
Note

Relative Futility: Limits to Genetic Privacy Protection Because of the Inability to Prevent Disclosure of Genetic Information by Relatives

Trevor Woodage*

In March 2009, Alan and Keri Bearder joined eight other families to sue the State of Minnesota and the Minnesota Department of Health for violating the genetic privacy rights of their children.¹ They claimed that in retaining, using, and disseminating blood and genetic information derived from DNA samples taken from their children as part of a newborn genetic screening program without written, informed consent, the Department of Health violated state genetic privacy law.² The families alleged that they “suffered damages, including but not limited to, the fear of the use of their genetic information by government and unknown private entities.”³

Indeed, many, if not most, of the fears expressed about genetic privacy relate to concerns that other parties will gain

* J.D. Candidate 2011, University of Minnesota Law School; B. Med. Sci. 1982, University of Newcastle, N.S.W., Australia; B. Med. 1984, University of Newcastle, N.S.W., Australia; Ph.D. 1994, University of Sydney, N.S.W., Australia. I thank Professor William McGeeveran for his insightful guidance in developing some of the concepts presented in this Note. I owe a debt of gratitude to the Editors of the *Minnesota Law Review*, in particular Joe Hansen, for constructive edits and comments. Many scientific colleagues developed my knowledge of, and interest in, genetics. Finally, nothing I do would be possible without the love and support of my family. Copyright © 2010 by Trevor Woodage.

1. See *Bearder v. Minnesota*, No. A10-101, 2010 WL 3307066 (Minn. Ct. App. Aug. 24, 2010); Complaint, *Bearder v. Minnesota*, No. 27-CV-09-5615 (Hennepin County, Minn., Dist. Ct. Mar. 11, 2009), available at http://www.cchconline.org/pr/FINAL_Plaintif_s_v_MDH_complaint.doc (last visited Nov. 7, 2010); Press Release, Citizens' Council on Health Care, Nine Families Sue State of Minnesota, Allege Violations of State Genetic Privacy Law in Newborn Screening (Mar. 11, 2009), available at <http://www.cchconline.org/pr/pr031109.php>.

2. Press Release, Citizens' Council on Health Care, *supra* note 1.

3. Complaint, *supra* note 1, ¶ 9.

access to personal genetic information.⁴ What perhaps is not widely appreciated is that genetic information is by its very nature not private because all humans share common genetic information with their relatives.⁵ Identical twins are genetically the same, sharing essentially the same DNA sequences,⁶ while other relatives share progressively smaller fractions of their genetic code, depending upon the degree of relationship.⁷ These observations give rise to an apparent paradox: how is it possible to keep genetic information private when the very DNA sequence on which it is based is held in common with an open-ended set of relatives? Federal and state legislation designed to preserve the privacy of genetic information largely fails to address this issue.⁸

This Note argues that strong protection of genetic privacy on an individual basis is likely to be an elusive goal. A more satisfactory approach may be to develop legislative solutions that ensure protection against uses of genetic information that run counter to individual interests. Part I of this Note describes existing approaches to genetic privacy and the manner in which they relate to the treatment of other types of personal information. Part II analyzes several situations in which traditional approaches to genetic privacy based on individual concepts of

4. See, e.g., Editorial, *Genetic Privacy*, BOS. GLOBE, June 6, 1999, at G6 (noting that legislators were “grappl[ing] with the basics of citizen [genetic] privacy, seeking to protect the individual from misuse of those secrets in a medical frontier that might easily become an Orwellian nightmare”); Douglas A. Levy, *Experts Call for Genetic Privacy Legislation*, UNITED PRESS INT’L, Oct. 18, 1991, available in LEXIS, Wire Service Stories (quoting U.S. Representative John Conyers as saying that “[p]ublic release of people’s genetic information is a Pandora’s Box that is best left unopened”); Sharon Schmickle, *Genetic-Privacy Fears Rippling Nationwide*, STAR TRIB. (Minneapolis, Minn.), Feb. 18, 2001, at 18A, available at 2001 WLNR 10302883 (quoting an employee subject to workplace genetic testing as saying, “I don’t want the entire world to know if someone in our family has a potential for a disease”).

5. See JAMES J. NORA ET AL., *MEDICAL GENETICS: PRINCIPLES AND PRACTICE* 216 (4th ed. 1994) (“[A]llesles at linked loci tend to be inherited by offspring in the same combinations in which they occur in parents.” (emphasis omitted)).

6. See *id.* at 395 (“Identical . . . twins result from the splitting of a fertilized egg, giving rise to two genetically identical individuals.”).

7. THOMAS D. GELEHRTER ET AL., *PRINCIPLES OF MEDICAL GENETICS* 52 (2d ed. 1998).

8. See Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (codified in scattered sections of 26, 29, and 42 U.S.C.); NANCY LEE JONES & AMANDA K. SARATA, CONG. RESEARCH SERV., RL 30006, *GENETIC INFORMATION: LEGAL ISSUES RELATING TO DISCRIMINATION AND PRIVACY* (updated Mar. 10, 2008).

dominion over DNA sequence information will not adequately address confidentiality issues raised by the sharing of genetic sequences among relatives. It also addresses other legal paradigms that relate to the issue of genetic privacy. Part III proposes that such concerns could be addressed by educating people about the ways in which genetic information can be used and misused. Specifically, this Note concludes that protections against the misuse of genetic information should be strengthened and, in parallel, proposes that the federal government or the states develop legislation that would allow people to have access to their own genetic records and to know who else has access to the information.

I. TRADITIONAL APPROACHES TO GENETIC PRIVACY

As is too often the case with new technology, advances in genetic research and the practical applications of such research threaten to overtake the public's readiness to understand these advances and the law's ability to deal with them.⁹ This Part describes the types of information that new methods of genetic testing have made available. It also discusses the underpinnings of privacy as a protectable interest and current legal protections of genetic privacy.

A. GENETIC INFORMATION AND GENETIC VARIATION

Genetic information comes in different forms. It is generally possible to tell if people have a Y chromosome just by looking at them.¹⁰ Physicians can confirm the presence of deleterious mutations that cause heritable diseases, such as cystic fibrosis or Huntington disease, by studying a patient's pedigree.¹¹ Yet, popular usage increasingly accepts that when people talk about genetic information they are referring to, either explicitly or implicitly, DNA sequence information.¹² DNA is composed of

9. See, e.g., Editorial, *Genetic Privacy*, *supra* note 4, at G6 (describing the Massachusetts Legislature's struggle to write genetic privacy laws that can keep up with the rapid scientific progress in the field).

10. See GELEHRTER ET AL., *supra* note 7, at 178–79.

11. See *id.* at 23 (defining common genetic conditions as “diseases that are the result of a single mutant gene . . . that are inherited in simple patterns”).

12. See *DNA Sequencing Fact Sheet*, NAT'L HUMAN GENOME RES. INST., <http://www.genome.gov/10001177> (last visited Nov. 7, 2010) (“Scientists need to know the sequence of bases because it tells them the kind of genetic information that is carried in a particular segment of DNA.”).

long chains of four types of molecules known as nucleotides.¹³ The nucleotides are commonly abbreviated as A, C, G, and T, and it is the order of these nucleotides that makes up the genetic information contained within DNA.¹⁴ The total set of DNA sequences contained within each organism is known as the genome.¹⁵ Humans carry two copies of the genome, one inherited from each parent,¹⁶ with each copy containing approximately three billion nucleotides.¹⁷

The ability to read small portions of a person's DNA sequence is now widely available, affordable, and used extensively for the study and diagnosis of genetic diseases.¹⁸ Continuing technological improvements make it possible to determine large amounts of genomic sequence for progressively lower costs.¹⁹ The Human Genome Project, a large, multinational effort, finished sequencing the human genome for the first time in 2003 at a total cost of approximately three billion dollars.²⁰ In 2009, it was possible to sequence a human genome for less than fifty thousand dollars.²¹ It is widely expected that total sequencing costs will be less than a thousand dollars, perhaps as little as one hundred dollars, by 2015.²² The expectation that there will be ubiquitous demand for genome sequencing drives much of this cost reduction.²³ At least part of this demand comes from the belief that examination of a person's DNA sequence will allow doctors and patients to identify predispositions to common diseases and take steps to prevent or ameliorate the effects of illness.²⁴

13. JAMES D. WATSON ET AL., *MOLECULAR BIOLOGY OF THE GENE* 68 (4th ed. 1987).

14. *See id.* at 74, 86–87. For instance, three nucleotides in the order CGA instruct a cell to insert the amino acid arginine in a particular position in a protein, or the sequence TAA tells a cell to complete the synthesis of a protein. BRUCE ALBERTS ET AL., *MOLECULAR BIOLOGY OF THE CELL* 367 (5th ed. 2008).

15. GELEHRTER ET AL., *supra* note 7, at 11.

16. NORA ET AL., *supra* note 5, at 12.

17. *Id.* at 11.

18. *See DNA Sequencing Fact Sheet*, *supra* note 12.

19. *Id.*

20. *The Human Genome Project Completion: Frequently Asked Questions*, NAT'L HUMAN GENOME RES. INST., <http://www.genome.gov/11006943> (last updated Apr. 7, 2009).

21. John Markoff, *I.B.M. Joins Pursuit of \$1,000 Genome*, N.Y. TIMES, Oct. 6, 2009, at D2, available at 2009 WLNR 19662265.

22. *See id.* (discussing technological advances and the timeline with which they are expected to reduce the total cost of sequencing the human genome).

23. *See DNA Sequencing Fact Sheet*, *supra* note 12.

