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Ilise L. Feitshans

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Spider Silk Jeans or Spider Silk Genes? The Future of Genetic Testing in the Workplace

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*Ilise L. Feitshans**

INTRODUCTION

When I was driving home one afternoon in August 2000, I heard for the first time about spider silk genes. It's one of those things heard on the radio that I so often hesitate to cite — even from as reliable a source as NPR — because the journalist's account seems so unreal I think I either misheard or perhaps that the data was incorrect or that the entire news story was a hoax. The fashion reporter, of all sources, was explaining on the radio that Spider silk genes were studied and cloned to make fabric for lightweight athletic gear. To be woven into the loom, just like any other threads. Visually, I could see the spider web in my brain and the picture of genes used to make stronger, lighter genes made very good sense to me. It was an image that holds logic. But the second part of the same news story account made little sense: it was stated that the same researchers were studying not the characteristics of spider silk, but the ability to replicate spider silk genes, so that athletes could undergo gene therapies that would enable their tendons or muscles to heal more rapidly and withstand more stress. Fewer surgeries for fewer reasons and the ability to heal less often. It all sounds too good to be true. And perhaps it is. But what does the prospect of spider silk genes in humans mean for the future of occupational health?

This small potential example brings forth important questions to examine about where the law draws the line for society regarding any incentives or limits upon genetic research: Does society's rights expressed under law trump the rights of individuals regarding ge-

* Ilise L. Feitshans, J.D., Sc.M., is an adjunct faculty member at Cornell University, and The George Washington University.

netic information and the application of genetic technologies to various situations? Whether discussing the information revealed through genetic testing and diagnosis or gene therapy and engineering, important questions arise under law. Present public health powers can be used to laws mandate testing or treatment to fix some of the bad genes or enhance existing genetic traits. How much of such genetic modification and retooling will law allow? Will spider silk genes become part of the basketball or soccer player's job descriptions? And what of the athletic parent who refuses such treatment for an unborn offspring—will that parent have not done enough for their child? Will the law allow employers to include genetic traits in job criteria for employment? Or will employers be required to accommodate every conceivable genetic disability under ADA, prohibiting genetic discrimination even if a genetic condition or the absence of a genetic enhancement exists by choice?

The laws that govern this area of human behavior, or human interaction with other species are yet to be written. Likely, too, the opportunity to write or implement any of these unwritten laws of the future will be given to every person in this room, in three areas of law and science: privacy; human rights and the legal definition of "human being" and the application of those laws to labor relations, specifically in workplace health and safety.

A. *The Role of the Rule of Law*

Critics of genetic research long ago cautioned, that "[t]he mapping of the genome . . . does not tell us anything about function, which is what the gene sequences do in the organism,"¹ and therefore have raised several policy questions about genetic testing. Consequently, critics of the Human Genome Project and related "Big Science" spending in commercial fields have expressed their concerns regarding the impact of new genetic tests on autonomy and informed consent, mindful that there can never be true informed consent in a workplace situation without also eroding protections under law that prevent workers from accepting the "assumption of the risk."

¹ Sydney Brenner, *The Human Genome: The Nature of the Enterprise*, in HUMAN GENETIC INFORMATION: SCIENCE, LAW AND ETHICS 149, 6-7 (CIBA Foundation Symposium Staff Press 1990).

Despite the temptation to immediately implement the medical advances that are represented by this new technology, the development of genetic testing based on “merely” taking a “simple” blood sample holds important implications for the autonomy of workers and their right to informed consent before testing. Looking at precedents in the case of HIV testing, the modern paradigm has shifted away from the “invasiveness” of testing, towards a hard look at the emotion burden that testing places upon patients. At present, there are no clear bioethical or legal standards to determine, how much information is necessary to be informed? Can a rational patient nonetheless make decisions that appear to be informed but are not, and are contrary to their own best interest?

This brings into question the conflict between principles of beneficence and principles of autonomy in bioethics and their implications for the theoretical construct that surrounds genetic testing in the workplace and any safeguards that ensuring that workers have undergone requisite gene therapies, as a part of occupational health care. To the extent that occupational health services also deal with pregnant workers, the role of gene therapies, fetal surgeries or genetic screening and testing as a part of prenatal care, possibly in response to workplace toxins or other aspects of the working environment, may also become included in the panoply of services that will be included in modern occupational health care. Further, preserving the workers’ rights to demand informed consent procedures such as counseling and the dissemination of information is crucial to preserving the right to refuse testing and treatment.

B. Implications for a “New Eugenics”

Just when U.S. President Clinton joined other world leaders to announce the completion of genetic cartography, four philosophers from academia have stepped forward together to perform an “ethical autopsy” of eugenics: exploring the implications of eugenic theory for new genetic interventions. *From Chance to Choice: Genetics and Justice*² could not be more timely. Appearing in print

² ALLEN BUCHANAN & DAN W. BROCK, *FROM CHANCE TO CHOICE: GENETICS AND JUSTICE* (Cambridge University Press 2000) (providing a succinct and concise statement of the questions that society will confront as genetic technology and interventions become commonplace in the years ahead). See also Ilise L. Feitshans, *From Chance to Choice: Genetics and Justice*, 820 NEW ENG. J. MED (Sept. 2000).

contemporary to press releases heralding the completion of full-scale mapping of the human genome, the authors could not have written for themselves a better timing for their book. As the title suggests, their treatise raises fundamental issues of justice, fairness and equality that lurk in the shadows of eugenics, just beneath the glitzy research of "Big Science" used to map the human genome. What does it mean when society views a trait as desirable? Does that make the trait good? Which traits trump others? Does genetic-based medicine only look for disease (whatever that is) or also for desirable traits? If so, which desirable traits are more important?

At the root of the eugenics movement was the fear that "racial poisons were threatening the health of the race; that the criminal, mentally ill, and morally dissolute were out breeding the more up-standing elements of society."³ One basic tenet of the eugenics movement was "biological determinism—the idea that biology lies at the root of most human talents and disabilities."⁴ States enacted sterilization laws aimed at "purifying and keeping pure blood in America." In 1907, Indiana passed the United States' first sterilization law, forcing the sterilization of people based on genetic defects.⁵ The United States Supreme Court upheld the sterilizations; the Court has never specifically overruled this decision.⁶ The Court upheld Virginia's forced sterilization law for "mental defectives" and found that the law did not violate the Fourteenth Amendment's Due Process or Equal Protection Clauses.⁷ Similar laws, never overturned, form an important part of our society's legal matrix.

I. PRIVACY

A. *Personal Privacy versus Commercialism*

"Genetic information is not only of value to the individual patient; employers, insurers, educational institutions, law enforcement officials and others may wish to gain access to an individual's personal genetic profile . . . [with a] great potential for third parties to

³ Robert M. Proctor, *Genomics and Eugenics: How Fair is the Comparison?*, in *GENE MAPPING: USING LAW AND ETHICS AS GUIDES* 57, 60 (George J. Annas & Sherman Elias eds., 1992).

⁴ *Id.*

⁵ *Id.* at 61 (citing Act of March 9, 1907, ch. 215, 1907 Ind. Acts 377 (held unconstitutional in *Williams v. Smith*, 190 Ind. 526, 131 N.E. 2 (1921), *repealed by* Act of February 23, 1963, Ch. 17, 1963 Ind. Acts 12.))

⁶ *Buck v. Bell*, 274 U.S. 200 (1927) (per curium).

⁷ *Id.* at 207.

misuse information.”⁸ Yet, there is no national consensus whether privacy of any type should be protected and what that law looks like in the United States. It seems that most people want to protect their personal privacy, but also want information about the people around them. Privacy rights are a fragile cluster of protections for personhood. “Although compulsory vaccinations, compelled blood tests, extractions of contraband narcotics from the rectal cavity and even surgical removal of a bullet have sometimes been upheld on a showing of clear necessity, procedural regularity, and minimal pain, in each case the matter has been taken with enough seriousness to warrant a conclusions that an aspect of personhood was at stake, and that government’s burden was to provide more than minimal justification for its action.”⁹

Consequently, the current status of privacy law in the U.S.A. is a patchwork of rules with many exceptions. There is no U.S. Constitutional right of privacy, other than relating to sexual relations between married people, to clarify or defend the right to privacy that people, especially occupational physicians prize. There is an important question whether there exists any especially protected information within the constitutionally protected “zone of privacy” concerning genetic information in personal or reproductive decision making, as defined by the U.S. Supreme Court. Privacy preserves the right to the most intimate forms of freedom that impact on personhood and sense of self.¹⁰ “Few values so fundamental to society as privacy have been left so undefined in social theory,”¹¹ according to Westin. He traced the role of privacy in the animal world and in primitive societies, fundamental and inherent character within social organizations. The flip side of privacy is the public interest in

⁸ Lori B. Andrews, *The Randolph W. Thrower Symposium: Genetics and the Law: Introduction*, 39 EMORY L.J. 619, 624 (1990).

⁹ LAURENCE H. TRIBE, *AMERICAN CONSTITUTIONAL LAW* 1331-1332 (4th ed. 2000).

¹⁰ See Kendall Thomas, *Beyond the Privacy Principle*, 92 COLUM. L. REV. 1431 (1992) (writing about *Bowers v. Hardwick*, 478 U.S. 186 (1986), “the most private of all privacy cases,” at 1437, 1448. “By recognizing a physical zone of privacy into which the state may not intrude to interdict consensual intimate conduct, the Supreme Court has shown itself to be sensitive to the mutually constitutive relationship between the intimate life of the individual and the places in which that intimate life unfolds.”) *Id.* See also RUTH MACKLIN, *GENETICS AND THE LAW III* (Plenum Press, 1985).

