantly more compelling.”).

7. *Greidinger*, 988 F2d at 1344 (cited in note 6).

8. 381 US 479 (1965).

9. 410 US 113 (1973).

refusal of medical treatment even in the face of death is founded on a similar extension of the right has been embraced by many state courts and was suggested by the United States Supreme Court.¹⁰ There seems to be no limit to the degree to which the "medical privacy" standard can be stretched—from abortion (*Roe*) to refusal of treatment (*Cruzan*) to assisted suicide (*Compassion in Dying*).

In the years since *Roe*, we have experienced a growing awareness of the many ways that information collected in the confidential health care setting can be stored and transmitted electronically.¹¹ That awareness has been accompanied by heightened concern that personal information stored in large databases can be recorded in error, replicated through disclosure and misused negligently or even with malice. One of the most troubling features of technological innovation is the ability of complete strangers to assemble personal information from a variety of sources surreptitiously, or at least without the knowledge of the person whom it purportedly describes.

Preceding concerns with possible abuses of information is the understanding that new informational technologies make the distribution of information to ever larger circles of recipients likely if not inevitable. In the current medical context, for example, the Institute of Medicine has estimated that "the number of authorized users of the computer-based patient record is too exhaustive to list, and would parallel the complete list of the individuals and organizations associated directly or indirectly with health care."¹² The combination of more personalized medical data—such as that generated by genetic testing—with the ability to manipulate that data electronically only heightens the fears of those who see technology encroaching on hard won rights to privacy.

Specific permutations of the law of medical confidentiality occurring in response to the HIV/AIDS epidemic have also had a significant impact on the way we now look at genetic information. Soon after the development of a test for the HIV antibody in 1985, states began to adopt specific statutory protections for the results of HIV testing¹³ and within a short interval, the concept of special treatment for AIDS-related medical information was endorsed by a federal commission. The presidential AIDS commission argued for federal legislation that would protect from disclosure identifying information obtained via HIV testing or counseling except under carefully circumscribed circumstances and with the written consent of the patient.¹⁴ The AIDS com-

10. See *Cruzan v Director, Mo Dept of Health*, 497 US 261 (1990). See also *Compassion in Dying v State of Washington*, 49 F3d 586 (9th Cir 1996) (en banc).

11. See, generally, Jed Rubenfeld, *The Right of Privacy*, 102 Harv L Rev 737 (1989); Arthur R. Miller, *The Right of Privacy—A Look Through the Kaleidoscope*, 46 SMU L Rev 37 (1992); and Robert S. Peck, *Extending the Constitutional Right to Privacy in the New Technological Age*, 12 Hofstra L Rev 893 (1984).

12. Lawrence O. Gostin, *Health Information Privacy*, 80 Cornell L Rev 451, 485 (1995). See also, U.S. Congress, Office of Technology Assessment, *Genetic Tests and Health Insurance: Results of a Survey—Background Paper*, OTA-BP-BA-98 (Oct 1992).

13. See, for example, Cal Health and Safety Code §120980 (West 1996).

14. *Report of the Presidential Commission on the Human Immunodeficiency Virus*

mission echoed concerns already lodged in state legislatures, where a standard of zero tolerance for breach of confidentiality had emerged.¹⁵

While the need for unique rules to protect the confidentiality of those who contracted HIV infection in the early years of the AIDS epidemic was obvious, the standard of confidentiality for HIV may not be appropriate for all genetic information. Yet the tenor of much recent scholarship on genetic confidentiality has partaken of the rhetoric characteristic of the mid-1980s, when HIV/AIDS discrimination was a paramount concern of the health law community. Though some genetic information may give rise to stereotypically phobic reactions analogous to the initial public response to AIDS (for example, genetic links to certain mental illnesses could provide the basis for serious social stigma), the vast majority of medical conditions thus far connected to specific genetic markers do not elicit the stigma, fear, or discomfort evoked by an inevitably deadly disease linked to socially marginal populations.

III. The Demise of Medical Confidentiality

While the technology, law, and public perception of privacy were changing, a tradition of medical confidentiality was deteriorating. In contrast to the broader rubric of privacy, the requirement of confidentiality is founded in the relationship of trust between doctor and patient. Hippocrates' ancient prescription for confidentiality in the medical setting describes a universal ethical requirement for those who work in health care settings.¹⁶ The vulnerability of the patient in the therapeutic encounter—yielding access to one's secrets no less than to one's body—demands a reciprocal promise of protection by the physician that intimate information will not be used to the patient's detriment.

It has become clear that this expectation of patients is not always warranted. In an often-quoted 1982 article in the *New England Journal of Medicine*, University of Chicago physician and bioethicist Marc Siegler declared that confidentiality in the medical setting was no longer a viable concept. Describing contemporary practice, with numerous caregivers easily in reach of presumably secret patient information, Siegler declared:

Medical confidentiality, as it has traditionally been understood by patients and doctors, no longer exists. This ancient medical principle, which has been included in every physician's oath and code of ethics since Hippocratic times, has become old, worn-out and useless; it is a decrepit concept.¹⁷

Epidemic 127 (1988).

15. See, for example, *Estate of Behringer v Medical Center at Princeton*, 249 NJ Super 597, 592 A2d 1251 (1991).

16. Ludwig Edelstein, *The Hippocratic Oath: Text, Translation and Interpretation*, in Henry E. Sigerist, ed, *Bulletin of the History of Medicine* 1, 63 (Johns Hopkins Supp 1943).

17. Mark Siegler, *Confidentiality in Medicine—A Decrepit Concept*, 307 New Eng J of

Siegler's lament focused on developing trends in the practice of medicine that give too many people access to patient data, and simultaneous erosion of an ethic of practice that recognized shared secrets as part of the foundation of trust characteristic of the doctor-patient relationship.

Since the appearance of Siegler's article, new technologies that require computerized medical records and convenient electronic data transmission have made the protection of clinical secrets even more difficult. Some commentators have asserted the irrelevance of the traditional rule: "The rule of confidentiality does not work nearly so well in a modern information society. . . . Focusing legal protection on a single therapeutic relationship within this information environment is an anachronistic vestige of an earlier and simpler time in medicine."¹⁸ These pessimistic comments about the viability of the very notion of medical confidentiality sound ironic alongside current public assertions of a right to informational privacy and anxiety about its potential loss.

How does the existence of a patient's genetic identity as a part of the medical record fit into this tradition of confidentiality? Physicians also perceive as novel the risks to medical privacy that the new genetics exacerbates. As one commentator has noted: "Physicians engaged in family practice must also be aware that the likely proliferation of genetic information about their patients has significant potential to harm patients' ability to obtain insurance, including health, life, and disability income coverage."¹⁹ It would appear that the inclusion of genetic data within the medical record will be just one more kind of information no longer protected by the once personal promise of confidentiality. Since the costs of genetic services—testing, analysis, interpretation and counseling—will inevitably be paid in most circumstances by health insurance, try though they may, family physicians will not be able to prevent personal genetic data from becoming another part of the electronic data base.

What other reasons do we have to fear genetic information?

