Genetic Privacy in Washington State: Policy Considerations and a Model Genetic Privacy Act

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I. INTRODUCTION

Maria Silverwood1 was excited when, on her twenty-fifth birthday, she was hired as a sales manager trainee for a Seattle company that manufactured computer graphic equipment. As a single mother, Maria needed a stable, secure job with potential for promotion. When Maria went for her mandatory new employee physical examination, she filled out a routine medical history form, on which she noted that her mother had died of Huntington’s disease. Maria was shocked when she later found out she was ineligible for company-sponsored disability insurance because of the information she included in her medical history.

Nonetheless, Maria expected to move quickly up the ranks at her new company. She consistently received “excellent” ratings in performance reviews, and she was named “employee of the year” during her second and third years with the company. Maria’s immediate supervisor repeatedly told her that she definitely was management material.

Four years after being hired, however, Maria was still classified as a trainee and paid at trainee’s wages. Since the salary raises she had expected never materialized, Maria, as a single mother, found it increasingly difficult to make ends meet. What Maria suspected, but could not prove, was that she was denied promotion on the basis of her genetic history, just as she had been denied disability insurance. The truth was that company managers knew of Maria’s genetic history, as reported when she was hired. They had not promoted Maria into a

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1. Maria Silverwood is a fictional character. Any resemblance between Maria and any person, living or deceased, is purely coincidental. For a “true life” example of how the issues related to genetic testing can have a dramatic, personal impact, see Catherine Sack, Washington Diarist, Tropic of Cancer, THE NEW REPUBLIC, June 2, 1997, at 46.
management position because of the possibility that she carried the Huntington's gene.

What Maria had experienced was discrimination on the basis of her unique and personal genetic information. Huntington's disease is an inherited disease. Since Maria's mother died from the disease, the disability insurer and her employer both made the assumption that Maria was at risk of developing the same affliction. Consequently, she was denied both disability insurance and a promotion that was rightfully hers. This is discrimination based on information on a person's genetic make-up, and is known as genetic discrimination.

In addition to being subjected to discrimination, Maria experienced an invasion of her privacy. When she completed the medical history form as part of her new employee physical, she assumed that the family history information she included would remain confidential. Similarly, when Maria signed a form authorizing her company's health insurance carrier to access her medical records, she thought that any information accessed would be used for claims verification and payment purposes only. Unfortunately, the health insurance carrier did not limit its disclosure of the information to claims verification. The health insurer redisclosed Maria's genetic information both to the disability insurance carrier and to her employer without Maria's knowledge or permission. This unauthorized redisclosure of her genetic information had unfortunate consequences for Maria, even though she was in good health and the odds are only one in four that

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2. Huntington's disease is a hereditary condition that causes a progressive deterioration of brain cells. Symptoms usually do not develop until middle age. It is perhaps best known as the disease that killed folk singer Woody Guthrie. The incidence of Huntington's disease in the general population is approximately 1 in 10,000. However, the Huntington's gene is always expressed, meaning that every individual who carries the gene will manifest symptoms of the disease, in middle age. If one parent carries the Huntington's gene, as in Maria's case, the child has a 25% chance of carrying the gene. See Peter H. Raven et al., Biology 268 (Times Mirror/Mosby College Publishing 2d ed. 1989); Henry T. Greely, The Control of Genetic Research: Involving the "Groups Between," 33 Hous. L. Rev. 1397, 1425-26 (1997).

3. Genetic discrimination has been defined as "discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the 'normal' genome in the genetic constitution of that individual." George P. Smith, Accessing Genomic Information or Safeguarding Genetic Privacy, 9 J.L. & Health 121, 124 (1995). Thus, genetic discrimination occurs when an asymptomatic individual receives disparate treatment based on information that is part of his genetic make-up. Id.

4. As used in this article, redisclosure of genetic information refers to secondary disclosure for some purpose other than that originally anticipated. For example, medical record information is typically disclosed to insurance carriers for the purpose of verifying that payment requests by physicians match actual patient diagnosis and treatment. A secondary disclosure, or redisclosure, occurs when an insurance carrier makes patient information available to others for some use unrelated to payment verification.
she will ever manifest the symptoms of Huntington's disease. Maria Silverwood found out what can happen if genetic information is not afforded special protection.

Current Washington state law is inadequate to protect people like Maria, because genetic information needs special protection but currently receives none. To prevent the Maria Silverwoods of Washington from experiencing invasions of genetic privacy and potential genetic discrimination, their genetic information must be given special protection. Accordingly, Washington legislators must adopt a Genetic Privacy Act that will provide the needed protection.

The next section of this Comment presents background information concerning genetic information and genetic testing. Section III then argues that privacy and autonomy are significant policy issues in connection with genetic information. As a result, the decision to have genetic testing performed should be an individual's choice, and genetic testing should never be compelled. Section IV argues that the failure to give genetic information special protection in the law has potentially harmful consequences. Section V surveys current efforts to protect genetic privacy, both by the federal government and states other than Washington. Section V also analyzes the current state of medical records privacy protection in Washington, and argues that the current state law is inadequate to protect genetic privacy and to prevent genetic discrimination. Finally, Section VI presents a substantive proposal for a Genetic Privacy Act in Washington, which would protect individual privacy, prohibit compelled testing, and prevent genetic discrimination. This Comment concludes that under current state law Washington citizens risk losing genetic privacy and experiencing genetic discrimination. Consequently, the legislature should enact a Genetic Privacy Act to ensure both protection of genetic privacy and prevention of genetic discrimination in Washington.

II. GENETIC INFORMATION AND GENETIC TESTING

Every cell of the human body carries genetic information. The information is encoded in DNA and organized in genes, which are the basic unit of heredity. Each person's genes are unique, and they carry a map of that person's biological past and future. In addition,

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6. Id. at 94.
7. See id. at 225.
8. See id. at 231-42.
genes are the vehicle by which characteristics are inherited from our parents and passed on to our children.9

The essence of the personal nature of genetic information is captured by the term "future diary."10 A diary contains past information that is very personal and private.11 By contrast, genetic information can be described as a "probabilistic future diary," because it carries predictive information about future health.12 Thus, the significance of genetic information arises both from its unique nature, different in each person, and its predictive nature, in what it might tell about each person's future.13

Genetic information is an important class of health information because a significant number of human disorders have a genetic component.14 Research scientists are currently attempting to develop technology which will allow greater diagnosis, understanding, and treatment of genetic disorders.15 The Human Genome Project (HGP),16 an international effort to build a complete map of the entire human genome, leads the way in this research.17 The HGP is expected to lead to improved understanding, treatment, prevention, and eventually cures for many genetic disorders.18 This knowledge is also expected to lead to the widespread availability of genetic testing in the near future.19

Genetic testing involves the direct testing of genetic make-up by laboratory analyses of DNA, in order to determine the presence or

9. See id. at 257.
11. See id.
12. See id.
13. See id.
14. At least 5,000 human disorders are thought to have a genetic component, and new genetic diseases are discovered at a rate of 150 per year. See Richard A. Bornstein, Genetic Discrimination, Insurability and Legislation: A Closing of the Legal Loopholes, 4 J.L. & POL'Y 551, 557 n.28 (1996).
15. See Smith, supra note 3, at 126-27.
17. Genome is the term used to describe the total genetic composition of an organism. In human beings, the genome consists of 42 chromosomes. Genes, the basic units which carry genetic information, are organized along the chromosomes. See RAVEN ET AL., supra note 2, at 256.
18. See Elizabeth J. Thomson, Ethical, Legal, and Social Implications of the Human Genome Project, 3 DICK. J. ENVTL. L. & POL'Y 55 (1994). See also Smith, supra note 3, at 126 (stating "The driving motive behind the Human Genome Initiative is . . . the identification and eradication of all genetically based disease.").
19. See Bornstein, supra note 14, at 558-62.
absence of defective genes. Genetic testing supplements family history information, which has been the traditional source of information on genetic make-up. The widespread availability of genetic testing may prove to be tremendously beneficial for some people. For example, genetic testing is a useful tool for the early detection of some diseases, which often increases the potential for successful treatment. In addition, the availability of genetic testing should facilitate a shift toward preventive medicine since preventive measures may be available in some cases where a genetic predisposition has been identified. Moreover, as technology advances, some diseases might be treatable on a genetic level, ultimately preventing symptoms entirely.