¹¹ See ALAN F. WESTIN, *PRIVACY AND FREEDOM* 7 (Atheneum New York 1967).

the otherwise protected information itself: If there are genes with high risk for Alzheimer's disease or some other disorder, should the newspaper be allowed or compelled to publish the President's genome? Genetic information can be trafficked, to target markets for procuring or selling commodities based on individual genetics.

The race to find genetic information and apply genetic technology unleashed a fierce battle in public health law regarding individual rights to privacy and informed consent, competing with society's interest in applying genetic information for commercial purposes and public health planning. Examples include: mandatory testing and registration of genetic information; commercial access to the names and identifying information of people with desirable genes that could be purchased for medical purposes, such as creating new tissue for gene therapies.

Is there a right to refuse treatment, or testing, as a part of genetic privacy regarding medical decisions? Is there a right to keep the "magic gene" that will cure someone else's ailment for oneself, one's family or the highest bidder? Or an obligation to accept such a cure, regardless of an individual's will or the will of a parent regarding the future health of a minor child because of the greater public good? Will people who are tested and refuse treatment for themselves or their children be held liable in tort for the subsequent consequences of their refusal? Even if the refusal is part of their religious beliefs? Is there informed refusal?

Heralding the benefits of genetic advances, the U.S. Supreme Court stated "Scientists, among them Nobel laureates, are quoted suggesting that genetic research may pose a serious threat to the human race . . . We are told that genetic research and related technological developments may spread pollution and disease, that it may result in a loss of genetic diversity, and that its practice may tend to depreciate the value of human life. . . .We disagree."¹²

¹² *Diamond v. Chakrabarty*, 447 U.S. 303, 316-17 (1980); E. RICHARD GOLD, *BODY PARTS: PROPERTY RIGHTS AND THE OWNERSHIP OF HUMAN BIOLOGICAL MATERIALS* (1996); PAULINE NEWMAN, *INTELLECTUAL PROPERTY LAW AND THE NEW BIOLOGY*, Summer 1997, at 46.

1. Benefits to Society That Outweigh Individual Genetic Privacy

Two theories of ownership of this information have emerged under the law:

a. Individual Ownership: Genetic information innately belongs to any one individual because it is personal and medical in nature.

b. Common Inheritance of Mankind: Yet, because genetic inheritance is shared within families, whole races or ethnic groups, there is a competing view that it is actually "owned" by not one person, but society as a whole. This theory views gene pool information as public property because it was developed with public funds, and the use of this data benefits society as a whole, rather than any given individual. This has implications for both: the testing and use of seemingly personal genetic information, and for the determination of ownership of "discoveries" and patentable inventions based on manipulation of genetic material. It would be difficult, from the standpoint of practice, to set forth a consistent rule that would uphold personal privacy in genetic information while also promoting commercial ownership and development of genetic technologies using genetic information. The inherent conflict in these two positions may explain the schizophrenic attitude regarding privacy and confidentiality manifest in the U.S. laws.

SALE OF DATABASES OF HUMAN GENETIC INFORMATION:

Personal health information is presently transferred to third parties, including the Medical Information Bureau ("MIB") under existing insurance laws, with no limitation based on the patient's general release at the time of treatment. This database can include genetic information, including genetic predictors for disease and candidates for transfer of desirable genetic material. There is fear also that such databases could be used for genetic discrimination in employment, or regarding eligibility for health insurance. Writing in reaction to a case where harm caused by gossip did not give rise to a cause of action at common law,¹³ Warren and Brandeis stated:

The intensity and complexity of life, attendant upon advancing civilization, have rendered necessary some retreat from the world, and man, under the refining in-

¹³ Pollard v. Photographic Co. Pollard v. Photographic Co, 40 Ch. Div. 345 (1888).

fluence of culture, has become more sensitive to publicity so that solitude and privacy have become more essential to the individual . . . The possibility of future profits is not a right of property which the law ordinarily recognizes; it must, therefore, be an infraction of other rights which constitutes the wrongful act, and that infraction is equally wrongful, whether its results are to forestall the profits that the individual himself might secure by giving the matter a publicity obnoxious to him, or gain an advantage at the expense of his mental pain and suffering.¹⁴

2. A Broader View of Ownership

If genetic information is indeed the property of more people than any given individual, this has implications for individual genetic privacy, public health strategies and intellectual property as well as privacy regarding the disclosure of information. Property rights therefore may have implications for a variety of social and private contracts regarding genetic information and the subsequent use of genetic technology, based on personal genomic status. Legal resolution of these property rights will determine: who to tell genetic information, (Mother? Father? Extended Family? Employers? Insurers? Prospective spouse and family? Other third parties?) Using property analysis, individual genetic information could be safeguarded in a shroud of procedural confidentiality. On the other hand, the individual right to genetic privacy may be outweighed, on balance by countervailing social and commercial interest: information should be readily available to third parties for the greater social good of promoting public health or generating financial profits. Balancing these existing rights against individuals in favor of the public health or commercial rights may mean that an individual who has a "genetic defect" required to change it, or to make available desirable genes for medical or corporate purposes. Extending these concepts from individuals to commercial uses of genetic information has implications for the mixture of human genetic material with other genetic information from other species, for genetically manufactured foods, cloning and sale of human body parts made

¹⁴ Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 5 HARV. L. REV. 193, 204 (1890).

from transgenic (or multi-parent genetic) material and genetic materials used in medical treatments. In light of new genetic technologies, society must decide whether or not to apply existing under disability laws, insurance laws and other regulatory mechanisms, to protect people against suffering from discrimination based on genetic conditions.

3. Who Cares About Privacy? Precedents Regarding Wrongful Use of Genetic Information and Eugenic Laws

Changes in technology alter our understanding of health.¹⁵ The disease that was viewed as incurable decades ago can now be cured and the irritating conditions that people lived with slowly become the red flag signals for other diseases and illness; thus changing whether the same person is regarded as manifesting an illness or in "good health." This is especially true for genetic diseases. For example, in the 1970s, sickle cell anemia screening programs were aimed at identifying carriers of sickle cell anemia, a disease common among African Americans and also among ethnic groups from Asia minor. Government programs were identified both healthy "carriers" individuals who had sickle cell anemia. The mistaken notion that carriers might be hyper-susceptible to certain workplace toxins such as benzene, lead, cadmium, carbon monoxide, and cyanide was used as an accepted reason to exclude black workers out of high-paying jobs in the heavy industries. In this time period, many state legislatures mandated sickle cell testing, leading to further fear and discrimination. Inadequate measures to keep the test results confidential led to stigmatization and discrimination against sickle cell carriers in employment. Ignorance about sickle cell trait compared to the genetic illness, sickle cell anemia, was mixed up with other prejudices, and became the touchstone of discrimination against many carriers of the trait even though "carriers" could not

¹⁵ World Health Organization ("WHO") Const. Preamble ("Health is a state of complete, physical, mental and social well-being and not merely the absence of disease and infirmity."). This remarkably broad definition bespeaks the basic human need for health. For this reason, it has been the undisputed benchmark of many practical standards as well as a host of national health laws. This definition is so encompassing, however, that it has been criticized as making virtually any human endeavor a matter of health jurisdiction. It encompasses vaccines and preventive strategies as well as medical programs.

develop the disease.¹⁶ Thirty states enacted legislation requiring African Americans to be tested for the sickle cell trait. Twenty-one states have not repealed their sickle cell screening laws. Some states required children be tested upon entering school while others would only issue marriage licenses if the individuals had been tested.¹⁷ Thus, the United States Air Force Academy refused African Americans who were carriers of sickle cell to participate in pilot training, fearing that the low-oxygen environment in flight would cause them to undergo a sickling episode.¹⁸ Under these theories, there is a national if not international communitarian interest in any person's health that transcends notions of individual privacy.

B. Public Health Implications of Genetic Testing At Work

Existing law may be interpreted to address genetic technologies to require mandatory testing or treatment to "correct" so-called genetic disorders ranging from arthritis to obesity and change personal attributes like intelligence and skin color. This information can potentially benefit society: cures and treatments for currently incurable genetic disorders. Critics fear that a concept of "genetic fitness" could be used to choose between parents in custody battles, or to determine whether future employment or incurability without regard to other human traits.¹⁹ Concepts of genetic fitness exist

¹⁶ PATRICIA A. KING, *THE PAST AS PROLOGUE: RACE, CLASS, AND GENE DISCRIMINATION*, IN *GENE MAPPING: USING LAW AND ETHICS AS GUIDES* (George J. Annas & Sherman Elias eds., 1992) (noting that these programs began with the best intentions, and were supported by African American leaders until they realized that such measures "would be used to stereotype and disadvantage the very people they sought to help.").

¹⁷ National Sickle Cell Control Act of 1972, Pub. L. No. 92-294, 86 Stat. 136 (as amended at 42 U.S.C. § 300B (1976) (withholding federal funding from states unless sickle cell testing is voluntary).

¹⁸ See King, *supra* note 16, at 99 (discussing how the mandatory testing of African-Americans for sickle cell anemia negatively affected them).

¹⁹ U.S. Congress, Office of Technology Assessment, (OTA), Report to Congress at the Request of the Board of the 101st Congress "Genetic Monitoring and Screening in the Workplace" 15, tbls.1-2 "Genetic Tests Available and Total Americans Affected"(1990). In that report the OTA staff further notes at page 20:

The workplace is an atypical setting for receiving information of such personal importance. It should not be overlooked that when genetic monitoring or screening are used in the workplace, the focus of the tests—the person—is being provided with information that could have a significant impact on decisions unrelated to employment: marriage; procreation and lifestyle. The absence of refer-

under eugenic-based sterilization laws from the early 20th century that were upheld by the U.S. Supreme Court and have not been repealed.²⁰ Absent uniform privacy and confidentiality protections throughout the United States, health care institutions, insurance companies and self-insured employers who transmit health information through interstate commerce, patients may lack the basis for meaningful consent to disclosure of information. The costs and benefits of genetic technologies may force to closure previous policy debates about privacy regarding medical data.

