

# PROTECTING GENETIC DIFFERENCE

By Michael S. Yesley<sup>†</sup>

*On February 20-21, 1998, the Berkeley Technology Law Journal co-sponsored a symposium with the Berkeley Center for Law and Technology entitled Biotechnology and the Law: New Perspectives on Public Access and Proprietary Rights. The symposium explored the impact of current patent law and policy on biotechnological research, as well as the legal and ethical questions stemming from that research. Mr. Yesley presented this paper during the Information Privacy session, which addressed the social ramifications of lax privacy rules for genetic data and considered whether there should be a property right in this data.*

## ABSTRACT

This article surveys current legislation related to genetic privacy and discrimination, including Federal and State laws that prohibit, or could be used to prohibit, genetic discrimination in employment and insurance, and laws that protect genetic privacy. The relationship between protecting genetic privacy and prohibiting genetic discrimination is discussed.

In part II of the article, the author discusses impediments to the creation of effective legislation to combat genetic discrimination. These include: (1) the difficulty of defining "genetic information," given the variety of information with genetic significance; and (2) the limited usefulness of laws narrowly focused on prohibiting genetic discrimination and the possibility of perverse results from such measures.

Finally, the article addresses whether a property right in genetic data is needed to address the issue of genetic privacy. The author concludes that, unlike the case where a person's biological materials are used to develop a commercial product, intangible genetic data probably would not generate sufficient value to warrant the cost of enforcement by those affected. As the author explains, "the goal of protecting genetic information is not to preserve any value of the information, but to control its use and disclosure. For this purpose, requiring informed consent is probably sufficient, and the disincentive of potential recovery for conversion of the property is unnecessary."

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† Staff Attorney, Los Alamos National Laboratory. A.B. 1960, J.D. 1963, Harvard. Coordinator of the U.S. Department of Energy Program on the Ethical, Legal, and Social Implications of the Human Genome Project, 1990-1995. The views are the author's.

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### I. INTRODUCTION

In the world of biotechnology, John Moore (an unwitting donor of cells for medical research) learned to his surprise that you can be valuable if you are different.<sup>1</sup> But in the rest of the universe, being different is not necessarily an advantage—particularly if one’s difference is a basis for discrimination. Genetics provides a new lexicon of difference, for better and for worse. We focus here on “worse:” the possibility that genetic difference can be used as a basis for discrimination in employment and insurance.

Anti-discrimination laws protect many kinds of difference—race, sex, national origin, disability, and more.<sup>2</sup> Privacy rules have also been used as a means to protect difference,<sup>3</sup> and privacy ranks high as an end in itself. But privacy may hinder as well as promote anti-discrimination efforts because one’s differences must often be revealed in order to protect them. Also, privacy will not protect a difference that is obvious.

Genetics reintroduces privacy as a potential weapon against discrimination, because unexpressed molecular differences are hidden. However, these differences can be identified by direct tests or inferred from a variety of sources, like family history and routine medical tests. Thus, the veil of

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1. Moore’s cells were obtained in the course of his treatment for leukemia at UCLA Medical Center and, unbeknownst to him, used to established a cell line that was patented. *See Moore v. Regents of the University of California*, 793 P.2d 479 (Cal. 1990), *cert. denied*, 499 U.S. 936 (1991).

2. *See, e.g.* Civil Rights Act of 1964, Pub. L. No. 88-352, 78 Stat. 241 (1964); American with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (1990).

3. For example, some genetic anti-discrimination laws bar insurers from requesting individuals to reveal whether they have been tested or the results of any genetic testing. *See, e.g.*, WIS. STAT. § 631.89 (1996).

molecularity can be pierced in many ways. This raises the question of how best to prevent genetic discrimination. Which approach—property, privacy, civil rights, the free market, public subsidy, or some other—will provide the greatest protection against social misuse of genetic difference?

This article addresses the question of whether the law should recognize a property right in genetic data. There are, of course, more direct ways to prevent the social consequences of losing genetic privacy. We can use privacy measures to control the development and disclosure of genetic information about individuals, or prohibit genetic discrimination, or eliminate economic incentives to discriminate. The last goal, for example, might be accomplished by providing health coverage to those with genetic disorders (or to everyone), or by discovering treatments and preventives that reduce the fateful significance of genetic difference. But until we can prevent as well as predict genetic disorders, we must use legal or economic tools to guard against potential misuse of genetic information. As this article will show, however, the laws on genetic privacy and discrimination, though well-intentioned, are ineffective, impracticable, ambiguous, inflexible, or too narrowly focused on genetics. The article concludes that creating a property interest in genetic information would not significantly increase the protection against misuse of genetic information afforded by informed consent requirements and other measures to protect privacy.