The advent of genetic testing, however, raises important policy questions concerning the privacy and control of genetic information. Legislative responses to these policy questions have not kept pace with the recent rapid advances in the medical sciences. Maria Silverwood's situation underscores the need for legislative action to protect individual privacy and control over genetic information. The interrelated issues of a person's privacy and control of his or her genetic information are discussed further in the next section.

III. PRIVACY AND AUTONOMY WITH RESPECT TO GENETIC INFORMATION

Privacy and autonomy are overlapping concepts in the context of genetic information. Privacy suggests limited access to a person, or

20. See id. at 551 n.2.
21. See id. at 558.
23. See generally Bornstein, supra note 14, at 569-72 n.3; Blake, supra note 22, at 872.
24. See Blake, supra note 22, at 872.
25. See Bornstein, supra note 14, at 555.
26. A general right to privacy is not guaranteed by the United States Constitution. Katz v. United States, 389 U.S. 347, 350 (1967). However, the United States Supreme Court has identified two types of privacy interests deserving of protection: (1) the right to be protected from disclosure to the government of certain personal matters, and (2) the right to make certain fundamental decisions without governmental interference. Whalen v. Roe, 429 U.S. 589, 599-600 (1977). Washington explicitly adopted Whalen v. Roe as being consistent with the privacy protections contained in Article 1, section 7 of the Washington state constitution in Peninsula Counseling Center v. Rahm, 105 Wash. 2d 929, 934-35, 71 P.2d 926, 928-29 (1986). Significantly, the privacy interests recognized in Whalen and Peninsula Counseling provide privacy protection only from the government. The privacy interests identified in Katz and adopted in Peninsula Counseling do not provide protection from third party, nongovernmental disclosure of personal information, or from nongovernmental interference with autonomous decisionmaking.
freedom for that person from intrusion by others.27 Autonomy, on the other hand, suggests that people should have the right to make decisions about personal and intimate matters without interference or intrusion by others.28 Together, these concepts underscore the essential nature of an individual's ability "to make personal decisions without interference."29 These two interrelated issues are explored further in the following subsections.

A. Privacy

Genetic privacy concerns an individual's right to control who can gain access to his or her private health care information. A person has a reasonable expectation that personal, sensitive information in medical records will remain confidential and will not be revealed to third parties without that person's consent.30 The privacy of health care information traditionally has been protected by rules regarding physician-patient confidentiality.31 In some states, the privacy of health care information is also protected by statute.32 In Washington, for example, the confidentiality of health care information is protected by the Health Care Information Access and Disclosure Act.33

Despite such legal protections arising from both custom and statutes, however, the privacy of genetic information as a class of health care information is seriously at risk for several reasons. First, patients typically are asked to authorize the release of medical information to third parties, such as insurance companies, as a routine part of the paperwork associated with a visit to a doctor's office. Maria Silverwood signed this type of release when she received her new-employee physical examination. Insurance companies make valid use of this information, such as verification of diagnosis and treatment, in order to authorize proper payment of claims. However, there is little limitation on what insurance companies can do with this information

28. See id.
30. See Rothstein, supra note 27, at 896. See also Lawrence O. Gostin et al., Privacy and Security of Health Information in the Emerging Health Care System, 5 HEALTH MATRIX 1, 2 (1995).
31. Confidentiality has been considered as one of the primary duties of a physician since the Oath of Hippocrates was first conceived in the fifth century B.C. See Rothstein, supra note 27, at 896. See also Gostin et al., supra note 30, at 20-23.
32. See id. at 15.
33. See WASH. REV. CODE § 70.02 (1996).
once they gain access to it.\textsuperscript{34} As Maria Silverwood ultimately discovered, third parties may redisclose information without the patient’s knowledge or consent.

Second, personal information about individuals is a profitable industry.\textsuperscript{35} There is a tremendous market for all kinds of personal information, including medical information.\textsuperscript{36} Thus, there is a strong incentive for third parties, such as insurance companies, to make personal information available to other users, without the knowledge or consent of the individual to whom the information pertains.\textsuperscript{37}

Finally, given the explosion in the computer industry over the last ten years, it is increasingly easy to collect and exchange information. It is relatively easy to develop a detailed profile of many aspects of an individual’s health, including genetic information.\textsuperscript{38} Credit reporting companies, employers, and insurance companies all have the potential to search medical histories.\textsuperscript{39} As a result, mortgage, employment, and insurance applications are potentially influenced by the applicant’s genetic information, without the applicant’s knowledge that the information is part of the decisionmaking process.\textsuperscript{40}

Currently, Washington citizens have no statutory or common law recourse to address the unauthorized third-party redisclosure of genetic information as an invasion of privacy. First, Washington courts do not recognize an invasion of privacy as a common law tort cause of action.\textsuperscript{41} In addition, the Uniform Health Care Information and Disclosure Act provides for a cause of action only if health care providers disclose information without consent.\textsuperscript{42} An equivalent cause of action is not available to address nonconsensual redisclosure of information by third parties, such as insurance carriers.\textsuperscript{43} Finally, the

\begin{itemize}
  \item \textsuperscript{34} See Gostin et al., supra note 30, at 16.
  \item \textsuperscript{35} Some reports estimate that there are over 10,000 available lists which contain data about individuals. In addition, the business of selling personal information was recently estimated as a three billion dollar per year industry. See Judith Beth Prowda, Privacy and Security of Data, 64 FORDHAM L. REV. 738, 740 (1995).
  \item \textsuperscript{36} See id. See also Michael Landau, Use of Genetic Testing by Employers and Insurance Companies, 3 J. ENVTL. L. & POL’Y 105 (1994).
  \item \textsuperscript{37} See Prowda, supra note 35, at 740.
  \item \textsuperscript{38} Elaine Alma Draper, Social Issues of Genome Innovation and Intellectual Property, 7 RISK: HEALTH, SAFETY & ENV’T 201, 205 (1996). See also Prowda, supra note 35, at 740.
  \item \textsuperscript{39} Interestingly, videotape rental records currently have more privacy protection than medical records. See Prowda, supra note 35, at 755.
  \item \textsuperscript{40} Draper, supra note 38, at 205.
  \item \textsuperscript{42} See WASH. REV. CODE § 70.02.030 (1996). See also discussion, infra, Part V.C.
  \item \textsuperscript{43} See generally WASH. REV. CODE § 70.02 (1996).
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right to privacy guaranteed by Article 1, section 7 of the Washington State Constitution applies to the disclosure of intimate information to the government, but not to third parties. Consequently, specific legislation is needed to ensure protection of genetic privacy in Washington.