THE STATE'S OBLIGATION TO PROTECT GENETIC INFORMATION:

The clearest and most succinct statement of the traditional approach to regulation of public health policy under law is Frank Grad's classic work, *The Public Health Law Manual*.²¹ This invaluable reference covers the legal sources of public health powers, restriction of the person, permits, licenses and registrations, abatement of nuisances, civil sanctions, etc. in the United States. Traditional approaches of public health regulation, include: quarantine and other restrictions of the person, mandatory testing for vaccination, and registration and reporting of communicable disease. These measures are firmly based in the well-established doctrine of *parens patriae*, the societal need for control over disease and public health uses of personal information in order to protect the public good. Under this construct, the so-called "police power" of the State provides the traditional justification that supports invasions of privacy or breaches of confidentiality, that are both implicit and expressly articulated in public health laws following the traditional

erals to trained professionals and reimbursement for costs of additional tests or counseling may be prohibitive factors influencing an individual's ability to obtain additional information. Genetic counseling and appropriate referrals for those at risk should accompany the use of either genetic monitoring or screening.

This statement was followed by discussion of then current data regarding the use of genetic monitoring and screening by Fortune 500 companies. *See also* Brian R. Gin, *Genetic Discrimination: Huntington's Disease and the Americans with Disabilities Act*, 97 COLUM. L. REV. 1406, 1411 (1997) (suggesting that in the future adoption agencies may choose suitable parents based on their genetic potential and that the same information may be used by courts in determining custody of children in divorce settlements).

²⁰ *See* *Buck v. Bell*, 274 U.S. 200 (1927).

²¹ THE PUBLIC HEALTH LAW MANUAL, AMERICAN PUBLIC HEALTH ASSOCIATION (1990).

public health paradigm. The use of the police power is rooted in the government's obligation to the people, as protector of the people in the social contract between a populace and its government.

C. Privacy Rights Under the U.S. Constitution

Genetic information from research may create preventive treatments, provide information about protective effects of genetic conditions considered to be defects; or about new diseases that were never viewed as genetically linked. Some conditions may be an admixture of environmental factors and genetic propensities. Other genes will not impact on the individual who is a "carrier," but may, through the happenstance of fate and attraction, appear in the next generation, depending on who the parent chooses as partners in reproduction. What will a judicial system in the twenty-first century do with information that particular genes give individuals a propensity for certain types of behavior? Will employers have the right to set forth particular genetic characteristics as part of their job criteria for employment? Or will such criteria violate the precepts of the Americans With Disabilities Act ("ADA") which prohibits discrimination? Will any of the embryos and fetal tissue cloned or raised using genetic technologies be endowed with individual rights and "human" status? Will there be a new underclass, created from materials using genetic technologies, or from the "old-fashioned" form of human reproduction without enhanced genetic techniques?

Constitutional basis for protection of privacy rights are found in several Amendments. Henkin²² views privacy rights as a public good. These rights include protection from unreasonable searches and seizures. Under his construct, "The essential private right," freedom, was established by the 13th amendment.²³ The U.S. Supreme Court created "substantive due process" as a limitation of the authority of government.²⁴ "The Constitution does not confer private rights; they are antecedent to and independent of the constitution . . . Justices Stone and Cardozo suggested that the freedoms of speech, press and religion required extraordinary judicial protection against invasions even for the public good, because of their place at the foundations of democracy and because of the unrelia-

²² Louis Henkin, *A Privacy and Autonomy*, 74 COLUM. L. REV. 1410 (1977).

²³ *Id.* at 1419.

²⁴ *Id.* at 1411.

bility of the political process in regard to them.”²⁵ “Since the Constitution . . . protects rights which partake of privacy it protects other aspects of privacy as well, indeed it recognizes a general complete right of privacy.”²⁶

First Amendment concepts of freedom of association include “[t]he associational model of the right of privacy presumptively insulates its holders from state interference even when that right is exercised in the public sphere.”²⁷ This theory of privacy severely limits the government’s ability to require genetic testing or to compel disclosure of genetic information within marriage or in reproductive decision making. Under the Fourth Amendment, prohibition against warrantless intrusions extends to the home as well as the person. This protection is limited to non-criminal purposes and might not reach DNA “fingerprinting” used in criminal prosecutions. Under the Ninth Amendment, this right against genetic discrimination is grounded fundamental attributes of the person, also as discussed in the jurisprudence of international human rights. The touchstone for U.S. Constitutional privacy, to the extent it exists, is embedded within “those personal rights that are fundamental . . . not confined to the specific terms of the Bill of Rights.” In Justice Goldberg’s concurrence in *Griswold v. Connecticut*,²⁸ the Court stated that a married couple’s right to privacy regarding contraception outweighed a state law that prohibited the use of contraceptives. Relevant to genetic privacy for purposes of family planning, the Court viewed the case as one that “operates directly on an intimate relation of husband and wife and their physician’s role in one aspect of that relation.”²⁹

As stated in *Eisenstat v. Baird*, “If the right of privacy means anything, it is the right of the individual, married or single, to be free from unwarranted government intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child.”³⁰ This view could be construed as having implications for

²⁵ See *id.* at 1428, 1429.

²⁶ See *id.* at 1421 (“[S]ince the Constitution in various ‘specifics’ of the Bill of Rights and in their penumbra, protects rights which partake of privacy, it protects other aspects of privacy as well, indeed it recognizes a general, complete right of privacy.”).

²⁷ U.S. Constitution, First Amendment, discussed by Thomas, *supra*.

²⁸ *Griswold v. Connecticut*, 381 U.S. 479 (1965).

²⁹ 381 U.S. 479, 482 (1965).

³⁰ *Eisenstat v. Baird*, 405 U.S. 453 (1972) (striking down a State law that prohibited unlicensed distribution of contraceptives to unmarried people).

the disclosure of human genomic information during family planning, absent an overarching public health interest. The U.S. Supreme Court was not contemplating sophisticated advances in genetic testing when it made this statement, but the right to privacy may prevent governmental intrusion via mandatory genetic testing, absent a strong governmental interest. The Court did not, however indicate which governmental interests would be sufficiently important to outweigh personal privacy concerns and thereby justify intrusion into personal privacy, if information was needed by third parties to save their life.

Under the Ninth Amendment also, abortion cases have determined that Constitutional protections for privacy extend to the decision whether or not to terminate a pregnancy.³¹ The U.S. Supreme Court took a broadbrush approach to safeguard information surrounding abortion decisions finding "freedom from unwarranted governmental intrusion into individual decisions in matters of child bearing."³² Autonomous decision making was not to be "burdened" by a statutory requirement for parental notification regarding the decision to have an abortion.³³

The government's ability to limit the exercise of independent decision making in matters that would otherwise be considered private was discussed in *Whalen v. Roe*.³⁴ The constitutional right to privacy in personal information was outweighed by the legitimate state interest in preventing drug abuse, when a state was allowed to require mandatory reporting of names and other identifying information for persons who were the recipients of prescriptions for controlled substances.³⁵ It seems as if one interpretation of the case could allow it to serve as precedent for allowing genetic testing of individuals by the government, insofar as it asserts the government's ability to gather data when there is a state interest in otherwise confidential, personal information. Under *Whalen*, government interests in the name of public health can provide a compelling state interest.

³¹ See *Roe v. Wade*, 410 U.S. 113 (1973) (discussing the right to terminate or continue pregnancy).

³² *Thornburgh v. Am. Coll. of Obstetricians and Gynecologists*, 476 U.S. 747, 775 (1986) (Stevens, J., concurring).

³³ See *id.*

³⁴ See *id.* at 772.

³⁵ *Whalen, Comm'r of Health of New York v. Roe*, 429 U.S. 589 (1977).

Protection against disclosures, even if self-incriminating, is found under the Fourth and Fifth Amendment. In Justice Brandeis' dissent to *Olmstead v. United States*, concerning the admissibility of evidence obtained by wiretapping of homes and offices, he argued that the Government should not have the ability "to obtain disclosure in court of what is whispered in the closet."³⁶ Thus, Justice Brandeis recognized privacy interests against government intrusion under the U.S. Constitution's Fourth and Fifth Amendments. Taken together, these Amendments "conferred, as against the Government, the right to be let alone—the most comprehensive of rights and the right most valued by civilized men."³⁷

Brandeis' opinion applied principles he had written about in a famous law review article entitled "The Right to Privacy."³⁸ Although privacy is not viewed as an inherent right under the common law,³⁹ The precinct call for an expanded scope to legal protections for the concept of individual privacy decried several developments of the modern age, is often cited by the dissent throughout the 20th century cases about privacy. "That the individual shall have full protection in person and in property is a principle as old as the common law; but it has been found necessary from time to time to define anew the exact nature and extent of such protection. . . . Later there came a recognition of man's spiritual nature, of his feelings and intellect."⁴⁰ Gradually the scope of these rights broadened; and now the right to life has come to mean the right to enjoy life—the right to be let alone. . . ."⁴¹

Warren and Brandeis recognized the need for legal remedy for unauthorized use of portraits and of modern inventions that replicated images and speech without authorization by the individual who was the subject of the portrait. This has direct relevance for genetic testing and cloning of human genetic material for medicine, "spare parts" or creating new human beings. Genetic technology can isolate and examine in detail the chromosomal image of an in-

³⁶ See *id.* at 606 (Brennan, J. concurring).

³⁷ *Olmstead v. United States*, 277 U.S. 438, 478 (1928) (Brandeis, J., dissenting).

³⁸ Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 5 HARV. L. REV. 193 (1890).

³⁹ *Id.*, at 213 (the benchmark for discussion of privacy jurisprudence under the common law).