IV. Sources of Concern

A. THE INTIMATE NATURE OF GENETIC DATA

The tone of alarm surrounding recent discussions of data yielded by the new genetic technologies echoes with an ominous ring. The rhetoric suggests that revealing one's genetic secrets, for example, the potential for future disease, will lead inevitably to discrimination or other distressing results. Similarly, genetic screening has been described as a process which "provides an ineradicable marker of deviance with potentially lifelong social consequences to the affected individual."²⁰ A diagnosis of disease condition with a genetic component has

Med 1518 (1982).

18. Gostin, 80 Cornell Law Rev at 512 (cited in note 12).

19. S. Van McCrary, et al, *Ethical and Practical Implications of the Human Genome Initiative for Family Medicine*, 2 Archives of Family Medicine 1158, 1160 (Nov 1993).

20. Note, *Insurers and Genetic Testing: Shopping for the Perfect Pair of Genes*, 40

been characterized as if it created a biological "scarlet letter,"²¹ marking the bearer as an easy target for discrimination, stigma and scorn. More generally, commentators have noted that "the systematic collection of genomic information holds the potential for grave personal and social detriment."²²

Nor is the fear of genetic victimization limited to America. Similar concerns have been voiced in Great Britain, among other countries:

So great is the degree of consensus among the medical genetics establishment [about the dangers of genetic discrimination] that the government has already acquiesced to the central recommendation of the [House of Commons Science and Technology Committee] report—the establishment of a regulatory body for medical genetics. . . . the committee (in its recent report "Human Genetics: The Science and its Consequences") called for a law guaranteeing genetic privacy, with criminal penalties for anyone misusing genetic information.²³

But genetic data may signal many conditions, most of which are not necessarily stigmatizing nor even particularly intimate. At least part of our fear of misuse of genetic information comes not from the nature of the data itself, but our history of abusing some people on the basis of their supposed hereditary propensity.

B. AMERICA'S EUGENIC HISTORY

One source of the anxiety is America's legacy of eugenics. For most of this century, the suggestion of biologically verifiable genetic inferiority was used as the basis for sexual sterilization of thousands of residents of state institutions,²⁴ laws to prohibit interracial marriage,²⁵ and immigration quotas for some ethnic groups.²⁶

Europeans, who experienced the horrors of the Holocaust first hand, are also sensitive to suggestions that increased genetic knowledge might clear the path for repressive legislation based on theories of genetic determinism. Recent scholarship has clarified how important such theories were to the development of the

Drake L Rev 121, 141 (1991) (quoting Marc Lappé, *The Limits of Genetic Inquiry*, 17 Hastings Center Report 5 (1987)).

21. Elaine Draper, *Genetic Secrets: Social Issues of Medical Screening in a Genetic Age*, 22 Hastings Center Report 515 (1992).

22. Gostin, 80 Cornell L Rev at 492 (cited in note 12).

23. David King, *The State of Eugenics*, 8 New Statesman 25 (1995).

24. See John Robertson, *Genetic Selection of Offspring Characteristics*, 76 BU L Rev 421 (1996).

25. Paul A. Lombardo, *Miscegenation, Eugenics and Racism: Historical Footnotes to Loving v. Virginia*, 21 UC Davis L Rev 421 (1988).

26. William H. Tucker, *The Science and Politics of Racial Research* 60 (Illinois 1994).

Nazi ideology,²⁷ and there is understandable sensitivity to the possibility that science could again be perverted for totalitarian ends.

The implication that biological traits and behavioral characteristics are lodged in the DNA as quantifiable determinants of a person's future is a staple of popular thought as well. That genetic information is available indirectly through psychological tests, which can be usefully employed to diagnose members of a biological "underclass"²⁸ is an assertion of books like *The Bell Curve*.²⁹ The suggestion that mental illness or crime may be genetically coded intrigues scientists and politicians alike, all the while continuing to engender strong protest as it did at a recent conference probing theories that rely on biological explanations of crime and violence.³⁰ The use of DNA data as a pretext for discrimination of all kinds is a common consideration among those who analyze the social implications of the "new genetics" yielded by the Human Genome Project.³¹

The more recent history of genetic discrimination is exemplified by the XYY controversy, where a chromosomal abnormality formed a basis for designating certain men "congenital criminals" whose "supermale" genetic identity supposedly marked them as prone to crime, and screening programs to deter criminality were proposed.³² Discovery of the gene for sickle-cell anemia led to a similar debacle, with carriers of the sickling trait being forced to leave the Air-Force Academy on the grounds that they were at risk for high altitude attacks, and grounding of airline pilots by many major airlines because they tested positive as carriers of the sickle-cell trait.³³ Others who carried the sickling trait were encouraged to undergo sterilization operations to avoid nonexistent dangers of

27. See generally Sheila Faith Weiss, *Race Hygiene and National Efficiency: The Eugenics of Wilhelm Schallmayer* (California 1987); Stefan Kühl, *The Nazi Connection: Eugenics, American Racism, and German National Socialism* (Oxford 1994); Gotz Aly, Peter Chroust and Christian Pross, *Cleansing the Fatherland: Nazi Medicine and Racial Hygiene* (Johns Hopkins 1994).

28. Dorothy Nelkin and Lawrence Tancredi, *Dangerous Diagnostics: The Social Power of Biological Information* 176 (Basic Books 1989).

29. Richard J. Herrnstein and Charles Murray, *The Bell Curve: Intelligence and Class Structure in American Life* 22-23 (Free Press 1994).

30. Wade Roush, *Conflict Marks Crime Conference*, Science 1808 (Sept 29, 1995); Natalie Angier, *At Conference on Links of Violence to Heredity, A Calm after the Storm*, NY Times C8 (September 26, 1995).

31. See, for example, Hille Haker, et al, eds, *Ethics of Human Genome Analysis: European Perspectives* (Attempo-Verlag 1993); Tom Wilke, *Perilous Knowledge: the Human Genome Project and Its Implications* (California 1989); Timothy F. Murphy and Marc A. Lappé, eds, *Justice and the Human Genome Project* (California 1994).

32. David Suzuki and Peter Knudtson, *Genethics: the Clash Between the New Genetics and Human Values* 149-52 (Harvard 1989).

33. Troy Duster, *Backdoor to Eugenics* 26 (Routledge 1990).

childbirth.³⁴ Only later was it clarified that neither XYY nor sickle-cell trait provided any rational grounds for differential treatment.³⁵

Eugenics, biological determinism and the all too recent examples of invidious discrimination justified on purportedly scientific grounds all cast a dark shadow over the prospect of new techniques that promise (or threaten) to make comprehensive genetic diagnoses available.

Lawmakers are sensitive to public concern over the potential for misuses of medical information. On the general medical front, a federal law to regulate medical confidentiality has been introduced in Congress.³⁶ The need for regulation of previously unknowable genetic information has led to a proposed model genetic privacy law.³⁷ Fears of misuse of genetic information by parents has even yielded arguments in favor of separate privacy protection for unborn fetuses.³⁸ Although there is high level of attention for potential abuses, and ongoing calls for new legislation, relatively little has been written about the variety of ways that genetic data are made available today, or how easy it is to obtain a sample upon which to perform a genetic test.

V. Collection of Genetic Data: Current Practices

The following list catalogues a number of the ways that genetic data is already collected, created, and stored.