24. *See Advanced Sequencing Technology Awards 2008*, NAT'L HUMAN

Inherent in the notion that genetic information can be used for individualized diagnosis of genetic disease is the recognition that DNA sequences differ between people.²⁵ If corresponding stretches of DNA are compared from any two human chromosomes, there will be, on average, a difference approximately once every thousand nucleotides.²⁶ These sequence variants are, at least in part, responsible for differences between people, including physical characteristics,²⁷ temperament and personality,²⁸ and risk of developing a wide range of diseases.²⁹ While there is a vibrant debate regarding the relative contributions that genetic, environmental, and other factors make towards individual development, even the staunchest opponent of genetic determinism would admit that an individual's DNA sequence is an important determinant of personhood.³⁰ This close association between DNA sequence and identification of a person as an individual lies at the root of at least some calls for genetic privacy.³¹

B. PRIVACY AS A PROTECTABLE INTEREST

American privacy jurisprudence dates, in large part, from 1890 with the publication of Samuel Warren and Louis Brandeis's seminal article, *The Right to Privacy*.³² Facing technolo-

GENOME RES. INST., <http://www.genome.gov/27527584> (last visited Nov. 7, 2010).

25. See *id.*

26. See David E. Reich et al., *Human Genome Sequence Variation and the Influence of Gene History, Mutation and Recombination*, 32 NATURE GENETICS 135, 135–36 (2002) (stating that the average rate of difference between two gene sequences was on the order of 0.1 percent).

27. See Hannah Pulker et al., *Finding Genes that Underlie Physical Traits of Forensic Interest Using Genetic Tools*, 1 FORENSIC SCI. INT'L: GENETICS 100, 102–03 (2007).

28. See M.R. Munafò et al., *Genetic Polymorphisms and Personality in Healthy Adults: A Systematic Review and Meta-Analysis*, 8 MOLECULAR PSYCHIATRY 471, 471–72 (2003).

29. See *DNA Sequencing Fact Sheet*, *supra* note 12.

30. See George P. Smith, II & Thaddeus J. Burns, *Genetic Determinism or Genetic Discrimination?*, 11 J. CONTEMP. HEALTH L. & POL'Y 23, 25–35 (1994) (discussing both the association between DNA sequence changes and complex traits and concerns that claims are being made that “one's fate is determined by genetic inheritance”).

31. Sonia M. Suter, *Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy*, 72 GEO. WASH. L. REV. 737, 744–45 (2004) (noting associations between genetic information, conceptions of self, and concerns about genetic privacy).

32. Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193 (1890); see also DANIEL J. SOLOVE & PAUL M. SCHWARTZ,

gical developments that threatened exposure of otherwise private information,³³ Warren and Brandeis proposed the recognition of a previously unprotected right—the right to privacy—deserving of common law protections.³⁴ Despite courts deciding over three hundred civil privacy cases after publication of the Warren and Brandeis article,³⁵ it was not until 1960 that Dean William Prosser formally classified the privacy torts.³⁶ Prosser's analytical framework was highly influential.³⁷ The four privacy torts that he described were subsequently recognized in the Restatement (Second) of Torts,³⁸ and have since been adopted either at common law or by statute in the great majority of jurisdictions in the United States.³⁹ The privacy tort most relevant to genetic privacy is described in the Second Restatement of Torts as “publicity given to private life.”⁴⁰ It states that publicizing information relating to another's private life that is “highly offensive to a reasonable person” and “not of legitimate concern to the public” is subject to liability.⁴¹

Although only protecting against possible government usurpation of available privileges, the Supreme Court in *Griswold v. Connecticut*⁴² famously located a constitutional right to privacy because “specific guarantees in the Bill of Rights have penumbras . . . [that] create zones of privacy.”⁴³ Although

INFORMATION PRIVACY LAW 10–12 (3d ed. 2009) (noting the origin and importance of the Warren and Brandeis article).

33. See Warren & Brandeis, *supra* note 32, at 195 (“Instantaneous photographs and newspaper enterprise have invaded the sacred precincts of private and domestic life; and numerous mechanical devices threaten to make good the prediction that ‘what is whispered in the closet shall be proclaimed from the house-tops.’”).

34. See *id.* at 218–19 (suggesting that the invasion of privacy should be protected at common law as are other personal interests).

35. See SOLOVE & SCHWARTZ, *supra* note 32, at 26.

36. See William L. Prosser, *Privacy*, 48 CALIF. L. REV. 383, 389 (1960) (characterizing the four privacy torts as: (1) “Intrusion upon the plaintiff's seclusion or solitude”; (2) “Public disclosure of embarrassing private facts about the plaintiff”; (3) “Publicity which places the plaintiff in a false light in the public eye”; and (4) “Appropriation . . . of the plaintiff's name or likeness”).

37. SOLOVE & SCHWARTZ, *supra* note 32, at 27.

38. RESTATEMENT (SECOND) OF TORTS §§ 652B–652E (1977).

39. See, e.g., *Lake v. Wal-Mart Stores, Inc.*, 582 N.W.2d 231, 234–35 (Minn. 1998).

40. RESTATEMENT (SECOND) OF TORTS § 652D.

41. *Id.*

42. 381 U.S. 479 (1965).

43. *Id.* at 484.

Griswold's protections related to marital privacy,⁴⁴ the Supreme Court subsequently extended substantive due process protections to information privacy.⁴⁵ Despite this case law, there is an unresolved circuit split as to whether there is a constitutional right to protection against disclosure of personal information.⁴⁶ Nine circuits support a constitutional right to protection against such disclosures.⁴⁷ However, the Sixth Circuit denies the existence of a constitutional right to privacy in personal information,⁴⁸ while the Eighth Circuit only regards the right as applicable in instances involving egregious disclosure.⁴⁹

In addition to federal constitutional protections, a number of states have constitutional provisions directly providing for the protection of privacy.⁵⁰ Interestingly, the Supreme Court of California held that, unlike most such provisions, the Californian constitutional right to privacy applies not only to state agencies, but also to private entities.⁵¹ Clearly then, a range of common law and constitutional protections can apply in any particular situation. The next section examines how other, especially statutory, protections apply to issues associated with genetic information.

C. STATUTORY PROTECTION OF GENETIC PRIVACY

Under one view, a person's DNA is personal property. As such, it is rightly considered subject to control by its "owner," and consequently deserves privacy protection.⁵² In *Moore v. Re-*

44. See *id.* at 485–86.

45. See *Whalen v. Roe*, 429 U.S. 589, 599 (1977) (noting that constitutional protection of privacy extends to an "individual interest in avoiding disclosure of personal matters").

46. Diane M. DeGroat, Comment, *When Students Test Positive, Their Privacy Fails: The Unconstitutionality of South Carolina's HIV/AIDS Reporting Requirement*, 17 AM. U. J. GENDER SOC. POL'Y & L. 751, 761–62 (2009).

47. *Id.* at 761; see also, e.g., *Walls v. City of Petersburg*, 895 F.2d 188, 192 (4th Cir. 1990); *Daury v. Smith*, 842 F.2d 9, 13 (1st Cir. 1988); *Fadjo v. Coon*, 633 F.2d 1172, 1175 (5th Cir. 1981).

48. *Doe v. Wigginton*, 21 F.3d 733, 740 (6th Cir. 1994).

49. *Alexander v. Peffer*, 993 F.2d 1348, 1350 (8th Cir. 1993).

50. SOLOVE & SCHWARTZ, *supra* note 32, at 34; see also Mark Silverstein, Note, *Privacy Rights in State Constitutions: Models for Illinois?*, 1989 U. ILL. L. REV. 215, 226–58 (reviewing existing state constitutional provisions as they relate to the protection of privacy).

51. *Hill v. Nat'l Collegiate Athletic Ass'n*, 865 P.2d 633, 644 (Cal. 1994).

52. See Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 31, 49 (Mark A. Rothstein ed., 1997) ("Proprietary genetic priva-

gents of the University of California,⁵³ the California Supreme Court upset this expectation.⁵⁴ In this widely cited case, the court held that a patient's property interests did not extend to spleen cells that a surgeon removed from his body.⁵⁵ Based on *Moore* and similar decisions, several scholars have argued that property rights are unlikely to provide meaningful protection of genetic privacy.⁵⁶

Beyond the apparent inability of property rights to protect genetic privacy and the incomplete privacy protections afforded by constitutional law,⁵⁷ there are both federal and state statutory safeguards for genetic privacy. The Privacy Act of 1974 prohibits disclosure of records maintained on individuals by federal government agencies except under specified conditions.⁵⁸ Although providing for private rights of action⁵⁹ and criminal penalties,⁶⁰ it does not provide broad genetic privacy protections, because the statute applies only to federal agencies⁶¹ and requires that a plaintiff show that any violation was "willful and intentional."⁶²

Congress created provisions that were more generally applicable to protecting the privacy of genetic information through passage of the Health Insurance Portability and Accountability Act (HIPAA) in 1996.⁶³ The main purpose of

cy is further suggested by the related notion that human DNA is owned by the persons from whom it is taken, as a species of private property.").

53. 793 P.2d 479 (Cal. 1990).

54. *See id.* at 488–93.

55. *See id.* (holding that a patient's ownership interest over his cells does not extend beyond the time the cells were taken from his body).