## II. CURRENT LAW RELATING TO GENETIC PRIVACY AND DISCRIMINATION

Before considering the recent legislation specific to genetic information, the applicability of general privacy and anti-discrimination law should be noted. An interpretation of the Americans with Disabilities Act<sup>4</sup> (ADA) by the Equal Employment Opportunity Commission (EEOC) may provide limited federal protection against genetic discrimination in employment. The ADA does not specifically mention genetics but clearly covers expressed genetic disorders to the same extent as impairments without a genetic component. Whether the ADA also covers unexpressed genetic predispositions and recessive traits is, however, unclear. The EEOC, which administers the employment provisions of the ADA, has taken the position that the ADA covers a genetic predisposition that is “regarded” as an impairment by an employer,<sup>5</sup> but this position has not yet been upheld judicially. However, the Ninth Circuit Court of Appeals re-

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4. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (1990).

5. See 2 EEOC COMPLIANCE MANUAL § 902 (1995).

cently found that genetic testing of prospective employees by Lawrence Berkeley Laboratory could violate both the federal and California constitutional rights of privacy if the employees did not authorize the tests and had no reason to know that the tests were part of a general physical examination.<sup>6</sup>

Last year, there was a flurry of state legislation regarding genetic privacy and discrimination. The number of states that prohibit genetic discrimination by health insurers more than doubled, to 23 states.<sup>7</sup> Also, four states prohibited genetic discrimination by employers, bringing the total in this category to 11 states.<sup>8</sup> In all, 13 states adopted laws last year to prohibit genetic discrimination in insurance and/or employment,<sup>9</sup> bringing the total to 28 states<sup>10</sup> that have enacted such laws since 1989. Earlier, several states had prohibited discrimination against carriers of recessive traits, like sickle cell anemia, that could affect only the carriers' offspring,<sup>11</sup> but the recent laws also protect individuals with genetic anomalies that could affect themselves.

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6. See *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260 (9th Cir. 1998) (reversing summary judgment against employees in part because material issues of fact existed as to whether the employees authorized or knew that a government-operated research facility employer was testing them for sensitive medical information).

7. See 1997 Ala. Acts 97-721; CAL. HEALTH & SAFETY CODE § 1374.7 (West 1998); CAL. INS. CODE §§ 742.405, 10123.3, 10140 (West 1998); COLO. REV. STAT. ANN. § 10-3-1104.7 (West 1998); 1997 Conn. Pub. Acts 97-95; 1997 Fla. Laws ch. 97-182; GA. CODE ANN. §§ 33-54-1 to 8 (1997); 1997 Haw. Sess. Laws 91; 1997 Ill. Pub. Act 90-25; IND. CODE ANN. § 27-8-26-7 (Michie 1997); 1997 Kan. Sess. Laws 190; 1997 La. Acts 1418; MD. CODE ANN., INS. § 223.1 (1997); MINN. STAT. § 72A.139 (1997); 1997 Nev. Stat. 412; 1997 N.C. Sess. Laws 350; N.H. REV. STAT. ANN. § 141-H:4 (1996); N.J. STAT. ANN. §§ 17:48-6.18, 17:48A-6.11, 17:48E-15.2, 17B:26-3.2, 17B-27-36.2, 26:2J-15.1 (West 1998); OHIO REV. CODE ANN. §§ 1742.42, 3901.49, 3901.50 (Banks-Baldwin 1997); OR. REV. STAT. § 746.135 (1996); 1997 Tenn. Pub. Acts 121; 1997 Tex. Gen. Laws 1215; VA. CODE ANN. § 38.2-508.4 (Michie 1997); WIS. STAT. § 631.89 (1996).

8. See 1997 Ariz. Sess. Laws 229; 1997 Ill. Pub. Act 90-25; IOWA CODE ANN. § 729.6 (West 1997); N.H. REV. STAT. ANN. § 141:H-3 (1996); N.J. STAT. ANN. § 10:5-12 (West 1998); 1997 N.C. Sess. Laws 350; N.Y. EXEC. LAW § 296 (McKinney 1993 & Supp. 1997); OR. REV. STAT. §§ 659.036, 659.227 (1996); R.I. GEN. LAWS § 28-6.7-1 (1997); 1997 Tex. Gen. Laws 1215; WIS. STAT. § 111.372 (1996).

