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Authentic Democracy: Endowing Citizens with a Human Right in Their Genetic Information

Richard Cole

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AUTHENTIC DEMOCRACY: ENDOWING CITIZENS WITH A HUMAN RIGHT IN THEIR GENETIC INFORMATION

Richard Cole*

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I. A POLICY-BASED ALTERNATIVE TO PRESENT AMERICAN LAW OF GENETIC INFORMATION PRIVACY

During the past generation American law has adopted what has been called a market approach to the question of who controls personal genetic information. But it is not a regime of \textit{laissez-faire}. Instead, it entails lawmaking whose goal is to maximize public interests, which are increasingly equated with market efficiency. In the concrete, lawmakers typically associate the public interest with generating and making available the maximum amount of information, for medical researchers, prospective employers and insurers, for governmental agencies, and others. This view tends to see genetic information as a commodity, and leads to the limited and sectoral protection that American law provides for personal genetic information.

Although contemporary American law concerning the control and uses of genetic information is the product of the Information Age, the human quest for empowering information is not new. It is as old as the
Tree of Knowledge in the Garden. Even after the Fall the quest for information that would transform the human condition retained allure for humankind. For millennia, humans have clung to the hope that they can reclaim power and immortality in an earthly utopia. Genetic science, which began during the last half of the nineteenth century, stimulated this hope. That quest for an enhanced humanity, however, ended with a eugenically-justified human catastrophe during World War II. Nevertheless, the early completion of the Human Genome Project, ("HGP") believed to provide a basis for understanding human life at its most elemental physical level, has rekindled the vision of advancing human power in an earthly utopia through genetic science.

2. Genesis 3:1-6 (King James).
4. There are evidences of human awareness of influences that we now attribute to genetics predating modern science. They include ancient Hebraic law's waiver of the requirement of circumcision for a male infant if his brother or maternal uncle bled excessively. The eighteenth-century French physician Maupertuis recognized that polydactyly (having more than five fingers) was passed through generations within families.

The origin of the modern science of genetics, however, can be conveniently fixed in 1859. Based upon experiments with successive generations of peas, in that year the Austrian monk Gregor Mendel, published Experiments in Plant Hybridization, in CLASSIC PAPERS IN GENETICS I (J. Peters ed., 1959). Mendel's work, however, did not receive widespread scientific recognition until the early twentieth century. Also in that year, Charles Darwin published THE ORIGIN OF SPECIES (1859). By the mid-1860s Darwin's cousin, Francis Galton, had adapted Darwin's evolutionary principle of survival of the fittest to human reproduction. This became known as the science of eugenics. Galton defined the new science as a discipline "which deals with all influences that improve the inborn qualities of a race." Eugenics: Its Definition, Scope, and Aims, 10 AM. J. SOCIOLOGY 1 (1904). By the late nineteenth century, eugenics became a recognized science with major political implications.

5. During the first half of the twentieth century, the eugenics movement aggressively sought to raise humanity to a higher level by cleansing the human gene pool. The movement was strong in the United States, and throughout the Western world, attracting adherents from all ideological stripes. Rather than enhancing human life, however, the eugenics movement culminated with German Nazism's extermination of groups of people it considered to be genetically inferior. See generally DIANE B. PAUL, CONTROLLING HUMAN HEREDITY: 1865 TO THE PRESENT (1995).


7. On June 26, 2000, when several leading scientists convened at the White House to announce the completion of the HGP, President Clinton observed: "Today, we are learning the language in which God created life." Press Release, The White House Office of the Press Secretary, Remarks Made on the Completion of the First Survey of the Entire Human Genome Project (June 26, 2000), available at http://www.genome.gov/10001356. James Watson, who oversaw the HGP,
As elaborated in Part II.A, advances in human knowledge concerning genetics have inexorably led to a limited, sectoral legal protection of individual control of personal genetic information. This result reflects the fact that lawmakers, some consciously, others without thought, have come to view personal genetic information as a commodity. This approach is based upon the view that personal control of genetic information is an individual value, devoid of social worth. Not only that, lawmakers typically view personal control of genetic information to be in conflict with important social values, most notably public health interests and market efficiency. The effect of this combination of views is that lawmakers favor third-party uses of genetic information, even when forced and sometimes surreptitious, to foster higher and more valuable social interests. American privacy law, based upon common law or constitutional law sources, and even in recent federal and state legislation, provides little real legal control to citizens over their personal genetic information.

Part II.B describes the ideology that shapes and justifies the limited and sectoral protection that American law affords citizens over their personal genetic information. This ideology is traceable to several phases of the Enlightenment. From the Moderate Enlightenment, American law has adopted the classic liberal vision of humans living in

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9. This view has led some to characterize the “cult of privacy” as pathological. See, e.g., H. W. Amdt, *The Cult of Privacy*, 21 AUSTL. Q. 68, 70-71 (1949).

10. This way of thinking is well-described in PRISCILLA M. REGAN, LEGISLATING PRIVACY: TECHNOLOGY, SOCIAL VALUES, AND PUBLIC POLICY 24-42, 212-45 (1995).

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an atomistic society. In it, people pursue their own interests, and they enjoy the liberty to think and act without outside constraints. This version of human liberty envisions a limited role for law in society. It acts solely as a shield protecting individuals from outside interferences so that they can exercise a wide sphere of free thought and action.

Nevertheless, contemporary American law concerning personal genetic information is not laissez-faire because it also draws heavily from the utilitarianism of the Radical Enlightenment. The goal of the utilitarian calculus is to maximize the aggregate public good. This calculus demands regulating individual interests, conceived of as private, for the public good. Therefore, unlike classic liberalism, utilitarianism embraces lawmaking (though its goal in contemporary American lawmaking is often to foster an efficient market).

In contrast to American law's commodification of personal genetic information, the law of the European Union (hereinafter "EU"), endows citizens with a human right in their personal genetic information. As described in Part III, it therefore provides a comprehensive protection, with some important limitations, for personal control of genetic information. For several reasons, scholars have already predicted that American law will someday adopt a position more protective of information privacy, similar to that of EU law. Of particular significance is the view that American law will adopt the EU's approach because that will be necessary to maintain the smooth operation of a growing international information market. Though this constitutes a valuable insight concerning instrumental realities, it can as easily be used as a basis for America to pressure the EU to reduce its level of protection of personal control of genetic information.

Instead, Part IV, the culminating section of the paper, elaborates a policy basis for American lawmakers to endow citizens with a human right in their genetic information. This proposal begins with the perception, elaborated in Part IV.A, that citizens of modernized societies

13. One view is that the present American law of information privacy is a way-station, a phase of an evolutionary process that will inevitably lead to greater legal protection of personal information privacy. See Gregory Shaffer, Globalization and Social Protection: The Impact of EU and International Rules in the Ratcheting Up of U.S. Privacy Standards, 25 YALE J. INT'L L. 1, 80 (2000).
are peculiarly weak and vulnerable to harm from powerful outside forces. In existing literature their vulnerability is typically attributed to scientific and technological developments.\textsuperscript{15} Scientific knowledge of human genetic information is increasing rapidly, and scientists can easily obtain the genetic information of individuals from blood samples or even a lock of hair. The development of computer technology allows the storage of huge swaths of genetic data, and more recent internet technology facilitates its instantaneous transfer to anywhere in the world.

It should not be forgotten, however, that these developments of science and technology are part of a larger and historically much older process of modernization that has in a number of important ways rendered individuals weak and vulnerable. The most important of these is by separating them from traditional communities and communal bonds. Also of importance is the rise of powerful nation states during the early modern period, and then much later, attendant to the Industrial Revolution, the rise of efficient governmental bureaucracies. The Industrial Revolution also spawned "private" corporate entities wielding unprecedented power in efficient ways over weak and isolated individuals and groups. The holocaust during World War II provides an ominous historical warning of what can happen to groups stigmatized based upon their genetic makeup. Whatever the amount of power that the Nazi regime could wield in Germany, the development of modern technology exponentially enhances the efficiency and power of both governmental bureaucracies and corporate enterprises relative to persons and groups in the contemporary world.\textsuperscript{16}

The cumulative impact of all of these forces is to make it important for contemporary law to empower citizens so that they can begin to regain some of their lost independence. One of the important ways that law can do this is to endow citizens with a human right in their genetic information. This is because of the special history and public perceptions of genetic information. Admittedly there are other forms of sensitive medical information.\textsuperscript{17} It is also difficult to isolate genetic information

\textsuperscript{15} This parallels the original basis for the formation of the American law of privacy based upon the landmark law review article by Samuel D. Warren and Louis D. Brandeis, \textit{The Right to Privacy}, 4 HARV. L. REV. 193 (1890). Their article constituted a reaction to intrusions upon privacy by recent developments in photography and communications. See generally \textit{id.}

\textsuperscript{16} These various strands of human history suggest rejecting the view that a reduction of personal control over one's genetic information would lessen human vulnerability. See also Richard A. Wasserstrom, \textit{Privacy: Some Arguments and Assumptions}, in PHILOSOPHICAL LAW: AUTHORITY, EQUALITY, ADJUDICATION, PRIVACY (Richard Bronaugh ed., 1978).

\textsuperscript{17} One example is a blood sample.
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from some other forms of human materials. Nor is all genetic information highly informative and sensitive. Nevertheless, it remains indisputable that the history of use of genetic information is exceptional. The dreadful history of the eugenics movement in western civilization during the first half of the twentieth century creates a cultural context that lawmakers can only ignore at their peril. Further, the public, and many scientists, entertain peculiarly high expectations for the potential contributions of genetic engineering to human health and capabilities. A related public perception, of great significance for this paper, is the view that people are genetically hard-wired. Though we are learning increasingly that this is not the case, the public perception is a reality

18. This is because of the immaterial nature of genes. Genes are not DNA molecules. DNA molecules are based upon what one’s mother ate while she was pregnant, and what one eats after birth. See Lee M. Silver, The Meaning of Genes and “Genetic Rights,” 40 JURIMETRICS J. 9, 11 (1999). In contrast, a “gene is a[n immaterial] packet of information encoded within the DNA molecule.” Id. Professor Silver compares the nature of genes to the configuration of computers: Just as the magnetic surface of a disk can act as the storage medium for a computer file, the DNA molecule acts as the storage medium for a genetic file, or gene. And, just as a file can be transferred from one magnetic disk to another without the actual exchange of matter, so a gene can be copied from one DNA molecule to another, even as the new DNA molecule is built up entirely from raw materials—brand new atoms, “pulled out of the air.” Id.

Further, there is no reason in the practice of medicine or medical research to make a clear distinction between genetic and non-genetic materials. For centuries, doctors have made use of genetic data, without recognizing it as such, by paying attention to family health histories in treating patients. In scientific medical research, often genetic and non-genetic materials are mixed together into the biological sample, which is the basic unit for such research. See Henriette D.C. Roscam Abbing, Introduction, UNESCO’s International Declaration of Human Rights, II EUR. J. OF HEALTH L. 93 (2004).

19. Over 99% of genetic materials are shared by homo sapiens. See Silver, supra note 18, at 13. Further, in the less than 1% of genetic information that is not universally shared, the differences in individual genes are very small. See id. These alterations are called alleles, and they typically vary only slightly from the usual gene, as by a single unit called a base (analogous to a bit, among hundreds of thousands of bytes, in a computer). See id. Given the size of the human population, it is unlikely that any single human being has a unique allele. See id. It is rather unique combinations of alleles that help to explain differences among persons. See id. It is true, however, that the small variations in human genes can sometimes have dramatic consequences for human health. See id.

20. This recalls the old maxim that those who ignore history are doomed to repeat its failures (and tragedies).

21. See supra notes 6, 8 and accompanying text.

22. An interesting anecdote illustrating how genetic determinism has penetrated popular culture is given by Professor Silver. In 1996 he heard the following conversation among friends in the tiny village of Zonza, isolated between mountain ranges in the middle of the island of Corsica in the Mediterranean Sea. One man was making the others laugh with his stories, and a woman in the group asked how it was that he was so funny. He instantly replied, “C’est genetique!” See Silver, supra note 18, at 10.

23. Science has been accumulating data suggesting that the linkages between genetics and diseases, for example, vary greatly. Alzheimer’s disease is interesting as an example. A small
that can, and has, lead to the stigmatization of individuals and ethnic groups.

The view that human beings are genetically hard-wired suggests another reason why it is important today to endow citizens with a human right in their genetic information. Based upon the experience of World War II, state-based eugenics is out of favor in most parts of the world today. Nevertheless, Part IV.A notes that private eugenic efforts, with little notice, have resurfaced, exerting pressures upon women and couples in making decisions concerning reproduction, as well as raising again the possibility of stigmatizing individuals and groups.24

Part IV.B concludes this Article by turning to home-grown ideological sources, alternative to those that presently shape America’s law of genetic information privacy, that provide a justification for lawmakers to endow citizens with a human right in their genetic information. These sources include: the founding fathers, most especially the thinking of Thomas Jefferson and his concern for the wide availability of land to all citizens; the Romantic reform movement of the Jacksonian period of American history, especially Horace Mann’s advocacy for universal public education; and finally, Progressive thought and the jurisprudence of Legal Realism that continued to support the availability of public education, as well as a new approach to contract law and governmental welfare benefits.

All of these thinkers were concerned with a loss of human independence. All of them also firmly believed that in modernizing communities human empowerment was necessary to resurrect the independence and dignity of each and every citizen. The independence of citizens was essential not only for individuals to realize their unique human potential, but also because an independent and diverse citizenry was the irreplaceable cornerstone of genuinely democratic communities.

number of persons who contract this disease, less than 1%, have genetic mutations that make it almost certain that they will contract the disease. Almost one-half of the persons who contract Alzheimer’s have a genetic predisposition that raises their vulnerability to contracting it by from 30% to 60% percent. But many people who suffer from Alzheimer’s have no known genetic basis for their disease. Thus, “Alzheimer’s disease is a strongly genetic, weakly genetic, and apparently non-genetic disease—all at the same time.” Henry T. Greely, Iceland’s Plan for Genomics Research: Facts and Implications, 40 JURIMETRICS J. 153, 156 (2000) (relying upon results published by Sara L. Tobin et al., The Genetics of Alzheimer Disease and the Application of Molecular Tests, 3 GENETIC TESTING 37 (1999)). Further, recent scientific research suggests that environmental factors far outweigh genetics as a causative force in people who are afflicted with cancer (suggesting that genetics is a significant causative element in only about 5% of cancer cases). See David L. Eaton, Scientific Judgment and Toxic Torts—A Primer in Toxicology for Judges and Lawyers, 12 J.L. & Pol’y 5, 23-29 (2003).

24. See DUSTER, supra note 8, at 37-57.
In contrast to present American lawmaking, the thrust of this ideology would be to view endowing citizens with a human right in their genetic information to constitute not only an individual value, but also a social value of inestimable worth.

II. HOW AMERICAN LAW AND LEGAL IDEOLOGY COMMODIFY GENETIC INFORMATION

A. American Law’s Limited and Sectoral Protection of Genetic Information Privacy

1. The Development of American Law and Medical Ethics

American law did not always view genetic information as a commodity. To the contrary, both traditional law and medical ethics strongly discouraged disclosures of all personal health information, including genetic information. This section will trace how American law, and medical ethics evolved to a position encouraging disclosures, even sometimes surreptitiously or without consent, of personal genetic information.

The oldest surviving example of information privacy in Western civilization is the physicians’ duty of confidentiality concerning everything they learned about their patients. This duty was formulated in the fifth century B.C. by the Hippocratic Oath, and its influence continued to prevail among physicians of the Western world into the modern period.25 The physicians’ duty of confidentiality was so strict that it seemed to conceive of a patient’s medical information as part of the person. During the latter eighteenth century English courts of common law imposed a duty of confidentiality upon doctors concerning information they learned about their patients.26

The duty of confidentiality that doctors owed to their patients was consistent with a personal service model of medicine. Pursuant to it,

25. By affirming the Hippocratic Oath the physician promised: “[W]hatsoever I shall see or hear in the course of my profession, as well as outside my profession in my intercourse with men, if it be what should not be published abroad, I will never divulge, holding such things shameful to be holy secret.” Robert M. Gellman, Prescribing Privacy: The Uncertain Role of the Physician in the Protection of Patient Privacy, 62 N.C. L. REV. 255, 267-68 (1984) (quoting 1 HIPPOCRATES 164-65 (W. Jones trans. 1923), reprinted in ETHICS IN MEDICINE 5 (S. Reiser et al. eds., 1977)).

doctors were to focus their efforts upon the care of their patients without regard for public health concerns.\(^2\) The personal service model of medical care converged with basic principles of classical common law that would fundamentally shape what would become tort and contract law. It held that persons who do not voluntarily take on duties to other persons, including to warn them of harms, by entering into contract privity had no legal duty to protect them from harm.\(^2\) The common law’s no-affirmative-duty principle was reinforced during the nineteenth century by a radical individualism that viewed contract as the almost exclusive way that persons took on legal duties to one another.\(^2\) All of these themes of common law reinforced the physician’s duty, now legal as well as ethical, to maintain the confidentiality of all medical information.