56. *See* Radhika Rao, *Property, Privacy, and the Human Body*, 80 B.U. L. REV. 359, 434–36 (2000) ("[P]roperty traditionally implies alienability Privacy, on the other hand, does not carry the same connotations. Personal privacy encompasses the right to possess one's own body and the right to exclude others, but does not embrace the power to give, sell, or otherwise transfer body rights to other individuals." (citations omitted)); Suter, *supra* note 31, at 746 ("[T]he property model is deeply problematic as a tool to protect our interests in genetic information.").

57. *See supra* Part I.B (noting that constitutional privacy protections generally only protect against government actors and describing the circuit split over whether there is a constitutional right to protection of personal information).

58. Privacy Act of 1974, 5 U.S.C. § 552a (2006).

59. *Id.* § 552a(g)(1).

60. *Id.* § 552a(i).

61. *Id.* § 552a(a)(1).

62. *Id.* § 552a(g)(4).

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

HIPAA was to allow employees to move between employers without having their new health insurance plans exclude pre-existing conditions from coverage.⁶⁴ Congress was also concerned about the privacy and security of medical data that insurers would transmit when they processed insurance claims.⁶⁵ Rather than directly creating privacy rules within HIPAA, Congress authorized the Department of Health and Human Services to propose regulations.⁶⁶ A final version of those rules went into effect in 2002.⁶⁷ The regulations defined the information that was covered as “[i]ndividually identifiable health information,” that “[r]elates to the past, present, or future physical or mental health or condition of an individual . . . and . . . [t]hat identifies the individual; or . . . there is a reasonable basis to believe the information can be used to identify the individual.”⁶⁸ This definition includes genetic information as well as information about an individual’s family history.⁶⁹ A significant limitation of the scope of privacy protections under HIPAA comes from the fact that the regulations do not apply to all individuals or entities with access to an individual’s health information; instead, they apply to “health plans[,] . . . health care clearinghouses[,] . . . [and] health care provider[s].”⁷⁰

The most recent federal attempt to secure genetic information was the Genetic Information Nondiscrimination Act (GINA).⁷¹ Congress primarily intended this legislation to prohibit discrimination based on a person’s genetic makeup in health insurance and employment settings.⁷² However, using a broad definition of “genetic information,”⁷³ GINA also explicitly

64. SOLOVE & SCHWARTZ, *supra* note 32, at 431.

65. *Id.*

66. *Id.* at 431–32.

67. Standards for Privacy of Individually Identifiable Health Information, 67 Fed. Reg. 53,182 (Aug. 14, 2002) (codified at 45 C.F.R. pts. 160, 164).

68. 45 C.F.R. § 160.103 (2009).

69. JONES & SARATA, *supra* note 8, at CRS-19.

70. 45 C.F.R. § 160.102.

71. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (codified in scattered sections of 26, 29, and 42 U.S.C.).

72. SOLOVE & SCHWARTZ, *supra* note 32, at 507.

73. 29 U.S.C. § 1191b(d) (Supp. II 2008) (defining “genetic information” to mean “with respect to any individual, information about—(i) such individual’s genetic tests, (ii) the genetic tests of family members of such individual, and (iii) the manifestation of a disease or disorder in family members of such individual,” and “genetic test” as the “analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes”).

defines such data as health information for privacy purposes under HIPAA.⁷⁴ A comprehensive discussion of GINA is beyond the scope of this Note, but the Act received a mixed critical reaction and is likely not the last piece of federal legislation in this field.⁷⁵

Perhaps due to the perception of slow or limited action in the federal arena, a convincing majority of state legislatures enacted laws relating to the use of genetic information.⁷⁶ Again, much of the impetus behind these bills arose from concerns relating to employment or health insurance discrimination.⁷⁷ Nonetheless, a recent survey of state legislative developments revealed that twenty-seven states required consent to disclose genetic information and eighteen states provided specific penalties for violations of genetic privacy.⁷⁸

The existence of this broad range of legal protection of genetic privacy—common law, constitutional, statutory—seems to be completely consistent with the suggestion that control of access to genetic information is a worthwhile goal. There are, however, arguments against relying on genetic privacy to protect underlying autonomy interests, both because maintaining confidentiality of genetic information is not always desired, or desirable, and because of inherent limits to the extent to which confidentiality can be maintained.

II. LIMITS TO GENETIC PRIVACY

Although a variety of legal approaches to the protection of genetic privacy interests exist, legislators and other concerned

74. 42 U.S.C. §§ 1320d-9(a)(1), 1320d(4)(B) (Supp. II 2008).

75. See, e.g., Timothy J. Aspinwall, *Imperfect Remedies: Legislative Efforts to Prevent Genetic Discrimination*, 19 ANNALS HEALTH L. 121, 122–23 (2010) (describing health insurance protection under GINA, but noting that the legislation fails to protect against the use of genetic information in the context of long-term care, disability, or life insurance); Mark A. Rothstein, *Is GINA Worth the Wait?*, 36 J.L. MED. & ETHICS 174, 177 (2008) (noting both the symbolic value of declaring a policy against genetic discrimination and the dangers of genetic exceptionalism—giving genetic information a privileged status as compared with other forms of health information); Joanne Barken, Note, *Judging GINA: Does the Genetic Information Nondiscrimination Act of 2008 Offer Adequate Protection?*, 75 BROOK. L. REV. 545, 572–77 (2009) (arguing that additional legislation will be needed to ensure adequate protection against use of genetic information in employment situations).

76. See JONES & SARATA, *supra* note 8, at CRS-20 to CRS-21.

77. See *id.*

78. See *Genetic Privacy Laws*, NAT'L CONF. ST. LEGISLATURES, <http://www.ncsl.org/IssuesResearch/Health/GeneticPrivacyLaws/tabid/14287/Default.aspx> (last updated Jan. 2008) (citing survey information current as of January 2008).

parties seem to have paid less attention to two particular issues. First, those parties have failed to focus on why the confidentiality of genetic information should be maintained, and, second, whether there are inherent limits to the amount of protection that can be given to genetic information. This Part discusses situations in which people may not desire genetic privacy or may even be harmed when genetic information is kept confidential.

A. GENETIC PRIVACY: ATTEMPTING TO LOCATE THE HARM

Before delving more deeply into factors that might limit a person's ability to keep their DNA sequence a secret, it is worth considering why such secrecy is even at issue. Why do people want genetic privacy? Do people even really want to keep their genetic information private? Moreover, what harm could occur through unconsented access to DNA sequence information? Consideration of these questions will help people understand what efforts they should take to try to keep their genetic information confidential or, alternatively, what steps they should take to minimize the chance of harm occurring through disclosure of this information.

1. Why Do People Want Genetic Privacy?

It is likely that some of the reasons underlying an individual's interest in maintaining the privacy of genetic information are the same as those for wanting to keep any personal information confidential.⁷⁹ There is a widely held belief that genetic information is an individual's "property" and that control over access to that information is one of the rights of ownership.⁸⁰ There is also a long-standing belief that establishing a distinction between public and private domains is essential to the development of an autonomous sense of self.⁸¹ Another common

79. GRAEME LAURIE, GENETIC PRIVACY: A CHALLENGE TO MEDICO-LEGAL NORMS 203–05 (2002).

80. See Margaret Everett, *The Social Life of Genes: Privacy, Property and the New Genetics*, 56 SOC. SCI. & MED. 53, 56–58 (2003) (discussing different approaches taken to the "genes as property" debate). *But see* Moore v. Regents of the Univ. of Cal., 793 P.2d 479, 493 (Cal. 1990) (refusing to recognize an ownership interest in human body parts).

81. See HANNAH ARENDT, THE HUMAN CONDITION 71 (1958) ("[T]he four walls of one's private property offer the only reliable hiding place from the common public world A life spent entirely in public, in the presence of others, becomes . . . shallow."); Edward Shils, *Privacy: Its Constitution and Vicissitudes*, 31 LAW & CONTEMP. PROBS. 281, 283 (1966) ("The 'private life' is a secluded life, a life separated from the compelling burdens of public authority.").

belief is the idea that privacy relates not only to keeping information about oneself from the public domain, but also to controlling the information that one makes available to others.⁸² It is possible to differentiate between “spatial” privacy, restricting access to a person’s physical or psychological self, and “informational” privacy, restricting access about personal information.⁸³ The second of these concepts is that which is most closely associated with the common public understanding of privacy and is most relevant to the discussion of genetic privacy.⁸⁴

Part of the motivation for wanting to keep genetic information secret may come from a belief that the information stored in one’s DNA represents a “diary” of sorts that reveals insights about one’s self and one’s future.⁸⁵ Treatment of genetic information as having unique characteristics is known as “genetic exceptionalism.”⁸⁶ Based on this concept, some argue that DNA sequence information warrants special forms of privacy protection.⁸⁷ Consider, for example, one expression of this claim: “[i]f genes determine aspects of our being and we cannot control our genes, we feel the more dire need to control others’ access to our genes and the information contained in them.”⁸⁸ The belief in the special importance of genetic data helps to feed concerns that malefactors could use this powerful information against the best interests of its “owner” and establishes the nexus between concerns about genetic privacy and genetic discrimination.⁸⁹ Many individuals and interest groups have cited fears relating to the possibility of genetic discrimination as a reason

82. See Charles Fried, *Privacy*, 77 YALE L.J. 475, 482 (1968) (“Privacy is not simply an absence of information about what is in the minds of others; rather it is the *control* we have over information about ourselves.”).

83. LAURIE, *supra* note 79, at 6.

84. *Id.* at 6 n.27.

85. See George J. Annas, *Genetic Prophecy and Genetic Privacy*, 32 TRIAL 19, 20 (1996) (“The information in one’s DNA can be thought of as a coded probabilistic future diary because it describes an important part of a person’s unique future and, as such, can affect and undermine our view of ourself and our life’s possibilities.”).