B. Autonomy

In contrast to privacy, genetic autonomy concerns each person’s ability to make the very personal decision of whether to undergo genetic testing. This private decision must be made without interference, intrusion, or coercion. In order to preserve individual autonomy, genetic testing should be performed only for the primary benefit of the person tested; genetic testing should never be compelled.

The decision to undergo genetic testing can be a very difficult choice to make. Certainly, some people will undergo genetic testing out of a desire to know all they possibly can about their future health status. However, others might be traumatized to learn that they carry genetic information which is beyond their control to change. Indeed, there are documented cases of individuals being so traumatized by learning that they carry the gene for the inevitably fatal Huntington’s disease, that they committed suicide.

Clearly, compelled testing forces an individual to face information he or she “did not know previously, and that perhaps he or she did not want to know.” Once a person learns about a genetic predisposition, that knowledge cannot be undone. Thus, someone who chooses not to know that she is at risk for a particular disease should not be

44. See Peninsula Counseling Center v. Rahm, 105 Wash. 2d 929, 932-935, 719 P.2d 926, 927-29 (1986). See also Doe v. Puget Sound Blood Center, 117 Wash. 2d 772, 783, 819 P.2d 370, 376 (1991) (declining to address the issue of whether a constitutional right to privacy can be invoked without state action).
45. See Bornstein, supra note 14, at 572.
46. See Rothstein, supra note 27, at 898.
47. See Lori Andrews, Body Science, 83 ABA J. 44, 46 (1997). A recent incident involving two members of the Marine Corps underscores the risk compelled genetic testing poses for personal autonomy. Two members of the Marine Corps were court-martialed in January, 1995, for refusing to submit to what they considered to be compelled testing. The marines resisted an order to provide blood and saliva samples for DNA sampling. The Marine Corps contended that it was collecting DNA from service members in order to have DNA samples available to aid in the identification of soldiers killed at battle. However, DNA can be stored in a stable condition for many years. The two marines were concerned that the samples might be used for genetic testing, without their knowledge or consent, at some future date.
48. See Sack, supra note 1, at 46.
49. Rothstein, supra note 27, at 898.
50. See id. at 898 n.166.
51. Id. at 900.
compelled to undergo testing.\textsuperscript{52} Seen from this view, autonomy with regard to genetic information includes a person’s right to know, as well as the right not to know, what information her DNA holds.

Maria Silverwood disclosed genetic information by way of family history. Maria currently lives with the knowledge that she might someday manifest symptoms of Huntington’s disease, as her mother did. However, her employer or her employer’s insurance company might have required her to submit to genetic testing, as a condition of accepting employment. Currently, compelled genetic testing is not prohibited either by Washington law\textsuperscript{53} or by federal law.\textsuperscript{54} If Maria had tested positive for the Huntington’s gene, she would have been forced to confront the knowledge that she is destined to have Huntington’s disease at some unknown future date. While it is true that Maria might also have learned that she does not carry the Huntington’s gene, the difficult choice of whether or not to face that knowledge belongs only to Maria, not to her employer or insurance company. Specific legislation is necessary to ensure that Washington citizens like Maria are not required to submit to compelled genetic testing.

Loss of genetic privacy and decisionmaking autonomy are two potential harms that careful legislation can help prevent. Additional harms that can result from unauthorized disclosure or misuse of genetic information are discussed in the next section.

\textsuperscript{52} Bornstein, supra note 14, at 573.

\textsuperscript{53} See Chapter 49.60, WASH. REV. CODE, prohibiting discrimination in employment, but not addressing either genetic information or compelled testing of genetic information by employers. See also Chapter 48.43, WASH. REV. CODE, regulating insurance but not prohibiting compelled genetic testing by insurance companies.

\textsuperscript{54} The federal Americans With Disabilities Act (ADA) prohibits discrimination in employment, but does not explicitly address genetic information. See 42 U.S.C. § 12112(a) (1996). The ADA permits employers to require that employees submit to genetic testing following an offer of employment, provided that the information obtained is not later unfairly used. See GARY PHELAN ET AL., DISABILITY DISCRIMINATION IN THE WORKPLACE § 13:07 (1996); Andrews, supra note 47, at 47.
IV. HARMs FROM UNAUTHORIZED DISCLOSURE AND MISUSE OF GENETIC INFORMATION

In addition to loss of genetic privacy and autonomy, other harmful outcomes can result when genetic information is misused or disclosed without authorization.

A. Undermining of the Physician-Patient Relationship

The unauthorized release of genetic information undermines the physician-patient relationship. Patients expect that information shared with their physician will remain confidential. The disclosure of personal, private information is an insult to dignity, and signals a lack of respect for the individual. In addition, patients are reluctant to be completely forthcoming with information in a clinical setting if they are not certain the disclosed information will remain confidential. Thus, a patient who thinks his family history or genetic test results will not remain confidential may withhold that information from his physician, especially if the patient fears the disclosure may jeopardize his insurance benefits. Withholding this information potentially interferes with the physician's ability to diagnose and treat the patient effectively. Therefore, a patient must be assured that any knowledge his physician has regarding genetic information will remain confidential. Otherwise, effective treatment and diagnosis are compromised.

B. Failure to Realize the Potential Benefits from Genetic Testing

Genetic testing can identify some genetic conditions which are not certain to occur. As a result, some individuals stand to benefit by making lifestyle changes which might drastically decrease the chances of a diagnosed genetic condition ever manifesting itself. For example, genetic testing will soon be able to identify some individuals at risk for heart disease. A person who learns through genetic testing that she carries this risk can make lifestyle changes (such as diet

55. See Rothstein, supra note 27, at 896.
56. Gostin et al., supra note 30, at 23.
57. See Rothstein, supra note 27, at 897. See also Gostin et al., supra note 30, at 20.
58. See Rothstein, supra note 27, at 897.
59. See id. at 896.
60. See id.
61. See Bornstein, supra note 14, at 560.
62. See Blake, supra note 22, at 872.
63. See Bornstein, supra note 14, at 560.
and exercise) to reduce the likelihood that she will ever actually experience heart disease.\textsuperscript{64} Yet this same person might avoid testing unless she knows that the test results will be kept confidential, especially if she knows that the test results could be used to discriminate against her in employment or insurance.

