

# Volume I, No. 2, “Testing and Telling: Genetic Privacy, Family Disclosure and the Law”

*Ethical Responsibilities of Patients and Clinical Geneticists*

Allen Buchanan

Genetic testing raises ethical issues in the areas of public policy and individual conduct. While acknowledging the interrelatedness of these two areas, the author stresses the importance of viewing them separately. In this essay, the author considers the ethical responsibilities of individuals who have received the results of genetic tests, as well those who are deciding whether to undergo a test, and the ethical responsibilities of clinical geneticists who provide the results of these tests.

In part II, the author describes five reasons for studying the ethical responsibilities of patients and clinicians at this time. In part III, the author examines the responsibilities of individuals who are considering to undergo a genetic test and of those who have already received their results, focusing on the latter group. In part IV, the author turns to an examination of the responsibilities of clinical geneticists, considering their obligations both before and after the test.

The author concludes that whether an ethical responsibility exists depends on the particular facts of each case. When this particularized or contextualized approach is applied, the author concludes that the traditional clinical approach of nondirectiveness will no longer be appropriate in all genetic testing situations.

## *Biological Truths and Legal Fictions*

R. Alta Charo, J.D.

The use of legal fictions is one way to manage the discordance between the social rules we need and the biological truths that we as a society perceive. In an article written by R. Alta Charo, the author suggests that influences such as Charles Darwin’s theory on “survival of the fittest” and Edward Wilson’s Sociobiology can be seen in years of case law and legislative enactments that assume biological underpinnings of human behavior should be encouraged by the law.

The author illustrates four primary categories in which society has become comfortable with rules treating people or things as if they meet the criteria for an underlying biological reality. In Category One, using the substitution of adoptive parents for biological parents as an example, the author sets forth those situations in which the

public is fully complicit in an outright fiction as the rules define people as things that biology shows they are not. Category Two addresses certain situations where the belief is that there is a biological truth, yet, the exact truth at that moment is clearly unknown. The author finds that absentee people being considered “dead” after a sufficient passage of time is one such example of this category.

Category Three, often distrusted by the public, involves situations where the biological truth is uncertain because the biological categories are unclear. This two-step analysis often involves the question of when human life begins and requires delineation between “male” and “female” for the purpose of eligibility requirements. The final category, Category Four, occurs when no biological truth exists but the impression of truth is so strong that the presumption simply cannot be overcome. Self-identification versus biological definitions is one of the many examples representative of this category. Although biological truths are unambiguous and unchangeable, R. Alta Charo in concluding the article warns against the importation of biological truths into the legal arena and advises that when contemplating doing so, the questions of Why? and For what social purpose will it serve? should always be asked.

## *What Should the Law Say About Disclosure of Genetic Information to Relatives?*

Ellen Wright Clayton, MD, JD

In her article, Ellen Wright Clayton, Associate Professor of Pediatrics and Associate Professor of Law, Vanderbilt University Schools of Medicine and Law, argues against the use of the law of negligence to enforce ethical obligations, suggesting that doing so represents an unwarranted expansion of legal duty and places significant cost burdens on the delivery of health care. The author divides ethical considerations into two categories. The first involving disclosure within the family focuses on the duty of the patient to inform their relatives of the chance they too may have inherited a treatable genetic disorder. The second set of considerations is based on the health care provider’s duty to warn their patients’ relatives even over the patients’ express objection to the disclosure.

In the case of family disclosure, the author demonstrates the problems inherent in diagnosing genetic diseases and characteristics by using a fictional character that learns he has colon cancer and may have a mutation that predisposed him to develop the cancer. Through a series of hypotheticals, the author shows the negative implications of a patient’s refusal to disclose genetic information to their relatives who may also have the genetic mutations.

The author shifts focus to the question of whether health care providers are either privileged or required to

warn their patients' relatives of the potential risks they may face. Using a line of cases including *Tarasoff v. Regents of University of California*, the author suggests that the current policy of ensuring privacy of genetic information is inconsistent with imposing a duty to disclose. Furthermore, fundamental to the patient-provider relationship is the notion of confidentiality. To require a physician to notify a patient's relatives would be difficult, if not impractical, and would impose too great of a burden on the physician.

In concluding, the author suggests that while physicians should talk to their patients about the risks and the patient's to their relatives should disclose those risks, neither should be legally required to do so. The author further concludes that imposing a legal obligation on either of the parties would be a major expansion of the law and would cause serious problems concerning the protection of patient confidentiality.

