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Accessing Genomic Information for Nonmedical Purposes

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ACCESSING GENOMIC INFORMATION OR SAFEGUARDING GENETIC PRIVACY

GEORGE P. SMITH, II¹

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I. SUMMARY

While abundant fears mark the pathways for the development of the New Biology, humanity's dehumanization and depersonalization will not be fostered—in reality—as a consequence of the continuing quest for mastery of the genetic code through pursuit of the Human Genome Initiative. Indeed, if actions are undertaken and performed here with the goal of minimizing human suffering and maximizing the social good, then the noble integrity of evolutionary and genetic progress will be preserved and the "slippery slope" of careless and irrational action will be avoided totally.

Obviously, attendant to the freedom to undertake research into the exciting frontiers of the New Biology is a co-existent responsibility to pursue the work in a reasonable and rational manner. The real—although often exaggerated—threats to genetic privacy, and the resulting forms of genetic discrimination, posed as a consequence of research in this field, can be contained by careful development and application of legal norms through legislative schemes at the state and federal levels of government. In

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This essay is a revised and extended version of a paper entitled, "Biological Determinism or Genetic Discrimination," presented at the 10th World Congress on Medical Law in Jerusalem on August 31, 1994.

partnership, law and science should seek to develop a contemporary agenda for social change that also seeks to fulfill socio-political goals.

When viewed as but a tool for enhancing the health of the nation's citizens, and of engineering humanity's genetic weaknesses out of the line of inheritance, biological determinism is an absolute necessity for trans-national survival in the 21st century. Simply stated, healthier and genetically sound individuals have a much better opportunity for pursuing and achieving the "good life" and making a significant contribution to society's greater well-being or, in other words, social good.

II. PROBLEMS OR OPPORTUNITIES

The publication of Aldous Huxley's *Brave New World* in 1946 predated the discovery by James Watson and Francis Crick of deoxyribonucleic acid (DNA)² by seven years. Commentators to this day continue to view the significance of advances in recombinant DNA (rDNA) technology through the lens of Huxley's totalitarian society,³ a genetic caste system made possible by genetic technology.⁴ The alternative characterization of such technology as a grail to treat or heal inherited diseases is perhaps less alarming but similarly fails to adequately describe the current state of technology both from the perspective of identifying specific genetic traits and from that of developing therapy.⁵ Nevertheless, in 1993, the fortieth anniversary of the discovery of DNA,⁶ the Human Genome Project continues its mapping of the human genome,⁷ and the

²James Watson & Francis Crick, *Genetic Implications of the Structure of Deoxyribonucleic Acid*, 171 NATURE 964 (1953).

³Kimberley Nobles, *Birthright or Life Sentence: Controlling the Threat of Genetic Testing*, 65 S. CAL. L. REV. 2081 (1992). See GEORGE P. SMITH, II, *THE NEW BIOLOGY: LAW, ETHICS AND BIOTECHNOLOGY* (1989).

⁴Such rDNA advances include germ-cell or germ-line therapy, whereby genes within sperm or eggs are replaced or repaired to the effect that such modified genetic material is passed on to the next generation. U.S. CONGRESS, OFFICE OF TECHNOLOGY ASSESSMENT, BIOLOGY, MEDICINE, AND THE BILL OF RIGHTS—SPECIAL REPORT 40 (OTA-CIT-371 1988). In contrast, somatic cell therapy will not cause inherited or inheritable changes. It might provide, however, a means of replacing the defective gene in the bone marrow cells of a child affected by genetic immune deficiency. If successful, such therapy would "cure" the child but would have no effect on his or her own offspring. *Id.* See also *The Aim is to Get Genes to Do the Work: Newsday Interview with James D. Watson*, NEWSDAY, July 6, 1993, at 59. See generally D. NELKIN & L. TANCREDI, *DANGEROUS DIAGNOSTICS: THE SOCIAL POWER OF BIOLOGICAL INFORMATION* (1989); GUSTAV NOSSAL, *HUMAN GENETIC INFORMATION: SCIENCE, LAW & ETHICS* (1990).

⁵THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT (Daniel J. Kevles & Leroy Hood eds., 1992). See generally George P. Smith, II, *Uncertainties in the Spiral Staircase: Metaethics and the New Biology*, 41 THE PHAROS MED. J. 10 (1978).

⁶NEWSDAY, *supra* note 4. See also *Changing Your Genes*, THE ECONOMIST, April 25, 1992 at 11; Leon Jaroff, *Making the Best of a Bad Gene*, TIME, Feb. 10, 1992, at 78.