A. DNA DATA BANKS—CRIMINAL CONTEXTS

Approximately half of the states have DNA banks created to allow identification of repeat criminal offenders.³⁹ Some use blood, others saliva samples, so the level of physical intrusion necessary to establish the banks is different. Some states bank DNA evidence for violent offenses or sexual offenses;⁴⁰ others such as North Carolina, Oregon, Virginia and West Virginia bank DNA for many nonviolent offenses.⁴¹ Congress has also authorized and fostered the develop-

34. See *Avery v County of Burke*, 660 F2d 111 (4th Cir 1981).

35. Suzuki and Knudtson, *Genethics* at 162-63 (cited in note 32).

36. Medical Records Confidentiality Act of 1995, 141 Cong Rec S 15575-01, S 15576 (1995).

37. George J. Annas, et al, *The Genetic Privacy Act and commentary* (BU 1995). This document is available on the World Wide Web at <http://www-bushp.bu.edu/Depts/HealthLaw/>.

38. Jeffrey R. Botkin, *Fetal Privacy and Confidentiality*, 25 Hastings Center Report 32, 35 (1995) ("A belief in genetic determinism by parents may severely limit the child's ability to find and chart his or her own course in life. . . . In short, it is appropriate to consider some information about the fetus as private and confidential.").

39. See generally Note, *Criminal DNA Data Banks: Revolution for Law Enforcement or Threat to Individual Privacy?*, 22 Am J Crim L 461 (1995).

40. See, for example, NC Gen Stat § 15A-266.4 (Michie Supp 1994); Wash Rev Code Ann § 43.43.754 (West Supp 1995); Fla Stat Ann § 943.325 (West Supp 1995); Mo Ann Stat § 650.050 (Vernon Supp 1994).

41. See NC Gen Stat § 15a-266.4, ORS 137.076, ORS 161.325, Va Code § 19.2-

ment of DNA data banks⁴² and the FBI is involved in a national effort to collect DNA for purposes of law enforcement investigation.⁴³

While the mere existence of these data banks raise significant questions for privacy advocates focused on criminal law issues,⁴⁴ at least one federal court of appeals has endorsed the involuntary blood sampling required of prisoners under state law.⁴⁵ The *Schmerber* principle,⁴⁶ allowing involuntary bloodletting for criminal justice motives, seems elastic enough to cover blood used for DNA identification and analysis.⁴⁷

The privacy of data bank information collected by the FBI is protected by criminal penalties.⁴⁸ Some states have similar protections,⁴⁹ but most do not have laws that apply uniquely to DNA and are designed to prevent inappropriate diversions of samples banked for official use.⁵⁰

B. PATERNITY TESTING

Almost half of the states recognize the use of genetic test results in parentage contests, and some have argued that DNA testing should be the gold standard for deciding paternity issues. The laboratory tests are now widely available.⁵¹

310.2, West Va Code Ann § 15-2-24a.

42. DNA Identification Act of 1994, Pub L No 103-322, 108 Stat 2069 (1994), codified at 42 USCA §14132 (Supp V 1995).

43. *Id.*

44. See E. Donald Shapiro & Michelle L. Weinberg, *DNA Data Banking: The Dangerous Erosion of Privacy*, 38 Cleve St L Rev 455 (1990); J. Clay Smith, *The Precarious Implications of DNA Profiling*, 55 U Pitt L Rev 865 (1994).

45. *Jones v Murray*, 962 F2d 302 (4th Cir 1992).

46. *Schmerber v California*, 384 US 757, 771 (1966) ("Extraction of blood samples for testing is . . . common place in these days of periodic physical examinations and experience with [these tests] teaches that the quantity of blood extracted is minimal, and that for most people the procedure involves virtually no risk, trauma or pain.").

Not to be forgotten, however, are the arguments of the dissenters in that case, concerning the intrusiveness of "bloodletting." *Id.* at 779 (Douglas, dissenting) ("No clearer invasion of this right of privacy can be imagined than forcible bloodletting of the kind involved here"); and *Id.* at 779 (Fortas, dissenting) ("the State has no right to commit any kind of violence upon the person, or to utilize the results of such a tort, and the extraction of blood, over protest, is an act of violence.").

47. See E. Donald Shapiro, et al, *The DNA Paternity Test: Legislating the Future Paternity Action*, 7 J L & Health 1, 2 (1992-93) ("It is well settled law that a court may constitutionally order blood tests. . . . By extension, there is no reason to doubt the constitutionality of a court-ordered blood or tissue test for DNA profiling, as long as it is not invasive.").

48. 42 USCA § 14133(c) (Supp V 1995) (fines up to \$100,000 may be levied for unlawful disclosure of identifiable DNA information or possession of DNA samples).

49. See, for example, Va Code Ann § 19.2-310.6 (Michie Supp 1995) (prohibiting unauthorized uses of DNA data bank and creating a felony for possession of forensic samples).

50. See Note, 22 Am J Crim L at 485-486 (cited in note 40).

51. Shapiro, 7 J L & Health at 2 ("Courts may now order the child, the biological mother and the putative father, as well as other relevant parties such as the child's

DNA testing is allowed or mandated by portions of federal law that condition receipt of funding on procedures to improve the effectiveness of child support enforcement.⁵²

C. ADOPTION

Several states allow adoption agencies to condition placement on medical testing of potential parents. The suggestion that disclosure of the genetic heritage of "birth parents" may be within the standard of care for adoption agencies has been made in cases where congenital illness of an adopted child was discovered.⁵³ Some commentators have argued for expanded authority of adoption agencies to perform genetic tests and make disclosures to adopted children and their adoptive parents.⁵⁴ They argue that the law should move toward more complete disclosure, for the benefit of new parents and adopted children.⁵⁵

D. GENETIC REGISTRIES FOR DISEASES OF NEWBORNS

Research and data collection on a number of inherited diseases has been encouraged by federal funding since the passage of the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs and Genetic Diseases Act of 1976.⁵⁶

siblings or grandparents, to submit to both traditional and DNA paternity tests. By extracting a small quantity of blood or tissue from the child, the mother and the putative father under highly controlled testing conditions and then subjecting the sample to DNA profiling, it is now possible to scientifically determine the probability of paternity almost to a near certainty which should more than fulfill both substantive and procedural legal requirements.") (cited in note 48).

52. See 42 USCA §666 (West Pamphlet 4A Nov 1996) (requiring statutorily prescribed procedures to improve the effectiveness of child support enforcement). Section 666 provides:

(a) Types of procedures required

In order to satisfy section 654(20)(A) of this title, each State must have in effect laws requiring the use of the following procedures, . . . to increase the effectiveness of the program which the State administers under this part;

. . .

(5)(B)(i) Procedures under which the State is required, in a contested paternity case (unless otherwise barred by State law) to require the child and all other parties . . . to submit to genetic tests upon the request of any such party"

42 USCA § 666(a)(5)(B)(i). See generally Shapiro, 7 J L & Health at 4 n14 (corresponding state enactments) (cited in note 48).