9. Specifically, Alabama, Arizona, Connecticut, Florida, Hawaii, Illinois, Indiana, Kansas, Louisiana, Nevada, North Carolina, Tennessee, and Texas prohibited genetic discrimination last year.

10. In addition to the 13 states listed *supra* note 9, California, Colorado, Georgia, Iowa, Maryland, Minnesota, Montana, New Hampshire, New Jersey, New York, Ohio, Oregon, Rhode Island, Virginia, and Wisconsin have prohibited genetic discrimination.

11. See, e.g., CAL. HEALTH & SAFETY CODE § 1374.7 (1993).

Nearly all the laws on genetic discrimination incorporate measures to protect genetic privacy. Also, four states have declared that genetic information is the property of the individual to whom the information pertains.<sup>12</sup> In New Jersey, however, the legislature adopted genetic anti-discrimination legislation in 1996 only after a declaration that genetic information is the property of the individual was deleted at the insistence of the governor. That action was prompted by a complaint from a biotechnological industry organization that characterizing "genetic information as property could create 'conflicts over ownership rights [that] will slow research and development efforts and likely [foment] unnecessary litigation.'"<sup>13</sup>

Most states have also adopted portability and access laws that limit preexisting condition exclusions and bar discrimination based on genetic information or, more broadly, health status in determining eligibility to enroll in group health insurance plans.<sup>14</sup> Following the terms of the federal Health Insurance Portability and Accountability Act of 1996,<sup>15</sup> the states adopted these laws in 1997 in order to preserve their jurisdiction over insurers.<sup>16</sup> The portability and access laws add little protection against discrimination, genetic or otherwise, because they apply to plans that do not look at individual employees' records but determine their eligibility for health coverage solely on the basis of their employment.<sup>17</sup>

One way to protect genetic privacy is to increase the protection of medical privacy generally, including genetic data. Unfortunately, medical privacy is a myth today. Our medical records are not well protected in hospitals, doctors' offices, employers' records, or pharmacies. Computerization has exposed medical records to a variety of worthy and not-so-

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12. See, e.g., COLO. REV. STAT. ANN. § 10-3-1104.7(1)(a) (West 1998); GA. CODE ANN. § 33-54-1(1) (1997); 1997 La. Acts 1418; OR. REV. STAT. § 659.715(1) (1996) (as amended by 1997 Or. Laws 780).

13. Philip R. Reilly, *Governor Not Expected to Sign New Jersey Genetic Privacy Act*, (visited Sept. 1, 1996) <<http://www.geneletter.org/0996/governor.htm>>.

14. See, e.g., 1997 Ark. Acts 997.

15. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat 1936 (1996).

16. The U.S. Department of Health and Human Services is responsible for enforcing Health Insurance Portability and Accountability Act provisions in states that do not pass and enforce laws imposing similar protections. U.S. General Accounting Office, *Health Insurance Standards: New Federal Law Creates Challenges for Consumers, Insurers, Regulators*, GAO/HEHS-98-67 (1998) at 5 (available at <<http://frwebgate.access.gpo.gov/cgi-bin/useftp.cgi?IPaddress=wais.access.gpo.gov&filename=he98067.txt&directory=/diskb/wais/data/gao>>).

17. See generally Health Insurance Portability and Accountability Act of 1996, *supra* note 16.

worthy enterprises. Federal protection of medical records is coming, by law and/or regulation,<sup>18</sup> and it will surely increase genetic privacy. The advantages of protecting genetic privacy as a subset of medical privacy include avoiding the problems of (1) defining what information is genetic and (2) justifying special protection for genetic information (we shall return to these issues). However, even enhanced medical privacy rules will not protect genetic information in non-medical contexts, such as genetic research unrelated to medical care or testing conducted by employers and insurers.