⁷See Carol Lee, *Creating a Genetic Underclass: The Potential for Genetic Discrimination by the Health Insurance Industry*, 13 PACE L. REV. 189, 195 (1993).

accelerated pace of mapping that began in the early 1970's⁸ is expected to continue due to innovations in genome mapping and sequencing.⁹

The salutary effect of this technology—the ability to catalog and analyze the genotype of a particular individual—creates the potential for abuse of such information. Indeed, for some, the eugenics movement¹⁰ to this day casts a shadow over the Human Genome Project. The risks of abuse engendered by the mapping of the human genome and emergent rDNA technology do not extend to social engineering and development of a "superior" human, a process necessitating germ-line modification. Rather, the potential abuse may result from discrimination based on the dissemination of key information about the genotype of an individual—information which reveals the risk factors inherent in that individual.¹¹ Genetic data is a particularly sensitive category of health care information.¹² Unlike information about a specific transient condition or illness, data pointing to a genetic disorder will affect, and may stigmatize, a person throughout his or her entire life.¹³ The handling of genetic information by the state or its agents, therefore, implicates individual liberty interests deriving from fundamental constitutional rights to equality and privacy.¹⁴ In

⁸Clive Cookson, *The Men Who Would Play God: Unravelling the secrets of the human gene could transform human life. But the possibilities for abuse of this power are terrifying*, FIN. POST (Weekly Edition), Feb. 10, 1992, at S37.

⁹Daniel Kevles & Leroy Hood, *The Deoxyribonucleic Acid Test*, S.F. CHRON., Dec. 6, 1992, § Z1, at 8.

¹⁰The basic idea of eugenics was to improve the human gene pool by increasing the number of supposedly desirable human beings ("positive" eugenics) and getting rid of undesirable ones ("negative" eugenics). *Id.* In Nazi Germany, the eugenics movement rationalized policies of mass sterilization and ultimately the creation of death camps for the extermination of individuals deemed undesirable by virtue of ethnicity, religion, or sexual orientation. Similarly, in the United States, many states enacted sterilization laws justified in large part by eugenic principles. In California alone, 6,255 individuals were sterilized by 1929. Most of these laws were overturned, however, by a decision of the United States Supreme Court in 1942. *Id.* See *Skinner v. Oklahoma*, 316 U.S. 535 (1942).

¹¹See Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENETICS 476, 479, 481 (1992). The findings of this study affirm the existence of discrimination against individuals who are completely asymptomatic, their only "abnormality" being in their genotype. Indeed, it appears that genetic conditions are regarded by many social institutions (i.e., insurance companies) as extremely serious, disabling, or even lethal conditions. See generally Andrea DeGorgey, *The Advent of DNA Databanks: Implications for Information Privacy*, 16 AM. J.L. & MED. 381 (1990).

¹²Lori B. Andrews, *The Future of Confidentiality of Genetic Information*, in MEDICAL GENETICS: A LEGAL FRONTIER 209 (1987); See George P. Smith, II, *Genetics, Eugenics and Public Policy*, 1985 SO. ILL. U. L.J. 435.

¹³Andrews, *supra* note 12, at 187-88, 209. Unlike an infectious disease, a genetic disorder is generally immutable. Thus, an inappropriate disclosure may cause serious financial, emotional and perhaps even physical harm to the individual in question.

¹⁴*Id.* See Neil A. Holtzman, *Recombinant DNA Technology, Genetic Tests and Public Policy*, 42 AM. J. HUM. GENETICS 624 (1988). See George J. Annas, *Privacy Rules for DNA Databanks: Protecting Coded Future Diaries*, 270 JAMA 2346 (1993). See generally George

this context genetic discrimination has been defined as "discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the 'normal' genome in the genetic constitution of that individual."¹⁵ Individuals identified as at risk are:

(1) those . . . who are asymptomatic but carry a gene(s) that increases the probability that they will develop some disease, (2) individuals who are heterozygotes (carriers) for some recessive or X-linked genetic condition but who are and will remain asymptomatic, (3) individuals who have one or more genetic polymorphisms that are not known to cause any medical condition, and (4) immediate relatives of individuals with known or presumed genetic conditions.¹⁶

Because the individuals who are likely to be discriminated against are asymptomatic or presymptomatic and are, therefore, not readily identified, genetic discrimination is most likely limited to two contexts: employment and insurance.¹⁷ Both employers and insurers may believe such discrimination is warranted for the profitable conduct of business.¹⁸ Furthermore, both

P. Smith, II, *Biotechnology and the Law: Social Responsibility in Freedom of Scientific Investigation*, 36 MERCER L. REV. 437 (1988).