During the twentieth century, this framework of traditional law and medical ethics, though not dismantled, nevertheless experienced substantial alteration. To Progressive thinkers, protecting public health interests became imperative in the now highly industrialized and urbanized American society in which many people lived crowded together. The primary methodology for protecting public health was what became known as public health utilitarianism. A fundamental characteristic of utilitarian analysis is an uncompromising consequentialism, or teleology (telos means end). The utilitarian calculus seeks to maximize the balance of values over disvalues relative to desired public ends.\(^3\) Since one of the goals of Progressive lawmakers was to maximize public health interests, they now began to require disclosures, even when they might be involuntary, of medical information that would assist public health officials in preventing the spread of diseases.\(^3\)

\(^2\) See BUCHANAN ET AL., supra note 8, at 1-26.
\(^2\) See RESTATEMENT (SECOND) OF TORTS § 314 (1965).
\(^2\) Many works could be cited for this proposition, but perhaps the most useful, even though it addresses English rather than American legal history, is P.S. ATIYAH, THE RISE AND FALL OF FREEDOM OF CONTRACT 226, 256 (1979).

It was also consistent with traditional common law’s lawmaking process, which, at least in theory, focused upon the interests of parties involved in particular cases without any regard for larger concerns of public policy. An interesting latter-day articulation of this approach to lawmaking, though its decision deviates from the stated theory, is by the New York Court of Appeals. See Boomer v. Atl. Cement Co., 257 N.E.2d 870, 877 (1970).

\(^3\) See BUCHANAN ET AL., supra note 8, at 11. Excellent reviews of utilitarian philosophy are found in BEAUCHAMP & WALTERS, supra note 12; UTILITARIANISM AND BEYOND (Amartya Sen & Bernard Williams eds., 1982).

\(^3\) See Skillings v. Allen, 173 N.W. 663, 664 (Minn. 1919). Later examples of courts addressing the applicability of the duty to warn family members of infectious diseases include
Reflecting the influence of public health utilitarianism, by the early twentieth century formulations of the Code of Ethics published by the American Medical Association began to carve out exceptions to the traditional strict duty of physician confidentiality of the Hippocratic Oath.\textsuperscript{32} Twentieth-Century law, both statutory and common law, traveled a parallel course with medical ethics. Courts, influenced by public health utilitarianism, began to impose a duty upon doctors and other health officials to warn the public of contagious diseases. Over the course of the twentieth century, state legislatures passed an array of public health statutes that required health care providers to disclose a variety of maladies, notably including infectious diseases and a number of sexually transmitted diseases.\textsuperscript{33}

Even today, the no-affirmative-duty rule remains as a general principle of the common law, it came under sharp criticism from legal scholars as justifying "morally outrageous and indefensible conduct."\textsuperscript{34}
Reflecting the impact of such criticism during the last forty years of the twentieth century, courts began to recognize affirmative legal duties owed to certain classes of persons not in contract privity. One of these classes of persons upon whom law has imposed duties to warn of dangers are those who had a "special relation" with either endangered persons or to third parties who might be harmed by persons under their control. Developing law also imposed a duty to warn upon persons who undertook "services to another which he should recognize as necessary for the protection of a third person," and who could suffer harm "because of the reliance of the other . . . or of the third person himself, upon his undertaking."

Utilitarian analysis has been important in both shaping and justifying the new legal duties to warn. This is illustrated by a series of cases decided by the California Supreme Court that became landmarks in developing this new structure of the law of tort duty. In its weighing of factors to determine whether to find a duty to warn, the California Supreme Court continued to consider traditional and individualistic moral considerations. But the influence of utilitarianism was also clear when the court explicitly considered the "consequences to the community of imposing a duty" as one of its factors.

The most famous duty to warn decision of the California Supreme Court was delivered in 1976 in *Tarasoff v. Regents of The University of California*. The court held that a psychiatrist had a legal duty to warn the former girlfriend of a patient who expressed to the doctor an intent to kill her. The court deduced the legal duty to warn the former girlfriend from the special relationship the doctor had with his patient. Judge Tobringer's opinion in *Tarasoff* also explicitly linked the finding of an

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35. *Restatement (Second) of Torts* § 315 (1965). Section 315 establishes an affirmative duty owing to persons outside of contract privity who are threatened with physical harms and who have special relationships with the party having the duty to warn family members of their patients. Subsection (b) extends the duty to warn when, "a special relation exists between the actor and the other which gives to the other a right to protection." *Id.*

36. *Id. at* § 324A and cmt. e (emphasis added).

37. For example, in drawing the scope of duty, judges were to consider "the moral blame attached to the defendant's conduct." *Rowland v. Christian*, 443 P.2d 561, 564 (Cal. 1968).

38. *Id.* The traditional foreseeability of harm test for defining scope of duty, which continues to be important today, can encompass both individual and public concerns.

affirmative tort duty to warn upon a utilitarian calculus protective of public safety. He observed:

Our current crowded and computerized society compels the interdependence of its members. In this risk-infested society we can hardly tolerate the further exposure to danger that would result from a concealed knowledge of the therapist that his patient was lethal.40

This framework of legal analysis has been applied by a number of recent decisions to impose a duty upon doctors to warn family members of dangers based upon knowledge they gained from treating patients. An important example is a Tennessee decision in 1993. Citing infectious disease cases, section 315 of the Restatement (Second) of Torts (1965), and Tarasoff as precedents, the court required a doctor, when a patient died of Rocky Mountain Spotted Fever, to warn family members of this danger because the insects that cause this disease cluster.41

Several recent cases also impose legal duties upon doctors to disclose genetic defects they discover while treating patients. In 1996, a New Jersey court imposed upon a doctor a duty to warn the child of his patient of her father’s genetic predisposition.42 Between 1956-1964 the defendant, Dr. Pack, treated the plaintiff’s father for colon cancer. The plaintiff, Donna Safer, contracted the same disease in 1990. Her multiple polyposis required that she undergo extensive medical treatment.43 In 1991, Mrs. Safer obtained her father’s medical records, and based upon them she filed a negligence claim against the estate of the now-deceased Dr. Pack. It alleged that because her father’s condition was hereditary, and it becomes metastatic colon-rectal cancer if left untreated, Dr. Pack had a duty to warn Safer concerning her genetic predisposition. Early warning would have allowed for timely monitoring and treatment of her cancer. The trial court rendered summary judgment for the defendant. But the Superior Court, in an opinion written by Judge Kestin, reversed, and in remanding the case for retrial suggested that there were cases in which doctors have a duty to warn family and relatives of their patients’ genetic predispositions. The trial court judge in Safer had distinguished cases of genetic defects from those where doctors have a duty to warn of contagious diseases. From a public health perspective, however, Judge

40. Id. at 347.
41. See Bradshaw v. Daniel, 854 S.W.2d 865, 871 (Tenn. 1993). One of the infectious disease cases cited by the court was Wojcik v. Aluminum Co. of Am., 183 N.Y.S.2d 351 (N.Y. Sup. Ct. 1959).
43. She had to undergo a total abdominal colectomy with ileorectal anastamosis. She then had to have her left ovary removed, and undergo chemotherapy. See id. at 1190.
Kestin analogized the cases, observing that both groups at risk (of contagious or genetic diseases) are easily identifiable, and in both cases substantial harms can be averted by timely warning and monitoring of the dangers they pose.44

Another notable case concerning a doctor’s duty to warn their patients of genetic defects is the Florida Supreme Court’s decision in Pate v. Threlkel.45 Decided in 1995, just one year before the New Jersey Superior Court’s decision in Safer, its fact pattern and legal issue are exactly the same as in that case. In language that resonates of the legal analysis of the California Supreme Court in Tarasoff, the Florida court held that a doctor has a duty to warn of the genetic defect, though it suggested that the duty could be fulfilled by warning the patient.46

As a lot, the genetic defect cases, as well as the Rocky Mountain Spotted Fever case, all seem to rely upon the concept of special relationship as a basis for imposing upon a physician a duty to warn. There are also cases, notably involving contagious diseases, in which courts adopt the concept of reliance, as articulated in section 324A of the Restatement (Second) of Torts (1965), as the basis for imposing a duty to warn.47

The preeminent example, however, of how the utilitarian calculus has led recent American lawmakers to commodify personal genetic information is the decision of the California Supreme Court in Moore v. Regents of the University of California.48 The defendant, Dr. David Golde, diagnosed Moore, the plaintiff, as suffering from hairy-cell leukemia, and he recommended the extraction of Moore’s spleen. Dr. Golde had Moore come back periodically, presumably for monitoring of his health, at which times he extracted blood serum, bone marrow aspirate, sperm, and other bodily materials from him. Covertly, Dr. Golde and an associate, Dr. Shirley Quan, were working on Moore’s body parts to patent a cell line. When Moore discovered the deception he filed a lawsuit alleging a bevy of claims seeking to recover royalties for

44. Judge Kestin cited Tarasoff and sections 314 and 314A of the Restatement (Second) of Torts, as legal precedents for his decision. See id. at 1192. To my knowledge, Judge Kestin’s ruling was never implemented. The case was tied up in the New Jersey courts for a number of years in litigation over procedural issues, and also limited by later New Jersey legislation.
45. 661 So. 2d 278 (Fla. 1995).
46. See id. at 280, 282.
47. For example, in DiMarco v. Lynch Homes–Chester County, Inc., the court found that when a doctor treated a person possibly infected with hepatitis, the doctor had a duty to warn her that she could transfer the virus through sexual contact. See 583 A.2d 422, 423-24 (Pa. 1990); see also Reisner v. Regents of the Univ. of Cal., 37 Cal. Rptr. 2d 518, 523 (Cal. Ct. App. 1995) (requiring a doctor to inform a patient of the dangers posed by the HIV virus).
the use of his genetic information and bodily substances. In granting a recovery the California Court of Appeals in Judge Rothman's majority opinion, upheld Moore's conversion claim. But on appeal, the California Supreme Court dismissed most of his actions, including the conversion claim. The opinion of the Supreme Court, as well as Judge George's dissent to the Court of Appeals decision, are models of utilitarian analysis. They find the value to human health of the patented cell line to the public, as well as its commercial value, to outweigh the violation of Moore's personal autonomy (by fraudulent means).

The utilitarian analysis employed by the California courts in the Moore cases seeks to meld public health interests with maximizing market efficiency in connection with the developing and marketing of a new and very lucrative medical product.

A clearer example of the commodification of genetic information is provided by the agreement that the government of Iceland consummated with a private scientific research corporation, DeCode Genetics. In 2000, DeCode negotiated a twelve-year license from the government of Iceland for what is called the Islandic Health Care Database. The Database includes: extensive genotypes; genealogical information for the past three centuries; and an array of information on the health and diseases of the persons whose genetic and genealogical information is included. DeCode is using this information to develop new treatments for diseases, and it has already made some very lucrative contracts with pharmaceutical companies for these anticipated products. Icelanders who wish not to be part of this Database must file a form to opt out of it.

The emphasis of contemporary law on market efficiency has led some scholars, as well as some leaders of the business community, to call for a return to contract as the way to determine the control and uses of all personal information, including genetic information. The contract approach has already had some application to the international flow of personal information.

50. For example, Judge George stated that "the vital competing interests of the patient, the health care provider, the commercial research laboratory, and the public at large" balanced out in favor of denying protection for a property interest in a "human bodily substance for research and commercial use." Id. at 540.
51. The cell line that Drs. Gould and Quan patented would have an estimated worth of three billion dollars. See Michael M.J. Lin, Conferring a Federal Property Right in Genetic Material: Stepping into the Future with the Genetic Privacy Act, 22 AM. J.L. & MED. 109, 113 (1996).
52. See Greely, supra note 23, at 162-69.
53. For an example of this proposal in academic literature, see Steven A. Bibas, A Contractual Approach to Data Privacy, 17 HARV. J.L. & PUB. POL'Y 591, 605-11 (1994). Gregory Shaffer discusses the growing support for this approach, especially with regard to the international flow of personal information. See Shaffer, supra note 13.
personal information, and if it is to be used at all, it seems best suited to that environment.  

By the mid-1990s, then, a substantial body of statutory and case law permitted or required involuntary disclosures and appropriations of personal genetic information. But just as this body of law was cresting a counter-wave of legislation, both federal and state, intended to limit disclosures of personal health information, including genetic information, began to form.

2. The Recent Wave of Health Information Privacy Legislation

Beginning during the mid-1990s there emerged a wave of lawmaking emphasizing personal control of health, and especially genetic, information. Some recent state and federal court decisions have held disclosures of medical information to breach the physician’s or health care institution’s duty of confidentiality, or the patient’s federal or state constitutional right of privacy. But by far the most important legal source protecting personal control of genetic information in contemporary American law is statutory law, both federal and state.

54. See generally Shaffer, supra note 13. In domestic law, the contract approach would disadvantage poor persons with weak bargaining power. In the international setting, governmental and corporate entities are the parties to these contracts. It should not be forgotten, however, that these international contracts often involve the personal information of everyday citizens.


57. Two recent cases rely upon constitutional provisions that relate to personal privacy rights to provide some limitations upon non-consensual testing for, and then use or dissemination of, personal medical information. See Hill v. Evans, No. 91-A-626-N, 1993 U.S. Dist. LEXIS 19878, at *30-43 (M.D. Ala. Oct. 7, 1993) (relying upon the Fourth Amendment’s prohibition upon illegal searches and seizures to afford some protection against non-consensual testing for HIV although finding testing pursuant to implied consent reasonable under a special needs analysis due to the need to protect health care personnel); see also Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260, 1269-70 (9th Cir. 1998) (limiting an employer’s testing of employees for various diseases, including sickle-cell anemia and venereal diseases, as well as for pregnancy, based upon federal constitutional search and seizure and the Fourteenth Amendment due process rights associated with personal privacy, as well as a state constitutional privacy right). The Ninth Circuit’s opinion, however, explicitly recognized a balancing of employer’s and its employees’ interests in defining the scope of the employees’ privacy rights. See id.
Occasionally statutes will confer a property right upon persons in their genetic information, but most endow persons with a privacy right.

In 1996 Congress adopted the Health Insurance Portability and Accountability Act ("HIPAA"). Both HIPAA, and a Health and Human Service ("HHS") regulation concerning the privacy of medical information published pursuant to it in 2000 restrict disclosure of "protected health information," including genetic information. The law broadly covers health care providers. The general structure of HIPAA and its HHS regulations also favor the privacy of medical information. They prohibit the disclosure of medical information unless the law specifically allows for it, and permits disclosures only of the minimum necessary information.

Nevertheless, five major features of HIPAA demonstrate that it affords little real legal protection against the non-consensual acquisition and dissemination of genetic information. First, health information privacy is just one, and not the main, purpose of HIPAA. Indeed, one of the primary goals of HIPAA, to mandate the collection and storing of all medical information electronically, facilitates the ready circulation of medical information. Second, though the original HHS regulation required that health care providers obtain written consent from patients before disseminating medical information gathered for the purposes of treating or billing them, the general rule of the present HHS regulation is that health care providers do not have to obtain a patient’s consent for uses and disclosures of information related to treatment, payment, and health care operations. Third, HIPAA does not address the issue of the non-consensual collection of medical information at all. Fourth, HIPAA does not cover all medical websites, nor does it cover medical

58. Pub. L. No. 104-191, 110 Stat. 1936 (codified as 29 U.S.C. § 1181 (1996)). It includes genetic testing, family medical history, and genetic counseling, but it does not cover blood or tissue from which genetic information is derived. See id.

59. It includes doctors, hospitals, clinics, pharmacies, all sorts of health and insurance plans, health maintenance organizations, and health care clearinghouses. Many websites that provide medical care are operated by one of these organizations. However, websites not operated by one of these organizations will not be covered by HIPAA unless they electronically transmit health information. See id.

60. See 45 C.F.R. § 164.506(a) (2003), which makes obtaining consent optional. Section 164.508 lists instances in which health care providers must obtain authorization for various uses and disclosures of personal medical information. See id. Senator Kennedy has vowed to introduce legislation reinstating the original HHS requirement of written consent for the disclosure of this information. See supra note 58.

61. Some federal law does protect against the non-consensual collection of medical information but only in the employment setting. See Norman-Bloodsaw, 135 F.3d 1260. But as already noted, it does not afford prospective employees absolute rights, and it does not explicitly mention genetic information.
information once it is in the hands of those other than health care providers. Finally, although HIPAA allows patients to access their medical records, and to trace who else has had access to them, it does not provide a private right of action for breaches of its privacy provisions.