\section{Reproductive Discrimination}

Opponents to the Human Genome Project and the development of genetic testing fear that genetic information will be used for eugenic purposes.\textsuperscript{65} A person's genetic code contains information about traits which are immutably a part of that person. Significantly, certain genetic traits, including predisposition to disease, tend to fall along ethnic and racial lines.\textsuperscript{66} The fear exists that certain races and ethnic groups will be selectively targeted for genetic testing and forced sterilization under the guise of trying to eliminate certain genetic diseases from the overall gene pool.\textsuperscript{67} Given that genetic information has been misused for eugenic purposes in the United States during this century, the danger of reproductive discrimination on the basis of racially associated genetic characteristics is a very real concern.\textsuperscript{68} The elimination of certain genetic diseases from the population may be beneficial, but not at the expense of the right to bear children. The right to procreate is firmly established in the United States, even if bearing children means perpetuating an undesirable trait.\textsuperscript{69}

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\item \textsuperscript{64} See Blake, supra note 22, at 872.
\item \textsuperscript{65} Eugenics is improvement of the human race by encouraging individuals with desired traits to reproduce, while preventing reproduction of those individuals with undesirable traits. The most widely known eugenics movement was seen in Nazi Germany through the sanctioning of mass sterilization and extermination of individuals seen as undesirable because of their ethnicity, religion, or sexual orientation. In the United States, laws which allowed sterilization of certain groups (such as the mentally retarded) were overturned by the Supreme Court in 1942. See Skinner v. Oklahoma, 316 U.S. 535 (1942); Rothstein, supra note 27, at 894. See also Smith, supra note 3, at 123.
\item \textsuperscript{66} See Smith, supra note 3, at 123. See also Rothstein, supra note 27, at 877.
\item \textsuperscript{67} See Smith, supra note 3, at 123.
\item \textsuperscript{68} See In re Primus, 436 U.S. 412 (1978) (discussing reports that pregnant mothers on public assistance were being sterilized or threatened with sterilization as a condition of continuing to receive welfare benefits). See also Rothstein, supra note 27, at 894 (1996).
\item \textsuperscript{69} See Skinner v. Oklahoma, 316 U.S. at 535.
\end{itemize}
D. Economic Harm

1. Genetic Discrimination in Insurance

It is well documented that insurance companies discriminate on the basis of genetic information. The resulting economic harm is significant, and includes increased premiums and denial of benefits. Maria Silverwood experienced genetic discrimination when she was denied the opportunity to purchase disability insurance through her employer. As a result, she was forced to forgo the insurance and to risk financial hardship should she unexpectedly become disabled by an injury. Alternatively, she could purchase private disability insurance at a much higher premium.

Insurance companies justify discrimination in rates and coverage because they are in the business of risk spreading. They view genetic information as being like any other information they scrutinize in making decisions about ratings and coverage. In other words, insurers believe they should be able to use genetic risk to classify applicants as a means of assigning risk, just as they use other risk factors (such as smoking) or pre-existing conditions (such as heart disease). From an insurer's perspective it is rational to discriminate on the basis of genetic information. According to this view, people with either a family history or a confirmed diagnosis of a genetic condition are presumed to use more services; thus they should either pay higher rates or be denied coverage altogether.

The insurance industry's approach to genetic information, however, contradicts public policy. Many people who carry a defective gene will never manifest symptoms of a genetic condition. Yet, insurance companies burden these individuals with higher premiums, or loss of insurance altogether, because they might be at risk of displaying certain disease symptoms in the future. In addition, insurers ignore the impact that lifestyle changes have on reducing the likelihood that symptoms of a genetic disease will develop. Moreover, denial of life and health insurance coverage on the basis of genetic

71. See id.
73. See id.
74. See Bornstein, supra note 14, at 558.
75. See id.
information has negative social consequences: denial of life insurance leaves dependents economically vulnerable, and denial of health insurance means more people will be dependent on the social welfare system for medical care.\textsuperscript{76} Overall, insurance coverage must be viewed as an important public good, which should be more available rather than less available.\textsuperscript{77}

2. Genetic Discrimination in Employment

As with insurance, genetic discrimination in employment is well documented.\textsuperscript{78} Economic harm results when prospective employers reject applicants or deny employees the opportunity for promotion on the basis of genetic information.\textsuperscript{79}

Employers have incentives to make employment decisions based on genetic information for several reasons. These include the risk of increased health insurance premiums, increased absenteeism, and decreased productivity.\textsuperscript{80} However, an employer who uses genetic information to make employment decisions is essentially treating the affected employee as if she is disabled or handicapped. Significantly, employment discrimination laws (federal and state) prohibit employment discrimination against disabled or handicapped individuals.\textsuperscript{81} These laws protect employers from discriminating against employees who "express," or outwardly display, symptoms of a genetic condition. It is extremely difficult to prove that an employer's hiring or promotion decision was based on an employee's genetic information when no disease symptoms are present, rather than some other factor. As a result, antidiscrimination laws appear to offer little protection from genetic discrimination in employment.\textsuperscript{82}


\textsuperscript{77} See Andrews, supra note 47, at 47 (stating "[c]arried to its extreme, that approach to coverage could make everyone uninsurable, since every human being carries between eight and 12 'defective' genes that might trigger various medical disorders.") See also Bornstein, supra note 14, at 558.

\textsuperscript{78} See Lapham et al., supra note 70, at 621-23.

\textsuperscript{79} See id. at 621.

\textsuperscript{80} See Smith, supra note 3, at 125.

\textsuperscript{81} Frank C. Morris et al., \textit{Privacy and Defamation in Employment}, in EMPLOYMENT DISCRIMINATION AND CIVIL RIGHTS ACTIONS IN FEDERAL AND STATE COURTS: ALI-ABA COURSE STUDY MATERIALS 559, 582 (1996).

\textsuperscript{82} The Americans with Disabilities Act of 1980 was an attempt on the part of the federal government to prohibit discrimination in the workplace based on handicap or disability. See 42 U.S.C. §§ 12101-12213 (1994). The ADA, which is administered by the Equal Opportunity Employment Commission (EEOC), broadly defines disability as:
The harms described in this section can largely be prevented by legislation specifically tailored to protect genetic privacy and prohibit genetic discrimination. The next section examines legislative efforts directed toward these goals, first at the federal level, then in states other than Washington, and finally in Washington.

V. PROTECTION OF GENETIC PRIVACY: FEDERAL AND STATE LEGISLATION

Currently, there is no comprehensive federal protection of genetic privacy or prohibition against genetic discrimination. In the absence of federal legislation, many states have enacted laws regulating access and use of genetic information. This section explores the current status of both federal and state laws which regulate genetic information.

A. Federal Legislation

Eleven separate bills which proposed regulating genetic information were introduced during the 104th Congress (1995-96). Eight of the bills specifically proposed protections against genetic discrimination, but none was passed into law. Three were directed toward ensuring health insurance portability and coverage. Of these three, one was signed into law as the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
(B) a record of such an impairment; or
(C) being regarded as having such an impairment.


While the ADA itself does not explicitly refer to genetic information, the EEOC compliance manual suggests that discrimination on the basis of a predisposition to a particular genetic disease would be prohibited by part (C) of this definition. See EEOC Compliance Manual § 902.8; see also PHELAN ET AL., supra note 54, at § 13:01 (1996). In other words, a person diagnosed with, but not displaying symptoms of, a genetic disease cannot be discriminated against in employment because he is "regarded as having an impairment." See EEOC Compliance Manual § 902.8. However, it is very difficult for employees to prove that they are denied employment or promotions on the basis of genetic information, rather than on some other factor. As of this writing, no case law was identified where a plaintiff like Maria Silverwood challenged an employer's alleged genetic discrimination under the ADA. Consequently, it is unclear what the chances are of a plaintiff like Maria prevailing on such a claim brought under the ADA.

83. See Andrews, supra note 47, at 47.
HIPAA ensures that employees are able to maintain health care coverage when they change jobs. Genetic information is protected under this bill only to the extent that health insurance plans may not use genetic information as a factor when determining eligibility for coverage. While this is an encouraging first step toward protecting genetic information and preventing genetic discrimination, the bill has been criticized for failing to include specific language protecting the confidentiality of patient health information. Thus, under HIPAA, genetic records are still vulnerable to unauthorized redisclosure.