One leading commentator has proposed four basic privacy rules for DNA databanks. First, no such databanks should be created or commence storing DNA samples until public notice and justification are given for establishing such a bank, a privacy impact statement is filed with the designated public (or licensing) agency; and proof is provided that such a bank advances a significant medical or societal goal. Second, no collection or storage of DNA samples can be undertaken without prior written agreement setting forth the purposes and uses (including commercial) permitted of the samples, and recognized guarantees of individual access to all samples and records thereof are given, together with a right to not only correct inaccurate information but an additional right recognized to order the destruction of the sample should the databank change significantly its identity, or for that matter, cease operation altogether. Third, strict security policies should be set that allow the DNA samples to be used exclusively for the purposes for which they are collected—with access by third parties being controlled strictly. Fourth, mechanisms should be developed which allow notification and counsel to those whose DNA samples are being stored when new information is made available that may have an important health impact on such individuals. Annas, *supra* note 14, at 2349.

¹⁵Marvin R. Natowicz et al., *Genetic Discrimination and the Law*, 50 AM. J. HUM. GENETICS 465, 466 (1992). The authors distinguish genetic discrimination from discrimination based on disability caused by altered genes and thereby clarify the point that genetic discrimination is not based on any notion of the present function of the individual. Rather the discriminating party relies on that individual's genotype to assess risk of future dysfunction.

¹⁶*Id.*

¹⁷*Id.* See U.S. CONGRESS, OFFICE OF TECHNOLOGY ASSESSMENT, GENETIC MONITORING AND SCREENING IN THE WORKPLACE, (OTA-BA-455 1990).

¹⁸See Natowicz, *supra* note 15, at 467.

employers and insurers normally have access to detailed medical records of employees and customers.¹⁹

For example, an employer may reject a job applicant based on information obtained through genetic testing for several reasons: increased medical and insurance premiums, absenteeism, lowered productivity, increased risk in the line of duty and increased liability for workers compensation.²⁰ In the area of insurance, genetic testing potentially undermines the principle that both the insurer and the insured ought to possess equal knowledge of a particular insured's risk of becoming ill.²¹ The availability of the genotype of a particular individual either to the insurer or to that individual alone presents the possibility of adverse selection.²² For example, an individual who knows he/she is at risk for developing Huntington's Chorea will buy a greater amount of life or health insurance as he/she knows that he/she is at greater risk of death or serious illness.²³ Conversely, insurers will either refuse to offer coverage or drop those individuals in a genetic high-risk category.²⁴

Although arguably fair when an individual chooses to engage in high risk activity such as smoking or sky-diving, the prospect of refusing to provide insurance to individuals because of a genetic trait is inequitable and contrary to public policy.²⁵ First, carriers of defective genes may never develop full symptoms that affect their ability to function.²⁶ More importantly, however,

¹⁹*Id.* See Mark A. Rothstein, *Genetic Screening in Employment: Some Legal, Ethical and Societal Issues*, 1 INT'L J. BIOETHICS 239 (1990).

²⁰Nobles, *supra* note 3, at 2089. A more accurate measure of safety risk instead of utilizing genetic testing would be a test of an individual's actual capacity to function in a safety sensitive job. Council on Ethical and Judicial Affairs, *Use of Genetic Testing by Employers*, 266 JAMA 1827, 1828 (1991).

²¹Nobles, *supra* note 3, at 2089. Over time, as the costs of genetic testing decrease and their degree of accuracy increases, insurers may well be expected to find it not only cost effective to screen genetically prospective clients but indeed a competitive necessity. The central problem with insurers, either in performing genetic testing themselves or obtaining genetic information about such tests performed independently, is that this practice would lead, in all likelihood, to discrimination (*i.e.*, higher premiums or rejection altogether) against those who carry genes or genetic markers which dispose them to future illness.

²²*Id.*

²³*Id.*

²⁴Nobles, *supra* note 3, at 2090. Florida, Louisiana, New Jersey and North Carolina have enacted legislation prohibiting discrimination in employment and insurance based on carrying the sickle cell trait, hemoglobin C trait, thalassemia, Tay-Sachs or cystic fibrosis. FLA. STAT. § 448.076 (1991); LA. REV. STAT. §§ 22:652.1.23:1002A (1992); N.J. STAT. §§ 10:5-12, 10:5-5 (1992); N.C. GEN. STAT. §§ 58-51-45, 58-58-25, 95-28.1 (1992).

²⁵Nobles, *supra* note 3, at 2090.