53. See, for example, *M H v Caritas Family Services*, 488 NW2d 282, 288 (Minn 1994).

54. See, for example, D. Marianne Brower Blair, *Lifting the Genealogical Veil: A Blueprint for Legislative Reform of the Disclosure of Health-Related Information in Adoption*, 70 NC L Rev 681 (1992).

55. Id at 687 ("Fewer than half of the states adequately address the need to collect, retain, and transmit to concerned parties medical and genetic information acquired subsequent to the adoption.").

56. Health Research, Health Services Amendments, 42 USCA §§ 300b-1 to 300b-4 (1994).

Almost all states have laws that mandate screening of newborns for specific diseases,⁵⁷ and a number of them also protect the information collected with specific provisions for confidentiality of the information, as well as the more general protections that are included in medical confidentiality statutes of the majority of the states.⁵⁸

E. DEPARTMENT OF DEFENSE—DNA DOG TAGS

Since 1991, every member of the Armed Forces has been subject to DNA banking via blood and tissue samples. According to the Department of Defense, such samples are collected solely for the purpose of identifying the bodies of people who have died in service. Two Marines who challenged the DNA banking procedures were recently subjected to special court martial, but received no punishment. Their subsequent lawsuit, attempting to have the practice declared unconstitutional, was dismissed by a federal district court.⁵⁹ Their appeal is pending as of this writing in the Ninth Circuit Court of Appeals.

F. OTHER SOURCES FOR DNA ANALYSIS

In addition to samples of DNA that may have been analyzed for the uses listed above, ready sources of blood or tissue are available from many sources. Many medical procedures require blood or tissue for diagnostic or research purposes, and there is no consistent regulation of the use of stored samples in the medical context. For example, the Red Cross or other blood banking organizations store massive quantities of blood donated by a wide segment of the population. Life and disability insurance companies routinely collect blood samples and administer medical examinations prior to issuing coverage. Large employers also commonly employ medical personnel to assist in an employee health plan or workers compensation program, and even in the post-ADA (Americans with Disabilities Act) era, physical examinations involving blood sampling are not unusual.

All of these stored samples of blood or tissue are available as potential repositories of DNA to be used for individual diagnosis or identification purposes. What law, if any, protects against disclosure of their contents, and how effectively is it enforced? One example of a federal statute meant to protect intimate information on health conditions provides an instructive example. For more than twenty years, the identity and records of anyone in a federally assisted program of drug treatment have been protected from disclosure and use, even in the context of law enforcement investigation, by a federal law that provides

57. See Lori B. Andrews, *State Laws and Regulations Governing Newborn Screening* 1 (Am Bar Found 1985).

58. Lori B. Andrews, *Overview of Legal Issues*, 83 *Pediatrics* 886, 889 (Supp 1989).

59. *Mayfield v Dalton* 901 FSupp 300 (D Hawaii 1995). A third serviceman refused to give a blood sample and faced charges in military court. See Gary Borg, *New DNA Court Martial*, *Chi Trib* (May 9, 1996).

criminal penalties for breach of confidentiality.⁶⁰ Yet in the face of thousands of violations and a general ignorance of the law by many whose work it affects, no prosecutions of violators have been reported in the history of the now twenty-year-old Drug Abuse Confidentiality Law. A review of the Specialty Law Digest (Health) from 1975-1995 revealed no reported cases, nor are any cases available in the Federal Supplement, the likely reporter for trial results concerning this federal statute.

For people who have provided no sample, how easy is it to obtain an adequate amount of blood or tissue to perform DNA analysis? Given the current technology, there is no need for intrusiveness in the collection of DNA. Blood is clearly adequate, but for the blood-averse, a salt-water wash of saliva contains enough epithelial cells to do the job, as do hair clippings, or small particles of skin. A resourceful technician could probably lift DNA from a licked stamp or abrasive doorknob, and a clever entrepreneur might very well devise an envelope seal that efficiently captures serviceable cells from the tongue sealing the envelope flap. The limits to the potential vehicles for castoff human cells that could provide a serviceable DNA sample are endless—so too the potential for looking into a stranger's DNA surreptitiously. No invasion of the body, of a private space, or of a relationship need occur for genetic testing. For recently born children, or hospital patients, blood may already be collected in stored tissue samples or on Guthrie Cards.⁶¹

Considering how much data is available in various data banks or medical specimens, how safe are the systems in which the data is stored? The literature on privacy or medical confidentiality does not include any systematic analyses of how often confidentiality provisions are breached. The rules protecting the systems provide some assurances of confidentiality, with many exceptions, but rarely do the rules provide a rigid privilege that would withstand challenges from private citizens, law enforcement personnel and requests that arise in the midst of litigation.

VI. Discrimination in Insurance

A. STATE LAW ANTIDISCRIMINATION PROVISIONS

In the absence of federal antidiscrimination law that would prohibit insurance discrimination on grounds of genetic test or condition, the states remain free to fashion their own laws to regulate the business of insurance. Fifteen states provide some level of protection for information derived from genetic tests by

60. 42 USCA § 290dd-2 (West Supp 1996). For corresponding federal regulations, see Confidentiality of Alcohol & Drug Abuse Patient Records, 42 CFR §§ 2.1 et seq (1995) (corresponding federal regulations).

61. Jean E. McEwen and Phillip R. Reilly, *Stored Guthrie Cards as DNA "Banks,"* 55 Am J Human Genetics 196 (1994).

prohibiting its use as a condition of insurance coverage. The following subsections catalogue the antidiscrimination provisions of state insurance law.⁶²

1. Alabama

Alabama law prohibits denial of health or disability insurance coverage to applicants diagnosed as having sickle-cell anemia, and forbids denial of medical claims related to the disease,⁶³ but does not characterize the disease as a congenital or genetic ailment, and makes no distinction between carriers of the trait and those who suffer from the disease itself.

2. California

California has one of the most extensive statutory schemes of all the states that prohibit discrimination in insurance. It also controls the confidentiality of genetic test information in private hands with civil and criminal penalties.

Until 1995, California provided civil and criminal penalties for negligent or willful disclosure of genetic information by a whole host of specifically defined and state regulated insurance companies and health concerns, including: health care service plans, life or disability insurers, self-insured employee welfare benefit plans, and nonprofit hospital service plans.⁶⁴ They were prohibited from dissem-

62. As this Article was going to press, New Jersey enacted a new Genetic Privacy Act that will regulate the use of genetic information as a condition of employment and for some types of insurance coverage. 1996 NJ Sess Law Serv 126 (West 1996). Incorporating protections against genetic discrimination into the general rubric of state civil rights law, New Jersey specifically prohibits the use of genetic information in hiring or other job-related decisions and also rules out reliance on genetic underwriting as a requirement for access to medical coverage. Genetic information may, however, be used by life insurers as long as it is "reasonably related to anticipated claim experience." Companies requiring genetic testing for life insurance and underwriting must notify applicants of the testing requirement and obtain written informed consent before proceeding. The subject of the test may request that the life insurer provide a copy of test results to a designated physician. The state Commissioner of Health and Human Services, in consultation with the Commissioner of Banking and Insurance, is charged with developing regulations that will outline procedures for obtaining written informed consent.

Criminal penalties, including fines and up to one year of imprisonment, are available—as are private civil damages—as remedies for wrongful disclosure of genetic information.