⁴⁰ *Id.* at 193.

⁴¹ *Id.*

dividual without the individual's knowledge or consent, and in a manner that has intrusive effects of embarrassment, social stigma and even detrimental judgments by unseen third parties, just as photography once had. Warren and Brandeis understood these problems, raised by new technologies for replication of a human image, as they stated the case for judicial recognition of these rights. Warren and Brandeis' ideas, although appealing from a conceptual standpoint, were not widely embraced by the courts in the twentieth century; although their influential documentation was often cited, theirs did not become the majority view. Their views represented the high water mark of rights to privacy that "ought" exist, rather than a realistic appraisal of rights under common law and therefore remains important when examining new assaults against personal rights to information used in decision making. Legal scholars in the 20th century have used their article as the cornerstone for the principle that there is a right to privacy that is intrinsic in "personhood." For Warren and Brandeis construct, rights as derived not from contract or special trust, "but are rights against the world. . . . The principle which protects personal writings and any other productions of the intellect or of the emotions is the right of privacy, and the law has no new principle to formulate when it extends this protection to the personal appearance, sayings, acts, and to personal relation, domestic or otherwise."⁴² This theory, not codified in U.S.A. laws is found under international law. UDHR Article 12, regarding privacy states: "No one shall be subject to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honor and reputation. Everyone has the right to the protection of the law against such interference or attacks."⁴³ International Covenant on Civil and Political Rights Article 17.1 provides: "No one shall be subjected to arbitrary or unlawful interference with his (sic) privacy, family, home . . ." and further assures the right to protection against such "attacks" against privacy.⁴⁴ Similarly, ICCPR Article 19.2 guarantees the right to receive and impart information "of all kinds."⁴⁵ This provision sug-

⁴² *Id.*

⁴³ G.A. Res. 217 A (III), U.N. Doc. A/810 (1948).

⁴⁴ International Covenant on Civil and Political Rights Art. 17.1.

⁴⁵ International Covenant on Civil and Political Rights Art. 19.2.

gests the ICCPR provides protection for genetic privacy within the family and for personal health information.⁴⁶

1. Applying Privacy Principles to Genetic Information

Privacy of medical records has implications under consumer protection laws as well as insurance laws. If a patient discloses personal information to a health care professional believing it is private, the professional may be liable in tort for disclosure without the patient's consent. Laws do not protect confidential medical information that is disclosed with the patient's consent. Most medical record and claims data enter the public domain through the Use of blanket consent forms. As a condition to apply for insurance or process claims. The forms often permit release of information to others not directly involved as a provider, *i.e.*, the Medical Information Bureau ("MIB"). MIB tracks patient information for insurance companies to evaluate applications for coverage and to develop targeted marketing. This data is made available to MIB through the general release. Several laws have been proposed in Congress provide uniform and confidentiality for individual genetic information.

2. Federal Regulation of Health Insurance

Use of medical records and claims data by third parties, such as medical and health policy researchers, employers, marketers, public health officials and the law enforcement community has led to Congressional hearings addressing the privacy rights of individuals balanced against access to the data, including medical and health policy researchers, whose work may benefit the public at large.⁴⁷

⁴⁶ See ALASKA STAT. §18.065.087 (1998) (authorizing the Department of Public Safety to maintain a central registry of sex offenders and to make the following information about those offenders available to the public: name, address, photograph, place of employment, date of birth, crime for which convicted, date of conviction, place and court of conviction and length of sentence).

⁴⁷ See Fair Health Information Practices Act of 1994, H.R. 4077, 103d Cong. (1994); Medical Information Protection Act of 1998, S. 2609, 105th Cong. (1998); Consumer Health and Research Technology (CHART) Protection Act, H.R. 3900, 105th Cong. (1998); Health Care Personal Information Nondisclosure Act of 1998, S. 1921, 105th Cong. (1998); Medical Information Privacy and Security Act, S. 1368, 105th Cong. (1997); Medical Privacy in the Age of New Technologies Act of 1997, H.R. 1815, 105th Cong. (1997); and Fair Health Information Practices Act of 1997, H.R. 52, 105th Cong. (1997).

Title V of The Patient Protection Act, passed by the House of Representatives on July 24, 1998, contained provisions that would authorize the Use of identifiable health care information for "health care operations."⁴⁸ Future laws following these bills may: prohibit denial or cancellation; prohibit changing premiums, terms, or conditions of policies; prohibit the request or requirement of a genetic test; or protect individual confidentiality "on the basis of any molecular genetic information about a healthy individual."⁴⁹

Although state laws historically stipulated that medical records were the sole property of the health care provider, most state laws also required health care professionals to maintain the confidentiality of a patient's personal information.⁵⁰ Medical records and claims data has spurred advances in quality and access to medical treatment. Access is needed by medical and health policy researchers to medical records and claims data has spurred advances in quality and access to medical treatment. The American regulatory regime on medical record access has politely been characterized as "fragmented" and less politely as a "black hole."⁵¹ For this reason, the Health Insurance Portability & Accountability Act ("HIPAA") specifically requires insurers to provide on-going health insurance to previously insured individuals without regard to "pre-existing conditions." Pregnancy and genetic conditions are expressly included in the list of situations that cannot be the legitimate reason

⁴⁸ See Patient Protection Act of 1998, H.R. 4250, 105th Cong. §1185 (1998).

⁴⁹ See S. Res. 89, 105th Cong. § 9811 (1997); H.R. Res. 306, 105th Cong. § 713 (1997); S. Res. 1045, 105th Cong. (1997); S. Res. 1694, 104th Cong. § 2 (1996); H.R. 2748, 104th Cong. (1995); S. Res. 1898, 104th Cong. § 302 (1996); S. 422, 105th Cong. § 402 (1997). See also H.R. 341, 105th Cong. § 6 (1997) (prohibiting an insurer from rejecting, denying, limiting, canceling, refusing to renew, increasing the rates, or otherwise affecting coverage).

⁵⁰ See Helena Gail Rubenstein, *If I Am Only for Myself, What Am I? A Communitarian Look at the Privacy Stalemate*, 25 AM. J.L. & MED. 203 (1999).

⁵¹ See *id.*, at 203 (citing U.S. Senator Edward M. Kennedy); see also WILLIAM W. LOWRANCE, U.S. DEP'T OF HEALTH & HUMAN SERVICES, *PRIVACY & HEALTH RESEARCH: A REPORT TO THE SEC'Y OF HEALTH & HUMAN SERVICES* 6 (1987); see also Richard C. Turkington, *Medical Record Confidentiality, Law, Scientific Research and Data Collection in the Information Age*, 25 J.L. MED. & ETHICS 113, 115 (1997); see also SENATOR EDWARD M. KENNEDY, *STATEMENT ON THE INTRODUCTION OF THE MEDICAL INFORMATION PRIVACY AND SECURITY ACT* (1999).

for exclusion from a policy, despite the expense and high-risk among these populations.⁵²

D. Ignorance is Bliss: The Ultimate Bastion of Privacy

Discovery of the gene for Huntington's Disease has altered the meaning of genetic testing and brought closer the promise of a cure for affected families. At the same time, genetic discoveries have raised issues of personal genetic privacy at the cutting edge of genetic jurisprudence. In light of these developments, the International Huntington Association ("IHA") and the World Federation of Neurology ("WFN") have proposed Recommendations to provide guidelines for the Use of the Huntington's Disease Molecular Genetics Predictive Test.⁵³ The first recommendation and comments indicates that individuals should have updated information "in order to make an informed voluntary decision."⁵⁴ The second recommendation ensures that taking the test is the "sole choice" of each individual, free of coercion from families, physicians insurance

⁵² See Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, 264, 110 Stat. 1936 (1996) (codified as amended at 42 U.S.C. § 1320d-2); see also *Protecting Our Medical Information, Rights, Responsibilities and Risks: Hearings Before the Senate Comm. on Labor and Human Res.*, 105th Cong. (1997); *Confidentiality of Patient's Medical Records: Hearings Before the Subcomm. on Gov't Mgmt. Info. & Tech. of the House Comm. on Gov't Reform & Oversight*, 105th Cong. (1998) (statement of Richard Harding, M.D., on behalf of health insurers, medical and health policy researchers, and pharmaceutical companies); *Confidentiality of Medical Information: Hearings Before the Senate Comm. on Labor and Human Res.*, 105th Cong. (1998).

⁵³ See *Concept: Ethical Issues Policy Statement on Huntington's Disease Molecular Genetics Predictive Test: IHA and WFN Research Group on Huntington's Chorea: Comm. on Genetic Testing*, 94 J. NEUROL. SCI. 1989, 327-32 (Establishing a committee with the specific task of preparing such guidelines was decided at the WFN and IHA conferences in Lille, September, 1985. The recommendations were adopted by both organizations at their respective meetings in Vancouver, Canada, June 30 to July 3, 1989.).