²⁶*Id.*

such disparate treatment and resulting risk minimization vitiates the purpose of traditional private insurance as a risk-spreading mechanism.²⁷

III. THE HUMAN GENOME INITIATIVE

The human genome refers simply to the chromosomal collection of twenty-three pairs of chromosomes that all humans carry, within which all human genes reside and, more specifically, to those genes that contribute directly to traits such as height, eye color, and the shape of body parts as well as to human behavior. Diseases develop when alterations of the genes, known as mutations, occur.²⁸ In all, more than 2,000 disease conditions have been found to have their origins in single gene defects.²⁹

The Human Genome Initiative is an undertaking coordinated by the United States Department of Energy and the National Institutes of Health and funded by the U.S. Congress that will complete "mapping" all 50,000 to 100,000 human genes within fifteen years. Although not fully funded at the \$3 billion set originally, Congress has funded the project sufficiently for there to be every reason to conclude the project will meet its deadline.³⁰ As of March, 1993, some 2,736 of the targeted genes had been in fact "mapped" or, in other words, located precisely on one of the twenty-three chromosomes.³¹

The driving motive behind the Human Genome Initiative is, then, quite simple and direct: the identification and eradication of all genetically based disease. With more than 2,000 conditions being recognized as having their origins in single gene defects,³² the ultimate success of the Initiative holds awesome opportunities for improving the health of all world citizens and minimizing human suffering from disease.³³ Yet, the secrets of the genome—when revealed—will generate a whole array of "what-if" fears: from

²⁷*Id.*

²⁸Jon Beckwith, *Foreward: The Human Genome Initiative: Genetics' Lightning Rod*, 17 AM. J.L. & MED. 1, 2 (1991). See MAXINE SINGER & PAUL BERG, GENES & GENOME: A CHANGING PERSPECTIVE (1991).

²⁹Catherine M. Valerio Barrad, *Genetic Information and Property Theory*, 87 NW. U. L. REV. 1037, 1043 (1993).

³⁰Seth Lubove, *Genomic Wildcatters*, FORBES, Feb. 3, 1992, at 97; James D. Watson, *The Human Genome Project: Past, Present and Future*, 248 SCIENCE 44 (1990).

³¹David Brown, *Filling in Gene Maps, But Far from Home*, WASH. POST, Mar. 8, 1993, at A3; Daniel E. Koshland, Jr., SEQUENCES AND CONSEQUENCES OF THE HUMAN GENOME, 246 SCIENCE 189 (1989).

In 1990, the federal government's Center for Biologics, Evaluation and Research at the Food and Drug Administration approved efforts to undertake human gene therapy. See Medical Research Council, HUMAN GENOME RESEARCH: A REVIEW OF EUROPEAN AND INTERNATIONAL CONTRIBUTIONS (Diane J. McLaren, ed. 1991).

³²Barrad, *supra* note 29, at 1043.

³³See George P. Smith, II, *Manipulating the Genetic Code: Jurisprudential Conundrums*, 64 GEO. L.J. 697 (1976).

fear of the unbridled use of genetic information to advance a program of positive eugenics³⁴ to concerns that disclosure of an individual's genetic profile and his susceptibility to illness (even alcoholism) will, in turn, form the basis for discriminatory action or stigmatization. There is concern that the disclosure of genetic information could result in a possible refusal by an insurer to pay medical costs if one were to elect not to undergo a recommended treatment or if a child with a prenatally identified genetic defect were to be born.³⁵

Equally worrisome is the fear that the widespread delineation of genetic profiles will result in the centralization of that genetic information—much as today credit information is centralized. Since DNA sequence databases are prone to error, there is also concern that even in the event gene mapping were to become routine, "comparison of an individual's genetic profile to an error-ridden prototype could have the same stigmatizing effect as do false positives on drug tests and tests for the HIV antibody."³⁶

A. *The Perils of Genetic Knowledge*

Once a "disease gene" is discovered, the release of the information normally incorporates a suggestion that treatments to arrest it are forthcoming. Yet, discovering the mechanism of a disease is not the same as knowing how to change that mechanism. With genetic information of this type, however, at least a chance is created for developing an effective therapy to combat the genetic disease.³⁷

The "heuristics of fear" all too often blot out rational analysis of emerging genetic knowledge³⁸ and do little to satisfy the need to promote medically and ethically informed public discussion³⁹ within "communities of moral discourse" where scientific, as well as medical, ethical and political issues can be discussed "by informed and intelligent persons who represent different perspectives on the nature of humanness."⁴⁰ Caution should always be the watchword in examining genetic assumptions, and oversimplification of genetic findings should be avoided.⁴¹

³⁴See GEORGE P. SMITH, II, *GENETICS, ETHICS AND THE LAW*, Ch. 5 (1981). See also PHILIP REILLY, *GENETICS, LAW AND SOCIAL POLICY*, 120 & Ch. 5 (1977).

³⁵Barrad, *supra* note 29, at 1046.

³⁶*Id.* at 1047.

³⁷Brown, *supra* note 31.

³⁸See INSEL VERLAG, Frankfurt am Main, *THE IMPERATIVE OF RESPONSIBILITY: IN SEARCH OF AN ETHIC FOR THE TECHNOLOGICAL AGE* (Hans Jonas trans., 1984).