Adoption of this law was delayed by New Jersey Governor Christine Todd Whitman's veto of a similar bill that was unanimously passed by the New Jersey Assembly. The earlier bill was more expansive in its protection of genetic data, defining tissue samples and information derived from DNA testing as the property of the individual from whom the samples were obtained. Those provisions were eliminated from the revised bill Whitman eventually signed into law. See generally *New Jersey: Gov. Whitman Conditionally Vetoes Genetic Privacy Protection Bill*, 5 BNA Health L Rptr 40 d17 (Oct 10, 1996).

63. Ala Code § 27-5-13 (1986) ("[A]ny insurance company doing business within the state which offers health or disability insurance, is hereby prohibited from denying coverage to applicants because the applicant has been diagnosed as having sickle-cell anemia, and is hereby required to pay any valid claim made involving treatment or care of sickle-cell anemia in accordance with other policy provisions.").

64. Cal Civ Code § 56.17 (West Supp 1996) (Negligent disclosure of genetic test re-

inating genetic information that they might otherwise lawfully collect. Health insurers were not allowed to discriminate on the basis of a person's genetic characteristics or those of a child or other family member.

A 1995 law imposes an increased penalty for a violation of these provisions by an insurer, and establishes additional remedies and administrative penalties. Of particular interest is the definition of "Genetic characteristics" that appears in several sections of California law:

"Genetic characteristics" means any scientifically or medically identifiable gene or chromosome, or alteration thereof, which is known to be a cause of a disease or disorder, or determined to be associated with a statistically increased risk of development of a disease or disorder that is presently not associated with any symptoms of any disease or disorder.⁶⁵

This definition applies to companies selling health insurance,⁶⁶ self insured plans,⁶⁷ and nonprofit hospital service plans.⁶⁸ The list of potential conditions falling into this category includes Tay-Sachs trait, sickle-cell trait, thalassemia trait, and X-linked hemophilia A.

Companies selling life or disability insurance may not discriminate in terms of enrollment, conditions or benefits "on the basis of a person's genetic characteristics that may, under some circumstances, be associated with disability in that person or that person's offspring."⁶⁹ Genetic characteristics are defined for life insurers as they are for health insurers,⁷⁰ though applications may be declined, rates increased, and coverage limited for people whose genetic diseases become symptomatic, or, in other words, "on the basis of manifestations of any disease or disorder."⁷¹

sults contained in an applicant or enrollee's medical records by a health care service plan carries civil penalty in an amount not to exceed one thousand dollars; willful disclosure not less than one thousand dollars and no more than five thousand dollars; willful or negligent disclosure of the results of a test for a genetic characteristic to a third party in a manner that identifies or provides identifying characteristics of the person to whom the test results apply, misdemeanor punishable by a fine not to exceed ten thousand dollars, and liable for all actual damages.). Similar provisions are contained in Cal Ins Code § 10123.35 (West Supp 1996) (self-insured welfare benefit plan); Cal Ins Code § 10140.1 (West Supp 1996) (insurer licensed to issue life or disability insurance); Cal Ins Code § 11512.965 (West Supp 1996) (nonprofit hospital service plan).

65. Cal Ins Code § 10147 (West Supp 1996). See also Cal Ins §10123.3(d) (§10123.3(d) adds the following clause: "or inherited characteristic that may derive from the individual or family member"). California's statutory scheme distinguishes between "insurers" and "health care service plans" and often repeats statutory language in two different parts of the code depending on the entity being regulated.

66. Cal Ins Code § 10143 (West 1993).

67. Cal Ins Code § 10123.3 (West Supp 1996).

68. Cal Ins Code § 11512.95 (West Supp 1996).

69. Cal Ins Code § 10140 (West Supp 1996).

70. Cal Ins Code § 10147 (West Supp 1996).

71. Cal Ins Code § 10148 (West Supp 1996).

3. Colorado

Colorado defines genetic information as “the unique property of the individual to whom the information pertains” and declares a legislative intent of preventing “information derived from genetic testing from being used to deny access to health care insurance, group disability insurance, or long-term care insurance coverage.”⁷² Colorado also declares that the information is confidential and privileged, and requires written consent of the test subject before test results can be released.⁷³

The suggestion of strong protections of confidentiality are illusory, however, in light of numerous exceptions that are catalogued in the law: genetic testing information can be released to law enforcement officials in a criminal investigation;⁷⁴ to research facilities (without identification of the individual research subject);⁷⁵ to a court in a parentage proceeding;⁷⁶ in civil litigation to determine the cause of a damage or injury;⁷⁷ in cases of sexual assault;⁷⁸ or to the state or local public health authorities.⁷⁹ Confidentiality also does not apply to the provision of life insurance or individual disability insurance.⁸⁰

Violation of the statute is declared an “unfair practice” and is subject to the provisions of sections 10-3-1106 through 10-3-1113. Relief for civil actions can include equitable relief, actual damages, costs and attorney fees.⁸¹

4. Florida

Florida declares the results of DNA testing to be confidential and—except for purposes of criminal prosecution, post-conviction banking, or determining paternity—the “exclusive property of the person tested.”⁸² Test results may not be disclosed without consent, and violators of this requirement assume liability for a misdemeanor. A person who performs DNA analysis or receives information derived from DNA analysis must provide the person tested with notice that the test was performed and the information was received. The notice must also state whether the information was used in any decision to grant or deny any insurance, employment, mortgage, loan, credit, or educational opportunity.⁸³

72. 1995 Colo Rev Stat § 10-3-1104.7(1) (1995).

73. 1995 Colo Rev Stat § 10-3-1104.7(3)(a) (1995).

74. 1995 Colo Rev Stat § 10-3-1104.7(4) (1995).

75. 1995 Colo Rev Stat § 10-3-1104.7(5) (1995).

76. 1995 Colo Rev Stat § 10-3-1104.7(6) (1995).

77. 1995 Colo Rev Stat § 10-3-1104.7(7) (1995).

78. 1995 Colo Rev Stat § 10-3-1104.7(8) (1995).

79. 1995 Colo Rev Stat § 10-3-1104.7(9) (1995).

80. 1995 Colo Rev Stat § 10-3-1104.7(10) (1995).

81. 1995 Colo Rev Stat § 10-3-1104.7(11) (1995).