86. Margaret Everett, *Can You Keep a (Genetic) Secret? The Genetic Privacy Movement*, 13 J. GENETIC COUNSELING 273, 274 (2004).

87. See Annas, *supra* note 85, at 25 (“To the extent that we accord special status to our genes and what they reveal, genetic information is uniquely powerful and uniquely personal, and thus merits unique privacy protection.”).

88. KEVIN M. KEENAN, *INVASION OF PRIVACY: A REFERENCE HANDBOOK* 143 (2005).

89. See Everett, *supra* note 86, at 277 (commenting on the relationship between genetic privacy and discrimination).

for restricting access to genetic information.⁹⁰ These concerns were also the prime motivation for the enactment of legislation protecting genetic privacy.⁹¹ Advocates for legislative safeguards were most worried about genetic discrimination in employment,⁹² and with respect to health insurance.⁹³ Recent passage of health care reform legislation will likely do much to reduce consumers' fears that they could be denied health insurance because insurers will not be able to deny such insurance due to preexisting conditions after 2014.⁹⁴ While this Note is primarily concerned with the subject of genetic privacy, it is relevant to mention that, despite great concerns regarding the potential for genetic discrimination, it is controversial whether actual genetic discrimination has occurred to any great extent.⁹⁵ Another apparent result of genetic exceptionalism has been the development of what are sometimes poorly defined fears relating to the possible misuse of genetic information by

90. See Patricia Nemeth & Terry W. Bonnette, *Genetic Discrimination in Employment*, 88 MICH. B.J. 42, 45 (2009) (“[M]any people were concerned that genetic information could be used by employers to discriminate in hiring or promotion decisions.” (quoting MICH. LEG., FIRST ANALYSIS, SB 593, 90th Sess., at 1 (2000), available at <http://www.legislature.mi.gov/documents/1999-2000/billanalysis/House/htm/1999-HLA-0593-A.htm>); Sheryl Gay Stolberg, *President Calls for Genetic Privacy Bill*, N.Y. TIMES, Jan. 18, 2007, at A14, available at 2007 WLNR 978490 (quoting President Bush’s statement that “it is important that [genetic] information not be exploited in improper ways”); *supra* note 4.

91. See *supra* Part I.C.

92. See, e.g., William J. McDevitt, *I Dream of GINA: Understanding the Employment Provisions of the Genetic Information Nondiscrimination Act of 2008*, 54 VILL. L. REV. 91, 93–96 (2009) (indicating that employment-related safeguards were among the chief concerns related to genetic discrimination under GINA).

93. See, e.g., Amy Harmon, *Fear of Insurance Trouble Leads Many to Shun or Hide DNA Tests*, N.Y. TIMES, Feb. 24, 2008, at A1, available at 2008 WLNR 3619695; Kathy L. Hudson et al., *Genetic Discrimination and Health Insurance: An Urgent Need for Reform*, 270 SCIENCE 391, 392 (1995).

94. Patient Protection and Affordable Care Act of 2010, Pub. L. No. 111-148, § 2704, 124 Stat. 119, 154; see also Peter Grier, *Health Care Reform Bill 101: Rules for Preexisting Conditions*, CHRISTIAN SCI. MONITOR, Mar. 24, 2010, available at 2010 WLNR 7558052.

95. See Pauline T. Kim, *Regulating the Use of Genetic Information: Perspectives from the U.S. Experience*, 31 COMP. LAB. L. & POL’Y J. 693, 695–96 (2010) (noting the rarity of cases of employment discrimination based on the use of genetic information in the United States); Jeffrey S. Morrow, Note, *Insuring Fairness: The Popular Creation of Genetic Antidiscrimination*, 98 GEO. L.J. 215, 225–26 (2009) (reviewing evidence for and against the occurrence of frequent instances of genetic discrimination).

government actors, such as the concerns raised by opponents of newborn screening programs.⁹⁶

Despite the similarities between genetic privacy and other forms of privacy, there are differences. One interesting and important distinction is the potential desire for privacy from oneself, that is, choosing not to find out one's own DNA sequence. Unlike other forms of personal information, sequence data is not "known" by an individual until there is a technological intervention—DNA sequencing. Especially in the context of genetic diseases that lack effective treatments, patients may choose not to know whether they carry mutations.⁹⁷ Indeed, there is some evidence suggesting that after learning that they would develop a fatal genetic condition, some carriers have chosen to attempt or commit suicide more commonly than would otherwise have been the case.⁹⁸

This discussion demonstrates that someone might choose to keep their genetic information private for a host of reasons. The most convincing of these arguments, however, seem to relate more to the occurrence of some manifest harm (denial of employment opportunities or health insurance) than to more abstract denials of personal autonomy.

2. Do People Want Genetic Privacy?

Having considered factors potentially leading to a desire for genetic privacy, it is worth taking a step back and asking whether most people actually care about keeping their DNA sequence information confidential. Despite a variety of theoretical rationales supporting calls for genetic privacy, there is em-

96. See *CCHC Testimony on MN Plan to Mandate Genetic Testing of Newborns*, CITIZENS' COUNCIL ON HEALTHCARE (Mar. 20, 2003) <http://www.cchconline.org/testimony/t032003.php> (discussing state government plans to implement a database for newborn genetic screening purposes: "This is not the proper role of government in a free society. History has shown the less than beneficent activities that can occur where such data systems exist"); see also Bradley Graham, *DNA Sampling Sparks Worries Two Marines Take Privacy Issues to Court*, SEATTLE TIMES, Apr. 14, 1996, at A22, available at 1996 WLNR 1342647 (citing concerns about the uses intended by the government for genetic information obtained as a result of acquiring DNA samples from military personnel).

97. Tuija Takala & Heta Aleksandra Gylling, *Who Should Know About Our Genetic Makeup and Why?*, 26 J. MED. ETHICS 171, 172 (2000) (noting that possible carriers are not under a prudential obligation to confirm their mutation status if a disease is incurable).

98. Elisabeth W. Almquist et al., *A Worldwide Assessment of the Frequency of Suicide, Suicide Attempts, or Psychiatric Hospitalization After Predictive Testing for Huntington Disease*, 64 AM. J. HUM. GENETICS 1293, 1300–01 (1999).

pirical evidence of widespread public support for the use of genetic information in a range of settings, at least some of which are not compatible with universal genetic privacy protection.⁹⁹ Public concerns with genetic information seem to coalesce around worries associated with particular uses of that information, particularly possible employment and insurance discrimination.¹⁰⁰ Studies of people whose relatives have had cancer support the argument that some individuals are concerned about the use of genetic information because of fears about potential genetic discrimination—they appear more likely than the general public to express concerns about who has access to their genetic information.¹⁰¹

Surveys of both the public and research study participants indicate the widespread support for the use of genetic information for research.¹⁰² An interesting, and large-scale, example of this phenomenon comes from Iceland where, despite the fact that deCODE Genetics, a private company, is carrying out much of the research,¹⁰³ the Icelandic public generally supports

99. An online survey carried out in August 2006 examined the opinions of 3091 U.S. adults towards genetics and the uses of genetic information. *Public Overwhelmingly Supportive of Genetic Science and Its Use for a Wide Variety of Medical, Law Enforcement and Personal Purposes*, HARRIS INTERACTIVE (Aug. 30, 2006), <http://www.harrisinteractive.com/news/allnewsbydate.asp?NewsID=1088> [hereinafter HARRIS INTERACTIVE]. Ninety-three percent of respondents agreed that the “science of genetics and DNA” was a “very good [or] good thing.” *Id.* The same percentage of respondents strongly or somewhat supported the use of genetic information “[t]o identify criminals in rape, murder and other crimes.” *Id.* Eighty-five percent or more of those surveyed were similarly supportive of the use of genetic information for establishing paternity, carrying out research to find new ways to prevent or treat diseases, testing by doctors to identify diseases for which people are at risk, and tracing one’s family tree and ancestors. *Id.*

100. *See id.* (stating that only fourteen percent of respondents supported the use of genetic information by insurance companies to determine who to insure and how much to charge, while twelve percent supported its use by employers to help decide whether to employ a person).

101. *See* Kira A. Apse et al., *Perceptions of Genetic Discrimination Among At-Risk Relatives of Colorectal Cancer Patients*, 6 GENETICS MED. 510, 513 tbl.2 (2004) (noting, for instance, that forty-seven percent of survey participants would be likely or very likely to ask that their genetic test results be excluded from their medical record).

102. *See* Jeantine E. Lunshof et al., *From Genetic Privacy to Open Consent*, 9 NATURE REVIEWS GENETICS 406, 408 (2008) (citing the willingness of subjects to participate in genetic research); HARRIS INTERACTIVE, *supra* note 99 (stating that ninety-one percent of survey participants supported the use of genetic information for genetic disease research).