Congress continues to be interested in health information privacy. Since the adoption of HIPAA, numerous health privacy bills have been introduced for congressional consideration. While many of these bills focus upon disclosures of medical information to insurance companies and employers, some have a broader scope. The Genetic Privacy Act provides for an elaborate procedure assuring that only those who obtain consent can have access to a person’s genetic information. But none of these proposals have been enacted, and the ultimate result of congressional consideration of the privacy of health information remains conjectural.

Congress intended HIPAA merely to set a floor of medical information privacy, and thus to allow states to pass more rigorous privacy laws. Since the mid-1990s, legislatures in about half of America’s states have passed statutes restricting the dissemination of genetic information. This body of state statutes presently constitutes the most important source of American law protecting personal control of health information. As with Congress, state legislatures are constantly reviewing proposals for regulating the control of personal health information, and much of it concerns genetic information.

62. In the year following the adoption of HIPAA, in the 105th Congress, five health privacy bills were introduced for Congress to consider. In the 106th Congress alone nine bills were introduced dealing exclusively with health information privacy. Eight other bills introduced in that Congress had provisions relating to health information privacy. See The Health Privacy Project, http://www.healthprivacy.org. These bills have both Republican and Democratic sponsors. See id.


65. Congress did not meet its 1999 deadline for the passage of further health information privacy legislation. See PRITTS ET AL., supra note 55.

66. Some states have passed statutes aimed at building upon HIPAA. See, e.g., TEX. HEALTH & SAFETY CODE ANN. § 181 (2004).

67. See PRITTS ET AL., supra note 55.
Themes of the new law protecting personal control of personal health information are not easy to synthesize. The body of potentially relevant state legislation is growing rapidly, and is diffused. In addition to statutes explicitly considering control of genetic information, there are, for example, some medical licensing statutes that address the issue. There is a regional flavor to health privacy statutes, the legislatures of southern states having adopted a disproportionate number of them. Nevertheless, these health care privacy statutes are widespread geographically. For example, New Jersey published one that limits the impact of the Safer decision. Rhode Island, Wisconsin, and California have published the most encompassing statutes regulating the privacy of personal medical information, including genetic information.

Despite the wide variations in state statutes protecting personal control of health information, a number of general themes emerge concerning their regulation of the dissemination of genetic information. First, a privacy right is the predominant justification offered by these statutes for restricting disclosures of genetic information. Next, while many of these statutes concern the disclosure of health, and especially genetic, information to insurance companies or employers, some contain

68. The most thorough study of state privacy laws concludes: Law relating to health privacy can be found in nearly every nook and cranny of a state's statutes [and] in obvious and obscure sections of a state's code, buried in regulations, developed in case law, and detailed in licensing rules. Florida, for example, has more than 60 statutes that address health privacy, and it is not unique. Id. at 8. Massachusetts departs from this norm in conferring upon citizens a general "right against [an] unreasonable, substantial or serious interference" with their privacy. MASS. GEN. LAWS ch. 214, § 1B (2005). But even it has a number of statutes that relate to specific medical health information issues.

69. One example is licensing legislation that punishes health care providers who non-consensually disseminate medical information. Florida law mandates that health care providers who violate privacy provisions shall be disciplined by appropriate licensing authorities. See FLA. STAT. ANN. § 456.057(14) (West 2005) (formerly § 445.667).

70. For example, Georgia provides heightened protection to genetic information whereas it may be released only to the persons tested and only to others with the consent of the tested persons. See GA. CODE ANN. § 33-54-3 (2004). Maryland has a similar law. See MD. CODE ANN. INS. § 27-909 (2004). South Carolina’s statute declares that all genetic information is confidential and, except for a few cases, can only be disclosed with the written consent of the patient. See S.C. CODE ANN. § 38-93-30 (West 2004).


73. For example, both Georgia’s and Colorado’s statutes succinctly state that one of their purposes is “[t]o protect individual privacy and to preserve individual autonomy.” COLO. REV. STAT. § 10-3-1104.7(c) (2004); GA. CODE ANN. § 35-54-11 (2004) (formerly § 33-54-1).
language broad enough to prohibit the non-consensual dissemination of genetic information to family and relatives. Whatever the scope of such statutes, almost all of them provide for numerous exceptions to their general rule of personal control over genetic information. For example, the focus of this legislation continues to be the uses and disseminations of personal health information, not upon its collection. Even the regulation of the dissemination of personal health information is often incomplete, for many of the statutes only concern the first disclosure of the information, and do not regulate its further distribution. The remedies for violations of medical information privacy in these statutes also vary.

The most important characteristic of this recent wave of law is that it is fragmented and sectoral. The Georgetown University study tracking the development of this law concluded that "with a few notable exceptions," recent state statutes "do not extend comprehensive protection to people's medical records." More pointedly, Lori B. Andrews observed "it is shocking how little protection exists for private medical information." As we will now see, neither American common law nor constitutional law of privacy measurably ameliorates the limited and sectoral protection that American law affords to control over personal genetic information.

3. Common and Constitutional Law and Genetic Information Privacy

The limitations of the recent wave of health privacy legislation are not cured by existing privacy law in America, in either its common law or constitutional forms. Like the recent statute law, common law affords sectoral protection to personal health information. For a number of reasons, federal constitutional law presently affords virtually no protection for personal control of genetic information, and the protection afforded it by state constitutional law varies.

74. See PRITTS ET AL., supra note 55, at 82.
75. Some provide for criminal sanctions. New Jersey provides for fines, imprisonment, or both for violations of health information privacy. N.J. STAT. ANN. § 10:5-49 (2005); see also OHIO REV. CODE ANN. §§ 3729.46 (repealed 2001), 3729.99, 2921.21 (West 2005). New Mexico provides for both the Attorney General and persons whose genetic information is violated to file civil claims. Victims may obtain both equitable remedies and damages, reasonable attorney fees, and court costs. For violations that are grossly negligent or willful, victims may recover up to $5,000 in addition to economic loss. N.M. STAT. ANN. § 24-21-6 (Michie 2004).
76. PRITTS ET AL., supra note 55, at 9.
As it has developed in the twentieth century, the common law does not protect a generalized privacy interest, but only four discreet privacy interests. Although these interests focus upon informational privacy, and arguably three of the four could be adapted to protect personal control of genetic information, no court has yet applied any of them to personal health information.

American federal constitutional law concerning personal privacy is circumscribed in a number of important ways. Of particular


79. This focus reflects the influence of Warren's and Brandeis's law review article, supra note 15, upon the development of the common law of privacy in American law. Though it is widely believed that Brandeis was the primary author of the article, the impulse to write the article came from Warren's smearing over what he considered to be intrusive publicity of his daughter's wedding. See Prosser, supra note 78, at 383.

80. These include the right against intrusion upon one's seclusion, public disclosure of embarrassing information, and publicity placing individuals in a false light.

81. In addition to the limitations in the general structure of the common law of privacy in America, there are several specific reasons of legal doctrine for this result. First, privacy violations require that the intruder act unreasonably. RESTATEMENT (SECOND) OF TORTS, § 652A(2) (1977). Further, in a notable Oregon decision the court held that an actionable invasion of one's seclusion requires an affirmative act of prying, not just a doctor disclosure of information in response to a request for it. See Humphers v. First Interstate Bank of Oregon, 696 P.2d 527, 532 (Or. 1985).

82. To begin, because of the privacy right's connections to substantive due process, the specter of Lochner v. New York, will forever hang over it. See 198 U.S. 45 (1905). For example, in Griswold v. Connecticut, Justice Douglas avoided using Lochner as precedent by grounding the privacy right in various provisions of the Bill of Rights rather than the Fourteenth Amendment. See 381 U.S. 479, 499 (1965). Next, though invasions of privacy trigger heightened constitutional scrutiny, in recent Court decisions state interests have frequently limited or outweighed privacy interests and justified their invasion. See Roe v. Wade, 410 U.S. 113, 165 (1973); see also Planned Parenthood of Southeastern Penn. v. Casey, 505 U.S. 833, 851-52 (1992); Cruzan v. Director, Mo. Dept. of Health, 497 U.S. 261, 270 (1990); Washington v. Glucksberg, 521 U.S. 702, 739-40 (1997). In addition, despite the equation of privacy rights with personal autonomy, as with the common law or privacy, a number of the justices view privacy as a set of discrete rights. At this time the band of constitutionally-protected privacy rights remains narrow. For example, in his concurring opinion in Casey, Justice Blackmun observed that Chief Justice Rehnquist views privacy as a "laundry list," rather than "a principled account" of rights "grounded on a more general right of privacy." 505 U.S. at 940. Finally, Chief Justice Rehnquist has articulated a historical test for determining what privacy rights are protected by the Constitution. One justification that Rehnquist proffered for his historical test is a preference for controversial questions of individual and community interests to be resolved by legislatures, not by the federal judiciary. See Glucksberg, 521 U.S. at 740. The latter preference is widely-shared by Rehnquist's judicial colleagues. See, e.g., id. at 736-38 (O'Connor, J., concurring); id. at 769-71 (Souter, J., concurring) (characterizing the historical test as a static approach to defining privacy rights that does not account for recent changes in popular values and practices) The Court has not shown any predisposition to join Justice Souter
significance is that violations of federal constitutional rights require establishing state action. Based upon its state action requirement, to employ the terminology of European legal scholars, American federal constitutional privacy law only addresses vertical intrusions upon privacy interests, by institutions or persons closely associated with government. It does not address horizontal intrusions upon them by so-called private actors at all. In spite of some stiff criticisms that the state action requirement has received from scholars, it remains vital. Indeed, in recent federal constitutional law jurisprudence, the trend is for courts to apply it with increasing rigor.83

Of great importance, and in contrast to the common law of privacy, the development of constitutional privacy law during the twentieth century by the United States Supreme Court has focused almost exclusively upon decisional privacy,84 and within that framework, almost exclusively upon choice of sexual practices.85 In 1977, in Whalen v. Roe,86 the Supreme Court did flirt with recognizing a constitutional right of information privacy. The state of New York had established a computer file of the names and addresses of all citizens who used certain drugs pursuant a doctor’s prescription. In a classic example of viewing privacy interests as individual, and of lesser value than social interests, the Court, in a unanimous opinion, affirmed the state’s power to establish this information base. But the Court did accord some constitutional basis to two individual interests. This included the “individual interest in avoiding disclosures of personal matters,” and

in adopting the more flexible approach to defining the scope of due process claims delineated by the second Justice Harlan’s dissent in Poe v. Ullman. See 367 U.S. 497, 540-41 (1961).


84. The modern law is a departure from its origins, which also focused upon informational privacy. Louis Brandeis again was the central figure in the birth of the constitutional strand of American privacy law. See Olmstead v. United States, 277 U.S. 438, 471 (1928) (Brandeis, J., dissenting). Brandeis dissented based on the view that a wiretap violated the Fourth Amendment’s limitations upon searches and seizures, which he connected to a privacy concept. See id. at 479.

85. Three cases decided between 1965 and 1973 established this focus. In Griswold, 381 U.S. at 497-98, the Court struck down a Connecticut statute prohibiting the use of a variety of mechanisms to prevent conception. Seven years later, in Eisenstadt v. Baird, the Court struck down a Massachusetts statute prohibiting the sale of contraceptives to individuals. See 405 U.S. 438, 454-55 (1972). Though the exact scope of this decision remains disputed, and Justice Brennan’s opinion was careful to ground the decision upon a rational scrutiny of equal protection, it did extend Griswold’s holding beyond the domicile and married couples. Within a year, in its landmark decision in Roe, the Court recognized a privacy right that conferred upon women a right to decide whether or not to have an abortion during the first two trimesters of pregnancy. See Roe, 410 U.S. at 153-54.

86. 429 U.S. 589, 598-600 (1977).
"the interest in independence in making certain kinds of important decisions." Because these are important interests, this language seemed promising. The Whalen Court did not, however, connect these interests with a privacy right, but instead founded their constitutional basis in the Fourteenth Amendment. To the extent that the Court did conceive of these interests in terms of privacy, it did so from the perspective of decisional, not informational, privacy. It is not surprising, then, that Whalen has not been the basis for developing any generalized constitutional concept of information privacy.

Unlike the federal constitution, some state constitutions have explicit provisions endowing citizens with privacy rights. Some courts have interpreted their state constitutions clearly to protect the individual’s privacy interest over personal medical information. But there remain a number of important limitations upon attempts to protect personal control of genetic information under state constitutions. One is that state constitutional rights are subordinate to federal statutory and constitutional law, and “operate only interstitially.” The expanded privacy rights under a state’s constitution cannot either conflict with federal statutory constitutional rights or diminish a right exercised by another party, like government or an employer. Substantively, state constitutional protections of privacy interests also suffer from major limitations. One, similar to federal law, is that state constitutional protection of health information seems to continue to focus only upon disclosures of this information, not its collection. Further, although state constitutional law is mixed on this point, the clear trend since at least the late 1980s is to require state action for privacy claims based

87. Id. at 599.
88. Nor do Hill or Norman-Bloodsaw provide a basis for such a generalized privacy right. See supra note 57 and accompanying text. An excellent analysis of the Whalen opinion is found in Paul Schwartz, The Computer in German and American Constitutional Law: Towards an American Right of Informational Self-Determination, 37 AM. J. COMP. L. 675, 679-86 (1989).
89. See, e.g., King v. State, 535 S.E.2d 492, 494 (Ga. 2000) (concerning hospital testing and disclosure of plaintiff’s blood alcohol level, not her genetic information). Id. The court characterized King’s privacy right as having “its foundation in the instincts of nature.” The court added that the “right of privacy guaranteed by the Georgia Constitution is far more extensive than that protected by the Constitution of the United States.” Id.
91. This point is best demonstrated by a privacy claim under the Alaska Constitution by a legal user of marijuana. The Alaska court dismissed the claim since the state government was merely collecting information about marijuana use, not disseminating it. See Rollins v. Ulmer, 15 P.3d 749 (Alaska 2001).
upon state constitutions.\textsuperscript{92} Though not all the cases apply the state action requirement with equal rigor, the trend again is to follow federal constitutional jurisprudence and adopt a rigorous approach to what constitutes state action.\textsuperscript{93}

Despite the jagged character of the protection of personal control of health information in American law, in its common law, statutory, and constitutional forms, cumulatively this law is consistent, affording only limited and sectoral protection for personal and genetic information. This reflects a preference for public health interests and market efficiency over personal control of health information. This configuration of law, though not all of it has this intent, supports the impulse of contemporary American law to treat genetic information as a commodity. This view of personal genetic information reflects powerful ideological currents in contemporary America.

\textbf{B. An Enlightenment-Based Legal Ideology}

The limited and sectoral protection that American law provides for personal health information is based upon a number of ideological premises rooted in the Enlightenment. It was a broad and diverse movement, with more moderate and radical phases.\textsuperscript{94} Premises from both moderate and more radical Enlightenment thought have influenced the legal ideology of American health information law. Sometimes ideas drawn from these two phases of the Enlightenment do not fit nicely together. For example, classical liberalism, a product of the moderate Enlightenment, asserts that the free market acts benevolently in creating wealth. Accordingly, if government, for the most part, would just keep out of the way, the public interest would naturally be advanced by the

\textsuperscript{92} In a case that has attained some renown, the California Supreme Court interpreted Article 1, § 1 of the state’s constitution not to require state action for a violation of a privacy right. In that case, the court upheld a damage judgment against the doctor, insurance company, and lawyer who disseminated the fact that the plaintiff had AIDS, a fact he disclosed to protect a nurse drawing his blood for a workers’ compensation claim. \textit{See} Urbaniak v. Newton, 277 Cal. Rptr. 354 (Cal. Ct. App. 1991). But this decision is decidedly an exception in contemporary American constitutional jurisprudence, even in the states.

\textsuperscript{93} \textit{See} Devlin, \textit{supra} note 90, at 859; \textit{see also} JENNIFER FRIESEN, 1 \textit{STATE CONSTITUTIONAL LAW: LITIGATING INDIVIDUAL RIGHTS, CLAIMS, AND DEFENSES} (3d ed. 2000); ROBERT F. WILLIAMS, \textit{STATE CONSTITUTIONAL LAW: CASES AND MATERIALS} 247-84 (3d ed. 1999); Cole, \textit{supra} note 83.

One modest exception to the trend to require state action with increasing rigor is the California Supreme Court’s finding of state action in Gay Law Students Ass’n v. Pac. Tel. & Tel. Co., 595 P.2d 592 (1979). But that case was decided in 1979. Further, it is more plausible to find state action when dealing with a telephone company than for most American companies.

\textsuperscript{94} \textit{See} TAYLOR, \textit{supra} note 11 and accompanying text.
sum of thousands of private interests. In contrast, the utilitarianism of the radical Enlightenment called for law, sometimes comprehensive schemes of law, that would create the public interest by subverting private interests to the greatest good for the greatest number. But both phases of the Enlightenment shared a number of the premises, and when they are conjoined with a focus upon market efficiency, their differences narrow. This section will briefly explore, and suggest problems with, the Enlightenment-based premises and methodologies that shape the American law of personal genetic information privacy.

