

# SENATE BILL REPORT

## SB 5929

---

---

As Reported By Senate Committee On:  
Children & Family Services & Corrections, February 26, 2003

**Title:** An act relating to informed consent in the use of genetic information.

**Brief Description:** Requiring informed consent before an employer or insurer uses a person's genetic information.

**Sponsors:** Senators Franklin and Kline.

**Brief History:**

**Committee Activity:** Children & Family Services & Corrections: 2/25/03, 2/26/03 [DP].

---

### SENATE COMMITTEE ON CHILDREN & FAMILY SERVICES & CORRECTIONS

---

**Majority Report:** Do pass.

Signed by Senators Stevens, Chair; Carlson, Deccio, Hargrove, McAuliffe and Regala.

**Staff:** Edith Rice (786-7444)

**Background:** Over the last several years, the Legislature has directed that studies be done to address the policy implications of scientific advances involving the use of DNA (deoxyribonucleic acid). DNA is uniquely identifiable to every individual. Scientists are able to derive information about health characteristics, familial relationship and risks related to certain specific diseases from DNA samples.

Current law does not have a requirement that informed consent be obtained when a person's individually identifiable DNA is obtained for purposes of genetic testing. Health care providers are required to obtain informed consent for health care treatment, and must have consent to communicate health care information. Genetic testing is performed for purposes other than medical treatment, and may be used by a health care provider for purposes other than health care.

**Summary of Bill:** Informed consent is required when an individual's identifiable DNA is obtained for genetic testing purposes.

"Genetic information" is defined. "Informed consent" is defined and includes: an explanation of the purpose for which the genetic information is being taken, what form it will take, with whom it may be shared and for how long, risks involved with providing the information, possible benefits and contact information.

Exceptions exist to the informed consent requirement for criminal matters, paternity or child support cases, emergency medical care, research conducted under the regulation of an institutional review board, health care providers operating under state or federal privacy laws, and pursuant to a specific authorizing statute. Deceased persons cannot consent; therefore,

a court of law or institutional review board weighs the privacy concerns and determines whether testing could occur.

**Appropriation:** None.

**Fiscal Note:** Not requested.

**Effective Date:** Ninety days after adjournment of session in which bill is passed.

**Testimony For:** Genetic information is personal information. Its disclosure can have long-term consequences. People have the right to know how and why it will be used.

**Testimony Against:** None.

**Testified:** Tony Orange, Executive Director, Commission on African American Affairs (pro).