82. Fla Stat Ann § 760.40(2)(a) (West 1994).

83. See, generally, Fla Stat Ann § 760.40 (West Supp 1996).

5. Georgia

Georgia forbids any insurer, including most entities that provide prepaid health care, along with "accident and sickness insurance companies,"⁸⁴ from using genetic information to deny coverage.⁸⁵ It asserts that "[g]enetic information is the unique property of the individual tested."⁸⁶ It prescribes "prior written consent" for testing, declares the results of testing "confidential and privileged" and prohibits any insurer that receives information derived from genetic testing from using the information for a "nontherapeutic" purpose, as well as prohibiting insurers from seeking information derived from genetic testing.⁸⁷

The privilege breaks down in the criminal context, where no consent is required to release information on a defendant or suspect.⁸⁸ A similar exception allows disclosures for scientific research.⁸⁹ The nondiscrimination provision all but disappears in light of exceptions listed in another part of the statute, which allows use of genetic testing in the context of:

a life insurance policy, disability income policy, accidental death or dismemberment policy, Medicare supplement policy, long-term care insurance policy, credit insurance policy, specified disease policy, hospital indemnity policy, blanket accident and sickness policy, franchise policy issued on an individual basis to members of an association, limited accident policy, health insurance policy written as a part of workers' compensation equivalent coverage, or other similar limited accident and sickness policy.⁹⁰

Violations of the law are declared an unfair trade practice, giving rise to statutory penalties, and a civil cause of action is created, with equitable relief, actual damages and attorney's fees and costs listed among the remedies.⁹¹

6. Louisiana

Discrimination in life or disability insurance on the basis of sickle-cell trait is prohibited, but waiting periods, pre-existing conditions, or dreaded disease rider exclusions are not ruled out "if they do not unfairly discriminate."⁹²

84. Ga Code Ann § 33-54-2 (Michie Supp 1995) ("Definitions").

85. Ga Code Ann § 33-54-1(4) (Michie Supp 1995).

86. Ga Code Ann § 33-54-1(1) (Michie Supp 1995).

87. Ga Code Ann § 33-54-3, § 33-54-4 (Michie Supp 1995) ("Prohibited use of information").

88. Ga Code Ann § 33-54-5 (Michie Supp 1995).

89. Ga Code Ann § 33-54-6 (Michie Supp 1995).

90. Ga Code Ann § 33-54-7 (Michie Supp 1995).

91. Ga Code Ann § 33-54-8 (Michie Supp 1995).

92. La Rev Stat Ann § 22:652.1(D) (West 1995).

7. Maryland

Maryland formerly proscribed "unfair discrimination" in life, health and annuity contracts for insurance, but apparently leaves the definition of "unfair" up to the actuaries, allowing all differential ratemaking, underwriting, and so on, that is accompanied by an "actuarial justification."⁹³ Maryland's 1996 statutory revisions remove anti-discriminatory provisions that applied to life, life annuity or disability insurance policies, maintaining the prohibition on use of "genetic tests" in health insurance policies only.⁹⁴

8. Minnesota

Minnesota's "genetic discrimination act" defines a "genetic test" as "a presymptomatic test of a person's genes, gene products, or chromosomes for the purpose of determining the presence or absence of a gene or genes that exhibit abnormalities, defects, or deficiencies, including carrier status, that are known to be the cause of a disease or disorder, or are determined to be associated with a statistically increased risk of development of a disease or disorder."⁹⁵

The act prohibits insurers, in determining eligibility for insurance, setting premiums, or limiting coverage, from requiring applicants to submit to genetic tests, or considering whether a genetic test was taken by an applicant or their relative, except when the insured voluntarily takes such tests following informed consent. The written consent document must inform the applicant that she should consider consulting with a genetic counselor prior to taking the test and it must state whether the insurer will pay for the consultation.⁹⁶

Minnesota prohibits discrimination in health plans, but not in life insurance coverage.⁹⁷

9. New Hampshire

New Hampshire defines genetic testing "as a test, examination or analysis which is generally accepted in the scientific and medical communities for the purpose of identifying the presence, absence or alteration of any gene or chromosome, and any report, interpretation or evaluation of such a test, examination or analysis."⁹⁸ The law prohibits the use of genetic tests for health insurance, but not for life, disability income, or long-term care insurance. The fact of genetic testing or its results are protected from disclosure unless the subject of

93. Ann Code of Md § 223 Unfair discrimination—Life, health and annuity contracts.

94. Ann Code of Md §223.1. See also Eric Wulfsberg, et al, *Antitrypsin Deficiency—Impact of Genetic Discovery on Medicine and Society*, 271 J Am Med Assoc 217, 221 (1994) ("[A] major unresolved issue is what constitutes actuarial justification and how it will be determined, given the rarity of most genetic diseases."). See generally Harry Ostrer, et al, *Insurance and Genetic Testing: Where are We Now?*, 52 Am J Human Genetics 565, 574 (1993).

95. Minn Stat Ann § 72A.139 (West 1996).

96. Id.

97. Id.

98. NH Rev Stat Ann § 141-H:1 (IV) (Equity 1995).

the test has given written, informed consent. Exceptions to this rule are allowed to establish paternity, to test newborns for metabolic disorders and for purposes of criminal investigations and prosecutions.

An unusual feature of the New Hampshire legislation appears to establish a right to have access to testing. It provides that:

No person shall refuse to perform genetic testing, or to arrange for genetic testing to be performed, or to do business with an individual, solely because the individual to be tested refuses to consent to providing the test results to some or all persons.⁹⁹

This could be interpreted to preclude physicians or genetic counselors from involving family members in genetic counseling sessions without the specific consent of the tested person.

10. North Carolina

North Carolina law prohibits discrimination against persons who carry the trait for sickle-cell or hemoglobin C in provision of policies or rates for medical,¹⁰⁰ dental, or hospital coverage,¹⁰¹ and life insurance.¹⁰²

11. Ohio

Ohio defines "genetic screening or testing" as:

[A] laboratory test of a person's genes or chromosomes for abnormalities, defects, or deficiencies, including carrier status, that are linked to physical or mental disorders or that indicate a susceptibility to illness, disease, or other disorder . . . which test is a direct test for abnormalities, defects or deficiencies, and not an indirect manifestation of genetic disorders.¹⁰³

It forecloses the use of genetic test results by HMOs,¹⁰⁴ sickness or accident insurers,¹⁰⁵ or self-insurers,¹⁰⁶ but allows them to consider such results if they are submitted voluntarily and the results are favorable to an applicant.

12. Oregon

Oregon¹⁰⁷ law prohibits some types of insurance discrimination, and exhaustively lists when genetic information may be used, disclosed and demanded. It also includes what may be the most extensive and elaborate state legislative

99. NH Rev Stat Ann § 141-H:2 (II) (Equity 1995).

100. NC Gen Stat § 58-51-45 (1994).

101. NC Gen Stat § 58-65-70 (1994).

102. NC Gen Stat § 58-58-25 (1994).

103. Ohio Rev Code Ann § 1742.42 (Baldwin 1994).

104. *Id.*

105. Ohio Rev Code Ann § 3901.49 (Baldwin 1995).

106. Ohio Rev Code Ann § 3901.50 (Baldwin 1995).

107. Or Rev Stat § 659.705 (1995).

statement on the uses and abuses of genetic testing.¹⁰⁸ It defines “genetic test” as “a test for determining the presence or absence of genetic characteristics in an individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order to diagnose a genetic characteristic,”¹⁰⁹ and requires informed consent for all testing and use of testing results except for purposes of federal criminal law relating to the identification of persons, for the purpose of establishing the identity of a person in the course of an investigation conducted by a law enforcement agency, or a medical examiner; for anonymous research where the identity of the subject will not be revealed; for identification of deceased individuals; for newborn screening; and for establishing paternity.¹¹⁰