Protecting genetic privacy continues to be a major topic of interest to federal legislators. The issue gained national attention during a recent White House briefing, when President Clinton endorsed the bipartisan legislative efforts of Representative Louise Slaughter (Dem., N.Y.) and Senator Olympia Snowe (Rep., Maine). Senator Snowe introduced the Genetic Information Nondiscrimination in Health Insurance Act of 1997 in the Senate on January 21, 1997. Representative Slaughter sponsored similar legislation in the House of Representatives as part of the Children's National Security Act. In addition to these two bills, three others have been introduced to Congress since January 1, 1997.

Bipartisan support and presidential endorsement suggest that some form of federal legislation protecting genetic privacy has a reasonable chance of becoming law in the near future. However, passage of such

89. See HEALTH CARE DAILY REP. (BNA), May 22, 1996, at D15.
91. Id.
federal legislation will not fully resolve the issue, because it will raise new questions regarding federal preemption of individual state efforts to protect genetic privacy.  

In the meantime, given the uncertainties surrounding federal legislation, many states have taken their own affirmative steps to protect their citizens from invasions of genetic privacy.

B. Legislation in States Other than Washington

To date, fourteen states have taken affirmative measures to protect their citizens from invasions of genetic privacy and from potential genetic discrimination, using a variety of different approaches. One approach is to expand state law pertaining to the confidentiality of health records by including specific provisions to protect genetic information. Other approaches include explicitly prohibiting employers from using genetic information to discriminate, prohibiting insurers from requiring genetic tests, and prohibiting the use of information derived from genetic testing in making decisions regarding coverage.

State laws that prohibit genetic discrimination in health insurance have been described as a "hollow victory," because the laws do not apply to all insurance plans. State laws apply only to insurance which is directly purchased either by consumers, or by employers on behalf of their employees. They do not apply to employer-based health insurance plans that are self-insured, where the employer assumes the risks typically associated with insurance plans, because the application of state laws to self-insured plans is explicitly preempt-

96. The following states have enacted legislation regulating disclosure and/or use of genetic information: Virginia, Iowa, New Hampshire, New Jersey, New York, Oregon, Rhode Island, Wisconsin, Georgia, Maryland, Minnesota, Ohio, and Colorado. See generally Andrews, supra note 47.
97. Colorado has taken this approach and provided statutory protection to information derived from genetic testing. See COLO REV. STAT. ANN. § 10-3-1104.7 (West 1994).
98. Iowa, New Hampshire, New Jersey, New York, Oregon, Rhode Island, Texas and Wisconsin have laws prohibiting employers from using genetic information to discriminate. Colorado, Oregon and Texas prohibit insurance companies from denying coverage or changing coverage ranges based on genetic test results. New Hampshire, New Jersey, Georgia, Maryland, Minnesota and Ohio prohibit insurance companies from requiring genetic testing, in addition to prohibiting insurance companies from making policy decisions based on genetic test results. See Andrews, supra note 47, at 44 (1997).
99. Id.
100. Id.
ed by federal law under the Employee Retirement Income Security Act of 1974 (ERISA). Significantly, the majority of people in this country obtain their health insurance through employer self-funded insurance plans. As a consequence, ERISA preemption of state laws aimed at prohibiting genetic discrimination in health insurance makes those laws meaningless to the majority of Americans. ERISA preemption underscores the need for federal legislation to prohibit genetic discrimination in health insurance.

The next section examines Washington law, analyzing the Washington State Health Care Information Access and Disclosure Act and concluding that this law is inadequate to protect genetic privacy and to prevent genetic discrimination in Washington. The final section presents a substantive proposal for a Washington State Genetic Privacy Act, which would ensure that the Maria Silverwoods of our state do not experience invasions of genetic privacy and genetic discrimination.

C. Protection of Genetic Privacy In Washington State: Current Law

The Washington legislature enacted the Health Care Information Access and Disclosure Act in 1991 (hereinafter the Disclosure Act). The Disclosure Act was adopted following a legislative finding that "[h]ealth care information is personal and sensitive information that if improperly used or released may do significant harm to a patient's interests in privacy, health care, or other interests." Adoption of the Disclosure Act was consistent with the


103. See Farrell, supra note 101, at 269.
104. See Andrews, supra note 47, at 44.
105. See Smith, supra note 3, at 122.
106. WASH. REV. CODE § 70.02 (1996).
107. Id. The Disclosure Act was modeled after the Uniform Health Care Information Act, which was developed by the National Conference of Commissioners on Uniform State Laws in 1984. To date, only two states (Washington and Montana) have adopted this uniform law.
108. "Health care information" is defined in title 70, chapter 2 of the Washington Revised Code as "any information, whether oral or recorded in any form or medium, that identifies or can readily be associated with the identity of a patient and directly relates to the patient's health care. The term includes any disclosure of health care information." WASH. REV. CODE § 70.02.010 (1996).
high regard for protection of personal privacy which is defined in the Washington State Constitution.\textsuperscript{109} The Disclosure Act's legislative history indicates that it was seen as necessary to help patients overcome difficulty "in obtaining access to their medical and health records."\textsuperscript{110} The legislature acknowledged that changes in the processing of health care information (including insurance audits, health care research, and use of computers) threaten the confidentiality of information in individual medical records.\textsuperscript{111} Thus, the legislative intent behind the Disclosure Act was to provide "specific standards for information disclosure by health care providers and facilities, and guarantee of access to vital health care information by clients."\textsuperscript{112} Prior to passage, testimony in support of the original bill was provided by, among others, Group Health Cooperative of Puget Sound and the Washington State Medical Records Association.\textsuperscript{113} No testimony was presented in opposition to the Disclosure Act.\textsuperscript{114}

Under the Disclosure Act, health care providers must obtain written authorization before disclosing patient health care information.\textsuperscript{115} With limited exceptions, such an authorization for disclosure is subject to revocation by a patient at any time.\textsuperscript{116} Disclosure of health care information without patient authorization is allowed under specific circumstances, such as to another provider treating the patient, in order to avoid or to minimize an imminent danger to the safety or

\begin{footnotesize}
\footnote{109. Article 1, § 7 of the Washington State Constitution states, "No person shall be disturbed in his private affairs, or his home invaded, without authority of law." \textit{WASH. CONST.} art. 1, § 7.}
\footnote{110. Senate Bill Report, SHB 1828, Reg. Session (Wash. 1991).}
\footnote{111. \textit{See id.}}
\footnote{112. \textit{Id.}}
\footnote{113. \textit{See id.}}
\footnote{114. \textit{See id.}}
\footnote{115. \textit{WASH. REV. CODE} § 70.02.020 (1996). The statute provides, in part: Except as authorized in RCW 70.02.050, a health care provider, an individual who assists a health care provider in the delivery of health care, or an agent and employee of a health care provider may not disclose health care information about a patient to any other person without the patient's written authorization.}
\footnote{116. \textit{WASH. REV. CODE} § 70.02.040 (1996). The statute states: Patient's revocation of authorization for disclosure. A patient may revoke in writing a disclosure authorization to a health care provider at any time unless disclosure is required to effectuate payments for health care that has been provided or other substantial action has been taken in reliance on the authorization. A patient may not maintain an action against the health care provider for disclosures made in good-faith reliance on an authorization if the health care provider has no actual notice of the revocation of the authorization.}
\end{footnotesize}
health of the patient or some other individual, or in order to provide directory information. 117

Prior to adoption of the Disclosure Act, no clear case law or statutory guidelines existed in Washington regarding the confidentiality of health care records. 118 Consequently, the Disclosure Act was a significant step toward ensuring the privacy of health care information for Washington citizens. However, the Disclosure Act does not go far enough to ensure protection of genetic privacy and prevention of discrimination on the basis of genetic information for several reasons. First, all health care information is treated equally under the Disclosure Act. Genetic information is a unique type of personal information because it predicts a future result rather than simply diagnosing a present ailment. 119 As such, genetic information should receive special consideration beyond that provided for health care information in general by the Disclosure Act. The Washington legislature has previously recognized that several types of health care information require special statutory protection. Under Washington law, test results for HIV and sexually transmitted disease infections are given special protection from unauthorized disclosure. 120 Similarly, genetic information deserves consideration as a class of information separate from other health care information.