103. *See* Sarah Lyall, *A Country Unveils Its Gene Pool and Debate Flares*, N.Y. TIMES, Feb. 16, 1999, at F1, available at 1999 WLNR 3030501 (explain-

access to genetic information.¹⁰⁴ With a genetically homogeneous population of approximately 280,000 people and a well-developed medical record system, geneticists regard Iceland as particularly fertile ground for studies aimed at identifying disease genes.¹⁰⁵ The database cataloguing the study's subjects and their family members contains information on almost half the people who have ever lived in Iceland.¹⁰⁶ While Icelanders may be particularly well disposed to participating in genetic research because of pride in their homogeneous ancestry,¹⁰⁷ they exemplify the willingness to allow access to personal genetic information also seen in the United States in the research setting.¹⁰⁸

In an interesting paradigm shift, the Personal Genome Project (PGP), an initiative exploring issues related to genome sequencing of individuals, moved from traditional conceptions of genetic privacy to an "open consent" model for its genetic research and DNA sequencing.¹⁰⁹ The PGP provides for open-access distribution of sequence data and medical information, with the aim of developing an improved understanding of the ways in which scientists and physicians can use genetic information for medical research.¹¹⁰ The first ten participants in the program, the PGP-10, volunteered to make their names, personal medical histories, and full genome sequences publicly available.¹¹¹ Although beginning as a small-scale pilot project,

ing the breadth of the deCODE project).

104. See Gísli Pálsson & Kristín E. Harðardóttir, *For Whom the Cell Tolls: Debates About Biomedicine*, 43 CURRENT ANTHROPOLOGY 271, 283 (2002) (noting that many Icelanders were eager to contribute their blood samples and medical records to genetic research programs).

105. *Id.* at 275–76.

106. *Id.* at 277; see also *id.* (noting also that Icelanders have a particular interest in maintaining comprehensive family trees).

107. See *id.* at 283 ("Many Icelanders seem proud of their 'Nordic' roots and their genetic makeup, and they are eager to 'offer' their 'unique' blood samples and medical records . . . to science and the advancement of human well-being." (citation omitted)).

108. See *supra* notes 99, 102 and accompanying text.

109. See Lunshof et al., *supra* note 102, at 406.

110. See *Mission*, PERS. GENOME PROJECT, <http://www.personalgenomes.org/mission.html> (last visited Nov. 7, 2010) (discussing the goals of the project, among which is to improve "understanding of personal genomics and its potential").

111. *PGP-10*, PERS. GENOME PROJECT, <http://www.personalgenomes.org/pgp10.html> (last updated Mar. 16, 2009).

the PGP plans to enroll up to 100,000 participants.¹¹² That over 11,000 people registered for information about participating in the PGP demonstrates that a substantial number of people appear to be willing to allow open access to their genetic information.¹¹³

The willingness of large numbers of individuals involved in medical research or initiatives such as the PGP to allow access to their DNA sequence and other genetic information shows that a desire for strict maintenance of genetic privacy is not universal.

3. The Flip Side: Can Genetic Privacy Do Harm?

Even assuming an increasing acceptance of the notion that strict maintenance of genetic privacy is not necessary in all circumstances, there may also be times when restricting access to genetic information can actually be harmful.

While a person might choose to keep genetic information private from herself when faced with the prospect of finding that she might carry a mutation for an untreatable genetic condition,¹¹⁴ in a different circumstance, she might instead choose not to know when there was a chance that she might be at risk of developing a preventable or treatable disorder. Such scenarios are well known in the case of common malignancies such as breast cancer, with knowledge of carrier status allowing for effective preventative measures.¹¹⁵ A person's right not to know this type of information can be justified on the grounds of autonomy or individual self-determination.¹¹⁶ The situation

112. See *Events*, PERS. GENOME PROJECT, <http://www.personalgenomes.org/events/> (last visited Nov. 7, 2010) (noting that the Harvard Medical School Institutional Review Board approved the involvement of one participant in the PGP in 2005, expanded that approval to ten participants in 2006, and again expanded approval to 100,000 participants in 2008).

113. See *Newsletter #1*, PERS. GENOME PROJECT (Apr. 2009), <http://www.personalgenomes.org/newsletter/01.html>.

114. See *supra* note 97 and accompanying text.

115. Deborah Schrag et al., *Life Expectancy Gains from Cancer Prevention Strategies for Women with Breast Cancer and BRCA1 or BRCA2 Mutations*, 283 JAMA 617, 617 (2000).

116. See R. Andorno, *The Right Not to Know: An Autonomy Based Approach*, 30 J. MED. ETHICS 435, 436–37 (2004) (discussing the theoretical underpinnings of the “right not to know”). *But cf.* Gillian Nycum et al., *Intra-Familial Obligations to Communicate Genetic Risk Information: What Foundations? What Forms?*, 3 MCGILL J.L. & HEALTH 21, 42–45 (2009) (suggesting that people might owe a duty of care to their genetic relatives and would thus be obliged to disclose knowledge of mutations associated with disease risk).

becomes more complicated, though, when a person's exercise of a right not to know could affect the health of another. For example, a man might decide that he did not want to know that he carried a mutation in a gene that was associated with a high risk of developing breast cancer in females. His sister, however, might have wanted to have been alerted to a need to be tested for the mutation, and, if she proved positive, to take steps to reduce her chance of developing cancer. This type of consideration suggests that it would be appropriate to limit the right not to know in certain circumstances.¹¹⁷ These situations can, of course, be particularly complicated in the case of parental consent to genetic tests for minor children, where considerations of the importance of genetic information to other family members are further complicated by children's autonomy becoming subservient to that of their parents.¹¹⁸

These considerations provide evidence for the contention that unfettered restrictions on the dissemination of genetic information can, at least in some circumstances, result in harm. Difficult issues arise when the autonomy interests of different individuals are balanced. At the least, these concerns strengthen arguments for flexibility in access to genetic information when benefits outweigh harms. However, even when a person's interests in keeping DNA sequence information confidential are not challenged by a need for access by others, that person's ability to prevent others from reaching conclusions about that sequence information may be constrained by factors beyond his control.

B. LIMITS TO GENETIC PRIVACY

Many things outside a person's control can result in the violation of his or her genetic privacy. Such forces include accidental or intentionally malicious data release, hacking, and hardware and data theft.¹¹⁹ While this Note will not discuss

117. See Andorno, *supra* note 116, at 439 (noting that the right not to know "is a relative right, in the sense that it may be restricted when disclosure to the individual is necessary in order to avoid serious harm to third parties, especially family members"); see also Nycum et al., *supra* note 116, at 39–47 (discussing possible moral and legal obligations requiring disclosure of genetic information to at-risk family members).

118. See Lainie Friedman Ross & Margaret R. Moon, *Ethical Issues in Genetic Testing of Children*, 154 ARCHIVES PEDIATRIC & ADOLESCENT MED. 873, 873–74 (2000) (discussing implications of parental control over consent for genetic tests).

119. Lunshof et al., *supra* note 102, at 407.

these computer technology-related occurrences in any more detail, the fact that computerized databases containing personal data can be targets of malevolent activity provides a background level of concern that, no matter what the “owners” of genetic information choose to do with that information, the ultimate disposition of the data may be beyond their influence. Indeed, a primary thesis of this Note is that, by its very nature, people cannot exert complete dominion over their genetic information and, for that reason, concerns about genetic privacy, as such, warrant reconsideration. Factors limiting genetic privacy include sharing of DNA sequence information between relatives and computational techniques that can identify specific individuals from large DNA sequence databases. These concepts coalesce with recent developments in the ability of crime investigators to use partial forensic matches to identify suspects based on their relationship to defendants that have already been typed by DNA forensic laboratories.

1. DNA Sequence Information as a Shared Attribute

Except for identical twins¹²⁰ and, potentially in the future, clones,¹²¹ no two human beings have identical genomic DNA sequences.¹²² This unique association between each person and his DNA sequence would seem to support a strong, and protectable, privacy interest. However, of course, people did not create their own DNA; rather, they inherited it from their parents, with equal maternal and paternal contributions.¹²³ Similarly, everyone shares DNA sequences to a greater or lesser degree with family members, depending upon the degree of genetic relatedness.¹²⁴ That is not to say, of course, that because a scientist knows the complete genetic sequence of someone’s mother, brother, or daughter, that she knows the precise content of fifty percent of that person’s genetic code. Rather, the scientist can make a probabilistic statement that the index

120. NORA ET AL., *supra* note 5, at 395.

121. See Lori B. Andrews, *Is There a Right to Clone? Constitutional Challenges to Bans on Human Cloning*, HARV. J.L. & TECH. 643, 647 (1998) (noting that clones are genetically identical to the source individual except for the minor contribution from mitochondrial DNA).

122. See A.J. Jeffreys et al., *Individual-Specific “Fingerprints” of Human DNA*, 316 NATURE 76, 76–77 (1985) (describing the development of a genetic test producing results that are “completely specific to an individual”).

123. See NORA ET AL., *supra* note 5, at 6–7 (describing the formation of an embryo from equal numbers of chromosomes from each gamete).

124. See GELEHRTER ET AL., *supra* note 7, at 52.

subject shares half the DNA sequence of his first-degree relative, but it is not possible to say precisely which parts of the sequence are in common.¹²⁵ With the availability of DNA sequence information from multiple relatives, however, it is possible to make increasingly certain inferences about the DNA sequence that is present in a specific person.¹²⁶ There are several ways that shared DNA sequences could manifest as limitations on a person's ability to maintain genetic privacy. For instance, someone whose father died of Huntington disease, a rare, fatal neurodegenerative condition inherited by fifty percent of a sufferer's offspring,¹²⁷ might decide that she did not want to know whether she carried the mutation. If that person's daughter decided that she did want to be tested and, for whatever reason, announced to the world that she had inherited the mutation, then her parent would, in effect, be "outed" as a carrier, despite his wishes to the contrary.