Oregon’s legislative policy makes an individual’s genetic information that person’s property, requiring specific authority for retaining DNA samples and mandating destruction of all others.¹¹¹ It creates a qualified privilege, allowing anyone to refuse to disclose or be compelled, by subpoena or any other means, to disclose the identity of an individual upon whom a genetic test has been performed or to disclose genetic information about the individual in a manner that permits identification of that person, except in specifically enumerated cases. It also prohibits redisclosure of genetic information by those who hold it without the consent of the owner.¹¹²

In contrast to Minnesota, Oregon forbids underwriting on the basis of good test results as well as negative results. An insurance provider may not use genetic

108. *Id.* ((1) “The Legislative Assembly finds that: (a) The DNA molecule contains information about an individual’s probable medical future. This information is written in a code that is rapidly being broken. (b) Genetic information is uniquely private and personal information that should not be collected, retained or disclosed without the individual’s authorization. (c) The improper collection, retention or disclosure of genetic information can lead to significant harm to the individual, including stigmatization and discrimination in areas such as employment, education, health care and insurance. (d) An analysis of an individual’s DNA provides information not only about an individual, but also about the individual’s parents, siblings and children, thereby impacting family privacy, including reproductive decisions. (e) Current legal protections for medical information, tissue samples and DNA samples are inadequate to protect genetic privacy. (f) Laws for the collection, storage and use of identifiable DNA samples and private genetic information obtained from those samples are needed both to protect individual privacy and to permit legitimate genetic research. (2) The purposes of sections 1 to 5 and 8 of this Act and the provisions of ORS 659.036, 659.227 and 746.015 relating to genetic characteristics, information and testing are as follows (a) To define the rights of individuals whose genetic information is collected, retained or disclosed. (b) To define the circumstances under which an individual may be subjected to genetic testing. (c) To define the circumstances under which an individual’s genetic information may be collected, retained or disclosed. (d) To protect against discrimination by an insurer or employer based upon an individual’s genetic characteristics.”).

109. See Or Rev Stat § 659.700 (1995).

110. See Or Rev Stat § 659.715 (1995).

111. *Id.*

112. See Or Rev Stat § 659.720 (1995).

information to discriminate against existing or potential policyholders of any policy for hospital or medical expenses. No other insurance coverage is protected.¹¹³

13. Tennessee

Refusal to issue a life insurance policy may not be conditioned upon the existence of sickle-cell trait or hemoglobin C trait in a potential insured.¹¹⁴

14. Virginia

Virginia's law establishes a two-year moratorium on the use of genetic information by "accident and sickness" insurers for the purposes of denying, restricting, canceling or otherwise limiting insurance coverage or availability.¹¹⁵ It also makes all information obtained from genetic screening or testing that was conducted prior to the conclusion of the moratorium period confidential and unavailable for underwriting purposes.¹¹⁶

15. Wisconsin

Wisconsin prohibits "unfair genetic tests" in employment¹¹⁷ and specifies remedies of reinstatement and/or back pay.¹¹⁸ It restricts the use of genetic tests to determine health insurance coverage. Life insurance or income continuation insurers may not set rates or condition any other aspect of coverage on factors "not reasonably related to the risk involved."¹¹⁹

Written, informed consent is required before any employer or labor entity can perform genetic tests, and no disclosures of test results may be made to employers without the prior written and informed consent of the subject of the test. Violations carry misdemeanor liability.¹²⁰

B. WHAT DO STATE INSURANCE LAWS PROHIBIT—A HYPOTHETICAL CASE

As the previous sections demonstrate, great variety exists among state provisions protecting genetic information from discriminatory use in the insurance context. The following hypothetical case is offered as a vehicle for exploring how effectively, a particular state's antidiscriminatory law would affect a person with a sensitive medical record and a very serious genetic disease.

113. *Id.*

114. Tenn Code Ann § 56-7-207 (1994).

115. Va Code § 38.2-508.4(B) (1996) (effective until 1998).

116. Va Code § 38.2-613.1 (1996), Va SB 335 (amending § 38.2-613 and adding § 38.2-508.4).

117. Wis Stat Ann §§ 111.32, 111.372 (West Supp 1995).

118. Wis Stat Ann § 111.39 (West Supp 1995).

119. Wis Stat Ann § 631.89 (West Supp 1995).

120. Wis Stat Ann § 942.07 (West 1995).

Carl's Secret

Carl is 40 years old. He migrated from Argentina ten years ago to pursue graduate education as a physicist. Several of Carl's relatives died in their mid-40's from Huntington's disease. Their medical records are lost in Argentina, and none of Carl's doctors in America have been told of his family background.

Upon graduation, Carl started Atomic Dumping Inc., ("ADI"), a nuclear waste disposal company, which he recently sold for several million dollars. Part of the sale involved an agreement by Carl to remain employed for five years as chief executive officer of the company.

The new owners propose to offer health insurance, including a long and short-term disability plan, to all full-time employees of ADI. A life insurance benefit equal to twice an employee's annual salary will be available at no charge and employees may purchase additional coverage at prevailing rates. Subsidized liability insurance will also be an optional employee benefit.

Carl applies for health, disability, and personal liability coverage, and life insurance with a death benefit equivalent to his net worth—2.5 million dollars. He is informed that he will have to submit to a medical examination and DNA analysis before the policies will be issued.

Assume that Carl is affected with Huntington's. He knows of his family background but is unaware of his own condition. He decides to litigate the question of conditioning insurance coverage on the results of a DNA analysis. How might he fare under the various state laws now in force?

In California, Carl's genetic characteristics could not be used as the basis of discriminatory treatment in life, health or disability insurance as long as he was asymptomatic. The law would appear to protect individuals who have autosomal dominant diseases such as Huntington's, even though they are virtually certain to develop symptoms of that disease, and at high risk for premature disability and death. California law seems to allow for cancellation or nonrenewal of Carl's insurance coverage at the first hint of symptoms. It is not clear whether insurance companies could ask, absent testing, whether Carl had a family history of Huntington's and use his truthful response to deny coverage, or whether benefits that would pay for treatment of Carl's eventual symptoms could be excluded from coverage.

In Florida, Carl would apparently only have the right to receive notice that he didn't get insurance because of his DNA test—not a right to coverage.

Maryland law would not allow a health insurer to demand genetic testing, but also would not prohibit questions about the health or cause of death of Carl's family members. It would also not preclude a policy provision that ruled out medical payments for Huntington's disease. Should Carl choose not to answer, or answer dishonestly, his health insurance might not be forthcoming. On the other hand, a life or disability insurer could demand a genetic test.

In New Hampshire, Carl could agree to be tested—but refuse to release the results if they confirm his Huntington's disease. A similar result would seem to apply in Minnesota. Carl would then be able to receive health insurance, but would not be able to purchase the life, disability or liability insurance he desires.

In Virginia, Carl would be protected in his search for health insurance for two years, but would have no guarantee that coverage would be extended beyond that period, or that any other type of insurance would be available.

Most of the other states would, in general, protect Carl's ability to purchase a health insurance plan, while making life, disability, long-term care, accident, liability or other types of coverage potentially subject to DNA testing.