1. Three Premises

i. The Importance of Market Efficiency

This foundational premise is rarely analyzed in literature in relation to personal information privacy. This is sometimes because, like all bedrock premises, it is assumed. In addition, when lawmakers started to intrude upon personal health information, they did so to further public health interests. It is only recently that furthering public health interests has been linked in some lawmaking and legal scholarship with market efficiency.

Numerous areas of contemporary American law have been influenced by the impulse for economic efficiency. The development of American antitrust law during the past quarter of a century provides an excellent example of its growing influence in shaping American lawmaking. Presumably, lawmakers view maximizing economic efficiency as the most direct way to increase overall wealth, which they link to raising the quality of human life. The modern economists share this goal of increasing overall wealth with classical economists.

The impulse for economic efficiency, with the goal of increasing wealth and therefore the quality of human life, is also the foundational premise that justifies treating genetic information as a commodity. This

95. The foundational exposition of this position was contributed by Adam Smith. See generally AN INQUIRY INTO THE NATURE AND CAUSES OF THE WEALTH OF NATIONS (Edwin Cannan ed., 1937) [hereinafter THE WEALTH OF NATIONS].

96. Prior to the 1980s, judges applied a Populist interpretation to antitrust law. The Populist view emphasized a highly competitive market of smaller enterprises. Since 1980, however, the Chicago school interpretation of antitrust law has become ascendant. In contrast to the Populist approach, the Chicago school above all favors economic efficiency. The goal of the Chicago school is to maximize economic wealth even if this reduces economic opportunities for newcomers. See, e.g., Richard A. Posner, Legal Formalism, Legal Realism, and the Interpretation of Statutes and the Constitution, 37 CASE W. RES. L. REV. 179 (1987).
is because it is believed that the maximum availability of information fosters market efficiency.

ii. The Availability of Information Fosters Market Efficiency

A fundamental article of faith animating contemporary American lawmaking that facilitates the uses and disseminations of personal genetic information, sometimes covertly, is that the availability of as much information as is possible maximizes market efficiency. The leading modern advocate of this view, as applied to personal information, is Judge Richard Posner. Posner asserts that for the market to operate efficiently, it must have ready access to all possibly relevant information. For example, the more information available to employers when they make decisions about whom to hire and fire, and to insurers when they decide whom to accept or reject as clients, the more efficiently will they make these decisions.97

This position is ultimately traceable to the rational instrumentalism of the radical Enlightenment. It “conflates information with knowledge of (or truth about) reality.”98 There are, however, a number of problems with this position. First, human knowledge is based not only upon information, but also upon technique, that is, the cognitive tools employed to process information. In contemporary American society “the prevailing technique is rationalizing” the information.99 Though extolling the power of reason has a long and distinguished lineage in Western civilization, at least as far back as Plato, there have also been thinkers and movements that emphasize the importance of human emotions, and subjective human motivations, as a basis of human knowledge and experience.100

97. Judge Posner proposed a two-prong test for the privacy of personal information, including genetic information: (1) whether it is the “byproduct of socially productive activity”; and (2) whether non-consensual disclosures would impair incentives to engage in such activity. Richard A. Posner, The Right of Privacy, 12 GA. L. REV. 393, 403-04 (1978). By these tests, Judge Posner concluded that personal information should generally not be legally protected. See id.; George J. Stigler, An Introduction to Privacy in Economics and Politics, 9 J. LEGAL STUDIES 623 (1980) (taking the same approach as Posner).


99. Id. at 1405.

100. Two groups that readily come to mind who value emotions as a critical part of human experience and knowledge are religious evangelicals, who have dotted the landscape of Christianity since apostolic times (and have strong roots in the Gospel of John), and the Romantic movement of the late eighteenth and early nineteenth centuries in both Western Europe and America.
In addition, a conflation of information and reality relies both upon the objectivity of reality, and the accuracy of human senses to perceive this objective reality. Instead, a number of factors shape how one perceives and understands information. They include a person’s background of education and experience, including shared cultural perceptions; the process by which a person obtains knowledge; and how a person uses it. There are a number of interesting examples that graphically illustrate how these and other factors shape human processing of information. A most interesting contemporary example is how differently allergists and clinical ecologists evaluate and treat a similar group of symptoms presented by their patients. A more relevant contemporary example is provided by data processors. First, their pre-existing biases and conceptualizations of reality help to shape what information they wish to collect and how they gather it. Further, their access to vast amounts of personal information endows data processors with enormous power in two senses. One, of course, is that they obtain power vis-à-vis the persons whose personal information they control. They also can use this information to construct reality. Similar points can be made concerning biomedical researchers. For example, it is in their interest, even if honestly and unconsciously, to reconstruct the so-called reality of medical science in ways that increase their companies’ profits.

101. The common set of symptoms include red and watering eyes, congestion, nausea, headaches, etc. Allergists view these symptoms as evidence of the body’s immune system reacting to such things as pollen and dust mites. Clinical ecologists view these symptoms as signs of environmental harms from pollution, food additives, chemicals, and other features of the modern environment, upon the human body. Some psychologists view people who have such symptoms and seek treatment from clinical ecologists as neurotic. See Nicholas A. Ashford & Claudia S. Miller, Chemical Exposures: Low Levels and High Stakes (1991).


[T]he ability to assemble information selectively, or to correlate existing information, can be functionally equivalent to the ability to create new information. This capacity, obviously facilitated by information technology, enables agencies to identify, target, and perhaps manipulate a certain segment of the population that has common background characteristics.

Colin J. Bennett, Regulating Privacy: Data Protection and Public Policy in Europe and the United States 19 (1992). Cohen concludes: “If data reveals truth, it is possible to attain omniscience. If data constructs truth, it is possible to attain power.” Cohen, supra note 98, at 1408.
iii. Personal Information Privacy is an Individual Value that Harms Market Efficiency

If it were true that the more information available to the market, the more efficiently it operates, then it is easy to see why persons like Judge Posner view personal information privacy as a solely private value, harmful to the public interest in the efficient operation of the market. Unlike classical liberals who picture people wishing to be left alone, Posner believes that they wish to manipulate the world by selective disclosures of personal information. The desire of individuals to manipulate personal information and to create the most favorable impressions of themselves in their communities, is deceptive and positively harmful to the market, and therefore to society. This viewpoint, of course, ignores possibly legitimate reasons why people might wish to have control over their genetic information. These might include the history of stigmatization of persons and groups; the vulnerability of persons who live in modern societies, as described in Part IV of this Article, or the desire to profit from voluntary disclosures of their genetic information.

The cumulative effect of these three premises—the importance of market efficiency, that the more information that is available the more efficiently the market operates, and that personal information privacy is an individual value harmful to the operation of the market—creates for lawmakers a virtually irresistible impulse to view personal genetic information as a commodity to be used for society’s higher interests. They implement this view by a utilitarian calculus that shapes modern genetic information lawmaking.

2. The Utilitarianism Calculus Applied to Genetic Information

It is left to the utilitarian calculus to implement the three premises just discussed and feed the impulse to commodify personal genetic information. As noted in Part I.A, it seeks the maximum public utility. Utilitarian lawmaking therefore aggregates human pleasures and pains to attain the greatest good for the greatest number. Although this all seems quite straightforward, nevertheless the utilitarian calculus can prove to be highly unreliable. For utilitarian analysis to reach quantifiable conclusions, every relevant preference must be translated into a single

metric. Since reducing human preferences to a single metric can be quite difficult, utilitarian analysis can lead lawmakers in surprisingly different directions. For example, it has been used not only to justify disclosures of personal health information, but also non-disclosures of it.

The unreliability of the utilitarian calculus can violate the rule of law that Europeans insist is foundational to a democratic society. Other basic characteristics of the calculus can also lead to lawmaking that undermines genuine democracy. To begin, the utilitarian calculus abstracts human beings and their preferences and treats them as means, not ends. At its end point, in the utilitarian calculus the individual ceases to be a specific subject of moral concern. This in turn facilitates lawmaking that is coercive and paternalistic. Several centuries ago the German philosopher, Immanuel Kant, who remains one of the most important critics of utilitarianism in the history of Western civilization, stressed that even if the desire for happiness among humans is universal, happiness is a subjective and contingent value. By sacrificing


105. In its process of defining and balancing values and disvalues, utilitarianism “does not specify an external or objective basis for determining the good.” In a diverse and disorderly world, its valuation process is bound to be artificial and to yield diverse results. BEAUCHAMP & WALTERS, supra note 12, at 17; see also MARGARET RADIN, CONTESTED COMMODITIES 10 (1996). Professor Singer observed that it is exceedingly difficult to rationalize and compare costs and benefits within a single metric, and that there are many sources of indeterminacy in utilitarian measures that mask unarticulated value choices. See SINGER, supra note 104. An early critic of utilitarianism was the eighteenth century theologian Jonathan Edwards. He observed that utilitarian analysis “is without beginning, and hangs on nothing.” THE WORKS OF JONATHAN EDWARDS 123 (Edward Hickman ed. 1995).

106. This is demonstrated by the dissent in Tarasoff v. Regents of the Univ. of Cal., 551 P.2d 334, 355 (Cal. 1976) (Clark, J., dissenting). The essence of Judge Clark’s view that Dr. Moore had no duty to disclose the threat that his patient had made to the victim was that without an assurance of confidentiality, those needing therapy would be deterred from seeking it, and that the therapy that patients received would be less effective. Clark concluded: “Overwhelming policy considerations weigh against imposing a duty on psychotherapists to warn a potential victim against harm. While offering virtually no benefit to society, such a duty will . . . increase violence.” Id. at 358.

107. See generally UTILITARIANISM AND BEYOND, supra note 30. In another context Selya Benhabib criticized the abstraction of persons, stating: “If all that belongs to (people) as embodied, affective, suffering creatures, their memory and history, their ties and relationships to others, are to be subsumed under the phenomenal realm, then what we are left with is an empty mask that is everyone and no one.” Selya Benhabib, The Generalized and Concrete Other, in FEMINISM AS CRITIQUE 77, 89 (Selya Benhabib & Drucilla Cornell eds., 1988).

108. Kant wrote:

Men have different views on the empirical end of happiness and what it consists of, so that . . . their will cannot be brought under any common principle nor thus under any external law harmonizing with the freedom of everyone.
subjective personal interests and individual preferences to a conceptualized public good, Kant concluded that utilitarian analysis leads easily to coercive lawmaking. The same result occurs because utilitarians aggregate human pains and pleasures. The contemporary Kantian, John Rawls, observed that since utilitarianism justifies that "the greatest gains of some should...compensate for the lesser losses of others...the violation of the liberty of the few...[for] the greater good shared by the many," it can even justify human slavery. 109 Historically, this result has always been justified by the assertion that even citizens who are denied free choice over matters deeply personal to them benefit because the state embodies a higher consciousness of self. This view justifies a form of paternalistic lawmaking that fuses the interests of lawmakers with those of regulated citizens, coercively imposing a rationalized order upon diverse human preferences, and therefore upon basic human liberty.110

American law during the early twentieth century, when eugenic thought was in vogue, provides a tragic example of how utilitarianism can lead to coercive and paternal lawmaking with a vengeance. Starting in 1912 a number of American state legislatures began to adopt statutes permitting the sterilization of persons determined to be mentally defective. The goal of these statutes was to elevate the human race by purging it of defective genes.111 The influence of eugenics seeped down into popular culture, even impacting county fairs of that era.112 In what probably was a contrived case intended to test the constitutionality of Virginia's statute authorizing the sterilization of the mentally defective, the Supreme Court in Buck v. Bell113 upheld the constitutionality of this, and similar, state statutes. The Court's opinion, written by Justice Oliver

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109. JOHN RAWLS, A THEORY OF JUSTICE 22-23 (1999). Utilitarianism does not concern itself with the distribution of pain and pleasure throughout society, only with the net maximization of the balance of the two. See id. at 23.

110. See ISAIAH BERLIN, FOUR ESSAYS ON LIBERTY (1969); C.B. Macpherson, Berlin's Division of Liberty, in C.B. MACPHERSON, DEMOCRATIC THEORY: ESSAY IN RETRIEVAL (1973). The impetus of utilitarian lawmaking to lead to the imposition of a rationalized order, of course, allows it to converge nicely with the radical Enlightenment's rationalized approach of human knowledge. See discussion infra Part II.B.1.ii.

111. See PAUL, supra note 5.

112. At such fairs, particularly healthy people and animals, received recognition (providing a basis for E.B. White's classic, CHARLOTTE'S WEB (1952)). It may also have provided another basis for the massive regime of segregation, based on the Jim Crow laws of that era, though I have never seen any documentation of that connection.

113. 274 U.S. 200 (1927).
Wendell Holmes, asserted that the community’s higher interest in public health justified the forced sterilization of a young woman, Carrie Buck, who purportedly was mentally deficient. In a nightmarish paragraph Holmes reasoned:

the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes . . . . Three generations of imbeciles are enough. [174]

Carrie Buck was the shorn lamb. Not only does *Buck v. Bell* violate the solicitude of all of the major Western religions for the dispossessed, disabled, and powerless, [115] it also illustrates how utilitarianism can violate the most fundamental principle of democracy- the dignity of the individual. The second formulation of famous categorical imperative of

114. *Id.* at 207.

115. See Paul A. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v. Bell*, 60 N.Y.U. L. REV. 30 (1985). Lombardo describes in detail the sad story of Carrie Buck and her forced sterilization. She was very poor; devoutly religious; perhaps not mentally retarded; and her child, who was clearly not retarded, may have been the result of Carrie being raped. *See id.*

All of the major Western religions condemn harsh treatment of the weak, dispossessed, and disabled. The condemnations by Judaism and Christianity are closely linked. For example, in establishing the Jubilee Year, Mosaic law placed an obligation upon everyone to care for any “brother” who may “be waxen poor.” *Leviticus* 25:39 (King James). The prophet Isaiah foresaw that the principles of the Jubilee would be important in the future messianic age. One indication of this is that good news would be brought to the afflicted. *Isaiah* 61:1-2 (King James). The prophet Micah described that in “the last days,” the Lord would gather in Zion the lame, outcasts, and afflicted as a remnant, to walk in the ways of the Lord and live forever in peace. *Micah* 4:1 (King James).

Jesus adopted the Jubilee as a foundation of His ministry. When He returned from the temptation in the desert, Jesus announced His ministry by quoting from Isaiah: 61:1-2, though altering some of its language:

> The Spirit of the Lord is upon me, because he hath anointed me to preach the gospel to the poor; he hath sent me to heal the brokenhearted, to preach deliverance to the captives, and recovering of sight to the blind, to set at liberty them that are bruised, to preach the acceptable year of the Lord.


The QUR’AN, the scripture for Islam, has numerous passages warning against “devouring” the poor, and a number of forms of domination or exploitation of the weak and dispossessed. For example, it warns that those who devour the property of orphans will “soon endure a blazing flame.” 4:29-30. Muhammad also championed the cause of slaves and of exploited women. *See Frank Vogel & Samuel Hayes III, Islamic Law and Finance: Religion, Risk, and Return* 73-74, 78, 84 (1998).
Immanuel Kant eloquently states this bedrock principle of genuine democracy. Since humankind is a kingdom of ends, Kant asserted that no one should, “be dealt with merely as a means subservient to the purpose of another . . . For if justice and righteousness perish, human life would no longer have any value in this world.”

When utilitarianism emerged during the late seventeenth century in western thought it may have represented a well-intentioned response to the disintegrative effects of the process of modernization upon human communities, and the specter of an emerging and potentially deeply disruptive individualism that had emerged in Western culture a generation earlier. Unfortunately, rather than repair the damage done to both citizens and their communities by modernization, utilitarianism exaggerates it. As described in Part IV.A of this Article, the process of modernization isolated and weakened persons by rendering the bonds of traditional communities. The paternalistic, coercive, and unreliable utilitarian calculus further undermines human independence and dignity, and thereby subverts the renewal of genuinely democratic communities.