Second, under the Disclosure Act, disclosure of genetic information can be made under a general authorization for the release of medical or other information. The first time a patient visits a particular physician or clinic, the patient typically fills out a medical history and signs a form authorizing disclosure of information to the patient's insurance carriers for purposes of billing. The disclosure form makes virtually all health care information in the patient's file accessible to the health insurance carrier, including information not directly related to services for which the carrier reimburses the health care provider. 121 The disclosure form also acts as a general blanket authorization which is effective for the duration that the patient receives health care from that particular provider. Even though this authorization to disclose can be revoked under the Disclosure Act, 122

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117. See WASH. REV. CODE § 70.020.050 (1996).
118. See Peninsula Counseling Center v. Rahm, 105 Wash. 2d 929, 719 P.2d 926 (1996) (discussing release of patient information to government officials without defining parameters for disclosure to nongovernmental parties).
119. See discussion, supra Part II.
121. See WASH. REV. CODE § 70.02.030 (1996).
122. See WASH. REV. CODE § 70.02.040 (1996).
it is unlikely that most patients are aware of their right to revoke. More significantly, some insurance carriers make release of information a condition of coverage by a health insurance policy, leaving patients in a position of signing or losing coverage.\textsuperscript{123}

Third, the Disclosure Act does not do enough to protect against redisclosure of health care information after an authorized disclosure is made. For example, once health care information is legitimately disclosed, either to an insurance carrier under a blanket authorization or by specific written authorization, there is no specific prohibition in the Disclosure Act concerning redisclosure of that information. In other words, employers, potential employers, or others might gain access to information through redisclosure, without the knowledge or approval of the particular patient involved. The potential for redisclosure raises enormous concerns over who might potentially access genetic information, and how that information might be used or misused. Employers might use the information to determine whether or not to promote an employee, as in Maria Silverwood’s case. Financial institutions could use the information to decide whether or not to loan money to a particular person. While redisclosure of genetic information has some legitimate purposes, such as use for medical research,\textsuperscript{124} the risk of misuse of redisclosed information certainly outweighs any potential benefits. Consequently, genetic information needs greater protection than is provided under the Disclosure Act in order to prevent unauthorized redisclosure.\textsuperscript{125}

Fourth, the Disclosure Act also allows too much latitude for disclosure without patient authorization under its exceptions for specific circumstances. For example, oral disclosure of health care information is allowed under the Disclosure Act to family members or significant others, unless the patient has instructed the provider not to make the disclosure.\textsuperscript{126} Under this provision, disclosure of genetic

\textsuperscript{123} A useful analogy is that of an adhesion contract, where there is a disparity in bargaining power between the parties to a contract. Consumers do not typically have the opportunity to bargain over the terms of their insurance policies, especially when policies are obtained through employers. As a result, consumers often have no choice but to accept a term which might be unfavorable to them, such as disclosure of all medical information as a condition of accepting coverage.

\textsuperscript{124} See Rothstein, supra note 27, at 892.

\textsuperscript{125} Redisclosure following legitimate disclosure of test results for HIV and sexually transmitted diseases is specifically prohibited under title 70, chapter 24 of the Washington Revised Code. See WASH. REV. CODE § 70.24.105 (1996).

\textsuperscript{126} Title 70, chapter 2 of the Washington Revised Code allows disclosure without patient’s authorization to be:

Oral, and made to immediate family members of the patient, or any other individual with whom the patient is known to have a close personal relationship, if made in
information is allowed by default, and nondisclosure is the exception. 127 To protect genetic privacy and autonomy, disclosure must be made only by the choice of the individual the information pertains to. Disclosure to family members or anyone else cannot be allowed by default. 128

Finally, the Disclosure Act allows for denial of patient access to health care information under certain circumstances. For example, a health care provider may deny access to health care information if the provider concludes that the information would be injurious to the health of the patient. 129 This situation does not appropriately apply when considering genetic information. The reason a person would undergo testing would be to learn more about the status of his or her own health. Denial of access to genetic test results runs directly counter to the opportunity available to people, through testing, to learn more about their own health status. Further, individuals are more likely to forgo genetic testing if they can be denied access to, and control of, their test results. Consequently, the Disclosure Act fails to protect individual autonomy regarding genetic information, especially regarding results of genetic testing, by allowing potential denial of access to individual genetic test results.

As the above discussion clearly demonstrates, the Disclosure Act is an inadequate vehicle to protect genetic privacy or to provide individual autonomy and control over genetic information. 130

accurance with good medical or other professional practice, unless the patient has instructed the health care provider in writing not to make the disclosure.

WASH. REV. CODE § 70.02.050(1)(e) (1996).

127. See id.
128. See generally WASH. REV. CODE § 70.02.050 (1996).
129. See WASH. REV. CODE § 70.02.090(1)(a) (1996).
130. However, Washington lawmakers appear to be aware of the need to give genetic privacy special statutory protection. During the 1997 legislative session, a bill was introduced in the Senate which addressed discrimination by health carriers on the basis of genetic information. Senate Bill (SB) 5298 proposed adding a new section to title 48, chapter 43 of the Washington Revised Code, which regulates health insurance providers. SB 5298, 55th Leg., 1st Reg. Sess. (Wash. 1997). Under SB 5298, health insurance providers would have been prohibited from denying or canceling coverage on the basis of the genetic information of individuals or family members. Redisclosure following an authorized disclosure would also have been prohibited. SB 5298 failed to pass out of the Committee on Health and Long Term Care, and the bill was pronounced "dead" before the end of the 1997 legislative session.

While SB 5298 was an encouraging sign that Washington lawmakers are aware of the need to give genetic information special statutory protection, the bill was presented only in the context of health insurance regulation. Consequently, the bill did not go far enough to accomplish comprehensive protection of personal privacy and autonomy with regard to genetic information. In addition, while the bill attempted to prevent discrimination in health insurance, genetic discrimination in life insurance, disability insurance, and employment was not addressed. Moreover, if enacted, the law would have "related to" insurance, and would have been subject to
Consequently, Washington lawmakers need to enact specific legislation to address the limitations of the Health Care Information and Disclosure Act with respect to genetic information. Lawmakers must also address issues which are beyond the scope of the Disclosure Act, such as the prohibition of unauthorized or compulsory genetic testing and the destruction of samples following testing. The next section suggests what the legislation should substantively contain in order to provide Washington citizens with statutory protection of their genetic information.