Therefore, many have argued for a special embargo on disclosure of genetic information, like the protection afforded movie rental records.<sup>19</sup> In fact, as noted above, about half the states have laws of various sorts to protect genetic privacy. These measures include prohibitions on requiring a genetic test or disclosure of previous test results as a condition of employment<sup>20</sup> or insurance,<sup>21</sup> prohibitions on genetic testing or disclosure of genetic information without informed consent,<sup>22</sup> and statutory declarations that genetic information is confidential.<sup>23</sup> Provisions like these can provide some assurance of genetic privacy. Not all genetic privacy measures will guard against genetic discrimination, however. Merely requiring informed consent for genetic testing will not prevent an employer or insurer from insisting on testing as a condition of employment or insurance. An applicant can refuse testing but only at the cost of not becoming employed or insured. Unless testing itself or the use of test results is prohibited, the privacy protection is of limited value.

For example, New York requires all insurers to obtain informed consent for genetic testing but does not prohibit use of the test results for underwriting.<sup>24</sup> Several states require life insurers to obtain informed consent for genetic testing,<sup>25</sup> but no state bars life insurers from discriminating

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18. The present Congress is considering several comprehensive health privacy bills. Also, the "administrative simplification" provisions of the Health Insurance Portability and Accountability Act of 1996 require the Department of Health and Human Services to adopt uniform national standards, including measures to protect confidentiality, for the electronic processing of insurance claims.

19. See 18 U.S.C.A. § 2710 (1996) (consumer privacy protection law providing a remedy for wrongful disclosure of video tape rental or sale records).

20. See, e.g., IOWA CODE ANN. § 729.6(2)(a) (West 1997).

21. See, e.g., WIS. STAT. § 631.89(2) (1996).

22. See, e.g., CAL. CIV. CODE § 56.17 (West 1998); N.J. STAT. ANN. § 10:5-45 (West 1998).

23. See, e.g., N.Y. CIV. RIGHTS LAW § 79-1.3 (McKinney Supp. 1997).

24. See N.Y. INS. LAW § 2612 (McKinney Supp. 1997).

25. See, e.g., MINN. STAT. § 72A.139(5) (1997).

on the basis of genetic information about an individual, provided the differential treatment is actuarially supported.<sup>26</sup> Thus, life insurers may not conduct genetic testing without informed consent, but they may deny insurance to an applicant who refuses to be tested or who is tested and found to have a genetic anomaly that reduces life expectancy.

Finally, prohibiting genetic discrimination does not have to incorporate privacy laws. A few states that bar genetic discrimination do not have any provisions to guard the privacy of genetic information.<sup>27</sup> New York bars employers from discriminating on the basis of genetic information, but permits them to require genetic testing, as a condition of employment, for a genetic anomaly that indicates "increased risk of disease as a result of working in [the occupational] environment."<sup>28</sup> Employers may deny employment for refusal to be tested, but not on the basis of the test results. The decision whether to work in the risky occupational environment is left to the individual. Thus, New York permits employers to invade genetic privacy but not to discriminate on the basis of genetic information.

### III. DIFFICULTIES IN CREATING EFFECTIVE GENETIC ANTI-DISCRIMINATION LEGISLATION

#### A. Defining Genetic Information

Legislative efforts concerning genetic privacy and discrimination are complicated by the difficulty of determining what constitutes "genetic information." Information with genetic significance includes not only the results of tests for genetic material but also many non-genetic medical tests and family medical history. The plethora of genetically significant data makes it difficult, if not impossible, to distinguish what information should be protected by genetic privacy and discrimination laws.

All statutory definitions of "genetic information," "genetic testing," or similar terms cover testing, or the results of testing, for genetic material. Beyond this basic category, the definitions vary substantially. Several states broaden the definition to include inherited characteristics "derived" from a family member.<sup>29</sup> This phrase is apparently intended to extend

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26. *See, e.g.*, CAL. INS. CODE § 10148(e) (West 1998); ARIZ. REV. STAT. ANN. § 20-448E (West 1997).

27. *See, e.g.*, 1997 N.C. Sess. Laws 350.