3. American Privacy Law’s Concept of Human Liberty and Social Vision

To the extent that America’s health information privacy law protects citizens’ control of their personal information, it embodies a concept of human liberty that has been called negative liberty. Under this view people are free when they have ample space to think and act as they choose the American concept of negative liberty has its roots in English Enlightenment of the seventeenth-century, and specifically the writings of Thomas Hobbes and John Locke. Hobbes well-described this concept of liberty when he wrote: “Liberty, or Freedome, signifith (properly) the absence of Opposition; by Opposition, I mean external Impediments of motion . . .” Based upon this view of human liberty, an important function of modern American law, and especially its constitutional law, is to act as a shield, assuring individuals space to think and act as they choose, free from the intrusive acts of oppressive
government and majoritarian sentiment. Otherwise, government is to keep largely out of the affairs of its citizens (a view consistent with the classical economics described in Part II.B.1). 119

The privacy concept itself, as commonly understood in American jurisprudence, represents this concept of human liberty. 120 Incidentally, so does the state action limitation in American constitutional law jurisprudence that can limit constitutional review of intrusions upon privacy interests. 121 The concept of negative liberty is in turn linked to a vision of a deeply libertarian society. In its most extreme version, negative liberty leads to Hobbes' possessive individualism. This is a vision of separated and selfish individuals seeking their own ends in a competitive and atomized society (that even in the seventeenth century was becoming increasingly entrepreneurial). 122 But John Stuart Mill, whose famous essay, On Liberty, reflected influences of the Romantic Movement, presented a more uplifting vision of human creativity spawned by negative liberty. 123 More recently, Justice O'Connor articulated a contemporary version of the vision of creative human

119. Professor W. Cole Durham describes the privatized model of American constitutional jurisprudence, which he views as highly influenced by Lockean thought. General Assessment of the Basic Law-An American View, 14 Nomos (19) 37, 46-47. In this jurisprudence, the private sector is the domain of freedom. See id. Expanding governmental regulation contracts individual liberty, and so limited government is the goal. See id.

The American approach is graphically illustrated by a case in which a policeman came to the scene of an accident with an overturned car that caught fire. He directed traffic, but failed to discover that there were people in the car, who burned to death. When their estates sued the municipality, the Seventh Circuit, in an opinion written by Judge Posner, rendered a judgment for the defendant. Posner based his decision upon a strictly negative view of American constitutional rights. See David P. Currie, Positive and Negative Constitutional Rights, 53 Chi. U. L. Rev. 864 (1986).

120. This point is made well by a list of interests covered by the privacy concept in David Flaherty's selective study of Western privacy laws. See David H. Flaherty, Protecting Privacy in Surveillance Societies: The Federal Republic of Germany, Sweden, France, Canada, and the United States 8 (1989). These interests include: individual autonomy; being left alone; a private life; limiting accessibility; minimizing intrusions; confidentiality; enjoying solitude and intimacy, anonymity, and reserve; and enjoying secrecy. See id. The one element of privacy that Flaherty lists that comes closest to exceeding the negative liberty concept is the power, which he casts as a right "to control information about oneself." Id.

121. Professors Robert J. Glennon, Jr., and John E. Nowak argued that what courts do under the state action rubric is to weigh whether the alleged violation of the plaintiff's constitutional rights is sufficiently damaging to outweigh the liberty interest of the defendant. See Robert J. Glennon Jr. and John E. Nowak, A Functional Analysis of the Fourteenth Amendment "State Action" Requirement, 1976 Sup. Ct. Rev. 221, 226-27; see also Devlin, supra note 90; Cole, supra, note 83.


development nurtured by the free space of negative liberty. In Planned Parenthood of Southeastern Pennsylvania v. Casey she wrote:

At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. Beliefs about these matters could not define the attributes of personhood were they formed under compulsion of the State.\textsuperscript{124}

Justice O'Connor's vision of the creative human personality is much more appealing than was Hobbes' of selfish individualism. Nevertheless, her vision is still one of dispersed individuals who live in an atomized society (albeit a gentler one than that of Hobbes' imagination). This same separation of the individual from the social whole is distilled in the central metaphor for the American law of privacy rights, the "zone of privacy," as well as in the "right to be let alone" articulated by Charles Warren and Louis Brandeis in their landmark article on privacy law.\textsuperscript{125} These metaphors graphically depict legal boundaries drawn around citizens, separating them from communities, rendering them isolated and devoid of civic virtue.\textsuperscript{126}

The concept of negative liberty, and its related vision of human existence, is a relative newcomer in Western thought.\textsuperscript{127} Instead, for millennia Western thinkers, both secular and religious, and from many nations, have conceived of human beings flourishing within communities.\textsuperscript{128} However important community has been to human flourishing throughout Western history, in Part IV.A this Article will insist that it is even more so in a world in which people have been separated from most personalized human bonds by the process of modernization. Jennifer Nedelsky rightly concluded that the new "language of [American constitutional] law" that lawmakers should adopt must highlight relationships.\textsuperscript{129}

\begin{thebibliography}{9}
\bibitem{126} The feminist Robin West complained that the right of privacy is devoid of all civic virtue, demanding "nothing of the citizen beyond self-regarding behavior." Robin West, Taking Freedom Seriously, 104 HARV. L. REV. 43, 69, 71-72 (1990).
\bibitem{127} See MACPHERSON, POSSESSIVE INDIVIDUALISM, supra note 122.
\bibitem{128} Berlin, Two Concepts of Liberty, supra note 117; Taylor, supra note 123.
\bibitem{129} One example that graphically makes this point is found early in the Bible. When God relegated Cain to wander about the earth, Cain protested: "My punishment is too great to bear." Genesis 4:13 (King James). Eventually Cain would settle in the land of Nod, east of Eden, establish a city and have a family. See id.
\bibitem{129} Nedelsky, Bounded Self, supra note 125, at 162-63. An emerging view among feminist thinkers is that the real value of the communitarian critique of rights is not to destroy rights
\end{thebibliography}
A start in this direction is provided by the very different approach of the law of the EU to the control and uses of personal genetic information. It suggests a different social vision from that which underlies American law.

III. EUROPEAN UNION LAW: A HUMAN RIGHT IN PERSONAL GENETIC INFORMATION

From the inception of the European Community in the 1950s its lawmakers evinced concern for human rights, including a right of citizens in their personal information. There are a number of sources for the concern of European lawmakers for human rights. They begin with the awful experience of World War II, justified by eugenic science. The domestic laws of a number of European nations after World War II, notably Germany and Italy, gave special attention to human rights. So did post-war international law, two documents being of particular significance: They are the Universal Declaration of Human Rights, adopted by the United Nations General Assembly in 1948; and the Convention for the Protection of Human Rights and Fundamental Freedoms, ratified by a number of European nations in 1950. Another important source of human rights in the EU was the development of the concept of citizenship, most notably in the Maastricht Treaty of 1992. The development of contemporary EU law protecting personal information began in the 1970s, reflecting concern in Europe for personal privacy spawned by the birth of computer technology. The body of law that developed in member states over the next quarter of a century in turn provided background for the articulation of a comprehensive law of personal information privacy by the EU in 1995.

ideology, but to re-conceive of rights as “one way of regulating and constraining our behavior toward one another in a desirable manner.” Amy Gutmann, Communitarian Critics of Liberalism, 14 PHIL. & PUB. AFFAIRS 308 (1985).

130. German lawyers insisted that the emphasis of their domestic law upon human rights as a condition for Germany joining the European Community. BVerfG, 2 BvL 1/97 (Jun. 7, 2000).

131. For the development of human rights law in Europe, see CASES AND MATERIALS ON EUROPEAN UNION LAW (George A. Bermann et al. eds., 2d ed. 2002). In Nold v. Commission, Case 473 ECR 491 (1974), the court stated that in protecting human rights it “is bound to draw inspiration from constitutional traditions common to Member States,” and that “international treaties,” can supply guidance which should be followed within the framework of community law.

Significant in the earliest development of the emphasis of EU law to protect citizens’ control over their personal information was Article 12 of the Universal Declaration of Human Rights, adopted by the United Nations in 1948. It states:

No one shall be subjected to arbitrary interference with his privacy, family, home, or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.\textsuperscript{133}

The language of Article 12 directly influenced what became the foundation of the modern European law of information privacy. This is Article 8 of the Convention of Human Rights, which provides in subsection one that, “[e]veryone has the right to respect for his private and family life, his home and his correspondence.”\textsuperscript{134} Subsection two required that those who would intrude upon this right act “in accordance with the law ... [that] ... is necessary in a democratic society.”\textsuperscript{135} Reflecting the World War II experience of state-based eugenics, however, Article 8 addressed only intrusions upon personal privacy by governmental officials and bodies (the vertical effect). Violations of human rights are ultimately enforced by the European Court of Human Rights.\textsuperscript{136} Since 1950, the Court has greatly expanded the scope of Article 8 by interpreting its specific language according to what the Court perceives as its underlying rationales.

The development of the information privacy laws of the European states has been described well elsewhere.\textsuperscript{137} Some of the earlier state law would anticipate important features of later EU data protection law. The laws of Germany and France are of particular interest in this regard, since these two countries heavily influenced the shaping of the Data Protection Directive.\textsuperscript{138}

\begin{footnotes}
\textsuperscript{135} Id. at art. 8(2).
\textsuperscript{136} Cases alleging violations of human rights can be filed in the Court by the European Commission of Human Rights, by states either as plaintiffs or defendants, or by any state that signed the Convention in 1950. Individuals cannot file claims.
\textsuperscript{137} See FLAHERTY, supra note 120; JAMES MICHAEL, PRIVACY AND HUMAN RIGHTS: AN INTERNATIONAL AND COMPARATIVE STUDY WITH SPECIAL REFERENCE TO DEVELOPMENTS IN INFORMATION TECHNOLOGY (1994); SPIROS SIMITIS, DATA PROTECTION IN THE EUROPEAN UNION: THE QUEST FOR COMMON RULES (1994).
\textsuperscript{138} See Paul M. Schwartz, The Protection of Privacy in Health Care Reform, 48 VAND. L. REV. 295, 324-33 (1995) [hereinafter Privacy in Health Care Reform]. The focus upon facets of
\end{footnotes}
There are a number of themes of the law in these two countries that would help to shape later EU data protection law. One of these was to treat personal information as a human right. A foundation of German constitutional law since the end of World War II, for example, is respect for human dignity, and based upon it recognition of "the right to free development of his personality." From these principles of Germany's Basic Law its Constitutional Court has developed a constitutional right that applies to all personal information, including genetic information.

Various German statutes afford particularly strong protection for personal control over personal health information, and cumulatively they treat health information as "sensitive" data.

The laws of both countries recognize a human right in personal information as essential to human liberty. For example, Article 1 of the 1978 French law that is a foundation of its law concerning personal information states that "information shall be at the service of every citizen... It shall infringe neither human identity, nor the rights of man...

French and German law does not at all suggest that these facets of their laws are necessarily unique. For example, the constitutions of Greece, Netherlands, Spain, and Portugal all broadly protect personal privacy. See Spiros Simitis, From the Market to the Polis: The EU Directive on the Protection of Personal Data, 80 IOWA L. REV. 445, 450, 455-56, 462. (1995). Not only does German law consider health information to be sensitive, so do French, Belgian, Spanish and Portuguese laws. See id. at 450. French law is far from unique in establishing an independent commission to oversee who controls the uses of personal information. German law establishes both a federal Data Protection Commissioner, and also counterparts of this position in all of the German states. See id.


140. Grundgesetz für die Bundesrepublik Deutschland, GG, Basic Law for the Federal Republic of Germany, May 23, 1949, Federal Law Gazette, art. 2, subd. 1 (emphasis added). The Basic Law recognizes that "human dignity shall be inviolable." Id. at art. 1, subd. 1. It also recognizes, "inalienable human rights as the basis of every community." Id. at art. 1, subd. 2. Article 2 of the German Basic Law, entitled "Personal Freedom" states:

(1) Every person shall have the right to free development of his personality insofar as he does not violate the rights of others or offend against the constitutional order or the moral law.

(2) Every person shall have the right to life and physical integrity. Freedom of the person shall be inviolable. These rights may be interfered with only on a law.

Id.


142. For example, the Federal Data Protection Law prohibits the transfer of health information for direct marketing; the Code of Social Law permits the collection of health information for social welfare programs only when a specific legal provision provides for this, and it forbids the transfer of health information to clearinghouses. See Privacy in Health Care Reform, supra note 138, at 325-26. German law, however, views all sensitive data contextually.
nor private life, nor individual or public liberties. The German Constitutional Court also explicitly makes this connection.

Another important characteristic of the laws of these two countries is a broad protection of personal information, related to a wider concept of human liberty than the negative liberty characteristic of American law. French lawmakers, for example, coined a new word, l'informatique, to indicate that its law would protect a broadly defined sphere of personal information. The Tricot Report, the basis for the 1978 French law, elaborates upon the broad scope of what it conceives to be personal information. French law also established the important principle that "no judicial decision . . . [and] . . . [n]o governmental or private decision involving an appraisal of human conduct may be based solely on any automatic processing of data which describes the profile or personality of the person concerned." German law associates the law's wide protection of personal information with a concept of liberty that provides a basis for the development of the human personality.

Finally, although they are not unique among European countries in this respect, France and Germany established officials or institutions to oversee the administration of personal information law. For example, an important feature of the 1978 French Law was to establish an independent governmental body, the Nationale d'Informatique et des Libertés (National Commission on Informatics and Liberties, or "CNIL") to oversee all aspects of the administration of laws concerning personal information privacy, including transfers of personal information outside of France. The care that the CNIL exercises in protecting the


145. The Tricot Report discusses how the protection of private life with respect to the collection, processing, and harmful dissemination of certain information has been one of our dominant preoccupations. However, just what the term private life means has not been defined. The Report goes on to note that lawmakers should exercise their powers to protect all liberties, and not only those associated with private life. See La Rapport Tricot (Aug. 26, 1975) (on file with author).

146. See Act 78-17 on Data Processing, supra note 143. French law also regulates automated processing of most personal data by a system of licensing, but later EU law has not adopted this approach. See id. at § 16.

147. The leading German authority on European data protection law, Spiros Simitis affirmed that the goal of the Federal Data Protection Law was, "to protect the personal interests of the individual affected by the storage and retrieval of their data, and thus to ensure the free development of their personality." Spiros Simitis, Reviewing Privacy in an Information Society, 135 U. PA. L. REV. 707, 730, n.99 (1987).
anonymity of genetic information is illustrated by an arresting episode from France during the 1980s. Andre Chaventré, director of the Department of Anthropological and Genetic Demography of the Institut Nationale d'Etudes Demographique ("INED"), accidentally discovered a high incidence of juvenile, or open-angle, glaucoma in a region of northern France near the English Channel. Eventually a team of demographers were able to trace the origin of this disease to a single couple who lived in the small village of Wierre-Effroy during the late fifteenth century, (not coincidental since the village had a cistern filled with water believed to cure blindness). Since this form of glaucoma is insidious, but also treatable if detected early, Chaventré wanted to disclose the names of the young people who carried the open-angle glaucoma genetic defect to French ophthalmologists. But the CNIL asserted that such disclosures would violate the French Information Privacy Law of 1978. What the CNIL did allow was for INED to alert doctors about the existence of this genetic defect, and urge them to look for it in their teenage patients.

By the mid 1970s lawmakers began to explore the idea of establishing a privacy law for the EU itself. On October 24, 1995 the European Council published the Data Protection Directive ("DPD"), the centerpiece of the privacy law of the EU. The term data protection in Europe is similar to what American lawmakers refer to as information privacy, although, as in French and German law, defined more broadly. This is the most important single document in the entire constellation of European information privacy law.

The foundational theme of the DPD is that it confers a human right upon citizens in their personal information. It links this right to the existence of human liberty and genuine democracy. Article 1(1), states that, "Member States shall protect the fundamental rights and freedoms of natural persons, and in particular their right of privacy with respect to..."
the processing of personal data. The DPD's Preamble elaborates upon the linkage of this human right to human liberty and democracy. Section 1 makes the important assertion that the DPD seeks to promote "democracy on the basis of... fundamental rights." Section 2 asserts that since "data-processing systems are designed to serve man," they must be used in ways that respect "fundamental rights and freedoms, notably the right of privacy." Section 10, by citing Article 8 of the Convention of Human Rights as precedent, explicitly places the DPD within the framework of human rights law that had been developing in Europe since the end of World War II.

Consistent with the view that citizens have a human right in their personal information, the DPD broadly protects personal control of data, including genetic information. Section 10 of the Preamble states that because personal privacy is a human right, EU law must "seek to ensure a high level of protection" of data privacy. Consistent with this commitment, in a number of important ways the DPD provides comprehensive legal protection for personal information. To begin, the definition of personal data in Section 2 is broad, and it clearly covers all sorts of personal health information, including genetic information. Of great significance for the protection of personal health information, including genetic information, is that Article 8 of the DPD includes it among the "special categories" of sensitive data.

The DPD's scope of coverage of how data is obtained is also very broad. Resisting efforts by Britain to exempt manually-recorded data, the DPD brooks no distinction in how personal data is obtained and stored. Also, the DPD transcends the focus of post-World War II law upon governmental intrusions into personal privacy. Instead it makes no distinction between them (the vertical effect), and intrusions by any private person or organization (the horizontal effect).

153. DPD, supra note 151, at art. 1, § 1.
154. Id. at pmbl. § 1.
155. Id. at pmbl. § 2.
156. Id. at pmbl. § 10.
157. See id. Article 2(a) defines "personal data" to include "any information relating to an... identifiable natural person," and concerning his or her "physical, physiological, mental, economic, cultural, or social identity." Id. at art. 2(a). The Preamble to Article 29 makes clear, however, that the DPD does not cover anonymous clumps of personal data that cannot be traced to a specific person. See id. at art. 29.
158. See id. at art. 3, § 1 ("This Directive shall apply to the processing of personal data wholly or partly by automatic means, and to the processing otherwise than by automatic means.").
159. Spiros Simitis, who has been a leading figure in the development of EU privacy law, expressed the European viewpoint relative to who controls health information in the following passage:
recognize this distinction, the DPD departs from the state action requirement of American law.

