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Foreword

Personal Genetic Information: Implications for the Workplace and Criminal Justice

*Marta B. Varela**

When confronted with technology whose implications are not yet made out, human beings have a choice: fight or flight. While it may seem natural to many, trained in methods of analytic inquiry, to persevere against the specter of fear by asking the tough policy questions, a seemingly valid response is to throw up walls to its use, on the theory that if Pandora's Box stays shut, no one need fear what is clamped down inside.

Personal genetic information presents just such a dilemma. The massive amount of information gleanable from a fragment of individual human tissue presents a particular challenge to notions of privacy, long enshrined in the United States as the bedrock of our particular combination of individual freedom and independence from intrusive government.

The question "How shall use of genetic information be governed?" leads to a further, inquiry, "For what purpose?" and ultimately to a more fundamental inquiry, "Is the purpose legitimate in light of our values?"

In the criminal justice arena, the certainty DNA testing promises is, experts admit, tinged with qualification if the tested sample has been tainted by contact with other matter. More fundamental to civil libertarians is the propensity of law enforcement to use universal DNA testing as the next big advance in the battle to assert the police power of the state. Not surprisingly, thoughtful law enforcement representative representation object, explaining that the astounding accuracy of even the most economically low-

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cost test rules out the likelihood of a miscarriage of justice, even if juries are unduly swayed by the near-certainty DNA testing provides.

Of equal concern, not just to those who seek to avoid having technology disturb settled contractual relationships between insurer and insured, is the use of DNA testing as a predictive health tool. DNA testing at this stage is both diagnostic and projective: with respect to some medical conditions it can identify an almost-overwhelming likelihood that an individual will be afflicted with a particular condition during his lifetime. It also can provide much less definitive indications that an individual that an individual is susceptible to another medical condition. In the background of the debate over whether such information may be private, looms the much larger debate about access to health care and what private insurance companies should have to provide members. Even further in the background is debate over whether in consequence of advances in DNA testing and future greater predictive ability, some forms of health care may not be better shouldered by government entities better able to assume responsibility for individual claims projected on the basis of DNA evidence of a propensity to catastrophic illness. This is a public health use triggered by the not incomprehensible response of the public to the threat of being disqualified from health care on account of a genetic history they had no control over.

While genetics may be as incomprehensible to the public as programming languages once were, there is no doubt in the minds of those amateurs who have troubled to inform themselves somewhat, let alone in the minds of consumers of DNA technology, that its implications for Americans' lives will be immense. The symposium presented today seeks to disseminate a greater awareness of the significance of genetic testing, whether in law enforcement or among the law-abiding. The inquiry required will have to be a sustained one if it is to penetrate beyond an easy, surface understanding. Today's symposium brings together for the first time a scientist, civil libertarians, law enforcement officials, insurance industry representatives and policy-makers in the health care field. It is my hope that this successful meeting will spawn many more similar symposia. For only an intellectual search at the highest level will engage the difficult issues our society will have to confront in consequence of the development of DNA testing. It would not be inap-

appropriate to compare the information that can be collected in one place as a result of DNA analysis to Gutenberg's invention of movable type and the consequent explosion of the dissemination of information through printed means. Unlike the computer, movable type disseminated information that had not previously been available as it spurred writing for publication, while the computer merely guarantees a larger audience than printed matter might enjoy. Similarly, DNA testing makes available information that had not been previously available. As advances in accuracy of testing and efficiencies in the production of tests bring down the cost, it is important, in the interest of the privacy we value, to consider the policy issues before the technology outpaces our ability to manage its benefits and unintended consequences.