⁵⁴ World Federation of Neurology, International Huntington's Association WFN-IHA GUIDELINES, NUMBER 1 states that individuals should have updated information "in order to make an informed voluntary decision." See also, Ilise L. Feitshans, *Genetic Testing During Pregnancy: Implications For Womens' Autonomous Medical Decisions Under the Genome Project* (Thesis for Masters of Science Degree), JOHNS HOPKINS UNIVERSITY SCHOOL OF HYGIENE AND PUBLIC HEALTH (1996) (on file with the University), citing WFN-IHA Recommendations with commentary, at page 61.

companies, employers or other third parties,⁵⁵ although recommendations 3 and 3.1 indicate that “the patient should be encouraged to select a partner to accompany him/her throughout the different stages” of testing. The test would, under this approach, be offered without regard to financial status but only to people who have reached majority, with a strict prohibition against testing for the purpose of adoption. Recommendation 2.5 urges that laboratories meet “rigorous standards.” Recommendation 4 prohibits the disclosure of test results to third parties, absent the written consent of the patient. Recommendation 5.3 indicates the types of formation that should be given to the patient regarding potential consequences of taking the test. These consequences include the effect of test results on the individual patient, patient’s spouse, parents, other family members, and socio-economic consequences pertaining to “employ-

⁵⁵ World Federation of Neurology, International Huntington’s Association WFN-IHA GUIDELINES, NUMBER 2 states that individuals should have the opportunity for individual choice free from coercion by families, physicians, insurance companies employers or third parties” This Recommendation is problematic, because of the broad brush with which it has been written. Social pressures of many sorts may inadvertently conspire to create an atmosphere of coercion that may even lead to rational, well-reasoned decisions, yet it may be difficult for a court or other reviewing body to parse that decision post-hoc to allocate various levels of burdens to each of the relevant players or factors in the final decisional outcome. Thus, although sounding as if the recommendation is designed to ensure further autonomy and individual protection, this recommendation is actually problematic if it were ever to be implemented and begs the question of the line between social good and individual choice in genetic decisions. See also, Ilise L. Feitshans, *Genetic Testing During Pregnancy: Implications For Womens’ Autonomous Medical Decisions Under the Genome Project* (Thesis for Masters of Science Degree), JOHNS HOPKINS UNIVERSITY SCHOOL OF HYGIENE AND PUBLIC HEALTH (1996) (on file with the University), citing WFN-IHA Recommendations with commentary at pages 61 through 62. World Federation of Neurology, International Huntington’s Association WFN-IHA GUIDELINES, NUMBER 2 further states that individuals should the right to make these decisions alone but that laboratories must meet “rigorous standards.” This as a general public health policy matter remains an open question, as some policymakers believe that genetic decisions impact all of society and can only be made through the applications of technologies that are developed for the public good. The notion that some genetic decisions are too important for individuals to decide alone remains unresolved at the time of this writing under law or related guidelines. See Ilise L. Feitshans, *Genetic Testing During Pregnancy: Implications For Womens’ Autonomous Medical Decisions Under the Genome Project* (Thesis for Masters of Science Degree), JOHNS HOPKINS UNIVERSITY SCHOOL OF HYGIENE AND PUBLIC HEALTH (1996) (on file with the University), citing WFN-IHA Recommendations with commentary at pages 59 through 63.

ment, insurance, social security, data security and other problems.”⁵⁶ Recommendation 5.4 ensures that patients will have access to “alternatives” to taking the test, including but not limited to not taking the test or storing their DNA.⁵⁷ The IHA Recommendations also offer guidance for prenatal and antenatal testing, designed to ensure the integrity of the patient’s medical decisions. Recommendation 8 concerns the delivery of test results to patients through counseling in person, rather than over the telephone or by mail and the right to refuse having results. Decision making, thereby providing additional protection against undesired disclosure. HDA’s recommendations therefore give a deeper practical effect to theoretical principles protecting patient autonomy regarding medical decision making. This approach, giving primacy to autonomous decision-making, may also be applied to other genetic testing than the decision whether to take the test for Huntington’s Chorea may also apply to other areas of genetic testing.⁵⁸

Huntington’s disease is an example of a trait linked to a single allele or dominant contrasting gene. It causes “loss of muscle control, uncontrollable physical spasms, severe mental illness, and eventual death.” For example, the presence of Huntington’s disease

⁵⁶ World Federation of Neurology, International Huntington’s Association WFN-IHA GUIDELINES, NUMBER 5.3.5. states that individuals should consider several types of information to consider when making genetic decisions, specifically regarding genetic testing for Huntington’s disease, which is a late onset disease, impacting individuals in the forty to fiftieth years of life. Similar to the models that have been applied to HIV/AIDS testing, these factors weigh the so-called emotional freight of testing and knowledge produced as a result of the test. See Ilise L. Feitshans, *Genetic Testing During Pregnancy: Implications For Womens’ Autonomous Medical Decisions Under the Genome Project* (Thesis for Masters of Science Degree), JOHNS HOPKINS UNIVERSITY SCHOOL OF HYGIENE AND PUBLIC HEALTH (1996) (on file with the University), citing WFN-IHA Recommendations with commentary at page 63.

⁵⁷ World Federation of Neurology, International Huntington’s Association WFN-IHA GUIDELINES, NUMBER 5.4 states that individuals should have access to “alternatives” to taking the test. This recasts in legislative format the notion of the right “not to know” discussed above, as a method of striking a balance by creating a counterweight to the free flow of information. See Ilise L. Feitshans, *Genetic Testing During Pregnancy: Implications For Womens’ Autonomous Medical Decisions Under the Genome Project* (Thesis for Masters of Science Degree), JOHNS HOPKINS UNIVERSITY SCHOOL OF HYGIENE AND PUBLIC HEALTH (1996) (on file with the University), citing WFN-IHA Recommendations with commentary at page 62.

⁵⁸ For IHA Recommendations on the “Right Not to Know” about Huntington’s Chorea, see ALBERT TOWLE, MODERN BIOLOGY 171 (1993).

can be detected with 99% accuracy.⁵⁹ While a positive test result signals that an individual ultimately will get Huntington's disease, it is impossible to predict when the disease will manifest itself and how quickly the person will become debilitated. Thus, an individual with the genetic markers for Huntington's disease may lead a long, productive life before the onset of the debilitating symptoms.⁶⁰ IHA has recommended that genetic testing for Huntington's Disease be conducted only after counseling and only on adults.

Despite the clarity of these recommendations, there is an underlying confusion in theories and jurisprudence of privacy, which ultimately affects the ability to devise analytically clean and forthright protections for the privacy rights, including the right not to know, as eluded to by the HDA. Consistent with the salient characteristic of international human rights jurisprudence, these documents represent a codification of the international consensus to certain individual rights, such as the right to information or the right to privacy, without offering more than vague support for the notion that there should be international respect for these principles, and without fully addressing the necessary steps to achieve implementation of their meaningful protection. Examining these provisions nonetheless provides a useful starting point in order to determine the implications of privacy concerns for genetic issues in public health law and policy. In addition, several international human rights documents express the notion that there are separate and distinct, or perhaps "special" protections that ensure maternal health, especially during pregnancy. The intriguing separate regime regarding human rights protections during pregnancy calls into question whether "special" rights regarding privacy and autonomy also have an impact upon prenatal medical decisions in general, and genetic testing in the workplace. The sickle cell and sterilization laws precedent raise concern that mandatory testing is a potential tool for eugenics, enabling the state to filter out undesirable genetic traits through obligatory testing. Experience with sickle cell anemia testing suggests the dangers inherent to genetic testing. Like the

⁵⁹ See Gin, *supra* note 19, at 1415 (pointing out that test to diagnose Huntington's disease may be administered at any time in a person's life and will have no bearing in the accuracy of the diagnosis).

⁶⁰ See Gin, *supra* note 19, at 1414-15 (estimating that the disease begins to surface at age 35).

sickle cell tests of the 1970s, scientists today understand relatively little about genetic conditions. Although we have the ability to identify an increasing number of genes, we don't understand the relationship between genes, diseases and other human traits. Does this history of discrimination based on inadequate scientific data mean that people have a right NOT to have such personal information studies, in order to protect them from discrimination? Or, more importantly, to protect them from the harms they may suffer from "Bad Science," despite the researcher's best intent?⁶¹ The State's concern for the welfare of an infant justified blood transfusions notwithstanding the special religious beliefs of the Jehovah's Witnesses.⁶² But must be used wisely when fiercely competing interests demand their respective rights. The path we choose will shape humanity's destiny for many generations.

II. LEGAL AND MEDICAL CONSTRUCTS OF A HUMAN BEING ENDOWED WITH HUMAN RIGHTS

How much genetic difference through cloning or other genetic techniques will be tolerated under current definitions of humans? Will the people produced under these technologies accept those definitions or want a separate regime to govern themselves? Or will they be second class citizens? Kings or slaves? Human rights and the legal definition of "human being"? Tribe asks the precinct question, regarding children of sperm donation: "If such a child develops an hereditary disease, does it violate the donor's privacy if the state requires the sperm bank to reveal his identity to the parents and physicians of the child?"⁶³

A. *Who Holds the Human Right to Informational Privacy?*

There will be two radical changes in the definition of family to cope with social changes produced by the application and use of genetic technologies: First, genetic technologies will uncover long-standing historical biological linkages between many people who

⁶¹ See TROY DUSTER, *BACK DOOR TO EUGENICS* (1990); see also Abby Lippman, *Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*, 17 AM. J.L. & MED. 15, 34 (1991).

⁶² The *Jefferson* decision relied in part on the older case of *Raleigh Fitkin-Paul Morgan Memorial Hosp. v. Anderson*, 201 A.2d 537, cert. denied, 377 U.S. 985 (1964); see also *State v. Perricone*, 37 N.J. 463 (1962).

⁶³ See TRIBE, *supra* note 9, at 1360.

were treated as outcasts or outsiders to a given family, either through secrecy, illegitimacy or distant social relations. This will gain importance as we know more about the effects of that biology and as people who perceive themselves to be victims of genetically-based or genetically linked discriminations will band together for common protection and safety in their interactions with the rest of society. Second, even if all people are created equal, the law will find it necessary to step in and decide who are people and what are their relations to each other. Can a child who is linked to a celebrity genetically claim inheritance from them, even if that child was merely linked by donor eggs that were purchased from the celebrity under contract and has different parents legally? Conversely, will the same celebrity be bound by contract law or other laws to raise and pay for the children who bear their name, but are not linked to them biologically?