While formally prohibited by GINA,¹²⁸ it would be difficult to prove the possibility that a health insurer had decided to deny coverage to relatives of known mutation carriers. While the insurer would not be certain the people it denied coverage carried mutations themselves, even a fifty percent chance of avoiding the high cost of treating a cancer patient might be attractive.¹²⁹ While there is little evidence that insurers or other

125. Henry T. Greely et al., *Family Ties: The Use of DNA Offender Databases to Catch Offenders' Kin*, 34 J.L. MED. & ETHICS 248, 251–52 (2006) (discussing the degree and random nature of DNA sharing by relatives).

126. If individuals Alan, Bill, and Charlie are grandfather, son, and grandson, respectively, and an investigator had access to DNA sequence information from Alan and Charlie, then it would be possible to make accurate predictions about Bill's DNA sequence. For example, if at a particular region on chromosome fifteen, Alan had chromosomal sequences of CCTGATGC and CATGGTGT (one copy inherited from each of Alan's parents; underlined letters indicate nucleotides that vary between individuals), and Charlie's sequence showed CCTGGTGC and CATGGTGT, then an investigator could predict with a reasonable degree of certainty that Bill carried at least one copy of CATGGTGT, the sequence that Charlie had inherited—through Bill—from his grandfather Alan.

127. Michael R. Hayden & Berry Kremer, *Basal Ganglia Disorders*, in 2 PRINCIPLES AND PRACTICE OF MEDICAL GENETICS 2197, 2203–07 (David L. Rimoin et al. eds., 3d ed. 1997) (describing the fatal nature of the disorder and stating that it is inherited in an autosomal dominant manner, i.e., that half of a carrier's offspring will inherit the disease).

128. See 29 U.S.C. § 1191b(d)(6)(a) (Supp. II 2008) (including the use of DNA test results or disease manifestations in relatives under prohibited conduct).

129. See *Economic Impact of Cancer*, AM. CANCER SOC'Y, <http://www.cancer.org/cancer/cancerbasics/economic-impact-of-cancer> (last visited Nov. 7, 2010) (noting the estimated health expenditures for cancer topped ninety-three billion dollars in 2008).

potential users of genetic information have denied benefits or otherwise discriminated against the relatives of mutation carriers,¹³⁰ there is evidence to suggest that these relatives are concerned about what might be termed genetic discrimination by proxy.¹³¹

Whatever might occur in other settings, it is certainly the case that, in most research settings, direct consent from the subjects involved, and not from their relatives, is all that is required for genetic investigations and publications of DNA sequence data.¹³² Indeed, even in high-profile sequencing programs, such as the PGP, the most that research subjects are asked to do is to consider the impact of their participation in the research; there is no requirement that close relatives also provide consent.¹³³

2. Identification of Individuals from Large Data Sets

One of the primary ways that people have been able to maintain a level of comfort while participating in genetic research is that their consent to participate in studies was generally given under an assurance that any information disclosed consequent to the study would be made in an anonymous manner.¹³⁴ This promise of anonymity, however, can be defeated because genetic sequence information is uniquely capable of iden-

130. See *supra* note 95 and accompanying text.

131. Apse et al., *supra* note 101, at 512.

132. See David A. Wheeler et al., *The Complete Genome of an Individual by Massively Parallel DNA Sequencing*, 452 NATURE 872, 875 (2008) (“Third-party relatives are not typically considered research participants and their consent is not generally required for research participation.”).

133. See Harvard Medical School, Consent Form, PERS. GENOME PROJECT, http://www.personalgenomes.org/consent/PGP_Consent_Approved03242009.pdf (last visited Nov. 7, 2010) (stating that participants were “strongly encouraged to discuss this study and its potential risks with [their] immediate family members,” but were not required to seek their consent); see also Wheeler et al., *supra* note 132, at 875 (stating that, with respect to a research project resulting in the publication of the complete genome sequence of James Watson, the co-discoverer of the structure of DNA, Dr. Watson was “strongly encouraged to discuss these issues with biological relatives and to make a family decision about research participation and data release,” but that “[t]he participant’s autonomous decision to participation in research typically outweighs any objections raised by third-party relatives”).

134. See Lunshof et al., *supra* note 102, at 408 (“A crucial consideration is that consent for disclosure . . . is given only upon certain conditions; a key condition usually being the assurance of secrecy with regard to personal identity and information content.”).

tifying someone, providing greater discriminative capability than a person's name or standard demographic data.¹³⁵

A striking example of being able to identify someone using DNA sequence was the case of a teenage boy who, with the aid of genetic analysis, was able to track down his anonymous sperm-donor father.¹³⁶ In a similar vein, a direct-to-consumer genetics company recently announced the launch of a service that would let customers with DNA sequence information in its database identify and contact probable near and distant relatives.¹³⁷ To make things even worse, using newly developed genetic techniques and statistical approaches, it now appears possible for someone to "re-identify" an individual's genetic data from large pools of anonymized and aggregated genomic data.¹³⁸ The significance of these developments is magnified when contextualized by the ever-expanding nature of the genetic databases that are available on the Internet and the fact that, once information is online, it forms what is essentially a permanent record that cannot be expunged.¹³⁹ Thus, not only can a

135. See *ASHG Response to NIH on Genome-Wide Association Studies*, AM. SOC'Y HUM. GENETICS (Nov. 30, 2006), http://www.ashg.org/pages/statement_nov3006.shtml ("[T]he most accurate individual identifier is the DNA sequence itself or its surrogate here, genotypes across the genome. It is clear that these available genotypes alone, available on tens to hundreds of thousands of individuals in the repository, are more accurate identifiers than demographic variables alone . . .").

136. Alison Motluck, *Tracing Dad Online*, NEW SCIENTIST, Nov. 5, 2005, at 6, 6 (noting that a resourceful fifteen-year-old boy was able to identify his anonymous sperm-donor father by sending his own DNA for analysis of Y chromosome (paternal lineage) markers, matching the pattern to a surname in a genealogy database, and then using that name along with some basic demographic information about the sperm donor to identify and contact his genetic father); see also Dawn R. Swink & J. Brad Reich, *Caveat Vendor: Potential Progeny, Paternity, and Product Liability Online*, 2007 BYU L. REV. 857, 857–69 (discussing the same case and recent trends allowing for the identification of anonymous sperm donors through genetic analysis and the Internet).

137. See Lawrence Hon, *Introducing Relative Finder: The Newest Feature from 23andMe*, SPITTOON (Nov. 19, 2009, 5:13 PM), <http://spittoon.23andme.com/2009/11/19/introducing-relative-finder-the-newest-feature-from-23andme> (discussing the launch of the service and noting, with no apparent irony, that "[w]ith Relative Finder, you can discover more about your ancestry than you ever thought possible!" and that "[a]fter all, you never know who you might find").

138. See Dan Vorhaus, *Re-identification and Its Discontents*, GENOMICS L. REP. (Oct. 13, 2009), <http://www.genomicslawreport.com/index.php/2009/10/13/re-identification-and-its-discontents>.

139. See Daniel J. Solove, *Privacy and Power: Computer Databases and Metaphors for Information Privacy*, 53 STAN. L. REV. 1393, 1412 (2001) (noting that once information appears on the Internet it creates "a permanent record

person not be assured of anonymity of DNA sequence information, once that genetic information has been posted on the Internet it is essentially beyond his or her control forever.

3. Criminal Law and Partial Forensic Matches

There is at least one circumstance that, in what might otherwise be characterized as an invasion of genetic privacy, receives wide support. Every jurisdiction in the United States maintains a database containing genetic information from offenders to enable forensic DNA analysis.¹⁴⁰ These databases and associated DNA-sampling programs survived constitutional and other legal challenges, with the judiciary determining that the public interest in solving crimes overcomes the privacy expectations of suspects.¹⁴¹ While, to date, these initiatives have been restricted to those who were convicted of, or at least arrested in connection with, felonies,¹⁴² some commentators have called for the expansion of these databases to provide for population-wide coverage to assist crime-prevention efforts.¹⁴³

Having considered the ways in which information regarding shared DNA sequences can be used in other contexts, it should be no surprise to learn that similar applications are possible, and have begun to be used, in the criminal justice setting. Forensic investigators can use “familial searching” when a crime-scene DNA sample comes up with a partial match to a sample in an offender database.¹⁴⁴ The police have used this method successfully on a number of occasions in the United Kingdom and at least once in the United States.¹⁴⁵ The legal

of unparalleled pervasiveness and depth. . . . [A]lmost everything on the Internet is being archived”).

140. See Greely et al., *supra* note 125, at 250 (“[E]very American state ha[s] established forensic DNA databases.”).

141. Aaron B. Chapin, Note, *Arresting DNA: Privacy Expectations of Free Citizens Versus Post-Convicted Persons and the Unconstitutionality of DNA Dragnets*, 89 MINN. L. REV. 1842, 1847–55 (2005) (reviewing the general tendency under the “special needs” doctrine of the Fourth Amendment and the DNA Act of 2000 to uphold the legality of forensic DNA databases).

142. See Greely et al., *supra* note 125, at 250.

143. See, e.g., D.H. Kaye & Michael E. Smith, *DNA Identification Databases: Legality, Legitimacy, and the Case for Population-Wide Coverage*, 2003 WIS. L. REV. 413, 415; Michael Seringhaus, Op-Ed., *To Stop Crime, Share Your Genes*, N.Y. TIMES, Mar. 15, 2010, at A23, available at 2010 WLNR 5373377.

