

Genetic tests now are available directly to consumers (DTC) for a variety of applications. Genetic testing services offered through the Internet include testing for genetic disorders or risks, parentage determination, and ancestry. The combination of technology that permits the analysis of small amounts of DNA, increased availability of testing services, and lack of regulations to protect genetic privacy create an environment ripe for surreptitious testing—that is, the collection and analysis of DNA without consent, and the disclosure of information derived from such analysis without the permission of the person tested.

It is not known to what extent surreptitious DNA testing currently is taking place. Its practice is most familiar in the law enforcement context. Police have obtained DNA samples surreptitiously from suspects by collecting so-called “abandoned” DNA – i.e., samples left on envelopes or other articles. While some have argued that this practice violates the Constitution’s protection against unlawful searches under the Fourth Amendment, courts that have reviewed the practice have found it acceptable.

Surreptitious DNA testing also can occur outside the law enforcement context for a variety of purposes. While some DTC testing companies request a particular specimen type and amount – such as a vial of saliva or a cheek swab – that may preclude surreptitious sample collection, other companies are willing and able to analyze DNA left on discarded items, such as chewing gum, used Q-tips, cigarette butts, or strands of hair. Assuming DNA can be extracted from the sample, a variety of analyses can be performed, from health-related testing to parentage determination. Such testing could lead to parentage disputes, lawsuits, and other accusations. Further, a person unexpectedly might learn of health risks or family relationships that he or she would prefer remain unknown.

There are limited legal safeguards against surreptitious DNA testing or its potential consequences for those subject to nonconsensual testing. The 2008 Genetic Information Nondiscrimination Act (GINA), which prohibits genetic discrimination by employers and health insurers, also prohibits employers from purchasing genetic information about an employee or prospective employee from third parties. While GINA does not address surreptitious testing directly, the language of the law would prevent employers and insurers from using results of a surreptitiously acquired genetic test in decision-making.

Most states do not have laws restricting surreptitious DNA testing. Those that do generally place restrictions only on nonconsensual health-related testing. For example, Arizona law states that genetic testing results are confidential and considered privileged to the person tested and that they may be released only with that person’s consent. The law defines genetic testing to include only health-related tests. Only a handful of states

have laws that broadly restrict surreptitious DNA testing for both health and non-health-related purposes, such as parentage determination or ancestry. For example, Alaska prohibits any person from collecting a DNA sample, performing a DNA analysis, or disclosing the result of such analysis without the consent of the person tested, and the law defines DNA analysis as testing to “determine the presence or absence of genetic characteristics in an individual.” In some cases, state laws are ambiguous regarding their applicability to surreptitious testing. Even where state laws expressly prohibit surreptitious testing, it is unclear that these laws have ever been enforced. Four states (Alaska, Colorado, Florida, and Georgia) define DNA as the property of the person from whom it is derived. It is therefore possible that general laws against misappropriation of property could be used in these states to prevent surreptitious testing, but it does not appear that this has occurred.

*Compiled by Sara Katsanis and Gail Javitt
Last updated 1/2009*