1. Rights of Other Individuals to One's Genetic Information

Third parties have an interest in genetic information because genetic diseases by their very nature have an inherent intra familial component that arguably gives rise to a duty to disclose genetic information. Third parties such as lost extended family or significant others may be affected by information regarding genetic disease. This approach to the protection of personal genetic information has in fact been advanced by the Huntington's Disease Association. International public law concerning human rights also offers protections for autonomy, integrity of the person and the right to information about oneself or one's family members.⁶⁴

2. Family Members: Who is "Family"?

Genetic diseases run in families; but the high correlation between many genetic disorders and race or ethnicity, makes difficult screening applicants for many diseases without violating U.S.A. Title VII of the Civil Rights Act or the ADA. "The identification of relatives found through genome mapping to be at risk for genetic disease

⁶⁴ See U.N. CHARTER ARTICLES 13, 55, 62 reprinted in CENTER FOR THE STUDY OF HUMAN RIGHTS, COLUMBIA UNIV., TWENTY-FIVE HUMAN RIGHTS DOCUMENTS 1-5 (1994).

may result in inflicting unwanted information on those individuals.”⁶⁵

Furthermore, genetic information may also therefor reveal other information about family links that was not previously known but has unpredictable consequences, when an African American claims lineage to a President two hundred years after his death.⁶⁶ Sickle cell anemia, Bloom’s Syndrome, and other genetic diseases inherited from parents are sometimes closely linked to particular ethnic or racial groups such as African Americans, Ashkenazi Jews and Armenians.⁶⁷ There is precedent for protecting the integrity of family-based genetic information, insofar as family genetics are an extension of laws regarding genetic traits and race. Courts have found that tests for sickle cell anemia disproportionately impact African Americans. Many states prohibit employer testing for the disease. In *EEOC v. Trailways, Inc.*,⁶⁸ the court struck down a regulation requiring bus drivers to be clean shaven. The regulation was struck because it had a discriminatory impact on African Americans who demonstrated a higher incidence of a skin disorder that made shaving painful.⁶⁹ Similarly, most of the employers who pioneered sickle cell testing soon stopped, and some states have now prohibited the testing because of its disparate impact on African Americans.⁷⁰

⁶⁵ RUTH MACKLIN, MAPPING THE HUMAN GENOME, in GENETICS AND THE LAW III (1984); see also Lori Andrews & Ami Jaeger, *Confidentiality of Genetic Information in the Workplace*, 17 AM. J.L. & MED. 75, 81 (1991).

⁶⁶ See Melissa Hendricks, *A Daughter’s Declaration*, JOHNS HOPKINS UNIVERSITY MAGAZINE, (Sept/Fall 1999), Cover Story (demonstrating that she is the eighth generation after President Thomas Jefferson’s black son, whose mother was Jefferson’s slave).

⁶⁷ Karen H. Rothenberg, *Breast Cancer, The Genetic “Quick Fix” and the Jewish Community*, 7 HEALTH MATRIX 97, 98 (1997) (noting that nearly one percent of sampled Eastern European Jews contain a genetic predisposition to breast and ovarian cancer); see also Katherine Brokaw, Comment, *Genetic Screening in the Workplace and Employers’ Liability*, 23 COLUM. J.L. & SOC. PROBS. 317, 324 (1990).

⁶⁸ *EEOC v. Trailways Inc.*, 530 F. Supp 54 (D. Colo. 1981).

⁶⁹ But see *Woods v. Safeway Stores*, 420 F. Supp. 35 (E.D. Va. 1976) (upholding the dismissal of African American employees who grew beards as a result of a skin condition where customers found bearded workers in a grocery store distasteful).

⁷⁰ See generally Fla. Stat. Ann. § 448.076 (West 1997) (prohibiting sickle cell trait screening as a condition of employment); La. Rev. Stat. Ann. § 23.352 (West 1998) (prohibiting employment discrimination on the basis of sickle cell trait).

B. Tensions with Disability Rights

New genetic knowledge seems destined to bring genetic tests that will collide with a growing movement for disability rights. The battleground is likely to be prenatal genetic testing. For a disorder such as Tay-Sachs disease, dying, prenatal testing is generally accepted. Abortion of a prospective child destined to a short life filled with pain and inability to respond to the world is, to most, a morally acceptable if tragic choice. Abortion for conditions with greater clinical variability, with a mix of genetic and environmental causes of lesser severity or with late onset are less obviously beneficial . . . Choosing abortion on the basis of an expected disability raises the specter of choosing what kind of children there should be. The choices implicitly force judgments that echo debates about what lives are worth living, arguments that in an earlier era mushroomed into Nazi atrocities.⁷¹

Currently under international law, without stating what blood or other relationship constitutes a "family," protects "the right to found a family" as a "fundamental group unit" of society, UDHR Article 16.3 provides, "The family is the natural and fundamental group unit of society and is entitled to protection by society and the State." This law does not resolve conflicts within this "fundamental group unit" when there are competing interests, such as the potential conflict of interest between parent and fetus.⁷² For example, neither international norms nor U.S. law specifically grants rights to children or the unborn. International laws, however, have codified such rights, without defining "human" or "child." Article 6.1 recognizes that "every child has an inherent right to life," and Article 6.2, "States Parties shall ensure to the maximum extent possible the survival and development of the child."⁷³ This law provides assurances

⁷¹ ROBERT COOK-DEEGAN, *THE GENE WARS* 251 (1994).

⁷² See Universal Declaration of Human Rights, Dec. 10, 1948, art. 23(1); International Covenant on Economic, Social & Cultural Rights, Dec. 16, 1966, art. 6, 7(b), 10.

⁷³ Convention on the Rights of the Child, Nov. 20, 1989, art. 6 (entered into force on 2 September 1990 in accordance with Article 49(1)) *reprinted in* COLUMBIA UNIVERSITY, *TWENTY-FIVE HUMAN RIGHTS DOCUMENTS* (J. Paul Martin ed., 1994).

of education, housing, nationality, a name, prevention of forced separation of children from their parents. The European Social Charter Part I,(7) clearly states, "Children and young persons have the right to a special protection against the physical and moral hazards to which they are exposed."⁷⁴

III. APPLICATION OF LEGAL CONCEPTS TO LABOR RELATIONS AND OCCUPATIONAL HEALTH

Spider Silk Jeans or Spider Silk Genes: Can We Make People Who Can Work Without Sleep?

Lescohier described in the History of Labor Laws the evolution of many of the major labor laws that had come into force in the U.S.A. before or during the Great Depression of the 1930's. That book,⁷⁵ written contemporary to the Great Depression and therefore before most of the laws impacting health in workplaces today demonstrates that working conditions in general and employment laws that govern them have remained remarkably unchanged despite changes in technology; few changes in circumstances; paradigms remain surprisingly constant.⁷⁶ This makes good sense, however, if we look with a very sweeping brush of history at working conditions in different civilizations and cultures across geographic differences, national boundaries and time. The hallmark of the 20th century was the use of technology to undo the hard work of the Progressive Era, which brought strong wage and hour laws and limits on work.

⁷⁴ European Social Charter, Oct. 18, 1961, Part I (7), Council of Europe (entered into force on Feb. 26, 1965).

⁷⁵ DON D. LESCOHIER AND ELIZABETH BRANDEIS, HISTORY OF LABOR IN THE UNITED STATES, 1896-1932 (MacMillan and Co. 1935).

⁷⁶ Comments to US Dept of Labor's National Advisory Committee on Occupational Safety and Health (NACOSH) (June 6, 1997), and upon a chapter in the book, BRINGING HEALTH TO WORK, (Emalyn Press 1997). An earlier version of this paper and the videotape were presented at the First International conference on Occupational and Environmental Prevention, International Commission on Occupational Health (ICOH) Rome, Italy, 1998 and published in the ISRAEL JOURNAL OF OCCUPATIONAL HEALTH (2000), Vol. 4, no. 1, pp 63-66, entitled *Lessons Learned*: three centuries of occupational health laws, noting that many of the environmental, sanitation and public health issues that we grapple with today remain unresolved but important across the centuries and were addressed by laws in the colonial and early federal periods.

In recent years, Monsanto Corporation spent \$8 billion developing genetically modified seeds that it has patented.⁷⁷ Genetically modified seeds offer a significantly higher yield at harvest, but can-

⁷⁷ Genetically engineered seeds and foods from genetically engineered sources not only raise ethical issues, but have remained commercially controversial. Many nations view these seeds as an attempt to create a new form of economic monopoly, because the seeds require new purchases ever time the farmer wishes to start a crop. Although the genetically engineered seeds produce a greater harvest, they cannot reproduce themselves. Thus farmers cannot save aside part of a good crop to plant the next growing season, and become obligated to purchase new seeds each growing year. This has been the subject of lively on-line discussion at OEM-L, run by Duke University School of Medicine, because the health effects of many years of consuming such genetically engineered virulent but sterile crops are also unknown, leading to questions about the future of excessive long-term human consumption of the crops from genetically engineered seeds. These questions will be resolved by science in the years ahead, but have been litigated in the face of scientific uncertainty while the technologies remain unknown. For example, in Brazil, a judge enjoined sale of Monsanto Corp.'s patented soybean seeds until the government developed bio-safety rules. Soybean farmers planned to buy the seeds illegally from salesmen from Argentina, where they are legal. The farmers say they need the seeds to boost yields and keep competitive. See *Today's "Toxic News for the Net,"* available at http://www.epa.gov/opptintr/oppt_nb.txt; see also Jack Epstein, WASHINGTON TIMES, *Brazil Battles Over Ban on Altered Beans* (30 August 99), at A14. Japan will require labeling on 28 food items that contain detectable genetically modified organisms, or GMOs. UN Rulings Regarding Genetically Modified Food: The Codex Alimentarius Commission. The U.N. Food Safety Agency with 101 member nations ruled unanimously in favor of the 1993 European moratorium on Monsanto's genetically engineered hormonal milk (rBGH). The Codex Commission ruling has stopped the US challenge to the European moratorium before the World Trade Organization. U.S.A.'s FDA approved the sale of unlabeled rBGH milk in February 1994, supported by the Food and Agriculture/ World Health Organization's (FAO/WHO) Joint Expert Committees on Food Additives (JECFA), in its September 1998 report, which did not find adverse veterinary or public health impacts. The Codex Committee subsequently endorsed by the parent Codex Health Canada in January 1999 issued a formal "notice of non-Compliance," disapproving future sales of rBGH. See *Monsanto's Genetically Modified Milk Ruled Unsafe by The United Nations* available at <http://news.excite.com/news/pr/990818/il-un-milk-safety>.