³⁹James M. Gustafson, *Genetic Therapy: Ethical and Religious Reflections*, 8 J. CONTEMP. HEALTH L. & POL'Y 183, 190 (1992).

⁴⁰*Id.* at 199-200.

⁴¹Rochelle Cooper Dreyfus & Dorothy Nelkin, *The Jurisprudence of Genetics*, 45 VAND. L. REV. 313, 347-48 (1993).

As much as law should seek to avoid ambiguity, it should not rely on science for definitive answers. Science, within its own sphere, simply does not offer unambiguous answers.⁴² Two forms of uncertainty are inherent in any scientific undertaking. The first is conceptual and derives from fundamental changes in those concepts engendered by the new biotechnologies. The second is termed occurrence and applies to select issues that cannot be readily addressed.⁴³

The image of neutrality that science has sought to cultivate or "sell," is largely a myth created in an attempt to maintain autonomy and thus blunt increasing pressures from both church and state for intervention and control.⁴⁴ Indeed, the history of science is replete with cases where not only the choice of research topics but the nature of scientific theories as well as the representation of results from research have been socially constructed and shaped by cultural forces to reflect various societal assumptions of the times.⁴⁵

IV. TOWARD A PRINCIPLE OF BIOLOGICAL DETERMINISM

In today's society, a new and discernible preoccupation with biological determinism is all too evident. This preoccupation is spurred by successes in developing genetic tests that have found the markers indicating predispositions to certain single gene disorders such as Huntington's disease, and the hopes that complex conditions such as cancer, drug dependency and mental illness will be—with the successes of the Genome Project—predictable. Building upon the limited successes with Huntington's chorea, a number of states now mandate newborn infant genetic testing for conditions such as phenylketonuria (PKU).⁴⁶

Biological determinism evolves from the principle of genetic essentialism, which posits that personal traits such as mental illness, homosexuality, aggressive personality, exhibitionism, dangerousness, shyness, and stress have a genetic or biological disposition and, indeed, are predictable and determinable at conception. Thus, the social context in which the traits are

⁴²*Id.* at 343-45.

⁴³President's Commission for The Study of Ethical Problems in Medicine & Biomedical & Behavioral Research, *SPLICING LIFE: A REPORT ON THE SOCIAL & ETHICAL ISSUES OF GENETIC ENGINEERING WITH HUMAN BEINGS* 22 (1982).

⁴⁴Dreyfus & Nelkin, *supra* note 41, at 339. *See, e.g.*, the evolution of Darwin's theory of Natural Selection into a theory of Social Darwinism as a biological defense of the changing forces of industrialization and the extension of Gregor Mendel's theories of genetics and the eugenic principles of Francis Galton to prove deviant behavior and low intelligence as but aspects of heredity. *Id.* at 339, 340.

⁴⁵WASH. POST, Nov. 14, 1990, at 1, col. 5. *See generally* W. French Anderson, *Human Gene Therapy: Scientific and Ethical Considerations*, 10 J. MED. & PHIL. 275 (1985).

⁴⁶Dreyfuss & Nelkin, *supra* note 41, at 314. For an historical overview of early state mandated PKU testing between 1963 and 1968 and the state legislative citations to the forty-three states where such genetic testing is required, *see* Reilly, *supra* note 34, at 37 *passim*, 49-52, Ch. 4 (1977).

manifested is minimized under this principle.⁴⁷ In a word, biological determinism recognizes essentially that one's fate is determined by his or her genetic inheritance.⁴⁸

A. Contemporary Perspectives

In 1992 Louis Harris and Associates conducted a survey for The March of Dimes polling one thousand people in the United States regarding their views of genetic testing and gene therapy. Seventy-nine percent of those polled, while not in fact understanding totally what the two issues were all about, expressed their willingness to undergo gene therapy if necessary. Eighty-eight percent of these polled allowed that they would have their children undergo such therapy in order to prevent or cure a genetic disease that would usually be fatal if not found through testing. Approximately three quarters of those in the poll expressed their concern that gene therapy be undertaken only according to "strict regulations." And, interestingly, more than half in the survey stated their belief that when a genetic disease is discovered, someone needs to be appraised of this fact. Only about a third thought an employer should be advised of the genetic disease. Yet ninety-eight percent concluded one's spouse or fiancé should be told, and fifty-eight percent concluded insurers should be informed. Finally, forty-seven percent of those surveyed favored experimental gene therapy if its goal was to improve therapeutically ultimate physical characteristics, while forty-two percent would allow it if its goal was to improve a child's intelligence.⁴⁹

