

**LCB File No. R176-99**

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

**NAC 442 is hereby amended by adding thereto a new section to read as follows:**

*It is unlawful for any employee of the state to disclose data contained in vital statistics, except as authorized by this regulation or by the Board of Health. Information in vital statistics indicating that a birth occurred out of wedlock must not be disclosed except upon order of a court of competent jurisdiction.*

*The Board:*

- (a) Shall allow the use of data contained in vital statistics to carry out the provisions set forth in sections \_\_\_ to \_\_\_, inclusive of this regulation; and*
- (b) May allow the use of data contained in vital statistics for other research purposes, but without identifying the patients to whom the records relate.*

*Unless the context otherwise requires, the words and terms defined have the meanings ascribed to them.*

*“Birth defect” means any structural or chemical abnormality present in a child at birth.*

*“Adverse birth outcome” includes stillbirths.*

*“System” means the statewide system established and maintained by the health division, in cooperation with the University of Nevada School of Medicine, for the collection and analysis of information concerning birth defects and other adverse birth outcomes.*

*The health division, in cooperation with the University of Nevada School of Medicine, shall establish a statewide system for the collection and analysis of information concerning birth defects and other adverse birth outcomes. Information obtained from the system may be used only to:*

- (a) To investigate the causes of birth defects and other adverse birth outcomes.*
- (b) To determine, evaluate and develop strategies to prevent the occurrence of birth defects; and*
- (c) To assist in ensuring the delivery of services for children identified with birth defects.*

*The name of a patient must be excluded from the system if the patient, or if the patient is a minor, a parent or legal guardian of the minor, has requested in writing to exclude the name of the patient from the system.*

*Records from newborn screening tests performed, birth certificates and from the lists provided by facilities according to NRS 442 will be reviewed for information pertinent to the detection of birth defects. When individuals are identified with conditions specific to diagnoses related to birth defects, the state health officer or his representative will contact the patient/family to determine their willingness to be included in registry activities.*

*Following is the procedure to be followed to inform a patient that his name will be used for research and referrals to related services, unless he requests the exclusion of his name in writing from the system.*

- 1. The state health officer or his representative that wishes to obtain information of a patient for the system in a manner that allows identification of the patient must first:
  - (a) Inform the patient , or if the patient is a minor, a parent or legal guardian, that his name will be used for research and referrals to related services; and*
  - (b) Advise the patient that access to information contained in the system is limited to persons authorized and approved by the state health officer or his representative who are employed by the health division or the University of Nevada School of Medicine; and*
  - (c) Advise the patient that any information obtained by the system that would reveal the identity of a patient remains confidential; and*
  - (d) Advise the patient that information obtained by the system is used solely for the purposes set forth in these regulations.*
  - (e) Advise the patient that a request to exclude his name from the system must be in writing.*
  - (f) Maintain any written request for exclusion of the patient's name/identifier from the system in the patient record.**

*Access to information contained in the system shall be limited to persons authorized and approved by the state health officer or his representative who is employed by the health division or the University of Nevada School of Medicine. All information contained in the system that would reveal the identify of a patient shall remain confidential.*