International guidelines for organic foods were an agenda item of the 23rd Session of the FAO/WHO Codex Alimentarius Commission, Rome 28 June to 3 July 1999:

International guidelines on organically produced foods are important for consumer protection and information and because they facilitate trade. They are also Useful to governments wishing to develop regulations in this area, including developing countries and countries in Eastern Europe.

See *FAO/WHO Commission to Set Guidelines for Organic Foods*, available at www.fao.org/news/1999/990608-e.htm Future Directions in USA Laws.

not reproduce themselves, so farmers must buy seeds from the patent-holder again each year. By contrast, people cannot genetically engineer or change their own parents; people cannot genetically engineer or predict their grandchildren.

Within these two constants, the history of agriculture, preventive measures in public health and medicine is about legally changing the ability to achieve human potential; the possibility to improve or enhance the human race. In the next years, humanity will have the information to change many of these aspects of genetic destiny. Genes linked to color blindness, colon cancer, Huntington's disease, Downs Syndrome, or other conditions that are considered to be a "defect" today may be altered or deleted through new treatments or cures. For others, genes bring special gifts, such as physical strength, great intelligence, artistic ability or musical talent. Enhancement will be available to alter the capabilities of individuals and in turn, human potential, unless there are specific limits or safeguards on such enhancements under law. Maybe humans are different from foods like vegetable seeds, but maybe also the organisms that will resemble people but will be produced as a result of genetic engineering are not humans. Or are treated like human beings for some social purposes, but are not considered to be human beings under laws. The law has not yet addressed the rights of people or tissue masses that are cultivated for the manufacture and sale of human parts: Scientists demanded a moratorium on human cloning research in 1997. In response, President Clinton proposed legislation to impose a five-year ban on human cloning.⁷⁸

⁷⁸ The Cloning Prohibition Act of 1997 would have banned both the public and private sectors from using cloning technology to create a child but does not impact biomedical and agricultural advances. See *Bioethics Commission Backs Federal Human Cloning Ban Pending More Study, Debate*, 15 MEALEY'S LITIG. REP.: BIOTECHNOLOGY, June 13, 1997. The Human Cloning Research Prohibition Act of 1997 proposed a ban on the cloning of human embryos. The Act does not restrict areas of scientific inquiry that involves: "(1) the use of somatic cell nuclear transfer or other cloning technologies to clone molecules, DNA, cells other than human embryo cells, or tissues; or (2) the use of somatic cell nuclear transfer techniques to create animals other than humans." *Id.*

A. *Laws Prohibiting Genetic Discrimination*

Definitions of disability under law are elastic⁷⁹; changing to meet new developments in genetics. Eventually, social constructs determining the interpretation of "disability" under law may not include certain treatable conditions, that could be "cured" or rendered less debilitating using technology discovered through the genome project. Conversely, future interpretations of the term "disability" may have a broader scope, expanding to include conditions and effects of chromosomal abnormalities that have not yet been discovered.⁸⁰

GENETIC DISCRIMINATION IN EMPLOYMENT:

Generally, genetic information does not reveal anything about an individual's present ability to perform job functions safely and successfully. Rather, the information may reveal risks to the individual, but not risks to fellow workers. The government can express some interest in the protection of its workers against unnecessary risk of disease. Risks to co-workers could arguably support intrusive testing to secure the safety of co-workers.⁸¹ The U.S. Congress enacted the Americans with Disabilities Act of 1990 ("ADA") to protect individuals with disabilities from discrimination in such crit-

⁷⁹ The EEOC definition of "disability" includes genetic predispositions under the Americans With Disabilities Act, (ADA). See EEOC COMPLIANCE MANUAL 45. "This part of the definition of 'disability' applies to individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders. Covered entities that discriminate against individuals on the basis of such genetic information are regarding the individuals as having impairments that substantially limit a major life activity." See *id.* at 902-45; see also Brian R. Gin, *Genetic Discrimination: Huntington's Disease and the Americans with Disabilities Act*, 97 COLUM. L. REV. 1406, 1406 (1997).

⁸⁰ See 29 C.F.R. § 1630.2(i) (1998); 28 C.F.R. § 36.104(2) (major life activity under ADA: U.S. Department of Justice and the Equal Employment opportunity Commission define the term "major life activity" in the Code of Federal Regulations as "functions such as caring for one[']s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working."). See also *Bragdon v. Abbott*, 524 U.S. 624 (1998) (holding that an HIV infected individual was disabled because the possible transfer of disease to the next generation impaired the ability to reproduce). If a potential parent may pass a "genetic defect" to the next generation, the ADA may be interpreted as prohibiting genetic discrimination as protecting such individuals based on their impaired ability to reproduce. *Id.*

⁸¹ See *Leckelt*, 909 F.2d at 833. (5th Cir. 1990).

ical areas as employment, housing, public accommodations, education, transportation, and communication.”⁸²

There are few statutory limitations, but the law does not apply if a disabled person also presents a direct threat to be “a significant risk to the health or safety of others that cannot be eliminated by a modification of policies, practices, or procedures or by the provision of auxiliary aids or services.”⁸³ Upon acceptance of an offer, 42 U.S.C. § 12112(d)(3)(A) allows medical testing upon acceptance of an offer if all employees are tested as such.⁸⁴ Under the ADA, an employer cannot conduct pre-offer medical examinations on an applicant unless it can prove that the information so provided was not used in making job assignments or in any other discriminatory manner. In addition, the employer is prohibited from asking an applicant about the existence or severity of any disability. The employer may, however, inquire into the ability of the applicant to perform job-related functions so long as employee disclosure is voluntary and confidential.⁸⁵ According to an often-quoted EEOC policy statement, genetic discrimination falls under the term disability as defined in the ADA.⁸⁶ The Ninth Circuit has recognized the possibility of a privacy claim based on genetic testing in a publicly owned laboratory.⁸⁷ Congress enacted the Americans with Disabilities Act of 1990 (“ADA”) to protect individuals with disabilities from discrimination in such critical areas as employment, housing, public

⁸² ADA defines disability as “a physical or mental impairment that substantially limits . . . [a] major life activity. . . .” 42 U.S.C. § 12101(a)(3). A major life activity includes the ability to reproduce. See Bragdon, 524 U.S. 624.

⁸³ 42 U.S.C. § 12182(b)(3) (1994). See also Lynda M. Fox & Sherman G. Finesilver, *Genetics and the Workplace: ADA Applicability to Genetic Information*, 26 COLO. L. REV. 75, 75 (1997) (citing Warren Leary, *Using Gene Tests to Deny Jobs is Ruled Illegal*, N.Y. TIMES, Apr. 8, 1995, at A12) (reporting that the Equal Employment Opportunity Commission considers the use of genetic tests discriminatory if used to deny employment without informing the applicants of the tests against discrimination . . . shall include medical examinations and inquiries.”).

⁸⁴ 29 C.F.R. 1630.14(c) “A covered entity may require a medical examination . . . of an employee that is job-related and consistent with business necessity.” *Id.*

⁸⁵ 42 U.S.C. § 12101(a)(3) (ADA definition of disability).

⁸⁶ See EEOC COMPLIANCE MANUAL, *supra* note 79, at 902-45; see also Fox and Finesilver, *supra* note 83; Reuters, *Genes and Discrimination: Gore Urges Laws Banning Bias in Hiring and Insurance*, NEWSDAY, Jan. 21, 1998, at A20 (Vice-President Gore has been quoted as saying, “Genetic progress should not become a new excuse for discrimination.”).

⁸⁷ See *Norman-Bloodsaw v. Lawrence Berkley Lab.*, 135 F.3d 1260, 1269 (9th Cir. 1998) (acknowledging a cause of action based on privacy).

accommodations, education, transportation, and communication ADA defines disability as "a physical or mental impairment that substantially limits. . .[a] major life activity. . . ." ⁸⁸

The ADA recognizes, however, the right of employers to ask questions about disabilities in limited situations. In requesting this information the employer must inform the applicant that it is for remedial or affirmative action purposes, it is entirely voluntary, and that the information will be kept confidential and will not be used to discriminate against the applicant. EEOC guidelines suggest that an employer may list the essential job functions and ask an applicant whether he or she is capable of performing those functions. After the offer of employment has been extended: ADA provides that "[a] covered entity may require a medical examination after an offer of employment has been made to a job applicant and prior to the commencement of the employment duties of such applicant, and may condition an offer of employment on the results of such examination." ⁸⁹ These examinations must satisfy three requirements. First, an employer must test all entering employees regardless of disability. Second, the information collected must be maintained on separate forms and in a separate medical file and treated as confidential. Medical examinations may be used only "in accordance with this sub-chapter." ⁹⁰

ADA protects applies to individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders. ⁹¹ Courts consider several factors in balancing an employee's interest against the expense to an employer. The factors to be considered include: (1) the nature and cost of the modifications; (2) the overall financial resources of the facility; (3) the number of employees at the facility; (4) the overall financial resources of the entire company; (5) the type of operations of the

⁸⁸ 42 U.S.C. § 12101(a)(3).