VI. PROPOSAL FOR A WASHINGTON STATE GENETIC PRIVACY ACT

In designing legislation aimed at protecting genetic information, it is important to keep in mind the important functions to be served by legislation aimed specifically at protecting the privacy of genetic information. First, the privacy of information which is personal and unique would be assured. Second, autonomy in decisionmaking regarding personal health care would be maintained. Finally, discrimination on the basis of genetic information would be prevented. Accomplishing comprehensive protection of genetic information requires regulating all stages of the genetic testing process, from sample collection through access of genetic information in a patient’s medical records. In order to provide this comprehensive protection, legislators should enact a Washington State Genetic Privacy Act (WSGPA), containing provisions which address each of the issues detailed below.

A. Definition of Genetic Information

The WSGPA should define “genetic information” broadly to include both the results of genetic testing and any information about inherited characteristics obtained from family history.\footnote{131}

In contrast to this broad definition, some approaches to protecting genetic privacy have limited genetic protection only to the results of testing by DNA analysis, thereby excluding family history information from the range of protected information.\footnote{132} However, family history information about inherited diseases is also a legitimate source of federal preemption under ERISA. As a result, the law would not have applied to the many Washington citizens who obtain their health insurance through self-insured plans. See Smith, supra note 3, at 124.

131. An appropriate definition of genetic information was the one set forth in Senate Bill 5298, where “genetic information” was broadly defined as “information about genes, gene products, or inherited characteristics.” SB 5298, supra note 130.

genetic information. In fact, family history has long been used as a tool for making predictions about individual genetic characteristics.\(^\text{133}\) As Maria Silverwood learned, genetic information gleaned from family history is as likely to result in discrimination by insurance and employers as is information obtained from genetic testing. Consequently, genetic information drawn from family history must be within the range of information which is given statutory protection by the WSGPA if prevention of genetic discrimination is to be ensured.

**B. Prohibition of Unauthorized Sample Collection and Testing**

The unauthorized collection of samples for genetic testing must be prohibited by the WSGPA. Typically, genetic material is collected for testing by a simple blood draw. Ample DNA can be obtained from the cells in a small volume of blood for conducting the desired genetic test. However, it is also possible to obtain DNA from individuals without their knowledge. For example, DNA can be collected from hair, saliva, and other bodily tissues and fluids which could possibly be collected without an individual’s consent.\(^\text{134}\) Thus, sample collection, prior to testing, must require specific authorization by the person who desires testing. To ensure that no unauthorized sample collection occurs, laboratories performing testing must be required to ensure that samples are accompanied by documentation authorizing sample collection.

**C. Prohibition of Compelled Testing**

The WSGPA must prohibit any compulsory genetic testing. As discussed above, the decision to undergo genetic testing is a very personal and difficult one to make. The rights of individuals who choose not to undergo genetic testing must be protected.

Employers and insurance companies argue that they are left without access to all potentially available information regarding employees and enrollees without compulsory testing.\(^\text{135}\) These concerns are far outweighed by the individual’s right to privacy about one’s own body and autonomy in personal decisionmaking, both of which are threatened by compulsory testing. The ability to make personal decisions without government interference is recognized by

\(^{133}\) See Bornstein, *supra* note 14, at 598.

\(^{134}\) See ANNAS ET AL., *supra* note 10, at vi.

\(^{135}\) See Gauling, *supra* note 72, at 1686.
the United States Supreme Court and the Washington Supreme Court. It follows that the personal decision of whether or not to undergo genetic testing should not only be free from government interference and compulsion, but also free from interference or compulsion by private parties, such as employers and insurance companies.

Under current Washington law, employers and insurers are not prohibited from requiring genetic testing as a condition of employment or insurance coverage. This type of compelled testing comes at a price: the opportunity to make the independent choice of whether to undergo genetic testing is lost forever. This choice can be preserved for the person to whom it means the most if employers and insurers are prohibited from requiring genetic testing. The WSGPA must prohibit compulsory genetic testing in order to preserve personal autonomy in the decision of whether to undergo genetic testing.

D. Stringent Rules Regarding Authorized Disclosure and Redisclosure

Under the WSGPA, disclosure of genetic information must not be allowed on the basis of a general, blanket authorization of the type often used to release general medical information to insurance companies for reimbursement verification. Disclosure must only occur if there is written authorization allowing release of genetic information to a specific individual. Exceptions comparable to those found in the Disclosure Act (allowing unauthorized disclosure) must not be permitted. Any authorization must include a reasonable expiration date, such as thirty days after the patient signs the authorization.

Further, any disclosure must be revocable, and the authorization must inform the patient of her right to revoke. To ensure that the patient is aware of the possibility of revocation, the authorization form should include a separate section explaining that the authorization can be revoked. This section should be brought to the patient's attention, and initialed by her to verify that she has read and understood it.

The recipient of the information must be notified upon receipt of the information that the disclosure is confidential, and the information must not be redisclosed without the specific written consent of the patient. For example, if an individual voluntarily discloses genetic information to a health or life insurance carrier, that carrier must be


prohibited from disclosing the information to any other parties. In this manner, carriers or others who legitimately receive information are prohibited from selling the information on the "personal information market," or otherwise misusing the information. This will also help assure that disclosed genetic information will be put only to the limited use for which the patient gave the original authorization.

Further, if a patient authorizes release of information to claims management personnel associated with an insurer, the information may only be used for the purpose of prompt payment and evaluation of any medically related claims. Claims payment personnel must be on notice that the specifics of the information must not be redisclosed.

E. Assurance of Access

Under Washington's Health Care Information Access and Disclosure Act, patients may be denied access to their own medical records under certain circumstances. For example, a health care provider may deny a patient access to her own medical records if the provider believes that the information would be injurious to the person's health.

Access to genetic information, however, should never be subjected to such a restriction. A person who chooses to undergo genetic testing does so in order to learn more about her own health status. Unrestricted access to testing results is necessary to give that person the maximum benefit that can be derived from having the testing done. This is particularly important in cases such as testing for a predisposition for conditions such as heart disease, where life style changes are known to influence the likelihood of whether or not the disease will manifest itself. Clearly, rather than the knowledge of a genetic predisposition being potentially injurious to a person's health, denial of access to genetic information would be injurious by denying a person the opportunity to take advantage of the testing. Consequently, in order to both allow individual control over genetic information and maximize the potential benefits of testing, access to individual genetic information should never be denied. The WSGPA must include an assurance of a person's access to any and all testing results.

138. See id.
139. See WASH. REV. CODE § 70.02.090 (1996).
140. See id. (allowing denial of access and copying of medical records if "[k]nowledge of the health care information would be injurious to the health of the patient.").
F. Destruction of Samples

Typically, genetic testing involves a simple blood draw from a person, since DNA can be extracted from the cells in the blood. Once extracted, the DNA is stable for long periods of time if frozen. As technology progresses, it may be possible to obtain more and more information from samples collected at some previous date. The storage potential for DNA suggests a risk of unauthorized testing, and consequently of unauthorized release of genetic information.141

Since blood samples are typically very simple to collect, an original sample should be destroyed after analysis for the specific genetic condition the sample was collected for. An additional blood sample can be collected at a future date if a person wishes to have more testing done. Destruction of samples will reduce the risk of unauthorized testing and disclosure of genetic information, and must be required by the WSGPA.