144. See Greely et al., *supra* note 125, at 248–49.

145. See, e.g., *id.* (discussing the use of familial DNA to catch several felons in the United States and United Kingdom); Jennifer Steinhauer, “Grim Sleeper” Arrest Fans Debate on DNA Use, N.Y. TIMES, July 9, 2010, at A14, availa-

status of this procedure is not yet settled in the United States, with concerns relating to the constitutionality of searching familial DNA samples having, so far, escaped any significant litigation.¹⁴⁶ If the practice of familial DNA searching does become entrenched in criminal forensic practice, however, it could become a common example of a relative's DNA sequence being used to identify a person who did not wish his genetic information to be accessible to others. In light of such developments, new approaches to protecting individual interests in controlling the access to, and use of, genetic information are needed.

C. BEYOND GENETIC PRIVACY LAW: LOOKING TO OTHER LEGAL PARADIGMS FOR GUIDANCE

Given the absence of case law on point and that federal and state genetic privacy legislation was not designed to deal with the challenges of shared genetic information, it may be helpful to look to other bodies of law for guidance about how to deal with these issues. Looking to parallels with situations in which one party disclosed shared, non-genetic information in a manner that was adverse to the interests of another party provides useful analogies.

In 2001, Susana Kaysen published a memoir in which she described intimate details of her relationship with Joseph Bonome.¹⁴⁷ Despite altering certain details about Bonome's life, such as his occupation, and only referring to him as her "boyfriend," many of his friends and business clientele understood that he was the person portrayed in the book.¹⁴⁸ Kaysen did not tell Bonome of the content of the book or seek his permission for publication.¹⁴⁹ The Superior Court of Massachusetts held that Kaysen's First Amendment rights to expression outweighed any privacy interest enjoyed by Bonome so long as the

ble at 2010 WLNR 13801521 (recounting the role of familial DNA searching in leading to the apprehension of a serial killer in California).

146. See, e.g., Jessica D. Gabel, *Probable Cause from Probable Bonds: A Genetic Tattle Tale Based on Familial DNA*, 21 HASTINGS WOMEN'S L.J. 3, 26–57 (2010) (examining constitutional and other legal issues associated with familial DNA searching); Kimberly A. Wah, Note, *A New Investigative Lead: Familial Searching as an Effective Crime-Fighting Tool*, 29 WHITTIER L. REV. 909, 931–43 (2008) (making the case that familial searching does not pose insoluble constitutional dilemmas).

147. *Bonome v. Kaysen*, No. 032767, 2004 WL 1194731, at *1 (Mass. Super. Ct. Mar. 3, 2004).

148. *Id.* at *1–2.

149. *Id.* at *1.

details related to matters of “legitimate public concern.”¹⁵⁰ This suggests that actually overcoming the right to privacy in Massachusetts requires a publication of private facts that are of genuine interest to the public. The court, however, also suggested that “[t]here is an additional interest in this case: Kaysen’s right to disclose her own intimate affairs.”¹⁵¹ Further, it noted that “it is critical that Kaysen was not a disinterested third party telling Bonome’s personal story Rather, she is telling *her own* personal story—which inextricably involves Bonome in an intimate way.”¹⁵² Rather than requiring a balance with public interest, Professor Sonja West argues that when autobiographical speech is involved “[t]he power to decide what is of consequence in a person’s life story should ultimately lie with that person alone. As long as the content and intention of the speech is truly autobiographical, its perceived importance by others should not affect its constitutional protection.”¹⁵³

Given the proposed analogy between genetic information and a diary,¹⁵⁴ it is easy to read the preceding analysis as applying to disclosure of shared genetic information without the consent of a relative. This raises the issue of whether a First Amendment right to disclose genetic information requires that the disclosure be in the public interest to overcome the genetic privacy interests of relatives. If so, it is necessary to determine how high a bar is set by a requirement for public interest. In *Florida Star v. B.J.F.*, by holding that “where a newspaper publishes truthful information which it has lawfully obtained, punishment may lawfully be imposed, if at all, only when narrowly tailored to a state interest of the highest order,”¹⁵⁵ the U.S. Supreme Court set a low bar indeed. Professor Andrew McClurg has gone so far as to argue that the public disclosure tort produces an unconstitutional chilling of speech under the

150. *Id.* at *4 (citing *Peckham v. Bos. Herald, Inc.*, 719 N.E.2d 888, 892 (Mass. App. Ct. 1999)). The court came to an expansive reading of the interest, stating that “[t]he scope of a matter of legitimate concern to the public is not limited to ‘news,’ in the sense of reports of current events or activities. It extends also to the use of names, likenesses, or facts in giving information to the public for purposes of education, amusement or enlightenment, when the public may reasonably be expected to have a legitimate interest in what is published.” *Id.* at *5 (citing RESTATEMENT (SECOND) OF TORTS § 652D cmt. j (1977)).

151. *Id.* at *6.

152. *Id.*

153. Sonja R. West, *The Story of Me: The Underprotection of Autobiographical Speech*, 84 WASH. U. L. REV. 905, 966 (2006).

154. See Annas, *supra* note 85, at 20.

155. *Fla. Star v. B.J.F.*, 491 U.S. 524, 541 (1989).

First Amendment.¹⁵⁶ Following Professor Eugene Volokh's claim that contract law may be able to allow the enforcement of confidentiality obligations, even in the face of free speech challenges,¹⁵⁷ McClurg suggested that parties involved in intimate relationships have implicitly entered into contracts not to divulge confidential information about each other.¹⁵⁸

Despite the above arguments, it is difficult to conceive of a court that would interfere with a person's desire to publish his "own" DNA sequence data. Any such restriction, by the theories outlined above, could arise from some form of duty of confidentiality owed by one person to others with whom he or she shared genetic information. While English courts apply the law of confidentiality broadly to cover spouses, ex-spouses, and others, United States courts are much less inclined to impose a duty of confidentiality within interpersonal relationships.¹⁵⁹

The related concept of spousal privilege could also serve as an analogous, but flawed, model for preventing disclosure of genetic information shared by relatives. The spousal privilege precludes the testimony of one spouse that might be adverse to the interests of the other.¹⁶⁰ A person concerned about disclosure of her DNA sequence would most likely fail in her arguments that she could rely on the privilege to protect against disclosure of shared genetic information by her kin, as the spousal privilege is only available in criminal matters.¹⁶¹ Further, while in the traditional model for spousal privilege one spouse can prevent the other from testifying even if the spouse is willing to do so, this approach is now a minority view, with the modern tendency being for the witness spouse to hold the

156. Andrew J. McClurg, *Kiss and Tell: Protecting Intimate Relationship Privacy Through Implied Contracts of Confidentiality*, 74 U. CIN. L. REV. 887, 888 (2006).

157. Eugene Volokh, *Freedom of Speech and Information Privacy: The Troubling Implications of a Right to Stop People from Speaking About You*, 52 STAN. L. REV. 1049, 1057 (2000).

158. See McClurg, *supra* note 156, at 912–15.

159. See Neil M. Richards & Daniel J. Solove, *Privacy's Other Path: Recovering the Law of Confidentiality*, 96 GEO. L.J. 123, 126 (2007) ("[I]n England, spouses, ex-spouses, friends, and nearly anyone else can be liable for divulging confidences . . . [while] American privacy law has never fully embraced privacy within relationships.").

160. See Milton C. Reagan, Jr., *Spousal Privilege and the Meanings of Marriage*, 81 VA. L. REV. 2045, 2055 (1995) ("[T]he purpose of the privilege 'is to . . . prevent[] husband and wife from becoming adversaries in a criminal proceeding.'" (quoting *United States v. Armstrong*, 476 F.2d 313, 315 (5th Cir. 1973))).

161. *Id.*

privilege.¹⁶² It is likely that societal forces in favor of individual autonomy will continue to support uncoerced choice as the basis for imposing limits on permissible testimony such as traditional forms of spousal immunity,¹⁶³ and there is little reason to believe that the traditional doctrine would apply in the genetic privacy situation.

If First Amendment and other considerations will likely not impede consensual disclosure of shared genetic information, even when doing so is against the wishes and interests of another, it may be more helpful to find other ways to protect these interests. While there is a widespread consensus in the community that discrimination based on one's genetic constitution should not be allowed,¹⁶⁴ the arguments in Part II of this Note suggest that limits to the ability to enforce genetic privacy require a more nuanced approach than what may be untenable attempts to protect the confidentiality of shared DNA sequence information.

III. CRAFTING SOLUTIONS TO THE PROBLEMS OF GENETIC PRIVACY

Attempting to protect a person's genetic privacy interests by preventing others from having access to that individual's DNA sequence information may be ineffective because of the shared nature of genetic information. Rather, it may be more productive to focus on preventing harm brought about by the misuse of that data. This Part considers steps that legislators and others could take to strengthen protections against genetic discrimination. In particular, the fact that people do not have the untrammelled ability to control access to "their" DNA se-

162. *Id.* at 2053–54 (noting that the traditional approach binding one spouse to the wishes of the other applies in only thirteen states, while the approach in which the witness spouse alone could invoke the privilege applies in twenty-one states, federal court, and the District of Columbia).

163. *See, e.g.,* Malinda L. Seymore, *Isn't It a Crime: Feminist Perspectives on Spousal Immunity and Spousal Violence*, 90 NW. U. L. REV. 1032, 1064–80 (1996) (examining and criticizing the role of traditional spousal immunity from a feminist perspective, and arguing that individual autonomy should prevail over compelled testimony).