⁸⁹ See 29 C.F.R. § 1630.14(a). "A covered entity may make pre-employment inquiries into the ability of an applicant to perform job-related functions and/or may ask an applicant to describe or to demonstrate how, with or without reasonable accommodation, the applicant will be able to perform job-related functions." See 29 C.F.R. § 1630.14(a).

⁹⁰ 42 U.S.C. § 12112(d)(3); see also 29 C.F.R. § 1630.14(b) ("A covered entity may require a medical examination . . . after making an offer of employment . . . and may condition an offer of employment on the results of such examination.").

⁹¹ See EEOC COMPLIANCE MANUAL, *supra* note 79. See also EEOC INTERPRETIVE MANUAL 902.4(c)(1).

company; and (6) the impact the accommodations would have on the operations at the facility.⁹² The EEOC has not given guidelines as to how each of these factors should be weighed to determine whether accommodating a disabled worker would be an undue hardship.⁹³

B. Occupational Safety and Health Act (OSHA)

1. Purposes of OSH Act

The field of occupational health and safety encompasses many types of work and many aspects of municipal, state and international laws that could not be embraced by any single Act of Congressional legislation. Thus the federal Occupational Safety and Health Act of 1970 ("OSH Act")⁹⁴ merely represents one Act among several laws governing occupational safety and health legislation nationwide. The OSH Act was passed with the express purpose: "To provide safe and healthful employment and places of employment for every working man and woman in the Nation . . . by providing medical criteria which will assure insofar as practicable that no employee will suffer diminished health, functional capacity, or life expectancy as a result of his (sic) work experience."⁹⁵

Employers may have a countervailing duty to use genetic data to protect people with genetic predispositions to disease by excluding them from certain environments where they are more likely to be harmed. *i.e.*, people who are slow acetylators, and are sensitive to phenotype aromatic amines used in dyes.⁹⁶ People with this genetic propensity and exposed to certain dyes are believed to have a higher risk of bladder cancer. This conclusion was based on Ashford's study concerning workers with occupational exposure to benzidine. "Qualitatively, therefore, evidence of some increased susceptibility in this case is relatively strong. It is not possible from these limited data to calculate how much greater the risk of similar

⁹² See 29 C.F.R. 1630.2(p)(2).

⁹³ See 29 C.F.R. 1630.2(p) app. at 353-54 (stating "in other cases, consideration of the financial resources of the employer . . . may be inappropriate because it may not give an accurate picture of the financial resources available to the particular facility that will actually be required to provide the accommodation.").

⁹⁴ 29 U.S.C. § 651.

⁹⁵ 29 U.S.C. § 651.

⁹⁶ NICHOLAS A. ASHFORD, ET. AL. MONITORING THE WORKER FOR EXPOSURE AND DISEASE: SCIENTIFIC, LEGAL AND ETHICAL CONSIDERATIONS IN THE USE OF BIOMARKERS, 74 (1990).

aromatic amine exposure might be for average people with “slow” phenotype. However, the indicated difference seems likely to be at least several-fold. Whether this is enough to justify screening programs is a social policy judgment that needs to be made in light of the absolute magnitude of the risk indicated for a specific exposed population, and other opportunities to reduce risk.”⁹⁷

2. OSHA’s Role

In the United States, OSHA’s statutory mission makes OSHA responsible for “preserving our National Resources” by protecting safety and health at work. The key term is found in the title and in the purposes, Section 2(b) of the Occupational Safety and Health Act of 1970 (“OSH Act”) where the U.S. Congress wrote the word, “HEALTH.” The three decade old statute is consistent with the international laws discussed above, and clearly shares the values codified by the international human rights laws and their cultural matrix. Promoting “HEALTH” is not about the many issues that polarize labor and management relations; issues that frequently cloud the progress towards achieving OSHA’s statutory goal of protecting safety and health in every workplace throughout our nation. Promoting health is about asking hard questions and sometimes making unpopular decisions preventing economic loss to fragile families; preventing industrial disasters and ultimately saving human life. We do not know today, whether the redefinition of “work,” “employer,” “employee,” and “occupation” that we will experience will undermine occupational health laws, hard-won workers’ compensation and wage and hour laws, but it is easy to predict from this history that a great deal of scientific and medical expert testimony will be written and evaluated in order to resolve the questions that lay at the heart of these age-old controversies. Laws have already emerged that prohibit underwriting or rating based on specifically identified genetic traits. Some states bar genetic testing altogether from underwriting or rating, barring insurance industry use of genetic information broadened beyond information collected in laboratory tests, such as the Oregon law that banned the use of genetic tests for employer-based insurance purposes.⁹⁸

⁹⁷ *Id.*

⁹⁸ Or. Rev. Stat. § 659.700 (1997).

C. *Legal Models for Informed Consent Regarding Genetic Testing*

1. Historical Antecedents of U.S. Informed Consent Law

Privacy is intertwined with the concept of control over oneself. Cases establishing the requirement that a patient consent before being administered any medical treatment, every human being of adult years and sound mind has a right to determine what shall be done with his own body, and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages.⁹⁹ These notions seem impractical, if not totally utopian in the current workplace context. The application of these principles presumes a great deal of knowledge and choice that most workers lack in the overall balance of power in labor relations. Further, the concept of informed consent has two pitfalls: it presumes the state-of-the-art of genetic testing and application of genetic information will be such that it will be reliable, without untoward side effects and without unforeseen disastrous outcomes. More importantly, the use of informed consent in the workplace context is problematic because it erodes the workers' compensation compromise that promised workers would not be accountable under the assumption of the risk doctrine. That doctrine was used to hold workers unduly liable for any or all damages in the workplace for hundreds of years. It was overturned by 20th century legislation.

Informed Consent: "True consent to what happens to one's self informed exercise of a choice, and that entails an opportunity to evaluate knowledgeably the options . . . The average patient has little or no understanding of the medical arts, and ordinarily has only his physician to whom he can look for enlightenment with which to reach an intelligent decision. From these almost axiomatic considerations springs the need, and in turn the requirement, of a reasonable divulgence by physician to patient to make such a decision possible."¹⁰⁰

⁹⁹ HOLTZMAN, N., PROCEED WITH CAUTION at 186, (Johns Hopkins University Press 1989) (*quoting*, *Schloendorff v. Society of New York Hospital*, 211 N.Y. 125 (1914))

¹⁰⁰ *Canterbury v. Spence*, 464 F.2d 772, 780-81 (1972) (this principal has been extended to give patients the right to forego life-sustaining medical care. "Patient consent must be obtained every time information changes hands."); *see also* *Chouinard v. Marjani*, 575 A.2d 238 (Conn.App.Ct. 1990).

2. Autonomy-Based Model For Informed Consent Law in the Wake of AIDS

Bayer and Kirp posit two “polar ideal types,” of a “contain and control strategy” and a “cooperation and inclusion strategy,” approach to prevention in public health policy, that is the hallmark of the “post-antibiotic era” where patterns of behavior are “rooted in the normative structures of the communities at risk.” AIDS-rights advocates lobbied for new laws that protect confidentiality, individual rights and civil liberties over the traditional “coercive” approach antithetical to civil liberties: quarantine, partner notification, contact tracing, mandatory testing, registries, mandatory reporting, mandatory testing for pregnant women as “vectors” of disease and mandatory newborn screening, all without informed consent. Experience from the AIDS pandemic therefore initiated several legal changes that provide a valid precedent for preserving genetic privacy to prevent discrimination by employers and insurers.

CONCLUSIONS: THE PATH MUST BE CHOSEN SOON

Genetic technology from HGI industry will raise a host of new property, tort, and constitutional questions. To what extent will we permit intellectual property rights in genetic tests and materials or the actual ownership of human embryos? Will we be able to patent biological parts just as we can now patent biologically engineered plants and bacteria? What will the law have to say about cloning human body parts by test-tube genetic engineering or cloning a human being by manipulating germ cells? Will it be legal to patent human genetic characteristics? And will any or all of those changes be required under law, or for specific jobs?

This paper has described the current legal systems that will be used to address emerging genetic testing issues in the workplace. Law may approach new genetic technologies using traditional laws family laws, intellectual property, public health and informed consent laws or by embracing existing definitions of discrimination. As in the case of HIV testing, the modern paradigm has shifted away from the “invasiveness” of testing, towards a hard look at the emotional burden that testing places upon patients and how the information will be used: whether as a vehicle for unwanted discrimination, or for public health benefits, or commercial applica-

tion of information in profitable new markets. Whether significant scientific concepts, will play a strong role in shaping the social response, as articulated by legislatures and as implemented by occupational physicians in daily practice, up to the people in this room. Although the legislature is vested with powers that science lacks, there has been a grafting of science onto the actual laws and texts of the statutes. It can be expected that courts will admit into evidence a vast variety of genetic information that never would have previously been acceptable in a court of law. There is no need for a proposal for science courts, as was offered in the early 1960's during the Cold War and the "Space Race" to bring the latest technology to every school child in the U.S.A. Our courts of law are de facto science courts already. Instead, what is needed is not a science court or a new set of science-evidence rules for the application of genetic technologies to daily life; a system that will meaningfully bring genetics to the science of governance: jurisprudence, by enabling scientists to bring their full participation and knowledge to existing judicial decision making structures, that will prohibit certain types of bad uses of information, such as the resurrection of the assumption of the risk doctrine by providing sham forms for workplace "informed consent."

Congress has said that science and medicine have a place and should be appropriately integrated into the various parts of our legal system. And courts have listened by accepting all types of scientific and medical testimony that went unheard decades or a century ago. There is ongoing concern, however that courts will supplant their own judgment regarding the validity, reliability and probative value of scientific evidence. This can only be remedied by having scientists sit as judges. In fact, such courts exist under our present laws and with occupational physicians beside the legislatures as they define genetics for future workplaces.