Carl's options are not inviting. If he is not tested, he will not know whether he has Huntington's. And that may be his decision regardless of insurance questions. If he wants anything other than health insurance coverage, in most states he must be tested and surrender the option of remaining ignorant of his future health. If he tests positive he must live with the results: the knowledge of the terrifying disease process and death he faces, and no access to many kinds of insurance he wishes to purchase. Should he have the right (as California law would seem to give him) to purchase extravagant amounts of life insurance even if he knows there is a high likelihood of dying prematurely? Should he be precluded from buying casualty or liability insurance, even though he remains asymptomatic and would be no more at risk for accidents than any other person?

Framing the question of insurance discrimination in the context of a man with Huntington's disease highlights the conflicting policy objectives that are at work in attempts to protect against insurance discrimination. It also shows the arbitrary distinction between genetic data and other medical information. Even though we claim differences for genetic data, suggesting that it often points to conditions for which there is no treatment,¹²¹ conditions such as Carl's would be grounds for discrimination regardless of the source of information.

Existing practices of insurance discrimination against the "asymptomatic ill" have been monitored by watchdog groups who assert that insurance companies have used the results of gene-based tests to justify canceling coverage, saying that a genetic abnormality is a preexisting condition; to deny coverage to unaffected relatives of a person with a genetic disorder; and to refuse to issue a policy unless an applicant submits to a genetic test.¹²² Such practices are warranted, says the American Council on Life Insurance and the Health Insurance Association of America (HIAA), to protect against "adverse selection."¹²³ They assert the right of insurers to know the results of any test an insurance applicant has

121. T. H. Cushing, *Should There Be Genetic Testing in Insurance Risk Classification?*, 60 Defense Counsel J 249, 258-59 (1993) ("Those who oppose insurer's use of genetic testing assert that genetic information is fundamentally different from other types of medical information readily accessible to insurers. They argue that the immutable quality of genetic information sets it apart from other sorts of medical information, such as a person's blood pressure or cholesterol level.").

122. Paul R. Billings, *Discrimination as a consequence of genetic testing*, 50 Am J Human Genetics 476, 478 (1992).

123. Susan Ince, *Predictive Testing, A Bite of the Apple*, 20 Harv Health Letter 3, 4 (June 1995).

taken.¹²⁴ Critics of this position assert that the Human Genome Project could become “a welfare program for insurance companies.”¹²⁵

Confidentiality of test results—in those states where confidentiality is protected—guarantees that health insurance will be available, at least to the financially fortunate like Carl. Confidentiality of test results also underlines the moral hazard that Carl will overpurchase life coverage precisely because he knows how much he will need it. If he knows his genetic status, Carl can purchase life insurance as if it were a secure and predictable financial instrument, rather than buying into the lottery of risk that faces most people to whom life's prospects are unknown.

Is health insurance coverage, and health insurance discrimination, different? Perhaps so. While arguments in favor of a universal right to health care are readily available, it is hard to construct a reasoned argument for a “right” to life insurance. In both cases the real issue seems not to be confidentiality. Only for serious or socially stigmatic diseases is confidentiality crucial. What is so intimate about a one in 50 chance of being subject to hypertension, or a one in 200 chance of being a likely candidate for gallbladder surgery? The real issue is discrimination in health insurance—the threat of being wiped out because of the impact of major illness that may or may not be slightly more predictable because of genetic markers. If we had a national program that guaranteed health coverage, confidentiality beyond what is expected now in the medical setting would rarely be an issue.

Most of the arguments against discrimination in health insurance are not confidentiality arguments, but health policy arguments about who should get care and at what cost.

VII. The Rhetorical War

Supporters of the Model Genetic Privacy Act claim that genetic information is uniquely private and personal.¹²⁶ They call it a “future diary” that “will tell us more and more about a person's likely future, particularly in terms of physical and mental well-being.” They describe genetic testing as a process that involves “locating predictors of undesirable and stigmatizing conditions—such as cancers, and conditions that lead to mental illness and dementia.”

What is the impact of this image of genetic data as a “future diary”? First, it promises too much from the fruits of genetic research. It may be many years before we are able to define the functional utility of the millions of bits of genetic material that comprise our biological blueprint. We may, even at that point, still not be able to predict how that material relates to the environment in

124. Id.

125. Myk Cherskov, *Fighting Genetic Discrimination*, 78 ABA J 38 (1992) (quoting Theresa Morelli).

126. See, for example, George J. Annas, *Privacy Rules for DNA Databanks Protecting Coded 'Future Diaries'*, 19 J Am Med Assoc 2346 (1993). The authors of the Genetic Privacy Act are George Annas, Leonard Glantz, and Patricia Roche.

which it develops, or how often or why it changes form within a lifetime. It is unlikely that the Human Genome Project or any successor initiative will answer all the possible questions to adequately point us toward even a probabilistic "future diary."

But what else does the phrase suggest? A diary is a self-generated, personal reflection on the daily details of life. Many of these details are consciously planned and contingent upon our life choices, our individual history, and our career of social interaction, not our genetic makeup alone. Our diary may be a chronicle of disease (*A Diary of the Plague Year*) or a parade of unconventional behavior (*The Diary of Samuel Peppys*) or even a canticle of hope (*The Diary of Anne Frank*). Though we may, like Carl, be at high risk for disease, our life's significance should not be conceptualized as a mere product of our genes.

This metaphor of genes as "future diary" overemphasizes the language of fear that runs through many proposals for heightened genetic confidentiality. Phrases such as "the genetic underclass" and "asymptomatic ill" are dangerous in themselves and characterizing a genetic condition as an "immutable, heritable taint," "ineradicable marker of deviance," or "scarlet letter" tends to raise the implicit assumption of genetic determinism to an accepted fact. The diaries of the living are not yet complete and we shall all die eventually, with or without the knowledge of how little, or how much, our genetic heritage marked the moment of that death. The language of scientific reductionism need not be one more contributor to the potential for genetic discrimination.

VIII. Conclusion

The driving force in the calls for anti-discrimination in the health insurance market is not the problem of genetic discrimination, but the absence of affordable insurance for some 30 to 40 million Americans of unremarkable genetic endowment. Attention focused on the need for genetic confidentiality can have the unintended effect of creating an aura of stigma for a few noteworthy diseases, rather than heightening general awareness that many if not most diseases have some genetic component. Our recent experience with the HIV/AIDS epidemic should alert us that "exceptionalism"—the attempt to create discrete categories of law for particular groups of medical patients—can have the result of further marginalizing the group we are attempting to protect. Exceptional treatment for diseases for which we have only recently discovered a genetic component and raising the level of rhetoric in order to advocate legal change is likely also to raise the level of paranoia about those diseases rather than working toward removing whatever stigma that already surrounds genetic disease.

Discrimination on genetic grounds is only one part of the much larger problem of competitive risk-rating that puts many potential policyholders beyond the ambit of insurance coverage. Until that problem is fixed, and there is a system of accessible health care available to all who need it, the attempt to carve out some portion of the public for unfavorable treatment because of medical condition—genetic or not—will remain endemic. Rules for genetic confidentiality will not cure the health care crisis. This is not an argument against the very real

danger of genetic discrimination. It is a warning that precipitous legislation that does not take into account existing law and its efficacy (or lack thereof) may fall prey to the same shortcomings that have been demonstrated by earlier attempts at protective legislation.