In this respect the DPD is consistent with the wide protection that general European law affords personal information. A striking example is provided by the decision of the European Court of Human Rights in Niemietz v. Germany.\(^{160}\) It held that Article 8 of the Human Rights Convention encompassed the state’s seizure of documents in a lawyer’s office related to a criminal proceeding. In doing so the Court rejected any clear line between private and public spheres of life in the protection of citizens’ control of their information.\(^{161}\) In other cases the Court has made a similar point.\(^{162}\)

The DPD was the product of intense lobbying efforts. Sprinkled throughout it are provisions that recognize limited exceptions to personal information privacy. Even in Article 8, there are some important limitations placed upon data privacy. Of particular significance for genetic information is Paragraph 3, which allows for a number of uses of sensitive data for health-related purposes, when these uses are subject to member state law regulations of their secrecy, or to persons with “an equivalent obligation of secrecy.”\(^{163}\) In general, the limitations that the DPD recognizes upon personal control of information, including genetic information, can be classified under three general headings. One is to accommodate important concerns of member states, like national security, defense, public security, and economic and financial concerns.\(^{164}\) Second, the DPD recognizes the importance of the flow of

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Patients in a private clinic are, as far as the use of their data is concerned, in the same situation as those treated in a hospital belonging to the state. Employees are confronted by the same problems with respect to their data whether they are employed by a computer firm or by a tax authority. The implications of processing for customers do not change because a bank is... owned by the state.

Simitis, supra note 138, at 452.


161. See id. In this case, the court rejected the argument of Germany that Article 8 had drawn a clear line between private and public activities, observing that “[v]irtually all professional and business activities may involve, to a greater or lesser degree, matters that are confidential,” id. at 28, and that “[i]t is not always possible to distinguish clearly which of an individual’s activities form part of his professional or business life and which do not.” Id. at 29. It also added that in Germany the word “home” has come to include “business premises.” Id. at 30.


163. The Directive also delegates to member states to decide to what extent sensitive information can be used on a personal identifying card or system.

164. These concerns are listed in Article 13 of the DPD. See supra note 151. Public security includes criminal investigations, though, Neimetz demonstrates that there are limits upon how much government officials can intrude upon personal privacy even for this purpose.
information to the smooth operation of the market and for scientific endeavors.\textsuperscript{165} Third, the DPD, and European privacy law generally, will limit a citizen’s control of personal information when this significantly diminishes a right of another person.\textsuperscript{166} This last category of exceptions to citizens’ control over their personal information is related to another important characteristic of European data protection law. That is, it conceives of persons living within communities, and therefore their rights are also defined within the framework of the rights of others within the community.\textsuperscript{167}

Nevertheless, the exceptions themselves are hedged in three important ways. First, the structure of Article 5 of the DPD suggests a strong presumption for the privacy of personal information.\textsuperscript{168} Second, the DPD requires that “data which are capable . . . of infringing on fundamental freedoms or privacy should not be processed unless the data subject gives his explicit consent . . . .”\textsuperscript{169} Third, as in French law, the DPD mandates that “[m]ember States shall grant the right to every person not to be subject to a decision which produces legal effects . . . which is based solely on automated processing of [personal] data . . . .”\textsuperscript{170}

\begin{footnotesize}
\footnote{165. The early sections of the DPD’s Preamble demonstrate this concern. For example, they express the desire to contribute to “economic and social progress, trade expansion, and the well-being of individuals.” DPD, supra note 151, at pmbl. § 2. This includes “the functioning of an internal market, in which, in accordance with Article 7a of the Treaty, the free movement of goods, persons, services and capital is ensured.” Id. at pmbl. § 3. They envision that the DPD will contribute to “a substantial increase in cross-border flow of personal data.” Id. at § 5; see also DPD art. 26, § 1, (limiting Article 25’s prohibition of the trans-European flow of personal information to countries whose laws do not afford adequate protection for personal information privacy). Sections 29 and 34 of the Preamble state that processing of personal data for “scientific purposes” is not incompatible with the DPD. Id. at pmbl. §§ 29, 34.

166. See section 2 of the Preamble, which allows for the processing of personal information when this contributes to “the well-being of individuals.” Id. at pmbl. § 2.

167. In the often-cited Census Case of Germany, the court stated: “The individual does not possess any absolute, unlimited mastery over ‘his’ data; rather he is a personality . . . developing within the social community.” 65 BverfGE 1, (1983), reprinted in KOMMERS, supra note 141 at 322.

A very important case in modern German jurisprudence illustrating the application of this view is the decision of the Federal Constitutional Court finding a statute liberalizing abortion rights to violate the Basic Law. The Court limited the mother’s right of human personality because of recognition of the dignity of all human life, even of a pre-birth infant. Abortion Case, 39 BverfGE 1, (1975), reprinted in KOMMERS, supra note 141, at 348-62.

168. Article 5 states that all “personal data” is protected except when its use is legally authorized elsewhere in the Directive. DPD, supra note 151, at art. 5.

169. Id. at pmbl. § 33.

170. Id. at art. 15(1) (defining personal data as data “intended to evaluate certain personal aspects relating to him, such as his performance at work, creditworthiness, reliability, conduct, etc.”). An Explanatory Memorandum of the EU’s “European Agency for Safety and Health at Work” suggests a strict interpretation of this Article. See Agency’s Rules on Freedom of Information}

\end{footnotesize}
The general approach of how the DPD protects personal information is typical of European human rights law. That is, it endows citizens with a broadly-conceived human right. But, it carefully views the exercise of human rights by the impact they have upon the rights of their communities and other citizens living within them. If on balance the impact of the exercise of a human right is considered to be too harmful within the community framework, courts will limit it.\textsuperscript{171}

In contrast to American law, the DPD establishes a cradle-to-grave scheme of regulation of how personal data is collected, controlled, processed, and transferred while in the hands of outside parties. In sharp contrast to American law, the regulation of personal data under the DPD begins with its collection. This includes the requirement that the user prove a legitimate purpose for seeking the data.\textsuperscript{172} Pursuant to Article 5, the user can seek only as much data as is absolutely necessary for the user's legitimate purpose. When the collected and processed data is identifiable to a specific person it can be kept only as long as is necessary for the user's purpose.\textsuperscript{173} When a person's data is collected and processed, that person must be notified and given a considerable amount of information about the collection process.\textsuperscript{174} The user of the data must obtain an affirmative, unambiguous consent of the person whose data is at issue before it can be processed.\textsuperscript{175} Users must also act

\textsuperscript{171} See, e.g., Connolly v. Comm'n, Case C-274/99P 2001 ECR I-1611. In this case, the Court upheld a limitation upon the plaintiff's right of freedom of expression. It justified this decision "by the legitimate aim of protecting the rights of others. The rights at issue here are those of the institutions that are charged with the responsibility of carrying out tasks in the public interest. Citizens must be able to rely upon their doing so effectively." \textit{Id.} For example, if an employer includes factors about a person in addition to personal information data in making an employment decision, then presumably the employer has not violated the Article.

\textsuperscript{172} Article 13 lists some of these purposes, including: national security; defense; public security; in connection with criminal investigations or proceedings, or for breaches of professional ethics; for an important economic interest of the European Union or a member state; and as is necessary to protect the rights of others. \textit{See DPD, supra} note 151, at art. 13.

\textsuperscript{173} \textit{See id.} at art. 6.

\textsuperscript{174} \textit{See id.} at art. 10. It requires, for example, that the citizen whose personal data is collected be informed of who is overseeing the process, the purpose of the collection of the data, who will receive the data, and the individual's right of access to the data. \textit{See id.}

\textsuperscript{175} \textit{See id.} at art. 7. But there are some loopholes in this protection. First it is unclear whether the requirement of unambiguous consent applies to all data covered under the DPD. \textit{See Shaffer,
“fairly and lawfully” in processing the collected data, suggesting that they must act not only according to the provisions of the DPD and relevant domestic law, but ethically, in using another citizen’s data. Article 12 assures that citizens whose personal data is collected can have access to the data, and make corrections to it. Article 14 confers upon a person the power to “object at any time on compelling legitimate grounds relating to his particular situation,” regarding uses of personal data. A user of personal data cannot transfer it to a third party without disclosing the identity of the third party, and without the clear consent of the citizen whose personal data is being transferred. Individuals have a right, without cost, to object to transfers of their data. Of great significance, Article 25 of the DPD also restricts the transfer of personal data outside of the EU unless the recipient country provides an “adequate level of protection” of personal information privacy.

Again in contrast to American law, especially HIPPA, the DPD confers upon persons whose data is under scrutiny significant enforcement rights. First, to assure enforcement of the Directive, Article 28 mandates that member states designate an independent public authority responsible for monitoring the application of the entire data use system. Article 28 also delineates the minimum supervisory authority that these supervisors must possess. In general, they must be able to investigate data processing, and to block uses of personal data that they believe to violate the DPD or that state’s laws. Further, it confers a number of rights upon individuals whose data is being used, and also consumer advocacy groups, concerning the entire process of collection and use of the data. This includes the right of individuals to challenge the data’s accuracy, and to block further processing of it or its dissemination. Individuals and consumer groups can lodge complaints that require public supervisors to investigate the use of their data. Court review of this process must be made available to all aggrieved

supra note 13 at 14. Second, Article 7 provides for five categories of explicit exceptions to the requirement of consent. See DPD, supra note 151, at art. 7.

176. See DPD, supra note 151, at art. 6.
177. Id. at art. 14(a).
178. See id. at arts. 10, 11.
179. See id. at art. 14(b).
180. This language suggests assessing of each country’s information privacy laws case by case, taking into consideration all aspects of the law. Id. at art. 25. It also provides a number of exceptions to this requirement, including when the data subject consents to the transfer, are necessary for the performance of certain contracts, and is necessary to serve an important public interest.
181. Supervisors must also make regular reports on their work. See id. at art. 28.
182. See id. at art. 12.
183. See id. at art. 28(4).
citizens. Remedies for breaches of the DPD include civil damages, as well as civil and criminal fines and even imprisonment. 184

The DPD is a carefully crafted and detailed legal document. Nevertheless, its general themes are quite clear. They begin with endowing citizens with a human right in their personal information. The purpose of this right is to provide citizens with sufficient control over their personal information so that they can realistically and effectively exercise informational self-determination. 185 The document recognizes that the empowerment conferred upon citizens by a human right of information privacy is essential to the development of genuine democracy within the EU. More so than American law, the DPD conceives of personal privacy issues and democratic values from a community perspective.

Since the adoption of the DPD a decade ago, the European law of data protection has continued to develop, including the protection of personal genetic information. The DPD creates a floor of protection that the laws of all member states must at least meet, but which they can also exceed. Further, under European law, a directive requires lawmaking by member states to implement it. 186 Of great significance is that directives have only a vertical effect, regulating intrusions upon personal privacy by governments, and not a horizontal effect. Therefore, to limit intrusions upon personal privacy by private groups and institutions would require domestic lawmaking. 187 Once member states have adopted laws in response to the mandate of a directive, the directive actually becomes part of the nation’s law. Judges must integrate the two bodies of law in individual cases. Further, courts of member states can, in

184. See id. at arts. 22–24.
185. Mayer-Schönberger, supra note 132, at 232–35.
187. This description of the effect of directives is generally accurate. Nevertheless, in certain cases directives can have some horizontal effect. One of these is for triangular relations. Further, states are supposed to interpret their domestic laws consistently with relevant directives, giving directives what is sometimes called an “indirect”, and sometimes horizontal, effect.
particular cases, act as preliminary institutions in the resolution of cases before they go to the European Commission.

Since the publication of the DPD a decade ago, EU lawmakers have continued to address various aspects of information privacy, especially the privacy of personal genetic information. Notable documents include the Council of Europe's Convention on Human Rights and Bio-Medicine, adopted in 1997; twenty-five recommendations published by the European Commission in 2004 concerning the ethical, legal, and social implications of genetic testing; and also the EU's Charter of Fundamental Human Rights, published on December 2, 2000.

We can expect more lawmaking to be forthcoming from the EU in the near future concerning the legal protection afforded to citizens to control their genetic information. For example, an interesting concept that is presently floating within the circles of informed thought about genetics, in both Europe and America, is to view persons tied by blood, akin to the older extended family, as a new biological unit in legal thought. Presumably, the adoption of this view would permit the free flow of genetic information within this unit. Further, it would conceive of claims for the privacy of genetic information not from the viewpoint of a particular individual, but from the viewpoint of blood lines.


189. The Council of Europe defines genetic data as data relating to "the hereditary characteristics of an individual or concerning the pattern of inheritance of such characteristics within a related group of individuals." Council of Europe, Committee of Ministers, The Protection of Medical Data, REC(97) 5, Feb. 13, 1997. President Clinton's Executive Order of February 8, 2000 defines protected genetic information to include information "about the occurrence of a disease, or medical condition or disorder in family members of an individual." Exec. Order No. 13145, 65 Fed. Reg. 6877 (Feb. 8, 2000), available at http://www.genome.gov/10002084.

This view would seem to comport with the EU's view that human beings flourish within the bonds of human associations. On the other hand, the free flow of genetic information within blood lines allows the possibility of placing eugenic pressures upon women and couples in making reproductive decisions, and altogether too many possibilities for cases of human domination. See discussion infra. Further, it is difficult to maintain anonymity of genetic data when it is distributed among members of a blood line. All of these possibilities contradict the spirit of the EU's data protection laws, and suggest that any move in this direction by EU lawmakers will be cautious and measured.
As with its inception, the EU law of privacy continues to have a symbiotic relationship with international law. This was illustrated by the adoption in 1980 of the Guidelines on the Protection of Privacy and Transborder Flows of Personal Data by the Organisation for Economic Co-operation and Development ("OECD"). Some of the foundational principles of the guidelines were later incorporated in the DPD. More recently, UNESCO published the Universal Declaration on the Human Genome and Human Rights. One reason that the Declaration is important is that it recognizes the importance of limiting horizontal as well as vertical intrusions upon the privacy of genetic information. Another is its comprehensiveness, both in drawing from many fields, including science, law, and ethics; and in addressing a wide array of issues related to the uses of genetic information. The Declaration rejects a mechanistic view of human beings based upon their genetic materials. Though the Declaration is concerned with protecting human rights related to all forms of control and uses of genetic data (which it recognizes as particularly sensitive) it also embodies an optimistic vision of human progress.


191. The OECD can be found at http://www.oecd.org/document/18/0,2340,en_2649_201185_1815186_1_1_1_1,00.html. It is a group of major industrial countries from around the world, including the United States. See id.

192. For example, a basic principle of this document is limitations upon the collection of personal data. See supra notes 165-81 and accompanying text. The data must be obtained in accordance with law, and with the consent of the person whose data is being collected. See supra note 166 and accompanying text. Personal data can only be collected for a specific purpose, and can only be used for that purpose. See supra note 170 and accompanying text. The document also assures persons access to their personal data, including the right to correct inaccurate data. See supra note 174 and accompanying text.


195. Article 3 states, "The human genome, which by its nature evolves, is subject to mutations. It contains potentialities that are expressed differently according to each individual's natural and social environment, including the individual's state of health, living conditions, nutrition and education." See Universal Declaration, supra note 193, at art. 3.

196. Article 1 of the Declaration states "[t]he human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and
IV. AMERICAN LAWMAKERS SHOULD ALSO ENDOw CITIZENS WITH A HUMAN RIGHT IN THEIR GENETIC INFORMATION

This Article concludes by providing a policy basis for American lawmakers to endow citizens with a human right in their genetic information. It begins by reviewing how the historical process of modernization has rendered those who live in contemporary societies weak and vulnerable to harms from outside sources. It then notes evidence of the rising power of private eugenics in contemporary America. It concludes by reviewing American sources supporting the empowerment of persons so that they can regain the independence necessary to be citizens of genuinely democratic communities.

A. The Process of Modernization and Human Vulnerability

The material framework for considering contemporary genetic information privacy law has been shaped by a cataclysmic process of modernization that began to affect Western civilization as early as the twelfth century. It has already transformed Western culture, and is now having a similar impact upon the cultures of many Non-Western countries across the globe. Both secular and religious literature exist that describes the process of modernization well. The sources of modernization include fundamental socio-economic, demographic, and cultural changes. They have transformed not only social institutions and practices, but even the way people think, as well as the most mundane aspects of daily popular culture.

The process of modernization has had both creative and positive and destructive and negative impacts upon human life. Technological advances and new economies associated with modernization have

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diversity. In a symbolic sense, it is the heritage of humanity." Id. at pmbl. "The aims of the Declaration are to ensure the respect of human dignity and protection of human rights and fundamental freedoms in the collection, processing, use and storage of human genetic data." Id.