G. Prohibition of Genetic Discrimination

Legislation incorporating the safeguards described above would be significant progress toward protecting the privacy of individual genetic information. In some cases, however, individuals might voluntarily disclose genetic test results to employers and insurance companies. In order to be certain that no person is discriminated against on the basis of genetic information, the WSGPA must contain explicit prohibitions on discrimination in insurance and employment on the basis of genetic information which is voluntarily disclosed.

1. Insurance

Current Washington law does not expressly prohibit genetic discrimination in health insurance. Under title 48, chapter 3, section 25 of the Washington Revised Code, a health insurance carrier may not "deny, exclude, or otherwise limit coverage" on the basis of any pre-existing medical condition.142 Arguably, a genetic condition

141. See Andrews, supra note 47, at 44.
142. WASH. REV. CODE § 48.43.025(1) (1996). The statute provides:
No carrier may reject an individual for health plan coverage based upon any preexisting conditions of that individual and no carrier may deny, exclude, or otherwise limit coverage for an individual's preexisting health conditions; except that a carrier may impose a three-month benefit waiting period for preexisting conditions for which medical advice was given, or for which a health care provider recommended or provided treatment within three months before the effective date of coverage.

Id.
identified through genetic testing would be considered to be a "preexisting condition."143 As a result, Washington citizens may well be protected under existing law from having the results of genetic tests used to discriminate against them in health insurance.144 Nonetheless, the WSGPA must expressly prohibit genetic discrimination for all types of insurance. A comprehensive prohibition on genetic discrimination in insurance would be consistent with the existing law, because genetic discrimination in health insurance would continue to be prohibited by statute. Under the WSGPA, the scope of protection against genetic discrimination in insurance would be expanded to include life and disability insurance, as well as in health insurance.

Unfortunately, the WSGPA insurance provisions would not protect all Washington citizens from potential genetic discrimination in insurance. State laws that "relate to" insurance do not apply to self-insured plans because of federal preemption under ERISA.145 Since the WSGPA insurance provisions would probably be found to "relate to" insurance, these provisions would not apply in situations where insurance is obtained through employer-based self-insured plans.146 Nonetheless, the WSGPA would provide protection from genetic discrimination for Washington citizens who directly purchase their own insurance, as well as those who obtain insurance through employers who directly purchase insurance.147

2. Employment

Under the WSGPA, employers must be prohibited from discriminating in any manner on the basis of genetic information, in order to protect both current and potential employees.148 Thus, to protect potential employees, employers must not be allowed to use

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143. See Smith, supra note 90, at b1.
144. See id.
146. See Smith, supra note 90, at b1; Farrell, supra note 101, at 268-69.
147. Smith, supra note 90, at b1.
148. A useful approach is the one taken by New York state, which considers discrimination on the basis of genetic predisposition to be a violation of their Human Rights Law. Specifically, N.Y. Exec. Law § 296 (McKinney 1997) states:

Unlawful discriminatory practices. 1. It shall be an unlawful discriminatory practice: (a) For an employer or licensing agency, because of the age, race, creed, color, national origin, sex, disability, genetic predisposition or carrier status, or marital status of any individual, to refuse to hire or employ or to bar or to discharge from employment such individual or to discriminate against such individual in compensation or in terms, conditions, or privileges of employment.
genetic information when making hiring decisions. To protect current employees, employers must be prohibited from using genetic information when making decisions regarding employee compensation and promotion. In this manner, employers would be required to treat genetic information in the same manner as other immutable and genetically determined characteristics, such as age, race, or sex, when making employment decisions. Under this approach, employees will receive maximum protection against potential discrimination in employment on the basis of their unique genetic make-up.

H. Enforcement

In order to encourage compliance with the provisions of the legislation, the WSGPA must provide for a private right of action against anyone violating its provisions. Thus, a person would be able to bring an action against a physician who disclosed personal genetic information without consent, or against an employer who denied a promotion based on an employee's genetic test results. Without the "teeth" of civil remedies behind it, health care providers, insurance companies, and employers will have little incentive to comply with the WSGPA.

In sum, adequate protection of genetic information requires comprehensive regulation—from sample collection through disclosure of information and ultimate destruction of samples. The Washington legislature should incorporate the suggestions presented in this section and develop a Genetic Privacy Act for the state, in order to protect the genetic privacy of Washington citizens.

I. Consistency with the State Constitution

The Washington State Constitution provides extensive protection of personal privacy through Article 1, section 7, which states:

No person shall be disturbed in his private affairs, or his home invaded, without authority of law.151

In the context of medical records, the Washington Supreme Court recognizes that the right to avoid disclosure of personal matters to the

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149. Washington law prohibits discrimination in employment on the basis of "race, creed, color, national origin, families with children, sex, marital status, age, or the presence of any sensory, mental, or physical disability." WASH. REV. CODE § 49.60.010 (1996).


151. WASH. CONST. art. 1, § 7.
government is the essence of privacy, and is a right that is constitutionally protected.\textsuperscript{152} It follows that genetic information, as part of a medical record, is subject to the privacy protections offered by the state constitution. In other words, Washington citizens have a right to avoid disclosure of genetic information to the government. In this regard, the proposed WSGPA is consistent with the right to privacy available under the state constitution.

However, under the Washington constitution, the right to medical records privacy is not absolute.\textsuperscript{153} The disclosure of intimate information, including medical records, to state government agencies is allowed if there is some legitimate state interest necessitating disclosure, and if the disclosure is carefully tailored and no greater than necessary.\textsuperscript{154} Consequently, the WSGPA would not totally prevent nonconsensual disclosure of genetic information to government agencies. However, any such disclosure to a state agency must serve some legitimate state interest, and must only be as extensive as reasonably necessary to further the state’s interest.

While Washington case law has defined constitutional protections against government access to intimate information, those same protections do not appear to apply to nongovernmental access to intimate information.\textsuperscript{155} Therefore, a party harmed because an insurance company or some other nongovernmental entity disclosed genetic information without consent would probably not be able to rely on the state constitution as a basis for a remedy. The WSGPA would essentially extend the privacy protections of the state constitution, by providing a private cause of action to parties harmed by nonconsensual disclosure of genetic information.

\section*{VII. CONCLUSION}

This Comment concludes that genetic information must be given special status as health information that is part of a medical record in order to protect individual privacy and autonomy with respect to unique, personal, and predictive genetic information. As Maria

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\item[152.] See Peninsula Counseling Center v. Rahm, 105 Wash. 2d at 940-41, 719 P.2d 931-32. In this regard, the state constitution provides a greater right to privacy than is found under the federal constitution, where the same interest is not explicitly recognized. \textit{Id.}
\item[153.] See id. at 933-34, 719 P.2d at 928-29 (1986).
\item[154.] See id.; see also \textsc{Wash. Rev. Code} § 70.02.050(2) (1996) (authorizing disclosure of health care information to government health authorities under specific circumstances).
\item[155.] See Doe v. Puget Sound Blood Center, 117 Wash. 2d 772, 783, 819 P.2d 370, 376 (1991) (declining to address the issue of whether a constitutional right to privacy can be invoked without state action).
\end{itemize}
\end{footnotesize}
Silverwood learned, failure to provide this special status gives rise to concerns about personal privacy and autonomy and creates a significant risk of harm, including discrimination in insurance and employment. The current law in Washington does not adequately protect the privacy of personal genetic information, and regulation to protect genetic information does not appear to be forthcoming from the federal government. Consequently, Washington should enact its own Genetic Privacy Act in order to protect genetic privacy and to prevent genetic discrimination within the state.