*Family Disclosure in Genetic Testing For Cancer Susceptibility: Determinants and Consequences*

Caryn Lerman PH.D., Beth N. Peshkin M.S., Chanita Hughes PH.D. & Claudine Isaacs M.D., Lombardi Cancer Center, Georgetown University Medical Center

Along with the medical benefits of being able to isolate the BRCA1 and BRCA2 gene, the ability to identify women at increased risk of breast and ovarian cancer has profound implications on the participant being tested and their family members. The authors of this article address one of the more pressing but least studied issues involved in genetic testing and present statistical data on the determinates and outcomes of disclosure within hereditary breast cancer families. Through intensive research and case studies, the authors suggest that the ability to control the process of disclosure is of extreme importance to genetic counseling participants.

Among their findings, the authors note that individuals are highly motivated in pursuing testing for the sake of their families but disclosure by a carrier of the gene depends primarily on the family's pattern of communication. The study also indicates that to whom in the family the information is disclosed depends greatly on the gender of the carrier. One further finding of the study indicates that women are more likely to disclose information to relatives than men. Such a pattern of disclosure may have profound impacts on women in the legal arena, especially in the context of family law disputes.

The authors conclude their article by advocating for better counseling by clinicians and enacted legislation to enforce and protect patient autonomy and confidentiality. This strategy, according to the authors, will ensure that individuals will pursue genetic testing and obtain the

maximum medical benefits that BRCA1 and BRCA2 have to offer.

*Boling v. Romer: Federal Courts Condone Forced Withdrawal of Blood for DNA Banks Despite Constitutional Concerns.*

C. Teddy Li

Recent increases in the establishment and application of DNA data banks raise grave concerns surrounding individual privacy rights. The United States military maintains a bank of soldiers' blood samples for the alleged purpose of identification. Law enforcement utilizes DNA evidence to identify suspects in criminal cases. In this note, the author examines the Tenth Circuit case of *Boling v. Romer*, in which the maintenance of a DNA bank of prison inmates convicted on sex crimes constituted a reasonable search and seizure.

In the analysis, the author argues that the forcible extraction of blood samples represents an unreasonable search and seizure due to the lack of warrant or probable cause and the violation of bodily integrity. The author then discusses a number of potential threats to privacy from the abuse and misuse of DNA information. Among them are the potential abuses by the government, the lack of DNA bank regulation, and the falsification of DNA evidence. The author also raises the concern of the validity and reliability of DNA technology.

The author concludes that *Boling* poses a serious threat to individual privacy rights. The author urges that strict regulations regarding the extraction, analysis, and storage of samples must be established. Finally, the author concludes that these regulations must be strictly enforced by a governmental agency to safeguard individuals' remaining privacy rights.

*The Argument Against a Physician's Duty to Warn for Genetic Diseases: The Conflicts Created by Safer v. Estate Of Pack*

Angela Liang

Courts have attached liability to physicians and psychiatrists for failing to warn patients and third parties. Courts have also held physicians liable for failing to properly diagnose a patient with a contagious disease. In this note, the author examines the case of *Safer v. Estate of Pack*, in which the Superior Court of New Jersey held that a physician has a duty to warn individuals known to be at risk for a genetic disease.

In the analysis, the author begins with a comparison of HIV-related and genetic information. The author

continues with a consideration of the implications of early detection and treatment of a genetic disease, the knowledge of having a genetic disease, and the preventability of the genetic disease. The author then turns to an examination of the consequences of imposing liability on physicians by considering potential employment and insurance discrimination and domestic violence resulting from the disclosure of such genetic information.

The author concludes that the Safer court has imposed liability on physicians a duty to warn family members of the risk of potential harm from a genetic disease without considering the practical consequences. The author cautions against adoption of this holding until further information is known about the risks of disclosure of genetic information. The author concludes that courts should instead provide physicians with a list of factors for consideration in deciding whether to warn family members. Finally, the author recommends that the Safer court reassess its holding.

### *Medical Implications of the Genetic Revolution*

Monique K. Mansoura, PH.D. & Francis S. Collins, M.D., PH.D.

The Human Genome Project (HGP), a multi-disciplinary, multi-institutional, multi-dollar effort to identify the molecular basis of virtually every disease, has mobilized the efforts of thousands of scientist and has even gained the support of Congress. The authors begin their article by outlining the scientific concerns regarding the HGP. While highlighting the scientific benefits of the project, the authors address the negative implications that may result from genetic testing. One area of concern the authors explore is the possibility of discrimination by insurers and employers based on individual's predisposition to certain diseases and illness. The authors also examine the improper use of genetic information in legal contexts, suggesting that such concern has instilled trepidation in many patient advocacy groups.

The authors suggest that the potential benefits of the project are such that ethical discussions and legal debates cannot be held without insisting on a thorough understanding of the fundamental principles of genetics and what science realistically can and cannot offer. The authors conclude that the genetics research community must educate lawyers, ethicists, policymakers, and others on genetic information privacy and this group must work in a collaborative effort to reduce the negative consequences of the misuse of genetic information.