197. See generally Lenoir, supra note 191.


expands human choice and enhanced human lifestyles in unprecedented and desirable ways. But modernization has also engendered many dislocations, including massive geographical, as well as social and economic, mobility that undermined traditional communities. Older hierarchies and personal bonds dissolved, and persons living in modernized societies became rootless and disempowered. Modernization also increased the power of outside forces that can intrude upon persons and their communities. In early modern Europe powerful monarchs began to emerge who reduced or eliminated the power of local aristocrats and consolidated power into new nation-states. They established governmental bureaucracies that were small, but still acted with unprecedented efficiency. Later, the industrial revolution spawned large enterprises, organized as corporations, that operated with unprecedented power and efficiency. Meanwhile, in modern industrial nations, governmental bureaucracies grew much larger, more efficient, and powerful.

Leading nineteenth century thinkers insightfully described how modernization destroyed traditional communities and isolated people. One of these thinkers was Alexis de Tocqueville, the acute French observer of antebellum America. America’s democracy had engendered a new man, the individual, separated from all human bonds, vertical and horizontal. According to the German thinker, Max Weber, the primary human relationships of the new man were forged through contracts, “the most impersonalized relationships of practical life into which humans...”

200. For example, it has expanded the range of affordable goods available to most people; facilitated expanded educational and travel opportunities; and in manifold ways elevated the lifestyle of those who live in modernized societies. Smith’s The Wealth of Nations, supra note 95, foresees many of these changes.


203. de Tocqueville wrote:

As social conditions become more equal, the number of persons increases who...have...retained sufficient education and fortune to satisfy their own wants. They owe nothing to any man, they expect nothing from any man; they acquire the habit of always considering themselves as standing alone, and they are apt to imagine their whole destiny is in their own hands.

Thus, not only does democracy make every man forget his ancestors, but it hides his descendants, and separates his contemporaries, from him. . . .

Alexis de Tocqueville, 2 Democracy in America 120 (Henry Reeve trans., 1961).
can enter into with one another.\footnote{\textcopyright 2004 Max Weber, \textit{On Law in Economy and Society} 192 (Max Rheinstein ed., Edward Shils & Max Rheinstein trans., 1954). The end of these human relations became who could cheat whom. See id.} The end result of this process, according to Karl Marx, was human alienation. Human beings became abstracted from all social and historical contexts, and in the process had become profane and viewed merely as means.\footnote{Karl Marx, \textit{On the Jewish Question} (1843), in \textit{The Marx-Engels Reader} (Robert C. Tucker ed., 1978).} Even contemporary conservative thinkers like Robert Nozick have also emphasized the devastating impact of modernization upon human community, observing that a defining characteristic of contemporary life is the “fact of our separate existences.”\footnote{Robert Nozick, \textit{Anarchy, State, and Utopia} 33 (1974).}

The destructive effects of modernization upon human life constitute what Charles Black called the “agony of modernization.”\footnote{Charles Black, \textit{supra} note 196. Among the disruptive effects of modernization listed in \textit{Gaudium et Spes}, supra note 196, at 2, ¶ 6, is the breakdown of “traditional local communities.”} The process of social disintegration that modernization entailed is represented by the evolution of the word “individual” during the seventeenth and eighteenth centuries. The meaning of the word “individual” experienced a metamorphosis, from being conceived of as something indivisible to its modern meaning of the isolated, distinctive, and self-contained, person.\footnote{See Raymond Williams, \textit{Keywords: A Vocabulary of Culture and Society} 133-34 (1976). The etymological roots of the word “individual” are “in-not-dividere,” (which means divide). Id. Although the meaning of “individual” evolved over several centuries, its use by Adam Smith in \textit{The Wealth of Nations}, supra note 95, published in 1776, was critical in its transition to its modern meaning. See also Macpherson, supra note 122.} Like Cain, after he killed Abel and was relegated to wandering rootlessly about the earth, modern people live an isolated existence that renders them disempowered and vulnerable to harms from a multitude of powerful outside forces.\footnote{Genesis 4:12-14 (King James).}

The process of modernization also has made personal genetic information easier to obtain and disseminate. Today, a person’s genetic code, as well as other health information, is easily obtainable: from saliva, a single cell of a blood sample, or even from a lock of one’s hair. Modern science can also easily reproduce a person’s genetic code.\footnote{With present technology scientists can make an infinite number of copies of DNA from a single blood sample. See George J. Annas, \textit{Genetic Privacy: There Ought to be a Law}, 4 \textit{Tex. Rev. L. & Pol.} 9, 10 (1999).} These advances in scientific knowledge, coupled with the recent trend to customize health care, increase the possibilities for misuses of personal health information. Customized health care requires the collection and...
storage of extensive medical information, including one’s genetic code, for each patient. Until recently patient medical information was recorded on paper and stored in community-based health care offices or institutions. In this setting the circulation of medical information was limited. The rise of electronic information technology, coupled with new integrated delivery systems of medical services, transformed the entire system of storage and distribution of personal medical records.211 Today this system has become thoroughly nationalized. Further, mainframe computers and the Internet facilitate the collection, analysis, storage, and wide and rapid distribution of huge amounts of genetic information to potentially unlimited numbers of users anywhere across the globe.212

The new technology is also creating a worldwide information market. In it the control, uses, and flow of personal genetic information are of particular importance.213 For example, those engaged in medical research view the accessibility of personal genetic information as basic to their efforts to improve human health. Corporations, which are increasingly multi-national, desire genetic information in making all sorts of decisions relative to the employability and insurability of persons. All levels of governments in modernized countries seek enormous amounts of information about persons, including genetic

211. According to the American Health Information Management Association, an average of 150 persons, including doctors, nurses, x-ray technicians, and billing clerks, have access to the medical records of patients who are hospitalized. See DEP’T OF HEALTH AND HUMAN SERVS., STANDARDS FOR PRIVACY OF INDIVIDUALLY IDENTIFIABLE HEALTH INFORMATION (1998).

And this is just the beginning of who can gain access to personal health information once its privacy is violated. See DEP’T OF HEALTH AND HUMAN SERVS., STANDARDS FOR PRIVACY OF INDIVIDUALLY IDENTIFIABLE HEALTH INFORMATION, FINAL RULE (2001) [hereinafter STANDARDS FOR PRIVACY (2001)], available at http://biotech.law.lsu.edu/cases/medrec/hipaa_final_rule.pdf.


Some recent lawmaking also recognizes the implications of the new technology for personal control of genetic information. See, e.g., MONT. CODE ANN. § 50-16-501; WASH. REV. CODE § 70.02.005 (2005). The nexus of technological change and concern for health information privacy is captured in a bill introduced into the 105th Congress by Representative McDermott of Washington. See Medical Privacy in the Age of New Technologies Act of 1997, H.R. 1815, 105th Cong. (1997). Its stated purpose was to “protect the privacy of health information in the age of genetics.” § 2(a)(6) asserts that “technologies that permit an individual’s health information to be computerized increase the possibility of unauthorized electronic access to the information.” Id. at § 2(a)(6).

213. Most transactions will tend to be recorded; the records will tend to be kept longer; information will tend to be given to more people; more data will tend to be transmitted over public communication channels; fewer people will tend to know what is happening to the data; the data will tend to be more easily accessible; and data can be manipulated, combined, correlated, associated and analyzed to yield information which could not have been obtained without the use of computers. See PAUL SIEGHART, PRIVACY AND COMPUTERS, 75-76 (1976).
information, for a variety of purposes, especially for the prevention and prosecution of crime and for making some decisions concerning eligibility for state benefits. Now armed with computer technology, all of the organizations, public and private, that have emerged since the early modern period, exercise an exponentially increased capacity to gather, use, and disseminate all manner of personal information, including genetic information.

Within the material framework of the process and effects of modernization briefly outlined in this section, American law is inadequate in the protection that it affords to citizens from harms by intrusions upon their genetic information. Concern about these intrusions is heightened by the recent rise of private eugenics.

The Recent Rise of Private Eugenics

Since the conclusion of World War II, state-based eugenics has fallen into disfavor in most countries of the world. However, with little notice, during the past generation attempts to enhance or cleanse the human gene pool have resurfaced. Egg and sperm banks provide an example of efforts to enhance the gene pool. An example of the impulse to cleanse the gene pool is efforts to encourage women and couples to consider the genetic implications of having children. The Office of Technology Assessment stated the implications of the HGP in the following way:

Human mating that proceeds without the use of genetic data about the risks of transmitting diseases will produce greater mortality and medical costs than if carriers of potentially deleterious genes are alerted to their status and encouraged to mate with noncarriers or to use artificial insemination or other reproductive strategies.214

More coercive is a joint resolution adopted by the International Huntington’s Association and the World Federation of Neurology in 1990. It refused to test women for a genetic predisposition to Huntington’s Disease (“HD”) unless they promised to terminate a pregnancy when it was discovered the fetus had an increased risk of HD.215


As we have seen, coercion deeply marred the first, state-based eugenics movement and it is not entirely absent from recent practices of private eugenics. Two practices that can place pressures upon women and couples in making reproductive decisions are genetic counseling and genetic screening. In response to the horror engendered by the eugenics during the second quarter of the twentieth century, after World War II genetic counseling in theory became non-directive, and thereby supportive of genuine individual autonomy. There exists substantial evidence, however, that even non-directive genetic counseling is not neutral. Similarly, offering genetic screening can place subtle pressures upon women thinking about procreation, and can also stigmatize the dispossessed and powerless.

Although women and couples whose socio-economic status is low are most vulnerable to practices that can influence reproductive decisions, no one is immune from such pressures. At the root of attempts to influence women and couples in making reproductive decisions is the persistence of the view, foundational to all stripes of supporters of eugenics from the late nineteenth to the mid-twentieth century, that decisions to have children are a matter of public concern. External pressures upon reproductive decisions will increase as new genetic knowledge fuels the present hope for enhanced human health, and the future vision of a superior human race. For example, a futuristic book published by Professor Philip Kitcher suggests various mechanisms, including the education of teenage students to encourage

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217. Professor Roscam Abbing observes that: “The mere offer of a screening programme puts the individual under strain to know or not to know.” H.D.C. Roscam Abbing, *Some Legal Aspects of Genetic Screening*, 22 MED. LAW 201, 209 (2003). When “the screening test is offered for the purpose of procreative choice (pre-natal or pre-conceptual), it can put the individual under constraint of ‘socially correct’ decision-making. The increased possibilities of prenatal screening may contribute to a climate in which acceptance of the handicapped will come under great pressure.” *Id.*

218. In third-world countries a lack of available services and economic constraints often exert great pressure upon women and couples in their reproductive decisions. Even in America, in which wealth is distributed primarily by market forces, such factors can have an impact. This depends upon a number of variables, relating to the economic status of the woman and couple, as well as the availability of services offered to them from municipal, county, state, and federal governments. *See ANDREWS, supra note 77 at 59.*

219. Even John Stuart Mill, the most eloquent defender of individual autonomy in nineteenth-century English culture, classified decisions to parent and have children “as one of the most responsible actions in the range of human life,” and as “matters of public interest” that government could validly regulate. John Stuart Mill, *On Liberty*, in *THE ESSENTIAL WORKS OF JOHN STUART MILL* 353-54 (1961).
what he perceives to be responsible family reproductive decisions that take account of genetic defects.\textsuperscript{220} Recent laws that would place a legal duty upon doctors to disclose genetic defects they discover in their patients to family members or the even newer idea that it is the family blood line that is the unit rather than the individual who controls genetic information, also raise the possibility of creating eugenic pressures upon persons to cleanse their gene pools.

Disclosures of genetic information among family members, though seemingly quite private, can sometimes create the basis for human domination. Martha Minow reminds us that "\textsuperscript{221}in reality, the family is not an entity, but a collection of individuals who have relationships with one another." John Hardwig warns of the real, and sometimes, deep conflicts of interests, beliefs and values among family members.\textsuperscript{222} Hardwig's warning of conflicts of interests and values among family members is particularly relevant because involuntary disclosures of genetic information confer power upon their recipients. There is a huge difference between voluntary and involuntary disclosures of personal information like one's genetic makeup. The latter renders one constrained, coerced, or manipulated to act on behalf of another's interests or aims. Such actions not only do not contribute to the person's self-development, they are forms of domination.\textsuperscript{223} In contrast, empowered persons, endowed with control over their genetic information, can freely choose to disclose personal genetic information, providing an important basis for the deepest and most personalized of human relationships.\textsuperscript{224}

\textsuperscript{220} KITCHER, supra note 8. In 1910 Francis Galton, the founder of the science of eugenics, delineated the characteristics of a utopia, called Kantsaywhere, in which people adhered to strict laws regulating procreation. See Pierpoint, supra note 8. Kitcher's focus is upon family planning, but one can without difficulty imagine the use of genetic information for greater intrusions upon reproductive choice.

\textsuperscript{221} Martha Minow, \textit{Who's the Patient?}, 53 MD. L. REV. 1173, 1182 (1994). In the Bible the deepest human bonds were shared by persons without blood ties, like Jonathan and David; or even persons with different ethnic backgrounds, as were Ruth and Naomi. Conversely, the Bible is replete with examples of family discords and betrayals, including of Abel by Cain, of Joseph by his brothers, and of Esau by Rebekah and Jacob.


\textsuperscript{223} CAROL C. GOULD, \textit{RETHINKING DEMOCRACY: FREEDOM AND SOCIAL COOPERATION IN POLITICS, ECONOMY, AND SOCIETY} 48-50 (1988). This domination can be manifested either by reshaping relationships among family members and blood relatives, or by a recipient of such information disclosing it outside the family circle. \textit{See id.}

\textsuperscript{224} Relying heavily upon the philosophers Immanuel Kant and John Rawls, Professor Charles Fried argued that the individual's control of personal information is the precondition for voluntarily disclosures of information that are essential to forming relationships of love, friendship, and trust.
B. An American Ideology of Empowerment Justifying a Human Right in Personal Genetic Information

There exist several contemporary factors that encourage American lawmakers to seriously consider adopting the approach to information privacy of EU law. One is international comity. This is a consideration that American lawmakers must begin to pay heed as a global information market becomes a reality. A second factor is American public opinion. The recent wave of health privacy legislation during the past decade in America is rooted in increasing popular support for such law in America. This is demonstrated by a Harris survey finding that eighty-five percent of patients surveyed asserted that the confidentiality of the medical information they provided to doctors was very important to them. The recent wave of health information privacy legislation reviewed in Part II.A.2 of this Article attests to the public support for the view that genetic information privacy is an important matter.

This section, however, will elaborate an ideology that justifies endowing citizens with a human right in their personal genetic information, one that is rooted in American history. Basic democratic values of respect for human dignity, of human liberation, and of the empowerment of citizens have strong roots in American legal traditions. This lawmaking tradition has had a number of manifestations, including the empowerment of persons by endowing them with land, the right to public education, and more recently, the expansion of public benefits. The intended result of this lawmaking is liberated and independent


225. The root word *comitas* suggests the practice of courtesy or civility.

226. For examples of the numerous scholarly writings that have addressed this very issue, see SOLOVE & ROTENBERG, supra note 152; Shaffer, supra note 13. So far, both American diplomacy and companies have sought to facilitate the globalizing information market by trying to persuade the EU to lower its information privacy standards. But as other scholars, notably Shaffer, have pointed out, another way to harmonize the global information market is for American law to "ratchet up" its standards. *Shaffer*, supra note 13, at 11.


A survey of popular opinion conducted by the California Health Care Foundation in 1999 concluded that "public distrust of private and government health insurers to keep personal information confidential is pervasive." Only one-third of the persons surveyed expressed trust in private and governmental health plans to "maintain confidentiality all or most of the time." One-fifth of the respondents believed that their health care information had been disclosed inappropriately. Mistrust of the uses of medical information provided to web sites to obtain medical advice was even deeper, with almost ninety percent of the respondents asserting that this information would be misused. ELIZABETH HADLEY, Preface, in THE STATE OF HEALTH CARE PRIVACY: AN UNEVEN TERRAIN (1999).
citizens who can flourish and provide the basis for authentic democratic communities.

A wide distribution of landholding has deep roots in American history, back to the early colonial period in New England. But the emergence of a democratic ideology justifying a wide popular distribution of land to Americans occurred during the eighteenth century. Celebration of agriculture and the agrarian lifestyle was in the air in the eighteenth century, in both Europe and the American colonies. It had multiple sources. American agrarianism was ultimately forged within the particular context of the colonies' democratic revolution and the abundance of land in the New World. In retrospect, historians have called the ideology justifying the wide distribution of land the freehold concept. It has a number of propositions, two that are of particular importance for us. The first is that ownership of land, the means of production in a pre-industrial society, provides a basis for human virtue, dignity, and self-realization. The second, less recognized in literature, is that though land ownership provides the basis for independence, citizens are integral to, and provide the foundation for, virtuous democratic communities.

