

**REVISED PROPOSED REGULATION OF
THE STATE BOARD OF HEALTH**

LCB File No. R018-98

March 26, 1998

EXPLANATION – Matter in *italics* is new; matter in brackets [] is material to be omitted.

AUTHORITY: §§1 to 3, NRS 629.181.

Section 1. Chapter 629 of NAC is hereby amended by adding thereto the provisions set forth as sections 2 and 3 of this regulation.

Sec. 2. *1. A person, governmental agency or political subdivision of a government that wishes to obtain genetic information of a person, retain genetic information that identifies a person, disclose or compel a person to disclose the identity of a person who was the subject of a genetic test or to disclose genetic information of a person in a manner that allows identification of the person must first:*

(a) Inform the person who is the subject of the genetic test or his legal guardian of the restricted uses and confidentiality of the genetic information set forth in NRS 629.101 to 629.201, inclusive; and

(b) Obtain from the person who is the subject of the genetic test or his legal guardian the consent document described in section 3 of this regulation. The consent document must be signed and dated by the person who is the subject of the test or his legal guardian and must be witnessed by another person.

2. *Possession of a consent document that has been signed, dated and witnessed conclusively establishes compliance with subsection 1.*

3. *A consent document must be kept on file by the person, governmental agency or political subdivision of a government that obtained the document pursuant to subsection 1 for not less than 5 years.*

Sec. 3. *The consent document for obtaining genetic information of a person must be in substantially the following form:*

**CONSENT FOR OBTAINING, RETAINING OR
DISCLOSING GENETIC INFORMATION**

As used in this document, “genetic information” means any information that is obtained form a genetic test.

1. *I understand that no insurer or corporation that provides health insurance, carrier serving small employers or health maintenance organization may:*

- (a) Require me or any member of my family to take a genetic test;*
- (b) Require me to disclose whether I or any member of my family has taken a genetic test;*
- (c) Request my genetic information or the genetic information of a member of my family; or*
- (d) Determine the rates or any other aspect of the coverage or benefits for health care for me or my family based on whether I or any member of my family has taken a genetic test or based on my genetic information or the genetic information of any member of my family.*

2. *I also understand that:*

(a) I have the right to receive the results of a genetic test, in writing, within 10 working days after the person conducting the test has received the results. The written results must indicate that my genetic information may not be obtained, retained or disclosed without first obtaining my informed consent.

(b) It is unlawful for a person or entity to obtain my genetic information without my informed consent, unless the information is obtained:

(1) By a federal, state, county or city law enforcement agency to establish the identity of a person or a dead human body;

(2) To determine the parentage or identity of a person in certain circumstances;

(3) To determine the paternity of a person in certain circumstances;

(4) For use in a study where the identities of the persons from whom the genetic information is obtained are not disclosed to the person conducting the study;

(5) To determine the presence of certain inheritable disorders in an infant in certain circumstances; or

(6) Pursuant to an order of a court of competent jurisdiction.

(c) It is unlawful for a person to retain genetic information that identifies me without first obtaining my informed consent, unless retention of the genetic information is:

(1) Necessary to conduct a criminal investigation, an investigation concerning the death of a person or a criminal or juvenile proceeding;

(2) Authorized pursuant to an order of a court of competent jurisdiction; or

(3) Necessary for certain medical facilities to maintain my medical records.

(d) If I have authorized a person to retain my genetic information, I may request that the person destroy the genetic information. Such a person shall destroy the information, unless retention of the information is:

(1) Necessary to conduct a criminal investigation, an investigation concerning the death of a person or a criminal or juvenile proceeding;

(2) Authorized by an order of a court of competent jurisdiction;

(3) Necessary for certain medical facilities to maintain my medical records; or

(4) Authorized or required by state or federal law.

(e) Except as otherwise provided by federal law or regulation, a person who obtains my genetic information for use in a study shall destroy the information upon completion of the study or my withdrawal from the study, whichever occurs first, unless I authorize the person conducting the study to retain my genetic information after the study is completed or upon my withdrawal from the study.

(f) It is unlawful for a person to disclose or to compel another person to disclose my identity if I was the subject of a genetic test or to disclose to another person genetic information that allows the other person to identify me without first obtaining my informed consent, unless the information is disclosed:

(1) To conduct a criminal investigation, an investigation concerning the death of a person or a criminal or juvenile proceeding;

(2) To determine the parentage or identity of a person in certain circumstances;

(3) To determine the paternity of a person in certain circumstances;

(4) Pursuant to an order of a court of competent jurisdiction;

(5) By a physician after I am deceased and my genetic information will assist in the medical diagnosis of persons related to me by blood;

(6) To a federal, state, county or city law enforcement agency to establish the identity of a person or dead human body;

(7) To determine the presence of certain inheritable preventable disorders in an infant in certain circumstances; or

(8) By an agency of criminal justice in certain circumstances.

I, (name of person giving consent), hereby give my consent to (name of person or agency obtaining genetic information) to obtain my genetic information; or

I, (name of person giving consent), hereby give my consent to (name of person or agency retaining genetic information) to retain my genetic information; or

I, (name of person giving consent), hereby give my consent to (name of person or agency disclosing genetic information) to disclose my genetic information to (name and address of person or agency to receive genetic information).

This consent document is valid until (date of expiration).

If the person tested is unable to sign, please indicate the reason here:

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*Signature of consenting
person or his legal representative*

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Witness

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Date

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Date