28. N.Y. EXEC. LAW § 296(19)(b) (McKinney 1993 & Supp. 1997).

29. *See, e.g.*, CAL. HEALTH & SAFETY CODE § 1374.7(d) (West 1998); CAL. INS. CODE § 10123.3(d) (West 1998) (covering genetic discrimination in health insurance, but see the narrower definition of "genetic characteristic" in California Insurance Code section 10147(b) for purposes of barring unfair (which is defined as not actuarially sup-

protection to genetically significant aspects of family medical history. On the other hand, two states specifically exclude family medical history,<sup>30</sup> and several states exclude routine tests such as blood and urine analysis done in the course of a physical examination, unless the tests were conducted specifically to identify a genetic anomaly.<sup>31</sup> Some states specify "direct measures" of genetic alterations and exclude "indirect manifestations" of such alterations.<sup>32</sup> About half the definitions include tests for gene products.<sup>33</sup> A few states use different definitions in different contexts (for example, in the context of a prohibition on genetic discrimination in employment versus health insurance).<sup>34</sup>

Illustrating further the variety of possible definitions, the Maryland legislature considered a definition of "genetic test" that included gene products and inherited characteristics, but finally adopted a narrow definition limited to a "laboratory test of human chromosomes or DNA."<sup>35</sup> New Hampshire excludes a test "undertaken for the purpose of determining whether an individual meets reasonable functional standards for a specific

ported) genetic discrimination in life and disability insurance); 1997 Conn. Pub. Acts 95; 1997 Haw. Sess. Laws 91; N.J. REV. STAT. § 10:5-5(oo) (1997) (covering genetic discrimination in employment, but see the narrower definition of "genetic characteristic" in New Jersey Revised Statutes sections 17:48-6.18, 17:48A-6.11, 17:48E-15.2, 17B:26-3.2, 17B-27-36.2, and 26:2J-15.1 for the purposes of barring genetic discrimination in health coverage); 1997 N.C. Sess. Laws 350; VA. CODE ANN. § 38.2-508.4(A) (Michie 1997).

30. See 1997 Fla. Laws ch. 182; 1997 Tenn. Pub. Acts 121.

31. See 1997 Fla. Laws ch. 182; GA. CODE ANN. § 33-54-2(1) (1997); 1997 Ill. Pub. Act 90-25; MINN. STAT. § 72A.139, subd. (2)(b) (1997); N.Y. CIV. RIGHTS LAW § 79-1.1(a) (McKinney Supp. 1997); 1997 Tenn. Pub. Acts 121; 1997 Tex. Gen. Laws 1215.

32. COLO. REV. STAT. ANN. § 10-3-1104.7(2)(b) (West 1998); IND. CODE ANN. § 27-8-26-7 (Michie 1997); 1997 Kan. Sess. Laws 190; OHIO REV. CODE ANN. §§ 1742.42(A), 3901.49(A)(1), 3901.50(A)(1) (Banks-Baldwin 1997).

33. See 1997 Ariz. Sess. Laws 229; 1997 Conn. Pub. Acts 97-95; 1997 Haw. Sess. Laws 91; 1997 Ill. Pub. Act 90-25; IOWA CODE ANN. § 729.6.1.c (West 1997); 1997 La. Acts 1418; MINN. STAT. § 72A.139, subd. (2)(b) (1997); N.J. REV. STAT. 10:5-5.oo (1997) (covering genetic discrimination in employment, but the definitions used in the prohibitions of genetic discrimination in health coverage under New Jersey Revised Statutes sections 17:48-6.18, 17:48A-6.11, 17:48E-15.2, 17B:26-3.2, 17B-27-36.2, 26:2J-15.1 do not include gene products); N.Y. CIV. RIGHTS LAW § 79-1.1(a) (McKinney Supp. 1997); 1997 N.C. Sess. Laws 350; R.I. GEN. LAWS § 28-6.7-2 (1997); VA. CODE ANN. § 38.2-508.4(A) (Michie 1997); WIS. STAT. §§ 111.32, 942.07 (1996) (covering genetic discrimination in employment, but the definitions used in the prohibitions of genetic discrimination in health coverage under Wisconsin Statutes section 631.89 do not include gene products).

34. California, New Jersey, and Wisconsin use different definitions in different contexts. See *supra* notes 29 & 33.

35. MD. CODE ANN. INS. § 223.1 (1997).



job.”<sup>36</sup> Louisiana includes “all information about genes, gene products, inherited characteristics, or family history/pedigree that is expressed in common language.”<sup>37</sup> It is not clear what the Louisiana legislation intended by the last clause—perhaps a comment on scientific expression.