V. THE HUMAN GENOME PRIVACY ACT: A MODEL LEGISLATIVE SOLUTION?

In the area of privacy, there has been only one legislative proposal which, as a model statute, merits study. The Human Genome Privacy Act (HGPA) was introduced before the House of Representatives by Representative John Conyers on September 13, 1990.⁵⁰ Although no action was taken on the bill following its introduction, its language responds in many respects to the

⁴⁷Dreyfuss & Nelkin, *supra* note 41, at 320-21. See Owen D. Jones, *Sex Selection: Regulating Technology Enabling the Predetermination of a Child's Gender*, 6 HARV. J.L. & TECH. 1, 21 (1992) where the principal justification of sex selection is that its use serves to reduce or eliminate "certain sex-linked diseases, such as hemophilia, Cooley's anemia, Down's syndrome, and more than 400 others, that increase aggregate social anxiety and tax society's medical and financial resources."

⁴⁸Dr. James Watson, Director of the Human Genome Initiative, said, "Our fate is in our genes." Leon Jaroff, *The Gene Hunt*, TIME, Mar. 20, 1989, at 62, 67.

⁴⁹Sandy Rovner, *Many Americans Say Gene Therapy Okay*, WASH. POST HEALTH MAG., Sept. 29, 1992, at 5. See generally Howard Markel, *The Stigma of Disease: Implications of Genetic Screening*, 93 AM. J. MED. 209 (1992). See also Philip Elmer-Dewitt, *The Genetic Revolution*, TIME, Jan. 17, 1994, at 46.

⁵⁰H.R. 5612, 101st Cong., 2d Sess. (1990). This legislation is no longer pending. In October, 1992, Congress adjourned *sine die*. Thus, all unpassed bills pending at that time died. Neither this HGPA nor similar legislation has been reintroduced.

problems of confidentiality of genetic information in the workplace. It may be fully expected that similar legislation will be proposed over time.⁵¹ The purpose of the bill was "to safeguard individual privacy of genetic information from the misuse of records maintained by agencies or their contractors or grantees for the purpose of research, diagnosis, treatment, or identification of genetic disorders."⁵² The bill would have provided individuals access to records concerning their genome as maintained for any purpose by agencies of the federal government.⁵³ The language of this proposed legislation may be studied as a potential model for future legislation both at the federal and state levels.⁵⁴

From a policy perspective, the HGPA would overlap with two important federal statutes. In lieu of enacting new legislation, Congress could easily amend either the Americans with Disabilities Act (ADA)⁵⁵ or the Privacy Act⁵⁶

⁵¹Lori B. Andrews & Ami S. Jaeger, *Confidentiality of Genetic Information in the Workplace*, 17 AM. J.L. & MED. 75, 108 (1991).

⁵²H.R. 5612, *supra* note 50.

⁵³*Id.*

⁵⁴Preexisting federal legislation protecting against discrimination as to individuals with mental and physical impairment and limiting the type of information the government may collect is found in the Americans with Disabilities Act of 1990, 42 U.S.C.A. §§ 12011-12213 (West Supp. 1992) and the Privacy Act of 1974, 5 U.S.C. § 552a (1988) respectively.

⁵⁵The Americans with Disabilities Act of 1990, 42 U.S.C.A. §§ 12101-12213 (West Supp. 1992). Specifically, "the ADA prohibits employers from discriminating against individuals who have, or have had a history of, a disability that involves a mental or physical impairment that limits a major life activity." Charles B. Gurd, *Whether a Genetic Defect Is a Disability Under the Americans with Disabilities Act: Preventing Genetic Discrimination by Employers*, 1 ANNALS HEALTH L. 107, 118 (1992). Section 12112(a) of the Act states specifically that:

[n]o covered entity [employer, employment agency, labor organization or joint labor-management committee excluding the federal government] shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, or other terms, conditions and privileges of employment. 42 U.S.C.A. § 12112(a) (West Supp. 1992).

Section 12112(d)(2)(A) prohibits preemployment medical examinations. Accordingly, no preemployment questionnaires may be used by prospective employers nor may they inquire of potential employees whether they have any medical conditions such as epilepsy, diabetes or hypertension. Only questions that focus on specific, job-related functions may be asked of applicants. 42 U.S.C.A. § 12112(d)(2)(B) (West Supp. 1992). Statutory prohibition against preemployment medical examinations will assist greatly in curing abuses in discriminatory hiring that would otherwise be based on genetic testing.