164. *See, e.g.,* Editorial, *A Ban on Genetic Discrimination*, N.Y. TIMES, Nov. 22, 2009, at WK9, available at 2009 WLNR 23542177 (welcoming the effects and intent of the genetic nondiscrimination features of GINA). *But see* Jeremy A. Colby, Note, *An Analysis of Genetic Discrimination Legislation Proposed by the 105th Congress*, 24 AM. J.L. & MED. 443, 459–63 (1998) (discussing arguments that have been made against genetic nondiscrimination legislation, most prominently by employer organizations and the insurance industry).

quence needs to be more widely appreciated and understood. Additionally, Congress could provide a powerful means to guard against genetic discrimination by enacting legislation that assures individuals know who accesses their genetic information and for what purpose. Resulting public scrutiny would likely produce strong normative pressures inhibiting misuse of genetic information and prevent possible genetic discrimination.

A. THE REAL TARGET—PREVENTING GENETIC DISCRIMINATION

If, as suggested, the real problem is genetic discrimination, it is important that legislators, interest groups, and the public understand the difference—and indeed that there is a difference—between the need for protections against genetic discrimination and the need for genetic privacy. The first step is to educate stakeholders about the issues involved. One way to do this is to educate and encourage those who purport to be expert in the field to use the terms carefully and correctly. As an example of information that only serves to mislead, the public website for the United States Department of Energy Genome Program headlines an otherwise informative webpage about the effects of GINA with the title: “Genetics Privacy and Legislation.”¹⁶⁵ The accompanying text makes no mention of genetic privacy, but rather discusses the impacts of the legislation with respect to genetic discrimination.¹⁶⁶ While the task of educating the community about the issues discussed in this Note is undoubtedly a challenging one, it is not hopeless.¹⁶⁷

Another important objective is to ensure that strong protections against genetic discrimination continue to be developed and enforced. It is too soon to be certain of the impact of GINA and other federal legislation against the occurrence of genetic discrimination.¹⁶⁸ The high-profile nature of such matters will

165. *Genetics Privacy and Legislation*, HUM. GENOME PROJECT INFO., http://www.ornl.gov/sci/techresources/Human_Genome/elsi/legislat.shtml (last modified Sept. 16, 2008).

166. *See id.*

167. Progress is evident as displayed in a recent *New York Times* editorial discussing GINA. The editorial focuses squarely on the issue of genetic discrimination with no conflation between the concepts of genetic discrimination and genetic privacy. Editorial, *A Ban on Genetic Discrimination*, *supra* note 164, at WK9.

168. *See, e.g.*, Rothstein, *supra* note 75, at 174 (suggesting that GINA is “fatally flawed” and its goals cannot be met without addressing broader issues relating to the health finance system).

help ensure that any deficiencies in current legislation and associated regulations are quickly exposed. It is worth noting that GINA makes provision for, and forbids, the possibility of genetic discrimination based on genetic test results performed on relatives.¹⁶⁹ Other legislation and regulations, both state and federal, likewise should include similar provisions to ensure they have similar reach.

B. TOWARD A SEMI-TRANSPARENT SOCIETY: DISCLOSING DISCLOSURE

In an influential book from 1998, the science fiction writer and futurist David Brin developed the concept of what he termed the “Transparent Society.”¹⁷⁰ He considered a world of ubiquitous surveillance and data gathering in which despotism was avoided and accountability maintained by “transparency” and two-way flows of information, allowing tabs to be kept on those behind the surveillance and data gathering.¹⁷¹ The point Brin was making was that

[t]ransparency is not about eliminating privacy. It is about giving us the power to hold accountable those who would *violate* it. Privacy implies serenity at home and the right to be let alone. It may be irksome how much other people know about me, but I have no right to police their minds. On the other hand I care very deeply about what others *do* to me and to those I love.¹⁷²

Strictly applying the same underlying precepts put forward by Brin to the flow of genetic information may be neither practicable nor meet the desired goals. It would probably not benefit a consumer who feared that an insurance company would deny him health insurance to have access to the complete genome sequence of the CEO of the insurance company. What would likely be more helpful is what could be called “semi-transparency”—allowing people to know who had accessed their genetic information and for what purpose.

In fact, there is already federal legislation in another sphere that, if applied in an analogous manner, could provide just the desired functionality. Congress passed the Fair Credit

169. See 29 U.S.C. § 1191b(d)(6)(A)(ii) (Supp. II 2008) (defining genetic information as including “genetic tests of family members”); see also *id.* § 1191b(d)(5)(B) (defining family members as including any “first-degree, second-degree, third-degree, or fourth-degree relative”).

170. DAVID BRIN, *THE TRANSPARENT SOCIETY: WILL TECHNOLOGY FORCE US TO CHOOSE BETWEEN PRIVACY AND FREEDOM?* (1998).

171. *Id.* at 3–14.

172. *Id.* at 334.

Reporting Act (FCRA) in 1970 to regulate credit reporting agencies.¹⁷³ The FCRA, among other things, sets out permissible uses of credit reports, discusses authorized and unauthorized uses, and makes provision for disclosures to consumers.¹⁷⁴ This last provision is of particular relevance to the discussion of genetic information. The FCRA requires credit reporting agencies, upon request of the consumer, to disclose information in the consumer's file, the sources of the information, the identification of anyone that procured consumer reports, and reasons for adverse characterizations of the consumer.¹⁷⁵

Applying similar rules to the access to, and use of, DNA sequence and other genetic information would provide useful complements to GINA and other genetic nondiscrimination laws. Just as the FCRA regulates credit reporting agencies, legislation controlling the use of genetic information could apply to entities that generate and store DNA sequence information. Because of the highly fragmented ways in which medical care is delivered in the United States, legislation aimed at controlling organizations storing DNA sequence information would be more effective if it provided for "trusted brokers" that could maintain sequence information databases that were independent of the end users of the data, applying a further layer of protection preventing misuse of the data.¹⁷⁶

Admittedly, even as the FCRA has not prevented the misuse of personal financial information in cases of, for instance, identity theft, controls over the disclosure of genetic information would, by themselves, probably not prevent all instances of genetic discrimination. Even if a person was aware that his employer had accessed his DNA sequence, he might not know what actions his employer took based on that information. Fundamentally, it is the task of genetic nondiscrimination legislation, such as GINA, to address such abuses. Still, knowledge that his employer had examined his genetic information

173. SOLOVE & SCHWARTZ, *supra* note 32, at 716; *see also* 15 U.S.C. § 1681(b) (2006) ("It is the purpose of this subchapter to require that consumer reporting agencies adopt reasonable procedures for meeting the needs of commerce . . . in a manner which is fair and equitable to the consumer . . .").

174. SOLOVE & SCHWARTZ, *supra* note 32, at 716–19.

175. *See* 15 U.S.C. § 1681g.

176. *See, e.g.*, Andrew Pollack, *New Venture Aims to Guard Genetic Data*, N.Y. TIMES, Oct. 9, 2000, at C2, *available at* 2000 WLNR 3300345 (noting the example of First Genetic Trust, a company that billed itself as a "genetic bank," holding a person's genetic information in a secure account and only releasing it with that person's permission).

shortly before terminating his employment might allow an employee to develop a case that he had been discriminated against because of his genetic constitution.

It is also likely true that merely allowing people to determine the identity of those who had access to their genetic information will not result in the majority of them actually monitoring the use of that information. It may be necessary to develop easy-to-understand protocols demonstrating how to obtain and understand genetic "credit reports" to encourage their use. Education may help allay concerns that genetic information is too complicated to understand, but instead the important thing is the more manageable task of being aware of the entities looking at the information. Further, it is reasonable to expect that employers, insurers, and others with inclinations to misuse genetic information would be more careful in their actions if they knew that the "owners" of the information could monitor those actions. Even if everyone did not scrupulously monitor access to and use of his or her genetic information, it is likely that public interest groups would bring instances of misuse to light and engender powerful normative forces inhibiting genetic discrimination.

Combining efforts aimed at educating policy makers and the public about the distinctions between genetic privacy and genetic discrimination with legislation allowing people to monitor access to their genetic information should empower those concerned about abuses of their genetic data to prevent such misuse. Establishing these normative forces would reduce genetic discrimination by employers, insurance carriers, and other groups that might otherwise be inclined to misuse genetic information.

CONCLUSION

People are both fascinated with and concerned about the ways that advances in biomedical research could shape their lives. It is imperative that physicians, scientists, and others use new insights into genetics to benefit the public by allowing the development of new disease prevention and treatment options, rather than hurt them by limiting access to health insurance or free choice of employment. Given the nature of DNA, the idea that an individual can maintain complete control over the way his or her genetic information is used is flawed. People need to better understand the limits inherent to genetic privacy so that they can make educated decisions about how to use that infor-

mation. It would be unfortunate if the children of people like Alan and Keri Bearder were denied the benefit of genetic tests such as newborn screening programs because of concerns, however well- or ill-placed, about the fate of the DNA sequence information needed for the tests.

As well as making comprehensive efforts to teach the public about genetic information and the ways it can be used and misused, it is important that genetic nondiscrimination measures be strengthened. A protective measure that needs to be developed is a mechanism to allow individuals to have access to their genetic “report cards” and to make sure they know who else has had access to their genetic information. Making the availability and use of genetic information more transparent will benefit everyone by reducing opportunities for misuse of genetic information and the possibility of genetic discrimination.

Efforts directed to the protection of genetic privacy at first glance seem uncontroversial. In trying to curtail access to genetic information in ways that are ineffective because of inherent limits to the extent that it is possible to control access to DNA sequence information and that work to prevent socially beneficial outcomes, genetic privacy protections may be ineffective or even harmful. Rather than concentrating attention on genetic privacy, directing efforts to the prevention of genetic discrimination will produce greater social good.