This variety of definitions reflects the difficulty of determining what information should be protected. In a forthcoming article, Joseph S. Alper and Jon Beckwith note that most clinical tests detect abnormal concentrations of biochemical entities, which can provide information about the genes that code for those entities, as well as the functioning of various organs.<sup>38</sup> Thus, practically every clinical test may be considered a test for gene products. The determination whether a test is genetic may depend on the context or purpose of the test: for example, whether cholesterol is tested in an individual with a family history of hypercholesterolemia or as part of a routine physical.<sup>39</sup> A National Institute of Health task force on genetics and health insurance has noted that the categorization of health risk information as genetic or nongenetic is becoming increasingly difficult, and most contents of medical records will soon have genetic significance.<sup>40</sup>

Laws that limit the definition of genetic information to the results of direct tests for gene alterations are easier to implement but may not provide sufficiently broad protection. Employers and insurers in states where such laws are in effect know they cannot use the narrowly defined genetic tests to discriminate. But the laws do not prevent them from substituting indirect tests or family history to obtain information about genetic predisposition (albeit with less precision), and using such information as a basis for discrimination. The scope of protection against genetic discrimination is significantly expanded in the states with definitions that include gene products and family medical history as well as direct genetic test results. Such broad definitions may, however, be impractical to implement; George Annas, Leonard Glanz and Patricia Roche, for example, used a narrow definition of “private genetic information” for their model Genetic

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36. N.H. REV. STAT. ANN. § 141:H-1.IV (1996).

37. 1997 La. Acts 1418 (relevant section codified at LA. REV. STAT. ANN. § 213.7(A)(8) (West 1998)).

38. Joseph S. Alper & Jon Beckwith, *Distinguishing Genetic from Nongenetic Medical Tests: Some Implications for Antidiscrimination Legislation*, SCIENCE AND ENGINEERING ETHICS (forthcoming 1998).

39. *See id.*

40. NIH-DOE WORKING GROUP ON ETHICAL, LEGAL AND SOCIAL IMPLICATIONS OF HUMAN GENOME RESEARCH, GENETIC INFORMATION AND HEALTH INSURANCE: REPORT OF THE TASK FORCE ON GENETIC INFORMATION AND INSURANCE (1993) (available at <[http://www.nhgri.nih.gov/About\\_NHGRI/Der/Elsi/itf.html](http://www.nhgri.nih.gov/About_NHGRI/Der/Elsi/itf.html)>).

Privacy Act, arguing that a broader definition would "necessitate the overhaul of well established medical information practices and policies."<sup>41</sup>

## B. The Meaning of Genetic Discrimination

It is important to note that whether genetic information is defined narrowly or broadly in the laws barring genetic discrimination, the term generally does not include information about expressed, or existing, genetic disorders. The quintessential feature of genetic discrimination is the use of genetic information about an asymptomatic person. If the disorder related to a genetic characteristic has occurred, discrimination based on the disorder may be unfair but is not customarily considered "genetic discrimination."

Some state laws specifically limit protection to asymptomatic individuals. For example, New York's law barring genetic discrimination in employment protects carriers of recessive traits and persons who have a genetic predisposition "associated with an increased statistical risk of being expressed as a physical or mental disease or disability in the individual *but which has not resulted in any symptoms of such disease or disorder.*"<sup>42</sup> The effect is the same if a law merely prohibits discrimination based on genetic information: an individual with a genetic disorder is protected from discriminatory use of genetic test results, but not from discrimination based on the presence of the disorder itself. Other laws, not specific to genetic discrimination, but instead protective of all persons with disabilities, may prohibit discrimination based on an existing genetic disorder. The laws that focus specifically on genetic discrimination are intended to protect only asymptomatic individuals.

### 1. Utility of Genetic Discrimination Laws

This conception of genetic discrimination raises a question: why should special protection be provided to asymptomatic individuals who possess a gene associated with a disease? In the case of health insurance, why not protect all persons with indications of future illness, whether or not the indications are genetic, and persons whose need for health coverage is greatest—those who are sick? Unfortunately, universal health coverage is not yet politically feasible in this country, and we appear able to work toward it only incrementally. Indeed, the laws barring genetic discrimination in health insurance are a very slight increment, since they

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41. George J. Annas, et al., *The Genetic Privacy Act and Commentary*, Boston: Health Law Department, Boston University School of Public Health (1995), at 48.