⁵⁶Privacy Act of 1974, 5 U.S.C. § 552a (1988). The Privacy Act restricts the type of information that the federal government may collect. Thus, it provides that the government may retain only the minimal amount of records possible:

(e) Agency requirements—Each agency that maintains a system of records shall—

in order to include relevant provisions of the HGPA. Although addressing analogous discrimination and privacy issues, the ADA and the Privacy Act fall short of extending explicit protection to asymptomatic individuals with abnormal genotypes.⁵⁷

Regarding disabilities under the ADA, the current policy is "can't ask, don't tell." The major uncertainty with this policy is "whether a genetic trait that has not manifested itself counts as a disability within the meaning of the statute."⁵⁸

It would appear that the most fruitful path in the legislative arena would be by amendment to these legislative schemes. As amended, these statutes should

(1) maintain in its records only such information about an individual as is relevant and necessary to accomplish a purpose of the agency required to be accomplished by statute or by executive order of the President;

5 U.S.C. § 552a(3)(1). Furthermore, subject to certain exceptions, the Act provides for protections from disclosure:

(b) Conditions of disclosure—No agency shall disclose any record which is contained in a system of records by any means of communication to any person, or to another agency, except pursuant to a written request by, or with the prior written consent of, the individual to whom the record pertains. . . .

5 U.S.C. § 552a(b). This legislation, however, only serves as a protection against disclosure by the federal government.

⁵⁷ See Gurd, *supra* note 55, at 118. Because of the statutory requirement of some past or present dysfunction, many individuals who have a genetic defect are not covered. Furthermore, the ADA may be "inapplicable to carriers or individuals receiving treatment to prevent gene expression." *Id.* Accordingly, the ADA provides no protection from "discrimination based on an individual's genetic profile." *Id.* See also Larry O. Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109, 123 (1991) (explaining that a genetic condition which does not cause substantial impairment may not constitute a disability as defined under the Act).

The agency charged with enforcing the ADA, the Equal Employment Opportunity Commission, has determined that there is no individual coverage under the law until one is determined to be symptomatic. Thus, presymptomatic individuals with late-onset disorders as, for example, adult polycystic kidney disease, would have no coverage under the Act. Similarly, those "carriers of recessive disorders such as cystic fibrosis . . . are [also] not covered and could be denied employment." Neil A. Holtzman & Mark A. Rothstein, *Invited Editorial: Eugenics and Genetic Discrimination*, 50 AM. J. HUM. GENETICS 457, 458 (1992). See also E. Juengst, *Priorities in Professional Ethics and Social Policy for Human Genetics*, 266 JAMA 1835 (1991).

What can be seen in the disability rights movement is a direct ideological challenge to medical genetics or genetic determinism. It has been urged that rather than prevent the birth of persons with significant disabilities (e.g., blindness), society should change the ways in which it views these individuals and thus accept them as equals. ROBERT COOK-DEEGAN, *THE GENE WARS: SCIENCE, POLITICS AND THE HUMAN GENOME* 252 (1994).

With respect to the Privacy Act, the main defect is that it restricts only the types of information that may be collected by the federal government. However, its provisions seem to apply broadly, and would thus include genetic information with other types of personal data. See Andrews & Jaeger, *supra* note 51, at 101.

⁵⁸ Richard A. Epstein, *The Legal Regulation of Genetic Discrimination: Old Responses to New Technology*, 74 B.U. L. REV. 1, 13-18 (1994).

recognize the fundamental importance of privacy and equality rights while explicitly extending the protection of these principles to problems of discrimination based on disclosure and dissemination of genomic information. Such amendments to an established statutory framework would simplify the process of effectuating newly enacted protections, rather than establishing a new area of law subject, in turn, to the promulgation of complex regulations and interpretative judicial clarification.

VI. INTERNATIONAL STRATEGIES

At the international level, three strategies are available: (1) imposition of an international moratorium on the use of genetic information obtained from testing in connection with applications for employment and private insurance; (2) development of a common set of principles under the planned Bioethics Convention of the Council of Europe that would guide the future collection and use of genetic information; and (3) inclusion within Articles 2 and 26 of the United Nations International Covenant on Civil and Political Rights, which prohibits discrimination on the grounds of race, sex or religion, provisions applying to genetic discrimination.⁵⁹

As to the first strategy, enforcement of a moratorium would be difficult, but certainly reasonable since there is no regular practice of genetic testing being undertaken presently throughout the world community. Even though the Council of Europe has no enforcement powers, the second approach would appear to be the most achievable. Consensus might be more readily attained since the Steering Committee on Bioethics of the Council has recently, after two years, produced a draft convention and referred it to European governments for consultation.⁶⁰ The third alternative would be merely palliative since, again, there would be no supervisory or enforcement powers other than *self* regulation among the signatories.

VII. A NEW PARTNERSHIP

While the Human Genome Initiative will provide startling genetic maps, it remains for the law to sequence or identify the policy issues inherent in the complex programming of medical genetics and then to proceed to resolve conflicts, to the extent possible, within legal doctrines.⁶¹ This, in turn, forces a need to critically examine the true social significance of the concepts of normality and abnormality.⁶² With this all comes a fear, rational or irrational,

⁵⁹Sjef Gevers, *Use of Genetic Data, Employment Data, Employment and Insurance: International Perspective*, 7 *BIOETHICS* 126 (1993). See YVONNE M. CRIPPS, *CONTROLLING TECHNOLOGY: GENETICS, ENGINEERING AND THE LAW*, Ch. 5 (1980).