A number of American colonial writers, notably Benjamin Franklin, George Logan, and St. John de Crevecoeur, contributed to the development of the freehold concept. After America's successful revolution from British colonial rule, the federal constitution for the new

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228. Both law and practice of the early Puritan New England colonies provided for a much wider distribution of land among settlers than existed in the England they had just left. This point is clear from both the initial distributions of land that the colony and its towns made to settlers, and from the law regulating the intestate inheritance of land. In contemporary England the principle of primogeniture guided intestate succession of land, and so the eldest son inherited all of a family's real property. In stark contrast, the law of intestate succession in the seventeenth-century New England colonies was by partible inheritance. Pursuant to it, each child, male and female, received an equal portion of the family's real estate, with the exception of the eldest son, who received a double portion.

The seventeenth century English colonies in America were not democratic. Other factors, including the need for labor; Puritan Biblicism, (the basis for the adoption of partible inheritance); and the availability of land in the New World; influenced law and practice of land distribution in these early colonies. See generally LAWRENCE M. FRIEDMAN, A HISTORY OF AMERICAN LAW (2d ed. 1985).

229. These included the ideologies of the Physiocrats, and later the Romantics, in Europe, as well as a revival of interest in ancient classics. See Paul H. Johnstone, In Praise of Husbandry, 11 AGRIC. HIST. 80, 80-95 (1937); see also A. WHITNEY GRISWOLD, FARMING AND DEMOCRACY (1948).


231. GRISWOLD, supra note 229, at 43-47. For a classic exposition of the freehold concept, see HENRY NASH SMITH, VIRGIN LAND: THE AMERICAN WEST AS SYMBOL AND MYTH 166-73 (1950).
nation contained strong protections for property rights. One reason for this was the influence of James Madison during the drafting of the document.

But it was Thomas Jefferson who most fully developed the freehold philosophy, and whose writings were most influential in shaping later American culture's celebration of it.\(^2\) By 1776, the young Jefferson had already formulated his version of the freehold concept. In that year he wrote the Declaration of Independence, which included the most famous statement in all of American political literature, that all men have a natural right to "life, liberty, and the pursuit of happiness." In the same year, in the legislature of his home colony Virginia, which was in the process of becoming a state, Jefferson introduced three bills that tried to implement the Declaration's philosophy by providing the material basis for an independent yeomanry. These bills proposed the abolition of both the common law of entails and primogeniture, and that every citizen be endowed with fifty acres of land.\(^3\)

Throughout his life Jefferson remained steadfast in his commitment to create an empowered and independent yeomanry as a basis for a virtuous democratic community. Unlike the aristocratic Physiocrats of his era, who favored large landed estates, Jefferson, in both his writing and lawmaking, sought a wide distribution of land. This is because he believed that landowning, particularly as a basis for agriculture, provided the basis of economic independence of citizens. What was of greatest importance to Jefferson was that this economic independence had salutary moral, political, and broadly cultural effects. He made this point clearly in one of the most quoted passages in his *Notes on the State of Virginia* (1785). In it Jefferson wrote that, "[t]hose who labor in the earth are the chosen people of God . . . whose breasts He has made His peculiar deposit for substantial and genuine virtue."\(^4\) In contrast to the virtue of the independent yeoman, Jefferson continued, "Dependence begets subservience and veniality, suffocates the germ of virtue . . . generally speaking, the proportion which the aggregate of the other classes of citizens bears in any State to that of the husbandman, is the proportion of its unsound to its healthy parts, and is a good enough

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232. Jefferson's freehold philosophy was enormously influential in shaping nineteenth-century American culture, and its premises remains important even today. See SMITH, supra note 231. See also JOYCE APPLEBY, THOMAS JEFFERSON (2003).


234. THOMAS JEFFERSON, NOTES ON THE STATE OF VIRGINIA 164-65 (William Reden ed., 1955)
barometer whereby to measure its degree of corruption." \(^{235}\) Jefferson was particularly worried about human dependence because he was aware of the beginnings of the Industrial Revolution in England. He foresaw that landless wage laborers in industrial factories would become particularly dependent and vulnerable.

There are two related and very important premises that are implicit in the views that Jefferson expressed in his *Notes on Virginia*. First, the premise of Jefferson's view that widespread landowning could provide the basis for a morally uplifted citizenry is that the human personality is not static, but rather capable of attaining a higher self. Next, although Jeffersonian valued and championed the concept of negative liberty (exemplified, by his ardent support of freedom of religious conscience), implicit in his association of landownership with human independence is a concept of moderately positive liberty. That is, human liberty is comprised not merely of free space for thought and action, but requires conditions empowering persons to attain their higher selves. \(^{236}\)

Four years after the publication of his *Notes on Virginia* Jefferson again affirmed the importance of a wide distribution of unencumbered land as critical to establishing empowered and independent citizens. In a letter he wrote to James Madison on September 6, 1789, Jefferson asserted that, "the earth belongs in usufruct to the living." \(^{237}\) Like the Declaration's "life, liberty, and pursuit of happiness," this assertion seems to be pregnant with potential implications. In this context, what is most significant about this letter is that Jefferson begins it by expressing concern about law that allows debts of one generation to be passed onto the next. To him, such law is contrary to "natural right," for it allows the dead to burden the free use of the land by the living. \(^{238}\) Jefferson's advocacy for law that prohibited contracting debts that could be passed on to later holders of land reinforced the empowerment theme in his vision of a freehold republic, and was consistent with his earlier legislation abolishing entail and primogeniture and endowing all white males with fifty acres of land.

But without doubt the act that demonstrated Jefferson's unwavering support for an empowered citizenry living in a empire of liberty with a wide diffusion of land ownership was the Louisiana Purchase. The Purchase encompassed almost 900,000 square miles of land—as large as

\(^{235}\) Id.
\(^{236}\) See Taylor, *supra*, note 123.
\(^{237}\) This letter can be found in 14 THE PAPERS OF THOMAS JEFFERSON 292-97 (Julian P. Boyd ed., 1958).
\(^{238}\) Id. at 293.
the combined territory of Spain, Portugal, Italy, Germany, France, and the United Kingdom—and its acquisition would almost double the size of the United States at that time. In Jefferson’s view it would provide the basis for a freehold republic for generations to come. France, needing money for the Napoleonic wars, wanted to consummate the deal quickly. During the negotiations Jefferson drafted a constitutional amendment to provide a legal basis of authority for the Purchase, but there was not time to adopt it. So Jefferson departed from his usual strict construction of the Constitution and made the deal. It is commonly believed that limited government was a core characteristic of Jeffersonianism. The Louisiana Purchase, however, demonstrates that Jefferson’s bedrock commitment was to the liberation and empowerment of independent citizens. When limited government did not serve this end, he was willing to depart from it.

The vision of a society of empowered, virtuous, and independent citizens living in a democratic society remained vital in American legal culture long after Jefferson’s presidency. During the antebellum, or Jacksonian, period of American history, there occurred a hydra-headed movement calling for reforms, including legal reforms, of many aspects of American society. Within this constellation of antebellum reformism, of particular relevance here is the movement for universal public education of children. In a letter written to John Tyler in 1812, Jefferson had expressed support for the universal education of citizens. By the antebellum era, a reform movement supporting it was spearheaded by Horace Mann of Massachusetts. In his twelfth report on education in 1846, Intellectual Education as a Means of Removing Poverty, and Securing Abundance, Mann expressed concern about the increasing disparity in the distribution of wealth during the antebellum period, raising the possibility of class conflict and a new feudalism in America. Mann’s antidote to this dreaded specter was universal education, transcending the lines of class, and providing each man “the

239. APPLEBY, supra note 232, at 65.
240. Jeffersonian limited government was shaped not only by his support for civil liberties, but also by his recognition that centuries of mercantilist regulations of human economy had been a tremendous drag upon human creativity. See id. Jefferson’s views of political economy were highly influenced by Smith’s THE WEALTH OF NATIONS, supra note 95.
241. John L. Thomas, Romantic Reform in America, 1815-1860, 17 AM. Q. 656 (1965). Popular reform movements included intense missionary work, utopian communities, Sunday schools and universal public education, proper diet, and a variety of legal reform movements. The list of these movements is long, and includes antislavery, a women’s movement, Sabbath-observance, temperance, and institutional care for the deviant and dependent. Id.
242. The letter is published at LIPSCOMB & BERGH, WRITINGS OF JEFFERSON, 12: 93-94.
independence and the means by which he can resist the selfishness of other men" and attain his higher self.\textsuperscript{243} Mann envisioned that universal education, stirring the infinite capabilities of each person, would lead to a more perfect American democratic community.\textsuperscript{244}

Reflecting both the influence of Romantic thought and evangelical religion, Mann, in contrast to the utilitarianism that shapes contemporary American law of genetic information privacy, viewed the human personality not as static, but as a reservoir of potential, capable of perfectability.\textsuperscript{245} Mann affirmed that everyone, even the blind, the deaf and dumb, and mentally disabled, had within them "the latent spark of intelligence."\textsuperscript{246} As had Jefferson, Mann believed that true human liberation entailed empowering persons with the means to develop their human potential. Like other reformers of that era, Mann also believed that social progress was rooted not in institutional reforms, but in citizens, through moral reform, realizing their higher selves.

The Civil War proved to be the death-knell of the antebellum period's broad-based impulse for social reform. Nevertheless, the vision of the freehold republic retained vitality. It undergirded the Homestead legislation passed by Congress during that period.\textsuperscript{247} Even into the New Deal era, when America for many reasons had moved far from the reality of that vision, remnants of the freehold concept persisted.\textsuperscript{248}

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243. & Horace Mann, Report No. 12 of the Massachusetts School Board (1848), available at http://usinfo.state.gov/usa/infousa/facts/democrac/16.htm. Mann wrote: \textit{Under the Providence of God, our means of education are the grand machinery by which the 'raw materials' of human nature can be worked up into inventors and discoverers, into skilled artisans and scientific farmers, into scholars and jurists, into the founders of benevolent institutions, and the great expounders of ethical and theological science.} Id. \\
244. & \textit{Id.} \\
246. & Mann, \textit{supra} note 243, at 58. How different this is from the view of the disabled and dispossessed that underlay the eugenics statutes of the early twentieth century, and the forced sterilization of Carrie Buck in \textit{Buck v. Bell}. \\
247. & It allowed families who settled upon and farmed land to own up to three hundred and sixty acres of land after five years. The legislation had a number of ideological justifications, but in the West the critical one was the vision of the freehold republic. SMITH, \textit{supra} note 231, at 170. Homestead legislation culminated several generations of political activism attempting to democratize the distribution of land in America. \textit{See generally} PAUL GATES, \textit{THE FARMERS AGE: AGRICULTURE, 1815-1860} (1960). \\
248. & Franklin Delano Roosevelt's Secretary of Agriculture, Wickard wrote in 1944: "The U.S. Department of Agriculture believes that the welfare of agriculture and of the nation will be promoted by an agricultural land tenure pattern characterized by efficient family-size owner-operated farms." GRISWOLD, \textit{supra} note 229, at 661. Several of the reasons why the vision had become obsolete include an exponential rise of American population, making less land available for
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By the late nineteenth century forward-thinking Americans had to come to grips with the end of the American frontier and the nation's now full-blown industrial order. The Progressive ideology that came to dominate American culture during much of the twentieth century would depart sharply from the American tradition of local and limited government. For example, Progressive thought was the seedbed for paternalistic lawmaking, including public health utilitarianism. Nevertheless, one of the central concerns of Progressives was how, in a modernized world that seemed to dwarf the individual, to maintain the Jeffersonian vision of independent citizens enjoying real liberty in authentic democratic communities. For Progressives, in a modernized world this would require affirmative lawmaking providing a basis for human autonomy. As early as 1907, in his popular and influential book The Promise of American Life, Herbert Croly asserted that in contemporary America, "Hamiltonian means" were necessary to assure "Jeffersonian ends" of an independent and empowered citizenry. In The New Freedom Woodrow Wilson echoed Croly's view. Much of New Deal lawmaking was based upon this concept, an important example being the establishment of the system of collective bargaining that is the cornerstone of modern American labor law.

Progressives varied in how they sought to facilitate an independent citizenry in a modernized economy and culture. Some, notably the most famous of all American historians, Frederick Jackson Turner, again stressed educational opportunity as the critical basis for establishing citizen independence in an America that no longer had a frontier that could support the freehold concept. Building upon Turner's history, Franklin Delano Roosevelt, asserted that the end of the frontier justified New Deal welfarism. Near the end of his long tenure as president of the United States, and of his own life, FDR recalled the Jeffersonian tradition of inalienable rights to justify a new list of rights necessary for citizens living in a modernized world. In an address to Congress in 1944 he asserted: "We have come to a clear realization of the fact that true individual freedom cannot exist without economic security and

250. Wilson wrote: "I feel confident that if Jefferson were living in our own day he would see what we see . . . Without the . . . resolute interference of the government, there can be no fair play between individuals and such powerful institutions as the trust." APPLEBY, supra note 232, at 134.
independence.” He proposed a list of new freedoms to be added to the now inadequate freedoms embodied in the original Bill of Rights of the Constitution. Among these included “the right to earn enough to provide adequate food and clothing and recreation,” and the “right to a good education.”

The American jurisprudence of legal realism emerged simultaneously with the New Deal. One of its important goals was to reshape law to assure Jeffersonian independence of citizens in modern legal transactions. This is illustrated by Morris R. Cohen’s important essay on contract law, *The Basis of Contract.* Building upon the concern of other realist thinkers about what constituted real human consent in contracting, Cohen attacked the classical conception of freedom of contract, that people enjoyed liberty if they could make any contract agreements they desired. He observed that, “mere freedom in absence of restraint, without positive power to achieve what we deem good, is empty and of no real value.” Recalling the Jeffersonian tradition, Cohen suggested that because of disparities in bargaining power, in the modern world negative liberty was inadequate to assure the real freedom of contract necessary for genuine human independence. Another major theme of legal realism that was prominent in Cohen’s article was an attack upon the distinction in classical law between public and private activity. He observed that not only did the ability to make contracts constitute a delegation of power to citizens, but the law legitimately placed certain limits upon this power, to create a genuine capacity to contract, or restrain overreaching through contracts. All of these themes, the coalescence of public and private, the lack of real bargaining in many contracts, and a positive view of liberty, justified increased legal supervision of contracts and the contracting process.

Twenty years after FDR called for an expanded bill of rights Charles Reich published an important article in the Yale Law Journal. In terms akin to Horace Mann he expressed concern that a new feudalism would arise in modern America, in which many citizens would become

252. EDWARD S. CORWIN, LIBERTY AGAINST GOVERNMENT 4 n.3 (1948).
253. Id.
256. For example, Cohen believed that for the person who could not obtain a job the ability to contract was meaningless. See generally Cohen, supra note 254.
257. The Supreme Court adopted this position in *Shelley v. Kramer,* 334 U.S. 1 (1948), when they struck down a racially restrictive covenant in a land sale contract.
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Economically servile. To avoid this eventuality required that American law recognize a new form of property: welfare benefits.\footnote{258. Charles Reich, \textit{The New Property}, 73 \textit{Yale L.J.} 733 (1964); see also Frank Michelman, \textit{The Supreme Court, 1968 Term, Forward: On Protecting the Poor Through the Fourteenth Amendment}, 83 \textit{Harv. L. Rev.} 7 (1969).}

In the same year that Reich published his "new property" article, Edward Bloustein argued that the "inviolable personality," referred to by Warren and Brandeis in their landmark article on privacy law, required the development of a more generalized law of privacy than the four strands of common law of privacy synthesized by Dean Prosser in his then recently-published article.\footnote{259. Bloustein, \textit{supra} note 78.} Bloustein argued that citizens in modern society, lacking the protection of privacy law, were highly subject to public scrutiny. They would therefore conform themselves to standardized societal expectations and become purely conventional, part of an undifferentiated mass of cloned citizens, (a fear that had been central to Mill's essay, \textit{On Liberty}, a century earlier). The development of each person's unique moral personality would be completely stifled. Bloustein therefore believed that privacy law was essential not only to provide the basis of independence necessary for the development of the human personality, but also for the necessary tolerance of individual diversity essential to a genuinely democratic community.

The tradition of those Americans who, based upon democratic values, have advocated for law supporting a wide diffusion of landholding, universal public education, public benefits, and a wider concept of human privacy, provide precedents for endowing citizens with a human right in their genetic information. In a world that has experienced the enormously dislocating effects of the long historical process of modernization, in which new forms of technology in unprecedented ways threaten citizens' control of their personal information, and in which private eugenic efforts are resurgent; lawmakers should endow vulnerable citizens with a human right in their genetic information. This legal reform is essential if contemporary America is to maintain the reality of the beautiful vision of our ancestors, of empowered and independent citizens living in genuinely democratic communities.