42. N.Y. EXEC. LAW § 292, subd. 21-B (McKinney 1993 & Supp. 1997) (emphasis added).

protect only the few persons who purchase individual health coverage. For the great majority of individuals, who are insured by employers or government plans, there is no individual underwriting and little threat of genetic discrimination in health insurance.<sup>43</sup>

The laws barring genetic discrimination in health insurance do not respond to a substantial problem but to a perceived threat of loss of insurance that might hinder genetic researchers' search for human subjects. Removing the basis for this fear of insurance loss may seem a reasonable step, but the possible cost of laws barring genetic discrimination in health insurance should also be weighed. Although the piecemeal approach of barring genetic discrimination may help a few people, it also removes a compelling argument for the ultimate goal of universal health coverage, which would benefit far more people.

## 2. *Perverse Effects of Genetic Discrimination Laws*

In the case of employment, absolute prohibitions of genetic discrimination ignore the possibility that under certain circumstances, such discrimination might be appropriate to protect the safety of workers or the public. A genetic anomaly might predict a disease that could endanger the public when it first manifests itself too quickly or subtly to detect in advance, or it might indicate a susceptibility to an occupational exposure.

In the first situation, genetic discrimination should be the last resort. If routine physical examinations can detect manifestations of the disease before the public is endangered, there is no need for early exclusion from employment. However, if detection is not possible and the likelihood of harm to the public is significant, the genetic anomaly may be an appropriate disqualification for the position.

Discrimination should also be the last resort in the case of genetic susceptibility to an occupational exposure. The first effort should be to remove the exposure and make the workplace safe for everyone. But if that step is impossible, and the likely result of exposure is a serious, untreatable illness, exclusion of susceptible individuals may be justified. However, the laws barring genetic discrimination in employment generally do not permit any exceptions.

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43. See Michael S. Yesley, *Genetic Privacy, Discrimination and Social Policy: Challenges and Dilemmas*, 2(1) MICROBIAL & COMPARATIVE GENOMICS, 19, 26-27 (1997).

#### IV. SHOULD THE LAW RECOGNIZE PROPERTY RIGHTS IN GENETIC DATA ABOUT INDIVIDUALS?

We return to the question posed at the outset—should the law recognize a property right in genetic data about individuals? A few states have already taken this step,<sup>44</sup> but its ramifications are uncertain. In opposing such legislation, the biotechnology industry is probably concerned that ownership of genetic data might permit the result that eluded John Moore: recovery of the value of the property (cells from his body) that was used without his permission. The California Supreme Court found Moore had a cause of action for the performance of medical procedures without informed consent, because his doctor did not disclose that he was using Moore's cells in research.<sup>45</sup> But the court denied Moore's "novel claim to own the biological materials" and accordingly refused to impose liability for conversion of the cells.<sup>46</sup> In dissent, Justice Mosk noted that if Moore were found to have an ownership interest in the cells, his share in the profit from commercial exploitation of his cells might be substantial, but the remedy allowed by the court for lack of informed consent was "largely illusory."<sup>47</sup> Thus, the penalty for failure to obtain Moore's permission to use his cells in research would have been greater if the court had recognized an ownership interest in the cells.

The value of intangible genetic data about an individual is probably not comparable to the value of an individual's cells from which a commercial product is derived. A class of individuals might have an aggregate claim of significant value for conversion of their data used in product development, if the data were their property and had been used without permission, but this possibility is somewhat remote. Thus, the goal of protecting genetic information is not to preserve any value of the information, but to control its use and disclosure. For this purpose, requiring informed consent is probably sufficient, and the disincentive of potential recovery for conversion of property is unnecessary. Virtually the same informed consent will authorize use of genetic information, whether or not it is considered property. That consent will be granted or withheld on the basis of the individual's attitude toward the use and disclosure of the information, not the amount or lack of remuneration.

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44. See *supra* note 12.

45. See *Moore v. Regents of the University of California*, 793 P.2d. 479, 486 (Cal. 1990), *cert. denied*, 499 U.S. 936 (1991).

46. See *id.* at 487-97.

47. See *id.* at 519 (Mosk, J. dissenting).

## V. CONCLUSION

A property right might buttress the obligation of those conducting genetic testing to obtain informed consent, but that obligation has already become entrenched. The growing number of statutes requiring informed consent for the development or disclosure of genetic information, the *Moore* court's reading of the common law requirement of informed consent, and, most recently, the Ninth Circuit's application of constitutional privacy protection to genetic testing make it imperative to obtain an individual's authorization of any genetic testing and use of identified test results. Overlaying an ownership interest would not add to this protection but might create uncertainty about the use of previously collected data, similar to issues surrounding the use of stored tissue samples.