⁶⁰Tony Sheldon, *European Experts Produce Draft on Bioethics*, 309 *BR. MED. J.* 221 (1994).

⁶¹Lori B. Andrews, *The Randolph W. Thrower Symposium, Genetics and the Law, Introduction*, 39 *EMORY L.J.* 619, 620 (1990).

⁶²Alexander M. Capron, *Which Ills to Bear?: Reevaluating the 'Threat' of Modern Genetics*, 39 *EMORY L.J.* 665, 693-94 (1990).

that laws will be passed requiring everyone to submit to gene therapy or even, as the case may warrant, to "provide personally identifiable genetic material for purely scientific uses."⁶³ Yet, interestingly, individuals are less likely to be interested in knowing about their genetic profiles if they are obsessed with an overriding fear that such knowledge will then be used (or misused) to punish them. Society will thus be forced to develop both ethical and legal norms to protect those members of society at higher risk for genetic discrimination.⁶⁴

Tens, if not hundreds, of new genetic screening tests will be in competition with each other for introduction into routine clinical practice as the pace of the Human Genome Project quickens. It is urged, consequently, that "new strategies based on [a form of] general or generic consent . . . be developed for genetic screening—the aim [of which] would be to provide [adequate] information to [thereby enable patients] to make informed decisions about carrier screening yet prevent information overload that could lead to misinformed consent."⁶⁵ The stakes in reproduction genetics are inevitably high because they involve exercise of a right to decide whether or not to engage in genetic testing, balanced by a coextensive right to *refuse* testing if a potential harm—in terms of stigma, for example—outweighs the benefits derived from it for the at-risk individual or his family.⁶⁶

From a more positive side, universal access to the wide opportunities of genetic services will allow persons "to act on the perception that it is good to want to know about genetic risks."⁶⁷ Accordingly, when the benefits of genetic diagnosis and treatment become more evident over time, genetic information will, in turn, become far less threatening and stigmatizing.

In order to meet these new challenges, law and science must march together as full partners and not, as in the past, with law behind the scientific cadence. All too often, as former Chief Justice Warren E. Burger has observed, "The law does not search out as do science and medicine; it reacts to social needs and demands."⁶⁸ It is thus vital for the law to develop an agenda for social change and changing socio-political needs instead of simply reacting to change itself—especially in the Age of the New Biology.⁶⁹ In the final analysis, then, it

⁶³*Id.* at 695. See generally Sidney A. Shapiro, *Biotechnology and the Design of Regulation*, 17 *ECOLOGY L.Q.* 1 (1990).

⁶⁴John C. Fletcher & Dorothy C. Wertz, *Law and Medical Genetics: After the Human Genome is Mapped*, 39 *EMORY L.J.* 747, 759 (1990).

⁶⁵Sherman Elias & George J. Annas, *Generic Consent for Genetic Screening*, 330 *NEW ENG. J. MED.* 1611 (1994).

⁶⁶*Id.*

⁶⁷Fletcher & Wertz, *supra* note 64.

⁶⁸Warren E. Burger, *Reflections on Law and Experimental Medicine*, in 1 *ETHICAL, LEGAL AND SOCIAL CHALLENGES TO A BRAVE NEW WORLD* 211 (George P. Smith, II ed., 1982).

⁶⁹See George P. Smith, II, *Biomedicine and Biomedical Ethics: De Lege Latta, De Lege Ferenda*, 9 *J. CONTEMP. HEALTH L. & POLY* 233 (1993); George P. Smith, II, *Toward an International Standard of Scientific Inquiry*, 2 *HEALTH MATRIX, J. L. MED.* 167 (1992).

is well to recognize that, "Each new power won *by* man is a power *over* man as well."⁷⁰

EPILOGUE

On March 16, 1995, the United States Equal Employment Opportunity Commission concluded that the Americans With Disabilities Act will protect healthy people carrying abnormal genes against employment discrimination.⁷¹ As such, this becomes the first pronouncement making it illegal for an employer to discriminate against a worker on the basis of genetic makeup. Interestingly, it does not address the central question of whether insurance companies may deny health insurance to people with abnormal genes. Both issues will ultimately have to be tested in the courts.

⁷⁰C. S. LEWIS, *THE ABOLITION OF MAN* 71 (MacMillan 1965) (1947).

⁷¹EEOC COMPLIANCE MANUAL, vol. 2, EEOC Order 915.002, Def. of the term Disability (1995).